

PHYSICAL HEALTH CARE OF CAREGIVERS OF AUDISM SPECTRUM DISORDER CHILDREN

DR.G.SINGARAVELU

ICSSR Senior Fellow, New Delhi

Former Professor & Head

Dept of Education, Bharathiar University,

Coimbatore-641 046.

(Abstract)

Autism Spectrum Disorder children have to be saved from the distress in physical activities, health issues and mental illness and social problems and self-care. For the purpose of caring the Children of ASD, support of caregivers is mandatory for satisfying their primary health demands. In this juncture, Caregivers are indispensable to care the children of ASD. Health of Caregivers are concentrated for happy survival of Caregivers who can help their ASD children. The role of Caregivers and their continuous support is inevitable and this paper is need of emergency for making ASD children's caregivers to learn about self-health care and ways to improve their health by exercises and yoga. Hence this paper illuminates the Caregivers' understanding for steering ASD children, support for caregivers, Physical problems of caregivers, Causes of stress of caregivers, Needs of physical health care for caregivers, Physical stress of caregivers, Treatment for caregivers' physical stress, Steps for mental wellbeing of caregivers, Resources and support groups for autistic caregivers, Health care interventions for caregivers, Embellishment of ASD children's caregivers and Analysing the overall impact on the Caregivers or parents

Keywords: Caregivers with ASD, Causes of stress, Mental wellbeing, Self-care and **interventions for caregivers**

INTRODUCTION

Autism, a spectrum disorder, manifests differently in each child. However, by gaining a deeper understanding of autism and employing effective strategies, caregivers can create a nurturing environment, promote communication, develop social skills, and collaborate with professionals to provide the best possible care. Caregivers of Autism Spectrum Disorder are acted as the main responders to satisfy the demand of Autism Spectrum Disorder students. They are responsible for assistance with toileting, dressing, feeding, therapy, medical supporting and ensure to acquire necessary communicative skills to a person with autism. So Caregivers are torch bearers of alleviating the problems and stress of the ASD Children. Need of the hour to develop physical health of caregivers of ASD children.

REVIEW OF LITERATURE

Ten Hoopen, Leontine W.; de Nijs, Pieter F. A.; Duvekot, Jorieke; Greaves-Lord, Kirstin; Hillegers, Manon H. J.; Brouwer, Werner B. F.; Hakkaart-van Roijen, Leona (2022) This study investigated the association of child, caregiver, and caregiving measurements with the quality of life (QoL) in 81 caregivers (mostly parents) of clinically referred children with autism spectrum disorder (ASD). We used the EuroQol five-dimensional (EQ-5D) questionnaire and the care-related QoL questionnaire (CarerQoL) to respectively assess health-related QoL and care-related QoL. Health-related QoL was associated with the caregiver's internalizing problems and adaptive coping, explaining 38% of the variance. Parenting stress and adaptive coping were associated with the care-related QoL and explained 60% of the variance. Child variables were not associated with the caregiver's health- and care-related QoL if caregiver and caregiving variables were taken into account. Findings indicate the importance of the caregiver's mental health, coping, and parenting stress in caring for children with ASD.

Bradshaw, Jessica; Gillespie, Scott; McCracken, Courtney; King, Bryan H.; McCracken, James T.; Johnson, Cynthia R.; Lecavalier, Luc; Smith, Tristram; Swiezy, Naomi; Bearss, Karen; Sikich, Linmarie; Donnelly, Craig; Hollander, Eric; McDougle, Christopher J.; Scahill, Lawrence (2021) Parents of children with autism spectrum disorder (ASD) face higher levels of caregiver strain compared to parents of children with other disabilities. This study examined child clinical features that predict high levels of caregiver strain for 374 parents of children with ASD. Caregiver strain was measured using the Caregiver Strain Questionnaire (CGSQ) objective, subjective internalized, and subjective externalized subscales. Confirmatory factor analysis indicated an acceptable fit for the original CGSQ three-factor solution. The strongest child predictors across CGSQ subscales were: disruptive behavior for objective strain, autism severity and disruptive behavior for subjective internalized strain, and oppositional behavior and hyperactivity for subjective externalized strain. Individualized interventions that attend to specific elements of parental strain may reduce strain and improve family wellbeing.

CAREGIVERS' UNDERSTANDING FOR STEERING ASD CHILDREN

ASD affects how children communicate, interact, and process the world around them. It is a progressive condition that **varies widely from child to child**, but with the proper support, all children with autism can learn and grow. Understanding their unique strengths and challenges is the first step in helping them thrive. Caregivers play a crucial role in shaping their children's improvement and edifice a strong foundation for their future. Steering the path of caregiving a child with autism can feel like navigating a tangle; it requires strategy, patience, and a commitment to finding the best route. This journey becomes easier with practical tools such as specific praise, reward systems, behavioral encouragement, and visual supports. These techniques not only encourage positive behaviors but also build self-esteem, motivation, and a sense of achievement in the child.

