

February 2021

SELF CARE, MENTAL HEALTH AND COVID-19: AN EXPLORATORY STUDY OF THE COPING STRATEGIES OF CAREGIVERS OF INDIVIDUALS WITH AUTISM DURING THE PANDEMIC (IN HYDERABAD, INDIA)

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Recommended Citation

Goswami Vernal, Triveni (2021) "SELF CARE, MENTAL HEALTH AND COVID-19: AN EXPLORATORY STUDY OF THE COPING STRATEGIES OF CAREGIVERS OF INDIVIDUALS WITH AUTISM DURING THE PANDEMIC (IN HYDERABAD, INDIA)," *BAU Journal - Society, Culture and Human Behavior*. Vol. 2 : Iss. 2 , Article 9.
Available at: <https://digitalcommons.bau.edu.lb/schbjournal/vol2/iss2/9>

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SELF CARE, MENTAL HEALTH AND COVID-19: AN EXPLORATORY STUDY OF THE COPING STRATEGIES OF CAREGIVERS OF INDIVIDUALS WITH AUTISM DURING THE PANDEMIC (IN HYDERABAD, INDIA)

Abstract

COVID-19 (Coronavirus Disease-19), an infectious condition was first identified in December 2019, in Wuhan, in China. It has led to a worldwide pandemic with millions of people affected—not just health wise, but also economically and psychologically. The uncertainty associated with it, has caused immense anxiety, stress and trauma to people all over the world. India's response to COVID-19 has comprised of a series of phases of Lockdown and subsequent Unlock. In mid-March, India announced a nationwide Lockdown, that led to the closure of educational institutions, factories, work places, transport, cinema halls, hotels, malls etc. The only places that were open during the Lockdown were essential services. Over the next few months, India has entered the Unlock phase, with most services opening to business. The Lockdown and the subsequent Unlock phases had an immense impact on the lives of the common people, who were confined within their houses, or with some flexibility, within their gated communities. In such a context, the researcher made an attempt to *understand how caregivers of individuals with Autism coped with the changes* brought on by COVID-19, how it *impacted on their self-care and mental health* and the *creative strategies adopted by them to keep their children on the Autism spectrum, engaged*. To this end, a *Qualitative* approach was adopted and a small sample of five (5) parent caregivers, were selected through *Purposive Sampling*, in the city of Hyderabad, in south India. A Caregiver Self-Assessment Checklist (developed by the Parkinson's Foundation) was administered to the participants. An open-ended questionnaire was constructed and telephonic interviews were conducted with the participants. The detailed interviews were then thematically analysed. The study revealed the following—First, the *pandemic and the Lockdown was stress inducing* (and had far reaching impacts on the caregivers and their families). Secondly, although bogged down by the stressors, the caregivers *focused on the positives* that the situation brought. Thirdly, the caregivers went above and beyond to *creatively engage with their children*, even with limited resources at hand. Fourthly, the caregivers tried to *engage in self-care activities to improve their mental-health*. Fifthly, the *scores on the Caregiver Assessment Checklist ranged between 'Excellent job at taking care of yourself' and 'Room for Improvement'* and Sixthly, the caregivers believed that *technology provided an important sense of connectedness during the pandemic*.

Keywords

self care, mental health, Covid-19, India, autism, caregivers

*“An empty lantern provides no light. Self-care is the fuel that allows your light to shine brightly.”-
Unknown*

1. INTRODUCTON

COVID-19 (Coronavirus Disease-19), an infectious condition was first identified in December 2019, in Wuhan, in China. It has led to a worldwide pandemic with millions of people affected—economically, physically and psychologically. According to the website (<https://www.worldometers.info/coronavirus/>), as of Oct 21, 2020, the total number of Coronavirus cases worldwide is 41,277,937, the number of deaths stands at 1,132,668 and the number of recovered cases are 30,779,349. COVID-19 has disrupted the global economy, leading to loss of income, employment opportunities and increased economic deprivation, hunger and instability.

The most common symptoms of COVID are extreme fatigue, shortness of breath or breathing difficulties, and loss of smell and taste. It is to be noted however, that not all individuals, affected by COVID, experience the same symptoms and while most people have mild symptoms, some people may develop an acute respiratory distress syndrome. The recommended preventive measures include maintaining social distance between individuals, wearing a mask to prevent small droplets that can carry the infection via coughing, sneezing or even talking and washing hands frequently/using a sanitizer wherever possible. The response to the pandemic varied across countries.

