

Caregiver Strain and Coping Strategies Among Caregivers of Children with Autism Spectrum Disorder (ASD)

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Being a caregiver for a chronically ill child is very challenging and stressful for the caregivers. It much more challenging if there is an autistic child in family, a child with autism plays a major role that negatively affects the family and its daily functioning. The carers of children with autism spectrum disorder undergoes lot of strains. The present study focused on the caregiver strain and coping strategies among carers of children with autism spectrum disorder. **AIM:** The present study aim is to assess the level of strain, type of strain and type of coping strategies and relationship between the subscales of variables namely caregiver strain and coping strategies. **METHODS:** For analysing this study methods used were descriptive statistic, Pearson correlation, student t-test and one way ANOVA using SPSS version 29.0. Sample size collected was 248, where 73.40% were primary caregivers and 26.60% were secondary caregivers. **RESULTS:** The findings of this study shows that the majority of respondents had high and moderate level of strains. 55% of caregivers experienced objective strain (i.e., financial burden, disruptions in family relations, and difficulties with neighbours). 62% of participants were using family integration, cooperation, and an optimistic definition of the situation as their coping strategy. The finding also reveals that there is negligible negative correlation among the subscales of two variables namely caregiver strain and coping strategies.

Keywords: Caregiver Strain, Coping Strategies, Autism Spectrum Disorder.

Offering care to children with developmental disability can be gratifying but demanding and challenging too. Usually, the families take care of an ill person especially when the person has a developmental disability or Autism. This differently able person can be any member of the family like a kid, an adult kid who lives with his/her parents, siblings or some other relative at home with them. The children with developmental disabilities especially Autism show mixed feelings such as like joyfulness, irritation, annoyance, pleasure, satisfaction, harm, resentment and envy though they might find it difficult to express, understand and manage these emotions. The children with autism spectrum disorder may have reported co-morbidities, in such cases the family members bear a double burden and it is progressively more

ubiquitous and complicated among children having severe level of autism. Physiological health, mental health, quality of life and well-being are reported to decline among primary caregivers of relatives with multifaceted disabilities. The primary caregivers especially the parents usually undertake bigger responsibility for resolving difficulties for their disabled children hence are more vulnerable to psychological strain.

The present research makes an attempt to explore the situation of the carers of children with autism spectrum disorder. The Caregivers of autism spectrum disorder children faces high levels of caregiver stress compared to carers of children with other disorders. The changeability in coping techniques among carers of children with

autism spectrum disorder may provide to broader health outcomes. Therefore, this study focused on the groups of carers based on coping strategies and will investigate the differences in strain among groups.

Autism Spectrum Disorder

A developmental disorder that deserves special attention, by virtue both of its fame and its severity, is autism. An abnormality in the neurological network of the brain evident into the spectrum of autism. Children with autism have risked mental capacities due to subnormal functioning is affected. It is a neuro-developmental dysfunction which leads to difficulties in communication, social relations, speech, behaviour, sensory issue and thinking ability.

In 1943, Leo Kanner, a well-known psychiatrist describes his observations of a child in his classic paper "The Autistic Disturbances of Affective Contact", in these words – "The child seems to be self-satisfied. Has no apparent affection when petted. Does not observe the fact that anyone comes or goes, and never seems glad to see father or mother or any playmate. The child seems almost to draw into own shell and live within himself." Kanner suspected that these children were often misdiagnosed with mental retardation or childhood schizophrenia. Thus, he put forth a trait of impairment in the region of, communication, speech and social-interaction and imagination. He observed that these children did not express the usual motivation towards affective and social relations with others; for example; they seemed to be living in their own world. Their communication was manifested either by absence of speech or they had odd nature of speech for example; echolalia.

Caregiver

The terms caregiving and caregiver in general terms have been defined as when family members provide particular assistance

and communal support to each as a part of normal family interactions. Caregiving has been explained as interactions in which one family member is helping another on a daily basis with tasks that are essential for independent living. According to the Primary Caretaker Law and Legal Definition (2012) caregiver can be referred to as one who renders help and assistance to another person who is incapacitate in performing the crucial assignments related to individual or household chores which are essential for continued existence. The caregiving duties and responsibilities are performed by different types of caregivers.

Caregiver Strain

Caregiver Strain defines the physical and emotional strains experienced by providing caregiving. Anyone providing care to his or her loved one can experience this type of strain.