A premeditated environment with predicted routines, visual schedules, and clear guidance helps create a sense of security. Plummeting uncertainty and providing consistent support eases anxiety and allows children to explore their world with confidence. For many families, adopting an authoritative caregiving approach—combining clear expectations with warmth and support—can foster trust and growth. Therapies like podiatric

occupational therapy play a critical role in helping children develop self-care skills such as dressing, eating, and hygiene. These skills are essential for fostering independence and building confidence. Alongside therapy, using positive reinforcement, maintaining open communication, and understanding sensory or emotional triggers can make daily life smoother for both the child and their family.

Above all, unconditional love, patience, and consistency are key. By collaborating with caregivers, educators, and therapists, parents can create a nurturing environment where their child's unique potential shines. Every small victory is a step forward, and with the proper support, children with autism can reach incredible milestones.

SUPPORT FOR CAREGIVERS

As we continue our exploration of autism caregiving, we now turn our attention to the critical area of caregivers support and resources. Our focus here is twofold: the **importance of collaboration with professionals** and the effective use of family resources. These components can provide parents/ caregivers with knowledge, guidance, and the crucial tools to navigate the complexities of autism caregiving. Early intervention in speech therapy, such as early detection, is also vital for addressing communication challenges and ensuring better long-term outcomes. In addition, we also provide a Caregiver/ parent Guided Ebook, a comprehensive resource offering practical strategies for daily challenges, focusing on the emotional well-being of parents and children.

PHYSICAL PROBLEMS OF CAREGIVERS

Caregiving can negatively impact a person's physical health. Caregivers may experience physical problems like back pain, high blood pressure, and headaches. They may also have a weakened immune system and an increased risk of heart disease

Chronic stress: Caregiving can create chronic stress, which can lead to physical and psychological strain

Secondary stress: Caregiving can create secondary stress in other areas of life, like work and relationships

Personal care and Physical demands of caregivers is necessary by following the activities such as : Bathing ,Dressing and Toileting etc.

CAUSES OF STRESS OF CAREGIVERS

The following reasons and causes make caregivers become more stress

- Becoming easily angered or impatient
- Feeling lonely or disconnected from others
- Having trouble sleeping or not getting enough sleep
- Feeling sad or hopeless, or losing interest in activities used to enjoy
- Having frequent headaches, pain, or other physical problems
- Not having enough time to exercise or prepare healthy food for themselves
- Skipping showers or other personal care tasks such as brushing teeth
- Misusing alcohol or drugs, including prescription medications

NEEDS OF PHYSICAL HEALTH CARE FOR CAREGIVERS

Physical Health care of Caregivers is emerging need to support the ASD children. Caregiving can take a substantial toll on a caregiver's physical health. The responsibilities involved, such as administering medications, assisting with mobility, and providing emotional support, can lead to chronic fatigue and exhaustion. Many caregivers report physical symptoms like back pain, joint issues, and headaches due to the physical demands of their role. Over time, this stress can weaken the immune system, making caregivers more susceptible to illnesses

Physical Health care of Caregivers can be developed by the followings health care supports

- Nutritional food,
- Medication Management
- Regular exercises
- Sleep and Rest
- Pain management
- Personal hygiene
- Regular health check up

PHYSICAL STRESS OF CAREGIVERS

- **Constant exhaustion:** Feeling tired even after adequate rest.
- **Physical symptoms:** Headaches, muscle pain, and other stress-related ailments.
- **Emotional strain:** Feelings of anxiety, sadness, or irritability.

physical stress associated with caregiving, it is crucial for caregivers to seek support. Here are some options:

- **Consult Healthcare Providers:** Caregivers should discuss their stress and health concerns with a family physician, who can recommend appropriate support services.

Support Groups: Joining caregiver support groups can provide emotional relief and a sense of community, helping to alleviate feelings of isolation.

