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## CAREGIVER BURDEN, COPING MECHANISMS AND CATHARSIS: AN EXPLORATORY STUDY

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Adopting a qualitative approach, with narrative analysis, an attempt will be made to understand the experience of 'Caregiver Burden' amongst 5-7 primary caregivers of children with Autism, in India. An attempt will also be made to capture their coping mechanisms and cathartic behaviours, to reduce stress. To this end, a Caregiver Burden Inventory and an Open Ended questionnaire, touching upon the main issues, will be used. The study also aims to perceive how autonomy as a personality trait can play a significant role in empowering oneself as a caregiver and subsequently have noteworthy consequences on the coping mechanisms and cathartic behaviour.

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Caregiver Burden, Autism, Autonomy, India, coping mechanisms, cathartic behavior

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*TRIVENI GOSWAMI VERNAL<sup>1</sup>*

### **ABSTRACT**

*Adopting a qualitative approach, with narrative analysis, an attempt will be made to understand the experience of 'Caregiver Burden' amongst 5-7 primary caregivers of children with Autism, in India. An attempt will also be made to capture their coping mechanisms and cathartic behaviours, to reduce stress. To this end, a Caregiver Burden Inventory and an Open Ended questionnaire, touching upon the main issues, will be used. The study also aims to perceive how autonomy as a personality trait can play a significant role in empowering oneself as a caregiver and subsequently have noteworthy consequences on the coping mechanisms and cathartic behaviour.*

### **KEYWORDS**

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### **1. WHAT IS AUTISM SPECTRUM DISORDER?**

Autism is a neurodevelopmental communication disorder and includes a range of conditions across a spectrum. The fifth edition of the Diagnostic and Statistical Manual (DSM-V, 2013) redefined the Autism Spectrum to include a range of neuro-developmental disorders characterized by social deficits and communication difficulties, stereotyped or repetitive behaviors and interests, sensory issues, and in some cases, cognitive delays (Autism Spectrum, 2015).

According to the National Institute of Mental Health (NIMH), "Autism spectrum disorder (ASD) is the name for a group of developmental disorders. ASD includes a wide range, "a spectrum," of symptoms, skills, and levels of disability. People with ASD often have these characteristics:

- Ongoing social problems that include difficulty communicating and interacting with others.
- Repetitive behaviours as well as limited interests or activities
- Symptoms that typically are recognized in the first two years of life
- Symptoms that hurt the individual's ability to function socially, at school or work, or other areas of life (Autism Spectrum Disorder, 2018).

Action For Autism (AFA), a non-profit organization, based out of New Delhi, India is regarded as a pioneer organization working on Autism in South Asia. Throwing light on this further, the AFA website states the following:

Autism results in qualitative impairments. What this means is that in a person with autism, skills are present (not absent) but do not develop age appropriately. Therefore, different skills develop at a different pace in different people with autism. Another characteristic and perhaps the most confusing feature of autism is an uneven skill development. If a neurotypical child were at the biological age of 4 years, his overall development would be that of a 4-year child. In autism however, a 4-year child,

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may have speech development like that of a 2-year, gross motor skills developed like an 8-year, fine motor skills of a 6-year, and self-help skills of a 3-year child. So a person may be able to do basic arithmetic but not speak; or may know the alphabet, numbers and nursery rhymes, but may not be able to ask for or tell his/her needs or desires. Because of all these characteristics, no two people on the autistic spectrum, look or behave the same (Definition of Autism, 2015).

Individuals with autism experience emotions but have a difficulty expressing them. A child with autism may have to learn emotional behaviours cognitively rather than instinctively. Often times, understanding tonal inflection and the context in which it is spoken, can be problematic for an individual with autism (for example, sarcasm, metaphors etc).