Coping Strategy

Coping is the mode which helps the person to respond to a traumatic situation. The coping has an objective to curtail the pressures on the physical, emotional, and psychological level of an individual caused by daily life's nuisance. Coping strategies show the behavioural and psychological efforts made by a person to tackle any situation. Coping strategy is a style that shows how an individual responds to a situation. To deal with a dangerous circumstance, one uses various ways. These ways are termed as a coping strategy. Coping can be defined as thoughts that an individual builds in build to dealing with daily life stress, for problem solving and to control, reduce and endure stressful situation so the situation would not harm person's physical and psychological well-being. It is a response individual made towards stressful situation. It includes a mental process that is complex and helps to decrease and minimize the stress. The strategies that aim to deal with

the internal or external stress-causing circumstances. These techniques may be cognitive and behavioural. When an individual goes through hurdles between personal aims, the person may feel frustrated and fearful. Also tries the best to remove the hurdles and move towards the destination. And may either try to alter the circumstances or to mould as per the present situation.

Objectives

- To assess the levels of strain experienced by caregivers of children with autism spectrum disorder.
- To study the more affecting type of strain among caregivers of children with autism spectrum disorder.
- To find out the type of coping strategies used by majority of caregivers of children with autism spectrum disorder.
- To examine the association between caregiver strain and coping strategies among caregivers of children autism spectrum disorder.
- To assess the difference in caregiver strain and coping strategies among caregivers of children with autism spectrum disorder based on the different demographical characteristics.

Hypotheses

1. There would be no significant association between caregiver strain and coping strategies among parents and caregivers of children with autism spectrum disorder.
2. There would be no significant difference in caregiver strain among caregivers of children with autism spectrum disorder on the basis of type of carers.

3. There would be no significant difference in caregiver strain among caregivers on the basis of family type.
4. There would be no significant difference in caregiver strain among caregivers on the basis of marital status.
5. There would be no significant difference in coping strategies among caregivers of children with autism spectrum disorder on the basis of type of carers.

Method

Sample

According to cross-sectional study method the sample size was found to be 245. The sample collected for the present study is 248. The age group of the children range from 3 to 15 years were included in this study, total 248 samples collected to represent the descriptive study. It consists of 182 (73.4%) primary caregivers and 66 (26.6%) secondary caregivers. In primary caregivers 142 (78.02%) were mothers and 40 (21.98%) fathers of autism spectrum disorder children. Out of total sample 189 were male children and 58 were female children.

Instruments

Caregiver Strain Questionnaire: The questionnaire contains “21 items” which designed to examine the 3 dimensions of strain experienced by caregivers. “Objective Strain, Subjective Externalized Strain & Subjective Internalized Strain”. This scale is a “five-point Likert-type scale”. The options for responses range from “one (not at all a problem) to five (very much a problem)”. The total “caregiver strain questionnaire” and its subscales demonstrated good internal reliability with “Cronbach alpha coefficient” for the entire scale 0.93 tested and good validity of the caregiver strain questionnaire among caregivers of children with ASD.

Coping Health Inventory for Parents Scale: The questionnaire contains “45 statements” designed to examine the 3 dimensions of coping strategies utilized by caregivers. “Maintaining family integration, cooperation, and an optimistic definition of the situation, maintaining social support, self-esteem, and psychological stability & understanding the medical situation through communication with other parents and consultation with medical staff”. The CHIP-scale is “four-point Likert- type scale”. The options for responses range from “zero (not at all helpful) to three (extremely helpful)”. The scale shows the reliabilities for the three subscales listed are .79, .79, and .71 and it has good criterion validity.

Results

Caregiver’s Strain

The level of strain among carers of children with autism spectrum disorder were measured by frequency distribution, where the majority of the carers undergoes high and moderate level of strain about 66.90% which is 166 out of total had high level of strain, 32.30% which is 80 carers experienced moderate level of strain and the rest about 0.80% (2) carers had low level of strain. This reveals that caregiver of children with ASD faces lot of challenge in their daily life because of the behavioural and emotional problems of children.

The Descriptive analysis was conducted to measure three subscales of caregiver strain questionnaire (CGSQ) and total caregiver strain questionnaire (CGSQ). The Standard Deviation and Mean score of total Caregiver Strain Questionnaire were SD=18.47 and M=54.48. The Standard Deviation and Mean score of three subscales were Objective Strain (OS) SD= 9.93 and M= 26.50, Subjective Externalized Strain (SES) SD= 2.95 and M= 9.65 and Subjective Internalized Strain (SIS) SD= 5.59 and M= 18.33. It’s quite vivid that Caregiver Strain

and its sub variables that the values of standard deviation were highly inconsistent, which implies each individual experience different kinds of strain. Majority of the participants about (51%) of caregivers were experiencing Objective Strain, which defines the observable negative events that result from the child’s problems (e.g., financial strain, disrupted family relations, and difficulty with neighbours or police).