1.1 India’s Response to Covid 19: Multiple Phases Of Lockdown And Unlock

In India, a nationwide lockdown was announced, on March 24th, for a period of 21 days, to contain the spike in COVID cases. Over a series of further announcements, the lockdown extended till May 30, 2020.

The announcement had deep implications---all educational institutions, work places, recreational centres, public transport, community retailers, playgrounds and parks etc were shut down. Only emergency services such as hospitals, police stations, medical support services and Government authorized market places were allowed to function. A large segment of the informal economy suddenly found themselves without employment, and a reasonable source of income, thereby being caught in spaces of vulnerability and exploitation.

From June 1, 2020 till date, India eased its restrictions on the lockdown, bringing into fore the phases of Unlock 1 (June 1-30, 2020), Unlock 2 (July 1-31, 2020), Unlock 3 (August 1-31, 2020), Unlock 4 (September 1-30, 2020) and Unlock 5 (October 1-31, 2020). Shopping malls, restaurants, air travel, places of worship, hotels, gymnasiums etc were opened, with strict protocols in place, over several months but large gatherings of people are still banned. Wearing of masks was made compulsory in public places.

The implications of the lockdown were felt by all households that were expected to stay in, within the confines of their homes. Most of the housing complexes had stringent rules, not allowing residents to take walks within the gated community, not to mingle with other residents and preventing the usage of common facilities, such as elevators, parks etc.

In such a context, thus, the researcher makes an attempt to understand how the caregivers of individuals with Autism, reacted to the pandemic and the subsequent lockdown, the self-care strategies adopted by them and the creative ways in which they tried to keep the child and the family engaged. To this end, a *qualitative approach* was adopted and through *purposive sampling*, a small sample of five (5) caregivers was selected. Telephonic interviews were conducted and the narratives were analysed thematically.

1.2 Autism Spectrum Disorder And Its Prevalence

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. 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 behaviors 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

According to Juneja and Sairam (2018), “Recent estimated prevalence of ASD in India ranges from 0.15% to 1.01% in various studies, depending on the screening method used, and the areas surveyed [4,5]. In the INCLIN study, the prevalence of ASD (then termed as PDD) was 1 in 125 in children 3-6 years and 1 in 85 in children 6-9 years of age. The prevalence in rural areas was 0.90%, 0.6% in hilly regions, 1.01% in urban areas, 0.1% in tribal areas and 0.61% in the coastal regions”.

According to the Autism and Developmental Disabilities Monitoring (ADDM) Network of the Centres for Disease Control and Prevention (CDC), in the US, about 1 in 54 children has been identified with Autism Spectrum Disorder.

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.

1.3 Caregiver And Caregiver Burden: Definition

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 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 syndrome or caregiver stress is a condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a chronically ill dependent. . 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) ,

1.3.1 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

1.3.2 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

1.4 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.

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:

- **Appraisal-Focused** (adaptive cognitive): directed towards challenging personal assumptions.
- **Problem-Focused** (adaptive behavioural): 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 also 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. COVID-19, MENTAL HEALTH AND SELF-CARE

Mental Health is much more than the absence of mental illness. It "includes our emotional, psychological, and social well-being. It affects how we think, feel and act. It also helps determine, how we handle stress, relate to others, and make choices. Mental Health is important at every stage of life, from childhood and adolescence through adulthood."

The Department of Mental Health and Substance Abuse of the World Health Organization (WHO) developed a series of messages on Self Care for various kinds of Caregivers during COVID-19. The underlying belief of these messages was that the global pandemic has caused immense stress

to all, and especially to the Caregivers and therefore, steps should be taken to nurture their emotional, psychosocial and mental health.

In a section on **Messages for Carers of Children**, the following has been listed:

“18. Help children find positive ways to express feelings such as fear and sadness. Every child has his or her own way of expressing emotions. Sometimes engaging in a creative activity, such as playing or drawing can facilitate this process. Children feel relieved if they can express and communicate their feelings in a safe and supportive environment.

