

**ROLE OF PERCEIVED SOCIAL SUPPORT ON CAREGIVER BURDEN AND  
SOMATIC SYMPTOMS IN MOTHERS OF CHILDREN WITH DISABILITY**

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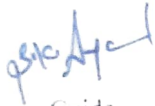
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## CERTIFICATE

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Hereby, it is certified that the dissertation titled **"ROLE OF PERCEIVED SOCIAL SUPPORT ON CAREGIVER BURDEN AND SOMATIC SYMPTOMS IN MOTHERS OF CHILDREN WITH DISABILITY"** is the original research work done by **Shama Anzum (Register No: 154221104510)** submitted in partial fulfilment of requirements for the Degree of Master of Philosophy in Clinical Psychology and has not previously formed the basis of award for any other degree or diploma to the candidate.



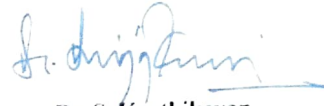
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## DECLARATION

I, **Shama Anzum** hereby declare that the thesis titled “**ROLE OF PERCEIVED SOCIAL SUPPORT ON CAREGIVER BURDEN AND SOMATIC SYMPTOMS IN MOTHERS OF CHILDREN WITH DISABILITY**” was carried out by me at NIEPMD, Chennai, during the year 2021-23, is an original research work carried out under the guidance and supervision of Ms. S.K. Anandhalakshmi, Lecturer, Department of Clinical Psychology, NIEPMD, Chennai. This work has not formed the basis of award for any other degree.



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This is to certify that, the project entitled "ROLE OF PERCEIVED SOCIAL SUPPORT ON CAREGIVER BURDEN AND SOMATIC SYMPTOMS IN MOTHERS OF CHILDREN WITH DISABILITY" submitted by Ms. S. SHAMA ANZUM, II year M.Phil. Clinical Psychology was placed before the Institutional Ethics Committee. The committee has given ethical clearance to conduct the study.



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This is to certify that this dissertation work titled “**ROLE OF PERCEIVED SOCIAL SUPPORT ON CAREGIVER BURDEN AND SOMATIC SYMPTOMS IN MOTHERS OF CHILDREN WITH DISABILITY**” of the candidate **S. Shama Anzum** with Registration Number **154221104510** for the award of **Masters in Philosophy** in the branch of **Clinical Psychology**. I personally verified the urkund.com website for the purpose of plagiarism Check. I found that the uploaded thesis file contains from introduction to conclusion pages and the result shows **4** percentage of plagiarism in the dissertation.

  
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**SHAMA ANZUM**

## **ABSTRACT**

The aim of the study is to assess the role of perceived social support on caregiver burden and somatic symptoms of children with disability and to examine the differences in somatic symptoms and sociodemographic variables. 60 mothers raising children with disability availing services in NIEPMD, were selected through purposive sampling and administered multi-dimensional scale of perceived social support, Zarit Caregiver burden scale and Somatic symptom scale. The results were analysed using Pearson correlation coefficient, Independent t-test and Hayes process. The results revealed that there was significant relationship between caregiver burden and somatic symptoms, caregiver burden, and perceived social support as well. Results also revealed that differences were found between somatic symptoms in mother's age and type of disability of the child. The results highlights need for social support for caregivers raising children with disability and provides insight about their long-term caregiving impacts their mental and physical health as well, which helps mental health professionals support them using therapy and intervention to treat such long-term condition effectively.

**Key words:** Perceived social support, caregiver burden, somatic symptoms, children, disabilities.



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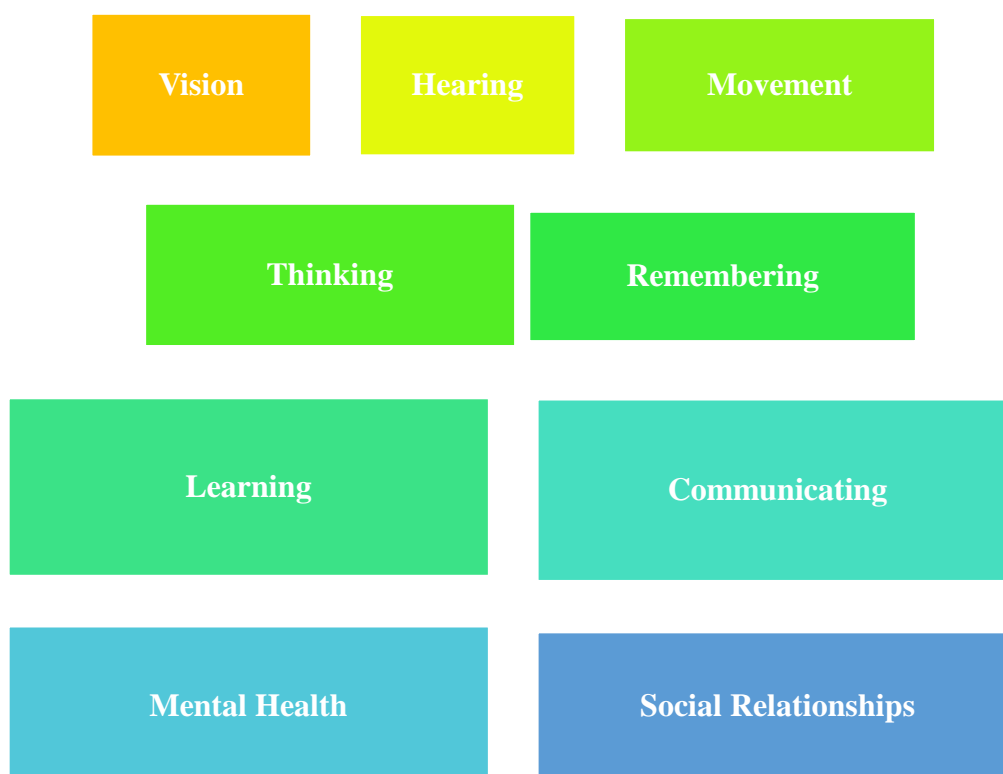
## CHAPTER I

### INTRODUCTION

The term "disability" covers a wide range of impairments, activity limitations, and participation limitations. The World Health Organisation (WHO) defines three aspects of disability:

1. **Impairment** in a person's body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss.
2. **Activity limitations**, such as difficulty seeing, hearing, walking, or problem-solving.
3. **Participation restrictions** in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health care and preventive services.

Disabilities come in a variety of forms, including those that affect a person's:



*Figure 1, Different forms of Disabilities*

Although the term "people with disabilities" is occasionally used to describe a single demographic, this is a diverse group of individuals with a variety of requirements. Even two people with the same handicap may experience its effects very differently. Any parent would find it difficult to raise a child with developmental and mental disabilities. due to the cognitive, motor, medical, psychopathological, and other issues that affect children with disabilities. Parents will have concerns for their children for the rest of their lives. Mothers react and handle these situations differently depending on their families, personalities, children's traits, and social support.

In today's society, raising disabled children is a complex and emotionally taxing task that is frequently given to moms. As they negotiate the challenging process of raising children with various needs, these committed parents encounter particular hurdles. Caring for a child with a disability can significantly impact maternal well-being, resulting in elevated caregiver burden and the manifestation of somatic symptoms. Amidst these challenges, the role of perceived social support emerges as a crucial determinant in shaping maternal coping mechanisms and overall quality of life.

Raising a child with a disability has a tremendous effect that extends beyond the child and pervades all part of the mother's life. Mothers who care for their disabled children have emotional, physical, economical, and social difficulties, which together make up the multifaceted concept of caregiver load. Additionally, the physical effects of the emotional toll frequently result in somatic complaints, which can aggravate mother stress. It is essential to comprehend the underlying causes of carer stress and somatic symptoms in order to design focused interventions that will assist and improve the wellbeing of these strong mothers.

**Understanding Caregiver's burden of children with disabilities:**

According to Floyd and Gallagher (1997), caregiver burden is the stress or pressure that a person bears while providing care for an immediate family member who is disabled.

According to Erikson and Upshur (1989), caregiver burden is a multifaceted reaction to the physical, psychological, emotional, social, and economic difficulties associated with the caring experience.

DiBartolo (2000) defines caregiver burden as the ongoing difficulty, stress, or unfavourable experiences brought on by providing care. Developmental abnormalities in children necessitate extensive caregiving, frequently throughout childhood and into adulthood, as well as access to the health care system. Many children have sensory, physical, and intellectual disabilities, and they may also have complicated limits when it comes to activities of daily living like eating, dressing, bathing, and moving around. These restrictions may lead to long-term care needs significantly greater than children typically require as they grow. While providing the high degree of care needed by a child with long-term functional limitations is a typical aspect of being a parent of any young child, doing so can become taxing and may have negative effects on the parent's physical and mental health.

According to Wade et al. (1986), family members who are caregivers for others frequently have fewer opportunities to engage in regular social activities and experience a decline in their wellbeing. However, the challenges that caregivers have might be lessened when they have strong community support (e.g., access to informational, emotional, and practical resources). As a result, individuals with disabilities receive care of a higher calibre and experience better functional rehabilitation and community reintegration (Mayo et al., 2000; Stephens et al., 1991). In contrast, caregivers who lack resources and support bear higher



financial, physical, and emotional costs (Zarit and Whitlatch, 1992), which can ultimately lower the level of care they are able to deliver.

Being a long-term disability caregiver involves taking on a new role, therefore it will involve some rearranging of priorities and refocusing of energy. Not only is this likely to cause stress on a personal level, it is also likely to elicit responses—some of which may be unfavourable—from numerous people who are connected to the person through roles outside of caregiving. As a result, it is possible to see how the burden of being a caregiver manifests both in the delivery of care and in other spheres of life. The literature frequently focuses on the strain involved in providing direct care.

Family sizes have shrunk during the previous two decades, and the rate of divorce has gone up. Children with impairments are living longer thanks to medical technology advancements throughout the same time span. The transition of healthcare to ambulatory and community-based care settings may raise the responsibilities placed on family members, requiring them to take a more active role in their child's care. Smaller family units are left to face the burden of increased caregiving obligations as a result of this confluence of variables, making it even more crucial to recognise and meet the needs of the carer.

If the health care and social service institutions fail to recognize these problems and support such families, caregivers for children with a handicap may encounter a varied, difficult, and stressful life situation with significant ramifications. The idea of a "caregiver career" connotes a dynamic process, similar to a professional career, where an individual progresses through a succession of phases, requiring significant adjustments and restructuring of duty over time.

These phases for a caregiver include:

- preparation for and acquisition of the caregiver role
- enactment of the associated tasks and responsibilities
- eventual disengagement from the role.

Within these stages, there are numerous patterns of change, such as the requirement for more support with ADLs. Parenting stress has been shown to be mediated by a number of variables, including social support (Crnic & Greenberg, 1987; Krauss, 1993), child age (Bristol, 1979), and physical disability, hyperactivity, or lack thereof (Dumas, Wolf, Fisman, & Culligan, 1991; Mash and Johnston, 1983). However, there has been widespread agreement that child functioning has a major impact on parenting stress among the range of factors. The characteristics of a child, such as the kind of impairment, distinctive caring needs, and demanding behaviour, may exacerbate stress (Gallagher, Beckman, & Cross, 1983). Parents of these various categories of children experience parenting stress in relation to both children with and without disabilities.

