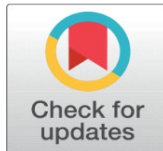


ASSESSMENT OF FAMILY BURDEN, SOCIAL SUPPORT AND QUALITY OF LIFE AMONG PARENTS OF CHILDREN WITH MULTIPLE DISABILITIES

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Received 10 June 2025
Accepted 16 July 2025
Published 11 September 2025

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DOI
[10.29121/granthaalayah.v13.i8.2025.6254](https://doi.org/10.29121/granthaalayah.v13.i8.2025.6254)

Funding: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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ABSTRACT

The increasing prevalence of childhood disabilities across various socio-cultural settings due to various reasons necessitates a deeper understanding of the psychosocial implications for families. The family, especially the parents, often becomes the primary source of care and advocacy for a child with disabilities. This caregiving role brings about significant physical, emotional, financial, and social challenges. The findings discussed in this article are drawn from data collected in the community, with a focus on socio-demographic condition of parents of children with disabilities and from social work perspective. The study findings are from pilot study.

Keywords: Social, Family, Parents, Children, Disabilities

1. INTRODUCTION

The increasing prevalence of childhood disabilities across various socio-cultural settings due to various reasons necessitates a deeper understanding of the psychosocial implications for families. The family, especially the parents, often becomes the primary source of care and advocacy for a child with disabilities. This caregiving role brings about significant physical, emotional, financial, and social challenges. The findings discussed in this article are drawn from data collected in the community, with a focus on socio-demographic condition of parents of children

with disabilities and from social work perspective. The study findings are from pilot study.

2. OBJECTIVES OF THE STUDY

To assess socio-demographic condition of parents of children with disabilities. To assess family burden, social support and quality of life among parents of children with disabilities.

3. RESEARCH METHODOLOGY

This study employed a quantitative research approach with a descriptive research design. A semi-structured interview schedule used to assess socio-demographic condition of respondents. In addition, scandalized scales applied in the current study such are Family Burden Interview Schedule (FBIS) by Pai and Kapur in 1981. The multidimensional scale of Perceived social support (MSPSS) and the WHOQOL-BREF is 26 item questionnaires used. The study adopted a purposive sampling design to select respondents from in Dharwad district. The sample size was 64, consisted of 64 respondents, divided equally into 32 males and 32 females, representing both parents of children with disabilities. Statistical analysis was done using the Statistical Package for Social Sciences (SPSS). The informed consent was obtained from the respondents to participate in this study.

4. FINDINGS

Table 1

Table 1 Gender of Parents

Gender of Parents		Frequency	Percentage	Valid Percentage	Cumulative Percentage
Valid	Male	32	50.0	50.0	50.0
	Female	32	50.0	50.0	100.0
Total		64	100.0	100.0	

Gender Distribution of Participants: The above table represents an equal distribution of male and female participants, with 32 males (50%) and 32 females (50%), making up a total of 64 respondents.

Table 2

Table 2 Age of Parents

Respondents Age		Frequency	Percentage	Valid Percentage	Cumulative Percentage
Male	Valid	20-30	1	3.1	3.1
		31-40	19	59.4	62.5
		41-50	9	28.1	90.6
		51-60	2	6.3	96.9
		61-70	1	3.1	100.0
		Total	32	100.0	
Female	Valid	20-30	15	46.9	46.9
		31-40	14	43.8	90.6
		41-50	2	6.3	96.9
		51-60	1	3.1	100.0
		Total	32	100	
				100	

The above table depicts the age and gender distribution of a sample consisting of 64 parents, equally divided between males and females (32 each). Among male participants, the majority fall within the 31–40 age group, making up 59.4% of the male sample. This is followed by 28.1% in the 41–50 age group, while smaller proportions are observed in the 20–30 (3.1%), 51–60 (6.3%), and 61–70 (3.1%) age brackets. This indicates that male participants are primarily middle-aged, with fewer younger or older individuals represented. The age range spans from 20 to 70 years. In contrast, the female participants show a noticeably younger age profile. The largest portion, 46.9%, are in the 20–30 age group, closely followed by 43.8% in the 31–40 age group. Only a small fraction of females falls into the older age categories: 6.3% are aged 41–50, and 3.1% are aged 51–60. Notably, no female participants are recorded in the 61–70 age group.