Coping Strategies: Techniques such as mindfulness, light exercise, and setting boundaries can help caregivers manage stress effectively

TREATMENT FOR CAREGIVERS' PHYSICAL STRESS

The following strategies can strengthen the Caregivers' physical stress

- Learning information about the way to tackle the self-problems , Children's problems , Social problems and financial problems
- Planning to goal achievement
- Making to join in the supporting group
- Seeking social support
- Taking care of personal health
- Having adequate regular health check up
- Developing emotional health of Caregivers
- Planning with family and friends
- Avoiding negative talk
- Providing coping skills
- Setting goals for celebrating achievement
- Learning mental tricks to maintain emotional stability
- Creating boundaries of activities
- Self-monitoring

STEPS FOR MENTAL WELLBEING OF CAREGIVERS

Mental health of Caregivers of ASD can be developed by the following steps

- Good relationship with others
- Active in physical activities
- Learning new skills
- Attending the present moment of health care

SELF-CARE FOR AUTISM CAREGIVERS

Caring for individuals with autism can be emotionally and physically demanding. It's crucial for caregivers to prioritize their own well-being to avoid burnout and maintain the quality of life

1. Managing and Recognising stress of caregivers

Caregivers must be attuned to signs of stress and burnout in themselves. This includes physical symptoms like fatigue or headaches, as well as emotional signs like irritability or feelings of hopelessness. Developing stress management techniques, such as mindfulness, practices is essential

2. Supporting Network

No caregiver should work in isolation. Building a network of fellow caregivers, professionals, and supportive friends and family is crucial. This network can provide emotional support and opportunities for respite.

3. Importance of Respite care

Regular breaks are essential for maintaining caregiver well-being. Respite care, whether provided by family members, friends, or professional services, allows caregivers to recharge and attend their own needs

4. Balancing personal life and caregiving responsibilities

Maintaining a healthy work-life balance is challenging but crucial for long-term success as a caregiver. This involves setting boundaries, prioritizing personal relationships, and pursuing interest outside of caregiving.

RESOURCES AND SUPPORT GROUPS FOR AUTISTIC CAREGIVERS

Numerous organizations offer resources and support groups specifically for autism caregivers. These can provide valuable information, emotional support, and opportunities to connect with others. The world of autism caregiving is complex, challenging, and deeply rewarding. It requires a unique blend of skills, knowledge, and personal qualities. As we continue to advance our understanding of autism and develop new strategies for support, the role of the autism caregiver will undoubtedly evolve. However, the core elements of patience and empathy

For those already working in the field, remember the importance of **looking after ASD children** as well. Self-care is not selfish; it's essential for providing the best possible care to those who support. And for those considering entering this field, know that the work can make a profound difference in the lives of individuals with autism and their families. The journey of an autism caregiver is one of continuous learning, growth, and the opportunity to make a lasting impact on the lives of others.

HEALTH CARE INTERVENTIONS FOR CAREGIVERS

This is because healthcare providers are often the first to interact with those assuming the caregiver role, usually before they step into it. This para discusses the value of healthcare providers intervening at the earliest possible juncture to help parents interpret their new role and thereby be better prepared to cope with the stresses of raising an ASD child. Pertinent intervention includes educating the caregiver, enhancing acceptance, and facilitating

adaptation to change, for it is an unfortunate fact that many parents thrust into this role neglect self-care, relaxation, and socialization, all of which tend to exacerbate their burden. It is thus vital to parents' mental and physical health that they lose no time seeking clinical, professional, and social support for the acquisition of the knowledge and skills to effectively cope with the challenges of this role. Ultimately, then, reduction of caregiver burden requires providing parents the tools and resources that, among other things, describe what to expect from treatment providers, explain the importance of self-compassion, and promote confidence in one's ability to meet the needs of the youngster diagnosed with this disorder.

EMBELLISHMENT OF ASD CHILDREN'S CAREGIVERS

Physical impact

Families with children who have autism might have an indirect impact on their physical health along with their mental health. Dealing with anxiety, depression, and much more takes a toll on the physical health of the caregiver and parents. Being stressed can lead to lowered immunity and less sleep, which would cause difficulty in concentrating on a particular thing or memory impairment. It could even lead to other health complications.

Emotional impact

Allocating child with ASD is an emotional roller coaster throughout life. Mothers of kids on the autism spectrum mostly have poor mental health. Parents and caregivers often feel overwhelmed and guilty for something that they did which caused the challenge for their children. They often feel isolated from the society as the way society looks their autism-affected child, taunts, and comments on the family. In fact, the fake sympathy that people try to show might affect them emotionally. There are also chances that the caregiver or parent might feel embarrassed with the behaviour of the kid in the public.

Financial impact

The treatment and consulting charges for a person with autism can be enormous. Hence, the family of an autism-affected child might have to go through a lot of financial problems. Most private insurance plans do not cover the expenses related to the therapy and the treatments for autism, and even the visits and the medicines are costly. The families tend to get into huge financial debts, which might affect the mental health of the Caregivers of ASD.

