

**DISPOSITIONAL MINDFULNESS, SELF-COMPASSION AND CAREGIVER
BURDEN AMONG CAREGIVERS OF CHILDREN WITH MULTIPLE
DISABILITIES AND TYPICALLY DEVELOPING CHILDREN**

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CERTIFICATE

This is to certify that **VARDHINI KRISHNAMURTHY** has been a research scholar for M.Phil. Degree in Clinical Psychology, National Institute for Empowerment of Persons with Multiple Disabilities (Divyangjan), Chennai during the academic year of 2021-2023.

Hereby, it is certified that the dissertation titled “**DISPOSITIONAL MINDFULNESS, SELF-COMPASSION AND CAREGIVER BURDEN AMONG CAREGIVERS OF CHILDREN WITH MULTIPLE DISABILITIES AND TYPICALLY DEVELOPING CHILDREN**” is the original research work done by **Vardhini Krishnamurthy (Register No: 154221104512)** 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, **Vardhini Krishnamurthy**, hereby declare that the thesis titled “**Dispositional Mindfulness, Self-Compassion And Caregiver Burden Among Caregivers Of Children With Multiple Disabilities And Typically Developing Children**”, was carried out by me at the National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai, during the year 2021-2023, is an original research work carried out under the guidance and supervision of 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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CERTIFICATE - II

This is to certify that this dissertation work titled “**DISPOSITIONAL MINDFULNESS, SELF-COMPASSION AND CAREGIVER BURDEN AMONG CAREGIVERS OF CHILDREN WITH MULTIPLE DISABILITIES AND TYPICALLY DEVELOPING CHILDREN**” of the candidate **Vardhini Krishnamurthy** with registration Number **154221104512** for the award of **Master of 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 result shows **2** percentage of plagiarism in the dissertation.


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ABSTRACT

Background: Caring for a child and especially one with a disability comes with its own share of challenges. Parents of children with disabilities are usually stressed with caring for their child and the decision making that accompanies the care. Previous research reported higher maternal stress, less well-being as well as more psychiatric morbidity, like depression and anxiety among these caregivers compared to typically developing children.

Objective: To compare dispositional mindfulness, self-compassion and caregiver burden among caregivers of children with multiple developmental disabilities and typically developing children.

Method: A total sample of 50 parents of MD children and 50 parents of TD children were surveyed. The Burden Scale for Family Caregivers – short version, Mindfulness Attention Awareness Scale and Self-compassion Scale were administered along with a socio-demographic questionnaire. Data was analysed using parametric methods such as Pearson's Correlation, Independent Sample t-test, ANOVA and descriptive analysis.

Results: The results showed that there was significant negative correlation between self-compassion and caregiver burden. Overall, parents of typically developing children tend to have higher caregiver burden and higher dispositional mindfulness and lower self-compassion than parents of children with multiple disabilities.

Implication: The results suggest that self-compassion may act as a strong barrier against developing caregiver burden. Inculcating self-compassion in parents of typically developing children may help them combat levels of caregiver burden. Being kind to oneself and recognizing the nature of shared humanity can help in finding solace and support and interventions must focus in this field.

Key Words: Self-Compassion, Multiple Disabilities, Caregiver Burden, Dispositional Mindfulness

CHAPTER I
INTRODUCTION

SELF-COMPASSION, DISPOSITIONAL MINDFULNESS & CAREGIVER BURDEN

Multiple Disabilities (more than one of the following disabilities), including deaf blindness which means a condition in which a person may have combination of hearing and visual impairments causing severe communication, developmental, and educational problems.

1. Physical Disability

- a. Locomotor Disability – Leprosy cured person, Cerebral Palsy, Dwarfism, Muscular Dystrophy, Acid attack victims
- b. Visual Impairment – Blindness, Low vision
- c. Hearing Impairment
- d. Speech and language disability

2. Intellectual Disability

- a. Specific Learning Disability
- b. Autism

3. Mental Behaviour

4. Disability caused due to

- a. Chronological neurological conditions such as – Multiple Sclerosis, Parkinson's Disease
- b. Blood Disorder – Haemophilia, Thalassemia, Sickle Cell Disease

Long-term physiological impairments known as developmental disabilities have a major impact on a child's capacity to carry out activities of daily life, such as independent eating, communicating, and moving around (World Health Organization and UNICEF 2012). An estimated 10% of children require significant caregiving, frequently throughout childhood and into adulthood, and access to the healthcare system for developmental disorders (Raina et al., 2004). In high income nations, it is believed that 1 to 4% of children have intellectual and

developmental disabilities, though this number may be as high as 17% in India (Ansari, 2021). Typically, the classification of these disorders encompasses Down syndrome, epilepsy, vision/hearing loss, and Autism Spectrum Disorders (ASD). If a criterion for disability severity is applied, estimates may also differ.) (Masefield et al., 2020). Multiple disabilities include individuals who have been diagnosed with conditions like Autism Spectrum Disorder along with Intellectual Disability, Cerebral palsy with Intellectual Disability, Intellectual Disability along with Hearing Impairment, and/or Visual impairment and/or Locomotor Disability.

Since time immemorial, there have been multiple perspectives to explain the presence of a disability in an individual. The two opposing perspectives being the medical perspective which states that the disability is an innate aspect of the individual whereas the social perspective put forward by sociologists claiming that the disability is in fact a consequence of the society rather than within the individual. Sociologists have claimed that labelling the individual as having a disability comes from people around them which makes them disabled in the lens of the society (Oliver, 2013). One such aspect of the society is the family or the caregivers of the individual who face both positive and negative consequences of the individual's disability. Since they are the ones most impacted by the disability and also may be the ones who in turn impact the disability in the individual it is important to study the burden they are withstanding (Bailey et al., 2007).

1.1 Caregiver Burden

A caregiver is usually an individual who provides care for someone who requires help in taking care of themselves. In this situation, caregiver could refer to parents, aunt, uncle, grandparents, foster parents, or anyone else closely associated with the child who has been the primary agent in taking care of all those needs which the child is not able to do

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themselves. This refers to the care they need in performing their daily activities due to the disability as well as the help they need due to their age. This metaphorical explanation of the caregiving process is a helpful approach to think about the difficulties that many families could confront when rearing a kid who has ongoing health or developmental issues. But keep in mind that there are certain significant ways in which the "caregiver career" is different from an occupational job. Being an informal caregiver is not normally something one chooses or plans for; when people look ahead, they rarely picture themselves in a caregiver role. As a result, training for this position will often begin after it has been obtained (Eicher & Batshaw, 1993; Raina et al., 2004).

Caregiver Burden is defined as the perceptions of the parent or guardian regarding how they have been negatively affected by the stresses and caregiving responsibilities of taking care of a child or individual with a diagnosed disability. It looks at how the responsibility is impacting their own life and the differences it has created in their life when they were not taking care of an individual with disability versus when they are (Khanna et al., 2012; Roper et al., 2014). The kind of the stress would vary depending on the family dynamics, the environment, the behaviour of the child and also the lack or the presence of support from friends, family and society (Hastings et al., 2005; Mulroy et al., 2008; Roper et al., 2014). According to research, the severity of the disability is correlated with the stress and ensuing burden that parents bear. Compared to parents of children with impairments or typically developing children (TDC), parents of children with ASD report feeling more stressed (Hastings et al., 2005; Mulroy et al., 2008; Roper et al., 2014).

A caregiver is usually not considered as a valuable profession by members of the society. It is usually seen as something that comes along as a part of life. Due to this, the caregiver does not have any other benefits like what is given to individuals working in any

other profession. The advancement in this line is motivated by the increase or decrease of the disorder and the level of dependence rather than by motivation or desire. Finally, unlike a career choice made based on an occupation, one cannot enter or leave the caregiving profession on their own volition (Eicher & Batshaw, 1993; Raina et al., 2004).

1.1.1 Caregiver Burden in caregivers of children with multiple disabilities

Some family members claim that having a child with a disability has positively changed their lives, giving them a fresh perspective on what's essential in life and giving them a sense of meaning and purpose that they might not have otherwise experienced. (Bailey et al., 2007; Nicholas, 1999; Skinner et al., 1999). However, most studies conducted have spoken about how family members look at having a child with a disability as a negative aspect rather than as something positive. They find the news as a burden that they need to put in extra effort to cope with (Bailey et al., 2007; Esbensen et al., 2012).

Various studies have suggested how caregivers of children with disabilities comes with its share of difficulties and stress. These difficulties could lead to Caregiver Burden. The burden encompasses multiple aspects like financial cost, taking physical care of the child which involves their own strength, capability to be resilient, and a cost of their own personal freedom and leisure activities (Chadda et al., 2007). Studies show a strong link between the stress and depressive symptoms experienced by parents of children with developmental disabilities than the parents of typically developing children (Masefield et al., 2020; Plant & Sanders, 2007; Singer, 2006).

The challenges of raising children with disabilities may not only result in health issues for families, but they may also increase their risk taking behaviours like alcoholism, smoking, taking illicit drugs, driving under influence, or engaging in unprotected sex . Family carers for children with disabilities may not have enough time or energy to lead healthy lifestyles

because they spend so much time caring for the kid, which may jeopardise their own physical and/or mental health. Despite the lack of large-scale surveillance research, there is evidence to suggest that carers are more susceptible to health risky behaviours than the general population (Lee, 2013).

1.1.2 Theories of Caregiver Burden

Caregiver health has been studied using the stress-health mechanism, which postulates that worry causes poorer health outcomes in caregivers compared to parents of typically developing children (Raina et al., 2004).

Based on the Caregiver Burden model (Raina et al., 2004), differing child disability diagnoses and socioeconomic circumstances can alter the direct linkages between caring for a child with any level of functional impairment and carer psychological and physical ill health. Caregiving for a child with severe ASD, or behavioural issues, for instance, has been linked to worse health, while financial advantage has been linked to better health (Garriot et al., 2014; Masfield et al., 2020; Plant & Sanders, 2007; Roper et al., 2014).

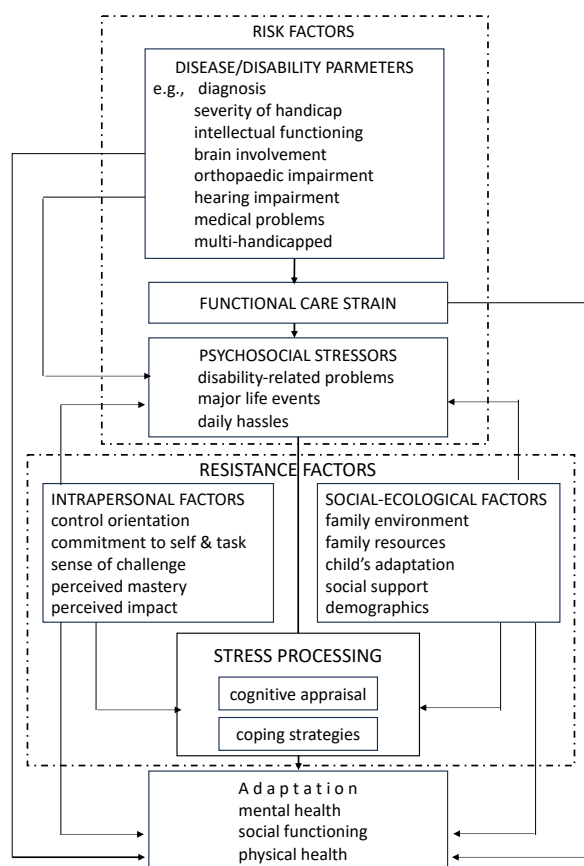


Figure 1.1 Caregiver Strain – Risk and Resilience Model

The first model proposed in understanding caregiver strain was the risk and resilience model by Wallander et al in 1989. This model talks about the adaptation of mothers of children with physical disabilities based on multiple dimensions (King, 1999; Raina et al., 2004; Wallander et al., 1989). Wallander's model includes risk factors that worsen mothers' reactions to the stress of raising a child with a disability (disability parameters, functional care burden, and psychosocial stress) and resistance factors that reduce these reactions (social-ecological factors like social support, intrapersonal strengths, and coping mechanisms) (King, 1999; Raina et al., 2004; Wallander et al., 1989).

The model is wholesome in the sense that it looks at demographic factors of the caregiver, factors of the disability or disease, psychosocial factors in the environment like major life events and daily hassles. It also includes resistance factors like intrapersonal factors of the mother, social-ecological factors, stress processing and ways to adapt to the

situation. All this is equally important in understanding the level of strain that the caregiver is experiencing and the ways in which they are trying to manage or cope with that burden.

The notion of receiving family-centered care, the existence of protective socio-ecological factors, the absence of persistent child behaviour issues, and improved satisfaction with care were all related to better parent well-being. Their findings underline the importance of offering services within a family-centered framework that cater to the requirements of the parents and lend credence to the idea that socio-ecological factors have a direct bearing on parent well-being (King, 1999; Raina et al., 2004).

1.1 Self-Compassion

In its most basic form, Self-Compassion refers to treating oneself with love and care while they are experiencing pain or stress (Murfield et al., 2020; K. Neff, 2011; Reyes, 2012). By defining Self-Compassion as the dominance of three positive attitudinal components over their dichotomously paired negative counterparts, the current definition broadens this concept. Self-Compassion over self-judgment, shared humanity over isolation, and mindfulness over over-identification (Murfield et al., 2020; K. Neff, 2011).