Table 3**Table 3 Age of Children with Disabilities**

Age of Children with disabilities			Frequency	Percentage	Valid Percentage	Cumulative Percentage
Male	Valid	6.00	3	9.4	9.4	9.4
		7.00	1	3.1	3.1	12.5
		8.00	1	3.1	3.1	15.6
		9.00	8	25.0	25.0	40.6
		10.00	4	12.5	12.5	53.1
		11.00	1	3.1	3.1	56.3
		12.00	2	6.3	6.3	62.5
		13.00	6	18.8	18.8	81.3
		14.00	3	9.4	9.4	90.6
		15.00	2	6.3	6.3	96.9
		16.00	1	3.1	3.1	100.0
		Total	32	100.0	100.0	
Female	Valid	6.00	3	9.4	9.4	9.4
		7.00	1	3.1	3.1	12.5
		8.00	1	3.1	3.1	15.6
		9.00	8	25.0	25.0	40.6
		10.00	4	12.5	12.5	53.1
		11.00	1	3.1	3.1	56.3
		12.00	2	6.3	6.3	62.5
		13.00	6	18.8	18.8	81.3
		14.00	3	9.4	9.4	90.6
		15.00	2	6.3	6.3	96.9
		16.00	1	3.1	3.1	100.0
		Total	32	100.0	100.0	

Age Distribution of Special Children by Gender: The above table indicates that the age of special children ranges from 6 to 16 years, with a mean of approximately 10.8 years for both genders. The most frequently reported age is 9 years, accounting for 5% of the total responses. This is followed by 13 years (18.8%), and 10 years (12.5%), suggesting that a significant portion of special children are in their mid-childhood to early adolescence.

Table 4

Table 4 Gender of Children						
Gender of Child			Frequency	Percentage	Valid Percentage	Cumulative Percentage
Male	Valid	Male Child	19	59.4	59.4	59.4
		Female Child	13	40.6	40.6	100.0
		Total	32	100.0	100.0	
Female	Valid	Male Child	19	59.4	59.4	59.4
		Female Child	13	40.6	40.6	100.0
		Total	32	100.0	100.0	

The above table shows that the gender distribution of children based on the gender of the parent. Both male and female participants report identical patterns: 59.4% have male children, while 40.6% have female children. This suggests a consistent trend across both male and female respondents, with a higher proportion of male children reported in each group. The symmetry in responses indicates no significant variation in the gender of children between male and female parents in this sample of 64 individuals.

Table 5

Table 5 Religion of Respondents						
Religion			Frequency	Percentage	Valid Percentage	Cumulative Percentage
Male	Valid	Hindu	25	78.1	78.1	78.1
		Muslim	6	18.8	18.8	96.9
		Others	1	3.1	3.1	100.0
		Total	32	100.0	100.0	
Female	Valid	Hindu	25	78.1	78.1	78.1
		Muslim	6	18.8	18.8	96.9
		Others	1	3.1	3.1	100.0
		Total	32	100.0	100.0	

The data presents the religious affiliation of participants categorized by gender, showing identical distributions for both males and females. In each group of 32 individuals, 78.1% identify as Hindu, 18.8% as Muslim, and 3.1% fall under the "Others" category. This indicates that the majority of both male and female participants share the same religious background, with Hinduism being the predominant religion in the sample. The uniformity across genders suggests a consistent religious composition within the overall group of 64 participants.

Table 6

Table 6 Domicile						
Domicile			Frequency	Percentage	Valid Percentage	Cumulative Percentage
Male	Valid	Rural	15	46.9	46.9	46.9
		Urban	17	53.1	53.1	100.0
		Total	32	100.0	100.0	
Female	Valid	Rural	15	46.9	46.9	46.9
		Urban	17	53.1	53.1	100.0
		Total	32	100.0	100.0	

The data on domicile status reveals an identical distribution between male and female participants. In both groups, 46.9% come from rural areas, while 53.1% reside in urban areas. This suggests a nearly balanced representation of rural and urban backgrounds, with a slight majority from urban settings.