Coping Strategy

To examine the type of coping strategies used by caregivers and parents of children with autism spectrum disorder the Coping Health Inventory for Parents (CHIP) scales were used in the present study. The Descriptive analysis was conducted to measure three subscales and total of Coping Health Inventory for Parents (CHIP). The Standard Deviation and Mean score of total Coping Health Inventory for Parents were SD= 19.61 and M=94.98. The Standard Deviation and Mean score of three subscales were Maintaining family integration, cooperation, and an optimistic definition of the situation. (FI) SD= 7.98 and M= 40.99, Maintaining social support, self-esteem, and psychological stability. (SS) SD= 7.25 and M= 37.73 and Understanding the medical situation through communication with other parents and consultation with medical staff. (MS) SD= 4.38 and M= 16.26. The values of standard deviation of sub variables were inconsistent, which indicates the fact that, caregiver coping strategy adoption vary from each person to person as it is unique in their structure and dynamics. Mostly used coping strategies by carers was Family integration, cooperation, and an optimistic definition of the situation about 62% of participants uses this coping style to cope up with their strain.

Correlation between caregiver strain and coping strategies:

The Pearson’s correlation was conducted to find out the relationship between the

subscales of the variables namely caregiver strain and coping strategies. Each subscale of both variables was showing negligible negative correlation as shown in Table 1. The subscales of both variables were negatively correlated. This concluded hypothesis 1 (There would be no significant association between the caregiver strain and coping strategies among caregivers of children with autism spectrum disorder) was rejected.

Table 1. Correlation between the subscales of Caregiver Strain and Coping Strategies

Variables	Subscales of (Coping strategies)					
	Family Integration		Social Support		Medical Situations	
	r value	p value	r value	p value	r value	p value
Subscales of (Caregiver Strain) Objective						
Strain (OS)	-0.178**	0.008	-0.168**	0.008	-0.204**	0.001
Subjective Externalized Strain (SES)	-0.281**	0.000	-0.162**	0.011	-0.233**	0.000
Subjective Internalized Strain (SIS)	-0.144*	0.023	-0.135**	0.034	-0.201**	0.001

(**Correlation is significant at 0.01 level)

(*Correlation significant at 0.05 level)

Student t-test Analysis

The student t-test had been conducted to examine the differences on the basis of demographical characteristics of both the variables namely caregiver strain and coping strategies. Shown below in table 2. The difference in caregiver strain among carers of children with autism on the basis of carers types the absolute value of p value is 0.000 which is less than the critical value 0.001. This concluded the hypothesis 2 (There would be no significant difference in caregiver strain among caregivers of children with autism spectrum disorder on the basis of type

of carers) was rejected. This indicates that caregiver strain had a significant difference among caregivers of children with autism spectrum disorder on the basis of type of carers. On the basis of family type. The absolute value of p value is 0.43 which is greater than the critical value .001. This concluded the hypothesis 3 (There would be no significant difference in caregiver strain among caregivers of children with autism spectrum disorder on the basis of family type) was accepted. The difference in coping strategies among carers of children with autism on the basis of family type. The absolute value of p value is 0.009 which is greater than the critical value 0.001. This concluded the hypothesis 4 (There would be no significant difference in coping strategies among caregivers of children with autism spectrum disorder on the basis of family type) was accepted.

Table 2. The student t-test analysis on the basis of demographical characteristics.

Variables	Demographical Characteristics	t-value	p-value
Caregiver Strain	Primary & Secondary Caregivers	4.73	0.000**
Caregiver Strain	Nuclear & Joint Families	1.72	0.43
Coping Strategies	Nuclear & Joint Families	-2.36	0.009

**Level of significance at 0.001 level

One way ANOVA had been conducted to compare the caregiver strain among caregivers of children with autism spectrum disorder on the basis of their marital status. Shown below in table 3. The absolute value of p-value is 0.001 which is similar to the critical value 0.001, this indicates that caregiver strain had a significant difference among caregivers based on their marital status. This concluded the hypothesis 5. There would be no significant difference in

caregiver strain among caregivers on the basis of marital status.) were rejected. The mean scores indicated that higher strain experienced by caregivers who were separated where.

Table 3. Data and results of One Way ANOVA: Comparison of Caregiver strain based on marital status.