1.1.1 Self-kindness versus self-judgement

Self-kindness in this sense refers to being compassionate and understanding oneself whenever we are doing something wrong rather than blaming or critiquing oneself for doing that. Rather than saying that we should have done it better or differently it involves accepting oneself unconditionally with the flaws and inadequacies. However, we are frequently considerably tougher with ourselves, using judgemental and unpleasant language that we would never use with a friend. Instead of condemning ourselves harshly, we adopt a loving and supportive attitude when we practise Self-

Compassion. We accept our inadequacies while still taking care of ourselves. Self-acceptance of this kind reduces feelings of unworthiness (Murfield et al., 2020; K. Neff, 2011).

1.1.2 Shared Humanity versus Isolation

The second part which is the sense of shared humanity believes that all humans make mistakes and nobody is perfect so one person who does something wrong must not be segregated rather should be accepted as being equally human. We often have an unreasonable belief that everyone else is doing just fine and we are the only ones who screwed up when we fail or make mistakes. This is an emotional response rather than a logical one, which limits our comprehension and distorts reality. But when we have Self-Compassion, we understand that overcoming obstacles in life is a universal experience that is a part of being human. Self-Compassion from self-pity can also be distinguished by the shared humanity (Kabat-Zinn, 2005; Pepping & Duvenage, 2016).

1.1.3 Mindfulness versus overidentification

When practising Self-Compassion, mindfulness entails being mindful of one's painful experiences in a balanced manner that avoids ignoring or dwelling on unfavourable facets of oneself or one's circumstances. To be able to show compassion to oneself, one must be acutely aware of their own pain (Mills & Chapman, 2016; K. D. Neff & Germer, 2013). Overidentification is a tendency to reify our present-moment experience, causing us to see passing events as final and permanent. But when we practise mindfulness, we can lessen our attachment to and identification with negative ideas and feelings by acknowledging that they are merely thoughts and feelings (K. D. Neff, 2023).

Self-Compassion entails treating oneself with the same empathy that one would treat others. This way, having compassion for oneself does not imply having narcissistic self-interest.

Additionally, Self-Compassion increases positive emotional states to shield a person from negative mental states. Although the ability to maintain negative emotions in non-judgmental consciousness without suppressing or denying the negative aspects of experience is a trait of Self-Compassion, it is not just a technique for positive thinking (Ghorbani et al., 2012).

According to Neff et al. (2007), Self-Compassion increases emotional tolerance, which makes people with greater levels of this personality trait less likely to suppress their thoughts or engage in ruminative behaviour. Compassion is linked to lower levels of anxiety and despair (MacBeth & Gumley, 2012; K. Neff, 2011).

1.1.4 Theories of Self-compassion

Self-Compassion is a long-standing idea that has its roots in the philosophical and religious teachings of Buddhism. It just recently began to appear in the psychological sciences literature (Ghorbani et al., 2012). The western philosophers earlier referred to the term compassion which always meant feeling care and being moved by the sufferings of others and helping them build strength and resilience by providing support. However, the importance of Self-Compassion and having the similar feelings towards oneself was initially seen only in Buddhist philosophical traditions (NEFF, 2003).

The Dalai Lama in 2013 explains the importance of Self-Compassion as being: “For someone to develop genuine compassion towards others, first he or she must have a basis upon which to cultivate compassion, and that basis is the ability to connect to one’s own feelings and to care for one’s own welfare ... Caring for others requires caring for oneself”.

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This shows that for us to have the ability to show compassion and care for others, it is first very important to show compassion to ourselves. Only when we build that reservoir will we be able to provide for other people.

Evolving from these prior definitions, today Self-Compassion has evolved into a concept developed by Neff in 2003 as being a continuum. It comprises of the three major aspects explained above which are self-kindness versus self-judgement, common humanity versus isolation and mindfulness versus overidentification. These three form together to create the framework of Self-Compassion as how it is viewed today. This continuum ranges from uncompassionate self-responding on one side which includes being critical and judgement towards oneself and compassionate self-responding on the other end which means accepting your own flaws and practicing mindfulness. Therefore, it is not just that individuals are on two opposite ends but they could lie anywhere on the spectrum (NEFF, 2003).

1.2 Dispositional Mindfulness

Kabat-Zinn in his book “Wherever you go, there you are: Mindfulness Meditation in everyday life” initially described the concept of mindfulness as a process in which we pay attention to everything that is in the present moment without thinking about the past or the future but in a non-judgemental way (Kabat-Zinn, 2005; Pepping & Duvenage, 2016). Ever since the term was coined, a lot of research has been directed towards this new concept and the advantages of being in that particular moment and living each moment. It has been associated with a lot of positive psychological traits and benefits. The concept has its roots in Buddhist philosophy where meditation focusses a lot on being in the present and active awareness and cultivation of each moment (Brown & Ryan, 2003).

Mindfulness can be visualised as being both a state as well as a trait. All individuals are capable of achieving a state of mindfulness when during some time of the day they are mindful. A mindful state is distinguished by paying just passing attention to the current moment and attending solely to experiences that are genuinely noticed as opposed to reacting in accordance with habitual responses or previous experiences (Brown & Ryan, 2003; Pepping & Duvenage, 2016). Although it has been suggested that almost everyone is capable of practising mindfulness, there are individual differences in Dispositional Mindfulness, and as a result, mindfulness may be thought of as a trait-like construct (Brown & Ryan, 2003; Kabat-Zinn, 2005; Pepping & Duvenage, 2016). Therefore, a person's capacity and "tendency to abide in mindful states over time" are referred to as Dispositional Mindfulness which is a trait rather than a state (Brown & Ryan, 2003; Pepping & Duvenage, 2016).

Having Dispositional Mindfulness as a trait, has proven to have better life satisfaction (Brown & Ryan, 2003; Pepping & Duvenage, 2016), good management of emotions (Baer, 2003; Pepping & Duvenage, 2016), increased positive perspectives, reduced negative perspectives, and also better satisfaction in relationships (Brown & Ryan, 2003; Pepping & Duvenage, 2016; Shaver et al., 2007). Overall, having a mindfulness trait or Dispositional Mindfulness helps individuals in having a more positive social and psychological life compared to those who do not.

1.2.1 Theories of Dispositional Mindfulness (Dispositional Mindfulness)

The origins of the term and the concept lie in the Buddhist philosophy where The *Abhidhamma* one of the doctrines outlining the principles of Buddhism spoke about people who are alert and mindful compared to those who are unmindful. It described individuals who are mindful as called *Upatthitasati* and stated that this is a

characteristic that is innate and also constructed over the years due to nature of upbringing and training (Pāthaka & Gaur, Veena, 2000).

In the early years of the 1900s the Transcendentalist movement was important in bringing the teaching of Eastern and Buddhist philosophy to the Western part of the world. Jon Kabat-Zinn was one of the first people to introduce the practice of mindfulness to the rest of the world by opening a clinic in 1979 called the Stress Reduction Clinic in Massachusetts, USA which popularised the Mindfulness-based stress reduction technique (Kabat-Zinn, 2005; Rau & Williams, 2016).

According to the theories of mindfulness, Dispositional Mindfulness consists of these major characteristics:

Clarity of Awareness - Clear awareness of one's inner and exterior worlds, including thoughts, feelings, sensations, actions, and surroundings as they exist at any given time (Brown et al., 2007).

Nonconceptual, Non-discriminatory Awareness - By allowing inputs to enter awareness through the simple act of perceiving what is happening, mindfulness focuses on a non-interference with experience. It's possible that thought can be used more effectively and precisely as a result of this detachment of consciousness from cognitive content (Brown et al., 2007).

Flexibility of Awareness and Attention - The flexibility of mindfulness is another essential quality. It can zoom in on specific details (focused attention) or step back from particular states of mind to acquire a wider perspective on what is happening (clear awareness), according to preference or situation (Brown et al., 2007; Cullen, 2006; Welwood, n.d.)

Empirical Stance towards Reality - The traits that have been mentioned thus far suggest that being mindful is essentially empirical, since it aims to have the "full facts" in a way

that is akin to an objective scientist seeking accurate information of a phenomenon.

This viewpoint encourages withholding judgement until after a thorough investigation of the facts (Brown et al., 2007; Thera, 2014).

Present-oriented Consciousness - The traits mentioned here also emphasise the idea of presence. The mind is skilled at "time-traveling" into memories of the past, dreams about the future, and generally, away from the immediateness of experience in the present. It is simple to forget that we only have direct experience of the present moment and have no direct access to either the past or the future. This time travel serves the significant regulatory purpose of protecting, maintaining, and enhancing the self in, for example, the pursuit of goals (Brown et al., 2007; Sheldon & Vansteenkiste, 2005).

Stability or Continuity of Attention and Awareness - Consistency of consciousness and concentration reduces the likelihood that concepts, ideas, and related emotions may be hastily or automatically added to basic facts. This steadiness also makes it easier to recognise when one is mired in conceptual ideas or feelings that are based on the past or the future and to bring oneself back to the present. Observing what is present, including the fact that one is no longer present, is mindfulness (Brown et al., 2007; Kabat-Zinn, 2005).

1.3 Self-compassion and Caregiver Burden

Having higher levels of Self-Compassion can help alleviate the level of Caregiver Burden that is faced by parents of children with disabilities. Compassion, deeply rooted in Buddhist teachings, holds significant importance as a fundamental element within the care sector. It possesses the inherent capacity to alleviate the suffering experienced by individuals, especially such parents and their burden (Hlabangana & Hearn, 2020; Murfield et al., 2020)

Self-care and Self-Compassion are crucial for both the general population and those in caregiving roles, as they provide essential benefits and help prevent burnout and enhance overall well-being (Hlabangana & Hearn, 2020; Murfield et al., 2020).

Individuals with higher levels of Self-Compassion demonstrate a faster recovery and resilience in the face of stressors, in contrast to those with lower Self-Compassion. This is specially noticed in terms of resilience from factors like Caregiver Burden (Figley, 2002; Hlabangana & Hearn, 2020; Leary et al., 2007). These findings emphasize the significance of implementing Self-Compassion interventions for high-risk individuals, such as caregivers, to enhance their resilience and ability to cope with the challenges associated with caregiving (Hlabangana & Hearn, 2020; Murfield et al., 2020).

1.5 Self-compassion and Dispositional Mindfulness with Caregiver Burden

In Neff's well-known theory on Self-Compassion, mindfulness has been termed as one of its facets. Studies have spoken about how parents who are able to build a mindful parenting approach for their children are able to provide parental support which has more positive outcomes for the child. This in turn has a better effect on the mental health of both the parent and the child (Duncan et al., 2015; Gouveia et al., 2016). One of the aspects of building this mindful parenting approach involves Self-Compassion along with many other aspects like kindness, warmth, forgiveness and self-awareness. Only when the parent is aware of the approach they are using and the way that they are bringing up their child will they be able to involve the Self-Compassion as a part of this mindful practice of parenting (Gouveia et al., 2016; Pakdaman, 2014).

Although there has been limited investigation into the role of Self-Compassion in parent-child relationships, it is widely recognized as a crucial factor for effective parenting by assisting parents in managing negative emotions and specifically addressing the challenges

and frustrations that arise in the parenting journey (Gouveia et al., 2016; Moreira et al., 2015; K. Neff, 2011; K. D. Neff & Faso, 2015). In a recent study, Moreira et al. (2015a, b) discovered a positive correlation between Self-Compassion and mindful parenting. These findings provide evidence that the manner in which parents treat themselves is closely linked to their adoption of specific parenting practices and attitudes, as well as their interactions with their children (Gouveia et al., 2016; Moreira et al., 2015).

Individuals who exhibit higher levels of Self-Compassion tend to possess greater self-kindness, displaying care and support towards themselves, their failures, and their suffering. As a result, they are less self-critical when it comes to their parenting behaviors and feel more confident in their ability to care for their children, which aligns with the principles of mindful parenting. Their enhanced sense of common humanity, allows Self-Compassionate individuals to accept their limitations as parents and the imperfections of their children without judgment, which is another crucial aspect of mindful parenting.

Another noteworthy characteristic of Self-compassionate individuals is their capacity to mindfully observe and acknowledge painful emotions and thoughts, rather than denying or ruminating on them. This ability enables Self-compassionate parents to maintain a state of decentering, avoiding excessive identification with negative thoughts about their children and their role as parents. Consequently, this heightened mindfulness capacity enhances emotional awareness of both their own and their children's emotional states, facilitating greater self-regulation within the parent-child relationship. Such self-regulation allows parents to be less reactive, diminishes their dependence on their children's emotions, and enables them to align their parenting practices with their desired goals, all of which are fundamental aspects of mindful parenting.

Higher scores on Dispositional Mindfulness and higher levels of Self-Compassion have always been associated with lower levels of Caregiver Burden (Chen et al., 2020; Liu et

al., 2021; Murfield et al., 2020). Cultivating mindfulness and Self-Compassion may have beneficial effects in reducing stress among parents and educators. Prior studies have indicated links between mindful parenting and factors such as parents' Dispositional Mindfulness and Self-Compassion, as well as reduced parenting stress and positive parenting outcomes (Gouveia et al., 2016).

Lastly, the concept of mindful parenting itself emphasizes the significance of compassion towards oneself as a parent and towards the child as a fundamental component of parent-child interactions. (Gouveia et al., 2016; Moreira et al., 2015; K. Neff, 2011; K. D. Neff & Faso, 2015).

