

# Mental Agony of Caregivers of Autism Spectrum Disorder Children at Primary Level

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**Abstract:** This paper revivifies Mental Agony among Caregivers of Autism Spectrum Disorder Children in Special schools at Primary level. Researcher tried to reduce the Mental agony of Caregivers of ASD children at Primary level. **Objectives of the study:** 1. To perceive the Mental agony 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 in terms of Mental agony of Caregivers. 3. To find out whether there is any significant difference between the location of Rural and Urban of caregivers with regard to Mental agony of Caregivers and 4. To find out how to reduce the Mental agony of caregivers. **Methodology:** Normative Survey method was adopted in the study. **Sample:** Fifty 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 split-half method. **Statistical technique:** 't' test was used to analyze the study. **Findings** Caregivers' Interview schedule is useful for findings the mental agony of Caregivers. **Educational implications:** It can be implemented in all the Special schools.

**Keywords:** Mental agony, Autism Spectrum Disorder Children, Caregivers, Special school

## 1. Introduction

Caregivers of Autism Spectrum Disorder Children are facing many problems in which Mental health challenges and Physical health challenges such as anxiety, depression and sleep disorder. Mental challenges is completely disturbed the Caregivers' freedom and intake of the food. Mental agony of the Caregivers try to withdraw from ASD children and sometime instigate them for suicide. Poor communication and aggressiveness of ASD children increase irritability of the Caregivers. Necessary relationship with relatives and society is disturbed to the Caregivers by fostering ASD children. Personal needs of the caregivers are not satisfied which creates more agony to caregivers. Rural caregivers fail to learn different therapies available in website and poor in digital learning. Some of the Urban caregivers fail to understand various platforms available for helping them. Alleviating the mental stress of the Caregivers with ASD children. Communication barrier is lacuna for the caregivers. Therapeutic interventions such as cognitive-behavioural therapy (CBT) is a valuable tools for promoting wellbeing of ASD children and Caregivers for smoothen their services. Mindfulness helps autistic individuals develop self-awareness and emotional regulations skills, while therapy provides structural support for managing anxiety and depression. Caregivers can collaborate with mental health professionals to ensure their loved ones receive necessary support for long term emotional health. Even if many distress among Caregivers of ASD children, Mental agony is major distress to the Caregivers. Hence the researcher took the study on distress of Caregivers on Mental agony through collecting data from the Caregivers of ASD children.

### Significance of the study

Autism Spectrum Disorder children's caregivers have many glitches such as self-care, Health issues, Mental problems, and social problems. All the above problems disturbed them physically, mentally and psychologically. Mental Agony is a major issues to the Caregivers of ASD children. Alleviating mental agony of the Caregivers of ASD children is need of

the hour. Hence the researcher identified this research to assuage the Mental Agony of Caregivers of ASD children.

## 2. Review of Literature

Katey N Hayes, Kristina G Rossetti, Kimberly Zlomke (2022) discuss on mental health of Caregivers of Autism Spectrum Disorder children. Caregivers of children with autism spectrum disorder (ASD) have been shown to have unique mental health vulnerabilities that community support may buffer. Positive caregiver mental health can stimulate family resilience behaviours, such as strong communication and problem-solving. Further, community support has been found to be related to caregiver mental health, as well as improved child functioning. The current study aims to investigate caregiver mental health as a mediator between community support and family resilience in families of a child with an autism spectrum disorder.

**Methods:** Data obtained from caregivers of 654 children with a reported diagnosis of ASD were utilized from the 2016 National Survey of Children's Health (NSCH) public database.

**Results:** Community support was positively correlated with family resilience and caregiver mental health. Bivariate correlations indicated significant positive associations between community support and family resilience. Caregiver mental health, significantly, partially mediated the relationship between community support and family resilience.

**Conclusions:** The present study provides important insight into fostering caregiver health as a strategy to promote family resilience behaviours. Interventions designed to address family resilience behaviours among families of children with ASD should focus on ways that positively impact caregiver mental health.

**Gloria K Lee & Carolyn M Shivers(2018)** focussed on **Caregivers's** quality of life. Although studies have examined quality of life (QOL) among family caregivers of individuals with autism spectrum disorder (ASD), little is known about potential differences in QOL based on the age of the individual with ASD, particularly in relation to caregivers' needs, beliefs and coping mechanisms. **Method:** This study investigated 132 caregivers of school-age children and 61 caregivers of transitioning young adults with ASD on measures of caregiving, strain, coping, family needs and QOL.

**Results:** The results indicated that there were no significant differences in QOL based on the age of the individuals with ASD, although parents of children reported significantly more caregiving behaviours, with coping, internalized strain and health information needs predicted mental health QOL.

**Discussion:** Age of the individual with ASD was not significantly related to caregivers' QOL. More research is needed to determine independent predictors of caregiver QOL across the lifespan.

### Objectives

- To perceive the Mental agony faced by the Caregivers of ASD children
- To find out whether there is any significant difference between Male and Female of caregivers of ASD children in terms of Mental agony of Caregivers.
- To find out whether there is any significant difference between the location of Rural and Urban of caregivers with regard to Mental agony of Caregivers
- To find out how to reduce the Mental agony of caregivers.

### Hypotheses

- Caregivers of ASD children have Mental agony.
- There is no significant difference between Male and Female of caregivers of ASD children in terms of Mental agony.
- There is no significant difference between the qualification of Rural and Urban of caregivers of ASD children with regard to Mental agony of Caregivers
- Need to reduce the Mental agony 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. 50 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 reduce the Mental agony of caregivers of Caregivers of ASD children from interview schedule. Three point scale was prepared. Three points are considered as AGREE, DISAGREE 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 AGREE, DISAGREE and NEUTRAL. Scoring marks are given the value for calculation as follow, AGREE -2, DISAGREE-0 and NEUTRAL-1. Highest score is 67, lowest score is 33 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 Mental agony 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.