19. Keep children close to their parents and family, if considered safe, and avoid separating children and their caregivers as much as possible. If a child needs to be separated from his or her primary carer, ensure that appropriate alternative care is provided and that a social worker or equivalent will regularly follow up on the child. Further, ensure that during periods of separation, regular contact with parents and carers is maintained, such as twice-daily scheduled telephone or video calls or other age-appropriate communication (e.g. social media).

20. Maintain familiar routines in daily life as much as possible, or create new routines, especially if children must stay at home. Provide engaging age-appropriate activities for children, including activities for their learning. Where possible, encourage children to continue to play and socialize with others, even if only within the family when advised to restrict social contact. 21. During times of stress and crisis, it is common for children to seek more attachment and be more demanding on parents. Discuss COVID-19 with your children in an honest and age-appropriate way. If your children have concerns, addressing them together may ease their anxiety. Children will observe adults' behaviours and emotions for cues on how to manage their own emotions during difficult times”.

2.1 Self Care

Self-Care refers to the practice of actively taking care of one's wellbeing. It has emerged as the single most important aspect of nurturing mental health and ensuring psychological well-being in Caregivers. Since the outbreak, a lot has been written on Self-Care and Mental Health of Caregivers. Some of the measures suggested are—*exercise* (to boost cognitive health and improve one's mood), *maintaining a healthy diet* (a healthy and nutritious diet as far as possible), *good sleep*, *engaging in hobbies* (every day, try to reserve some time for oneself, to relax one's mind and body), *paying attention to how one is feeling* (feeling overwhelmed during these times, is normal), *engaging in a mindful activity*, and *taking advantage of 'quiet time'* (when the child is resting). *Taking time for oneself*, *prioritizing healthy choices*, *being realistic* (not just in parenting but also in the work, one does), and *setting boundaries* (keeping away from news that is worrying or causing too much stress).

While several organizations (providing intervention services for Autism), both in India and abroad, switched to the online /digital platform, to conduct one-on-one sessions with the children on the spectrum, training programs for the caregivers as well as sessions on art, sports and crafting for the children, during this pandemic, the researcher came across two Canada based organizations (*Autism Society Newfoundland and Labrador* and *Autism Society of Edmonton Area*), that went a step further and developed well thought out Resources and Self Care Kits that were made available, for both, caregivers as well as children, on their websites.

The Resources included detailed lists of museums across the world that were open for virtual visits, sensory activities, LEGO, activities available on YouTube, Coding, Structured activities at home, yoga/dance classes online etc. The Self Care Kit for the Kids included downloadable activities for colouring, word games, information on structured activities, play, identifying feelings and emotions etc. and the Self Care Kit for Adults with Children included information on maintaining a structure/schedule for activities, maintaining a journal, activities to

relax, snack ideas for children, yoga, meditation, breathing exercises and also an entire list of virtual tours to museums etc.

2.2 Caregiver Self-Assessment Checklist

The Caregiver Self-Assessment Checklist chosen for this study, was selected due to its simple yet comprehensive coverage of the basic challenges faced by a caregiver for Self-Care. The Checklist was developed by the Parkinson's Foundation, to identify risk factors and to assess challenges and needs, faced by caregivers, at regular intervals. The Parkinson's Foundation is a US based organization that was formed by merging the National Parkinson Foundation (NPF) and the Parkinson's Disease Foundation (PDF), that were both established in 1957, with offices in New York and Miami.

Parkinson's disease (PD) is a neurodegenerative disorder, originating in the central nervous system, that affects predominately dopamine-producing neurons in a specific area of the brain. It can have wide ranging symptoms, starting with tremors in the hand to one's movement (stiff muscles, muscle contractions, involuntary movements), cognitive (amnesia, dementia, difficulty thinking and comprehending), speech (difficulty speaking, soft speech), sleep (sleep disturbances), mood, facial (jaw stiffness or reduced facial expressions), nasal (distorted smell, or losing the sense of smell) etc.

As described on its website, the Caregiver Self-Assessment checklist, can add great value in assessing oneself, to,

Become more self-aware now and over time. Measure your reactions to various aspects of caregiving. Tease out the areas of greatest concern to you. Acknowledge and validate your role, experiences and feelings. Put into words an experience that you may have been unable to define, e.g., "How do I balance my needs with the needs of my partner?"

