

Determinants of Mental Health Among Parents of Children with Disabilities

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Abstract

In rural areas of India, approximately 6 percent of persons with some disabilities are in the age group of 0-14 years. Children with disabilities (CwDs) experience long-term intellectual, physical and/or sensory impairment that is significant enough to interfere with or hinder their active and full participation in academic and social interactions as compared to their peers. Among the various types of disabilities reported, the highest disability rate of 1,060 has been recorded from rural areas in the case of persons suffering from visual disability while the category of hearing disability recorded the lowest disability rate of 138 in rural areas. An identical pattern of disability rate was recorded in the urban areas. As Barton & Oliver (1996) maintained, 'disability is a social phenomenon and needs understanding of social determinants of the experiences of disability'. The emotional stress and social stress that these parents undergo have been reported by various investigators that the parents of mental disability children had low level of sound mental health due to high level of perceived stress (Sone and Jain., 2016). Kumar and Aktar (2001) reported that mothers of children with mental disability had a higher level of anxiety and stress in comparison to the mothers of children with normative development. The objective of the study was to assess the mental health of parents of disabled children and to identify the factors influencing the mental health of parents of children with disability. The quantitative study was conducted through purposive sampling technique to select the participants of the study. 240 parents and 120 disabled children were selected from 6 institutions working for children with disability in Bijapur district of North Karnataka. Semi-structured questionnaire was used to elicit the personal and demographic information parents & children and Depression, Anxiety and Stress Scale (DASS) was used to identify determinants of mental health of parents of children with disability.

The data was statistically processed by using SPSS package version 16.0. Mean and standard deviation were calculated for the study variables and t-test were used to know the significant differences between mental health of parents and χ^2 -test and r-test were applied to identify the determining factors for mental health of the parents. The results of the study found that the mothers had severe level of stress (67.17%), depression (43.75%) and anxiety (52.13%). Mothers reported significantly high level of mental health problems compared to the fathers ($17.14 \pm 3.16 > 12.16 \pm 1.24$). Parents age, education, occupation, number of children and income of the family were significantly associated with mental health of the parents. The study recommended that providing enhanced support services, including counseling and respite care, targeted at mothers who bear a heavier burden of mental health challenges to the parents of children with disability. Education and awareness programs are crucial to reduce stigma and increase community

support. Financial assistance initiatives should be implemented to alleviate financial stressors, while policy advocacy is needed to ensure adequate access to healthcare, education, and employment opportunities for families of children with disabilities. Further research is essential to broaden the understanding towards and evaluate the effectiveness of interventions supporting parental well-being.

Keywords: Mental health, Determinants, Disability

Introduction

In India, the child population in the age group of 0-6 years as per the 2011 Census was 158,789,287 million with boys accounting for 51.88 percent. Approximately 6 percent of persons with some disabilities are in the age group of 0-14 years in rural areas and slightly more than 5 percent in urban areas. Among the various types of disabilities reported, the highest disability rate of 1,060 has been recorded from rural areas in the case of persons suffering from the disability “in seeing” while the category of disability “in hearing” recorded the lowest disability rate of 138 in rural areas. An identical pattern of disability rate was recorded in the urban areas. As Barton and Oliver (1996) maintained, ‘disability is a social phenomenon and needs understanding of social determinants of the experiences of disability’. Significantly, the problem of disability is defined mostly in terms of impairment and dysfunctions thereby suggesting the need for skill development (Murali et al., 2021). The emotional stress and social stress that these parents undergo have been described by various investigators that the parents of children with mental disability had low level of sound mental health due to high level of perceived stress (Sone and Jain., 2016). Kumar and Aktar (2001) reported that mothers of children with mental disability had a higher level of anxiety and stress in comparison to the mothers of children with normative development. They reported that the mothers of children with mental disabilities differ significantly from the parents of normal children on anxiety and stress level. The impact of disabilities are not confined to the children with disabilities, it extends beyond the children to the physical and mental well-being of the parents. It is frequently reported that parents of children with disabilities are at increased risk of mental illness than parents of children without disabilities. There are atleast two reasons to explain the reported high prevalence of mental illness in parents of children with disabilities. First, parents steer away from their social life to accommodate their children, as caring for a child with a disability requires immense attention and increases the complexity and scope of the parent's role. For example, around one-quarter of parents of children with disabilities stated that the care taking role affects their social life; 30.8% of parents reported that they completely lost contact with friends, relatives, and even their extended family. Similarly, lower ‘couple satisfaction’ was reported among parents of children with disabilities compared to that of children without disabilities (Chen et. al., 2023). Hence the study was conducted with the following objectives,

