



# PSYCHOLOGICAL DISTRESS OF CAREGIVERS OF AUTISM SPECTRUM DISORDER CHILDREN AT PRIMARY LEVEL

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## (Abstract)

This paper brightens Psychological distress among Caregivers of Autism Spectrum Disorder Children in Special schools at Primary level. Researcher tried to reduce the psychological distress of Caregivers of ASD children at Primary level. . **Objectives of the study:** 1.To find out the distress of psychological distress of Caregivers. 2. To find out whether there is any significant difference between Male and Female of caregivers of ASD children in related psychological distress of Caregivers. 3. To find out whether there is any significant difference between the qualification of Under graduate and Post graduate of caregivers in related to psychological distress. **Methodology:** Normative Survey method was adopted in the study. **Sample:** Twenty five caregivers those who were looking after the ASD children, Coimbatore were taken as sample for the study. **Tool:** Researcher's self-made Interview schedule was used as a tool for the study. **Validity** of the tool was established by the opinion of the juries. **Reliability** of the tool was established by the test-retest method. Statistical technique: 't' test was used to analyze the study. **Findings** Caregivers' Interview schedule are useful for findings the psychological distress of Caregivers. **Educational implications:** It can be implemented all the Special schools.

**Index Terms:** psychological factors, Autism Spectrum Disorder Children, Caregivers, Special school

## Introduction

Caregivers of ASD children may have difficulties in initiating or responding to social interactions, maintaining eye contact or using gestures, and may also present repetitive motor movements; persistence in the repetition of routines, including verbal or non-verbal behaviors; difficulties with transitioning from one activity to another; or focus on a specific interest with too strong intensity in Accelerating learning. Teachers of ASD have more knowledge about the ASD children and challenges of caregivers faced with ASD children. Caregivers of Autism Spectrum Disorder children are facing many distress in fostering ASD children. There are some dimensions of caregiver burden. First burden includes restrictions on the caregiver's time available for personal interests and activities (Altieri & von Kluge, 2009; Smith et al., 2010) or privacy (Marsack & Perry, 2018). Second, *developmental burden* refers to personal or social underdevelopment compared to peers who do not have a relative who requires care (Novak & Guest, 1989), which can lead to feelings of isolation and a perception of being disconnected or detached from the social environment (Hare et al., 2004; Hines et al., 2014; Marsack & Hopp, 2018). Third, *physical burden* describes caregivers' feelings of chronic fatigue and damage to physical health (Novak & Guest, 1989). Fourth, *social burden* comprise feelings of role conflicts, as well as limited time and energy that they can invest in relationships or in occupational participation (Novak & Guest, 1989). Fifth, *emotional burden* refers to negative feelings towards the relative with ASD (Novak & Guest, 1989), such as guilt and blame (Marsack & Hopp, 2018; Marsack-Topolewski & Graves, 2019). In extension to this initial definition by Novak and Guest (1989), prior research reported caregiving to also worsen family caregivers' mental health, including higher levels of psychological distress (Abbeduto et al., 2004; Blacher & McIntyre, 2006), and higher prevalence's of mental disorders (Magallon-Neri et al., 2018; Schnabel et al., 2020). Even if many distress among Caregivers

of ASD children, psychological distress are major distress to the Caregivers. Hence the researcher took the study on distress of Caregivers on psychological distress through collecting data from the Caregivers of ASD children.

## Need of the study

Caregivers of ASD children face the many problems such as personal problems, Health issues, Psychological problems, Mental problems, and social problems. All the above problems affect them physically, mentally and psychologically. Psychological distress is a major issues to the Caregivers of ASD children. Wellbeing of Caregivers of ASD children is need of the hour to foster ASD children .Hence the researcher selected this study to alleviate the psychological distress of Caregivers of ASD children.

