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PARENTAL BURDEN IN CAREGIVING OF SPECIALLY ABLED CHILDREN: A CROSS-SECTIONAL STUDY

Occupational Therapy

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KEYWORDS

INTRODUCTION

A care giver is defined as the person who fulfils the need of physical and psychological wellbeing of a diseased or disordered individual. Developmental disabilities are long term physiological impairments which significantly affect a child's ability to perform activities of daily living, such as independent feeding, communicating and mobilizing. Studies provide substantial evidence that parents of school-age and older children with developmental disabilities experience elevated levels of stress and depressive symptoms, above that of parents of typically developing children. Higher rates of general ill health, sleep problems, headaches and musculoskeletal pain have also been found. [1,2]

The role of the family of the disabled child is vital. The family is thought to be the optimum environment for the development of disabled individuals. The addition of a disabled member usually results in substantial adjustments in the roles, norms, goals and communication patterns of the family. The level of acceptance of the disabled may vary from one family to the next.[3,4]

A child's growth and development depends heavily on the different aspects of his/her environment. Parents have an irreplaceable influence on their child's growing years. The Quality of Life and Stress experienced by parents in turn affects the psychological adjustment of the child. Also, rehabilitation programs usually focus only on the management of the child's difficulty. There is little or no emphasis on the parent, who constitutes an important part of the child's environment. Identifying and managing parental distress and other difficulties faced by them may help increase acceptance of the child's difficulty.[5,6]

The current study thus aimed to find out the caregiver burden on parents of children with developmental disabilities.

METHODOLOGY

The current study was conducted on parents of children with developmental disabilities (including Autism, ADHD, Down's syndrome, CP, Hemiplegia and learning disabilities, Seizure disorder). The study was conducted on parents whose children received therapy from a Non-profit organization (Vatsalya trust) based in Mumbai. A convenient sampling method was chosen for the study. All the parents were explained about the study and an informed consent was taken from all the parents who agreed to participate in the study. All the parents were asked to fill a caregiver burden inventory.

Caregiver Burden Scale

The Caregiver Burden Scale is a simple instrument composed of 22 questions grouped into five dimensions (general tension, isolation, disappointment, emotional involvement and environment), covering important areas for caregivers, such as health, mental wellbeing, personal relationships, physical overload, social support, finances and home environment. An overall score can be obtained or individual scores can be obtained for each dimension, thereby facilitating the understanding of what specific dimensions most affect the caregiver. The questionnaire can either be administered by an interviewer or self-administered and takes about 10 min to complete. [7]

All data was entered into Microsoft Office Excel (v 2010 Microsoft Redmond Campus, Redmond, Washington, United States) in a spreadsheet which was prepared and validated for the study data to avoid errors. Data was entered and checked for errors and discrepancies. Data was subjected to statistical analysis using Statistical SD Package for Social Sciences. (SPSS v 20 IBM)

RESULTS

Table 1: Age Distribution Of The Participants

Group	N	Mean ± SD	CI
ASD	35	9.37 ±3.45	8.23, 10.5
LD	13	9.62 ±2.73	8.14, 11.1
ADHD	12	9.25 ±3.31	7.38, 11.1
Other DD	19	7.58 ±3.32	6.09, 9.07

ASD=Autism Spectrum disorder, LD= Learning Disabilities, ADHD= Attention deficit hyperactive disorder, DD=Developmental disabilities.

Table 2: Caregiver burden scale

Group	ASD	ADHD	LD	Other DD	*P<0.007**
N	35	13	12	19	
Mean	48.29	40.25	33.69	44.79	
SD	13.76	12.41	13.11	11.95	
CI	43.7, 52.9	[33.5, 47]	[26.3, 41.1]	[39.4, 50.2]	

ASD=Autism Spectrum disorder, LD= Learning Disabilities, ADHD= Attention deficit hyperactive disorder, DD=Developmental disabilities.

The above results indicate that parents of children with ASD experience the maximum caregiver burden as compared to parents of children with other conditions.

Also when the Tukey's HSD (honestly significant difference) procedure was carried to facilitate pair wise comparison, the results indicated a significant difference [Q=4.55 *(P=0.01)]* in caregiver burden in parents of children with ASD as compared to caregivers of children with LD.

DISCUSSION

The current study aimed to find out the caregiver burden on parents of children with developmental disabilities. When the results were analyzed, it was found that the parents of children with ASD experienced the maximum caregiver burden as compared to parents of children with other developmental disabilities.

Parents of children with developmental disabilities face challenges placing them at risk for high levels of stress and other negative psychological outcomes. Parenting a child with autism may pose additional stressors related to the child's challenges in communicating, difficult behaviors, social isolation, difficulties in self-care, and lack of community understanding. Several studies reported increased psychological distress, including depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic complaints and burnout, among parents of children with autism and related autism spectrum disorders (ASDs) in comparison to parents of typically developing children or parents of non autistic children with mental retardation or other developmental disabilities.[8-11]

The analysis also reflect, after the parents of children with ASD, the maximum caregiver burden is experienced by parents of children with other developmental disabilities. According to Reichman *et al.*

(2008:680), one impact of having a child with a disability in the family concerns the financial effects on the family. Families may experience difficulties in finding appropriate and affordable child care, the out-of-pocket costs of medical care and other services may be substantial, and they might have to rely on public support. As indicated before, caring for a child with a disability is often a life-long commitment, obviously having huge financial implications. having a disabled child and having to provide lifelong care may increase stress and take a toll on the mental and physical health of parents. The demands of caring for a person with a disability often result in stress for families, particularly for women, who tend to be responsible for domestic chores, which would then have to be balanced with caretaking.[12]

Also, when a Tukey's HSD test was conducted to analyze the intergroup comparison, the results were significant for parents of children with ASD and parents of children with Learning disabilities. Parents whose children have Specific Learning Disability perceive their child's disability as stressful and thus experience parenting stress and lowered quality of life. [13]

CONCLUSION

The study thus concludes that the highest parental burden was observed in caregivers of children with ASD, but all caregivers of children with developmental disabilities experience caregiver burden. It is thus necessary to address this aspect as well, as caregiver burden may act as a predisposing factor in progress of the child.

Suggestions

The Quality of Life and Stress experienced by parents in turn affects the psychological adjustment of the child. Also, rehabilitation programs usually focus only on the management of the child's difficulty. There is little or no emphasis on the parent, who constitutes an important part of the child's environment. Identifying and managing parental distress and other difficulties faced by them may help increase acceptance of the child's difficulty.

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