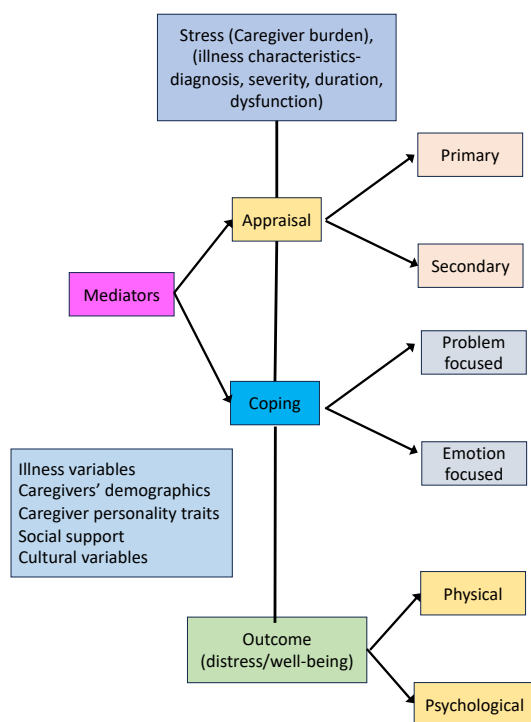


Figure 1.2 Caregiving and coping model

The current chapter talks about the variables used in the study along with previous theories that have tried to explain all of them. It also looks at the connections between Self-Compassion, Dispositional Mindfulness and Caregiver Burden as concepts. The following

chapter would delve into the previous research that has been done using these concepts especially in the population that this research is talking about. This will help to understand the research gap and establish the significance of this study.

The described model offers a theoretical framework to understand how individuals cope with stress in different situations, including caregivers supporting individuals with physical and/or psychological difficulties. Caregiving for someone with disabilities can be particularly stressful for the caregiver, as they face various stressors related to the person's health, diagnosis, severity, duration, dysfunction, disability, and overall burden. Central to caregiving is the appraisal of these stressors and caregiving demands. Appraisal is categorized into primary and secondary. Primary appraisal involves caregivers' judgments regarding the challenges associated with caregiving, while secondary appraisal includes assessing the stressful situation and available coping resources. By understanding and appraising these factors, caregivers can employ coping strategies such as seeking support, self-care, problem-solving, and professional assistance. It's important to acknowledge that caregiving experiences are complex and diverse, and individual factors may influence how caregivers appraise and cope with stress. Caregivers utilize different coping skills to manage the stress of caregiving. They employ either "problem-focused coping" to actively address difficult situations or "emotion-focused coping" to handle the emotional distress associated with caregiving. However, mediating factors such as illness variables (diagnosis, severity, duration) and caregiver profile (education, gender, relationship) can influence the burden, appraisal, and coping of caregivers. The interaction between stressors, burden, appraisal, and coping determines the caregiver's outcome in terms of distress or well-being. Effective coping leads to well-being, while ineffective coping results in distress. Recognizing these factors is crucial in developing appropriate support systems and interventions to enhance caregivers' coping skills and overall well-being. By addressing the unique challenges

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caregivers face and providing targeted assistance, we can improve their ability to manage stress while caring for others.

CHAPTER II
REVIEW OF LITERATURE

2.1 Self – Compassion and Caregiver Burden

Zoe Biddle, Frances V. O’Callaghan, Amy L. Finlay-Jones & Natasha E. Reid (2020) studied caregivers of children and adolescents with Fetal Alcohol Spectrum Disorder (FASD) and how Self-Compassion could be a tool for intervention for these caregivers. Since FASD is a lifelong neurological condition the caregivers have their own set of challenges to deal with. The study looked at 175 caregivers and assessed the levels of shame, guilt, pride, Self-Compassion associated with caregiver psychological distress. They also assessed if there was a difference between biological and non-biological caregivers. The level of Self-Compassion was positively associated with pride and negatively associated with psychological distress, shame and guilt. Shame, pride, guilt, and Self-Compassion accounted for 68.1% of the variance in caregiver psychological distress, according to a hierarchical multiple regression analysis that controlled for key caregiver demographics. Comparing biological caregivers to non-biological caregivers, biological caregivers reported feeling more guilty. The current research found that Self-Compassion, pride, blame, and shame were linked to caregiver psychological distress. Shame and Self-Compassion were found to be particular sources of caregiver psychological distress.

Bella Siu man Chan, Ju Deng, Yan Li, Tianbi Li, Yanmei Shen, Yuyin Wang & Li Yi (2020) in their correlational study assessed the role of Self-Compassion in the relationship between the post-traumatic growth and psychological distress in caregivers of children with ASD. It has been established that caregivers of children with ASD have various negative symptoms but this study aimed to understand exactly which dimensions of post-traumatic growth and psychological distress which included depression, anxiety and stress levels could have an impact along with Self-Compassion acting as a relating variable. 121 participants were assessed in the study who were taken from special schools and online chat platforms.

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The results concluded that there was no correlation between post-traumatic growth and psychological distress but this relationship was evident through Self-Compassion. Therefore, with the help of Self-Compassion, post-traumatic growth can help protect the mental health of these caregivers.

Moslem Asli Azad, Soheila Shariat, Tahere Farhadi & Lale Shahidi (2018) assessed the psychological well-being of caregivers of people with physical, mental and multiple disabilities by looking at Self-Compassion and self-esteem (SE) of the participants. The study hypothesised that Self-Compassion and SE can help counteract the negative feelings arising from being a caregiver and therefore, lead to improved psychological well-being. Data was collected from 54 individuals in Iran both men and women in the age range of 20 to 55 years. The data analysis proved that SE and Self-Compassion can predict the psychological well-being of the caregivers of individuals with disabilities. Therefore, enhancing these aspects could improve well-being of caregivers.

2.2 Caregiver Burden for Caregivers of Children with Multiple Disabilities (Caregivers of MD Children)

Sarah C. Masefield, Stephanie L. Prady, Trevor A. Sheldon, Neil Small, Stuart Jarvis & Kate. E. Pickett (2020) in their meta-analysis study tried to understand the health effects that caregivers face as a result of caring for their young children with developmental disabilities and the impact of various disability diagnoses as well as socioeconomic position. Studies which looked at any one symptom for mother of children with and without developmental disabilities in the age group 0-5 years were looked at across Medline, EMBASE, PsycINFO, and CINAHL databases. In the meta-analysis, there were 23 estimates of associations for the outcomes of stress (n = 11), depressive symptoms (n = 9), general health (n = 2), and fatigue (n = 1) from 14 retrospective investigations. Being a caregiver for

a child with a developmental disability was linked to worse health. Down syndrome had the smallest association, while mixed developmental disabilities had the largest. The health of mothers of young children with developmental problems may be worse than that of mothers of children who are typically developing.

G. Cetinbakis, G. Bastug & E.T. Ozel-Kizil (2018) investigated the various factors that could be leading to Caregiver Burden among mothers of children with ASD in Turkey. The factors they chose to assess were expressed emotion, social support, life satisfaction, dyadic adjustment, post-traumatic growth, and socio-demographic characteristics. 62 mothers of children with ASD and 60 mothers of typically developing children were employed as participants in the study. The main three factors which led to higher caregiving burden in the mothers was disability percentage, ASD-related behaviours and poor dyadic adjustment. These in turn led to higher expressed emotions and therefore lower life satisfaction. Mothers who had higher life satisfaction had low caregiving burden, high social support and dyadic adjustment and low expressed emotions. These women require expert advice and psychosocial help while they raise their children.

An Indian study conducted by Prerna Singh, Subharati Ghosh and Subhrangshu Nandi in (2017) examined mothers of children with ASD in India, assessing subjective burden, depression, and social support. 50% of mothers reported clinically significant depression. Subjective burden predicted higher depression. Medium/high family support directly impacted depression and moderated the burden's effect. Implications highlight the need to address depression and subjective burden in mothers of children with ASD, emphasizing the positive impact of family support. Policy and practice should focus on interventions promoting family support to improve maternal well-being and mental health outcomes.

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However, the study's limitations, like the small sample and specific context, warrant further research for broader generalizability.

Meenhye Lee, Chang Park, Alicia K. Matthews & Kelly Hsieh (2017) aimed to compare the prevalence of chronic conditions and health risk behaviors of family caregivers of children with and without disabilities and to examine associations between disability status of children and family caregivers' chronic conditions and health risk behaviors. The study used data from the 2015 National Health Interview Survey and compared chronic conditions and health risk behaviors across family caregivers of children with a disability (FCG-D) and family caregivers of children without a disability (FCG). Health risk behaviors were defined as heavy drinking, current smoking, physical inactivity, and unhealthy sleep. The study found that FCG-D had significantly greater likelihoods of chronic conditions such as asthma, back pain, chronic bronchitis, heart conditions, migraine, and obesity, than FCG. Additionally, FCG-D exhibited significantly more smoking and unhealthy sleep than FCG. These findings suggest that family caregivers of children with disabilities may be at higher risk for chronic conditions and health risk behaviors, highlighting the need for targeted interventions and health policies to address the health disparities experienced by this population.

Christina N. Marsack and Preethy S. Samuel (2017) aimed to explore the relationship between caregiver burden and quality of life (QOL) in parents aged 50 or older, who have adult children with autism spectrum disorder (ASD). A total of 320 parents participated in the research. The findings revealed that caregiver burden had a negative impact on the parents' QOL. The study also examined the mediating effect of formal and informal social support on this relationship. Informal social support was found to partially mediate the connection between caregiver burden and QOL, suggesting that having strong informal social support networks could help improve the QOL of these parents. However, formal social support did

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not show any mediating effect on this relationship. The results emphasize the significance of enhancing informal social support for aging parents of adult children with ASD to better support their well-being and QOL.

Susanne Olsen Roper, Diane W. Allred, Barbara Mandleco, Donna Freeborn & Tina Dyches (2014) aimed to explore the relationships between type of disability, Caregiver Burden, and sibling relationships in families raising children with disabilities, using family systems theory as a theoretical framework. The sample consisted of 172 families with typically developing children or a child with a disability who were recruited through meetings and workshops for families of children with disabilities and snowball sampling. Results showed that mothers reported higher levels of Caregiver Burden than fathers, and parents of children with Self-Compassion experienced higher levels of Caregiver Burden compared to parents of typically developing children. Mothers of children with Down syndrome and multiple disabilities reported more positive sibling relationships than mothers of typically developing children. Caregiver Burden was negatively related to parents' perceptions of the sibling relationship, and it mediated the relationship between having a child with Self-Compassion and positive sibling relationships. The findings highlight the importance of considering the family system when examining families raising children with disabilities, and the need for interventions to reduce Caregiver Burden and promote positive sibling relationships.

Kristin D. Neff & Daniel J. Faso (2014) conducted a study among parents of children diagnosed with ASD to understand the level of difficulty they face in terms of depressive symptoms and parenting stress. The severity level of ASD of the child was also assessed along with variables like hope, goal reengagement, life satisfaction and Self-Compassion to look at whether any of these could be barriers to the negative emotions felt by the parents.

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This study used self-report measures to evaluate the relationship between Self-Compassion and wellbeing in 51 parents of children with ASD. Self-Compassion was adversely connected with depression and parental stress and positively associated with life satisfaction, hope, and goal reengagement. Self-Compassion consistently predicted parental well-being over and above the effects of child symptom severity, despite the fact that child symptom intensity is frequently the largest predictor of negative adjustment for parents. The findings imply that Self-Compassion may be crucial to the wellbeing of parents of children with ASD.

Asley C. Woodman, Helena P. Mawdsley & Penny Hauser-Cram (2014) conducted a study to examine the transactional relationship between parenting stress and child behavior problems in families of children with developmental disabilities. The study involved 149 families of children diagnosed with developmental disabilities, and data was collected at three different time points, with a 5-year gap between each assessment. The study found that there was a significant positive correlation between parenting stress and child behavior problems, which remained stable over the 15-year period. Moreover, the relationship between parenting stress and child behavior problems was found to be bidirectional, indicating that parenting stress was both a cause and a consequence of child behavior problems. Overall, the study highlights the importance of identifying and addressing parenting stress in families of children with developmental disabilities. By promoting effective parenting strategies and addressing parenting stress, healthcare providers and clinicians may be able to improve the well-being of both the child and the family.

D. Norlin & M. Broberg (2012) compared the couple relationship and individual well-being of parents of children with and without intellectual disability (ID). The sample consisted of 80 couples, 40 of whom had a child with ID and 40 of whom had typically developing children. Participants completed a self-reported questionnaire on their couple

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relationship and individual well-being. The results showed that parents of children with ID reported lower levels of couple relationship quality and individual well-being compared to parents of typically developing children. The level of severity of the child's ID was negatively correlated with the couple relationship quality and individual well-being of parents.

Moreover, parents of children with ID reported higher levels of stress and lower levels of social support compared to parents of typically developing children. These findings suggest that parents of children with ID are at greater risk for poor couple relationship quality and individual well-being, highlighting the need for support and intervention programs for these families.

Emilie Cappe, Marion Wolff, Rene Bobet & Jean-Louis Adrien (2011) tried to establish quality of life as a variable to create an effective intervention plan for parents of children diagnosed with ASD, PDD-NOS and Asperger's Syndrome. They intended to identify the cognitive and behavioural profiles of these parents and how it affects their adjustment so that they can suggest an effective intervention plan. The main finding was that coping techniques that emphasise emotions appear to be less successful. The majority of their lives were more stressful and disrupted for parents who used emotion-focused techniques. Additionally, they reported feeling more guilty and having more misconceptions regarding PDD.

Charles D. Hoffman, Dwight P. Sweeney, Danelle Hodge, Muriel C. Lopez-Wagner & Lisa Looney (2009) aimed to explore parental perspectives on social communication interventions for children with ASD. The study examined the levels of stress experienced by mothers of 342 children diagnosed with Self-Compassion, compared to mothers of typically developing children. The results showed that mothers of children with Self-Compassion reported significantly higher levels of stress than the control group, across 13 of the 14

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subscales of the Parenting Stress Index. The only subscale that did not differ between the two groups was the Attachment subscale, indicating a lack of emotional closeness and cold patterns of parent-child interaction. The mothers of children with Self-Compassion also had very high scores on the Child Domain subscale. Despite the stress, the study found that mothers of children with Self-Compassion reported close relationships with their children. The study highlights the need for interventions to help reduce stress levels in mothers of children with Self-Compassion.