According to a review of the literature on parenting stress in families with disabled children, the majority of studies have concentrated on the impact of having children with specific disorders or disabilities, such as Autism, Down syndrome, learning and behavioural disorders, or physical disabilities (Baker, 1994; Baker & Mc Cal, 1995; Dumas, Wolf, Fisman, & Culligan, 1991; Kobe & Hammer, 1994). Other research in this area has indicated a link between parenting challenging children and psychological distress in parents (Wolf, Noh, Fisman, & Speechley, 1989), life satisfaction (Milgram & Atzil, 1988), and marriage satisfaction (Fischer, 1990). Fischer (1990) came to the conclusion after analysing the relevant literature on parenting stress for parents of disabled children that studies of parent-child interaction patterns are more indicative of a child-to-adult direction of parenting stress. Fischer (1990) came to this conclusion after assessing the relevant literature on

parenting stress for parents of children with disabilities: studies examining patterns of parent-child interaction is more suggestive of a child-to-adult direction of influence with relation to parenting stress than the opposite. This would seem to imply that parenting stress is more likely to occur the more problematic or challenging the child is to handle.

General phrases used to describe the connection between caregiving and health are stress and burden. According to Aneshensel et al., "the problematic conditions and difficult circumstances experienced by carers (i.e., the demands and obstacles that exceed or push to the limit one's capacity to adapt)" are stressors in the context of caregiving. This conceptualization emphasises that stress arises when demands imposed by a patient's condition conflict with a caregiver's subjective capacity to respond or when these demands interfere with the pursuit of other goals. Stress occurs when demands imposed by a patient's condition conflict with a caregiver's subjective capacity to respond. This interaction between an individual's surroundings and behaviour helps to explain why some carers appear to be less impacted by caregiving burden while others have more negative health effects.

Children and teenagers with comorbid diseases may need to follow a medical regimen that typically entails taking drugs, going to doctor's appointments, or having procedures like injections, catheterization, or home dialysis performed. Additionally, there is a greater demand for support with fundamental everyday activities (such mobility or self-care) for people with conditions like physical impairments. Children depend on their carers for support and management of these responsibilities early in life. Children who have disabilities require support their entire lives. Poor sleep, family strife, worry, depression, financial stress, and a reduced quality of life can all affect caregivers of children who have comorbid disorders.

According to research by Heller et al. from 1997, "mothers spent much more time than males helping the child and taking care of home duties, giving the child more sorts of support, being more involved in organisations, and working fewer hours. The caregiving load described by moms was much greater than that of fathers. With the exception of giving financial aid, the mothers performed more supportive roles like locating resources and offering encouragement. Before the birth of the disabled child, mothers who were employed frequently quit their jobs to care for the child (Mardios, 1985). According to Ramasubramanian et al. (2019), mothers were virtually usually the primary caregivers in India because it was viewed as more acceptable.

According to Trivette and Cross (1986), moms of children with impairments also felt that their children made more demands on their time and that their mental and physical health was worse. According to Gowen, Johnson-Martin, Goldman, and Applebaum (1989), mothers of disabled children experienced greater difficulties with child care and felt that they did not have enough time for themselves as a result of the increased daily demands associated with raising a disabled child.

### **Impact of Perceived Social Support on Caregivers:**

The difference between perceived and actual support is that the former refers to people's convictions that they can count on others for help when they need it. Informal support is the help that people get from their friends and relatives, whereas formal support is the help that people get from institutions or organised groups.

A person who perceives appropriate support and believes that the support will shield them from harm may not find a frightening situation distressing. (1985; Cohen and Wills). According to studies (Song, 1999; Edwards and Scheetz, 2002), perceived social support has a balancing effect on caregiver burden. Caregivers who receive greater assistance report feeling less burdened. Therefore, the level of social support women receive from their surroundings has an impact on how well they provide care.

Positive mental and physical health outcomes have regularly been linked to perceived social support (Broadhead et al., 1983). Also, other literature by S. Cohen & McKay, 1984; Thoits, 1982; Wallston, Alagna, DeVellis, & DeVellis, 1983; Wortman, 1984) has similar results and supports the findings.

Based on Robert Weiss's (1974) idea of the benefits of social interactions, a multidimensional concept of social support was adopted in these experiments. The main components of the majority of recent conceptualizations of social support, such as those by Caplan, 1974; Cobb, 1976; S. Cohen & McKay, 1984; Hirsch, 1980; House, 1981; Schaefer, Coyne, & Lazarus, 1981, are all included in Weiss' theoretical framework. Weiss outlined six distinct social provisions or functions that might be acquired through interpersonal connections.

He claims that all six elements are necessary for people to feel supported properly and to avoid loneliness, albeit particular provisions might be more important at other phases of life. Each of the provisions is most frequently derived from a specific form of relationship, while

one individual may provide for more than one provision. Weiss listed six relationship clauses, and they are as follows:



*Figure 2, Weiss 6 elements of social support*

- **Attachment:** a feeling of security and emotional closeness typically offered by a partner or romantic interest.
- **Social integration:** a feeling of belonging to a group of individuals who partake in similar hobbies and pastimes, typically acquired from friends.
- **Reassurance of worth:** acceptance of one's knowledge and abilities.
- **Reliable alliance:** the confidence that one can always rely on others for support, typically acquired through family members.
- **Guidance:** direction and knowledge typically gained from instructors, mentors, or parents.
- **The opportunity of nurturing:** a sense of obligation to another person's welfare, typically acquired via one's children.

In terms of educational attainment, marital status, physical and mental health, parents of children with developmental disabilities were comparable to parents without such children. There were differences among these parents in terms of lower employment rates, larger families, and lower rates of social participation because of the responsibilities of caregiving. (1991; Floyd, Pettee, and Hong).

A study demonstrates that two social support variables—one received and one perceived—were the best at predicting the caregiver burden. According to Chi Jun Chou et al. (2009), caregiver burden was more likely to be higher when carers had lower levels of family function and perceived social support than actual social support. Perceived social support was also better at predicting caregiver burden.

Thus, a mother's perception of social support is a crucial protective element that can have a big impact on her capacity to handle the challenges of raising a child with a disability. Social

support protects against the negative consequences of caregiver burden in the form of emotional, practical, or educational support from family, friends, and communities. A strong support system can improve coping mechanisms, boost self-esteem, and lessen the emotional toll of caregiving, allowing moms to handle problems more successfully.

### **Somatic symptoms as a result of caregiver burden:**

Somatization, or the occurrence of physical symptoms in reaction to psychosocial stress, is a fairly common occurrence in patients, especially in the primary care context. Four components make up somatization.

- The patient expresses somatic symptoms and experiences them
- Physical symptoms are not explained by pathological results
- The patient believes they are caused by a physical ailment
- Seeks medical attention; or the symptoms are thought to be a reaction to psychosocial stress.

The following etiological elements are some of the many things that can affect the somatization process. biological weaknesses, such as past sexual or physical abuse or other tumultuous or stressful events. Pessimism, low self-esteem, and negative mood are all linked to increased physiologic reactivity and increased concern over imagined medical symptoms. In some families, physical symptoms serve as the primary means of interpersonal communication. Impairment of the ability to perceive and express emotions, such as repressed rage or violence. The persistence of symptoms and ensuing lengthy periods of disability from work, along with high costs associated with the use of extensive but insufficient and ineffective medical diagnostic investigations in outpatient and inpatient settings, highlight how crucial it is to create effective treatments for these patients.



Regardless of the etiology, it is a feature of all therapy modalities that the patient does not identify psychosocial stress as the root of their symptoms.

Any physiological sensation or symptom that lacks a biological cause is referred to as a somatic symptom. Due to similar neural connections, people who are psychologically upset often experience concomitant physical symptoms (Kreutzer et al., 2009; Trivedi, 2004).

The most frequent justification for seeing a doctor is typically for physical concerns, commonly known as somatic or physical symptoms or complaints. It should be highlighted that a clinical evaluation and currently available preliminary investigations do not readily reveal the reason of these physical problems. As a result, many terminology, including somatic symptoms/complaints, physical symptoms/complaints, bodily symptoms, functional somatic symptoms, somatization symptoms, and medically unexplained physical symptoms, have been used to characterise such complaints for which there is no physical or medical basis. While each of these labels these symptoms, none of them is able to adequately define the phenomenon.

To refer to the sense of physiological suffering brought on by any physical symptom in the body, the terms somatic symptoms, bodily symptoms, and physical symptoms have been used. Any underlying mental condition, such as anxiety, depression, common mental illnesses, and other stress-related disorders, can show as somatic symptoms. Despite having erroneous, psychotic, or morbid explanations, persons with psychosis might nonetheless report somatic symptoms. Somatic symptoms are regarded as characteristics of somatoform or bodily distress disorders when they are persistent, difficult to attribute to a physical or medical condition, and associated with psychosocial variables. The frequency of somatic symptoms that are not explained by medicine varies.

The proportion of somatic symptoms that are medically unexplained varies across research for potential methodological reasons, and it is challenging to compare the results because somatic symptoms are measured using various scales.

Wallander et al. (1989) reported that mothers of children with psychiatric disabilities and mothers of children with physical disabilities experienced a similar proportion of physical and mental complaints and reported significantly more health complaints than mothers in general, which supported these findings. According to another study (Jessop, Riessman, & Stein, 1988), psychiatric symptoms are linked to the mother's lack of confidence.

According to the findings of Baillie et al. (1988), 'caregivers who have been giving care for an extended period of time, and who have limited social support are at significant risk for psychological distress and depression'.

Long-term caregivers were more likely to report headaches, body pains, and abdominal discomfort than both short-term carers and non-caregivers, net of controls, and carers continued to perform worse than non-caregivers in terms of mental health and weariness. Long-term carers are statistically more likely than short-term caregivers to report headaches, body pains, abdominal discomfort, and other somatic complaints (Sung, 2020). Both types of carers are equally likely to express weariness.

We will examine the current literature, outline the methodology used, outline the research objectives, analyze the findings, and offer conclusions and recommendations based on the study's findings in the following sections. Through this project, we hope to make a substantial contribution to the field of caring research and emphasize how crucial it is to develop a compassionate and supporting society for mothers of children with disabilities.

## CHAPTER II

### REVIEW OF LITERATURE

#### **Perceived social support and caregiving burden:**

Parents of disabled children as well as individuals living at home and in other settings were the subjects of a study by Heller, Hsieh, and Rowtiz (1997) that looked at both the objective and subjective components of caregiving. It also looked at how these results were influenced by the characteristics of the family, the children, and the parents' time commitments. When compared to fathers, mothers spent more time caring for others, offered more types of support, and felt more of a burden. Children's behaviour and health had a greater impact on mothers than on fathers.

Parents of children with Autism Spectrum Disorders are more likely to feel severe psychological distress than parents of children with other developmental disorders, according to a study by Bromley et al (2004). Interviews were conducted with 68 mothers of children with ASD to probe aspects of social support, mental health status, and service satisfaction in order to assess the impact of a variety of factors on psychological wellbeing. Findings showed that significant psychological discomfort was present in more than half of mothers, and that this was linked to raising children who exhibited more problematic behaviour and had little family support.

A study examines how South Korean mothers of disabled children view their responsibilities as caregivers and the social supports available to them. In the mail survey, mothers (n=181) who live in Seoul's metropolitan areas responded with a response rate of 56.6%. The respondents admitted that there was a great deal of overall hardship, particularly in the financial areas. The higher subjective caring difficulties of these women were associated with younger ages, better educational attainment, a lower level of social support, and higher

disability-related expenditures. The strongest indicator of increased caregiver burden was the higher cost of caring for a disabled individual. The findings imply that social support can reduce this burden.

The study looked at the stress of caring for people with CP, their access to social support, and their quality of life. The research design for the study was a cross-sectional survey. This study included 78 informal caregivers in all. The quality of life, social support, burden, and other patient and caregiver-related factors of CP patients' caregivers. The findings of this study demonstrated that the burden on the caregivers and the effect on their quality of life were both considerable. However the degree of burden experienced by the caregivers has no bearing on how much social assistance they feel they are receiving. Additionally, the majority of the study's carers felt a significant amount of hardship, and the perceived social support among caregivers was of a moderate intensity. Additionally, the quality of life for the caregiver was very high in every way. We came to the conclusion that informal caregivers' levels of burden, social support, and quality of life were all significantly impacted by caring for children with CP.