### 1.1 Causes of Autism

There is no single known cause for Autism, hence there is no single cure for it. It is instead increasingly believed amongst researchers that "it is a complex disorder with a set of core aspects that have distinct causes ((Happe' et al, 2008). According to the Autism Society (USA), "it is generally accepted that it is caused by abnormalities in brain structure or function. Brain scans show differences in the shape and structure of the brain in children with autism compared to in neuro-typical children. Researchers ... are investigating a number of theories, including the links among heredity, genetics and medical problems (Causes, 2015).

There has also be a huge, long running debate on the link between vaccinations and the onset of autism, especially the MMR (Measles, Mumps and Rubella) vaccine. But no conclusive evidence has emerged to nail the linkage.

### 1.2 Prevalence rates of Autism

According to the Mayo Clinic (USA), the numbers of children diagnosed with autism spectrum are increasing over the years., but whether this is due to "better detection and reporting or a real increase in the number of cases, or both (Definition of Autism Spectrum Disorder, 2015), is not certain. The Centre for Diseases Control (CDC) placed the incidence of autism in the U.S. at approximately 1 in 68 children, in 2014. There is no India-specific data available to reveal the exact rate of prevalence but it is believed that over 15 million people have autism in India (Autism in India, 2015).

### 1.3 Autism in India

Awareness in India regarding Autism is lacking both within the medical fraternity as well as the general populace, with the result that, more often than not, there are delays in diagnosis as well as incidents of misdiagnosis. In a historical landmark event, the Rights of Persons with Disabilities Bill (2016), was passed by the Parliament in 2016. It increased the number of disabilities from 7 to 21, and for the first time, it included Autism Spectrum Disorder, within its ambit. Amongst many other provisions, one significant provision is that, Government funded educational institutions as well as the Government recognized institutions will have to provide inclusive education to the children with disabilities, and that includes children with Autism Spectrum Disorder. (Rights of Disabilities, 2018).

Autism in India has witnessed a shift in the levels of awareness, provision of services and in its early detection and diagnosis, in comparison to the last two decades, yet the understanding that Autism is a lifelong condition has not begun to gain ground amongst the general populace.

## 2. CAREGIVER BURDEN: DEFINITION

*“Caregiver burden has been defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member (Stucki & Mulvey, 2000). It is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience” (Caregiver Burden, 2018)*

The term Caregiver refers to any individual who supports and helps a person, in need of care, regularly. Caregiver Burden is the stress perceived by the caregivers, in a home care situation. The perceived burden can be based on several factors such as challenging behaviours (of the individual

cared for), social isolation, no time for oneself etc. Caregiver syndrome or caregiver stress is a condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a chronically ill dependent (Caregiver Stress, 2018).

Caregiver syndrome is acute when caring for an individual with behavioural difficulties, such as: faecal incontinence, memory issues, sleep problems, wandering, and aggression. Typical symptoms of the caregiver include: fatigue, insomnia, stomach complaints, and so on, with the most common symptom being depression. Due to the deterioration (both physical and mental) of these caregivers, health professionals have given this condition a name, *caregiver syndrome* or "caregiver fatigue" (Ibid). If the caregiver doesn't get the required physical and emotional support that he or she requires, the stress of caregiving can leave one vulnerable to a wide range of problems, including depression, anxiety, and burnout. According to a website for support resources, Help Guide ([www.helpguide.org](http://www.helpguide.org)).

Common signs and symptoms of Caregiver Stress:

- Anxiety, depression, irritability
- Feeling tired and run down
- Difficulty sleeping
- Overreacting to minor nuisances
- New or worsening health problems
- Trouble concentrating
- Feeling increasingly resentful
- Drinking, smoking, or eating more
- Neglecting responsibilities
- Cutting back on leisure activities

Common Signs and Symptoms of Caregiver Burnout:

- You have much less energy than you once had
- It seems like you catch every cold or flu that's going around
- You're constantly exhausted, even after sleeping or taking a break
- You neglect your own needs, either because you're too busy or you don't care anymore
- Your life revolves around caregiving, but it gives you little satisfaction
- You have trouble relaxing, even when help is available
- You're increasingly impatient and irritable with the person you're caring for
- You feel helpless and hopeless