Objectives

- To assess the mental health of parents of disabled children and
- To identify the factors influencing on mental health of parents of children with disability

Methodology

Research design: A cross-sectional study was conducted to assess the determinants of mental health among parents of children with disabilities. Correlational research design was used to know the

relationship between dependent such as mental health of the parents and independent variable such as age, education, occupation of parents and child characteristics gender, age and birth order age.

Sampling technique: Purposive sampling technique was used to select the 240 parents and 120 disabled children were selected from six institutions from Bijapur District of North Karnataka. The inclusive criteria of the study were the parents with special child /and special children enrolled in special school.

Research tools

- Self-structured questionnaire was used to elicit the personal and demographic information parents and children.
- Depression, Anxiety and Stress Scale (DASS)

The Depression, Anxiety, and Stress Scale (DASS), developed by Lovibond and Lovibond in 1995, consists of three self-report scales designed to measure the emotional states of depression, anxiety, and stress. Each of the three DASS-21 scales contain 7 items, divided into subscales with similar content. The depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The anxiety scale evaluates autonomic arousal, skeletal muscle effects, situational anxiety, and the subjective experience of anxious affect. The stress scale measures chronic non-specific arousal, including difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive, and impatient. Scores for depression, anxiety, and stress are calculated by summing the scores for the relevant items. Each item is rated on a four-point Likert scale, with a maximum score of 21 and a minimum score of 0 for each subscale. Higher scores indicate higher levels of depression, anxiety, and stress. The total score is categorized as follows:

DASS category	Depression	Stress	Anxiety
Mild	0-7	0-7	0-7
Moderate	8-14	8-14	8-14
Severe	15-21	15-21	15-21

The collected data were scored and interpreted according to the norms given in the manual of the scale. Further, the data were statistically processed by using SPSS package version 16.0. Mean and standard deviation were calculated for the study variables and t-test were used to know the significant differences between mental health of parents and χ^2 -test and r-test were applied to identify the determining factors for mental health of the parents.

Results and discussion

Table 1: Personal information of children

Information about children		No	%
Gender	Male	72	60
	Female	48	40
Age (Years)	5years to 7 years	45	37.5
	8 years and 9+ years	75	62.5
Birth Order	First born	71	59
	Second born and letter born	49	41

The study gathered personal information about children, including their gender and age distribution in Table 1. Among the children with disabilities, 72 were male, accounting for 60% of the total participants, while 48 were female, making up the remaining 40%. This indicates a higher prevalence of disabilities among male children compared to female children in the sample. The children were categorized into two age groups: 5 to 7 years and 8 years and older. In the 5 to 7 years age group, there were 45 children, representing 37.5% of the total. In contrast, the 8 years and older group comprised 75 children, accounting for 62.5%. This distribution shows that the majority of children with disabilities were older, falling into the 8 years and older category. Regarding birth order, 71 of the children were first-born, making up 59% of the total, while 49 children were second-born or later-born, representing 41%. This indicates a higher prevalence of disabilities among first-born children compared to their later-born siblings.

The analysis of personal information of children with disabilities revealed a higher prevalence of disabilities among males (60%) compared to females (40%). Additionally, a larger proportion of children with disabilities were older (62.5% in the 8 years and older group) and were first-born (59%) compared to their younger counterparts. These findings provide important demographic insights into the population of children with disabilities studied.