The Checklist comprises of twelve items that focuses on activities that promote positive mental health, such as being able to take time out to exercise, engaging in a recreational activity of one's choice/hobby, use of alcohol/tobacco, eating two-three balanced meals a day, having a confidant to share one's feelings and emotions with, working on personal goals, taking time out for oneself, having a voluntary/regular job that is gratifying etc. Each item is then rated 1 (*Almost always*) to 5 (*Never*), depending on how true the statement is, for the caregiver. The Checklist also provides a range of scores and the interpretation for each:

2.2.1 Interpretation of scores:

- 12–24 You are doing an excellent job taking care of yourself.
- 25–36 You have room for improvement. Examine the areas where you struggle, and seek help from family, friends or healthcare professionals to make some changes.
- 37–48 You are doing a poor job taking care of yourself and are at moderate risk for personal health problems. Talk to your healthcare provider or others who can help you create and stick to a plan to take better care of yourself.
- 48–60 You are at extremely high risk for personal health problems. It is important for you to talk to your personal healthcare provider as soon as possible. Remember, you can only provide good care for someone else if you take good care of yourself

2.3 Review of Literature

For the purpose of the study, a brief review of literature was carried out. It was seen that a number of studies have already been conducted on the mental health of frontline caregivers in China, the epicentre of the COVID-19 pandemic. Also, till the time of the submission of this paper, the researcher came across three studies on the impact of COVID-19 on individuals with Autism and their families.

In the study *Prevalence of depression, anxiety, and insomnia among healthcare workers during the COVID-19 pandemic: A systematic review and meta-analysis*, by Pappa S, et. al (August 2020), a detailed literature review was conducted up to April 17th, 2020 covering thirteen

studies with a combined pool of 33,062 participants. The most significant findings were the following –at least one in five healthcare professionals, reported symptoms of anxiety and depression and almost one in four healthcare workers experienced sleeping difficulties and insomnia, and the rates of anxiety and depression were higher for female healthcare workers and nursing staff.

A qualitative study on the psychological experience of caregivers of COVID-19 patients, conducted by Sun, N et al (June 2020), adopted a phenomenological approach and 20 nurses who provided care to COVID-19 patients in the First Affiliated Hospital of Henan University of Science and Technology (between January 20 2020 to February 10, 2020) were selected. Interviews were conducted either face to face or via telephones. Analysis of the interviews revealed 4 kinds of psychological experiences of the nurses—first, negative emotions were present in the early stages of caregiving (characterized by high-intensity work, fear, anxiety, and concern for patients and family members). Second, self-coping styles included psychological and life adjustment, altruistic acts and team support. Third, the researchers found ‘growth under pressure’ (it included increased affection and gratefulness, development of professional responsibility and self-reflection). Fourth, positive emotions occurred simultaneously with negative emotions. In conclusion, the study revealed that self-coping styles and psychological growth played an important role in maintaining mental health of the nurses.

Zhang, Y et al’s study *The Psychological Change Process of Frontline Nurses Caring for Patients with COVID-19 during its Outbreak*, aimed at identifying the change in the psychological processes of the registered nurses in a hospital in Wuhan, China that was at epicentre of the pandemic. The study was conducted between February 9, 2020 to March 15, 2020. The purposive sampling approach was adopted and 23 nurses were interviewed. The study revealed three stages of change in psychological processes—an *early stage* (characterized by ambivalence), a *middle stage* (characterized by emotional exhaustion) and the *later stage* (characterized by renewal of energy). The study also found the important role played by the ‘nurse leaders’, to facilitate the psychological adaptation (of the nurses), to the changing situations but also to create and implement various intervention programs in tune with their psychological changes, thereby improving their mental health.

The experiences of health-care providers during the COVID-19 crisis in China: a qualitative study conducted by Liu, Q et al (June 2020), adopted a phenomenological approach. Nurses and physicians were taken from five COVID-19 designated hospitals in Hubei province, using the approaches of purposive and snowball sampling. Semi-structured telephonic interviews were carried out. There were 13 participants in the study (9 nurses and 4 physicians). Three thematic categories emerged from the data analysis:

The first was ‘being fully responsible for patients’ wellbeing-‘this is my duty. Health-care providers volunteered and tried their best to provide care for patients. Nurses had a crucial role in providing intensive care and assisting with activities of daily living. The second category was “challenges of working on COVID-19 wards”. Health-care providers were challenged by working in a totally new context, exhaustion due to heavy workloads and protective gear, the fear of becoming infected and infecting others, feeling powerless to handle patients’ conditions, and managing relationships in this stressful situation. The third category was “resilience amid challenges”. Health-care providers identified many sources of social support and used self-management strategies to cope with the situation.