Table 7

Table 7 Education of Parents						
		Education	Frequency	Percentage	Valid Percentage	Cumulative Percentage
Male	Valid	illiterate	9	28.1	28.1	28.1
		Primary	10	31.3	31.3	59.4
		Secondary	4	12.5	12.5	71.9
		PUC	6	18.8	18.8	90.6
		Diploma	1	3.1	3.1	93.8
		PUC above	2	6.3	6.3	100
		Total	32	100	100	
Female	Valid	illiterate	8	25	25	25
		Primary	10	31.3	31.3	56.3
		Secondary	11	34.4	34.4	90.6
		PUC	1	3.1	3.1	93.8
		PUC above	2	6.3	6.3	100
		Total	32	100	100	

The data on parental education levels shows notable differences between male and female participants. Among male respondents, the highest proportion (31.3%) have completed primary education, followed closely by 28.1% who are illiterate. Smaller percentages have attained secondary education (12.5%), PUC (18.8%), diploma (3.1%), and education above PUC (6.3%). In contrast, female respondents show a slightly higher level of education overall. While 25% are illiterate and 31.3% have primary education—similar to males—34.4% have completed secondary education, which is significantly higher than the male figure. Only 3.1% of females have PUC education, and 6.3% have education beyond PUC, with no female respondents holding a diploma. Overall, the data indicates that while both male and female parents have a substantial proportion with only primary or no formal education, female respondents show a higher percentage in secondary education, suggesting a modest educational advantage in that category.

Table 8

Table 8 Type of Family						
		Type of Family	Frequency	Percentage	Valid Percentage	Cumulative Percentage
Male	Valid	Joint family	12	37.5	37.5	37.5
		Nuclear family	20	62.5	62.5	100.0
		Total	32	100.0	100.0	
Female	Valid	Joint family	12	37.5	37.5	37.5
		Nuclear family	20	62.5	62.5	100.0
		Total	32	100.0	100.0	

The data on the type of family structure reveals identical distributions among both male and female participants. In each group of 32 individuals, 62.5% belong to nuclear families, while 37.5% belong to joint families. This indicates a general

preference or prevalence of nuclear family setups across both genders in the sample. The equal distribution suggests that family type does not differ by gender in this group, with nuclear families being the dominant family structure overall

Table 9

Table 9 Employment of Parents						
Employment			Frequency	Percentage	Valid Percentage	Cumulative Percentage
Male	Valid	Agriculture	3	9.4	9.4	9.4
		Coolie	15	46.9	46.9	56.3
		Private Job	2	6.3	6.3	62.5
		Business	1	3.1	3.1	65.6
		Other work	11	34.4	34.4	100.0
		Total	32	100.0	100.0	
Female	Valid	Agriculture	2	6.3	6.3	6.3
		Coolie	10	31.3	31.3	37.5
		Other work	20	62.5	62.5	100.0
		Total	32	100.0	100.0	

The employment data reveals distinct differences in the types of work undertaken by male and female participants. Among males, the most common occupation is working as a coolie (46.9%), followed by other forms of work (34.4%). Smaller proportions are engaged in agriculture (9.4%), private jobs (6.3%), and business (3.1%). In contrast, the majority of female participants (62.5%) are involved in "other work," which may include informal or domestic labor, while 31.3% work as coolies and 6.3% in agriculture. Notably, no female participants are reported in private jobs or business. This suggests that while both genders are predominantly engaged in labor-intensive or informal employment, males show slightly more occupational diversity, including some presence in private sector and entrepreneurial roles, whereas females are more concentrated in unspecified or informal work categories.