K.M. Plant & M.R. Sanders (2006) aimed to identify the predictors, mediators, and moderators of parent stress in families of preschool-aged children with developmental disabilities. A total of 105 mothers of preschool-aged children with developmental disabilities completed assessment measures addressing the key variables. The analyses showed that parents' difficulty in completing specific caregiving tasks, behavior problems during these caregiving tasks, and the level of child disability were significant predictors of parent stress. Furthermore, parents' cognitive appraisal of caregiving responsibilities had a mediating effect on the relationship between the child's level of disability and parent stress. Mothers' level of social support had a moderating effect on the relationship between the key independent variables and parent stress. These findings suggest that difficulty in caregiving tasks, difficult child behavior during caregiving tasks, and the level of child disability are the primary factors that contribute to parent stress.

George H. S. Singer (2006) aimed to investigate the prevalence of depression in mothers of children with developmental disabilities compared to mothers of typically developing children. The study involved a meta-analysis of 18 studies that met the inclusion criteria. The study found that mothers of children with developmental disabilities were at a higher risk of experiencing depression compared to mothers of typically developing children.

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The effect size was found to be moderate, indicating a significant difference in depression rates between the two groups. Furthermore, the study found that the effect size was larger for mothers of children with severe developmental disabilities compared to mothers of children with mild to moderate developmental disabilities. This highlights the need for increased support and resources for families with children with severe developmental disabilities.

Overall, the study emphasizes the importance of screening and providing support for maternal mental health in families of children with developmental disabilities. By identifying and addressing depression in mothers of children with developmental disabilities, healthcare providers and clinicians may be able to improve the well-being of both the mother and the family as a whole.

2.3 Self-compassion and Dispositional Mindfulness

M.J. Gouveia, C. Carona, M.C. Cannavarro & H. Moreira (2016) in their article spoke about mindful parenting, a relatively recent concept in parenting research, focusing on enhancing present-moment awareness within the parent-child relationship through specific practices or skills. Prior studies have indicated links between mindful parenting and factors such as parents' Dispositional Mindfulness and Self-Compassion, as well as reduced parenting stress and positive parenting outcomes. However, there has been a lack of integrated models incorporating these variables. This study aimed to investigate the associations between parents' Dispositional Mindfulness, Self-Compassion, parenting stress, and parenting styles through the lens of mindful parenting. The study included a sample of 333 parents (87 fathers, 246 mothers) aged between 27 and 63 years. The findings revealed that higher levels of Dispositional Mindfulness and Self-Compassion were positively correlated with greater levels of mindful parenting. In turn, mindful parenting was associated with lower levels of parenting stress, higher levels of authoritative parenting style, and lower

levels of authoritarian and permissive parenting styles. This study contributes valuable and innovative insights to the field of mindful parenting research by elucidating some of the modifiable variables that can facilitate the adoption of mindful parenting practices, adaptive parenting styles, and a reduction in parenting stress. The findings hold significant clinical implications, particularly in identifying vulnerable parent groups who could benefit the most from interventions promoting mindful parenting.

Need and Significance of present study

Studies on caregiver health are frequently performed without the addition of a typically developing comparison group which is the main focus of this study. Previous studies have spoke more about the burden in caregivers of children with cerebral palsy, Self-Compassion, or mixed disability groups (composed primarily of children with these disabilities and Down syndrome) (Bailey et al., 2007; Masefield et al., 2020). Very few research studies have spoken about what could be the factors that may be able to help caregivers to combat the stress associated with the burden that is attached with caregiving. More researches have only focussed on the negative factors like depression, anxiety, life stress, daily hassles and less overall well-being that has come as a part of the caregiving burden. However, research needs to look into whether positive psychology intervention focussed on Self-Compassion, mindfulness, kindness, gratitude, etc. can help reduce the effects of Caregiver Burden in parents of children with disabilities. Research also needs to look into the level of acceptance that parents of children with disabilities tend to develop after many years of the child being diagnosed with that disability. Also, regularly coming for therapy or treatment might help them build resilience against the effects of this burden as they begin to understand how their child is a little different from typically developing children which is why they need to be given that extra love and support to develop.

CHAPTER III
METHODOLOGY

SELF-COMPASSION, DISPOSITIONAL MINDFULNESS & CAREGIVER BURDEN

3.1 Aim:

To compare dispositional mindfulness, self-compassion and caregiver burden among caregivers of children with multiple disabilities and typically developing children.

3.2 Objectives

1. To compare dispositional mindfulness among caregivers of children with multiple disabilities and typically developing children.
2. To compare self-compassion among caregivers of children with multiple disabilities and typically developing children.
3. To compare caregiver burden among caregivers of children with multiple disabilities and typically developing children.
4. To examine the relationship between dispositional mindfulness and self-compassion among caregivers of children with multiple disabilities.
5. To examine the relationship between self-compassion and caregiver burden among caregivers of children with multiple disabilities.
6. To examine the relationship between dispositional mindfulness and caregiver burden among caregivers of children with multiple disabilities.

3.3 Hypotheses

1. Dispositional mindfulness will be significantly lower among caregivers of children with multiple disabilities as compared to caregivers of typically developing children.
2. Self-compassion will be significantly lower among caregivers of children with multiple disabilities as compared to caregivers of typically developing children.
3. Caregiver burden will be significantly higher among caregivers of children with multiple disabilities as compared to caregivers of typically developing children.

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4. Dispositional mindfulness and self-compassion will have a significant positive relationship among caregivers of children with multiple disabilities.
5. Self-compassion and caregiver burden will have a significant negative relationship among caregivers of children with multiple disabilities.
6. Dispositional mindfulness and caregiver burden will have a significant negative relationship among caregivers of children with multiple disabilities.
7. Dispositional mindfulness and self-compassion will have a significant positive relationship among caregivers of typically developing children.
8. Self-compassion and caregiver burden will have a significant negative relationship among caregivers of typically developing children.
9. Dispositional mindfulness and caregiver burden will have a significant negative relationship among caregivers of typically developing children.
10. There will be a significant difference in caregiver burden based on sex of the child.
11. There will be a significant difference in caregiver burden, dispositional mindfulness and self-compassion based on occupational status of the caregiver.
12. There will be a significant difference in caregiver burden, dispositional mindfulness and self-compassion based on educational status of the caregiver.
13. There will be a significant difference in caregiver burden, dispositional mindfulness and self-compassion based on age of child and caregiver.

3.4 Sample

The methods followed in determining and recruiting the samples of the study are explained in the following subsections.

3.4.1 Sample Estimation Protocol

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The priori analysis in G*Power 3.0 was done to estimate the sample size for the present study. The configuration was setup for t-test with an effect size 0.5.

3.4.2 Sample Size – Based on the sample estimation protocol, the following sample size has been proposed $N_{\text{Total}} = 100$ ($N_{\text{MD}} = 50$; $N_{\text{TD}} = 50$). The data was collected from a total of 100 participants.

3.4.3 Sampling Method – For the present study, purposive sampling was used.

3.4.4 Sampling Criteria

The following were the sampling criteria which were adopted in the present study.

Inclusion criteria for the caregivers of children with Multiple Disabilities:

1. Caregivers of children who have been diagnosed with one of the following multiple disabilities: ASD with ID, ID with CP, ID with Visual or Hearing Impairment
2. Children must be in the age of 6-16 years
3. Caregivers must be biologically related to the child

Exclusion criteria for the caregivers of children with Multiple Disabilities:

1. Caregivers who are in distress due to any physical health condition affecting them and are availing treatment for the same.
2. Caregivers who are diagnosed with any psychiatric or mental health condition due to which they are facing distress or availing treatment.

Inclusion criteria for the caregivers of typically developing children:

1. Caregivers of typically developing children in the age group of 6 to 16 years.

Exclusion criteria for the caregivers of typically developing children:

1. Caregivers of children who have any major learning difficulty.
2. Caregivers of children who have major emotional disturbances.
3. Caregivers of children who have behavioural problems.
4. Caregivers of children who have any major addictions.

3.5 Research Design

The present research follows correlational design.

3.6 Variables

The following are the variables considered in the study:-

Independent Variables – Self-compassion, Dispositional Mindfulness

Dependent Variables – Caregiver Burden

3.7 Tools of Assessment

In the following subsections, the description of the tools of assessment were discussed in detail along with their psychometric properties:

1. Socio-Demographic Questionnaire

The socio-demographic variables such as age and sex of child and caregiver, nature of disability, marital status, place of residence, family type, educational status, employment status, socio-economic status, and level of family support were collected using a self-constructed questionnaire.

2. Mindfulness Attention Awareness Scale (Brown & Ryan, 2003)

The MAAS is a 15-item instrument that measures people's tendency to be mindful of moment-to-moment experience. Thus, the instrument focuses on the presence or absence of attention and awareness of what occurs in the present. This scale has been shown to relate to various aspects of well-being and to how effectively people deal with stressful life events. The 15 items are scored on a 6 point Likert scale with 1 being almost always, 2 being very frequently, 3 being somewhat frequently. It has strong internal reliability for women and men. The MAAS demonstrates convergent and discriminant correlations in the expected direction with other measures such as the NEO-PI, NEO-FFI, the Mindfulness / Mindlessness scale (MMS), Beck's Depression Inventory (BDI), Rosenberg's Self-esteem Scale, and the State-trait Anxiety Inventory (STAI). It is a validated scale used to assess Dispositional Mindfulness and there are no gender differences in terms of validity. The scoring pattern involves a mean score of all the items with 11 and above indicating high, 6-10 indicating moderate and below 6 indicating low levels of Dispositional Mindfulness. The MAAS was found to have good internal consistency, with alphas ranging of .82 and .87 in student and adult samples (respectively).

3. Burden Scale for Family Caregivers – Short Version (Graessel et al., 2014)

It is a 10 item scale to assess the level of subjective burden of family caregivers of the individual. It follows a 3 point Likert scale with 0 being strongly disagree, 1 being disagree, 2 being agree, and 3 being strongly agree. The statements help understand various facets of the life of the caregiver which may have been impacted due to caregiving for the child or family member with a disability or illness. It has strong internal reliability Cronbach Alpha =0.92 and all items showed high

discriminatory power. It also has strong predictive and construct validity. Higher scores represent higher levels of Dispositional Mindfulness.

4. Self-Compassion Scale (NEFF, 2003)

The Self-compassion scale is used to assess the three major components of Self-Compassion which include self-kindness versus self-judgement, common humanity versus isolation and mindfulness versus overidentification. The scale is appropriate for any individuals above 14 years of age and should be self-administered. On the whole, the scale seeks to assess how the individuals act towards themselves in difficult times through answering 26 items. The items are to be marked on a 5 point Likert scale from 1 being “Almost never” to 5 being “Almost always” and 2,3,4 have not been specified in particular but fall in the spectrum. In the 26 item coding key: Self-kindness items: 5, 12, 19, 23, 26, Self-judgment items: 1, 8, 11, 16, 21, Common humanity items: 3, 7, 10, 15, Isolation items: 4, 13, 18, 25, Mindfulness items: 9, 14, 17, 22, Over-identified items: 2, 6, 20, 24. Subscale scores can also be computed individually and for the total scale higher scores represent higher Self-Compassion.

3.8 Procedure

The participants who matched the criteria were identified and approached for the study. Informed consent form was provided to all caregivers who matched the criteria and who were willing to participate in the study. An online consent form was attached along with the Google form for the TD group. The participants were briefed about confidentiality and debriefing was given if any distress was faced by the caregivers. The children should have been diagnosed by a qualified psychiatrist/ clinical psychologist. The questionnaires were administered in person to each caregiver of the MD population and an online google form

was circulated to the caregivers of the TD population. Screening questions were asked in the socio-demographic data form to identify whether the caregiver would belong to the experimental group or the control group and would be eligible for the study.

The three questionnaires (MAAS, BFSC – SV and SCS) were provided to the caregiver who responded to all the questions given.

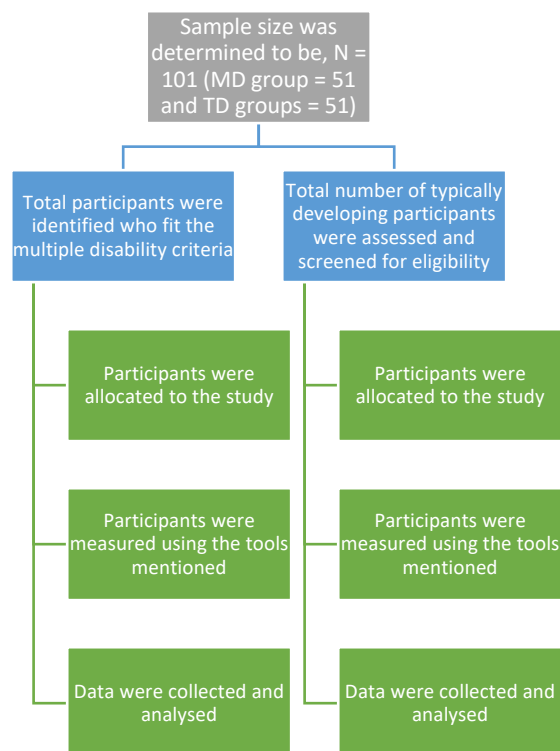


Figure 3.1 Schema profile of current study

Ethical Considerations:

- Informed consent was taken from all participants.
- Participation in the study was voluntary.
- Debriefing was given whenever required.
- Anonymity of the participants and the confidentiality of the data was maintained.
- The participants were not subjected to any physical or psychological harm.

