



## Caregiver's Burden and Perceived Spousal Support in Mothers with Autistic Children

Sara Renni\*, Kumar, K. B\*\*

\*Clinical Psychologist, CDMRP, Department of Psychology, University of Calicut, Kerala, India.

\*\* Professor of clinical psychology, Director & Head AIBHAS

### Abstract

Received: 23 July 2016  
Revised: 30 Aug 2016  
Accepted: 11 Sept 2016

#### Keywords:

Autism, Caregiver burden,  
Perceived Spousal Support.

Mothers of children with autism have found to experience greater stress and difficulties in adjustment compared with mother of children with other physical and intellectual difficulties. This study was undertaken to assess caregiver burden and perceived support in mothers of children with Autism with an aim to examine the prevalence of the burden and extent of support perceived by the caregiver. Results revealed no significant difference with respect to perceived spousal support in mothers of autistic children and mothers of normal children, though mothers of normal children reported higher instrumental support and higher level of general strain as compared to mothers of autistic children. Result also showed no significant difference with respect to caregiver burden in mothers of autistic children and mothers of normal children. Future studies may consider relevant variables such as life events, sample size, quality of marital relationship which could influence the perceived burden and support received by the spousal.

© 2016 Guru Journal of Behavioral and Social Sciences

Autism is a brain developmental disorder characterized by impaired social interaction and communication and by restricted and repetitive behaviour. These signs all begin before a child is three years old (DSM IV2000).

The appearance of autism within a family always brings about its challenges. Indeed, for those families whose child appeared to be developing normally, it can be particularly difficult if the child suddenly goes through a period of regression.

Child with autism typically requires vast amount of parental time and energy (Tarakeshwat & Paragament, 2001). Mothers of children with autism have found to experience greater stress and difficulties in adjustment compared with mothers of children with other physical and intellectual difficulties (Parenham, 2005). There is considerable and consistent evidence that mothers experience greater impact than fathers (Sharpley et al., 1997; Shelzer, 2001). There is relatively less severe impact of the child's autism on most of the fathers appeared to be a least partially due to the gender roles connected to work and child rearing. A study by Bromly et al (2004) found over 50% screened positives for significant psychological distress and this was associated with low levels of family support and with bringing up a child with challenges behaviour. Darly (2005) conducted a study on coping and social support for parents of children with autism. On half of the families identified serious stressors in addition to autism acquiring social support and reframing were the most frequently used coping strategies. Kerus (2007) found that parents of children with autism frequently turn to the service delivery system to access supports designed to help adapt to the challenging of having a child with a life long impairment.

#### Objective

1. To determine caregiver's burden and perceived spousal support in mothers with autism children as compared mothers with normal children.

## Method

### Participants

The participants of this study consisted of mothers having a child who is diagnosed to have autism and accompanying the child's intervention session either at autism centre of Sweekar Academy of Rehabilitation Center or at National institute of mental health (NIMH), Secunderabad, Andra Pradesh. On the whole 38 mothers were included into the study of which 27 mothers were of autism group (hereafter referred to as "M-AG").

#### *Inclusion criteria*

- Age between 25 and 50years
- Having a child diagnosed to have childhood Autism(F84.0) or Atypical Autism (F84.1) according to ICD-10
- Criteria without any co morbid conditions such as Mental retardation and ADHD
- Age of the affected child is above 3years
- Studied up to 7<sup>th</sup> std or above
- Willing to participate in the study

#### *Exclusion criteria*

- Single mothers, windows, separated and divorced
- Past or current psychiatric illness and any chronic physical illness
- A score of 4 or above General health questionnaire
- Child meeting the criteria for significant problem on child behaviour Check List