Table 10

Table 10 Family Income						
Family Income			Frequency	Percentage	Valid Percentage	Cumulative Percentage
Male	Valid	less than 1lakh	30	93.8	93.8	93.8
		1L 1Rs to 2L Rs	2	6.3	6.3	100.0
		Total	32	100.0	100.0	
Female	Valid	less than 1lakh	32	100.0	100.0	100.0

The data on family income reveals that the vast majority of participants, regardless of gender, fall within the low-income bracket. Among male respondents, 93.8% report a family income of less than ₹1 lakh per year, while a small minority (6.3%) earn between ₹1 lakh and ₹2 lakh. In comparison, all female respondents (100%) report a family income of less than ₹1 lakh. This highlights a predominantly economically disadvantaged population, with female-led households experiencing slightly lower income levels overall, as none report earnings above ₹1 lakh. The data underscores widespread financial hardship across both groups, with limited income diversity

Table 11

Table 11 Gender of Parents: * Which Professionals Have U Consulted? Cross-Tabulation							
Gender of Parents			Which professionals have u consulted?				
			Ayurveda Doctor	Homeopathic	Nati specialist	Allopathic	Others
Male	Count		1	0	1	22	8
	% of Total		1.6%	0.0%	1.6%	34.4%	12.5%
Female	Count		1	1	0	22	8
	% of Total		1.6%	1.6%	0.0%	34.4%	12.5%
Total	Count		2	1	1	44	16
	% of Total		3.1%	1.6%	1.6%	68.8%	25.0%

The above table indicates that a majority of both genders (68.8%) sought help from allopathic doctors, while some also turned to alternative systems like Ayurveda and traditional healing. This pattern indicates general trust in mainstream medicine with occasional cultural inclinations influencing health-seeking behavior.

Figure1

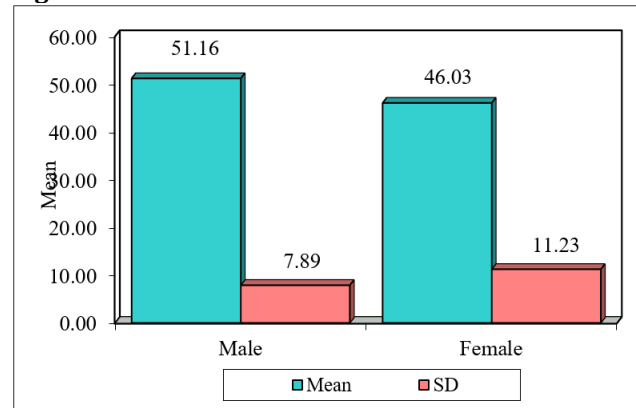


Figure 1 Comparison of Male and Female Caregivers with Social Support Scores

Null hypothesis: There is no significant difference between male and female caregivers with respect to family burden scores

To test the null hypothesis, the non-parametric i.e. Mann-Whitney U test was applied, and the results are presented in the following table.

Table 12

Table 12 Comparison of Male and Female Caregivers with Respect to Family Burden Scores by Mann-Whitney U Test

Gender	n	Mean	SD	Mean rank	U-value	Z-value	P-value
Male	32	22.03	4.99	27.59			
Female	32	25.25	7.27	37.41	355	-2.1013	0.0356,S

From the above table, it can be seen that, the mean and SD of family burden scores in male caregivers is (22.03±4.99) and in female caregivers (25.25±7.27). The difference between male and female caregivers with family burden scores is found to be statistically significant (Z=-2.1013, p=0.0356) at 5% level of significance. Hence, the null hypothesis is rejected, and alternative hypothesis is accepted. It

means that, the family burden scores are different in male caregivers and female caregivers. The mean scores are also presented in the following figure.