In such a context, thus, the study found that comprehensive support as well as regular and intensive training should be imparted to all the health-care workers, to safeguard their mental health and promote awareness for effective crisis management.

The study, *The impact of COVID-19 on children with autism spectrum disorder* by Amorim, R et. al (2020), aimed to study how children with ASD and their caregivers, experienced the social isolation during the pandemic in Portugal. The study combined observational, cross-sectional and analytical methods to gather and analyse data. An anonymous questionnaire was used that included the children’s demographic and clinical characteristics, along with the impact of the COVID-19 outbreak on different aspects of the family’s daily life. The results reported by the study is as follows:

Out of 99 questionnaires obtained, 43 were related to children with ASD and 56 to control group. Children with ASD predominantly had changes in behaviour, while children from control group mostly found no changes. The majority of parents of ASD children reported a negative impact in emotion management against those in control group reporting mostly positive or no impact. Caregivers reported higher mean scores of anxiety levels in themselves than in their children. ASD children and their parents had higher levels of anxiety than healthy ones. In the group with ASD, children that did not maintain routines had higher mean levels of anxiety than children that maintained routines.

Thus, the study was able to capture the essence of the impact of COVID-19 on the children with ASD as well as their caregivers. The findings of the study are important as elevated levels of anxiety and negative emotions, can affect familial relations and subsequently, impact upon the quality of life for both the caregiver as well as the child.

Impact of COVID-19 on the mental health and wellbeing of caregivers and families of autistic people: A rapid synthesis review by Lee, V. et.al (2020) , looks at the documentation (through available literature—peer reviewed published and in the press articles, organizational reports, surveys, newspaper reports and articles) on the impact of the COVID-19 pandemic on caregiver and family functioning, of individuals with Autism (below 25 years old) and the subsequent mental health response, which have emerged thereafter. Some of the findings of the study were as follows:

The literature and media provided examples of the consequences of increased demands on the wellbeing of caregivers and families as they found ways to cope with these stressors. Some of the literature provided advice in the form of “tips”, opinion pieces, or infographics to help caregivers and families manage their demands and to support their capabilities. We found limited literature that focused on programs or interventions that supported caregiver and family mental health and wellbeing through the COVID-19 pandemic. Some media reports from the perspective of caregivers underlined the protective effects of connection and close social relationships (via online communications or communities like Facebook groups) in fostering a sense of “togetherness” that helped families find meaning during the pandemic. Some reports highlighted the potential long-term impact of prolonged exposure to increasing demands on the mental health and wellbeing of caregivers and families of autistic children and alluded to the need for the rapid development and evaluation of flexible, timely, and web-based support programs.

The study raises important questions about the increased demands on caregivers and families as they cope with the effects of the pandemic and more importantly, the role of social relationships (via online communications/communities) in fostering a sense of togetherness in these trying times.

Psychosocial and Behavioural Impact of COVID-19 in Autism Spectrum Disorder: An Online Parent Survey, by Colizzi, M et.al (2020), aimed at investigating the impact of the COVID-19 pandemic on ASD individuals. The study included 527 participants in the survey. Parents and guardians of ASD individuals filled out an online survey consisting of 40 questions investigating socio-demographic and clinical characteristics of their children, impact of the COVID-19 outbreak on their wellbeing and needs to deal with the emergency. The results of the study revealed that 93.9% of families, experienced increased difficulties in managing daily activities, especially free time (78.1%) and structured activities (75.7%), and, 35.5% and 41.5% of children, respectively, presented more intense and more frequent behavioural challenges. Even though children with ASD were receiving various kinds of support (therapeutic interventions / specialist interventions and even emergency interventions in a low proportion of cases), the study threw light on the emergence of “more healthcare support (47.4%), especially in-home support (29.9%), as well as interventions to tackle a potentially disruptive quarantine (16.8%)”.

