

Impact of Early Autism Spectrum Disorder Intervention on Caregivers' Mental Health in Three Centres in Lucknow: A Survey Study

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Abstract

This research examines the impact of early intervention for Autism Spectrum Disorder (ASD) on the mental health of parents. As early diagnosis and intervention are critical for improving outcomes for children with ASD, it is equally important to assess how these interventions affect the well-being of their families. Despite the advantages for children, parents often face emotional challenges and elevated stress. This study quantified the psychological impact on 72 caregivers through e-surveys, revealing a 64% decrease in stress levels and overall moderate-to-good mental well-being among parents whose children participated in Early Intervention (EI). Caregivers also reported increased optimism (48%) and reduced anxiety (67%). By exploring parents' emotional responses, perceptions, and coping strategies, the research aims to identify the key factors affecting parental mental health. The findings provide valuable insights into family support needs and offer recommendations for developing targeted interventions to improve parental well-being and family quality of life.

Keywords: Autism spectrum disorder, early intervention (EI), holistic development, stress and mental health, caregivers.

Introduction

According to the American Psychiatric Association [APA], 2013, autism spectrum disorder (ASD) is a neurodevelopmental illness marked by limited and repetitive patterns of behaviors,

interests, and activities as well as poor social communication and interaction. People with ASD may interact, communicate, conduct, and learn differently from others, but it is not possible to identify them from others. They might have very gifted cognitive talents or substantially damaged cognitive abilities (Centers for Disease Control and Prevention [CDC], 2020). Given the diverse and chronic nature of autism and the wide variety of potential co-occurring illnesses, caring for children with ASD can be difficult (Vohra *et al.*, 2014). Parents of autistic children are always looking for assistance from a variety of sources and professionals to meet their children's requirements because of the disorder's complex nature and the dearth of evidence-based treatment choices (An *et al.*, 2020; Srinivasan *et al.*, 2021). Parenting children with ASD can be more stressful and challenging as compared parenting children with typical development (Ilias K *et al.*, 2018). Compared to parents of children without any developmental disabilities or parents of children with other forms of developmental disabilities, parents of children with ASD report greater levels of parental stress, according to several previous research (Estes *et al.*, 2009; Hayes & Watson, 2013; Rodriguez *et al.*, 2019). Studies carried out in settings with and without higher resources highlighted unmet requirements, including the emotional load on parents as a result of their child's condition and parental mental health (Divan *et al.*, 2012; Lushin and O'Brien, 2016; Tilahun *et al.*, 2016; Papadopoulos, 2021). Numerous studies have shown that the degree of the child's handicap, such as their intelligence quotient (IQ), and the intensity of the child's autism symptoms are among the stresses that parents of autistic children face. Global studies have documented heightened stress levels among parents of children with autism, stemming from the distinctive challenges of caregiving. Research indicates that caregiver stress is linked to both the demographics and behavioral traits of parents and their autistic children. However, few studies have specifically examined how caregivers' unmet needs influence different facets of the family burden they experience. As early diagnosis and intervention are increasingly recognized as pivotal for improving outcomes for children with ASD, it is crucial to understand how these interventions affect the well-being of their families. Despite the potential benefits of early intervention for children, many parents report experiencing significant mental stress and emotional challenges. The research aims to assess the levels of stress experienced by caregivers of children with autism and to identify the specific stressors they face. The study seeks to determine whether early intervention and

counseling can effectively reduce this stress. Additionally, it will explore caregivers' awareness of the benefits of early intervention.

Key Questions:

1. Does EI reduce the stress experienced by caregivers of children with autism?
2. Does holistic intervention approach influences the overall level of stress among the caregivers?
3. Are caregivers aware of the benefits associated with early intervention?
4. What are the ways in which caregivers stress could be reduced?

This survey study is crucial as it will help uncover stressors that may not be immediately visible but could have significant impacts if left unaddressed. Understanding these stressors and the potential benefits of early intervention can lead to better support strategies for caregivers.