## Theoretical Framework

Ferenc, Kinga; Byrka, Katarzyna; Król, Magdalena Ewa (2023)focused on Attitude of mothers towards their children's autism may play a role in mothers' psychological well-being. We investigated the predictive value of how mothers understand autism (as a neurodivergence or a developmental disorder) on their psychological distress. A group of 371 mothers of children on the autism spectrum participated in this study. We found that understanding autism as a neurodivergence was related to lower psychological distress in mothers, even after controlling for the level of autism symptoms. However, when controlling for caregiver burden, their attitude towards autism was no longer significant in explaining their psychological distress. These findings suggest that the way mothers understand autism may be important for their psychological adjustment. However, it also suggests that mothers of children on the autism spectrum may adopt different attitudes towards autism, depending on their child's level of autism symptoms and the caregiver burden.

[Neha Gupta, Manya Khanna, Rashi Garg, Vedantika Sethi, Shivangi Khattar, Purva Tekkar, Shwetha Maria, Muskan Gupta, Akash Saxena, Parul Gupta, Sara Ann Schuchert](#) (2023)aims to examine the psycho-emotional and social experiences of caregivers of children with autism spectrum disorder. Various facets of the caregiving experience are explored, including the feelings and thoughts of the parents/caregivers, such as the resilience experienced in their journey, how they coped with the challenges and also their positive experiences. Method: caregiving experience are broadly probed using semi-structured interviews subjected to narrative analysis. Lastly, there is a focus on the role of therapist-led intervention, specifically, the Eye to I<sup>o</sup> intervention model and its contributions to the parent/caregiver experience. Findings : Findings from this study indicate that parents benefit from interventions that bridge gaps in skills and interpersonal communication which parents/caregivers feel they encounter in their day-to-day activities. Additionally, support groups for parents and caregivers could further address these issues.

[Venkata Tejo Prasanna and Ruby John](#) (2024) attempts to critically examine the existing qualitative literature relevant to caregivers of autism spectrum disorder (ASD) in India. Caregiving for ASD is a unique journey filled with experiences that pose challenges and opportunities; while providing unwavering support and sensitivity for individuals on the spectrum. Qualitative research methods provide avenues to understand this exclusive experience which equips the professionals and policymakers to understand the distinctive needs of the caregivers and elevate their well-being. A database search has been conducted and the selected literature has been reviewed thoroughly. The results are discussed in a narrative style to understand the methodologies used, various hurdles and aspects that can affect their well-being along with recommendations for future exploration.

[Yun-Ju Hsiao](#)(2024) focus on Parenting children with autism spectrum disorder (ASD) can be challenging, demanding, and overwhelming to parents and families. Understanding parental resilience can help develop appropriate support for parents of children with ASD and their families. This article discusses parental resilience by exploring what is known about parental resilience in families of children with ASD and examining factors that may contribute to parental resilience for practitioners to work with these parents. This article focuses on three strong predictors of parental resilience in families of children with ASD: (a) locus of control of parents, (b) cognitive appraisal of parents, and (c) informal support for families. Implications for practitioners to help parents build resilience from the above three aspects are discussed.

## Objectives

1. To detect the Psychological distress faced by the Caregivers of ASD children
2. To find out whether there is any significant difference between Male and Female of caregivers of ASD children related psychological distress.
3. To find out whether there is any significant difference between the qualification of Under graduate and Post graduate of teachers related to distress of Caregivers
4. To find out the need to minimize the psychological distress of caregivers.

## Hypotheses

1. Caregivers of ASD children have Psychological distress.
2. There is no significant difference between Male and Female of caregivers of ASD children related to psychological distress.

3. There is no significant difference between the qualification of Under graduate and Post graduate of caregivers of ASD children related to Psychological distress of Caregivers
4. Need to minimize the psychological distress of caregivers.

### Research Methodology

Normative survey method was adopted in the study.

### Population and sample

Teachers, Children and Caregivers of ASD children from three special schools Coimbatore were population of the study. 25 Caregivers of ASD children from primary schools named Gowmaran Special School, Saravanampatti, WVS Special School, Goundam palayam and Amrit Multi speciality school, Goundam palayam from Coimbatore district were selected as sample for the study.

### Instrumentation

Researcher's self-made Interview schedule to the Caregivers was used as a tool for the study. Validity of the tool was established by the opinion of the juries. Reliability of the tool was established by test-retest method.