## 2.1 Coping Strategies

One of the major reasons for Caregiver Burden is the negative perception of the caregiving situation, fuelled by the stressors associated with the caregiving environment. According to the Transactional Model of Stress and Coping originally developed by Richard S. Lazarus and Susan Folkman (1981), people deal with stressful situations by appraisals of stressors and resources. The primary appraisal deals with the individual meaning of the specific stressor, which is the care situation. The secondary appraisal analyses one's own abilities and resources to cope with that situation. On this basis, the individual coping efforts are used to deal with the stressful situation (Caregiver Burden, 2018).

According to Folkman and Lazarus, there are two kinds of coping strategies, The first, termed problem focused coping, is aimed at problem solving or doing something to alter the source of the stress. The second, termed emotion focused coping, is aimed at reducing or managing the emotional distress that is associated with (or cued by) the situation. Although most stressors elicit both types of coping, problem-focused coping tends to predominate when people feel that something constructive can be done, whereas emotion-focused coping tends to predominate when people feel that the stressor is something that must be endured (Folkman & Lazarus, 1980).

The coping strategy adopted by the caregiver can alter the caregiving experience and shape the perceived experience of subjective burden. If the caregiver adopts a problem focused coping strategy, it can reduce stress to a large extent. In comparison, if the caregiver adopts an emotion

focused coping, the aim is focused on working on one's emotions associated with the situation rather than the stressor, itself. According to Weiten (2008), there are four types of coping strategies (Coping Psychology, 2018):

- Appraisal-Focused (adaptive cognitive): directed towards challenging personal assumptions.
- Problem-Focused (adaptive behavioral): reducing or eliminating stressors.
- Emotion-Focused: changing personal emotional reactions.
- Occupation-Focused: directed towards lasting occupation(s), which generates positive feedback

Over time, people may employ a mixture of several coping strategies and the nature of the coping strategies may evolve. This in turn shapes one's experience of the caregiving situation. Coping Strategies can also be *adaptive* and *maladaptive*. *Adaptive coping strategies* are *constructive* in nature, where the individual proactively anticipates what to expect and makes preparations to cope with it. It could include strategies like seeking social support and meaning focused approach (where the individual derives meaning from the stressful situation). In contrast, *Maladaptive coping strategies* will initially show benefits in the short term while maintaining and strengthening the stressor. It could include strategies such as denial and social isolation etc.

## 2.2 Measuring Caregiver Burden

Several scales/inventories have been developed to measure caregiver burden. The assessment of caregiver burden enables one to judge the situation of the caregiver. In Anglo-American countries, a number of burden scales have been developed; e.g. the Burden Interview, the Caregiver Strain Index and the Cost of Care Index. The Burden Scale for Family Caregivers, which has been developed in Germany, is now available in 20 languages. In the present study, a *Caregiver Burden Scale developed by the Frontotemporal Lobar Degeneration Association (FTLDA)*, has been used. The Frontotemporal Lobar Degeneration Association (FTLDA) is dedicated to its mission to raise awareness, educate medical professionals, and advance research of FTD and related neurological disorders. The Caregiver Burden scale has 22 statements that can be rated on a scale of 0 to 4 (Key: 0: never, 1: rarely, 2: sometimes, 3: frequently, or 4: nearly always). The scoring key for the scale is as follows: 0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

Since the FTLDA concerns itself with neurological disorders and Autism Spectrum Disorder is a neurodevelopmental communication disorder, it was felt that the Caregiver Burden Scale developed by FTLDA will be a good fit, for the study.

## 2.3 Catharsis

Catharsis is the process of releasing, and thereby providing relief from, strong or repressed emotions. According to the theory of psychoanalysis, this emotional release is linked to a need to relieve unconscious conflicts. For example, an individual who may be experiencing stress at work, may choose to release the frustration and tension by engaging in an activity ...such as pursuing a hobby or doing a physical activity, instead of shouting or being angry about it. This process is called catharsis. In the light of caregiver stress, catharsis plays a significant role in maintaining a sense of equilibrium.