3. THE PRESENT STUDY: SAMPLE, APPROACH AND METHODOLOGY

The present study has made an attempt to explore the experiences of caregivers of individuals with Autism and create an understanding of how the COVID-19 pandemic, has had an impact on their anxieties and fear, engagement with the children, strategies for self-care and perceived ‘connectedness’ through technology.

A *qualitative lens* was adopted and a small sample comprising of five caregivers was selected. *Purposive sampling method* was adopted and the parents were chosen from the city of Hyderabad, in southern India. The sample of parent caregivers comprised of five (5) mothers. The age range of the caregivers was between 36-43 years. Except for one girl, the rest of the children, were boys. The age range of the children ranged from 8-14 years. Many of the children on the spectrum, had neurotypical siblings. All the children were on the Mild to Moderate end of the Autism Spectrum.

To this end, a Caregiver Self-Assessment Checklist, developed by the Parkinson’s Foundation, was administered and an open-ended questionnaire was constructed. The Caregiver Self-Assessment Checklist comprised of 12 statements that could be rated on 1-5 (1: *Almost Always*, 2: *Frequently*, 3: *Occasionally*, 4: *Rarely*, 5: *Never*). The key for the interpretation of the total score was as follows: 12-24 (An Excellent Job taking care of yourself), 25-36 (Room for improvement. Examine the areas where you struggle and seek help from family/friends/healthcare professionals), 37-48 (Poor Job taking care of yourself and are at Moderate Risk for personal health problems), and 48-60 (Extremely High Risk for personal healthcare problems).

Unstructured interviews were conducted electronically and via the telephone, through an open-ended questionnaire. The questionnaire comprised of several interconnected questions, each question seamlessly flowing into the other (7 questions in all), that touched upon the reaction of the caregivers and the children to the pandemic and the nationwide lockdown, their fears and anxieties, how they planned/scheduled their days ahead, the strategies adopted to keep themselves and the children busy and the role (if any) played by social media networks/technology, to adapt and cope with the pandemic.

The names of the caregivers and the children, have been kept confidential, to protect their identities and their names have been designated by their initials.

Table 1: Information on The Chosen Sample

Parent (Designated Initials)	Age	Educational Qualifications	Child (Designated Initials)	Age of Child with Autism (Yrs)	Age of Neurotypical Child
KS	43	MBA	A	12	---
MD	38.5	MA	T	12.5	4.5
KR	36	B.Ed.	D	11	14
MV	37	B.E.	K, A	8, 7	---
SS	38	BSc	S	14	4

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

Parent (Designated Initials)	Training /Courses Undertaken/Active Engagement with Autism Community/ Courses in Special Needs Education
KS	Parent Child Training Program (PCTP) at Action For Autism, New Delhi, Diploma in ASD and Registered Special Educator, Certifications in Curative Education, NILD etc
MD	Parent Child Training Program (PCTP) at Action For Autism, New Delhi
KR	Active engagement with the Autism Community through a social media platform of an organization, Navi Disha, (www.navi-disha.org), pursuing Diploma in ASD
MV	Pursuing B.Ed. in Special Education, Certification in Learning Disorders and various Courses on Functional Language, Communication and Executive Functioning in Autism
SS	Parent Child Training Program (PCTP) at Action For Autism, New Delhi, Certification in Special Education, Certification in Play Therapy for Special Needs

4. THEMATIC INTERPRETATION

The interviews with the parent caregivers threw up some interesting insights into their lives during the pandemic, the adaptation to the various changes during the lockdown period and the resilience and strength to face head on, the challenges brought on by COVID-19. For purposes of clarity, the narratives have been organized thematically—