ANALYSING THE OVERALL IMPACT ON THE CAREGIVERS OR PARENTS

Counselling and Therapies : Caregivers with an autistic child can be present at counseling sessions, as it assistances in dealing with emotions, and family counseling may support in bridging out the communication gap between the caregivers. Drugs can be helpful as short-term remedies for the ones dealing with anxiety or depression.

Being a part of support groups: There are small groups that help in supporting the caregivers to deal with children who have autism. Being a part of these groups eases the inner fear of being isolated, and increases the acceptance and understanding the disorder.

Accepting help when offered: It is often observed that families who have a disorder child tend to isolate themselves, and if anyone tries to lend their hands they might feel it might be to offer fake sympathy. Accepting help and seeking help, whenever necessary, will never make anyone feel bad. Instead, it just helps in breaking the barrier and helps one make a better caregiver to the child.

CONCLUSION

There are a variety of challenges connected to Caregivers of AD children. All the challenges of ASD children can be solved by Caregivers by dedicating themselves. Given strategies and guidance may reduce the problems of Caregivers. This study can solve the problems of caregivers through , Physical problems of caregivers, Causes of stress of caregivers, Needs of physical health care for caregivers, Physical stress of caregivers, Treatment for caregivers' physical stress, Steps for mental wellbeing of caregivers, Resources and support groups for autistic caregivers, Health care interventions for caregivers, Embellishment of ASD children's caregivers , Analysing the overall impact on the Caregivers or parents

References

Salomone E., Leadbitter K., Aldred C., Barrett B., Byford S., Charman T., Howlin P., Green J., Le Couteur A., McConachie H., et al.(2018) The association between child and family characteristics and the mental health and wellbeing of caregivers of children with autism in mid-childhood. *J. Autism Dev. Disord.* 2018;48:1189–1198. doi: 10.1007/s10803-017-3392-x.

Ten Hoopen, Leontine W.; de Nijs, Pieter F. A.; Duvekot, Jorieke; Greaves-Lord, Kirstin; Hillegers, Manon H. J.; Brouwer, Werner B. F.; Hakkaart-van Roijen, Leona(2022)

Caring for Children with an Autism Spectrum Disorder: Factors Associating with Health- and Care-Related Quality of Life of the Caregivers, *Journal of Autism and Developmental Disorders*, v52 n11 p4665-4678

Bradshaw, Jessica; Gillespie, Scott; McCracken, Courtney; King, Bryan H.; McCracken, James T.; Johnson, Cynthia R.; Lecavalier, Luc; Smith, Tristram; Swiezy, Naomi; Bearss, Karen; Sikich, Linmarie; Donnelly, Craig; Hollander, Eric; McDougle, Christopher J.; Scahill, Lawrence(2021) Predictors of Caregiver Strain for Parents of Children with Autism Spectrum Disorder *Journal of Autism and Developmental Disorders*, v51 n9 p3039-3049

Minhas A, Vajaratkar V, Divan G, et al. Parents' perspectives on care of children with autistic spectrum disorder in South Asia: views from Pakistan and India. *Int Rev Psychiatry.* 2015;27(3):247–256.

Parenting stress in caregivers of young children with ASD concerns prior to a formal diagnosis

Trent D DesChamps¹, Lisa V Ibañez¹, Sarah R Edmunds¹, Catherine C Dick¹, Wendy L Stone¹

Bischof NL, Rapee RM, Hudry K, Bayer JK.(2018) Acceptability and caregiver-reported outcomes for young children with autism spectrum disorder whose parents attended a preventative population-based intervention for anxiety: A pilot study. *Autism Res.* 2018 Aug;11(8):1166-1174. doi: 10.1002/aur.1963. Epub 2018 May 15.PMID: 29761836

Shannon Riccio(2022) Feeding problem: Autism Spectrum Disorder, BU Journal of Graduate studies in Education,Vol,14,issue-1

Singaravelu.G(2022)Autism Spectrum Disorder (ASD) Care Givers Stress And Challenges, International Journal of Innovative Science and Research Technology, Volume 7, Issue 10.

P Martínez-Castilla,, R Campos,, A. C Samson,, J Van Herwegen,, D Dukes,
.(2023) Perceived Anxiety in Family Caregivers of Individuals with Autism Spectrum Disorder, Down Syndrome and Williams Syndrome during the Lockdown of the First COVID-19 Wave in Spain, Actas Esp Psiquiatr 51(2): 56–64.

Yamada A., Suzuki M., Kato M., Suzuki M., Tanaka S., Shindo T., Taketani K., Akechi T., Furukawa T.A.(2007) Emotional distress and its correlates among parents of children with pervasive developmental disorders. *Psychiatry Clin. Neuros.* 2007;61:651–657. doi: 10.1111/j.1440-1819.2007.01736.x.