

# Autism Spectrum Disorder (ASD) Care Givers Stress And Challenges

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**Abstract:-** Autism Spectrum Disorder (ASD) Caregivers are essential service to save the children of ASD. Even if ASD Caregivers help to children but their health, stress, emotional imbalances, Challenges, mental health are neglected. Two types of ASD Caregivers face the problems and challenges. Identification of need of the ASD Caregivers are need of the hour. Society neglected such caregivers. Reducing stress, eliminating common issues faced by Caregivers and solves challenges of family caregivers are indispensable in the society or Government. This paper illuminates identification of challenges, stress, emotional problems, stress and how to overcome the challenges.

**Keywords:-** Autism Spectrum Disorder (ASD), Caregivers, Stress, Challenges.

## I. INTRODUCTION

Autism Spectrum Disorder (ASD) is a developmental disability with age of 3 years old. Additionally ASD is a family of neuro-developmental disorders which is characterized by definite impairments in social interactions, abnormalities in speech, and stereotyped pattern of behaviors. Although the etiology and pathogenesis of this disorder are still a matter of speculation. The consensus in the literature is that, autism is caused by both genetic and environmental factors. Caring for the children suffering with autistic spectrum disorder is challenging and affects the life of the caregivers. Depression, anxiety Psychological distress and other mental or physical health problems are the common symptoms that the caregivers face while caring for a child with autistic spectrum disorder. here is a range of services and therapeutic treatments available for children and adults who have autism. These include the provision of information and advocacy, assessment, early intervention therapies, help at school, behaviour support, individual support packages, supported accommodation and respite. Children with ASD become distressed when their surrounding environment is changed because their adaptive capabilities are minimal. They have co-occurring language problems, intellectual disabilities, and epilepsy at higher rates than the general population. At present, there is no remedy, although there are interventions that may be effective in alleviating some symptoms. Treatments pursued by families include a range of behavioral, psychosocial, educational, medical, and complementary approaches that vary by a child's age and developmental status. Caring for children with a severe form of the condition is demanding, especially where access to services and support are inadequate. ASDs often impose significant emotional and economic burden on people with these disorders and their

families. Autism is such a developmental disability which has a great impact on the family's adaptation and functioning more so the mother. Families with a child diagnosed of ASD have to pass through compromising; sacrificing, stressful, and adjustment lifestyle. The testimonials of the parents of autistic children in India, recently demonstrated how they are financially and emotionally burdened. Moreover the parents' children with ASD are known to experience higher levels of parenting stress compared to the parents of normally developing children.

## II. CAREGIVING STRESS

Cloete and Obaigwa's study demonstrated that the ASD children were reported to be chaotic by their caregivers. Additionally the caregivers noted that the ASD children have occurrences of delayed milestones, this could imply that they needed more close monitoring compared to their counterparts who were normal. ASD children include mental retardation, emotional indifference, hyperactivity, aggression, self-injury, and repetitive behaviors such as body rocking or hand flapping. The ASD children may have restricted behaviors which present as resistance to change or highly restricted interests, which are abnormal in intensity or focus. Some parents have disregarded their own children due to the caregiving burden. Many mothers of autistic reported that their most challenging part of raising their autistic child was to manage their hyperactivity and social interaction. The results of the present review imply that the caregiving or the parenting role to ASD children is challenging. This is attributed mostly to the unique clinical manifestations of the ASD children.

## III. TWO TYPES OF CAREGIVERS

Caregivers can be divided into two groups: one group includes caregivers (usually unpaid) who provide care to a loved one or friend who is ill, disabled, or experiencing aged symptoms. This care may be temporary, such as when a spouse or partner has surgery, or long-term, such as when a child experiences physical and emotional disabilities. Care is provided in the home of the person being cared but some may be provided in the caregiver's home, especially when long-term care is necessary.

The second group consists of caregivers who are paid to provide care in a person's home or in hospital. They are professionally trained and hired through an agency or an acquaintance employed by family members. Both paid and unpaid caregivers may experience physical, mental, and emotional strain as a result of their caretaking. Because caregivers often become attached to the person they are

caring for, it may be distressing if that person's health further declines.