## 2.4 Psychological Empowerment

According to Sanjay T. Menon (1999), the psychologically empowered state is considered to be "a cognitive state characterized by a sense of perceived control, perceptions of competence, and internalization of the goals and objectives..." (Menon, 1999).

According to Kwanghyun Kim, Soyeon Lee, psychological empowerment has been defined as "intrinsic task motivation reflecting a sense of self-control in relation to one's work and an

active involvement with one's work role" (Psychological Empowerment, 2018). For a caregiver, a sense of helplessness and powerlessness can contribute to depression, frustration and burnout. Thus, cultivating a sense of empowerment can go a long way in alleviating the tiring conditions that are often associated with caregiving. Multiple ways in which one can feel empowered according to the support services website, Help Guide ([www.thehelpguide.org](http://www.thehelpguide.org)) are:

- Embrace your caregiving choice
- Focus on the things you can control
- Celebrate the small victories
- Give yourself a break
- Prioritize activities that bring you enjoyment
- Get out of the house
- Take care of your health
- Join a support group

The ability to sort one's life, prioritize activities, allowing time for oneself to enjoy and taking ample breaks, helps the caregiver create a sense of balance in his/her life and not be overwhelmed by the various stressors, including loss of a sense of time and one's individual space. Taking care of one's health, eating well and keeping oneself fit (emotionally and physically) can go a long way, in injecting positivity in oneself. Making an effort to maintain social relationships and not be isolated from friends and family, and joining a support group, can also help bring about a sense of confidence, perceived control over significant matters and decisions and provide a space for guidance and emotional catharsis. Thus, psychological empowerment is of such immense significance in a caregiver's life.

## 2.5 Review of Literature

Caregiver Stress is a well-researched area but very little literature is available on its relation to ASD, per se. For the purpose of this paper, a brief review of literature was carried out on studies in the last five years.

Wei Wei Lai & Tian Po S Oei (2014) carried out a review of 37 studies that investigated the (a) underlying themes, (b) contributing factors, and (c) psychological outcomes of ASD-related parental and caregiver coping. The results revealed the following:

The two most useful coping resources, i.e., problem-focused coping (45.9 %) and social support (37.8 %), were supported by parental stress coping studies. Parents' and caregivers' use of coping strategies was also influenced by (1) demographical characteristics (i.e., gender, age, education, income, language) and psychological attributes (i.e., personality, cultural values, optimism, sense of coherence, benefit-finding and sense-making abilities, emotional health, coping styles), (2) child characteristics (i.e., age, gender, medical conditions, cognitive and adaptive functioning abilities, language difficulties, and behavior problems) and (3) situational variables (i.e., treatment availability, family function, and clinician referrals to support resources), (Lai & Oei, 2014).

Gwen Ling Tay's (2013) study *Caring for an Individual with Autism Spectrum Disorder in New Zealand: Caregiver Coping and Caregiver Stress*, sought to identify the predictors of subjective caregiver burden of those caring for an individual with ASD in New Zealand and was on one of the first kind of study in this area. A total of 184 informal caregivers participated in the study completing a questionnaire containing questions probing information regarding the care recipients, the caregivers' demographic details and their caregiving experience. The results revealed four main findings: 1) The severity levels of the ASD symptoms predicted subjective caregiver burden; 2) The caregivers' cognitive appraisals (i.e., self-esteem) does not mediate nor predict subjective caregiver burden; 3) Professional support was found to be the main moderator of subjective caregiver burden, followed by family and partner support; and 4) Problem-focused coping effectively buffers caregiver burden (Tay, 2013).

Max Holden's study on *Caregiver Empowerment: How occupational therapy can make a difference in the lives of family members in sub-acute rehabilitation* (2016) adopted both qualitative and quantitative approaches and included 7 participants. The study revealed that

family members are often deprived of meaningful occupational engagement resulting in diminished health, well-being, and quality of life (Max, 2016).