- 1) **THE STRESS INDUCING PANDEMIC:** The pandemic brought about a long phase of uncertainties—*financial insecurity*, the *pressures of shifting to a digital based education for children*, *restricted mobility*, amongst others. Almost all the participants shared how the initial days of the nationwide Lockdown created feelings of stress and anxiety. As the parent, KR mentions “There was a lot of stress regarding the future of my husband’s job and the possible financial difficulties, that could incur.”¹ KR, has a neurotypical daughter aged 14 years and a non-verbal son on the spectrum, aged 11. Her daughter had all her classes online and she was also taking supplemental classes on an educational app. The pressures and uncertainties regarding the payment of monthly rents, and fees towards these online classes/modules, caused immense insecurity and stress. This was corroborated by another parent, MD, who stated that “The lockdown has led to increased levels of stress and anxiety, for me. During this period, we also shifted houses and moved to an area closer to my daughter’s school. In this new housing complex, I have no friends. And T experienced regression in her already, acquired toileting skills, perhaps due to the change and the new surroundings.”² Her daughter, T is non-verbal, on the spectrum aged 12 and a half years old. For MV, the sudden announcement of the nationwide Lockdown meant, that her children (both on the spectrum), got stuck at their grandparents’ house, in another city. She states. “I was worried as my kids stayed with their grandparents in Chennai and I felt guilty initially, for burdening my parents with my kids.”³ KS mentioned how the Lockdown brought changes. She states, “Plans did backfire. My son could not start the new school (he had enrolled for) and we had to look for alternatives.”⁴ Children on the spectrum who attended special schools or had therapeutic interventions at home, had to switch to an online set up or be home-schooled by their parents. These adjustments took a toll, not only on the children, but also on the parents.
- 2) **UNEARTHING THE POSITIVES FROM WITHIN THE NEGATIVES:** Despite the stressors brought on by the pandemic, the narratives of the parent caregivers seemed to focus on the ‘positives’ that parallely came with it. As the saying goes “*every cloud has a silver lining!*” The participants spoke about how they adapted to the situation at hand and tried to make the most of it. In normal circumstances, the primary caregiver of a child with Autism, who bears the brunt of the *caregiver burden*, is invariably the mother. For a lot of participants, one of the positives of the lockdown was the *sense of relief* it brought about. Having the spouse at home all day, meant a substantial reduction of workload as responsibilities were shared, thereby reducing the total burden on oneself. As SS mentions “the Lockdown period has been a happy period for me till date, as my husband has taken 50% of my workload. That's why I did not experience any anxiety or stress...I have been happy all the time.” KS, also states, “Stress is there but I believe in keeping every hour organized and productive.”
- 3) **CREATIVE ENGAGEMENT WITH THE CHILDREN:** The Lockdown meant a closure of educational institutions, therapy centres and limited mobility, thus clamping down on home visits of special educators etc. Thus, parents had to come up with ideas to keep the children ‘creatively engaged’. The participants spoke about maintaining an informal schedule for the children to follow—a bit of physical activity/exercise, sensory activities, functional academics, extra-curricular activities (art/music/crafts) and activities of daily living (ADL). KS, maintained a strict schedule through the day for her child. She took due permission from the authorities in her apartment to allow her son to exercise regularly outdoors (within the gated community). She

¹ Interview conducted over phone with KR, on October 10, 2020

² Interview conducted over phone with MD on October 7, 2020

³ Interview conducted over phone with MV on October 8, 2020

⁴ Interview conducted over phone with KS on October 12, 2020

set a timetable for him, with regular timings for cognitive, sensory, math, art etc. MD taught her daughter basic ADL skills like laying the table for meals and washing her utensils, thereafter and wiping the table. SS also taught her son independent skills, such as cooking (jowar rice, sweet dish, juice etc), yoga and studying. Others, like KR and MV, used educational apps on the phone (such as pschool.com) to help the children, explore various activities related to visual perception, memory and cognitive development.