The findings revealed that mothers of intellectually impaired children experienced considerable burden and received insufficient social assistance. Burden and social support had a strong, adverse relationship. Stepwise regression analysis showed that the intellectually disabled children's dependent level of daily living activity, mothers' health status, social support, and amount of time spent as a caregiver, were the major predictors of caregiver's burden, which accounted for 38.4% of the total variance.

In a study, 96 mothers and 41 fathers who had 38 intellectually disabled, 29 physically challenged, and 29 developmentally at-risk children were studied for the mediating effects of social support. In order to evaluate the impacts of social support on individual well-being,

parental attitudes towards their children, family integrity, parental judgements of how children function, possibilities for parent-child play, and child behaviour and development, social system theory was used as a conceptual framework. In all sets of outcome measures, both satisfaction with support and the quantity of sources of support had main and/or interactive effects, according to a series of hierarchical multiple regression analyses by sets that took into account the socioeconomic status and income of the family, the sex and age of the children, as well as their developmental status and diagnosis. Better personal well-being, more positive attitudes, and more beneficial influences on parent-child play chances and child behaviour and development were all linked to more supportive social networks.

Parents' views of parental stress were compared between those of parents of children with developmental disabilities and those of children who are developing normally. The relationship between a few demographic characteristics, including Socio-economic Status (SES), number of children, years of marriage, parent and child ages, as well as social support, and parental stress was also examined for the mothers and fathers of these three groups. It is critical to establish accurate methods for identifying high levels of parenting stress because stress has been linked to psychological health, the potential for abuse, and a higher risk of poor adjustment for both parents and children. Mothers and fathers were shown to differ significantly from one another in terms of stress-related parenting traits. Mothers reported more limits on their parental roles, whereas fathers reported greater stress in the attachment-related areas. Significantly negative associations between parents' perceptions of the value of informal social support and parenting were also discovered. Age of the child and SES are two family demographic characteristics that have some predictive power for parenting stress in moms. Parents who had younger children and had lower SES were more likely to report feeling stressed out by parenting.

### **Prevalence of somatic symptoms in caregivers:**

**Hsing-Yi Chang, 2010** Caregiver burden and deteriorating physical and mental health are significant risks for those who provide at-home care for family members who are chronically ill. By controlling for variables like age, education level, number of hours spent caring for family members each day, and the emotional, functional, and physical support systems utilised by caregiver, this study intends to understand how family caregiver mental health and caregiver burden affect physical health concurrently. In Taiwan's Kaohsiung and Pingtung regions, we hired 388 caregivers. Caregivers must be at least 18 years old and devote the most of their time to caring for a sick family member at home. Caregiving for a long period of time was linked to poor emotional support, and high burden. Higher levels of emotional support were linked to improved mental health and fewer disease symptoms. The number of hours a day spent providing care, as well as the use of emotional, practical, and physical assistance, were linked to mental health, while the number of hours a day spent providing care and the use of physical support were indicators of burden. Caregiver health issues were concurrently and significantly correlated with mental health and burden. Our findings highlight the significant impact of carers' emotional health on their physical health. Carer interventions need to target health in a holistic approach.

Controlling for sociodemographic factors, parents of children with disability reported considerably greater physical symptoms, modestly worse psychological well-being, and higher levels of negative affect than parents of children without disabilities. In terms of their wellbeing, mothers and fathers were similar. Age-related reduction of the burden of non-normative parenting is shown by the fact that older parents were much less likely than younger parents to experience the negative effects of having a disabled kid. Negative affect and somatic symptoms were significantly influenced by gender, showing that the physical and mental health of both parents of disabled children and the comparison group varies by

gender. Compared to men, women experienced higher levels of negative emotions and more physical symptoms, although these trends were not more pronounced among parents of disabled children, but this was not the same with parents in control group.

Parental health results from the strain of caring for children with developmental disorders like Autism and Down syndrome have a tendency to focus on mental health with less attention given to the physical health repercussions. This study aimed to investigate the psychosocial factors that predicted poor physical health in these loving parents. Measures of stress, child problem behaviours, social support, mastery, and physical health were completed by 166 parents, which consisted of 109 caregivers and 58 control parents. Compared to control parents, parents of children with developmental disabilities had worse physical health. Stress and mastery were major indicators of poor physical health in parents who care for children with developmental disabilities, but not social support or problem behaviours. However, the relationship between mastery and physical health was mediated by perceived stress, so parents with higher levels of mastery reported less stress and had better physical health. In addition, the relationship between stress and physical health was mediated by social support, so parents with higher levels of social support and lower levels of stress had better physical health. These findings suggest a synergistic rather than an independent relationship exists between psychosocial stressors and poor physical health in the caring parents. Additionally, they stress how crucial it is to give multi-component interventions that provide a range of psychosocial resources to cater to the specific requirements of the parents (Joanne et.al.,2014)

A study explored the relationship between the perception of role overload and the presence of physical symptoms, as well as the potential moderating influence of social support among older adult carers. 1 471 caregivers' data from the 2017 National Study of Caregiving were examined. Participants' perceived role overload, physical symptom related activity constraints, and informal/official support sources were also evaluated during the survey.

Multiple logistic regression analysis with interaction terms were carried out. The physical symptoms and frequent activity limitations brought on by the symptoms were more likely to be experienced by caregivers who felt a greater role burden. Carer carers who received a lot of informal support showed less of the relationships between felt role overburden and discomfort and poor energy, respectively. Regarding pain, the moderating effect of formal support seems to be the opposite. The informal support of family and friends might help caregivers who feel a heavy burden avoid negative impacts on their physical health. (Soojung et. al.,2022)

A thorough examination of the literature uncovered significant shortcomings in studies of mothers, in particular, who care for children with disabilities. Few studies have found a connection between carer burden and perceived social support, but none have specifically looked at how perceived social support affects both carer burden and physical results. This study's major objective was to investigate the association between carer burden and somatic symptoms in order to determine whether perceived social support plays any kind of a part. It is crucial that mental health practitioners recognise the caregivers who are most at risk for receiving insufficient assistance and then create successful family-based interventions. To meet their unique needs and to preserve excellent mental and physical health, caregivers may need a variety of help and treatments.



## **CHAPTER III**

### **METHOD**

#### **AIM:**

To study the role of perceived social support on caregiver burden and somatic symptoms in mothers of children with disability.

#### **OBJECTIVES:**

- To find relationship among perceived social support, caregiver burden and somatic symptoms in mothers of children with disability.
- To find the role of perceived social support on caregiver burden and somatic symptoms in mothers of children with disability.
- To examine the relationship between different socio-demographic characteristics of mother and somatic symptoms.

#### **HYPOTHESES:**

- There will be significant relationship between caregiver burden and somatic symptoms in mothers of children with disability.
- There will be significant relationship between perceived social support and caregiver burden in mothers of children with disability.
- There will be significant relationship between perceived social support and somatic symptoms in mothers of children with disability.

- Perceived social support will be mediating the caregiver burden and somatic symptoms in mothers of children with disability.
- There will be a significant difference between Mother's age and somatic symptoms.
- There will be significant difference between Child's age and somatic symptoms in mothers.
- There will be significant difference in family type and somatic symptoms.
- There will be significant difference in number of children with disability and somatic symptoms.
- There will be significant difference in type of disability and somatic symptoms.

**SAMPLING DESIGN:**

Correlational Research Design.

**SAMPLING METHOD:**

Purposive sampling

**SAMPLE:**

Mothers of children with disability who are availing services in NIEPMD.

**SAMPLE SIZE:** 60

**TOOLS:**

- Consent form
- Socio demographic data sheet
- Multidimensional Scale of Perceived Social Support (Gregory Zimet, 2016).
- Zarit Scale of Caregiver Burden- Short (Zarit, SH et. al, 2001).

- Scale for Assessment of Somatic Symptoms-Revised (Desai et. al., 2015).

**INCLUSION CRITERIA:**

- Mothers of children with disability who are availing services from NIEPMD.
- Mothers who are primary caregivers.
- Mothers aged between 25-45 years.

**EXCLUSION CRITERIA:**

- Mothers who are diagnosed with any psychiatric and neurological condition.
- Mothers who are diagnosed with chronic pain and other medical illness.
- Mothers who are single parent.

**Multidimensional Scale of Perceived Social Support (MSPSS):**

Participants' perceptions of social support from three informal sources—family, friends, and significant others—were examined by the 12-item MSPSS. Participants gave their opinions using a seven-point Likert scale, with 1 denoting "very strongly disagree" and 7 denoting "very strongly agree." Items like "I get the emotional support and help I need from my family" are also included. Higher scores indicate better overall perceived social support from all three sources. The total scores range from 12 to 84. MSPSS was tested by Zimet et al., who noted a high internal consistency of 0.88. After completing the survey, test-retest reliability of 0.85 was noted across a 2- to 3-month period. In the current study, MSPSS has a Cronbach's alpha of 0.92.

### **Zarit Scale of Caregiver Burden- Short (ZSCB-S):**

The 12-item ZBI-S was chosen for the study to measure caregiver burden. Participants gave their opinions using a five-point Likert scale (0 = "never" to 4 = "almost always"). Included are questions like "Do you feel tense around your relative?" Greater burden is indicated by higher total scores, which range from 0 to 88. In this study, ZBI has a Cronbach's alpha of 0.93.

### **Scale for assessment of somatic symptoms- Revised (SASS-R):**

The scale has 20 items with 4 Likert-scale with levels of severity and four subscales namely pain related symptoms, biological function-related symptoms, nonspecific somatic symptoms, and sensory somatic symptoms. The severity of somatic symptoms is graded on a scale of 1 to 3, with 1 denoting mild symptoms, 2 denoting moderate symptoms, and 3 denoting severe symptoms. If the somatic symptoms started within the preceding two weeks, they are considered to be current. The test-retest's Cronbach's alpha was 0.982 and 0.840, both of which indicate strong internal consistency. Validity: Rather than being a diagnostic or analytical scale, the scale is merely descriptive. The words used are simple to understand and taken from the common English language for bodily complaints. For such metrics, no specific validity checks are required.

### **PROCEDURE:**

The consent form to participate in the research study is given to mothers of children with disability. Samples those who meet the inclusion criteria were selected for the study. Multidimensional Scale of Perceived Social Support (MSPSS), Zarit Caregiver Burden Assessment- Short (CBA-S) and Scale of Assessment of Somatic Symptom- Revised (SASS-R) were distributed individually. Respondents' anonymity was guaranteed by asking them not to write their names or other identification.

**STATISTICAL ANALYSES:**

- The data collected will be subjected to Statistical analysis using SPSS 20.0.
- Descriptive statistics to describe demographic variables.
- Pearson's correlation to find relationship among variables.
- Independent sample t-test& ANOVA to find out the differences among groups of the study variables.
- Haye's process to find moderating/ mediating effects on IV and DV.

