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## Research Article

# A Descriptive Study to Assess Parental Experiences and Challenges in Care for Specially Abled Children Among Parents of Specially Abled Children

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### Abstract:

**Introduction:** Parents of specially-abled children are greatly involved in the care and rehabilitation of their children. For planning of support services, understanding their care-giving experience and some of the challenges they may encounter is critical. **Aim:** To evaluate the perception about parent's experience and difficulties with special children. **Methods:** Quantitative descriptive exploratory research design was opted. The research was done with fifty parents of special children who are studying in Don Guanella Special School. Convenient sampling method was used in the identification of the participants. A structured demographic questionnaire, parental experience scale and a parental challenges scale were used to gather data. Descriptive statistics (frequency and percentage) and Chi-square test were used for data analysis. **Results:** The respondents included high level parental experience (n = 43, 86.0%) and moderate parental experience (n = 7, 14.0%). Regarding challenges, 20 (40.0%) had a moderate level, 19 (38.0%) had a low level, and 11 (22.0%) had a high level of challenges. **Conclusion:** Despite moderate caregiving challenges, most parents reported high levels of caregiving experience. Enhancing parent education, counselling and family support services may be a mitigation measure to reduce caregiver difficulties and, consequently, enhance the quality of caregiving for specially abled children.

**Key words:** specially abled children, parents, experience of caring, parental difficulties, disability, family support.

## INTRODUCTION

Raising a child with special needs is a unique and challenging journey, one that requires constant help from parents in the areas of physical, emotional, educational and social support. Children with special abilities include those with physical, intellectual, developmental, sensory and communication impairments who often require support long into adulthood. Parents may feel emotional following the diagnosis, and must adapt to increased responsibilities in caring for their pet, medical consultations, rehabilitation and education, etc.

This long-term maternal role can lead to psychological strain, social isolation and financial pressure due to treatment, therapy and special education costs. Despite these challenges, many parents develop a sense of perseverance and a sense of power from their child's success. Family, health care practitioners, teachers and community support is essential in easing caregiver burden.

It's estimated by the World Health Organization and UNICEF that nearly 240 million children worldwide have disabilities. In India, the current estimates indicate that 2.5–3% of children are disabled and more than 5 million children (2.21%) are disabled in the country.

Parents of children with disabilities face significant emotional, physical, social and financial challenges, and many parents report experiencing a strong sense of worry and sadness and increased caregiving stress. It is important to acknowledge these experiences and gaps in needs to design relevant support services, improve family-centred support and strengthen the well-being of children and families.

### AIM:

To evaluate the perception about parent's experience and difficulties with special children.

## METHODOLOGY

The quantitative research methodology using a descriptive exploratory design was used to assess the experiences and problems of parents of children with disabilities. The study was conducted at Don Guanella Special School, Chennai. The target population consisted of parents of children with disabilities aged 21–50 years, and the accessible population included parents of children with disabilities attending the selected special school. A purposive non-probability sampling technique was used to select 50 parents. The participants were parents of children aged 6–12 years diagnosed with autism, cerebral palsy, or intellectual disability who consented to participate in the study.

Data was collected using a self-structured questionnaire consisting of three parts: demographic data, a rating scale to measure parental experiences, and a checklist to measure physical, emotional, social, and economic challenges. Formal permission was obtained from the school authorities before data collection. Informed consent was obtained from all participants. Participant information was kept confidential and anonymous, and participants were informed that they could withdraw from the study at any time.

Data were analyzed using descriptive and inferential statistics. Descriptive statistics were used to describe the parental experiences and problems. Karl Pearson's correlation coefficient was used to determine the relationship between parental experiences and challenges, and the Chi-square test was used to analyze the association between selected demographic characteristics and the study variables.

## RESULT

Table 1 shows that among the 50 parents of specially abled children, most were aged 36–45 years (28, 56.0%), female (26, 52.0%), had secondary education (18, 36.0%), were homemakers (22, 44.0%), belonged to nuclear families (29, 58.0%), and had a monthly family income below ₹20,000 (40, 80.0%). Among the children, the majority were aged 11–12 years (31, 62.0%) and were male (31, 62.0%). Most common disabilities were: Intellectual disability (16, 28.0%), Physical disability (14, 28.0%) and developmental disability (14, 28.0%). Most of the children (18, 36.0%) had the condition for more than 3 years, were undergoing physiotherapy (17, 34.0%) were attending the special school (49, 98.0%).

Results from table 2 indicate that majority of the parents had high level of experience (43, 86.0%) and none had low level of experience while only 7 (14.0%) had moderate level. In terms of parental challenges, 20 (40.0%) reported moderate level, 19 (38.0%) low level and 11 (22.0%) high level.

The monthly income of family was found to be significantly associated with experiences in taking care of specially abled children ( $\chi^2 = 12.832$ ,  $p = 0.005$ ) as presented in table 3. There is a statistically significant relationship between educational qualification with parental challenge ( $\chi^2 = 16.324$ ,  $p = 0.038$ ). No significant associations were seen between any of the demographic parameters and parental experience and challenges.