Method

To assess stress levels related to mental health among caregivers of children with autism, a qualitative survey methodology was employed. This approach involves participants completing an electronic form on their mobile devices to respond to the survey questions.

Participants-

A total of 70 (n=70) participants recruited in the study with an age range of 30 years to 44 years (mean age- 36.25years). Samples were taken from three intervention centres in Lucknow. The inclusion criteria for this study stipulate that participants must be caregivers of children with autism (The diagnosis was generally made using a multi-team approach, based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013), diagnostically test and checklist who began receiving intervention services prior to the child reaching 36 months of age. Furthermore, the child must have engaged in at least 6 months of holistic intervention. This criterion ensures that the study focuses on caregivers of children who have received early and comprehensive intervention, allowing for a thorough examination of the associated stress and the potential benefits of such early support. All the participants were asked for an e-signed consent before filling the questionnaire.

Questionnaire and data collection-

The making of questionnaire consist of a review of existing questionnaire such as Parent Stress Scale (Judy Berry and Warren Jones (1995)), Depression anxiety stress scale (DASS-21) (Lovibond and Lovibond, 1995), etc. The questions were modified according to the research topic and present population of readers. After preparing a set of 15 questions, the questionnaire was sent to different speech therapist and rehabilitation psychologist for validation purposes. 5 questions was removed and few were modified on the bases of the feedback of majority. The research questionnaire consist of two parts- demographics and mental health & well-being questions. The later part consist of 10 questions related to current level of stress, changes in anxiety after few months of intervention, role of speech therapy in emotional regulation, sense of control over your child, therapists feedback related increase or decrease in stress, and so on. The response options consist of varied set of options including Likert scale, rating scale, range scale, etc.

Results

The primary aim of the study is to identify the impact of early intervention among the caregivers of the child with autism. Given our small sample size, we did not conduct formal statistical testing on our data. Instead, we report means and standard deviations on all outcome measures and also discuss individual data from participants.

Here are the research questions we aimed to explore:

1-Does early intervention reduce the stress experienced by caregivers of children with autism?

As early diagnosis and intervention become more widely acknowledged for enhancing outcomes in children with ASD, it is essential to examine their impact on family well-being. Although early intervention holds promise for improving children's development, many parents continue to face considerable mental stress and emotional difficulties.

In the current research, as shown in the table 1 out of 72 participants, 59 (81.4%) participants reported that the therapy initiated before the age of 36 months and 13 (18.6%). Early intervention is crucial in helping children acquire essential life skills from an early age,

establishing a strong foundation that has enduring benefits. Research highlights a significant positive trend: 81.9% of children began their early intervention before reaching 36 months of age.