## CHAPTER V

### RESULTS & DISCUSSION

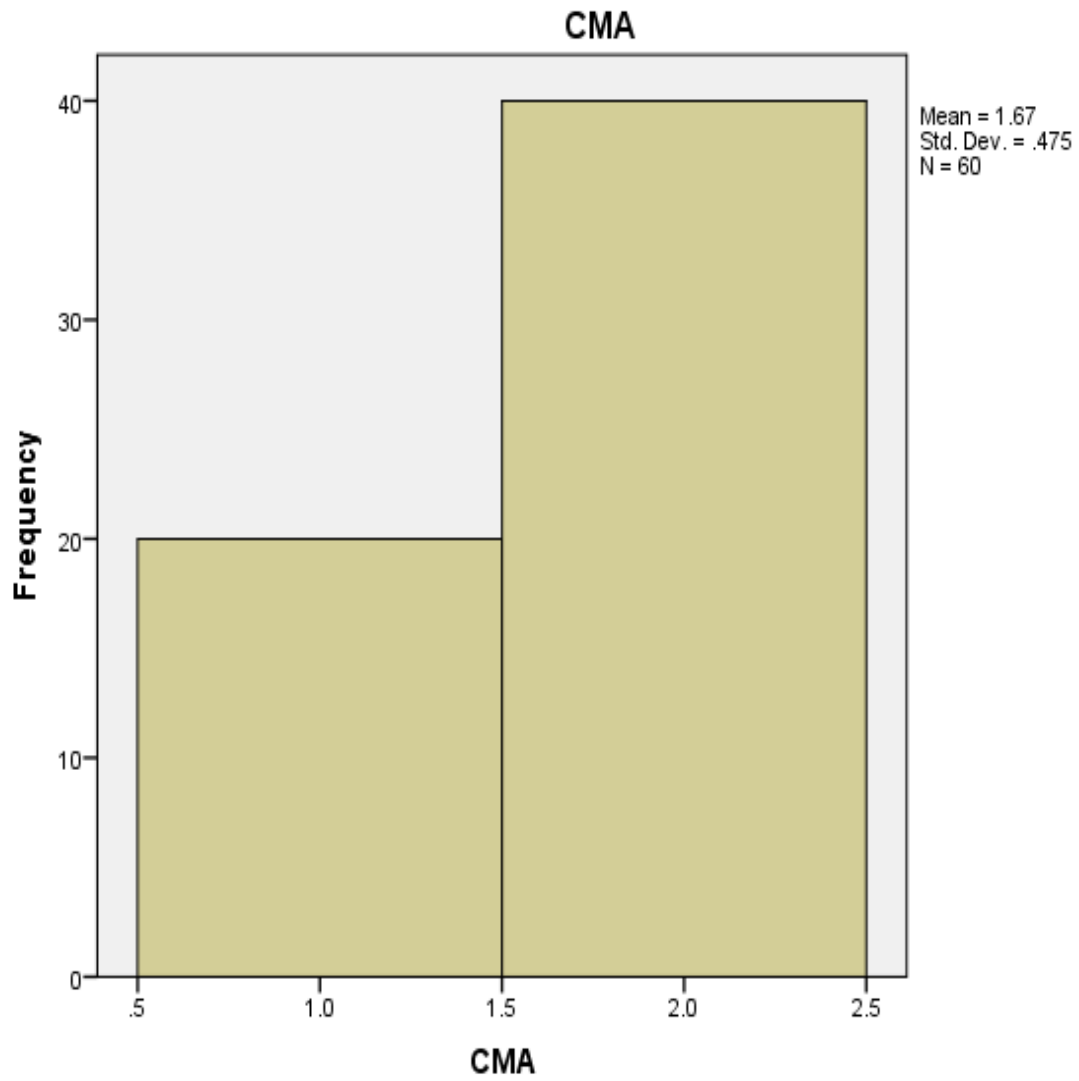
The study aim is to understand how caregiver burden and somatic symptoms in mothers of disabled children are influenced by perceived social support. 60 mothers who have been raising disabled children make up the sample. Data was collected, and descriptive and inferential approaches were used to test the study's hypotheses.

*Table 4.1 Descriptive statistics of the socio-demographics details (N=60)*

Variables	Groups	Frequency	%
Mother's age	25-35	20	21%
	36-45	40	42%
Child's age	7-12	32	34%
	13-18	28	29%
Family type	Nuclear	36	38%
	Joint	24	25%
Number of children with disability	1	53	56%
	2	7	7%
Type of Disability	UD	26	27%
	MD	34	36%

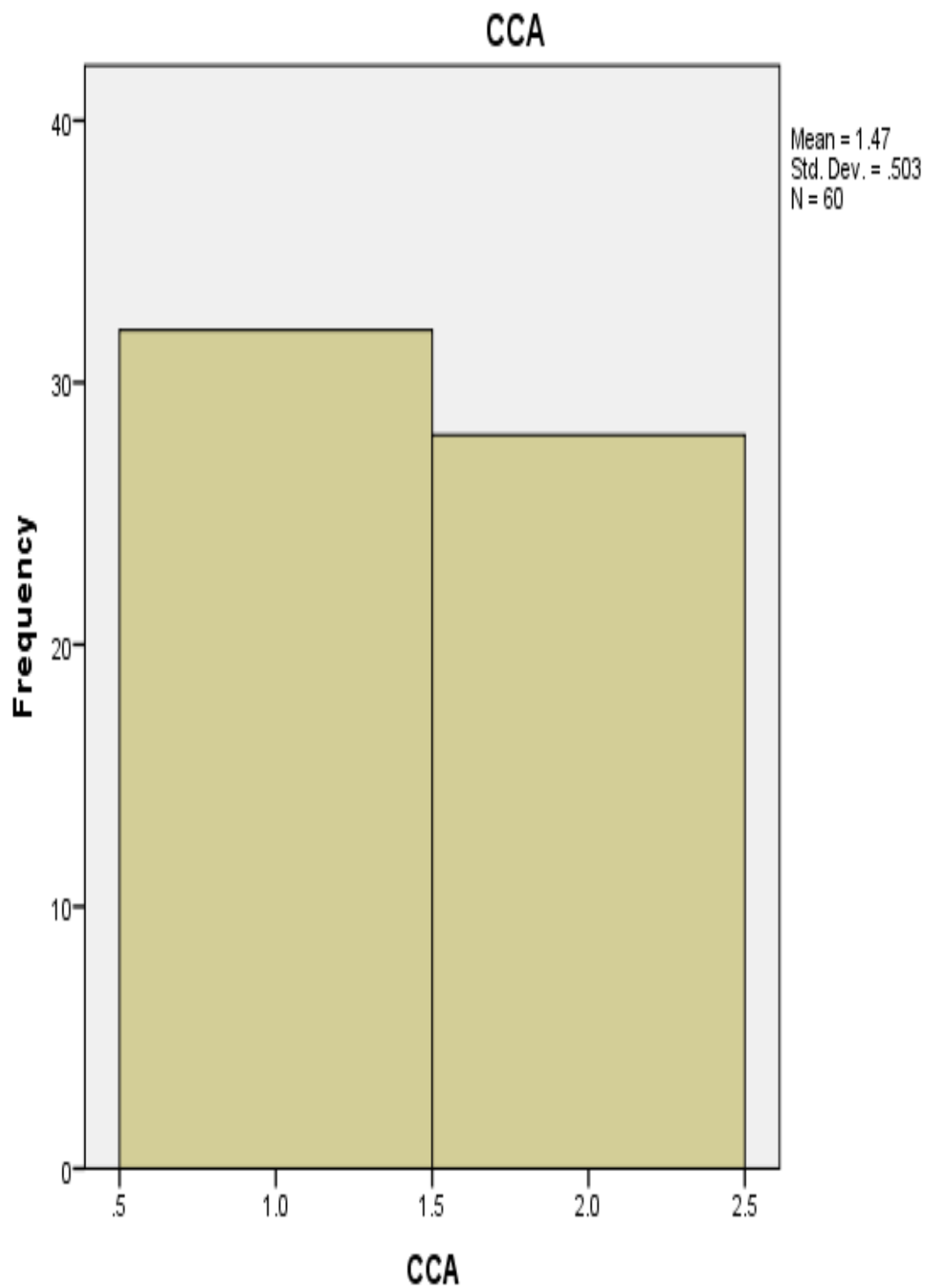
From Table 4.1, presents demographic information of the sample taken into the study comprises 60 mothers of children with disability, 20 (21%) mothers belonging to the age group between 25-35 and 40 (42%) mothers belonging to age group between 36-45, 32 (34%) of child's age group between 7-12 and 28 (29%) of child's age group between 13-18,

36 (38%) were from nuclear family and 24 (25%) were from a joint family, 53 (56%) were with single child disability and 7 (7%) were with two children with disability, 26 (27%) were with Uni disability and 34 (36%) were with multiple disabilities.

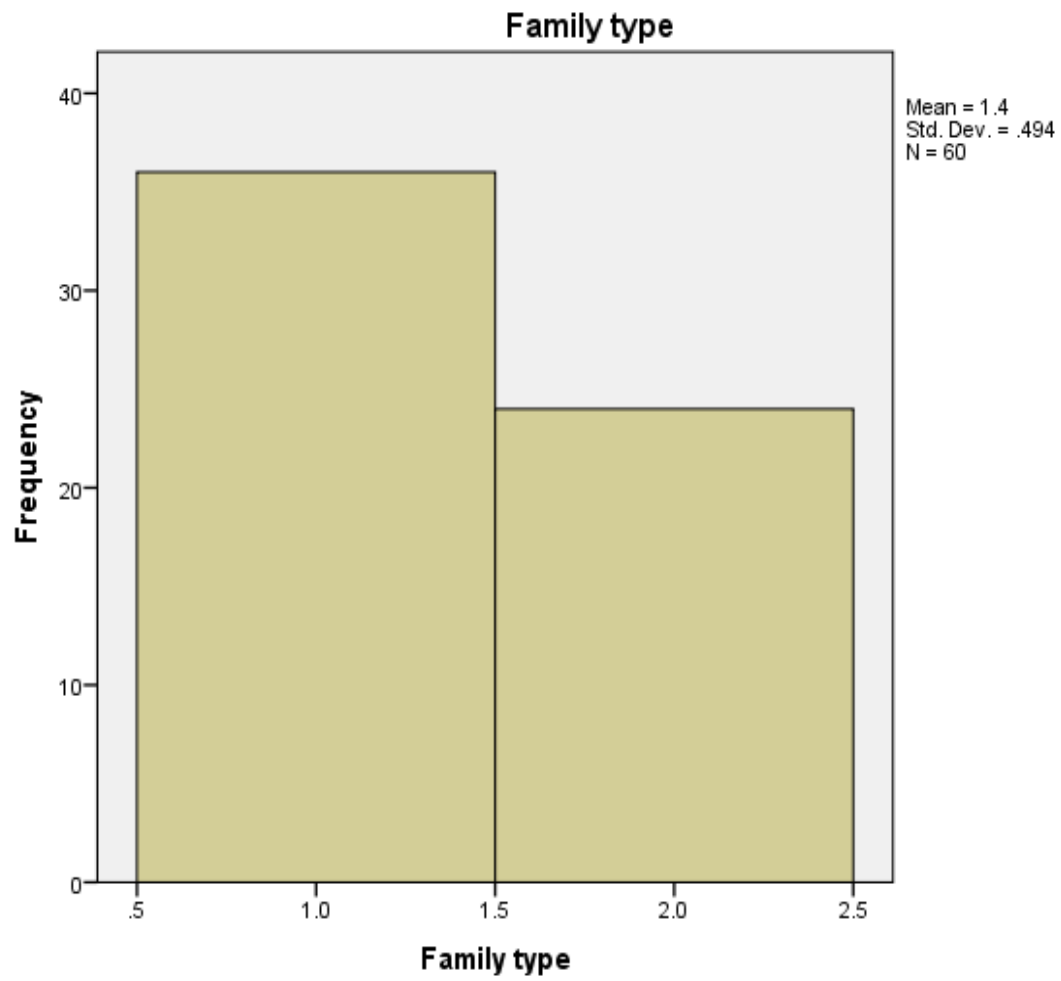


*Figure 3, Shows graphical representation of frequency distribution of mother's age*

