

Parental stress in raising children with special needs (CWSN)

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Received: 19.10.2019; Revised: 04.03.2020; Accepted: 18.04.2020

■ **ABSTRACT :** Parenting stress is an experience of every parent in the parenting process. It is experienced by almost all parents in raising their children, but it is more increased in parents having children with special needs (CWSN). The birth of a child with special needs often bring changes in the life of the parents for which they might not be prepared and will have bigger challenges to overcome in future. So, the present study entitled “Parental stress in raising children with special needs (CWSN)” was conducted in Jorhat district of Assam so as to assess the level of stress in parents raising children with special needs. A sample of 80 parents was selected purposively from special schools of Jorhat. Findings of the present study revealed that majority of the parents had an average level of stress in raising their children with special needs.

■ **KEY WORDS:** Parental stress, Children with special needs, Level of stress

■ **HOW TO CITE THIS PAPER :** Borah, Sushmita and Gogoi, Sampreety (2020). Parental stress in raising children with special needs (CWSN). *Asian J. Home Sci.*, **15** (1) : 12-16, DOI: 10.15740/HAS/AJHS/15.1/12-16. Copyright@ 2020: Hind Agri-Horticultural Society.

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Life is a beautiful gift from God to every human being, which is often full of smiles, tears, love, hatred, care, protection, peace and distress. In this journey of life, stress is also common among all individuals. Stress is an unpleasant feeling arising out of different responsibilities, obligations and pressures of one's own life. It is often caused by a wide variety of stimuli in the environment known as stressors. The stressors may be external or internal. The major life changes, unpredictable events that occurs in the life of an individual which are beyond one's control are the external stressors and the internal stressors includes the thoughts, attitudes, beliefs and expectations that arises within an individual, and it often causes stress. Lazarus and Folkman (1984) proposed that stress occurs when

people perceive that the demands from the external situations are beyond their coping capacity. The amount of stress experienced by an individual is determined by the perceived demands and resources of the individual. Stress experienced by an individual can be acute, episodic or chronic. Acute stress is caused by the daily demands of life situations and if it occurs frequently it may lead to episodic stress which ceases from time to time. Chronic stress is caused by unending long term exposure to stressors throughout the life which may lead to severe health problems. Some amounts of stress may be beneficial and even healthy but excessive amounts of stress may lead to some adverse effects on the individual. Parenting is a process of promoting and supporting the physical, emotional, social and intellectual development

of a child from infancy to adulthood. It refers to the process of raising a child by providing a safe, secure and nurturing environment and stress often arises in the parenting process when demands of the family exceed the expected and available resources. Children with special needs refer to those children who have impairment or a disability and challenges which are more severe than the normally developing children and could possibly last a lifetime. These children need extra support and additional services. They will need added guidance and help in meeting their academic, physical, social and emotional milestones.

Raising a CWSN can be an emotional experience and will undoubtedly have more challenges to overcome in the future than ever thought. Living with children with special needs can have profound effects on the entire family - the parents, siblings, and extended family members. "Parenting any child at times can be a stressful experience" (Cameron *et al.*, 1991). The arriving of a child with special needs into a family often brings changes in the life of the parents for which they might not be prepared and which may require life-long adjustment. Parental stress is more increased while raising children with special needs, as they require more parental support and attention as compared to normally developing children. Keeping this in mind an attempt was made to assess the level of stress in parents raising a child with special need.

■ RESEARCH METHODS

The study was conducted in special schools of Jorhat, with due permission from the concerned authority. A sample of 80 parents were selected purposively for the study. The data was collected through face to face interview of the respondents by using appropriate tools developed for the purpose of the study. After the collection of the data, raw data were categorized, coded and tabulated for statistical computation. Descriptive statistical methods such as frequency and percentage, mean and standard deviation was used to analyze the data. Mean and standard deviation were used to categorize the level of parental stress as low, average and high. The scores above Mean + Standard deviation were grouped as having high parental stress and the scores below Mean – Standard deviation were grouped as having low parental stress and the scores in between high and low were grouped

as average stress.

Tools used for the study:

A standardized tool namely Parental Stress Scale (PSS) developed by Berry and Jones (1995) was used to assess the level of parental stress. In addition to that an interview schedule was prepared for collecting the general information of the respondents.