## 3. Results

### Descriptive statistics

#### Hypothesis 1

Caregivers of ASD children have Mental agony

**Table 1:** Mental agony faced by the Caregivers of ASD children

S. No	Interview Statements	Agree	Disagree	Neutral
1	Mental-health and Psychological well beings are affected the Caregivers by over stress	41	05	04
2	Sleep disorder of ASD Children affect Caregivers also	38	07	05
3	Emotional problems of Caregivers affect Caregivers	42	03	05
4	Do you have Mental disability in your regular work?	37	04	09
5	Repetitive behaviors of the ASD children creates the monotony to the caregivers.	41	03	06
Total		199	22	29

The above table shows the Interview schedule of Caregivers of ASD children about the Mental agony related to Caregivers. Interview towards Caregivers of ASD children on “Mental-health and Psychological well beings are affected the Caregivers by over stress” is agreed by 41 Caregivers out of 50 Caregivers. In this statement, 5 caregivers Disagree but 4 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagree and Neutral.

Interview towards Caregivers of ASD children on “Sleep disorder of ASD Children affect Caregivers also” is Agreed by 38 Caregivers out of 50 Caregivers. In this statement, 7 caregivers Disagreed but 5 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagreed and Neutral.

Interview towards Caregivers of ASD children on “Emotional problems of Caregivers affect Caregivers” is Agreed by 42 Caregivers out of 50 Caregivers. In this statement, 3 caregivers Disagreed but 5 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagreed and Neutral.

Interview towards Caregivers of ASD children on “Do you have Mental disability in your regular work?” is Agreed by 37 Caregivers out of 50 Caregivers. In this statement, 4 caregivers Disagreed but 9 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagreed and Neutral.

Interview towards Caregivers of ASD children on “Repetitive behaviors of the ASD children creates the monotony to the caregivers” is accepted by 41 Caregivers out of 50 Caregivers. In this statement, 3 caregivers Disagreed but 6 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagreed 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	6	28.23	13.10	48	0.7959	Insignificant at 0.05 level
Female	44	34.45	18.44			

The table showing mean scores between between Male and Female of caregivers of ASD children in related psychological distress. Mean difference is 0.7959. The calculated "t" value is (0.7959) 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 Mental agony from Interview schedule of Caregivers.

#### Hypothesis 3

There is no significant difference between the qualification of Rural and Urban of caregivers of ASD children in related to Mental agony of Caregivers

**Table 3:** Mean scores between the location of Rural and Urban Caregivers of ASD children in related to Mental agony of Caregivers

Stages	N	Mean	S.D	df	t-value	Result
Rural	20	38.43	7.89	48	3.06	significant at 0.05 level
Urban	30	30.70	9.23			

The table showing mean scores between the location of Rural and Urban teachers of ASD children in the interview with Caregivers of ASD children. The calculated "t" value is (3.06) greater than table value (1.96). Mean difference is 1.97. Hence null hypothesis is rejected at 0.05 level. Hence there is significant difference between the location of Rural and Urban of caregivers of ASD children in related to Mental agony of Caregivers.

#### Hypothesis 4

Need to minimize the Mental agony of caregivers

As per the result of the study in the table no-1, Caregivers" interview score on Agree value is 199 compared to Disagree value is 22 and value of Neutral value is 29. So, the Mental agony has to be minimized to the Caregivers of ASD children.

### 4. Findings

- 1) Interview schedule of Caregivers of ASD children about the Mental agony related to Caregivers. Interview towards Caregivers of ASD children on “Mental-health and Psychological well beings are affected the Caregivers by over stress” is agreed by 41 Caregivers out of 50 Caregivers. In this statement, 5 caregivers Disagree but 4 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagree and Neutral.
- 2) Interview towards Caregivers of ASD children on “Sleep disorder of ASD Children affect Caregivers also” is Agreed by 38 Caregivers out of 50 Caregivers. In this statement, 7 caregivers Disagreed but 5 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagreed and Neutral.
- 3) Interview towards Caregivers of ASD children on “Emotional problems of Caregivers affect Caregivers” is Agreed by 42 Caregivers out of 50 Caregivers. In this statement, 3 caregivers Disagreed but 5 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagreed and Neutral.

- 4) Interview towards Caregivers of ASD children on “Do you have Mental disability in your regular work?” is Agreed by 37 Caregivers out of 50 Caregivers. In this statement, 4 caregivers Disagreed but 9 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagreed and Neutral.
- 5) Interview towards Caregivers of ASD children on “Repetitive behaviors of the ASD children creates the monotony to the caregivers” is accepted by 41 Caregivers out of 50 Caregivers. In this statement, 3 caregivers Disagreed but 6 Caregivers responded as neutral. Agreed statement of Caregivers is higher than Disagreed and Neutral.
- 6) There is no significant difference between Male and Female of caregivers of ASD children in related psychological distress.
- 7) There is significant difference between the location of Rural and Urban of caregivers of ASD children in related to Mental agony of Caregivers
- 8) As per the result of the study in the table no-1, Caregivers” interview score on Agree value is 199 compared to Disagree value is 22 and value of Neutral value is 29. So the Mental agony has to be minimized to the Caregivers of ASD children.

## 5. 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 Mental agony of Caregivers and they may take more improvement steps on this issue.

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