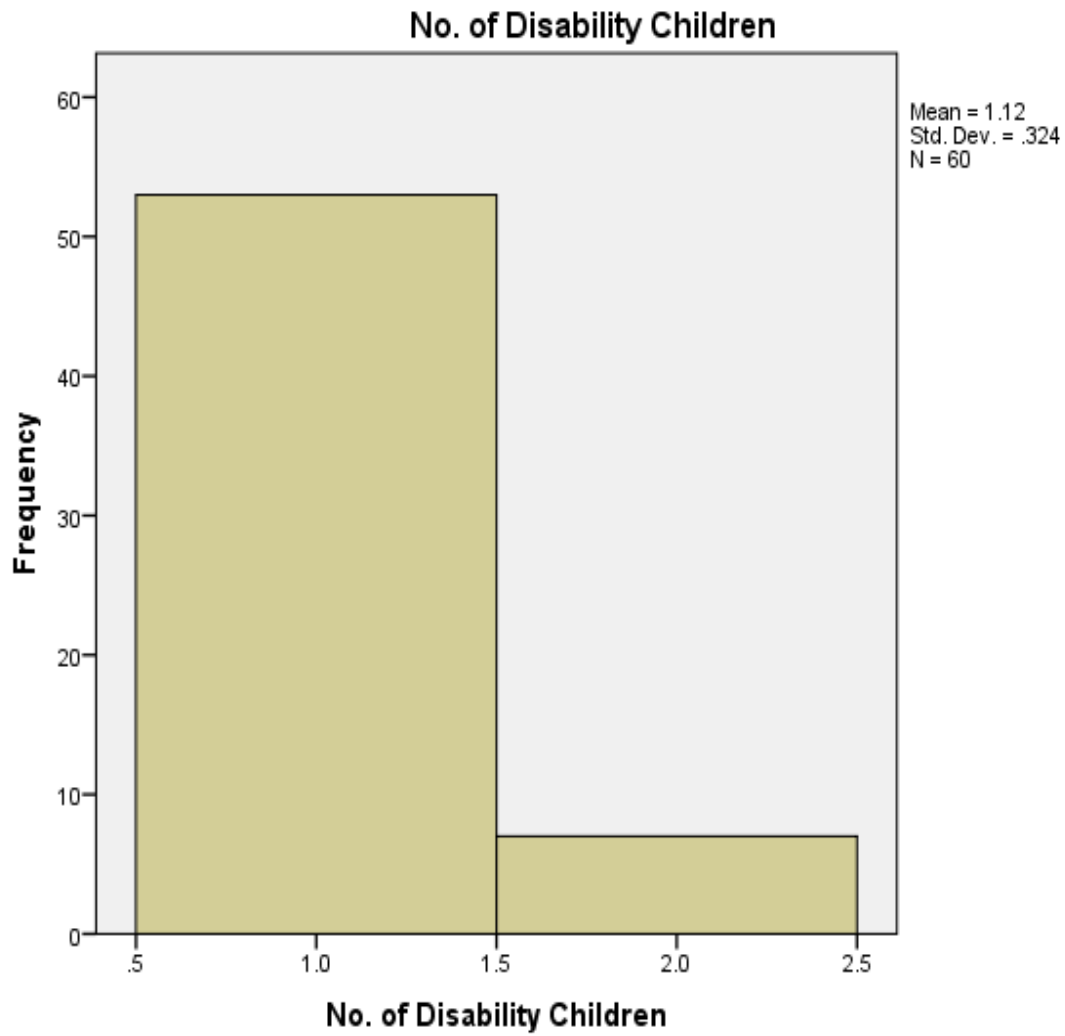




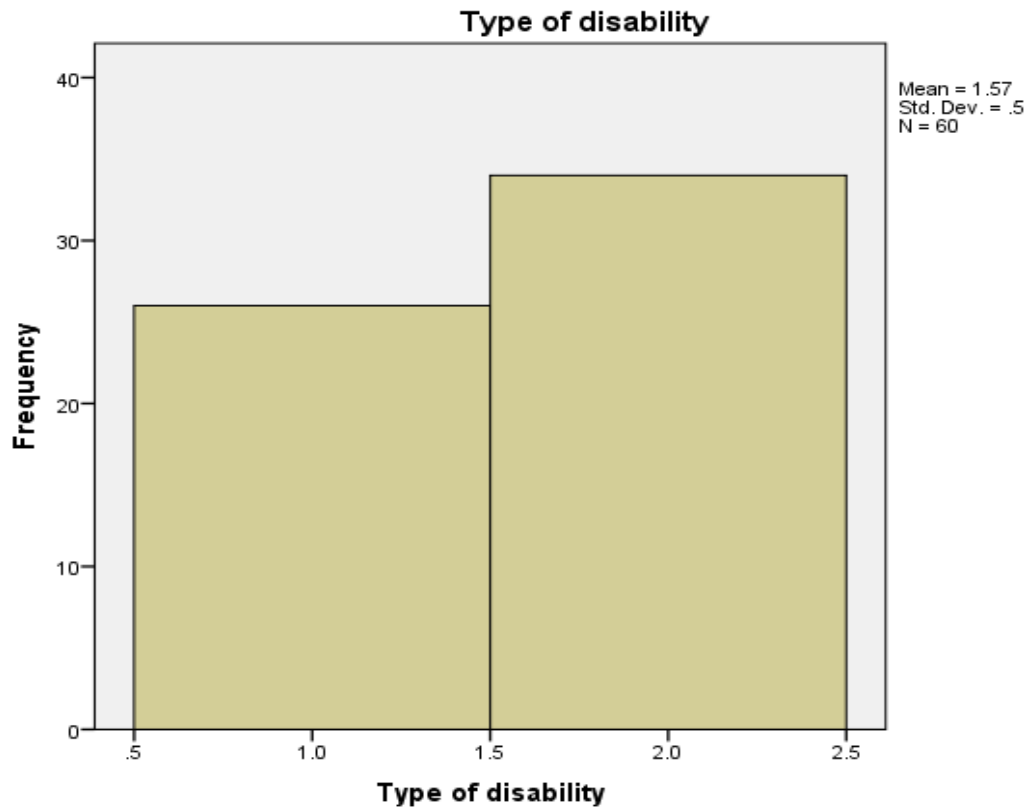
*Figure 4, Shows graphical representation of frequency distribution of Child's age groups*



*Figure 5, shows graphical representation of frequency distribution of family type*



*Figure 6, shows graphical representation of frequency distribution of the Number of children with disability*



*Figure 7, shows graphical representation of frequency distribution of type of disability of the child*

**Table 4.2 Karl Pearson Correlation coefficient between Perceived social support, caregiver burden and somatic symptoms**

Variables	Perceived social support	Caregiver burden	Somatic symptoms
Perceived social support	-	-	-
Caregiver burden	<b>-.363**</b>	-	-
Somatic symptoms	-.086	<b>.339**</b>	-

\* $p < 0.001$

From table 4.2, it is inferred that there is significant negative correlation between perceived social support and caregiver burden at  $r = -.363$ ,  $p < .001$ . Similarly, there is positive correlation between caregiver burden and somatic symptoms  $r = .330$ ,  $p < .001$  and no significant relationship was found between perceived social support and somatic symptoms  $r = -.086$ ,  $p < .001$ . Hence, we accept hypothesis that “There will be significant relationship between perceived social support, caregiver burden and somatic symptoms.

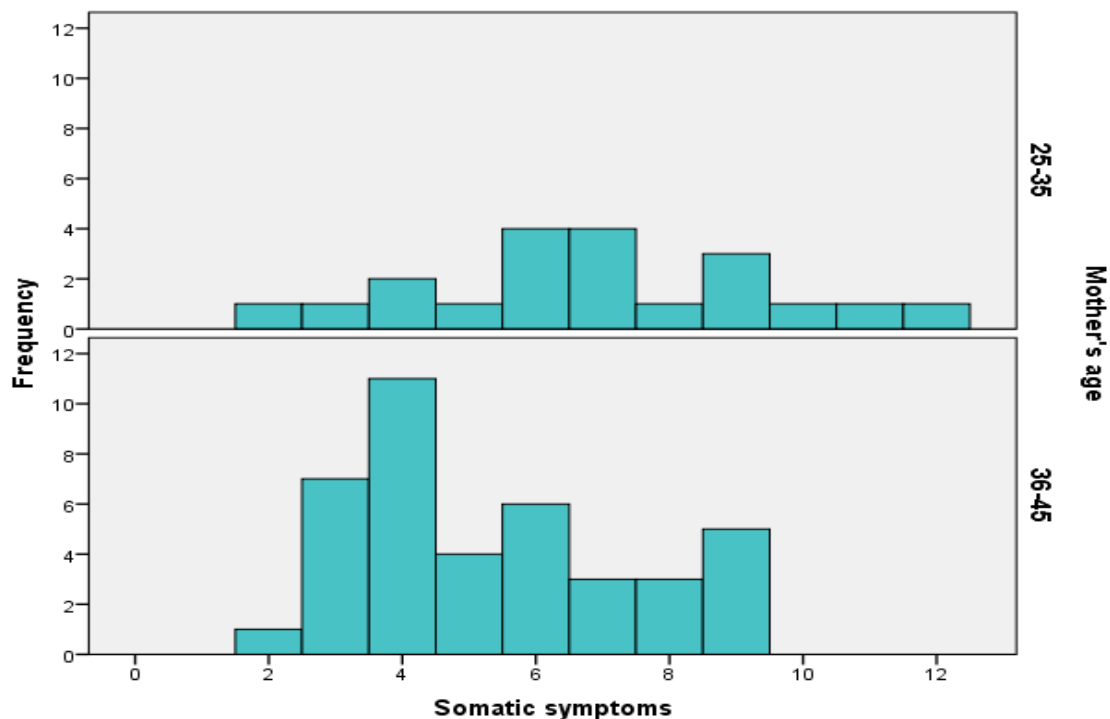
**Table 4.3 Independent sample t-test statistic for mothers' age and somatic symptoms**

Variables	Groups	Mean	SD	T	P-Value
Mother's Age	25-35	6.90	2.614	2.535*	.006982
	36-45	5.33	2.080		

\* $P < 0.05$

From the table 4.3, the results are that there is significant difference in somatic symptoms among the two different age groups of mothers of children with disability,  $t = 2.535^*$ ,  $p < 0.05$ .

There is a significant difference in the mean values of somatic symptoms of group 25-35 ( $M=6.90$ ,  $SD=2.614$ ) and somatic symptoms of group 36-45 ( $M=5.33$ ,  $SD= 2.080$ ). Hence, the hypothesis, "There will be a significant difference between Mother's age and somatic symptoms" is accepted.