- 4) **SELF-CARE, MENTAL HEALTH AND CAREGIVING:** The narratives shed light on the immense courage shown by the parent caregivers, to take steps to promote their mental health, during the pandemic. Consciously taking out time for oneself, might not have been possible for all of them, but they took efforts in that direction. Many of them, explored new avenues (like cooking various kinds of new cuisines), taking up a long-lost hobby (like painting), completing projects that were on the anvil, for a long time, experimenting with social media and new technologies etc. As SS stated, “I planned my day, as if there was no tomorrow. I wanted to do all that I could, when my husband was still around at home (he is in the Merchant Navy and is usually away from home for up to 6 months in a year). One, of the first things I did, was to complete the online Play Therapy course that had been pending for long. I had always wanted to start a YouTube channel of my own. The Lockdown in particular, helped in putting that plan into action. My brother provided me with the technical support and I launched my YouTube channel, chronicling my son, S’s journey in Autism. The YouTube channel showcases my work with S—adapted books to teach concepts, lessons on playing the keyboard, S doing Yoga independently. The channel has been like a dream come true.” Almost all the parents in the study, actively participated in online webinars on Autism and related issues and underwent online courses to upgrade their skills (*Executive Functioning in Autism, Functional Language and Communication in Autism, Learning Disorders, NILD* etc) and thereby, help their children. KR, MV and MD spoke about cooking new cuisines during the Lockdown and MV spoke about reviving her long-lost hobby of painting and sketching during that period. The participants also spoke about spending some time during the day to exercise (walk on the terrace/do yoga etc).
- 5) **SELF-CARE ASSESSMENT–INTERPRETATION OF THE SCORES ON THE CHECKLIST:** The *Caregiver Self-Assessment Checklist*, developed by the Parkinson’s Foundation, was administered for the study. It comprised of 12 statements (that encapsulated the very essence of Self-Care in caregivers) and the statements could be rated on a scale of 1-5 (1: *Almost Always*, 2: *Frequently*, 3: *Occasionally*, 4: *Rarely*, 5: *Never*). The key for the interpretation of the total score was as follows: 12-24 (An Excellent Job taking care of yourself), 25-36 (Room for improvement. Examine the areas where you struggle and seek help from family/friends/healthcare professionals), 37-48 (Poor Job taking care of yourself and are at Moderate Risk for personal health problems), and 48-60 (Extremely High Risk for personal healthcare problems). Of the 5 participants, two of them, KR and SS, scored 24 and 23 respectively, translating into an interpretation of “*an excellent job taking care of yourself*” on the self-assessment checklist. Although dogged by sleeplessness and anxiety from time to time, they both scored well on the assessment checklist, implying that small efforts taken towards one’s physical health, creatively engaging one self and the child, and having a confidant to share one’s innermost feelings and thoughts can go a long way in improving one’s mental health. The rest of the participants had scores as follows: MV (27), KS (26) and MD (32). All of these scores fall within the next range of “Room for Improvement”.

MD’s score of 32 is on the higher end of the range and perhaps requires more efforts on her part as well as changes in her immediate environment (of her spouse and children) to bring about more stability and improvement in her self-care skills. Her ratings on the *Caregiver Self-Assessment Checklist* reveal that she *rarely* has time for “exercise, adequate amount of sleep in a day and pursue a hobby/recreational activity” and *never* has time ‘to make and keep preventive medical and dental appointments.’ As she had mentioned in her narratives, relocation to a new house during the pandemic, has increased her levels of stress and anxiety. Other than her daughter (who is on the spectrum), she has a younger, neurotypical son (4.5years old) who is

quite mischievous and keeps her on her toes all day. Also, the relocation and subsequent uncertainty in a new place, has caused her daughter to experience regression (in the already acquired and previously established) toileting skills and an increased sensory sensitivity towards sticky textures (thus a need to touch faecal matter etc).

- 6) **TECHNOLOGY, CONNECTEDNESS AND THE PANDEMIC:** The participants unanimously agreed that technology (social media apps like Facebook, channels on YouTube and even WhatsApp) helped ease the anxiety and stress, wrought by the pandemic. Accessing information on the various teaching methods, practical activities to do with the children, educational games, acquisition of new skills, attend online programs, debate and discuss with like-minded individuals and most significantly, sharing one's thoughts, apprehensions and anxieties, were possible through the various fora, online.

Although the pandemic ensured that social distancing and physical interaction with others dwindled to next to nothing, being 'connected' through technology, helped bridge the gap. As MV sums it up, being able to be connected via technology meant, having someone to talk to, share one's feelings and realizing that one is never alone.

5. CONCLUSION

The global pandemic of COVID-19 has created widespread havoc and brought the world to a standstill—disrupting the global economy, livelihoods, spiralling vulnerable populations into poverty and unemployment and causing immense stress and anxiety to large swathes of the population. In such a scenario, the caregivers of individuals with Autism have had to adapt to the various changes in their environment and provide the best possible tools of enrichment (with their limited resources), for the growth and development of their children.

Although this study is limited by its small sample size, the rich narratives of the participants enables us to *acknowledge their struggles, identify their resilience and courage* in the face of such adversity, to *constantly push and reinvent themselves* and to *continuously work towards creating stimulating learning environments* for their children.

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