The study *Exploring Autism and the Caregiver Burden Relationship* (2017) by Mary C. Drockton, collected qualitative data on the different stresses and burdens associated with being a caregiver for an autistic individual, and discover strategies of stress relief for caregivers. The method of data collection included attending and observing (with documentation of the discussion between the moderator of the meeting and the caregivers in attendance) of four autism support group meetings. The observations revealed common themes of stress in caregivers: difficulty with the diagnosis process and finding medical treatment; seeking additional information on available medical treatments; becoming a “fit” caregiver; finding the right specialized education and services; funding the care and education of their child; difficulty finding time, resources, and maintaining a schedule; special needs and considerations; and the future of his or her child. Stress relief was typically sought through social support and therapy services, but the knowledge and awareness of these resources among caregivers was limited. Support groups tended to offer some relief to stress, while therapy services, including occupational therapy, offered great value and relief to the autistic individual and the caregiver (Drockton, 2017).

The brief review of literature reveals that problem focused coping strategies contributed towards the alleviation of caregiver stress. Additionally, support from family members, professional services, therapeutic services and being part of support groups offered great value to the caregiver and helped them cope with the various stressors.

### 3. THE PRESENT STUDY: SAMPLE, APPROACH AND METHODOLOGY

An attempt has been made to explore the perceived experiences of caregiver burden amongst a group of six parent caregivers of children with Autism, in India. The study is a small effort to tap into how parents, construct an understanding of their caregiving experiences vis a vis their children. A *qualitative lens* was adopted and a small sample comprising of six caregivers was selected. The parents were chosen from the cities of Hyderabad, Bangalore, Mangalore and Delhi. The sample of parent caregivers comprised of 5 mothers and 1 father. The age range of the caregivers was between 34 - 41 years. Except for one girl, the rest of the children, were boys. The age range of the children ranged from 5-11 years. All the children were in the Mild to Moderate end of the Autism Spectrum. To this end, a Caregiver Burden Scale *developed by the Frontotemporal Lobar Degeneration Association (FTLDA)*, was administered and an *open ended questionnaire* was constructed. The Caregiver Burden scale has 22 statements that can be rated on a scale of 0 to 4 (Key: 0: never, 1: rarely, 2: sometimes, 3: frequently, or 4: nearly always). The scoring key for the scale is as follows: 0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden. Unstructured interviews were conducted electronically through an open-ended questionnaire. The questionnaire comprising of 11 questions was constructed, covering issues such as the journey of the parent since the diagnosis of the child, their initial reaction to the diagnosis, access to therapeutic services, support from family and/friends, coping mechanisms, support groups and finally, their expectations from the future. Since many parents shared information on sensitive issues, *they requested to keep their names as well as that of their children, confidential*. To this end, other than the details, only the names of the participants and their children have been kept confidential. The sample comprising of 6 parent caregivers in the present study, represented a varied demography in their age, location, gender, education etc., yet they were bound by a common theme of working towards their child’s development. The evolution of a newbie parent, fumbling with the term ‘autism’, to taking on a more proactive role in the child’s intervention, over the years, can be clearly seen in all their narratives. Out of the six parents in the sample, 4 were parents to children aged between 9 and 11, and two were parents to children between 5-6 years of age. The average age range between which a child was diagnosed was 2- 5 years, with an exception of a child, who was diagnosed at birth with a scar on his occipital lobe and occurrence of seizures.