**Figure 8, Shows graphical representation of frequency distribution of mothers age and somatic symptoms**

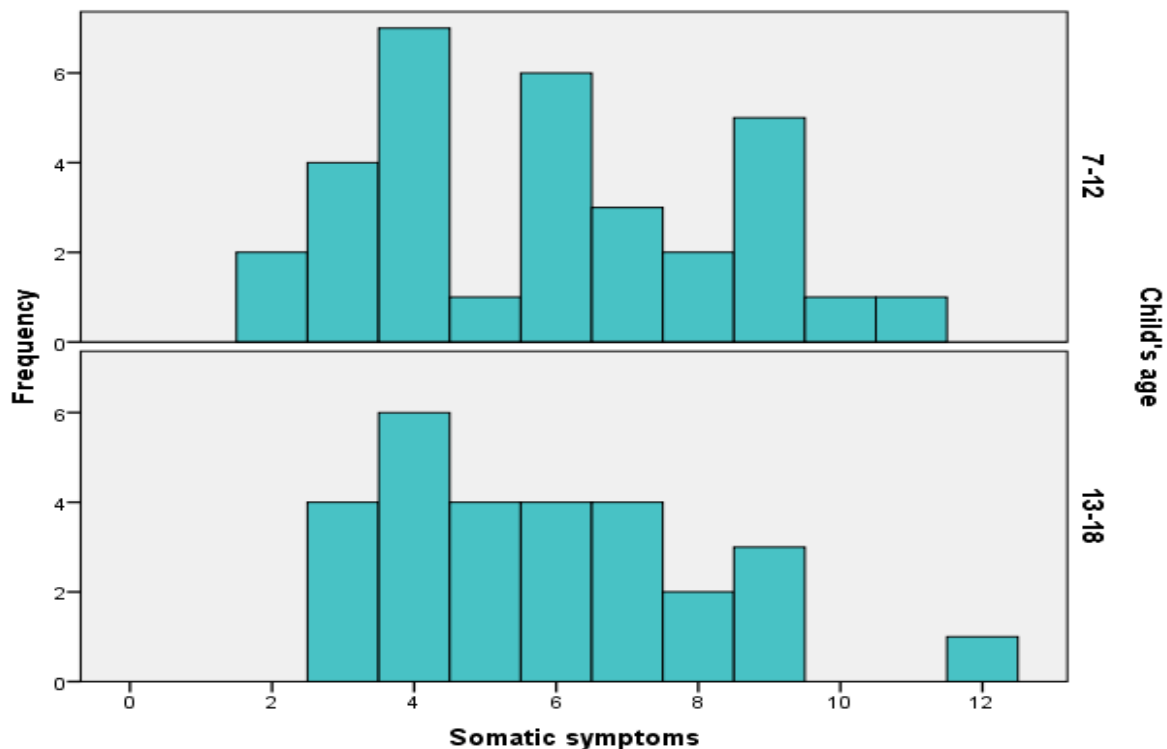
**Table 4.4 Independent sample t-test statistic for child's age and somatic symptoms**

Variables	Groups	Mean	SD	T	P-Value
Child's Age	7-12	5.88	2.498	.87 <sup>NS</sup>	.193943
	13-18	5.82	2.262		

*\*P<0.05: NS- Not significant*

From the table 4.4, the results are that there is no significant difference in somatic symptoms among the two different age groups of children with disability,  $t= 2.535^*$ ,  $p< 0.05$ . There is no significant difference in the mean values of somatic symptoms of group 7-12 ( $M=5.88$ ,  $SD=2.498$ ) and somatic symptoms of group 13-18 ( $M=5.82$ ,  $SD= 2.262$ ).

Hence, the hypothesis, "There will be a significant difference between Child's age and somatic symptoms" rejected.



**Figure 9, Shows graphical representation of frequency distribution of child's age and somatic symptoms**

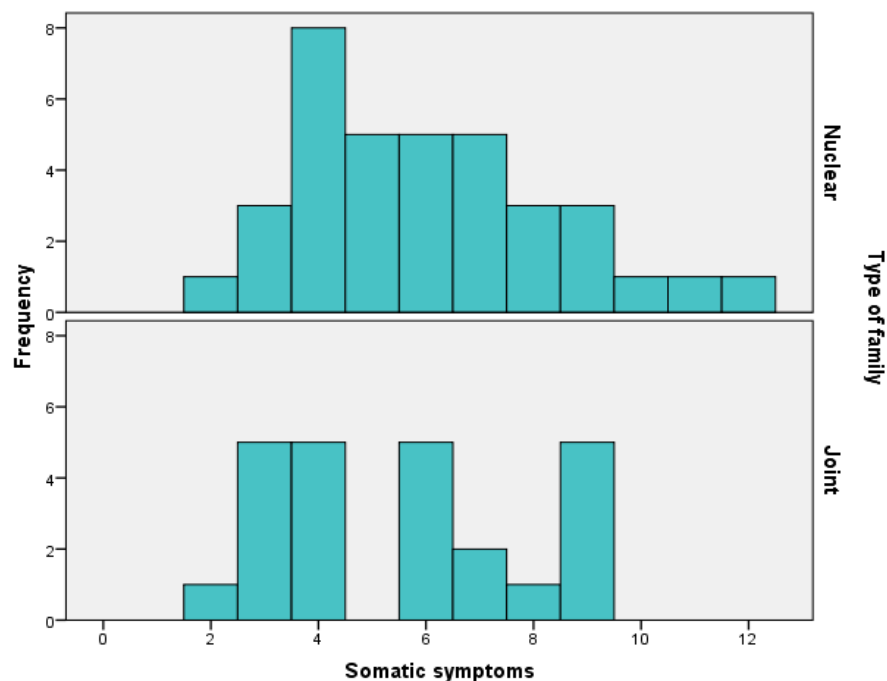
**Table 4.5 Independent sample t-test statistic for type of family and somatic symptoms**

Variables	Groups	Mean	SD	T	P-Value
Type of family	Nuclear	6.03	2.396	.708 <sup>NS</sup>	.24089
	Joint	5.58	2.358		

*\*P<0.05: NS- Not significant*

From the table 4.5 the results are that there is no significant difference in somatic symptoms among the type of family,  $t = .708^*$ ,  $p < 0.05$ . There is no significant difference in the mean values of somatic symptoms nuclear ( $M = 6.03$ ,  $SD = 2.396$ ) and somatic symptoms of group joint ( $M = 5.58$ ,  $SD = 2.358$ ).

Hence, the hypothesis, “There will be a significant difference between type of family and somatic symptoms” rejected.



**Figure 10, Shows graphical representation of frequency distribution of family type and somatic symptoms**



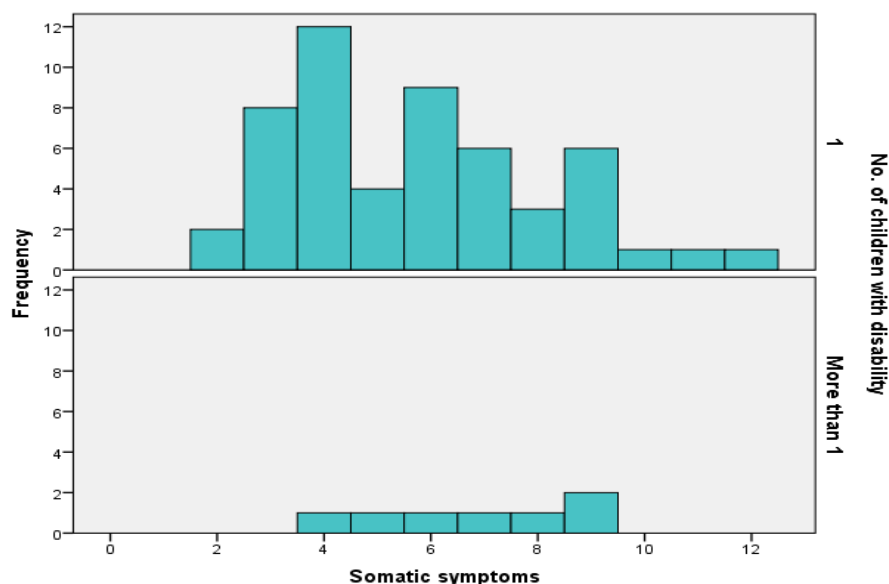
**Table 4.6 Independent sample t-test statistic for groups of Number of children with disability and somatic symptoms**

Variables	Groups	Mean	SD	T	P-Value
No. of Children with disability	1	5.72	2.405	-1.200 <sup>NS</sup>	.117509
	2	6.86	1.952		

*\*P<0.05: NS- Not significant*

From the table 4.6, the results show that there is no significant difference in somatic symptoms and number of children with disability,  $t = -1.200^*$ ,  $p < 0.05$ . There is no significant difference in the mean values of somatic symptoms of mothers with single child with disability 7-12 ( $M=5.72$   $SD=2.405$ ) and somatic symptoms of mothers with more than one children with disability 13-18 ( $M=6.86$ ,  $SD= 1.952$ ).

Hence, the hypothesis, “There will be a significant difference between number of children and somatic symptoms” rejected.



**Figure 11, Shows graphical representation of frequency distribution of number of children with disability and somatic symptoms**

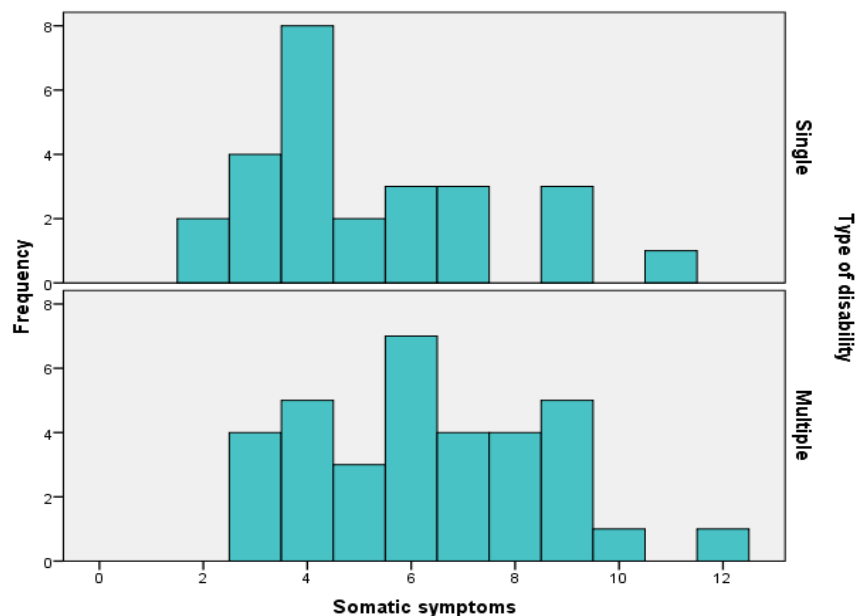
**Table 4.7 Independent sample t-test statistic for Type of disability and somatic symptoms**

Variables	Groups	Mean	SD	T	P-Value
Type of Disability	Single	5.19	2.367	<b>-1.921*</b>	<b>0.29826</b>
	Multiple	6.35	2.281		

**\*P<0.05**

From the table 4.7, the results show that there is no significant difference in somatic symptoms among the type of disability,  $t = -1.921^*$ ,  $p < 0.05$ . There is significant difference in the mean values of somatic symptoms with single ( $M=5.19$ ,  $SD=2.367$ ) and somatic symptoms with multiple disability ( $M= 6.35$ ,  $SD= 2.28$ ).

Hence, the hypothesis, “There will be a significant difference between type of disability and somatic symptoms” accepted.



**Figure 12, Shows graphical representation of frequency distribution of type of disability and somatic symptoms**

On analysing, differences between somatic symptoms and socio demographics variables. The above tables explain the differences in somatic symptoms of mothers and socio-demographic variables. There is a significant difference found in the somatic symptoms in mothers for mother's age,  $t(2.535^*)$ ,  $M= 1.67$ ,  $SD= .475$ . Similarly, there is a significant difference found in the somatic symptoms in mothers for the type of disability,  $t(-1.291^*)$ ,  $M= 1.57$ ,  $SD=1.95$ .