### Preparation of Instrumentation

The investigator's self- made Interview schedule was used for collecting the information about psychological distress of Caregivers of ASD children from interview schedule. Three point scale was prepared. Three points are considered as YES, NO and NEUTRAL.

### Establishment of Reliability

Reliability of the tool had been computed using Test-retest method and the calculated value is 0.78. The value is quite significant and implies that the tools adopted were reliable. Hence the reliability was established for the study.

### Establishing Validity of the instrument

Subject experts and experienced were requested to analyze the tool. Their opinions indicated that the tool had content validity and construct validity.

### Scoring procedure of the instrument

Three point scale was prepared and used after standardize the tool. Three points are considered as YES, NO and NEUTRAL. Scoring marks are given the value for calculation as follow , YES-2, NO-0 and NEUTRAL-1. Highest score is 70, lowest score is 35 and 0 value is nothing.

### Steps of the study

The Researcher got permission to collect the data from teachers of Special schools by approval of District Differently Abled Officer, Collectroate , Coimbatore. After getting permission from Collectorate and getting permission from principals of selected schools. The researcher approached the Caregivers of ASD children and discussed the psychological distress.

### Data Collection

. The Researcher interviewed the Caregivers of ASD children about their psychological distress and explained the need of the study. The Caregivers understood the purpose of interview for the study. After the interview with Caregivers, the collected data were analysed by using SPSS package.

### Statistical technique

t test was used to compute the study.

## RESULTS

### Descriptive statistics

#### Hypothesis 1

Caregivers of ASD children have Psychological distress

Table-1

Psychological distress faced by the Caregivers of ASD children

Sl.NO	INTERVIEW STATEMENTS	YES	NO	NEUTRAL
1	Are you feel unhappy due to ASD children	18	2	5
2	Anger ,Anxiety and frustration is disturbing the mood of Caregivers	20	4	1
3	Phobias of ASD children are suppressed the mood of Caregivers	15	6	4
4	Are you understanding the needs of ASD children?	18	1	6
5	Learning to reduce the Cognitive impairment of ASD Children is an essential service of Caregivers	20	4	1
6	Are you disturbed by the ASD children's behavior imbalance?	12	6	7
7	Are you using positive reinforcement to control aggressive behaviors among the ASD Children?	11	7	7
8	Are you able to control the aggressive behaviors of the ASD children?	15	3	7
TOTAL		129	33	31

The above table shows the Interview schedule of Caregivers of ASD children about the psychological distress related to Caregivers. Interview towards Caregivers of ASD children on “Are you feel unhappy due to ASD children?” is accepted by 18 Caregivers out of 25 Caregivers. In this statement, 2 caregivers not accepted but 5 Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral. . Interview towards Caregivers of ASD children on “Anger ,Anxiety and frustration is disturbing the mood of Caregivers ?” is accepted by 20 Caregivers out of 25 Caregivers. In this statement, 4 caregivers not accepted but 1Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral. Interview towards Caregivers of ASD children on “Phobias of ASD children are suppressed the mood of Caregivers” is accepted by 15 Caregivers out of 25 Caregivers. In this statement, 6 caregivers not accepted but 4Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral. Interview towards Caregivers of ASD children on “Are you understanding the needs of ASD children?” is accepted by 18 Caregivers out of 25 Caregivers. In this statement, 1 caregivers not accepted but 6 Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral. Interview towards Caregivers of ASD children on “Learning to reduce the Cognitive impairment of ASD Children is an essential service of Caregivers ” is accepted by 20 Caregivers out of 25 Caregivers. In this statement, 4caregivers not accepted but 1Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral. Interview towards Caregivers of ASD children on “Are you using positive reinforcement to control aggressive behaviors among the ASD Children?” is accepted by 12 Caregivers out of 25 Caregivers. In this statement, 6caregivers not accepted but 7Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral. . Interview towards Caregivers of ASD children on “Are you using positive reinforcement to control aggressive behaviors among the ASD Children?” is accepted by 12 Caregivers out of 25 Caregivers. In this statement, 6caregivers not accepted but 7Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral. . Interview towards Caregivers of ASD children on “Are you able to control the aggressive behaviors of the ASD children?” is accepted by 15Caregivers out of 25 Caregivers. In this statement, 3caregivers not accepted but 7Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral.