Table 1: Information on the chosen sample



Parent (Designated Initials)	Age	Educational Qualifications	Child (Designated Initials)	Age (Yrs)	Education	Age when diagnosed
K	41	MBA	A	10	Special School	At birth
M	35	MA	T	9	Special School	3.9 years
A	36	PhD (Ongoing)	R	9.5	Homeschooled (at present)	5 years
M	34	B.Ed.	A	5.9	Regular Playschool	2.2 years
R	34	MSc	S	5	Regular Playschool	2.5 years
S	35	BSc	S	11	Homeschooled	2 years

Table 2: Trainings undertaken/Active Engagement with the Autism Community

Parent (Designated Initials)	Training /Courses Undertaken/Active Engagement with Autism Community
K	Parent Child Training Program (PCTP) at Action For Autism, New Delhi
M	Parent Child Training Program (PCTP) at Action For Autism, New Delhi
A	Certificate on an online course on Autism Spectrum Disorder from the University of California
M	Active engagement with the Autism Community through a social media platform of an organization, Nayi Disha, ( <a href="http://www.nayi-disha.org">www.nayi-disha.org</a> )
R	-do-
S	Parent Child Training Program (PCTP) at Action For Autism, New Delhi

#### 4. THEMATIC INTERPRETATION

Several noteworthy issues emerged from the rich narratives of the parent caregivers. For purposes of clarity, they have been arranged around a few themes:

##### 1) The Lived Reality:

This theme touches upon the journey of the parent since their child's diagnosis, their struggles and their support systems, in their journey, if at all. With an initial diagnosis averaging around 2.5-3.5 years, most parents had to confront a reality that they were unprepared for. It was a shock for most of them. They had never really heard of the word 'autism' before, or even if they had heard and had a niggling suspicion about it, they did not want to accept the truth and lived in denial for months, before they sought intervention. As one parent, put it across, "The initial reaction to the diagnosis was definitely denial and as acceptance sunk in, there was an urge to cure. But we soon realised that the journey will change and might get much tougher than we had initially thought..." (Interview with K, January 5, 2018). The Early Intervention services for almost all children comprised of Speech Therapy, Occupational Therapy, Special Education through ABA approach, Biomed etc. In recent times, efforts have also been made to introduce Art Therapy and Music Therapy (Interview with M, mother of 9 yr old T) and the philosophical underpinnings of Anthroposophy (Interview with K, mother of 10 yr old A). While the younger parents of children (aged 5-6 years) are still trying to understand the complexities of Autism and its varying intervention techniques, a sense of cynicism can be sensed in the parents of the older children (9-11). Having come a long way, since their child was initially diagnosed, most parents of older children, have begun to accept the condition for it holds. As a parent, S (mother to an 11 year old boy, S), has stated "I have learned to keep working without

expectations.” There can also be seen a tilt towards more holistic approaches like Art Therapy, Music Therapy and Anthroposophy (that emphasizes on play, art and music) etc. Elaborating on the support received from extended family and friends, the parents stated that after the initial hiccups, over the years, most family members have made an effort to understand Autism better. It was also revealed that unlike a decade ago, there are much better support services available for parents facing a new diagnosis, today. This has been made possible through numerous support groups and forums available, pan India, across multiple social media platforms...including but not limited to, Facebook, WhatsApp, Twitter etc. This kind of support groups or parent driven networks were few and far between, when the older parents were struggling with a fresh diagnosis. The role played by these support groups is significant not only because it allows the parents to share their queries, and create an understanding of the challenges besetting their child, but also because it provides them with resources and an opportunity for real time knowledge sharing on various issues, such as sensory needs, inclusive schools, remedial educators, shadow teachers, intervention techniques, therapists etc.

## 2) Coping Strategies and Catharsis:

Most parents were found to be adopting Adaptive Coping Strategies (a proactive stance) in coping with the challenges associated with autism—whether it was taking initiatives to educate themselves on the nuances of the condition or undergoing some form of training to learn about managing the behaviours or learning about teaching strategies etc. Although their lives are stress laden, many of the parents expressed their growing interest in spirituality and meditation, as a means of coping with the stressors. M, mother of 9 year old T, described it as “Spiritual Socialization”. Elaborating further, she stated that she participated in weekly meetings at the ISKCON (International Society of Krishna Consciousness) temple with a group of devotees. S, the mother of 11 year old S, stated that working on herself and cultivating an understanding of the spiritual aspects, helps her to continuously improve herself and develop a positive approach towards life. Catharsis refers to the process of releasing pent up emotions and stressors. The parents reported that they engaged in various kinds of hobbies (reading, playing games, going for a walk, cooking, watching movies, playing a musical instrument, indulging in personal care, writing, seeking out the company of friends and other support networks etc) to keep their mind off the stress in their daily lives. M, a mum of a 5 year old child A, sums it up well. She states, “Sometimes I just give up everything and so want to take a break. Then start again because I know if I will not do for my son, no one else will make an effort. I keep taking small breaks from my routine, meet old friends, go for shopping, personal care etc.”