**Table 4.8 A Model summary of mediation analysis with outcome as perceived social support**

<b>R</b>	<b>R<sup>2</sup></b>	<b>MSE</b>	<b>F</b>	<b>df1</b>	<b>df2</b>	<b>Sig.</b>
3633	.1320	159.8283	8.8195	1.0000	58.0000	.0043

**Table 4.8 B Coefficient statistic of mediation analysis with outcome as perceived social support**

<b>Model</b>	<b>Coeff</b>	<b>SE</b>	<b>T</b>	<b>Sig.</b>	<b>LLCI</b>	<b>ULCI</b>
Constant	76.2028	4.0639	18.7511	.0000	68.0679	84.3377
Caregiver burden	-.5787	.1949	-2.9698	.0043	-.9687	-.1886

**Table 4.8 C Model summary of mediation analysis with outcome as somatic symptoms**

<b>R</b>	<b>R<sup>2</sup></b>	<b>MSE</b>	<b>F</b>	<b>df1</b>	<b>df2</b>	<b>Sig.</b>
.3417	.1167	5.1392	3.7666	2.0000	57.0000	.0291

**Table 4.8 D Coefficient statistic of mediation analysis with outcome as somatic symptoms**

<b>Model</b>	<b>Coeff</b>	<b>SE</b>	<b>T</b>	<b>Sig.</b>	<b>LLCI</b>	<b>ULCI</b>
Constant	3.4527	1.9366	1.7829	.0799	-.4253	7.3306
Caregiver burden	.0996	.0375	2.6565	.0102	.0245	.1747
Perceived social support	.0076	.0235	.3223	.7484	-.0396	.0547

*Table 4.8 E Direct effect of caregiver burden and somatic symptoms*

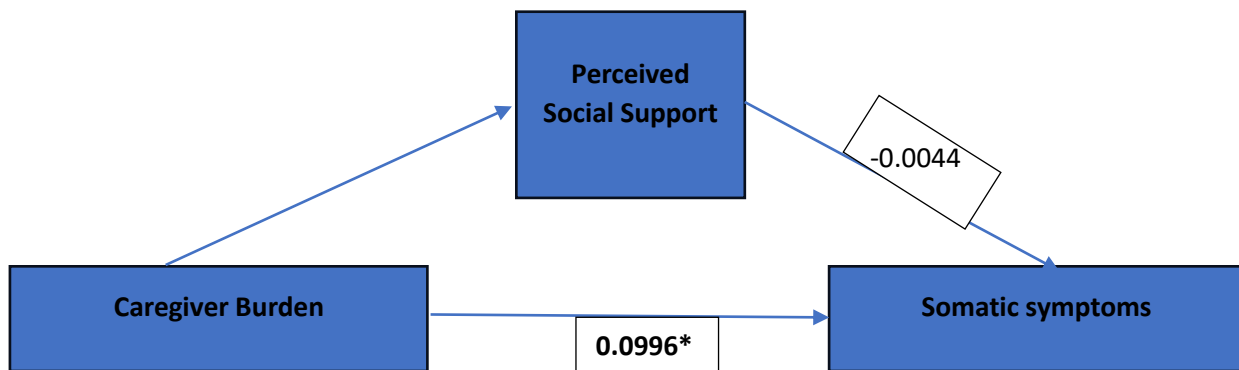
Effect	Se	T	Sig.	LLCI	ULCI	C'
.0996	.0375	2.6565	.0102	.0245	.1747	.3549

*Table 4.8 F Indirect effect of caregiver burden, perceived social support and somatic symptoms*

	Effect	BootSE	BootLLCI	BootULCI
Perceived social support	-.0044	.0153	-.0256	.0366

*Table 4.8 G Mediation Analysis Summary*

Relationship	Direct effect	Indirect effect	Confidence interval		T	Conclusion
			Lower bound	Upper bound		
Caregiver burden -> Perceived social support-> Somatic symptoms	0.0996	-0.0044	-.0256	.0366	2.6565	No mediation



*Figure 13, shows Mediation Analysis*

Table 4.8A, B, C, D, E, F and G reveals the results of the mediation analysis performed by using Hayes Process Macro to assess the role of perceived social support on caregiver burden and somatic symptoms. A direct effect was found between the Caregiver burden and somatic symptoms. Similarly, between the Caregiver burden and Perceived social support. But there was no indirect effect found in the presence of the mediator variable i.e., perceived social support did not mediate between the caregiver burden and somatic symptoms. Hence the hypothesis stated, “Perceived social support will have a mediating role on caregiver burden and somatic symptoms” is rejected.

The study aimed at finding the role of perceived social support between caregiver burden and somatic symptoms and to examine the difference in somatic symptoms and socio-demographic variables.

On finding the relationship between the study variables, perceived social support, caregiver burden and somatic symptoms, the results revealed that there is a significant positive correlation between caregiver burden and somatic symptoms. Similar results were found in the earlier research by Jung Hwa Ha et. al., (2018), which shows that having a child with a

disability is associated with more somatic symptoms. However, the negative consequences of the child's disability on parents' mental health are reduced when parents receive greater positive support from the family. Similarly, a significant negative relationship was found between perceived social support and caregiver burden. Research by Heykyung Oh & Eun Kyoung Othelia Lee (2009) has proved that, mothers of children with disabilities had a high level of strain and received inadequate social support indicating a negative correlation between social support and strain. Though the findings of the current study are in line with this, the participants have reported to have perceived adequate social support leading to less caregiver burden.

On finding the difference among mothers between those who are below 35 years and above 35 years of age, the experience of caregiver burden and experience of somatic symptoms were significantly low in the mothers whose age was high (36-45 years). This could be due to their better experience in parenting a child with disability and a certain level of resilience and adaptability built over the period. This allows them to handle the challenges of parenting a child with a disability with less negative impact compared to the younger parents. Along with this, the other factors which could have contributed for their better functioning are accumulated life experience, better emotional regulation, more stable financial situations, and a broader support network (Sommer, 1993). Study by Bromley et.al., (2004) has provided the same that older parents were significantly less likely to experience the negative effect of having a child with disability than younger parents, suggesting an age-related attenuation of the burden.

A significant difference was also found in the type of disability and somatic symptoms in mothers. Mothers of children with multiple disabilities were reported to have experienced more somatic symptoms when compared to mothers of children with single disability.

Naturally, the amount of support needed for a child with more than one disability is higher as they need more time and efforts from the parents, especially mothers in Indian context. The caregiving responsibilities can be more complex and challenging, as they require long term care and coordinating multiple therapy requirements of the child can potentially lead to higher levels of stress, physical strain and somatic symptoms in those mothers. This goes in line with the study by Pahl and Quine (1987), the results show a significant association between the physical and mental health of mothers and multiple impairments of the children. Children with more serious disabilities as indicated by the multiplicity of diagnoses, the combination of a physical and a mental problem, and the higher functional dependency.

The current study also explored the differences in the child's age, number of children with disability and family type. However, no significant differences were found among these groups in the levels of somatic symptoms in mothers. This indicates that regardless of family type, the caregiver burden is lesser when they tend to have a strong support network.

On analysing mediating effect of perceived social support on caregiver burden and somatic symptoms, the current findings reveals that there is a significant direct effect between caregiver burden and somatic symptoms. But no indirect effect was found in the presence of perceived social support. These results could be attributed to the fact that the caregiver burden and the experience of somatic symptoms were relatively less in the participants of the current study which could not elicit the mediating effect of the perceived social support on these variables. In addition to this, some caregivers may be more resilient and less affected by caregiver burden, so perceived social support may not significantly influence their somatic symptoms. Another possibility could be the relationship between these variables might be influenced by cultural and social norms. In some cultures, caregivers may be less likely to



report somatic symptoms or may have different expectations regarding social support, making it less relevant as a mediator.

## CHAPTER V

### SUMMARY AND CONCLUSION

The aim of the study was to examine the role of perceived social support on caregiver burden and somatic symptoms in mothers of children with disability. It also examined the relationship between variables and differences among socio-demographic variables of the study.

The study was conducted among 60 mothers of children availing services at NIEPMD, Chennai. The measures used to collect data was a multi-dimensional scale for Perceived social support, Somatic symptoms scale, and Zarit's Caregiver burden. The data were analysed using descriptive statistics like mean and Standard Deviation and Inferential statistics like Pearson Correlation coefficient, Independent sample t-test, and Mediation analyses.

<b>Hypotheses</b>	<b>Statements</b>	<b>Accepted/ Rejected</b>
H <sub>1</sub>	There will be significant relationship between caregiver burden and somatic symptoms in mothers of children with disability.	<b>Accepted</b>
H <sub>2</sub>	There will be significant relationship between perceived social support and caregiver burden in mothers of children with disability.	<b>Accepted</b>

H <sub>3</sub>	There will be significant relationship between perceived social support and somatic symptoms in mothers of children with disability.	Rejected
H <sub>4</sub>	Perceived social support will be mediating the caregiver burden and somatic symptoms in mothers of children with disability.	Rejected
H <sub>5</sub>	There will be significant difference between Child's age and somatic symptoms in mothers.	Rejected
H <sub>6</sub>	There will be significant difference between Mother's age and somatic symptoms.	<b>Accepted</b>
H <sub>7</sub>	There will be significant difference in family type and somatic symptoms.	Rejected

H <sub>8</sub>	There will be significant difference in number of children with disability and somatic symptoms.	<b>Rejected</b>
H <sub>9</sub>	There will be significant difference in type of disability and somatic symptoms.	<b>Accepted</b>

The results were:

- There is a significant relationship between Caregiver burden and somatic symptoms.
- There is a significant relationship between caregiver burden and perceived social support.
- There is no significant relationship between perceived social support and somatic symptoms.
- Perceived social support has no mediating role on caregiver burden and somatic symptoms.
- There is more experience of somatic symptoms among the mothers of children with multiple disabilities.
- There is more experience of somatic symptoms among mothers who are 35 years and less.

**Implications:**

- Research in this domain has the potential to not only augment theoretical knowledge but also to provide practical implications for various stakeholders involved in the well-being of mothers caring for children with disabilities.
- Health professionals, policymakers, and support organizations can draw valuable insights from this study to develop tailored interventions and support programs that address the unique needs of these caregivers.
- Ultimately, a comprehensive understanding of the role of perceived social support can pave the way for a more compassionate and supportive society, fostering an environment where mothers of children with disabilities can flourish amidst their caregiving responsibilities.

**Limitations of the study:**

- Sample size was small
- Confounding variables like duration of therapy undertaken for child and mothers themselves were neglected.

**Recommendations for future research:**

- The research can be done using a larger sample and longitudinally considering other factors that could mediate caregiver burden and somatic symptoms.
- Multiple mediating factors can be considered in research than a single factor to examine the effects on somatic symptoms.
- Further research can focus on identifying possible factors and sample characteristics like the number of years of therapy the child is undergoing.
- Comparison can be made with a group of caregivers who are not availing services anywhere.

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## APPENDICES

### INFORMED CONSENT FORM

#### ROLE OF PERCEIVED SOCIAL SUPPORT ON CAREGIVER BURDEN AND SOMATIC SYMPTOMS IN MOTHERS OF CHILDREN WITH DISABILITY

Researcher: Ms. Shama Anzum

Guide: Ms. Anandhalakshmi

#### STUDY INFORMATION SHEET

In this research, I plan to assess Role of perceived Social Support on Caregiver Burden and somatic symptoms of caregiver with children with disability. As caregiver exhibit responses to stressful conditions which puts their physical and mental health at risk. It is important that health professionals identify those caregivers at risk from inadequate support and then develop effective family-based interventions. Caregivers may require different assistance and interventions to meet their individual needs and to maintain good mental and physical health.

#### **Does this study involve any expenses?**

No, it does not have any fees.

#### **Is it legally enforceable?**

No, this is not a legally binding document. It is a research document.

#### **Who will be asked to fill the questionnaire?**

Caregiver of children with Disability will be asked regarding the somatic symptoms, caregiver burden and perceived social support.

#### **Will there be any negative consequences if I participate?**

No, this study procedure will not have any negative effects for the participant.

#### **Voluntary Participation**

Your participation in this study is completely voluntary and you can refuse to answer any question. You will be asked a series of questions by the researcher and your responses will be documented. This study does not involve any laboratory tests or any invasive procedure.