## DISCUSSION

In the current study, 86.0% of the parents had high level of experience in raising especially abled children which means that the longer the children had been under the care of parents led to their greater confidence and practical skills in managing the needs of their child. Despite this gain in experience, however, 40.0% of parents still experienced moderate challenges, and 22.0% faced high challenges, suggesting that parenting is still a challenging, emotional, financial and social experience even with more experience.

Furthermore, it was found that the monthly income of a family was significantly related with the experience of parents ( $\chi^2 = 12.832$ ,  $p = 0.005$ ) as well. Parents who have greater economic resources may have access to better health care service, rehabilitation and systems of supports that could result in more experience with caregiving. Furthermore, there was a statistically significant association between education level and parental challenges ( $\chi^2 = 16.324$ ,  $p = 0.038$ ), meaning that the level of education might have an impact on the parental understanding of the child's condition, how

## CONCLUSION

The study results are that although the majority of parents were very experienced in caring for their children, many still had moderate difficulties as caregivers. Parental experience was significantly related with monthly family income and parental challenges with educational qualification. The results point out that continuous parent education and counseling and parent support services are needed to minimize the challenge of parenting and enhance the parents' parenting capacity. Based on the study findings, an informative pamphlet was developed and distributed to the parents of specially abled children to improve their knowledge and support effective caregiving practices.

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**Table 1: Distribution of Demographic Variables of the Parents of Specially Abled Children (N = 50)**

Demographic Variables	Category	Frequency (F)	Percentage (%)
<b>Age of the parent (years)</b>	21–25	3	6.0
	26–35	4	8.0
	36–45	28	56.0
	46–50	15	30.0
<b>Gender of the parent</b>	Male	24	48.0
	Female	26	52.0
<b>Educational qualification</b>	No formal education	5	10.0
	Primary education	16	32.0
	Secondary education	18	36.0
	Higher secondary	6	12.0
	Graduate and above	5	10.0
<b>Occupation of the parent</b>	Homemaker	22	44.0
	Daily wage worker	5	10.0
	Private employee	5	10.0
	Government employee	0	0.0
	Self-employed	18	36.0
<b>Monthly family income</b>	Below ₹10,000	20	40.0
	₹10,001–₹20,000	20	40.0
	₹20,001–₹30,000	8	16.0
	Above ₹30,000	2	4.0
<b>Type of family</b>	Nuclear	29	58.0
	Joint	11	22.0
	Extended	10	20.0
<b>Age of the child (years)</b>	6–7	3	6.0
	8–9	1	2.0
	10–11	15	30.0
	11–12	31	62.0
<b>Gender of the child</b>	Male	31	62.0
	Female	19	38.0
<b>Type of disability</b>	Physical	14	28.0
	Intellectual	16	32.0
	Developmental (Autism/ADHD)	14	28.0
	Others	6	12.0
<b>Duration of illness/condition</b>	Less than 6 months	3	6.0
	6 months–1 year	12	24.0
	1–3 years	17	34.0
	More than 3 years	18	36.0
<b>Type of therapy received</b>	Physiotherapy	17	34.0
	Occupational therapy	8	16.0
	Speech therapy	13	26.0
	Behavioural therapy	12	24.0
<b>Schooling status</b>	Attending special school	49	98.0
	Attending regular school	1	2.0
	Not attending school	0	0.0

**Table 2. Frequency and Percentage Distribution of Parental Experience and Challenges in Caring for Specially Abled Children (N = 50)**

Variable	Level	Score	Frequency (F)	Percentage (%)
<b>Parental Experience</b>	Low	10–20	0	0.0
	Moderate	21–30	7	14.0
	High	31–40	43	86.0
<b>Parental Challenges</b>	Low	0–3	19	38.0
	Moderate	4–6	20	40.0
	High	7–10	11	22.0

**Table 3. Association of Experience and Challenges in Caring for Specially Abled Children Among Parents with Selected Demographic Variables (N = 50)**

Demographic Variable	Experience $\chi^2$ (p-value)	Inference	Challenges $\chi^2$ (p-value)	Inference
Age of the parent	3.389 (0.335)	NS	10.290 (0.113)	NS
Gender of the parent	1.231 (0.267)	NS	0.264 (0.876)	NS
Educational qualification	4.561 (0.335)	NS	16.324 (0.038)	S*
Occupation of the parent	1.072 (0.784)	NS	5.759 (0.451)	NS
Monthly family income	12.832 (0.005)	S*	9.195 (0.163)	NS
Type of family	3.238 (0.198)	NS	3.549 (0.470)	NS
Age of the child	4.274 (0.233)	NS	7.104 (0.311)	NS
Gender of the child	1.943 (0.163)	NS	1.264 (0.532)	NS
Type of disability	0.883 (0.830)	NS	9.570 (0.144)	NS
Duration of illness/condition	7.087 (0.069)	NS	2.326 (0.887)	NS
Type of therapy received	3.046 (0.385)	NS	6.131 (0.409)	NS
Schooling status	0.166 (0.684)	NS	3.618 (0.164)	NS

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