### Instruments

1. Berlin social support scales (BSSS): To measure Perceived spousal support, Berlin social support scales (BSSS) by Schwarzer and Schulz (2000) was used. Internal consistency for subscales in Perceived Social support (8items): Cronbach's Alpha=.83, Recieved Social support (general score, 11items) Cronbach's Alpha= .83, need for support (4items), Cronbach's Alpha= .63, support seeking (5items): Cronbach's Alpha= .81, protective buffering (6items): Cronbach's Alpha= .82. Internal consistency for provided social support general score,11 items) in partner sample Cronbach's alpha=.75. Validity has been demonstrated in several studies. In this study four subscales been used and they were perceived available support, need for support, support seeking actually received support. Scales scores are obtained by adding up item responses. Similarly overall subscale scores were been split up by summarizing emotional support, instrumental support, informational support and satisfaction with support for further analysis of support. Higher the score means higher support and vise versa.
2. Caregivers Burden Scale (CBS): To measure mothers care giving burden Caregivers Burden Scale designed by Oemark for assessment of caregivers of chronically ill person was used. The scales was divided into five indices general strain, isolation, disappointment, emotional involvement and environment. The scale reasonable realiblity which was established by calculating the internal consistency.
3. General Health Questionnaire (GHQ): To screen the mothers with normal children general health questionnaire was used. It gives a measure of common mental health problems/domains of depression, anxiety, somatic symptoms and social withdrawal. Each item is accompanied by four possible responses, typically being 'not at all', no more than usual', rather more than usual and much more than usual', scoring from 0 to 3, respectively. Any score exceeding the threshold value of 4 is classed as achieving 'psychiatric caseness'. Validity reliability coefficients have ranged from 0.78 to 0.95 in various studies.
4. Children Behavioural Checklist (CBCL) was used to screen normal children of control group. CBCL was designed to assess behavioural problems ans social competencies of

children as reported by parents. The CBCL can also be used to measure a child's change in behaviour over time. This can be used for children age range between 4 to 16. The test-retest reliability coefficient ranges from .95 to .98 and internal consistency was reported ranges from .78 to .97. Criterion validity was assessed and found to be acceptable.

5. Childhood Autism Rating Scale (CARS) was used to rate the children diagnosed to autism and it consist of 15 items. And published by western psychological services USA (1971). The 15 item are based on clinical feature in Kauner's Rutter and DSM classification system. The score the CARS each of the 15 items is given a rating from 1 to 4 indicating the severity of problem from normal to severe. Children below the score of 30 are categories as non autistic while those with score above 30 are categories as autistic. In addition the autistic category can further divided into two categories. Scores ranging from 30-36.5, indicate mild to moderate autism, while scores ranging from 37 to 60 indicate severe disability.

### **Procedure**

#### ***Experimental Group***

Mothers accompanying their children with autism for intervention at Autism center were contacted and objective of the study was briefly explained and those consenting to participate in the study were assessed on the study criteria. Those meeting the criteria were included into the study. In all cases confidentiality of the conformation was assured. Mothers were administered all measures in a single session. If they had difficulty in comprehending any part of the measures, the same was explained.

#### ***Control group***

Mothers accompanying their children to the school were contacted and the aforementioned procedure was employed, except mothers scoring above the cut off on GHQ or child meeting the criteria for presence of problematic behaviour on CBCL were excluded.

## Results and Discussion

**Table 1:** Sociodemographic characteristics of the study population. Data is shown as Mean ( $\pm$  SD) or percentage.

Variable	M- AG	M-NG
<b>No. of years of education completed</b>		
Mothers	12.7 ( $\pm$ 2.91)	15.18 ( $\pm$ 2.31)
Spouse	14.59 ( $\pm$ 1.84)	14.72 ( $\pm$ 2)
<b>Annual income</b>		
< 60,000	30%	9.1%
60,000 – 1, 80,000	55.5%	72.7%
>1,80,000	14.8%	18.1%
<b>Family</b>		
Nuclear	81%	64%
Joint	18.5%	36.3%

There were no significant difference between groups with respect to sociodemographic variable viz education, income and family type as seen in Table 1. Higher percentage of mothers from normal groups belongs to middle income group and nuclear family.

**Table 2 :** Mean ( $\pm$ SD) score on Social support and Caregiver's burden scale in different groups.

Variable "p"	M- AG	M-NG	"U"
<b>Social support Scale</b>			
Total score .285	116.96( $\pm$ 11.19)	121.91( $\pm$ 5.7)	115.5
Emotional .194	48.44( $\pm$ 3.8)	49.72( $\pm$ 4.12)	110.0
Instrumental .066	56.7( $\pm$ 8.46)	61.27( $\pm$ 4.14)	93
Informational .130	7.66( $\pm$ .87)	7.09( $\pm$ 1.37)	115
Satisfaction .480	3.96( $\pm$ .19)	3.81( $\pm$ .60)	140
<b>Caregiver burden Scale</b>			
Total score .166	32.66(8.46)	36.45(8.28)	105.5
General strain .035	11.74(3.7)	14.9 (4.5)	83.5
Isolation .207	4.7(1.95)	3.9(1.3)	111
Disappoint .987	7.37(1.73)	7.63(2.65)	148
Emotional involvement .360	4.44(1.71)	4.90(1.75)	121
Environment .202	4.4(1.21)	5.09(1.64)	110