– The background information of the respondents was collected using an interview schedule developed by the researcher. The schedule elicited information about the age, type of family, marital status, educational qualification, occupation, income of parents. It also elicited information about the child such as the age, gender, ordinal position, type and level of disability, diagnosis of the child's disability and presence of any chronic disease in the child, and other required information such as pregnancy and birth complications, type and place of birth etc.

– Parental Stress Scale is a structured scale is used to assess the level of stress in parents of children with special needs. It contains 18 items representing pleasure or positive themes of parenthood such as emotional benefits, self-enrichment, personal development and negative components such as demands on resources, opportunity costs and restrictions. Respondents are asked to agree or disagree with items in terms of their typical relationship with their child and to rate each item on a five-point scale: strongly disagree, disagree, undecided, agree, and strongly agree. The 8 positive items are reverse scored so that possible scores on the scale can range between 18-90. Higher scores on the scale indicate greater stress. This scale is intended to be used for the assessment of parental stress having children with and without clinical problems.

■ RESEARCH FINDINGS AND DISCUSSION

The results regarding the background information of the respondents and the level of stress in parents are tabulated and discussed in Table 1.

Results in Table 1 revealed that 95 per cent of the respondents were mothers and they were the primary caregiver of their children. In terms of age, 55 per cent of respondents were in the age group of 31- 40 years as it is the child rearing stage as a parent. It was found that 75 per cent respondents belonged to nuclear families as they were residing in the urban areas. Findings showed

Table 1 : Demographic information of the respondents		
Characteristics	Frequency	Percentage
Primary caregiver		
Mother	76	95.0
Father	0	0
Guardian	4	5.0
Age		
21-30 years	13	16.3
31-40 years	44	55.0
41-50 years	20	25.0
51-60 years	3	3.75
Type of family		
Nuclear	60	75.0
Joint	15	18.8
Extended	5	6.3
Marital status		
Couples	68	85.0
Widow	11	13.8
Divorcee	1	1.3
Father's Qualification		
Illiterate	4	5.0
Below HSLC	19	23.8
HSLC	13	16.3
HSSLC	28	35.0
Graduate	12	15.0
Mother's qualification		
Illiterate	2	2.5
Below HSLC	18	22.5
HSLC	20	25.0
HSSLC	26	32.5
Graduate	10	12.5
Guardian's qualification		
HSLC	1	1.3
HSSLC	2	2.5
Graduate	1	1.3
Father's occupation		
Service	30	37.5
Business	22	27.5
Other	24	30.0
Mother's occupation		
Service	7	8.8
Business	3	3.8
Other	66	82.5
Guardian's occupation		
Service	0	0
Business	1	1.3
Other	3	3.8
Income		
Low (Below Rs. 10,000)	21	26.3
Middle (Rs. 10,000 – Rs. 30,000)	40	50.0
High (Above Rs. 30,000)	19	23.8

that 85 per cent respondents were couples, 13.8 per cent of them were widow and only 1.3 per cent were divorcee. With respect to educational qualification it was found that majority of the fathers (35%) and mothers (32.5%) passed their higher secondary and had the minimum level of education. In terms of occupation majority of fathers were found to be service holders and mothers were mostly housewives. It was found that 50 per cent of the respondents have a monthly income of Rs. 10,000-30,000 and they belonged to middle income group.

The results in Table 2 indicated that 53.7 per cent children with special need belonged to the age group of 11-20 years as these children require special help and support services even during the later years of life. Results showed that 67.5 per cent of the children with special needs were male children. Majority (61.3%) of them were the first born child, it may be due to the ignorance of the mother, irregular health checkups, lack of proper care during pregnancy, low socio-economic status or it may be due to various taboos associated with pregnancy that are prevalent among different communities. As depicted in Table 2, 51.2 per cent of the children had intellectual disability. The prevalence of intellectual disability may be on rise due to low level of awareness, difficulty in identification, poor health care and referral services. It was evident from the results in Table 2 that 66.2 per cent of the children with special needs were in moderate level. It may be attributed to the fact that a child born with mild disability is often left untreated due to low level of awareness and gradually over time the childhood disability may shift to moderate level and then into severe forms. Majority (72.5%) of them reported the presence of their child's disability at birth. According to the results most of the children *i.e.* 75 per cent were diagnosed at the age of 0 to 5 years. It may be because the level of awareness regarding disability is increasing among people. About 31.3 per cent children were found to have chronic disease in them and out of all chronic diseases, epilepsy was found in 11.3 per cent children.