**Withdraw from the study:**

You are free to choose whether or not you want to be a part of this study. Saying “NO” will not affect your relationship with the researcher and the institute.

**Confidentiality:**

The personal information given by you will be kept confidential. Only members of the research team will know your name and details. Your name will not appear in any report or publication. However, the overall results will be published in the research journals.

**Undertaking by the researcher:**

Your consent to participate in the above research by Ms. Shama Anzum, M Phil., Clinical Psychology, NIEPMD, Chennai is sought. You have the right to refuse consent or withdraw the same during any part of the research without giving any reason. If you have any doubts about the research, you are free to contact either the researcher (Ms. Shama Anzum- Mob: 9384421934) or guide (Ms. Anandhalakshmi- 044-27472113) for clarification if you so.

The information provided by you will be kept strictly confidential.

**Consent to participate in research study**

	YES/ NO
I confirm that I have had adequate explanation and have clearly understood the information sheet of the study and have had the opportunity to ask questions.	
I understand that my participation is voluntary and I am free to withdraw from the study at any time without giving a reason.	
I understand that I will have to respond to the series of questions asked by researcher.	
I understand that all personal information I share will be kept confidential and will not be shared with anyone other than those involved in the research study.	

I agree to take part in the above study voluntarily.	
I have received a copy of the study information sheet and consent form	

Name of the participant:

Signature:

Name of the Researcher:

Signature:

ஆராய்ச்சியாளர்: செல்வி. ஷமாஅஞ்சம்

வழிகாட்டி: செல்வி.ஆனந்தலட்சுமி

### **ஆய்வதகவல்தாள்**

இந்தஆராய்ச்சியில்,

பராமரிப்பாளர்சுமைமற்றும்குறைபாடுள்ளகுழந்தைகளுடன்பராமரிப்பாளரின்உடல்ரீதியானஅறிகுறிகளில்உணரப்பட்டசமூகஆதரவிற்பங்கைமதிப்பிடதிட்டமிட்டுள்ளேன்.

பராமரிப்பாளர்அவர்களின்உடல்மற்றும்மனஆரோக்கியத்தைஆபத்தில்ஆழ்த்தும்மனஅழுத்தசூழ்நிலைகளுக்குபதில்களைவெளிப்படுத்துகிறார்.

போதியஆதரவிறமையால்ஆபத்தில்உள்ளபராமரிப்பாளர்களைசுகாதாரவல்லுநர்கள்கண்டறிந்துபின்னர்பயனுள்ளகுடும்பஅடிப்படையிலானதலையீடுகளைஉருவாக்குவதுமுக்கியம்.

பராமரிப்பாளர்களுக்குஅவர்களின்தனிப்பட்டதேவைகளைப்பூர்த்திசெய்வதற்கும்,

நல்லமனமற்றும்உடல்ஆரோக்கியத்தைப்பேணுவதற்கும்பல்வேறுஉதவிகள்மற்றும்தலையீடுகள்தேவைப்படலாம்.

### **இந்தஆய்வில்ஏதேனும்செலவுகள்உள்ளதா?**

இல்லை, இதற்குஎந்தகட்டணமும்இல்லை.

### **இதுசட்டப்படிஅமலாக்கப்படுமா?**

இல்லை, இதுசட்டப்பூர்வஆவணம்அல்ல. இதுஒருஆய்வுஆவணம்.

### **கேள்வித்தாளைநிரப்பயாரிடம்கேட்கப்படும்?**

ஊனமுற்றகுழந்தைகளைப்பராமரிப்பவர்உடலியல்அறிகுறிகள்,  
பராமரிப்பாளரின்சுமைமற்றும்உணரப்பட்டசமூகஆதரவுகுறித்துகேட்  
கப்படுவார்.

**நான்பங்கேற்றால்ஏதேனும்எதிர்மறையானவிளைவுகள்ஏற்படுமா?**  
இல்லை,

இந்தஆய்வுசெயல்முறைபங்கேற்பாளருக்குஎந்தஎதிர்மறையானவி  
ளைவுகளையும்ஏற்படுத்தாது.

### **தன்னார்வபங்கேற்பு**

இந்தஆய்வில்நீங்கள்பங்கேற்பதுமுற்றிலும்தன்னார்வமானதுமற்றும்நீ  
ங்கள்எந்தகேள்விக்கும்பதிலளிக்கமறுக்கலாம்.

ஆய்வாளரால்உங்களிடம்தொடர்ச்சியானகேள்விகள்கேட்கப்படும்மற்  
றும்உங்கள்பதில்கள்ஆவணப்படுத்தப்படும்.இந்தஆய்வில்ஆய்வகசோ  
தனைகள்அல்லதுஎந்தஆக்கிரமிப்புசெயல்முறையும்இல்லை.

### **ஆய்வில்இருந்துவிலகவும்:**

இந்தஆய்வின்ஒருபகுதியாகநீங்கள்இருக்கவிரும்புகிறீர்களாஇல்லை  
யாஎன்பதைத்தேர்வுசெய்யஉங்களுக்குசுதந்திரம்உள்ளது. "இல்லை"  
என்றுசொல்வதுஆராய்ச்சியாளர்மற்றும்நிறுவனத்துடனானஉங்கள்உ  
றவைப்பாதிக்காது.

**இரகசியத்தன்மை:**நீங்கள்அளிக்கும்தனிப்பட்டதகவல்கள்ரகசியமாக  
வைக்கப்படும்.

ஆராய்ச்சிகுழுவில்உள்ளவர்கள்மட்டுமேஉங்கள்பெயர்மற்றும்விவரங்  
களைஅறிவார்கள்.

உங்கள்பெயர்எந்தஅறிக்கையிலும்அல்லதுவெளியீட்டிலும்தோன்றாது.

இருப்பினும்,

ஒட்டுமொத்தமுடிவுகள்ஆராய்ச்சிஇதழ்களில்வெளியிடப்படும்.

**ஆய்வாளரால்மேற்கொள்ளப்படும்நடவடிக்கைகள்:**

திருமதி. ஷமாஅஞ்சம், M Phil., கிளிநிக்கல்சைக்காலஜி, NIEPMD,

சென்னையின்மேற்கூறியஆராய்ச்சியில்பங்கேற்கஉங்கள்ஒப்புதல்

கோரப்பட்டுள்ளது .

ஆராய்ச்சியின்எந்தப்பகுதியிலும்எந்தகாரணமும்கூறாமல்சம்மதத்

தைமறுக்கவோஅல்லதுதிரும்பப்பெறவோஉங்களுக்குஉரிமைஉண்டு .

ஆராய்ச்சியில்ஏதேனும்சந்தேகம்இருந்தால்,

நீங்கள்ஆராய்ச்சியாளரைசெல்வி .ஷமாஅஞ்சம் -மொப் :

9384421934அல்லதுவழிகாட்டியைதிருமதி. ஆனந்தலட்சுமி -044-

27472113தொடர்புகொண்டுதெளிவுபடுத்தலாம்.

நீங்கள்வழங்கியதகவல்கள்கண்டிப்பாகரகசியமாகவைக்கப்படும்.

**ஆராய்ச்சிஆய்வில்பங்கேற்கஒப்புதல்**

	ஆம்/ இல் லை
என்னிடம்போதுமானவிளக்கமும், ஆய்வின்தகவல்தாளத்தெளிவாகப்புரிந்துகொண்டுகேள்விக	

<p>ள்கேட்கும்வாய்ப்பும்கிடைத்துள்ளதுஎன்பதைஉறுதிப்படுத்துகிறேன்.</p>	
<p>எனதுபங்கேற்புதன்னார்வமானதுஎன்பதைநான்புரிந்துகொள்கிறேன், மேலும்எந்தநேரத்திலும்காரணத்தைதெரிவிக்காமல்படிப்பில் இருந்துவிலகிக்கொள்ளஎனக்குசுதந்திரம்உள்ளது.</p>	
<p>ஆய்வாளர்கேட்கும்தொடர்கேள்விகளுக்குநான்பதிலளிக்கவேண்டும்என்பதைநான்புரிந்துகொள்கிறேன்.</p>	
<p>நான்பகிரும்அனைத்துதனிப்பட்டதகவல்களும்ரகசியமாகவைக்கப்படும்என்பதையும், ஆராய்ச்சிஆய்வில்ஈடுபட்டுள்ளவர்களைத்தவிரவேறுயாருடனும்பகிரப்படமாட்டாதுஎன்பதையும்புரிந்துகொள்கிறேன்.</p>	
<p>மேலேஉள்ளஆய்வில்தானாகமுன்வந்துபங்கேற்கஒப்புக்கொள்கிறேன் .</p>	
<p>ஆய்வுதகவல்தாள்மற்றும்ஒப்புதல்படிவத்தின்நகல்எனக்குகிடைத்துள்ளது</p>	

பங்கேற்பாளரின்பெயர்:

கையொப்பம்:



ஆராய்ச்சியாளரின் பெயர்: ஷமா அஞ்சம்

கையொப்பம்:

### SOCIO- DEMOGRAPHIC DATA SHEET

Name (Initial):

Age:

Child' age:

Type of family: Nuclear/Joint/extended

No. of children with disability: 1/2/3/more

Type of Disability: UD/MD/HI/VI/DB

Type of Disorder: ASD/ADHD/CP/ID/SLD

Disability severity %- 100/75/50/40/25

Do you have body pain? Yes/ No

Are you undergoing any treatment for body pain/aches: Yes/No

If yes, what kind of treatment \_\_\_\_\_ how long? 3 months/6 months/ more than 6 months.

S. No	Items	Response
1	There is a special person who is around when I am in need.	
2	There is a special person with whom I can share joys and sorrows.	
3	My family really tries to help me.	
4	I get the emotional help & support I need from my family.	
5	I have a special person who is a real source of comfort to me.	
6	My friends really try to help me.	

7	I can count on my friends when things go wrong.	
8	I can talk about my problems with my family.	
9	I have friends with whom I can share my joys and sorrows.	
10	There is a special person in my life who cares about my feelings.	
11	My family is willing to help me make decisions.	
12	I can talk about my problems with my friends.	
S. No	Symptoms	Response
A.	Head and Neck	
	Backbone and Chest pain	
	Abdomen and Pelvis	
	Pain in extremities	
	Whole body ache	
B.	Tingling, burning	
	Numbness	
	Palpitations & breathlessness	
	Sensation of gas bloating or abdominal/pelvic discomfort	
	Head & cold sensations	
	Weakness of body, tiredness	

C.		
	Weakness of mind	
	Giddiness, dizziness, fainting	
	Trembling, tremors	
	Uneasiness	
D.	Sexual symptoms	
	Urinary symptoms	
	Altered bowel habits	
	Vision, hearing related	
	Others Unspecified	

E. Distress associated with the symptoms on a scale of 0-10, how distressed are you with the symptoms? \_\_\_\_\_SCORES

sum of the scores in the subscales.

Subscale A – Subscale B – Subscale C – Subscale D – Distress Score

TOTAL SCORE – Total number of symptoms – Total number of significant symptoms –

S. No		Response
1	Do you feel you don't have enough time for yourself?	
2	Do you feel stressed between caring and meeting other responsibilities?	
3	Do you feel angry when you are around your relative?	
4	Do you feel your relative affects your relationship with others in a negative way?	
5	Do you feel strained when are around your relative?	
6	Do you feel your health has suffered because of your involvement with your relative?	
7	Do you feel you don't have as much privacy as you would like, because of your relative?	
8	Do you feel your social life has suffered because you are caring for your relative?	
9	Do you feel you have lost control of your life since your relative's illness?	
10	Do you feel uncertain about what to do about relative?	
11	Do you feel you should be doing more for your relative?	

12	Do you feel you could do a better job in caring for your relative?	
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