Recent statistics show 80% of long-term care in the India is provided by paid caregivers. Of these, 61% are women, most have reached middle age, and 59% also have jobs. Though caregiver stress can affect anyone providing care, research shows 75% of caregivers experiencing significant strain are women. Family caregivers have been shown to be less likely than people who do not provide care to attend to their own health and need of individual care, making it more likely that their own well-being will be negatively affected. Caregivers between the ages of 66 and 96 who experience stress have a 63% higher risk of dying within four years than non-caregivers in the same age range.

#### IV. COMMON ISSUES AND CHALLENGES OF CAREGIVERS

As per a survey, thirty-five percent of caregivers find it difficult to make time for themselves, while 29% have trouble managing stress, and another 29% report difficulty balancing work and family issues. Some other common issues that caregivers may experience include, but are not limited to:

- **Frustration with angry** : It can be distressing to put one's life on hold to care for someone else or to take care of a person who is irritable, becomes upset easily, or wanders away often.
- **Fear** : A caregiver may worry on financial difficulties, their own health and mortality, or the decline and eventual death of a loved one.
- **Depression**: Between 40% and 70% of family caregivers experience of symptoms such as Isolation, loneliness, and lack of self-care might all contribute to the development of depression symptoms.
- **Worriiness**: Watching a loved one's health decline rapidly can be a deeply affecting experience.
- **Wrong** : A caregiver may feel guilty for not being able to provide better care or for not being able to pay as much attention to other areas of life.
- **Isolation** : Unpaid caregivers may spend all of their free time caring for another person and have no time to themselves. They may have to reduce their work hours or adapt their lifestyles and personal relationships. Individuals who are unable to interact with others or spend time tending to their own needs may experience emotional distress as a result.
- **Physical strain and exhaustion**: Caregivers may find themselves without time to exercise, eat properly, or get enough sleep. Those who care for others are also more likely to have a weaker immune system and spend more time sick than non-caregivers.

#### V. NEED OF CAREGIVERS

- Attend classes and training courses to learn new skills. These are often taught through a hospital or NGOs and WHO.
- Avoid isolation. Associate and interact with other people, especially other caregivers. Make time to meet with friends, however briefly.
- Find organizations and associations that specialize in helping caregivers.
- Seek support from family and accept help that is offered. Caregivers may find it especially important to be honest with the self and others about what can reasonably be accomplished alone.
- Develop self-compassion: Those who are compassionate to others may criticize themselves or hold themselves to high standards, which can exacerbate a distressed mental state. Recognizing that one can only do so much and comforting oneself when things become difficult can help one become better able to cope with difficult situations.
- Physical health can quickly become an area of concern for caregivers. Many caregivers report difficulty finding time to visit the doctor for themselves, and they might also neglect their own health care due to financial difficulties. However, caregivers who develop serious health problems may end up unable to care for anyone else. People providing care to others may experience health concerns such as:
  - The exacerbation or return of a preexisting or previous illness
  - Hypertension
  - Insomnia or fatigue
  - Frequent headaches
  - A weakened immune system
  - Substance abuse (drugs and/or alcohol)
  - An injury caused by improper lifting or transferring of the person being cared for

Taking time for basic personal needs can help reduce one's risk of developing physical health problems.

#### VI. CHALLENGES OF FAMILY CAREGIVERS

- Managing their time. Caregivers often find they have less time for themselves and other family members.
- Emotional and physical stress
- Lack of privacy
- Financial strain.
- Sleep deprivation.
- Afraid to ask for help
- Depression and isolation.

#### VII. CONCLUSION

Caregivers of autistic children and adolescents can be improved by improving their knowledge regarding autism. Thus, there is an immense need of increasing awareness among general population through information, education, and communication materials, mass media, and discussions regarding autism. This conceptual paper may be helpful to ASD Caregivers for solving the problems and challenges. If ASD Caregivers are isolated, ASD children will be

affected. Two types of Caregivers have to be saved to save the life of AD Caregivers. It is the right time to solve the problems of ASD Caregivers.

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