## 3) Hopes for the Future:

The study revealed interesting insights into the kind of expectations that the parents had from their child and more importantly the Administration in the Government, towards the fulfilment of legal obligations inherent in the Rights of Person’s With Disabilities Act (RPWD Act, 2016) and provisions for education, employment, insurance etc. In brief, some of their hopes for the future are as follows:

- Hope that the child becomes as independent as possible.
- The Government should provide for residential facilities
- Homes for autistic children/adults when their parents die or become old
- Government needs to sensitize the general public regarding autism. At a current prevalence of 1 in 68, autism is still not known to the general public
- More school/vocational training for autistic children and young adults
- Getting the biometric scan for the Aadhar card for autistic children is quite difficult as they usually do not cooperate for both the finger or the Iris scan
- The process to obtain a disability certificate for autism is very tedious, complicated and time consuming. The Government must take steps to make it easier
- More inclusive schools
- Professional help in every part of country, more employment opportunities, and aids for therapies.
- Better advocacy resulting in acceptance and understanding
- Legal provisions and issues of Guardianship.

#### 4) Initiative Taking and Caregiver Empowerment:

Almost all parents in the study have taken initiatives to train or educate themselves on Autism or a related field. Three out of the six parents, have undergone the Parent Child Training Program (PCTP) at AFA, Delhi. One parent has obtained a certificate from the University of California for its online course on Autism Spectrum Disorder. The remaining two parents, although not trained specifically in the field of Autism, are very active on a social media platform of an organization, Nayi Disha (nayidisha.org), focusing on Developmental Disabilities.

The author hypothesizes that individuals, such as these parents, who have taken the initiative to push themselves to train further or educate themselves on Autism or even taken up a proactive role in dissemination of resources/information on Autism, have created in themselves a sense of autonomy and empowerment, thus paving the way for a more positive outlook towards the caregiving experience. The motivation to train oneself is shaped largely by an inherent sense of wanting to take charge/be in control of the situation. This in turn can have significant consequences on their coping mechanisms and cathartic behaviour.

#### 5) Challenges and Perceived Caregiver Burden: Interpretation of the Caregiver Burden Scale:

The Caregiver Burden Scale comprises of 22 statements. The statements reflect how people sometimes feel when they are taking care of another person. After each statement, the respondent had to circle how often they felt that way: never, rarely, sometimes, frequently, or nearly always. The corresponding score for each of those responses were 0,1,2,3 and 4.