Scanned by CamScanner

No significant difference was found between groups with respect to any of the social support subscale as shown in table 2. Though mothers of normal children reported higher instrumental support, the difference was not significant. But Mothers of this group of children also reported significantly higher degree of general strain as compared to mothers of children with Autism. Generally the scores were non significantly higher on all of the subscales of caregivers burden in M-NG.

Caring for children with autism is often a complex and lifelong challenge. Mothers often play the role of caregiver of children with special needs in country like ours. Most mothers report that caregiving of children with disability greatly compromise their social and family life. Studies have indicated balancing of greater hours of care they provide against the fact they perform fewer ADL the net average "burden of care" for care givers of children is found to be higher than it is for caregivers of adults. Physical strain from caregiving is also one common source of stress among care givers of children with special needs (64%) that it is among those scaring for adults (55%). Most of the caregivers often experience feeling of inadequacy helplessness, frustration, and was not due to single stress but due to pile up demands. Studies also show that mothers have severely affected their emotional well being. Social support has long being regarded to mitigate distress. Studies show that caregiver experience more psychological distress due to low level of social support in bringing up child.

But the above findings are not always consistent. For eg, in one of the reports one third of caregivers varying for child with special need considered the care giving situation to be

emotionally stressful (34%) and about the same proportion indicate little or no stress (37%) in the same study. Further only 17% caregiving mothers in this study report facing a high level of strain. One possibility for these on consistent result in the area of caregiving burden may partially due to the fact that support received by the caregiving activity of disabled child influence the degree to which the burden is perceived by the caregiver. Several studies have indicated moderating role for the support variable. consistent with this mobilizing support have been recommended has one of the strategies for mitigating the stress and burden perceived by the caregiver. In a study it also found our that mothers who takes most of the day today responsibility of the care of these children with handicaps, but the assistance they do receive is important to them. Analysis by marital status show few differences in the help received. However married women perceived greater support from their husband and his family than single mothers did.

Another reason was low significance in caregiving burden is that mothers of children with autism in the present were selected directly from the center were they were receiving the professional support and help. Hence it is possible that the burden felt by the mother in care giving of disabled child has not being significantly high. Further more the burden perceive by the caregiver is reported by linked to the severity of the child's disability. Hence it is possible that the children diagnosed to have autism might have a less symptoms and therefore less burden on the mother. In a study showed that the parents of the children with autism frequently turned to the services delivery system access supports designed to help adapt tight challenging of having a child with a life long impairment. The present study explore the burden related to the care giving of the children with autism and perceived spousal support in 27 mothers. When compared with mothers of normal children mothers of autism were not significantly more burdened and reported the same degree of spousal support has their counterpart.

### Conclusion

Aim of the investigation is to determine caregivers burden and perceived spousal support in mothers with autistic children has compared mothers with normal children. For this purpose a group of 27 mother of autistic children were studied on caregivers burden and perceived support measures and results were compared with group of 11 mothers of normal children.

The result indicate that percieved spousal support in mothers with autistic child would not significantly differ from the perceived spousal support in mothers with normal child; the caregiving burden in mothers of autistic child had some significance from caregiving burden in mothers of normal child.

The above interpretation however, should be viewed in keeping in mind the limited sample size over winged to various reasons the sample couldn't be broadened for easy generalizability of the data. Further more, in the present study other relevant variable such has life events QOL, quality of marital relationship which could influence the perceived burden and support received by the spousal have not been studied. Further studies may consider these variables to understand the moderating effects on perceived burden in caregiving of disabled children

### References

- Bromley, J. (2004). Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. *Autism*, 8, 409-423.
- Pakenham, K., Samios, C., & Sofronoff, K. (2005). Adjustment of mothers of children with asperger syndrome: An application of the double ABCX model of family adjustment. *Autism*, 9, 191-212.



- 
- Sharpley, C. F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and developmental disability*, 22, 19-28.
- Tarakeshwar, N., & Paragament, K. (2001). Religious coping in families of children with autism. *Focus on autism and Other Development Disabilities*, 16, 247-260.