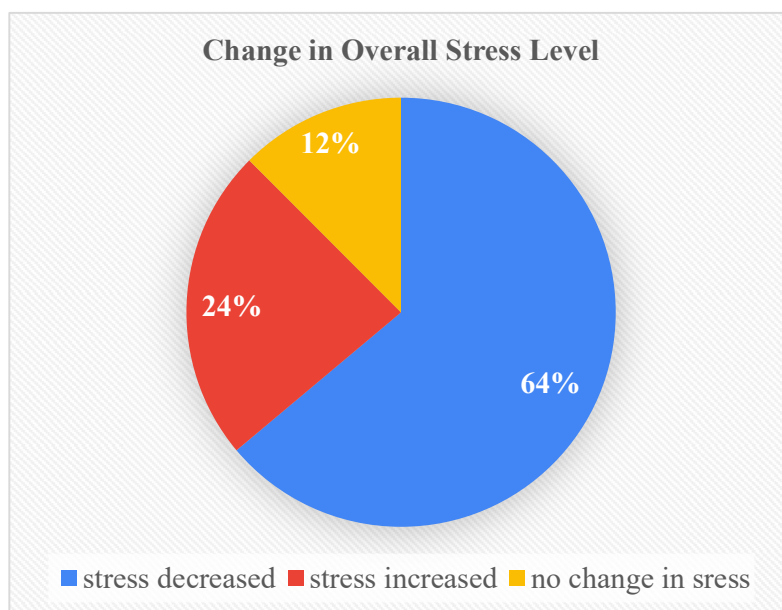
Table 1.1

EI Age range (months)	N (=72)
6-12	0
13-24	21
25-36	38
36-48	13

Level of overall stress-

When comparing mental stress levels before enrolling in the EI program to those after more than six months of therapy, a significant majority of parents—64%—reported a reduction in their overall stress levels (fig. 1). In contrast, 24% of participants experienced an increase in mental stress during this period. Additionally, 12% of the participants noted that their stress levels remained consistent, showing no change from the beginning of the intervention. This variation highlights the diverse impacts of the EI program on parental stress.

Figure 1

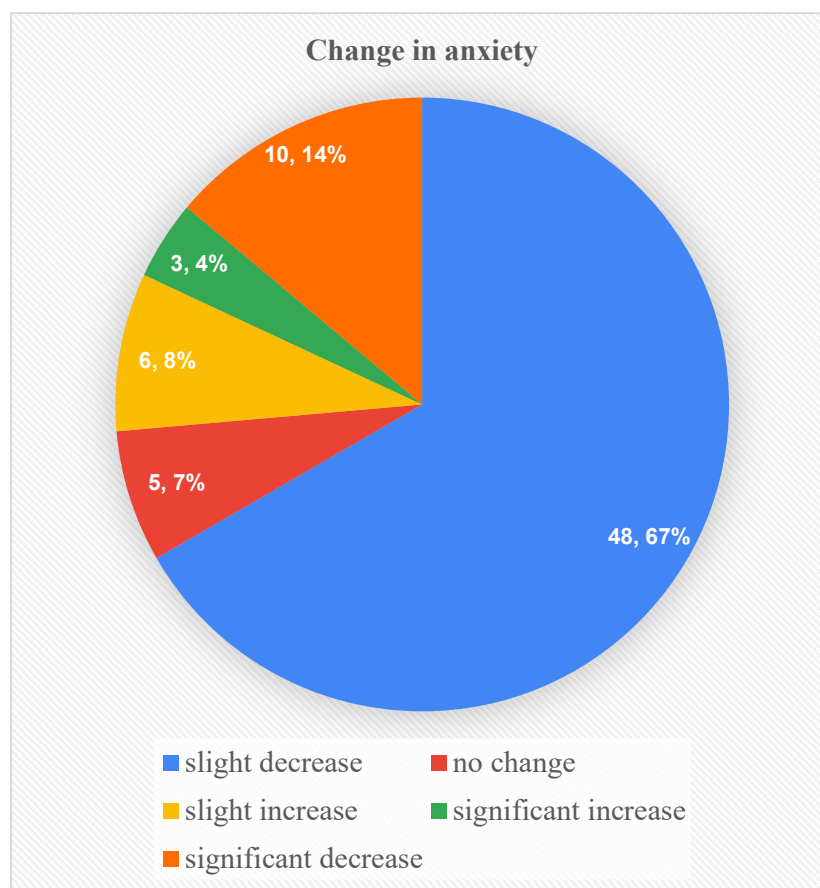


Change in anxiety-

Receiving a diagnosis of ASD or a high risk for ASD can be a source of significant anxiety and stress for parents. To evaluate the impact of early holistic therapy on parental anxiety, we assessed the anxiety levels of parents before and after their child

began early intervention. According to the findings (fig. 2), the majority of caregivers experienced a reduction in anxiety levels following early holistic therapy. Specifically, 67% of caregivers reported a slight decrease in their anxiety, while 14% experienced a significant reduction. In contrast, 8% of caregivers noted a slight increase in anxiety, and 4% observed a significant increase. Additionally, 7% of participants felt no change in their anxiety levels. These results demonstrate a general trend toward reduced anxiety among caregivers, though individual experiences varied.

