

## The Quality of Life and Burden Among Caregivers of Children with Autism and Caregiver of Children Without Disability

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### ABSTRACT

The aim of the research was to study the Quality of Life and Burden among caregivers of children with Autism and caregivers of children without disability. To see the same a comparative study was undertaken using Parental Stress Scale given by Berry and Jones, a self-report measure which was to study caregiver burden and WHOQOL-BREF to study the Quality of Life among the caregivers. The results show that caregivers of children with autism experience higher level of burden and lower level of quality of life on all the four domains of quality of life as compared to the caregivers of children without disability. These findings indicate that different effect as a consequence of different childhood conditions and also the need to provide adequate parental support when providing intervention to their children with disabilities.

**Keywords:** *Quality of life, Burden, Caregivers, Autism, Children, Disability*

Caregivers play very important roles in children's psycho-social and academic development. Taking care of children with chronic disabilities like autism can affect a parent's mental health in more negative ways. Autistic Disorder is one of the most complex childhood developmental disorders that can devastatingly affect the children's intellectual, social, and linguistic abilities. Children who have such significant impairments require access to a good health care facility and extensive caregiving. Such support however is not only required by the affected child but is also needed by the caregivers, as it has been found that taking care of a child with Autistic Disorder can disturb the whole family's life and result in several economic, social, physical and psychological problems (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, & Bolt, 2010). Therefore, it is important to consider the mental health of the caregivers in the interventions proposed for children with Autistic Disorder.

Quality of Life (QOL) is becoming a major health concern for caregivers who are forced to face many stressful situations while raising a child with disability. Quality of life can be defined as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 1996). It is a broad ranging concept affected in a

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complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. The definition highlights the subjective aspect of quality of life, which is both negative as well as positive and is multidimensional.

Thus, quality of life includes the conditions of life resulting from the combination of the effect of complete range of the factors such as those determining health, happiness and a satisfying occupation, education, social and intellectual attainments, freedom of actions and freedom of expression (WHO, 1996). Quality of life of caregivers with disabilities can be affected by the degree of disability, associated problems, amount of time spend on caregiving, presence of adequate social support etc. Thus, assessing Quality of Life of caregivers having children with disabilities is important as it can serve as a base for intervention for rehabilitation professionals, who work closely together with the child with special needs and his parents and in bringing efficient and effective treatment strategies, as well as an in-depth understanding of the needs of these parents. Such intervention may be aimed at improving the lifestyles of the caregivers in order to reduce the perceived stress. Interventions may also be aimed at actual targeting of any physical or psychological symptoms if the need arises. Caregivers and other children in the family thus, undergo a variety of profound changes to adapt to the presence of a disabled member (Kumar, 2008).

A child with autistic disorder difficult characteristics has been seen to predict mothers' quality of life (Dardas & Ahmad, 2014). The effect on the families of children with developmental disabilities can be seen in the fact that they perceived high levels of stress related to pessimism, child characteristics, and parent and family problems (Wang, Michaels, & Day, 2011). Environmental barriers in the form of availability of resources, behavioral difficulties of the child, family functioning/impact, general health and child physical functioning has been seen to have negative and significant associations with physical quality of life (Law, Hanna, Anaby, Kertoy, King, & Xu, 2014).

Caregivers who have children with disabilities are often reported to have physical and psychological distress related to caring for their children, thus affecting their quality of life (QOL). Social relationships and environmental domains of QOL differed significantly in parents of children with disabilities such that parents who have children with more severe disabilities were found to have lower scores in physical, psychological, and environmental domains (Leung, 2003). Children with severe disabilities are more physically demanding of their parents, who might feel more stress when taking care of them. As a result parents' physical and psychological well-being might directly affect their children. This study thus, indicates the need for parental support when providing intervention to their children with disabilities.

### **METHODS AND MATERIALS**

#### *Sample*

The total sample was 100 caregivers, consisting of 50 caregivers of children with Autism and 50 caregivers of children without any disability. The caregivers of ASD were approached from special schools in Delhi and NCR. The caregivers of children without disability were also selected through purposive sampling. The sample thus consisted of two groups- Group 1(caregivers of children with ASD) and Group 2 (caregivers of children without any disability).