- Tools used in the study were all either open source made publicly available for research under creative commons license.

Data Analysis

The data collected was analyzed in SPSS 25.0. The descriptive statistics were obtained for all the possible study measures and reported in the subsequent chapters. For inferential statistics, the data were tested for any outliers and normality analysis was done using Shapiro-Wilk statistic to meet the requirements of parametric statistics. The results showed that all the variables entered in the analysis was not significant indicating that the normality of the data was present. Consequently, Pearson correlation was performed to find the relationship among the variables of the study. Additionally, the homogeneity of variances was tested using Levene's test for equality of variances, in order to perform the independent sample t-test. T-test was then computed to compare the differences between the groups. For the variables having more than two groups, One-way ANOVA was performed to check the significance of differences between the groups.

Tukey's HSD was performed as the post-hoc analysis to understand which particular pairs of groups are showing significant differences between each other.

CHAPTER IV
RESULTS

SELF-COMPASSION, DISPOSITIONAL MINDFULNESS & CAREGIVER BURDEN

As proposed in the previous chapters the main aim of this research is to find out the relationship between Self-compassion, Dispositional Mindfulness (Dispositional Mindfulness) and Caregiver Burden (Caregiver Burden) among Caregivers of Children with Multiple Disabilities (Caregivers of MD Children) and Caregivers of Typically Developing Children (Caregivers of TD Children). The research tries to understand if caregivers may have a reduction in their levels of Caregiver Burden when they have higher levels of Dispositional Mindfulness as well as Self-Compassion which could act to help reduce the Caregiver Burden that they face. It also aims to compare both groups of caregivers, in their levels of Caregiver Burden, Self-Compassion and Dispositional Mindfulness to understand the comparison in order to aid further research and intervention in this area. The previous chapter laid out the methodology employed for the current study. The present chapter looks into the analysis for the results obtained.

The results are presented in the following sections:

Section I: Shows the participants characteristics and descriptive statistics for the variables.

Section II: Shows the descriptive and inferential statistics of the data collected from the participants.

4.1 Section I

Table 1 has the demographic details of the 50 participants who are the caregivers of the children identified with multiple disabilities whereas Table 2 has the demographic details of the caregivers of TD children.

As it is given in Table 1, there were 50 participants in the clinical group which had caregivers of MD children. Of the 50 participants, the minimum age was 28 whereas the maximum age was 46. 90% of the participants were females and mothers whereas 10% of

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them were males or fathers. The majority of the population of the child was male (72%) and Autism Spectrum Disorder with Intellectual Disability - ID+ASD (86%). A large number of the caregivers were educated up to graduate level (56%) and were homemakers (80%) and were married (92%). Most of them belong to middle socio-economic status (86%), residing in urban areas (70%) belong to nuclear family (64%). There was almost an equal division of people who believed that they receive poor (30%), satisfactory (36%), and good support from their family(34%).

Table 1: Participant Characteristics and Descriptive Statistics of Variables in MD

Population

| Variable | Group | N | % | Mean | SD | Min | Max |
|---------------------------|---------------------------------------|----|-----|-------|----|-----|-----|
| Age of Caregiver | | 50 | | 37.24 | | 28 | 46 |
| Sex of Caregiver | i. Male | 5 | 10% | | | | |
| | ii. Female | 45 | 90% | | | | |
| Relationship with Child | i. Mother | 45 | 90% | | | | |
| | ii. Father | 5 | 10% | | | | |
| | iii. Aunt | 0 | | | | | |
| Age of Child | | 50 | | 10 | | 6 | 16 |
| Sex of Child | i. Male | 36 | 72% | | | | |
| | ii. Female | 14 | 28% | | | | |
| Nature of Disability | i. ID + ASD | 43 | 86% | | | | |
| | ii. ID + CP | 7 | 14% | | | | |
| Educational Qualification | i. Uneducated | 4 | 8% | | | | |
| | ii. 10 th Pass | 6 | 12% | | | | |
| | iii. 12 th Pass | 6 | 12% | | | | |
| | iv. Graduate | 28 | 56% | | | | |
| | v. Post-graduate | 6 | 12% | | | | |
| Employment Status | i. Homemaker | 40 | 80% | | | | |
| | ii. Part-time | 0 | 0% | | | | |
| | iii. Full-time | 8 | 16% | | | | |
| | iv. Unemployed | 2 | 4% | | | | |
| Marital Status | i. Married | 46 | 92% | | | | |
| | ii. Unmarried | 0 | 0% | | | | |
| | iii. Divorced | 0 | 0% | | | | |
| | iv. Separated | 2 | 4% | | | | |
| | v. Single Parent due to other reasons | 2 | 4% | | | | |
| Socio-economic Status | i. Low | 4 | 8% | | | | |
| | ii. Middle | 43 | 86% | | | | |
| | iii. High | 3 | 6% | | | | |
| Place of Residence | i. Rural | 15 | 30% | | | | |
| | ii. Urban | 35 | 70% | | | | |
| Level of Family Support | i. Poor | 15 | 30% | | | | |
| | ii. Satisfactory | 18 | 36% | | | | |
| | iii. Good | 17 | 34% | | | | |
| Family Type | i. Nuclear | 32 | 64% | | | | |
| | ii. Extended | 11 | 22% | | | | |
| | iii. Joint | 7 | 14% | | | | |

As given in Table 2, there were 50 participants in the healthy control group which had caregivers of TD children. Of the 50 participants, the minimum age was 32 years and the

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maximum age was 68 years. The majority of the population was female (88%) and mothers (84%). This group had two aunts as caregivers along with mothers and fathers. There was almost an equal number of male (48%) and female (52%) children. This population had four adopted children (8%), all caregivers were either graduate (40%) or post-graduate (60%) and none were homemakers compared to the other group which had opposite characteristics. Majority of the caregivers were unemployed (40%), full-time employed (32%) or part-time (28%). A large number of the caregivers were married (96%), with middle socio-economic status (76%), all residing in urban areas (100%).

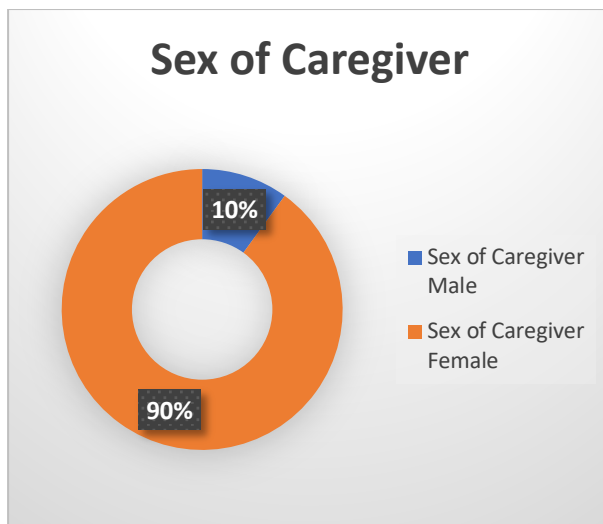


Figure 4.1 Graph depicting sex of caregiver

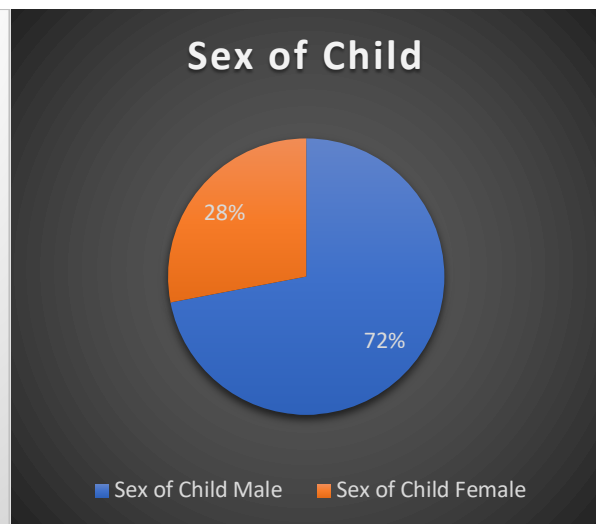


Figure 4.2 Graph depicting sex of child

Table 2: Participant Characteristics and Descriptive statistics of variables in TD**Caregiver Group**

| Variable | Group | N | % | Mean | SD | Min | Max |
|---------------------------|---------------------------------------|----|------|-------|----|-----|-----|
| Age of Caregiver | | 50 | | 43.52 | | 32 | 68 |
| Sex of Caregiver | i. Male | 5 | 12% | | | | |
| | ii. Female | 45 | 88% | | | | |
| Relationship with Child | i. Mother | 42 | 84% | | | | |
| | ii. Father | 6 | 12% | | | | |
| | iii. Aunt | 2 | 4% | | | | |
| Age of Child | | 50 | | 13 | | 6 | 16 |
| Sex of Child | i. Male | 36 | 48% | | | | |
| | ii. Female | 14 | 52% | | | | |
| Educational Qualification | i. Uneducated | 0 | | | | | |
| | ii. 10 th Pass | 0 | | | | | |
| | iii. 12 th Pass | 0 | | | | | |
| | iv. Graduate | 20 | 40% | | | | |
| | v. Post-graduate | 30 | 60% | | | | |
| Employment Status | i. Homemaker | 0 | | | | | |
| | ii. Part-time | 14 | 28% | | | | |
| | iii. Full-time | 16 | 32% | | | | |
| | iv. Unemployed | 20 | 40% | | | | |
| Marital Status | vi. Married | 48 | 96% | | | | |
| | vii. Unmarried | 0 | 0% | | | | |
| | viii. Divorced | 0 | 0% | | | | |
| | ix. Separated | 0 | 0% | | | | |
| | x. Single Parent due to other reasons | 2 | 4% | | | | |
| Socio-economic Status | iv. Low | 0 | | | | | |
| | v. Middle | 38 | 76% | | | | |
| | vi. High | 12 | 24% | | | | |
| Place of Residence | iii. Rural | | | | | | |
| | iv. Urban | 50 | 100% | | | | |

Table 3 shows the descriptive statistics for all the measures of the study. The mean Dispositional Mindfulness was 64.33 ± 14.894 , Caregiver Burden 26.74 ± 72.215 , Self-Compassion 66.12 ± 19.105 .

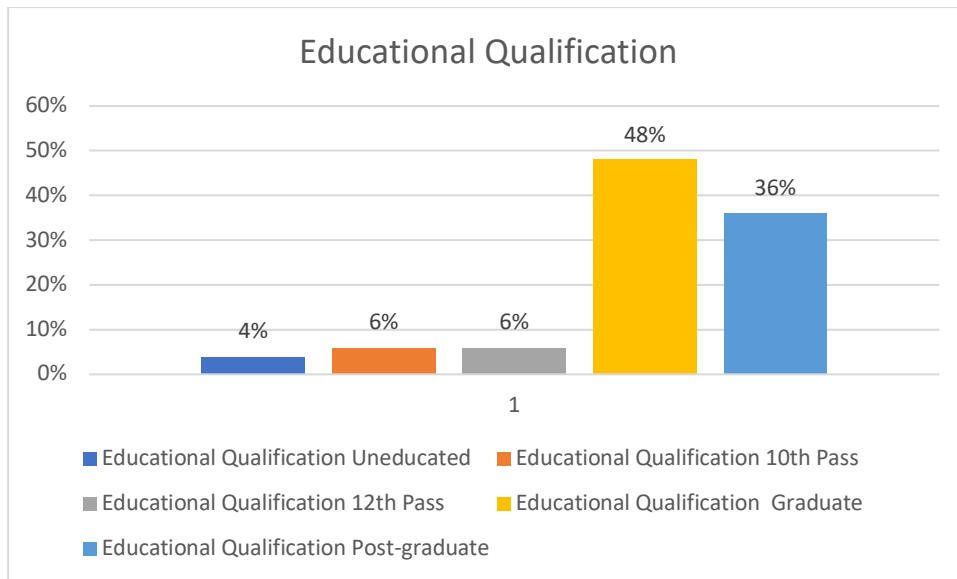


Figure 4.3 Graph depicting Educational Qualification of caregiver

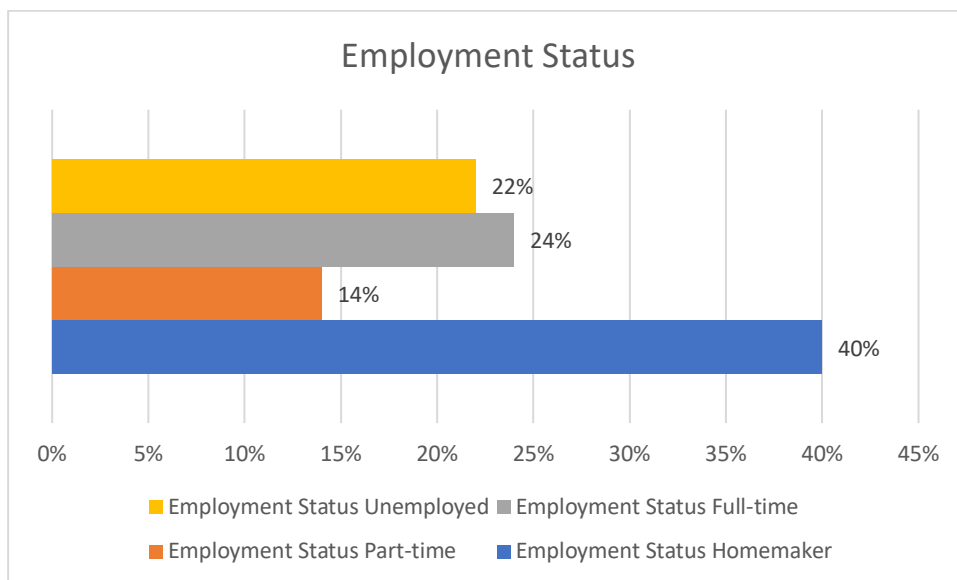


Figure 4.4 Graph depicting Employment status of caregiver

Table 3: Descriptive Statistics for all Measures of the study

| Measures | N | Minimum Statistic | Maximum Statistic | Mean Statistic | Std. Error | Std. Deviation Statistic | Variance Statistic |
|----------|-----|-------------------|-------------------|----------------|------------|--------------------------|--------------------|
| DM Total | 100 | 23 | 90 | 64.33 | 1.489 | 14.894 | 221.839 |
| CB Total | 100 | 0 | 39 | 26.74 | .850 | 8.498 | 72.215 |
| SC Total | 100 | 40 | 113 | 66.12 | 1.911 | 19.105 | 365.016 |

4.2 Section II

4.2.1 Descriptive statistics and Independent sample t-test

The level of Dispositional Mindfulness, Caregiver Burden and Self-Compassion along with its domains were calculated for the two different groups in the current study, i.e. caregivers of MD children and caregivers of TD children. The below table (Table 4) shows the average of all measures along with the standard deviation.