Figure 2

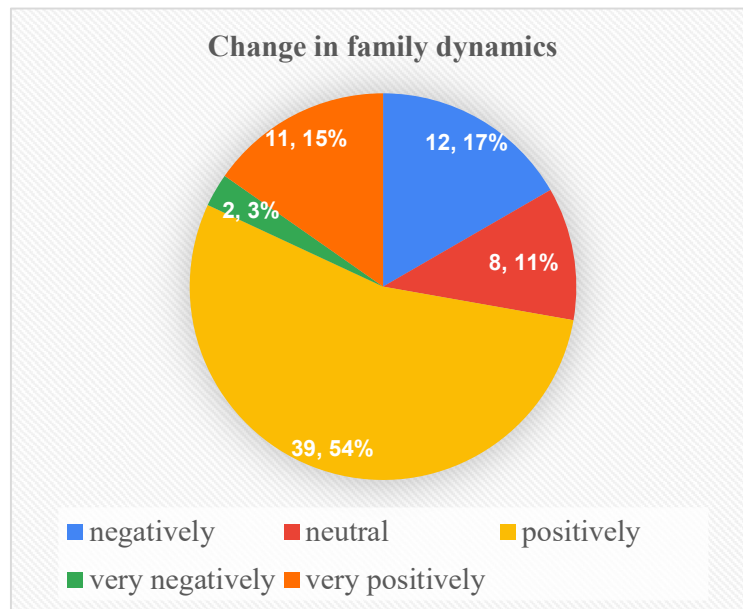


Change in family dynamics-

A neurodivergent child impacts not only the parents but the entire family dynamic. Supporting the child through challenges, social interactions, and various forms of play requires a collective family effort. In the research conducted (fig. 3), 54% of participants noted a positive change in family dynamics, with 15% observing a very positive change.

Conversely, 17% reported a negative change in family dynamics, and 3% experienced a very negative change. These findings highlight the varied effects that supporting a neurodivergent child can have on family relationships.

Figure 3



Feelings of Exhaustion and Overwhelm Due to the Demands of Early Intervention-

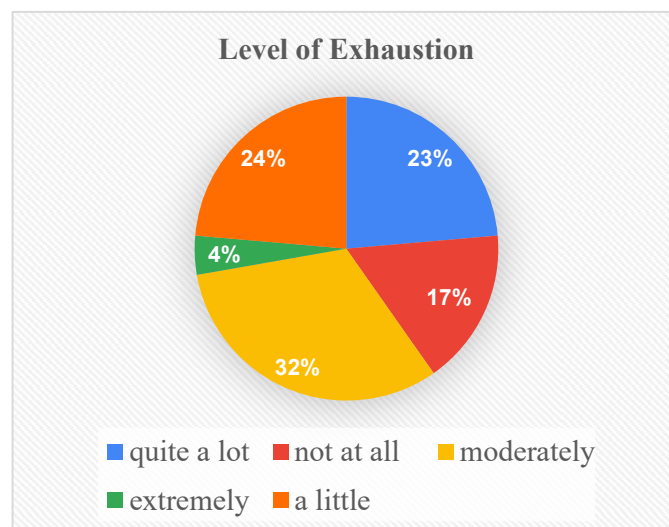
Parenting a child with autism can often be challenging and physically exhausting. Due to the child's unique behaviors, cognitive development level, and functional needs, they require constant supervision.

When therapy begins, therapists usually provide a home plan for parents, asking them to implement similar goal-oriented activities at home to supplement the limited time available in therapy sessions. This additional responsibility can sometimes become overwhelming for parents. The current research (fig. 4) found that 23% of caregivers reported feeling significantly fatigued. Additionally, 4% of parents experienced extreme exhaustion and stress. Another 32% felt moderately drained and overwhelmed by the demands of intervention sessions. On a positive note, 17% of participants reported feeling no exhaustion at all, while 24% felt only a slight level of fatigue.