Variables	Marital Status	N	Mean	SD	p
Caregiver Strain	Married	193	3.61	1.70	0.001
	Divorced	20	2.40	0.68	
	Separated	35	4.65	2.64	

**Level of significance at 0.001 level

Discussion

The study aim was to measure the level and examine the type of strain, type of coping strategies and relationship between subscales of both variables among carers of children autism spectrum disorder (ASD). The total samples collected for the study was 248 where about 73.4% which is 182 were primary caregivers which includes mother and father of autism spectrum disorder children, out of total primary caregiver about 78.02% (142) were mothers and 21.98% (40) were fathers, rest from the total samples around 26.6% which is 66 were secondary caregivers which includes grandparents, siblings and other relatives. About 76.20% (189) of male and 23.40% (58) females were included in the study. Children of age group from 3-15 years were included where the three distinct group division were 3-7 years in this age group 38.30% (95) children were included, 8-12 years 35.10% (87) and 13-15 years number of children included were 26.60% (66). Based upon the medical condition's children of different degrees of autism were as follows, children with mild autism 16.13% (40), moderate autism 36.70% (91) and children with severe autism 47.20% (117), It reveals

the fact that more than the majority of the children had severe and moderate autism. There were two types of family; it includes 60.50% (150) participants from the nuclear family and 39.50% (98) participants from joint family. Participants based on their marital status were 77.8% (193) married, 8.10% (20) divorced and 14.1% (35) separated. Level of caregiver strain experienced by caregivers; about 66.9% (166) participants had high level of strain, 32.30% (80) participants had moderate level of strain and the remaining 0.8% (2) had low caregiver strain. It reveals that majority of caregivers undergoes through high and moderate level of strain because of the challenges in their daily life. Rearing a child with autism spectrum disorder in a family plays a significant role that negatively affects the families. The scale "caregiver strain questionnaire" has three subscales which examined the type of strains experienced by the participants by descriptive analyses of total samples the result revealed that about 55% of parents experienced "objective strain" which refers to "the observable negative events that result from the child's problems (e.g., financial strain, disrupted family relations, and difficulty with neighbours or police)". 30% of participants experienced "subjective internalized strain" which refers to "the inwardly directed feelings experienced by the caregiver such as worry, guilt, and fatigue". 17% of participants experienced "subjective externalized strain" involves "outwardly directed negative feelings about the child's problems such as anger, resentment, and embarrassment". Another scale used in the present study to examine the coping strategies were "coping health inventory for parents" it also has three subscales with respect to the subscales the most used coping strategies about 62% of participants used to overcome caregiver strain was "maintaining family integration, cooperation, and an optimistic definition of the situation" which defines "involvements

with family members such as spending time with spouse and relatives, expressing feeling with spouse or other family members and developing positive attitude towards difficult situation and problem and emotional behaviour of the child”.

The correlation analyses had been done to examine the association between the subscales of “caregiver strain” and “coping strategies” of carers of children with autism spectrum disorder where it shows negligible negative correlation between each of the subscales of caregiver strain and coping strategies, and the p values were less than the critical value which concluded that null hypothesis got rejected i.e. (There is no significant correlation between the subscales of caregiver strain and coping strategies of caregivers of children with autism spectrum disorder).

The t-test analysis had been used in this study to assess the differences of both the variables with respect to collected demographical variables of the participants. To find out the difference in caregiver strain with respect to type of carers, where the absolute “p value” was 0.000 which is less than the “critical value 0.001” which “rejects the null hypothesis (There would be no a significant difference in caregiver strain among caregivers of children with autism spectrum disorder on the basis of type of carers)”. To find the difference in caregiver strain on the basis of family type the absolute “p value” was 0.43 which is greater than the “critical value 0.001” which “accepts the null hypothesis (There would be no significant difference in caregiver strain among caregivers on the basis of family type)”. To see the difference in coping strategies of parents and caregivers with respect to the family type where the calculated “p value” was 0.009 which is greater than the “critical value 0.001” which concluded “null hypothesis got accepted (There would be no significant difference in coping strategies

among caregivers on the basis of family type)”.

To compare the differences in caregiver’s strain on the basis of marital status of the participants one way ANOVA had been used. The calculated “p value” found was 0.001 which is similar to the critical value which “rejects the null hypothesis (There would be no a significant difference in caregiver strain among caregivers on the basis of marital status)” and the mean scores indicates that higher level of caregiver strain had been experienced by caregivers who were separated.

Implications

The present study helps to understand the type of caregiver strains and type of coping strategies used by caregivers of children with ASD. The present study helps to understand the association between the caregiver strain and coping strategies. This study provides insight to conduct quantitative research on “caregiver strain and coping strategies among caregivers of children with ASD” especially in the Indian context. The present study helps to develop awareness and encourage mental health professionals to develop care centres for caregivers of disabled people. This study helps to develop interventional modules to reduce strain and develop better coping styles which will help to maintain the overall well-being of caregivers of children with chronic illness.

Conclusion

The present study highlights that caregivers of the children with autism spectrum disorder were experiencing higher level of caregiving strain and the primary caregivers were having more strain. It was also found that objective strain is the most affecting strain to the majority of the participants. The coping strategies used by majority of the participants were family integration, cooperation, and an optimistic

definition of the situation. There is a negligible negative correlation between the subscales of caregiver strain and coping strategies.

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