Results in Table 3 revealed that 60 per cent of the parents had an average level of stress in raising their children with special needs and 21.3 per cent had low level of stress. It was found that 18.8 per cent of the parents were highly stressed, in raising their children.

Results indicated that 60 per cent of the parents

Table 2 : Demographic information on child characteristics		
Characteristics	Frequency	Percentage
Child age		
1-10 years	32	40.0
11-20 years	43	53.7
21-30 years	5	6.2
Gender		
Male	54	67.5
Female	26	32.5
Ordinal position		
1 st	49	61.3
2 nd	26	32.5
3 rd	4	5.0
4 th	1	1.3
Type of disability		
Low vision	1	1.3
Hearing impairment	11	13.8
Autism	6	7.5
Cerebral palsy	15	18.8
Multiple disability	6	7.5
Intellectual disability	41	51.2
Level of disability		
Mild	12	15.0
Moderate	51	62.5
Severe	17	22.5
Presence of disability		
Before birth	0	0
At birth	58	72.5
After birth	22	27.5
Diagnosed age		
0-5 years	60	75.0
6-12 years	19	23.7
13-18 years	1	1.3
Chronic disease in the child		
Yes	25	31.3
No	55	68.8
Chronic disease such as		
Frequent cough and cold	7	8.7
Epilepsy	9	11.3
Other	9	11.3

experience an average level of stress in raising their children with special needs. This may be due to the fact that most of the children were in moderate level of disability and they attended the special schools. Special education curriculum in special school aims to empower children with special needs through early intervention, education, proper rehabilitation, therapy, vocational training and leisure skills. It is through this curriculum, the children get the support, services, accommodations, modifications and remediation necessary for them for

their overall development. The special education curriculum helps the children learn various skills such as the self-help skills, motor skills, basic educational skills, vocational skills and leisure skills which aims to make the child independent of others. It provides a learning environment for the children with special needs so as to facilitate their education, help them develop their full potential, enhance their independence and enable them to become well-adjusted individuals in the community. This motivates the parents to enroll their children in special schools. Many parents thus reported an average level of stress as their children could perform better after being enrolled in special schools.

This high level of stress *i.e.* 18.8 per cent may arise due to various factors such as the severity of the child's disability, dependency of the child on the parents, behavioral problems, difficulty in education, thoughts about the future and also due to feelings of isolation and neglect. While conducting the study it was found that most of the parents had children with intellectual disability. Parents having children with severe intellectual disability was found to be more stressed as the children were very dependent on their parents for their daily needs, had difficulty in educational task, and likely to exhibit behavioral problems which becomes unmanageable for the parents and increases the level of parental stress. Whereas for parents, raising a child with cerebral palsy is a challenge. A child with cerebral palsy have muscular and movement problems, including poor muscle tone, stiff muscles, poor co-ordination and balance, limited range of movements. They are late in achieving the developmental milestones such as walking, crawling, speaking, problems in controlling bladder and bowel movements, problem of feeding, swallowing, sucking and drooling. For younger children, the child needs to be carried by their mother or caretaker, for their movement but as they grow older it becomes difficult for the parents. They need to be fed by parents and the mother or the caretaker should always be near to the child to fulfil his needs. Besides this, providing assistive aids to the child, providing therapies, inaccessible health

Table 3 : Level of stress in parents (n=80)		
Level of stress	No. of parents	
	Frequency	Percentage
High	15	18.8
Average	48	60.0
Low	17	21.3

and rehabilitation services, often adds up to high level of stress in parent.

Only 21.3 per cent of the parents had low level of stress. While analyzing the data it was found that most of the parents having a child with mild form of disability and those having a hearing impaired child experienced low stress as compared to other disabilities because these children could perform their activities as that of a normal child.

Conclusion:

Children with special needs are those, who differ from the normally developing children and they require either modification, special provisions in terms of school practices or special educational services to develop their unique capabilities. Since they differ from other children, they are perceived in a different manner. At times parents feel overwhelmed with the child which increases their stress in raising their children. Thus, it could be concluded that stress was prevalent among all parents in raising their children with special needs. But stress was found to be high among parents having children with moderate

and severe intellectual disability, cerebral palsy, autism and multiple disabilities. It was found to be low among parents having children with mild form of disability, hearing impairment and low vision.

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