Figure 4

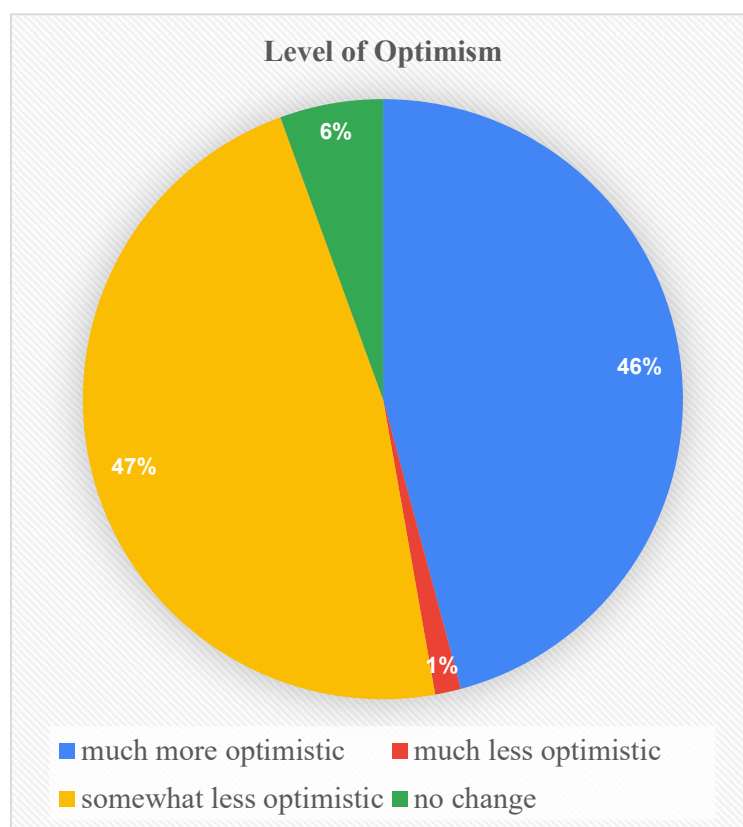
2- Does holistic intervention approach influences the overall level of stress among the caregivers?

Holistic intervention's influence on your overall outlook and optimism about your child's future-



Holistic approach not only supports immediate improvements but also lays a strong foundation for long-term progress in daily functioning and overall well-being. By integrating diverse therapeutic techniques and encouraging family involvement, this approach nurtures optimism about the child's future, as it promotes resilience, adaptability, and continuous progress, creating a hopeful outlook for their long-term growth and success. In the current study (fig. 5), when asked about hopefulness and optimism, 46% of participants expressed a high level of optimism, while 47% reported a moderate level of optimism. Encouragingly, only 1% of parents indicated being significantly less optimistic.

Figure 5

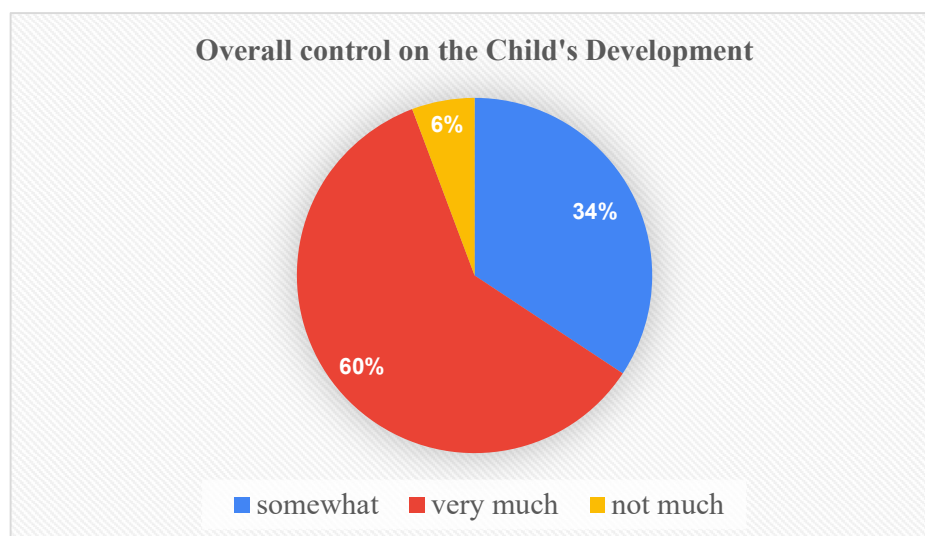


Holistic intervention has improved a sense of control on the child's development-