Figure 2

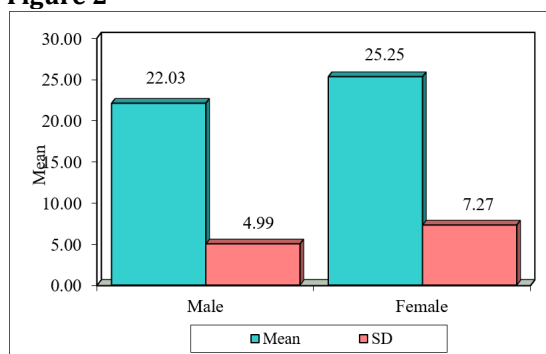


Figure 2 Comparison of Male and Female Caregivers with Family Burden Scores

Null hypothesis: There is no significant difference between male and female caregivers with respect to quality-of-life scores. To test the null hypothesis, the non-parametric i.e. Mann-Whitney U test was applied, and the results are presented in the following table.

Table 13

Table 13 Comparison of Male and Female Caregivers with Respect to Quality-of-Life Scores by Mann-Whitney U Test

Gender	n	Mean	SD	Mean rank	U-value	Z-value	P-value
Male	32	70.84	5.29	37.73			
Female	32	68.91	6.75	27.27	344.50	2.2423	0.0249,S

From the above table, it can be seen that, the mean and SD of quality-of-life scores in male caregivers is (70.84±5.29) and in female caregivers (68.91±6.75). The difference between male and female caregivers with quality-of-life scores is found to be statistically significant ($Z=2.2423$, $p=0.0249$) at 5% level of significance. Hence, the null hypothesis is rejected, and alternative hypothesis is accepted. It means that, the quality-of-life scores are different in male caregivers and female caregivers. The mean scores are also presented in the following figure.

Figure3

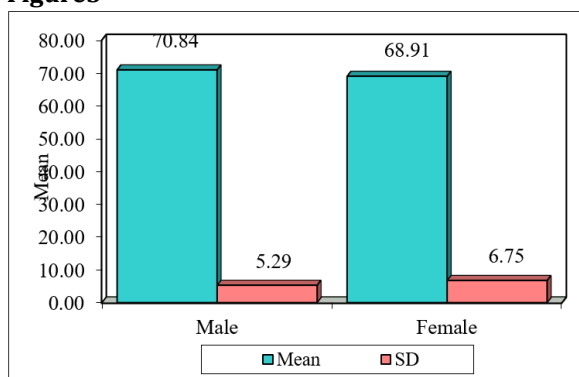


Figure 3 Comparison of Male and Female Caregivers with QOL Scores

Summary of Findings: Gender-Based Analysis on Experiences and Services Among Parents of Children with Disabilities

5. DISCUSSION

Social Work Interventions and Recommendations The findings emphasize several key areas for social work intervention:

- 1) **Emotional Support Services:** Counselling, therapy, and peer-support groups should be made accessible from the point of diagnosis.
- 2) **Awareness and Advocacy Training:** Workshops and campaigns to educate parents about their legal rights, available schemes, and advocacy methods.
- 3) **School Collaboration:** Social workers should facilitate effective communication between parents and schools to promote inclusive education.
- 4) **Stigma Reduction:** Community-level campaigns and sensitization programs to reduce the stigma associated with disabilities.
- 5) **Parental Training:** Equip parents with caregiving skills and knowledge about disability management.

6. SOCIAL WORK INTERVENTIONS AND RECOMMENDATIONS

From a social work standpoint, these findings highlight critical intervention points. First, emotional support services, such as counselling and peer support groups, should be made accessible to parents immediately after diagnosis. The high incidence of stress, sadness, and helplessness necessitates a structured psychosocial response. Second, awareness campaigns and training programs need to be conducted more in number and to be implemented to educate parents about their legal rights, government schemes, and available community resources. This will enhance their ability to advocate for their children and reduce dependence on ad hoc support. Third, there is a need to improve school involvement. Social workers can act as mediators between families and educational institutions to ensure inclusive practices and customized educational plans for children with disabilities. Fourth, stigma reduction programs must be introduced at the community level.

7. CONCLUSION

From a social work perspective, there is a pressing need for comprehensive and empathetic interventions that address not only the practical needs of caregivers but also their emotional and psychological well-being. Empowering families through information, support, and advocacy can significantly enhance the quality of life for both parents and their children with disabilities.

CONFLICT OF INTERESTS

None.

ACKNOWLEDGMENTS

None.

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