Table 4: Descriptive statistics for the measures based on the grouping variable – MD and TD caregivers

| Measures | Group | N | Mean | Std. Deviation |
|---------------------------|---------------------------|----|-------|----------------|
| Dispositional Mindfulness | Caregivers of MD Children | 50 | 56.90 | 2.024 |
| | Caregivers of TD Children | 50 | 71.76 | 1.616 |
| Caregiver Burden | Caregivers of MD Children | 50 | 20.96 | 1.044 |
| | Caregivers of TD Children | 50 | 32.52 | .682 |
| Self-Compassion | Caregivers of MD Children | 50 | 75.72 | 18.167 |
| | Caregivers of TD Children | 50 | 56.52 | 14.811 |

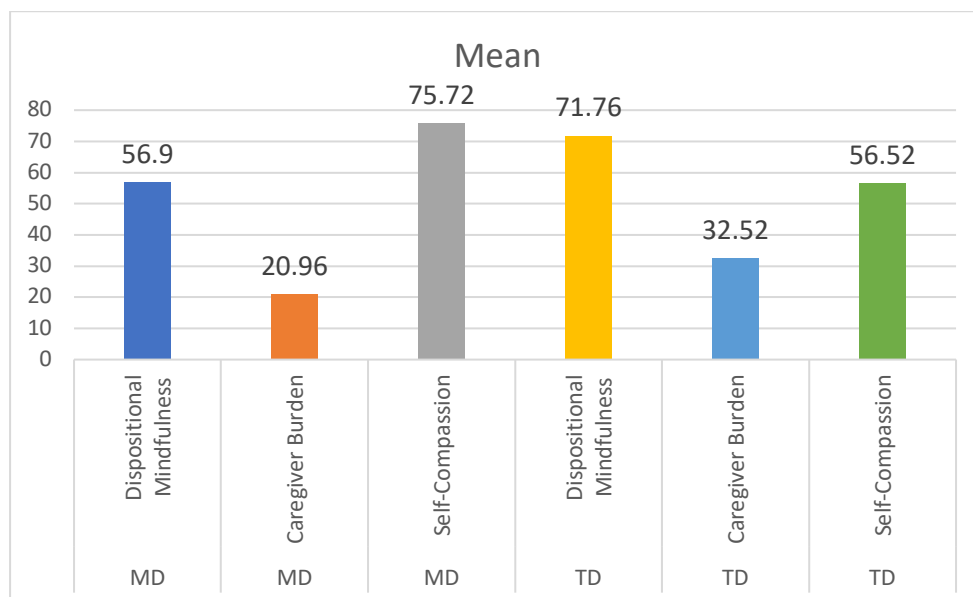


Figure 4.5 : Graph of Mean of study variables across the two groups

Table 5: Independent sample t-test statistic for study variables based on two groups – MD and TD

| Variables | | t | df | p value | Mean Difference |
|---------------------------|-----------------------------|--------|--------|---------|-----------------|
| Dispositional Mindfulness | Equal variances not assumed | -5.736 | 93.423 | .000* | -14.860 |
| Caregiver Burden | Equal variances not assumed | -9.272 | 84.420 | .000* | -11.560 |
| Self-Compassion | Equal variances not assumed | 5.792 | 94.177 | .000* | 19.200 |

*p value significant at the level <0.05

As the independent samples t-test assumption, i.e. homogeneity of variances was violated in some instances but maintained in other instances as seen on Levene's test for equality of variances, the equal variances assumed and equal variances not assumed statistic have both been considered based on the instance of each.

The independent sample t test analysis showed that there were significant differences on Dispositional Mindfulness, Caregiver Burden and Self-Compassion between the caregivers of MD children and the caregivers of typically developing children. The differences were also seen on two domains of Self-Compassion i.e., self judgement and isolation. The table depicts that there were significant differences between the two groups on Dispositional Mindfulness $t(93.423) = -5.736, p < 0.01$. From the descriptive statistic (Table 4) it was observed that the caregivers of TD children had higher levels of Dispositional Mindfulness (71.76 ± 1.616) than the caregivers of MD population (56.90 ± 2.024). It was found that there were significant differences in Caregiver Burden between the two groups $t(84.420) = -9.272, p < 0.01$. From the descriptive statistic (Table 4) it was observed that the caregivers of TD children had higher levels of Caregiver Burden ($32.52 \pm .682$) than the caregivers of MD population (20.96 ± 1.044). There were significant differences between the two groups based on Self-Compassion $t(94.117) = 5.792, p < 0.01$. From the descriptive statistic (Table 5), it was observed that the caregivers of MD children had higher levels of

Self-Compassion (75.72 ± 18.167) compared to the caregivers of TD children (56.52 ± 14.811).

Table 6: Descriptive statistics for the measures based on the grouping variable – caregivers of male and female children

| Variables | Sex of the child | N | Mean | Std. Deviation | Std. Error Mean |
|---------------------------|------------------|----|-------|----------------|-----------------|
| Dispositional Mindfulness | Female | 40 | 64.93 | 16.549 | 2.617 |
| | Male | 60 | 63.93 | 13.813 | 1.783 |
| Caregiver Burden | Female | 40 | 30.45 | 5.931 | .938 |
| | Male | 60 | 24.27 | 9.076 | 1.172 |
| Self-Compassion | Female | 40 | 65.10 | 18.383 | 2.907 |
| | Male | 60 | 66.80 | 19.696 | 2.543 |

*p value significant at the level <0.05

Table 7: Independent Sample t-test based on sex of the child

| Variables | | t | df | Sig. (2-tailed) | Mean Difference |
|---------------------------|-----------------------------|-------|----|-----------------|-----------------|
| Dispositional Mindfulness | Equal variances assumed | .325 | 98 | .746 | .992 |
| Caregiver Burden | Equal variances not assumed | .000 | 98 | .000* | 3.205 |
| Self-Compassion | Equal variances assumed | -.434 | 98 | .665 | -1.700 |

*p value significant at the level <0.05

As the independent samples t-test assumption, i.e. homogeneity of variances was violated in some instances but maintained in other instances as seen on Levene’s test for equality of variances, the equal variances assumed and equal variances not assumed statistic have both been considered based on the instance of each.

The independent sample t-test showed that there are significant differences on Caregiver Burden based on sex of the child, i.e., male and female children. The table depicts that there are significant differences between the two groups based on Caregiver Burden, $t(98) = .000$, $p < 0.01$. From the descriptive statistics table (Table 6) it was observed that the caregivers of female children had higher levels of Caregiver Burden (30.95 ± 5.931) than caregivers of male children (24.27 ± 9.076).

4.2.2 Pearson's Correlation

The following section shows inferential statistics results of the samples taken for the study.

Table 8: Pearson Correlation statistic for the study variables.

| | Age of Caregiver | Age of Child | DM | CB | SC |
|---------------------------|---------------------|-----------------|-------|---------|----|
| Age of Caregiver | - | | | | |
| Age of Child | .744** | - | | | |
| Dispositional Mindfulness | .222* | .193 | - | | |
| Caregiver Burden | .224* | .208* | .126 | - | |
| Self-Compassion | .254* | .312** | -.099 | -.520** | - |

*Significant at 0.05 level, **Significant at 0.01 level

The above table (Table 6) show the correlation for the study variables. The findings of the analysis are discussed here. The analysis revealed that the age of the caregiver had a significant positive correlation with Dispositional Mindfulness ($r = .222$, $p < 0.05$), with Caregiver Burden ($r = .224$, $p < 0.05$), with Self-Compassion ($r = .254$, $p < 0.05$). The age of the child had a significant positive correlation with Caregiver Burden ($r = .208$, $p < 0.05$), with Self-Compassion ($r = .312$, $p < 0.01$). Caregiver Burden had a significant negative correlation with Self-Compassion ($r = -.520$, $p < 0.01$).

4.2.3 ANOVA analysis

Table 9: ANOVA for Employment Status

| Variables | | Sum of Squares | df | Mean of Square | F | Sig. |
|---------------------------|----------------|----------------|----|----------------|-------|-------|
| Dispositional Mindfulness | Between Groups | 4724.201 | 3 | 1574.734 | 8.770 | .000* |
| | Within Groups | 17237.909 | 96 | 179.562 | | |
| | Total | 21962.110 | 99 | | | |
| Caregiver Burden | Between Groups | 1490.275 | 3 | 496.758 | 8.427 | .000* |
| | Within Groups | 5658.965 | 96 | 58.948 | | |
| | Total | 7149.240 | 99 | | | |
| Self Compassion | Between Groups | 4868.873 | 3 | 1622.958 | 4.983 | .003* |
| | Within Groups | 31267.687 | 96 | 325.705 | | |
| | Total | 36136.560 | 99 | | | |

*p value significant at the level <0.05

The ANOVA analysis was performed for employment status between the four groups namely, homemaker, part-time employed, full-time employed and unemployed. The analysis showed that there are significant differences between the employment status and Dispositional Mindfulness ($F = 8.770$, $p < 0.01$). The analysis also showed that there are significant differences between the employment status and Caregiver Burden ($F = 8.427$, $p < 0.01$). The analysis showed that there are significant differences the Self-Compassion and employment status ($F = 4.983$, $p < 0.01$). Tukey HSD showed that on Dispositional Mindfulness, unemployed caregivers (15.359), part-time employed caregivers (-14.664) and full-time employed caregivers (-11.867) had higher scores than homemakers. It also showed that on Caregiver Burden, unemployed caregivers (-7.175), part-time employed caregivers (-10.389) and full-time employed caregivers (-5.758) had higher scores than homemakers. It showed that on Self-Compassion, homemakers (-18.330) and full-time caregivers (-10.205) had higher scores than unemployed caregivers.

Table 10: ANOVA for Educational Status

| Variables | | Sum of Squares | df | Mean of Square | F | Sig. |
|---------------------------|----------------|----------------|----|----------------|-------|-------|
| Dispositional Mindfulness | Between Groups | 1508.492 | 4 | 377.123 | 1.752 | .145 |
| | Within Groups | 20453.618 | 95 | 215.301 | | |
| | Total | 21962.110 | 99 | | | |
| Caregiver Burden | Between Groups | 950.789 | 4 | 237.697 | 3.643 | .008* |
| | Within Groups | 6198.451 | 95 | 65.247 | | |
| | Total | 7149.240 | 99 | | | |
| Self Compassion | Between Groups | 4522.525 | 4 | 1130.631 | 3.398 | .012* |
| | Within Groups | 31614.035 | 95 | 332.779 | | |
| | Total | 36136.560 | 99 | | | |

*p value significant at the level <0.05

The ANOVA analysis was performed for the Educational Status between the five groups namely, uneducated, 10th. Pass, 12th pass, graduate and post-graduate. The ANOVA analysis revealed that there was significant difference between the five groups and level of Caregiver Burden ($F = 3.643, p < 0.08$). There was also significant difference between the five groups and level of Self-Compassion ($F = 3.398, p < 0.05$). Tukey HSD showed Caregiver Burden was significantly higher in individuals who were post-graduate than individuals who were than 10th pass (-11.194). Self-Compassion was significantly higher in individuals who were 10th pass than individuals who were post-graduate (23.472).

Discussion

The study was primarily aimed at understanding the differences that exist in the levels of Caregiver Burden, Dispositional Mindfulness and Self-Compassion between the two groups of the study namely caregivers of MD children and caregivers of TD children. The study also wanted to understand the relationship that exists between Dispositional Mindfulness, Self-Compassion and Caregiver Burden. The study tried to analyse if increase in levels of Self-Compassion and Dispositional Mindfulness would act to reduce the level of Caregiver Burden faced by the parent or family member taking care of the child.