##### Scoring key:

0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

In the study, the range of scores obtained on the Caregiver Burden Scale was between 23 and 81. The least, that one can score on the scale is 0 (No Burden) and the highest, is 88 (implying, the upper limit of severe burden). In the study, four out of the six parents scored within the range of 21 and 40 implying mild to moderate burden. One parent scored 46 (implying, moderate to severe burden) and the lone father in the study, scored an 81 (implying severe burden). Several statements in the Caregiver Burden Scale focused on whether caregiving per se, took over their lives, leaving little time for socialization or personal enrichment. It also looked into the question of how the caregiver (parent, in this study) views the child—do they find the child’s behaviour embarrassing? Do they feel stressed over the child’s condition? Are there concerns over money and what the future holds for the child? etc. The perceived burden experienced by the parents was shaped not only by the challenges of their children but also the prevalent family dynamics, the support systems available to them, access to various intervention services, access to schools, as well as the progress (however little) made by their child, over the years. The challenges experienced by the parents can be explained through three broad themes: First, concerns over limited communication of their children (sparse expressive speech, inability to express their emotions, pain etc). Secondly, lack of impulse control and concerns about body regulations. Thirdly, the fear of what will happen to the children, after the parents are no more. This fear is further exacerbated by the lack of residential facilities for children/adults on the spectrum, in India. There are a few such set ups available, but they are few and far between. Thus, most parents scored within the range of mild to moderate burden on the scale. The exception to this, was A (father to a 9.5 year old boy), who scored 81, implying severe burden. A’s son is mostly non-verbal and has had a history of hyperactivity and meltdowns (with screaming as an outlet of venting out his frustration). As mentioned by A, “During meltdowns, my son would scream non-stop. My neighbours have called the police, several times, but I don’t go out and argue with them. I tell myself to remain calm. I have become much more empathetic to others.” A’s life story is far more complex, in comparison to the other parents. By his own admission he is not the primary caregiver, yet his experience of caregiver burden is so high. The complex layers in his personal life has added to his levels of stress Elaborating on his life he has spoken about challenges at home—a strained relationship with his wife and the lack of support from his, as well as her parents, when the child was diagnosed. The diagnosis not only took a toll on his marital life (that was already under a lot of strain), but also

led to other complexities, such as depression and social anxiety in his wife. A brief overview of his life, in his words:

*“Since our son was 3 years old, we have been taking him to various therapies- speech, OT and sensory integration. We knew he was not a neuro-typical child, though the formal diagnosis of being autistic was not done, but we knew he had ADHD and possible ASD. We first denied that our child is autistic. Then we avoided all social connects (we still live isolated). We would not invite people to our house, nor would go to others, unless they are very close friends or relatives. Personally, it has been a really challenging journey for me. Our marriage was already going through a tough phase even before our child was conceived. Had the child not been there, we would have been divorced. But once the child came, I knew he/she would need both parents to live a healthy life. So, I tried my best to reconcile the differences. But the differences never disappeared. Finally, when I realized that my son is not neuro-typical, I knew that I must sustain the marriage. Living through a marriage just for the sake of the child is tough. I too undergo brief episodes of depression, but I have managed to overcome them. My wife is the primary caregiver, I just support her economically. My wife quit her job in 2010 after we realized our son is not neuro-typical, though the formal diagnosis happened only in 2013. She now suffers from social anxiety and depression. I continued my life with few compromises like I don’t travel much these days either on leisure or official trips as it is difficult for my wife to handle our child alone.”*

The responsibility of sustaining a marriage that is strained, adds to the already existing challenges of raising a child with Autism. In addition, the choices made by them (both he and his wife) to lead a life in relative social isolation reflects maladaptive coping mechanisms, that have further complicated matters. Thus, complex family dynamics, lack of support systems (friends and family) and the challenges associated with autism in the child, has led to a perception of ‘severe caregiver burden’ for A.

## 5. CONCLUSION

The level of awareness regarding Autism, in India, is still at a nascent stage. Much of the available information in the country is limited to the urban pockets, amongst the English literate population. In such a context, the concept of Caregiver Burden amongst the parents of children with Autism is relatively alien. Although beset with various kinds of stressors in their lives, parent caregivers were found to soldier on. M, a mother of 9 yr old, T, stated, “The journey of Autism is a marathon. And Autism has emerged as a strength in my life.” This sentiment was echoed by all parents, one way or the other, in their narratives.

There is a realization amongst all parents that Autism is a lifelong condition and the best way to cope with it, is to unconditionally accept the child, actively work towards their improvement and focus on the positives. A parent sums up this sentiment beautifully. She states, “I have come a long way in this journey, learned to be more patient, a calmer person, filter out the unwanted people from my life, learned how to enjoy tiny milestones, achievements and most importantly never give-up, accept the way things are and be thankful for it.

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