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### **Tools**

To assess the quality of life, the WHOQoL-BREF was used. The WHOQoL-BREF is an abbreviated version of the WHOQoL-100, which is a self-administered questionnaire. It comprises of 26 items categorized into four broad dimensions - Physical Health, Psychological Well-being, Social Relationships and Environment Domain. The items are rated on a 5-point scale (WHO, 1998). The reported values for Cronbach alpha were 0.82 for physical health, 0.81 for psychological domain, 0.68 for social domain and 0.80 for environment domain. Domain scores are scaled in a positive direction.

To assess the burden, Parental Stress Scale was created by Berry and Jones in 1995. It comprises of 18 items that depict the parent child relationship and the guardians' sentiments. Guardians react by showing the degree to which they concur or oppose this idea with the rating.

### **Procedure**

The sample was gathered from those going to OPD at special schools and from the parents of children without any disability in Delhi and NCR. An examining outline was made as indicated by the inclusion and exclusion criteria and Parents of these youngsters were chosen through purposive sampling. The sample in this way contained two gatherings, a total of 100 caregivers – Caregivers of children with Autism (n=50) and Caregivers of children without any disability (n=50). On being chosen for the examination the purpose behind investigation was disclosed to the guardians furthermore, consent was taken. Administration of the two scales was finished separately. All the response sheets were scored according to the particular manuals. Results were then analyzed using mean, standard deviation and t test.

### **Statistical Analysis**

The data was analyzed using mean and Standard deviation. Further, hypothesis was tested using the t test.

## **RESULTS**

**Table 1: Mean, Standard Deviation and t scores of the two groups on Perceived Stress.**

|  | N  | Mean  | Standard Deviation | t-ratio | P value |
|--|----|-------|--------------------|---------|---------|
| Parents of children with Autism        | 50 | 49.8  | 9.55               | 5.44    | 0.05*   |
| Parents of children without disability | 50 | 36.68 | 4.53               |         |         |
| Significant at 0.05*                   |    |       |                    |         |         |

**Table 2: Mean, Standard Deviation and t scores of the two groups on Quality of Life.**

| S.NO                 | Quality Of Life Domains | Group 1 |      | Group 2 |      | t- ratio |
|----------------------|-------------------------|---------|------|---------|------|----------|
|                      |                         | Mean    | SD   | Mean    | SD   |          |
| 1.                   | Physical Health         | 24.18   | 4.30 | 28.32   | 3.18 | 3.52     |
| 2.                   | Psychological Wellbeing | 20.08   | 3.63 | 23.44   | 2.61 | 7.08     |
| 3.                   | Social Relationship     | 10.84   | 1.34 | 12.52   | 1.32 | 9.20     |
| 4.                   | Environmental           | 26.58   | 4.53 | 32.04   | 3.97 | 5.31     |
| Significant at 0.05* |                         |         |      |         |      |          |

## **DISCUSSION**

The present study shows that caregivers of children with Autism feel more burden as compared to those without disability. The unforeseen and lasting nature of the introduction of a kid with incapacities puts guardians in danger for uplifted pressure (Kumar, 2008). Impressive proof proposes that guardians of kids determined to have Developmental Disabilities experience more prominent stress which is higher than the standard when contrasted with guardians of kids without DD (Lopez, Clifford, Minnes and Ouellette-Kuntz, 2008; Heath, 2011; Lundy, 2011; Gupta, Mehrotra and Mehrotra, 2012); with moms of kids having DD encountering more noteworthy worry when contrasted with their male partners (Shyam, Kavita and Govil, 2014; Sunayan, 2015). On the off chance that the circumstance is seen by having a skeptical disposition, exacerbated by many negative youngster factors and poor social help, at that point more significant level of pressure is experienced (Wang, Michaels and Day, 2010).