**Inferential Analysis**

**Hypothesis 2**

There is no significant difference between Male and Female of caregivers of ASD children in related psychological distress. .

Table-2

Difference between Male and Female of caregivers of ASD children in related psychological distress

Experiences	N	Mean	S.D	df	t-value	Result
Male	5	46.40	14.12	23	0.972	Insignificant at 0.05 level
Female years	20	41.70	8.44			

The table showing mean scores between between Male and Female of caregivers of ASD children in related psychological distress. Mean difference is 5.62. The calculated" t' value is (0.9724 ) less than table value (1.96). Hence null hypothesis is accepted at 0.05 levels. Hence there is no significant difference between Male and Female of caregivers of ASD children in related psychological distress from Interview schedule of Caregivers. .

**Hypothesis 3**

There is no significant difference between the qualification of Under graduate and Post graduate of caregivers of ASD children in related to Psychological distress of Caregivers

Table-3

Mean scores between the qualifications of Undergraduate and Postgraduate Caregivers of ASD children in related to Psychological distress of Caregivers

Stages	N	Mean	S.D	df	t-value	Result
Under graduate	15	41.73	10.07	23	0.5388	Insignificant at 0.05 level
Post graduate	10	43.80	8.23			

The table showing mean scores between the qualifications of Undergraduate and Postgraduate teachers of ASD children in the interview with Caregivers of ASD children. The calculated 't' value is (0.5388) greater than table value (1.96). Mean difference is 1.97. Hence null hypothesis is accepted at 0.05 level. Hence there is no significant difference between the qualification of Under graduate and Post graduate of caregivers of ASD children in related to Psychological distress of Caregivers.

**Hypothesis 4**

Need to minimize the psychological distress of caregivers

As per the result of the study in the table no-1, Caregivers” interview score on YES is 129 compared to NO is 33. So the Psychological distress has to be minimized to the Caregivers of ASD children.

**Findings**

1. Interview towards Caregivers of ASD children on “Anger ,Anxiety and frustration is disturbing the mood of Caregivers ?” is accepted by 20 Caregivers out of 25 Caregivers. In this statement, 4 caregivers not accepted but 1Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral.
2. . Interview towards Caregivers of ASD children on “Phobias of ASD children are suppressed the mood of Caregivers” is accepted by 15 Caregivers out of 25 Caregivers. In this statement, 6 caregivers not accepted but 4Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral.
3. Interview towards Caregivers of ASD children on “Learning to reduce the Cognitive impairment of ASD Children is an essential service of Caregivers ” is accepted by 20 Caregivers out of 25 Caregivers. In this statement, 4caregivers not accepted but 1Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral.
4. Interview towards Caregivers of ASD children on “Are you using positive reinforcement to control aggressive behaviors among the ASD Children?” is accepted by 12 Caregivers out of 25 Caregivers. In this statement, 6caregivers not accepted but 7Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral. .
5. Interview towards Caregivers of ASD children on “Are you able to control the aggressive behaviors of the ASD children?” is accepted by 15Caregivers out of 25 Caregivers. In this statement, 3caregivers not accepted but 7Caregivers responded as neutral. Accepted statement of Caregivers is higher than Negative and Neutral.
6. Caregivers of ASD children have Psychological distress
7. There is no significant difference between Male and Female of caregivers of ASD children in related psychological distress
8. There is no significant difference between the qualification of Under graduate and Post graduate of caregivers of ASD children in related to Psychological distress of Caregivers

#### EDUCATIONAL IMPLICATIONS

1. **The Normative survey study** may be extended to all the Special schools.
2. A training programme may be arranged to ASD Caregivers.
3. It may be activated in Special school education.
4. It can be implemented in Special school education.
5. Government and policy makers may learn the psychological distress of Caregivers and they may take more improvement steps on this issues.

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