The major hypothesis of the study which mentioned that higher levels of Self-Compassion would correlate with lower levels of Caregiver Burden was retained across both groups. It was found that caregivers who had higher rates of Self-Compassion and were depicting a form of self-love also significantly had lower levels of Caregiver Burden. This is very much consistent with the findings in previous literature as well. For example in a study conducted by Kristin D. Neff & Daniel J. Faso in 2014, it was found that for children diagnosed with Autism Self-Compassion emerged as a barrier against negative emotions felt by the parents. A similar study conducted by Moslem Asli Azad et al, in 2018 also proved that the negative feelings that arose from being a caregiver were repressed by boosting the self-esteem and Self-Compassion levels in both men and women(Asli Azad et al., 2018). Other similar studies also point towards the buffering effect of Self-Compassion (Biddle et al., 2020; Chan et al., 2020; K. D. Neff & Faso, 2015). Being kind to oneself, without judgement especially in the hard times is what is important. Through the course of the study, many caregivers reported that their understanding about others life problems helped to normalize their own problem as a challenge in everyone's life and could coped better. Instead those who questioned themselves as "why god has done this to me? Or why am I being punished?" is when they experienced greater burden. Hence, increasing the levels of Self-Compassion and mindfulness in caregivers could help to reduce levels of Caregiver Burden.

The study also hypothesised that Dispositional Mindfulness will be negatively correlated with Caregiver Burden and positively correlated with Self-Compassion in accordance with past research among both the groups (Alberto Voci et al., 2016; Chen et al., 2020; Hwang et al., 2019; Liu et al., 2021). However, these findings were not significant. The major reason could be that, Dispositional Mindfulness is a trait it needs to be present by birth and unlike mindfulness as a state which can be cultivated. (Brown & Ryan, 2003; Kabat-Zinn, 2005; Pepping & Duvenage, 2016). The study did not assess the state of mindfulness

rather the trait which might not have been present in all caregivers hence not leading to the expected results.

The study expected that caregivers of children with disabilities would have higher levels of Caregiver Burden than caregivers of TD children since these children have more level of dependence and required more time and effort to take care of. However, this finding was not supported. Previous literature proved that, such parents would have greater physical, social, financial and psychological impact typically leading to higher levels of depressive symptoms and in turn also Caregiver Burden. However, all the children of caregivers who participated in the study have been seeking therapy at an institution for a significant duration, which could be the reason for their better acceptance of their children's diagnosis helping them to overcome the initial stage of denial or frustration. The parents also have a significant support group comprising of other caregivers who are seeking therapy for their children at the same institution. This could help in building a good support group for them to share their problems, ventilate and discuss similar solutions with each other. Since the study also proved that this group had higher levels of Self-Compassion, this could be another reason why they are able to combat the levels of burden. Also, the parents of MD children have already approached and sought for help which shows that they have overcome the level of stigma from society. However, the parents of TD children are not yet ready to accept that sometimes they may need to help to deal with their child's difficulties since they believe that their children is completely alright. Appraisal also is one aspect of the impact of burden. Parents who have positively appraised the caregiving situation may have greater ability to deal with the situation like beliefs of self-efficacy and existential views like Faith in God and the Universe (Hooda, 2018; Lazarus & Folkman, 1984). The parents of TD children were asked certain open-ended questions to understand the difficulties they face in dealing with their children. They mentioned that sometimes it is difficult to handle the anger outburst and

temper tantrums depicted by the children. This might be one of the reasons why they report higher levels of burden and lower levels of Self-Compassion.

The study hypothesised that with increase in the age of caregiver and child, there would be increase in the level of Self-compassion, Caregiver Burden and Dispositional Mindfulness. This hypothesis was proven. As there is an increase in the age the caregiver would have other demands like their own health requirements and physical weakness that may contribute to increased burden. However, having become older and wiser, and also having had more time to accept their child's condition and spent time with oneself, they may have cultivated more Self-compassion and Dispositional Mindfulness (Bozkurt et al., 2019; Patel et al., 2022).

The study expected that the caregivers of the TD population would have higher levels of Dispositional Mindfulness than the MD population, and this hypothesis was proved. One study focussed on how improving the levels of Dispositional Mindfulness helped in promoting positive parenting strategies. Authoritarian and authoritative parenting styles, which are predominantly practiced by parents of typically developing children are shown to have correlation with Dispositional Mindfulness . This has been correlated with a mindful parenting approach which in turn helps to reduce the levels of Caregiver Burden. The adoption of mindful parenting practices, adaptive parenting styles, and a reduction in parenting stress (Gouveia et al., 2016).

The research hypothesis that there would be a significant difference in Dispositional Mindfulness, Caregiver Burden and Self-Compassion based on the occupational status of the caregiver was supported. Homemakers had the least caregiver burden and the reason for this could be since they do not have work pressure from elsewhere, they may be better at handling the issues of the child. This may also be true because they spend more time with their children so they may be able to accept the child's condition in a better way leading to less

burden. This is in alignment with two previous studies, one in an Indian setting who have shown similar results (Kaur et al., 2021; Mahmoud Mohammed & Abdel Hady Ghaith, 2018). The other facet that can add to this explanation is the results which depicted that caregivers who have a post-graduation degree have higher caregiver burden than caregivers who are 10th pass. The caregivers who have a post-graduation degree have higher chances to be employed rather than the caregivers who have completed 10th grade. Therefore, the occupational status findings correlate with the educational status one. In spite of being educated only till 10th grade, these caregivers have higher levels of self-compassion than the other groups. Therefore, more than just the educational and occupational level there are various other factors that could contribute. One reason for this could be that such caregivers were found in the MD population group and they mentioned the importance of having a social support system in helping them deal with the daily life hassles. A strong social support system also helps increase the levels of Self compassion, both contributing to better quality of life (Golmakani et al., 2020). When they spoke to other caregivers who faced similar problems, it gave them more strength. Two studies done in India have spoken about how in parents of children with ASD, social support moderated the relationship between caregiver burden and quality of life. A strong social support helped improve the quality of life in these caregivers with high burden (Marsack & Samuel, 2017; Singh et al., 2017).

Similarly, the results have shown that caregiver burden is higher for caregiver of female children than male children. This could be because raising a female child with disabilities requires educating them about menstrual issues, dressing, as well as thinking about their safety. Especially in a country like India, the caregivers also need to think about their future, marriage and the stigma they will face from society. These findings were also similar to an Indian study which found differences in burden level depending on gender of the child (Suresh et al., 2014). Another study also mentioned that caregiver burden is higher

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for parents of female children with ASD than male children with ASD (Bozkurt et al., 2019)

CHAPTER V
SUMMARY AND CONCLUSION

Summary

The present study had a well-defined research question which looked at understanding how certain positive psychological concepts, which if inculcated in the individual could lead to reduction in their levels of caregiver burden. The existing literature talks a lot about the reasons for this burden in caregivers of children with various disabilities however, not much has been studied about which facets can help improve this.

There were a total of 100 caregivers used in the study which included 50 caregivers of MD children and 50 caregivers of TD children. The sample was collected from NIEPMD for the MD population and the Google Form was circulated online for the TD population.

The tools used in the study were:

- Socio-Demographic Questionnaire
- Mindfulness Attention Awareness Scale (Brown & Ryan, 2003)
- Burden Scale for Family Caregivers – Short Version (Graessel et al., 2014)
- Self-Compassion Scale (NEFF, 2003)

This study aimed to understand how Self-Compassion and Dispositional Mindfulness could help reduce the level of caregiver burden among caregivers of MD children as well as TD children. This was assessed using correlation. The study also wanted to understand whether there would be a significant difference in the levels of Caregiver Burden, Dispositional Mindfulness and Self-Compassion among the two groups – namely caregivers of MD children and caregivers of TD children as well as the two groups of male and female children. Independent sample t-test was employed to understand this difference. For trying to understand whether there are differences in the level of Dispositional Mindfulness, Self-Compassion and Caregiver Burden among the caregivers based on occupational and educational status of the caregiver, ANOVA and post-hoc analysis was used.

The significant findings of the study were:

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- Dispositional Mindfulness was higher among caregivers of TD children than caregivers of MD children.
- Self-compassion was higher among caregivers of MD children than caregivers of TD children.
- Caregiver Burden was higher among caregivers of MD children than caregivers of TD children.
- Self-compassion and Caregiver Burden had a significant negative relationship among caregivers of MD children and caregivers of TD children.
- Age of child and caregiver had a significant positive relationship with Self-compassion and Caregiver Burden.
- Caregiver Burden is higher for caregivers of female children than male children.
- Homemakers have lowest Dispositional Mindfulness and Caregiver Burden
- 10th pass caregivers have lowest levels of Caregiver Burden and highest levels of Self-compassion
- Postgraduate caregivers have higher levels of Caregiver Burden.

Conclusion

- Self-compassion helps to decrease the level of caregiver burden among caregivers of children with multiple disabilities.
- Caregiver burden is higher for caregivers of typically-developing children
- Caregivers mentioned that the burden that caregivers of TD children face is mobile phone usage, anger management issues, and lack of attention in academic areas.
- Caregivers of MD children mentioned that good social support especially from other parents having children with disabilities makes them feel understood, motivated and get better directions to face the life challenge leading to less burden.
- Caregivers of female children face higher burden than those of male children.

SELF-COMPASSION, DISPOSITIONAL MINDFULNESS & CAREGIVER BURDEN

- Caregivers who are homemakers have lower levels of Caregiver Burden and Dispositional Mindfulness.
- There is a need for implementing positive psychology intervention programs to help reduce level of caregiver burden.
- Being associated with a multidisciplinary therapy centre for their child could have been one reason for the reduced levels of burden among the caregivers of MD children.

Implications

- The present study confirmed that Self-Compassion would act as a helpful measure to reduce the levels of Caregiver Burden of caregivers of TD and MD children.
- The findings imply that all caregivers would face a certain level of burden as a result of upbringing and this needs to be accepted and actively reduced to help balance their mental health.
- The Government to implement programs that can help in promoting awareness, especially with regards to educating the caregivers about how they can train their children whether it be sexual awareness, vocational guidance, knowledge about disability certification and various other aspects involved in bringing up children with disabilities.
- School and University mental health programs need to be implemented to raise awareness about the need for inclusion and reduction of stigma in the society.
- Mental health awareness among parents of Typically developing children also needs to be looked into to help them seek help whenever required and to identify when and how they can seek help.
- In light of the present findings, it is important to know that there are positive psychological variables that would help reduce the level of burden and enhancing

these through interventions can produce a significant positive outcome.

Limitations

- Dispositional mindfulness as a state needs to be assessed, while this study focussed on it being a trait which is present from an early stage in life whereas a state can be cultivated.
- The sample was primarily from Chennai and was inclusive of 100 caregivers, 50 from each group.
- The responses of the caregiver might also be biased as many parents have an attached stigma while talking about their child's disability in public.
- For parents of typically developing children in such a study they would not want others to assume that their child has some disability or difficulty.
- The length of the time that passed since the disability of their child would have been diagnosed would vary for each caregiver

Future directions

- All caregivers used in the study were seeking therapy for their child at an institution so in future it might be beneficial to use caregivers of clients who have not yet sought therapy for their child's condition.
- In further studies, the size can be increased for better generalisation.
- Future studies can focus on testing intervention programs which use concepts like Self-Compassion and Dispositional Mindfulness since they provide an effective way to reduce their level of burden and improve overall quality of life.
- Social support groups can also be a constructive way for the caregivers to find others who are facing a similar situation and teach each other effective ways to cope.
- The impact of the treatment based on the duration of treatment for each caregiver can be assessed. Whether there is a difference in the levels of the variables based on how

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long they have been taking therapy should also be measured.

- Other disabilities can be used as control groups to see how caregivers of individuals vary in their demand and level of understanding.

Studies need to be conducted to focus on enhancing the caregivers welfare and quality of life through building intervention programs like Self-Compassion and

Dispositional Mindfulness.

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APPENDICES

APPENDIX 1

INFORMED CONSENT FORM - ENGLISH

National Institute for Empowerment of Persons with Multiple Disability (NIEPMD)

Ministry of Social Justice and Empowerment, Govt. of India

Muttukadu, ECR Road, Chennai – 603 112

Ph: 9940215210, NIEPMD PHONE NO. 044-27472113, 27472046; E-mail:

anandhakaliappan@gmail.com

**Dispositional Mindfulness, Self-compassion And Caregiver Burden Among Caregivers
of Children With Multiple Disabilities And Typically Developing Children**

STUDY INFORMATION SHEET

Caregivers are not given much importance when it comes to their mental health and well-being. Researches have spoken about the negative symptoms and negative impact of caregiving for children with disabilities. However, not much has been spoken about the positive protective factors that need to be promoted to help caregivers cope with the issues.

This study looks into these protective factors like self-compassion and dispositional mindfulness which may help reduce caregiver burden. This would help in introducing new therapy models and techniques to help promote these protective factors among caregivers.

Who will be the participants?

Caregivers of children with multiple disabilities as well as caregivers of typically developing children.

What are my benefits if I participate in the study?

You would be able to understand the level of caregiver burden you are experiencing and the protective factors that you can employ to help you emerge out of these difficulties to feel better and to help cope with your child's difficulties in a better way.

Does this study involve any expenses?

No, it does not involve any expenses.

Is it legally enforceable?

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

Will there be any negative consequences if I participate?

SELF-COMPASSION, DISPOSITIONAL MINDFULNESS & CAREGIVER BURDEN

No, the participation in this study will not lead to any negative consequences.

Are there any basic requirement to participate in the study?

None.

Voluntary Participation:

Your participation in this study is completely voluntary and you can refuse to participate.

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 or the institute and your child will be receiving standard treatment.

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 of the study will be published in the research journals.

Mode of session & Video Recording:

All the sessions will be conducted in a room setting. The sessions will not be audio or video recorded.

Undertaking by the researcher

Your consent to participate in the above research by Ms S.K. Anandhalakshmi and Ms. Vardhini Krishnamurthy, Department of 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. In such an event, your child will still receive the best possible treatment, without prejudice. If you have any doubts about the research, please feel free to clarify the same. Even during the research, you are free to contact the researcher (Ms. Vardhini Krishnamurthy or Ms. S.K. Anandhalakshmi). The information provided by you will be kept strictly confidential.