After asking parents that how much you believe that starting early help or therapy has made you feel more in charge of and confident about your child's progress and growth, following were the results (fig. 6)- a total of 60% participants felt that they gained a good control the development. 34% of the individuals reported that they gained a somewhat better control as compared to before

intervention stage. 6% of the individuals believed that they couldn't gain a hold over the overall development of their child.

Figure 6



Discussion

This study used a survey method to identify the level of stress and quality of mental health and overall well-being of the caregivers of a child with autism who has initiated early intervention. The data was collected in three centres of the city Lucknow (India) with total number of participants being 72. A qualitative research test finding were incorporated to come to a conclusion.

The study revealed a significant positive outcome, with a 63% overall decrease in caregivers' stress levels. This substantial reduction suggests that early intervention has had a meaningful and beneficial impact on the child's development, contributing to a more manageable and less stressful experience for the caregivers. In contrast, 24% of participants reported an increase in their stress levels. This rise in stress could be attributed to several factors, such as the severity of the child's ASD, which may lead to more challenging behaviours and greater difficulty in addressing the child's functional needs. These intensified demands might contribute to heightened stress among caregivers, despite the overall positive impact of early intervention for many others.

In a study done by Papadopoulos (2021) on mother's experiences and challenges while raising a child with ASD, a mother reported –

"I believed that I did something wrong; I blamed myself because my child was not normal; I wondered if this condition was caused by my behavior as a mother. I was distressed for a long time after the diagnosis, and I cried every day before sleeping. I think the feeling of powerlessness is the worst, you want to do the best for your child, but you realize that you are not able to offer help".

The emotional toll of the child's diagnosis, feelings of dissatisfaction, and concerns for the child's future were the first significant themes to emerge from this study. In the current study, 59% of participants reported experiencing significant exhaustion and a sense of being overwhelmed while caring for a child with autism spectrum disorder (ASD). During the interview, it revealed that 20%-30% of parents experiences meltdowns quite often. Managing a child with autism spectrum disorder (ASD) can be extremely stressful because of the intricacies involved in meeting the child's special behavioral and developmental needs. Caregivers may experience significant mental and physical strain as a result of this constant duty, which can raise their levels of exhaustion, annoyance, and burnout. The general health and standard of living of caregivers are frequently impacted by the cumulative effects of these difficulties.

When a parent receives an unexpected diagnosis of autism for a child they believed to be perfectly healthy, it can be profoundly unsettling and disheartening due to the factors such as fear of the unknown, unmet expectations, social and emotional impact, adjustment period, etc. Various researches has revealed that the overall awareness of ASD has improved (Almalki et. al. 2023; Klinger et. al. 2023). In the study we discovered that more majority of the parents with a nonteaching background were not aware of the term autism. The diagnosis of autism spectrum disorder (ASD) was a shocking and stressful event for many parents, leading to significant emotional strain. This unexpected development resulted in noticeable disruptions to family dynamics for the majority of participants. However, following the commencement of holistic intervention, a positive shift was observed. Increased awareness and understanding of autism within the family contributed to improved coping and adaptation, highlighting the benefits of early and comprehensive support.

Are caregivers aware of the benefits associated with early intervention?