The results show that the caregivers of children without any disability have better Quality of Life in the physical domain as compared to those caregivers of children with Autism. The caregivers of youngsters with ASD encounter disappointment with their ability to work or in their exhibition of day by day living exercises. The duty of dealing with a ward may likewise be negatively affecting the guardians, with the end goal that they might be encountering some physical distress too. Independent of the kind of inability concentrates on guardians of youngsters with uncommon necessities show nearness of critical distinction from the guardians of ordinary kids on the QoL (Ravindranadan and Raju, 2008).

On Psychological wellbeing domain there is a significant difference in both the groups. The caregivers of children without disability have better Quality of life on psychological domain as compared to those caregivers of children with Autism. The caregivers of children with autism have lower psychological health as they described negative feelings about the future, negative body image, low concentration. It is further supported using the research. Caregivers of kids with incapacities face various difficulties concerning quality of life, their enthusiastic states, and their recognition about the agreeableness of life. Along these lines, guardians of kids with incapacities who see these difficulties in a negative way show more unfortunate mental prosperity when contrasted with those looked by caregivers of youngsters with no disability (Sunayan, 2015; Khan and Humtsoe, 2016). Caregivers of youngsters with ASD appear to have genuine worries about their kids' prosperity, particularly about their learning and being tormented by other kids coming about in reduced personal satisfaction (Lee, Harrington, Louie and Newschaffer, 2008; Hartley, et al., 2010); they likewise experience more unfortunate mental prosperity when contrasted with guardians of youngsters with different sorts of handicaps (Malhotra, Khan and Bhatia, 2012).

On Social relationship domain also, there was a significant difference between the two groups. The caregivers of children without disability have better social relationships than those with Autistic children. Caregivers of autistic children have lower scores on social relationship as they could not get along well with their personal relationship and may not get proper support needed. It is further described through the research. Caregivers of kids with Autism have been found to utilize social redirection in a very restricted way. The purpose behind guardians of youngsters with mental imbalance to utilize less of social redirection manage stressors could be that bringing up a youngster with ASD is oppressive which fundamentally limits guardians' social exercises. Moms of youngsters with Autism

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accordingly, show debilitations in social connections (Mungo, et al., 2007). In situations where there is nonattendance of a steady system, it expands the need 'to give assurance' to the youngster determined to have Autism. Then again, if there is bolstering accessible, at that point a parent gets the open door for guilty pleasure through social connections like family, companions and network which serves to decrease parental pressure and improve QoL (Armstrong, Birnie-Lefcovitch and Ungar, 2005).

On environmental domain, the caregivers of children without disabilities show better subjective wellbeing than those with Autism. The troubles looked in doing exercises of everyday living of youngsters with unique needs brings about requiring long haul care, which far surpasses the typical needs of creating kids, or the guardians' desires. Subsequently, while dealing with youngsters is a typical part of child rearing, giving the requesting level of care requested by a youngster determined to have long haul utilitarian constraints can be a distressing encounter, contrarily influencing abstract prosperity of guardians.

Caregivers of youngsters with MR and ASD appear to show a higher weight on environmental area in light of the fact that the kids with inabilities require particular consideration which puts money related, social, and word related trouble (Malhotra, et al., 2012). Groups of youngsters with Autism revealed a lot of weight in youngster care which influences their investment in social exercises and occasions, less association in network administrations (Lee, et al., 2008). Most guardians additionally report of either stopping their occupations or changing employments to guarantee better kid care for their youngsters with incapacities demonstrating money related weight.

### **CONCLUSION**

The aim of the present study was to study the Quality of Life and burden among caregivers of children with Autism and children without any disability. For the same 100 parents were purposively selected and the two tools Parental Stress Scale and WHOQOL-BREF were administered. The results show that there is a significant difference between caregivers of children with Autism and caregivers of children without any disability. The parents of children with autism experience higher level of burden as compared to caregivers of children without any disability. The quality of life of caregivers with autistic children is lower than that of caregivers of children without any disability on all the four domains i.e. physical, psychological, social and environmental.

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### ***Conflict of Interest***

The author(s) declared no conflict of interest.

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