Consent to participate in the research study

| | YES/NO |
|---|--------|
| I confirm that I have had an 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 that I am free to withdraw from the study at any time without giving a reason, without my treatment being affected. | |
| I understand that I will have to engage in activities at home as per the instruction from the researcher | |
| I understand that all personal informations I shared 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 Client:

Signature

Date:

Name of the Caregiver:

Signature:

Date:

Name of the researcher:

Signature

Date:

APPENDIX 2

INFORMED CONSENT FORM - TAMIL

ஒன்றுக்கும் மேற்பட்ட ஊனமுற்றோரின் மேம்பாட்டிற்கான தேசிய
நிறுவனம் (NIEPMD)

சமூக நீதி மற்றும் அதிகாரம் வழங்கல் அமைச்சகம், இந்திய அரசு
முட்டுக்காடு, கிழக்கு கடற்கரை சாலை, சென்னை - 603 112

தொ.பே: 9526115304, NIEPMD தொ.பே: 044-27472113, 27472046

மின்னஞ்சல்: vardhini.krishnamurthy@gmail.com

பல குறைபாடுகள் உள்ள குழந்தைகள் மற்றும் பொதுவாக வளரும்
குழந்தைகளைப் பராமரிப்பவர்களிடையே மனப்பான்மை, சுய
இரக்கம் மற்றும் பராமரிப்பாளர் சுமை

ஆய்வு தகவல் தாள்

பராமரிப்பாளர்களுக்கு அவர்களின் மன ஆரோக்கியம் மற்றும்
நல்வாழ்வு விஷயத்தில் அதிக முக்கியத்துவம்
கொடுக்கப்படுவதில்லை. குறைபாடுகள் உள்ள குழந்தைகளைப்
பராமரிப்பதன் எதிர்மறை அறிகுறிகள் மற்றும் எதிர்மறையான தாக்கம்
பற்றி ஆய்வுகள் பேசுகின்றன. இருப்பினும், பராமரிப்பாளர்களுக்குச்
சிக்கல்களைச் சமாளிக்க உதவும் வகையில் ஊக்குவிக்கப்பட வேண்டிய
நேர்மறையான பாதுகாப்புக் காரணிகளைப் பற்றி அதிகம்
பேசப்படவில்லை.

இந்த ஆய்வு இந்த பாதுகாப்பு காரணிகளான சுய-இரக்கம் மற்றும்
மனப்பான்மை நினைவாற்றல் போன்றவற்றைப் பார்க்கிறது. இது
பராமரிப்பாளரின் சுமையை குறைக்க உதவும். இது புதிய சிகிச்சை
மாதிரிகள் மற்றும் நுட்பங்களை அறிமுகப்படுத்தி,
பராமரிப்பாளர்களிடையே இந்த பாதுகாப்பு காரணிகளை மேம்படுத்த
உதவும்.

பங்கேற்பாளர்கள் யார்?

பல குறைபாடுகள் உள்ள குழந்தைகளைப் பராமரிப்பவர்கள் மற்றும்
பொதுவாக வளரும் குழந்தைகளைப் பராமரிப்பவர்கள்.

நான் ஆய்வில் பங்கேற்றால் என்ன பயன்?

நீங்கள் அனுபவிக்கும் பாதுகாவலர் சுமையின் அளவையும், உங்கள் குழந்தையின் சிரமங்களைச் சிறப்பாகச் சமாளிப்பதற்கும் இந்த சிரமங்களில் இருந்து வெளிவருவதற்கு உதவ நீங்கள் பயன்படுத்தக்கூடிய பாதுகாப்புக் காரணிகளைப் புரிந்து கொள்ள முடியும்.

இந்த ஆய்வில் ஏதேனும் செலவுகள் உள்ளதா?

இல்லை, இதில் எந்த செலவும் இல்லை.

இது சட்டப்படி அமலாக்கப்படுமா?

இல்லை, இது சட்டப்பூர்வ ஆவணம் அல்ல. இது ஒரு ஆய்வு ஆவணம்.

நான் பங்கேற்றால் ஏதேனும் எதிர்மறையான விளைவுகள் ஏற்படுமா?

இல்லை, இந்த ஆய்வில் பங்கேற்பது எதிர்மறையான விளைவுகளுக்கு வழிவகுக்காது.

ஆய்வில் பங்கேற்க ஏதேனும் அடிப்படைத் தேவைகள் உள்ளதா?

இல்லை.

தன்னார்வ பங்கேற்பு:

இந்த ஆய்வில் நீங்கள் பங்கேற்பது முற்றிலும் தன்னார்வமானது மற்றும் நீங்கள் பங்கேற்க மறுக்கலாம்.

படிப்பில் இருந்து விலக:

இந்த ஆய்வின் ஒரு பகுதியாக நீங்கள் இருக்க விரும்புகிறீர்களா இல்லையா என்பதைத் தேர்வுசெய்ய உங்களுக்கு சுதந்திரம் உள்ளது.

"இல்லை" என்று கூறுவது ஆராய்ச்சியாளர் அல்லது

நிறுவனத்துடனான உங்கள் உறவைப் பாதிக்காது, மேலும் உங்கள் குழந்தை நிலையான சிகிச்சையைப் பெறும்.

இரகசியத்தன்மை:

நீங்கள் அளிக்கும் தனிப்பட்ட தகவல்கள் ரகசியமாக வைக்கப்படும்.

ஆராய்ச்சி குழுவில் உள்ளவர்கள் மட்டுமே உங்கள் பெயர் மற்றும் விவரங்களை அறிவார்கள். உங்கள் பெயர் எந்த அறிக்கையிலும்

அல்லது வெளியீட்டிலும் தோன்றாது. இருப்பினும், ஆய்வின் ஒட்டுமொத்த முடிவுகள் ஆய்வு இதழ்களில் வெளியிடப்படும்.

ஆய்வாளரால் மேற்கொள்ளப்படுகிறது திருமதி எஸ்.கே அவர்களின் மேற்கூறிய ஆராய்ச்சியில் பங்கேற்க உங்கள் ஒப்புதல் ஆனந்தலட்சுமி மற்றும் திருமதி வர்தினி கிருஷ்ணமூர்த்தி, மருத்துவ உளவியல் துறை, NIEPMD, சென்னை தேடப்படுகிறது. ஆராய்ச்சியின் எந்தப் பகுதியிலும் எந்த காரணமும் கூறாமல் சம்மதத்தை மறுக்கவோ அல்லது திரும்பப் பெறவோ உங்களுக்கு உரிமை உண்டு. இதுபோன்ற ஒரு நிகழ்வில், உங்கள் பிள்ளை பாரபட்சமின்றி, சிறந்த சிகிச்சையைப் பெறுவார். ஆராய்ச்சியில் ஏதேனும் சந்தேகம் இருந்தால், அதைத் தெளிவுபடுத்தவும். ஆராய்ச்சியின் போது கூட, ஆய்வாளரைத் (திருமதி. வர்தினி கிருஷ்ணமூர்த்தி அல்லது திருமதி. எஸ்.கே. ஆனந்தலட்சுமி) நீங்கள் தொடர்புகொள்ளலாம். நீங்கள் வழங்கிய தகவல்கள் கண்டிப்பாக ரகசியமாக வைக்கப்படும்.

ஆராய்ச்சி ஆய்வில் பங்கேற்க ஒப்புதல்

| | ஆம் /இல்லை |
|--|------------|
| என்னிடம் போதுமான விளக்கமும், ஆய்வின் தகவல் தாளைத் தெளிவாகப் புரிந்து கொண்டு கேள்விகள் கேட்கும் வாய்ப்பும் கிடைத்துள்ளது என்பதை உறுதிப்படுத்துகிறேன். | |
| எனது பங்கேற்பு தன்னார்வமானது என்பதையும், எந்த நேரத்திலும் காரணம் கூறாமல் படிப்பில் இருந்து விலகிக் கொள்ளலாம் என்பதையும் புரிந்துகொள்கிறேன். | |
| பயிற்சி பெற்ற ஆராய்ச்சியாளர் தலையீட்டை நடத்துவார் என்பதை நான் புரிந்துகொள்கிறேன், அதைத் தொடர்ந்து ஒரு நேர்காணல் 2 மாதங்கள் எடுக்கும். | |

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|--|--|
| <p>நான் பகிரும் அனைத்து தனிப்பட்ட தகவல்களும் ரகசியமாக வைக்கப்படும் என்பதையும், ஆராய்ச்சி ஆய்வில் ஈடுபட்டுள்ளவர்களைத் தவிர வேறு யாருடனும் பகிரப்படமாட்டாது என்பதையும் புரிந்துகொள்கிறேன்.</p> | |
| <p>மேலே உள்ள ஆய்வில் தானாக முன்வந்து பங்கேற்க ஒப்புக்கொள்கிறேன்</p> | |
| <p>ஆய்வு தகவல் தாள் மற்றும் ஒப்புதல் படிவத்தின் நகல் எனக்கு கிடைத்துள்ளது</p> | |

பங்கேற்பாளரின் பெயர்:

கையொப்பம்:

தேதி:

ஆய்வாளரின் பெயர்:

கையொப்பம்:

தேதி:

APPENDIX 3

SOCIO-DEMOGRAPHIC DETAILS

Research No.

Socio- Demographic Details

Name:

Reg No:

Age of caregiver:

Age of the child:

Gender of caregiver:

Gender of the child:

Relationship of caregiver with the child:

Mother/Father/Grandmother/Grandfather/Sibling/Aunt/Uncle

Nature of disability of child:

Nature of the child: Biological/Adopted

Educational status of the caregiver: Uneducated/ 10th pass/ 12th pass/ Graduate/ Post-graduate/Other

Marital Status: Married/ Divorced/ Separated/ Single parent due to other reasons

Employment status of caregiver:

No. of children with disabilities in the family:

Socio-economic status – High/ Middle/ Low

Level of family support – Good/ Satisfactory/ Poor

Place of residence – Rural/Urban

No. of people in the family:

Type of family: Nuclear/Joint/Extended

APPENDIX 4

MINDFULNESS ATTENTION AWARENESS SCALE (Brown & Ryan, 2003)

Day-to-Day Experiences

Instructions: Below is a collection of statements about your everyday experience. Using the 1-6 scale below, please indicate how frequently or infrequently you currently have each experience. Please answer according to what *really reflects* your experience rather than what you think your experience should be. Please treat each item separately from every other item.

| | | | | | |
|------------------|--------------------|------------------------|--------------------------|----------------------|-----------------|
| 1 | 2 | 3 | 4 | 5 | 6 |
| Almost Always | Very Frequently | Somewhat Frequently | Somewhat Infrequently | Very Infrequently | Almost Never |

| | | | | | | |
|--|---|---|---|---|---|---|
| I could be experiencing some emotion and not be conscious of it until some time later. | 1 | 2 | 3 | 4 | 5 | 6 |
| I break or spill things because of carelessness, not paying attention, or thinking of something else. | 1 | 2 | 3 | 4 | 5 | 6 |
| I find it difficult to stay focused on what's happening in the present. | 1 | 2 | 3 | 4 | 5 | 6 |
| I tend to walk quickly to get where I'm going without paying attention to what I experience along the way. | 1 | 2 | 3 | 4 | 5 | 6 |
| I tend not to notice feelings of physical tension or discomfort until they really grab my attention. | 1 | 2 | 3 | 4 | 5 | 6 |
| I forget a person's name almost as soon as I've been told it for the first time. | 1 | 2 | 3 | 4 | 5 | 6 |
| It seems I am "running on automatic," without much awareness of what I'm doing. | 1 | 2 | 3 | 4 | 5 | 6 |
| I rush through activities without being really attentive to them. | 1 | 2 | 3 | 4 | 5 | 6 |
| I get so focused on the goal I want to achieve that I lose touch with what I'm doing right now to get there. | 1 | 2 | 3 | 4 | 5 | 6 |
| I do jobs or tasks automatically, without being aware of what I'm doing. | 1 | 2 | 3 | 4 | 5 | 6 |
| I find myself listening to someone with one ear, doing something else at the same time. | 1 | 2 | 3 | 4 | 5 | 6 |

| | | | | | | |
|---|---|---|---|---|---|---|
| I drive places on 'automatic pilot' and then wonder why I went there. | 1 | 2 | 3 | 4 | 5 | 6 |
| I find myself preoccupied with the future or the past. | 1 | 2 | 3 | 4 | 5 | 6 |
| I find myself doing things without paying attention. | 1 | 2 | 3 | 4 | 5 | 6 |
| I snack without being aware that I'm eating. | 1 | 2 | 3 | 4 | 5 | 6 |

APPENDIX 5
BURDEN SCALE FOR FAMILY CAREGIVERS – SHORT VERSION (Graessel et al., 2014)

We are asking you for information about your present situation. The present situation comprises your caregiving deduced from the illness of your family member (or friend).
 The following statements often refer to the type of your assistance. This may be any kind of support up to nursing care.

Please draw an “X” for the best description of your present situation.
Please answer every question!

| | strongly agree | agree | disagree | strongly disagree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. My life satisfaction has suffered because of the care. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I often feel physically exhausted. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. From time to time I wish I could “run away” from the situation I am in. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Sometimes I don’t really feel like “myself” as before. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Since I have been a caregiver my financial situation has decreased. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. My health is affected by the care situation. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. The care takes a lot of my own strength. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I feel torn between the demands of my environment (such as family) and the demands of the care. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. I am worried about my future because of the care I give. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