Autism children's aberrant growth can be corrected, and their behavioral development can be changed, with early holistic therapies beginning before the age of five. Early therapies are particularly crucial in the domains of speech and cognition, since they mitigate detrimental behaviors and severe symptoms associated with the disease. In the end, these interventions result in increased social, professional, and independent functioning as adults (Rogers et. Al., 2008; Dawson 2008) Furthermore, research has demonstrated that 50% of autistic children who received the therapies made some progress toward speaking. This probability may increase to between 75% and 95% if these interventions are carried out before the child reaches the age of five (Dawson 2008; Hojjati M. et. al. 2017). During the interview, parents shared that they experienced a significant sense of relief after their child began making noticeable progress toward specific goals that had been established by a multidisciplinary team of therapists. This collective effort, which focused on a set of common objectives, led to a wave of positive emotions for the parents. Observing their child's advancements in these targeted areas not only alleviated their concerns but also reinforced their confidence in the effectiveness of the intervention. The collaborative approach of the therapy team and the tangible progress achieved contributed to a renewed sense of hope and optimism about their child's development. 60% of parents reported feeling a greater sense of control over their child's development. Additionally, they found that they were able to implement therapeutic goals at home more effectively, benefiting from a clearer and more focused mindset.

What are the ways in which caregivers stress could be reduced?

This area of research was less explored. Though various concern counselling sessions were held along with the intervention team. The most helpful technique were-

Family counselling- A rehabilitation psychologist and clinical psychologist, along with other members of the therapy team, conducted a comprehensive session to address and resolve any doubts and queries from the child's family. This approach proved particularly beneficial for mothers who struggled to communicate the diagnosis and intervention strategies to older family

members. It also facilitated family cohesion, enabling all members to collaboratively engage in the child's care and support, thereby enhancing the overall effectiveness of the intervention.

Report discussion- In this approach, the therapy team and parents engage in open discussions about the child's current progress and future goals. This setting encourages parents to freely express their concerns and questions, fostering a collaborative dialogue. As a result, parents gain a clearer understanding of the next steps in the intervention process, while therapists can address these concerns and incorporate them into individualized therapy sessions, ensuring a more tailored and responsive treatment plan.

Self-Care and Stress Management: therapist encouraged the caregivers to engage in self-care activities and stress management techniques, such as mindfulness, exercise, and hobbies, can help them maintain their own mental and physical health. Various e-sessions were conducted on recreational activities, mindfulness, physical exercises, etc. so as to reduce the stress among caregivers.

Education and training- The centers organized a series of workshops focused on essential topics such as managing a child with autism, implementing anger management techniques specific to ASD, and effective classroom management strategies. These workshops were designed to equip caregivers with practical skills and knowledge, enabling them to effectively support their child even in the absence of professional guidance.

Celebrating festivals together- Parents reported that participating in festivals and special events with their child fosters a profound sense of connection and joy. Engaging in these activities alongside other parents allows them to share in these happy moments without facing any judgments, creating a supportive and inclusive environment.

Conclusion

The study's primary conclusion underscores the significant positive impact of holistic early intervention (EI) on reducing caregiver stress. The analysis demonstrated that the majority of parents experienced a notable decrease in stress levels following the implementation of a comprehensive EI approach for their child. This reduction in stress was largely attributed to the effective resolution of parents' concerns and the successful completion of goal-oriented

activities. Additionally, the study highlighted the role of brain plasticity during the early years, which facilitated observable progress in the child's development.

However, the study also revealed that caregivers occasionally felt overwhelmed and fatigued due to the extensive demands of managing the child's activities in conjunction with their other household responsibilities. Despite the overall benefits of holistic EI, the additional burden of balancing these responsibilities contributed to periods of exhaustion for caregivers.

With better awareness and understanding of autism, stronger support networks, and inspiring success stories, parents are finding renewed hope and becoming more optimistic about their child's future. These improvements help them feel more confident and positive about the progress their child can make.

Limitation

The study faced several limitations, including a limited amount of data, which may have affected the results. With a larger dataset, the findings could have been more robust. Additionally, the intervention plan was not distributed uniformly, which could have impacted the outcomes. While the study reports the percentage of individuals experiencing stress even with the early intervention program, a diagnostic test could have provided a more precise, quantitative measure of stress levels.

Conflict of interest- none conflict of interest have been reported.

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