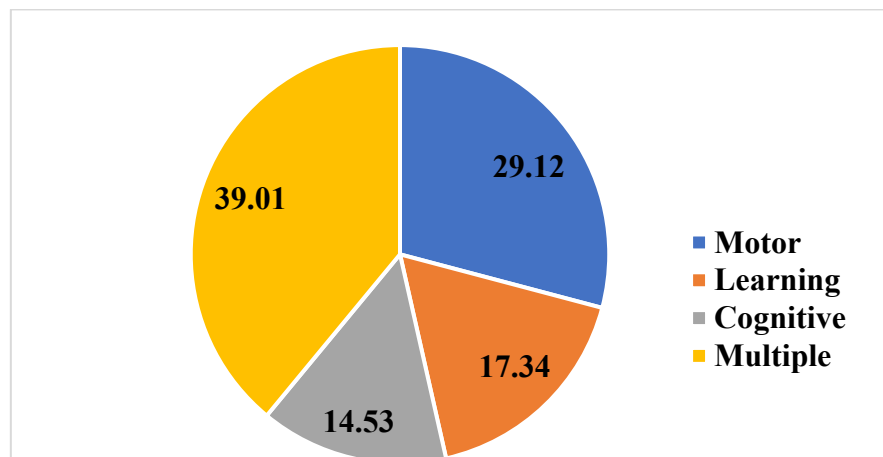


Fig. 1: Type of disability

Fig. 1 indicates the types of disability among children. Nearly 40% of children have multiple disabilities followed by motor disability (29.12%), learning disability (17.34%) and cognitive disability (14.53%).

Table 2: Association of child's characteristics with disability

Information about children		No.	%	χ^2 (df) Sig.
Gender	Male	79	65.83	21.56* (2) 0.012
	Female	41	34.17	
Age (Years)	5years to 7 years	67	55.83	19.76* (2) 0.032
	8 years and 9+ years	53	44.17	
Birth	First born	72	60	3.46 ^{NS}

Order	Second born and letter born	79	65.83	(2) 1.023
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Table 2 reported the relationship between specific characteristics of children namely gender, age, and birth order and the presence of disability. The associations were analyzed using chi-square tests to determine statistical significance. The analysis showed a significant association between gender and the presence of disability. Among the children with disabilities, 79 were male (65.83%) and 41 were female (34.17%). The chi-square test yielded a value of 21.56 with 2 degrees of freedom, resulting in a p-value of 0.012. This indicates that the difference in disability prevalence between males and females is statistically significant, with males being more likely to have a disability compared to females. There was also a significant association between age and the presence of disability. The children were divided into two age groups: 5 to 7 years and 8 years and older. In the 5 to 7 years age group, 67 children (55.83%) had disabilities, while in the 8 years and older group, 53 children (44.17%) had disabilities. The chi-square test produced a value of 19.76 with 2 degrees of freedom and a p-value of 0.032. This indicates that younger children (5 to 7 years) are more likely to have a disability compared to older children (8 years and older), and this difference is statistically significant. The analysis of birth order in relation to disability did not show a significant association. The children were categorized into first-born and second-born or later-born groups. Among the children with disabilities, 72 were first-born (60%) and 79 were second-born or later-born (65.83%). The chi-square test for birth order resulted in a value of 3.46 with 2 degrees of freedom and a p-value of 1.023. This high p-value indicates that the difference in the prevalence of disability between first-born and later-born children is not statistically significant. Birth order does not appear to influence the likelihood of a child having a disability.

The study found that gender and age are significantly associated with the presence of disability in children, males and younger children (5 to 7 years) are more likely to have disabilities. However, birth order does not have a significant impact on the likelihood of disability in children. The finding supported by the study conducted by Chu et. Al. in 2023 reported that there were high levels of mental health concerns among parents of children aged 4-11 years children compare to >11 years children.

Table 3: Information of parents/caregivers

Parent/caregivers	Mothers	120	50
	Fathers	120	50
Age	23-27 years	56	46.67
	>28 years	64	53.33
Education	Not educated	39	32.5
	Primary	54	45
	Secondary	27	22.5
Occupation	Agricultural	38	31.67
	Daily wagers	60	50
	Working in private sector	22	18.33

Table 3 represents the information of parents of the children. The study collected and analyzed data on the characteristics of parents of children with disabilities, focusing on their relationship to the child, age,

education level, and occupation. Among the parents of children with disabilities, 50 were mothers, representing 41.67% of the total, while 70 were fathers, accounting for 58.33%. This indicates that fathers were more likely to be the primary caregivers in this sample. The parents were divided into two age groups: 23-27 years and older than 28 years. The data showed that 56 parents (46.67%) were in the 23-27 years age group, whereas 64 parents (53.33%) were older than 28 years. This distribution suggests a slightly higher prevalence of older parents among the children with disabilities.

The educational background of the parents was categorized into three levels: not educated, primary education, and secondary education. The results showed that 39 parents (32.5%) were not educated, 54 (45%) had primary education, and 27 (22.5%) had secondary education. This indicates that the majority of parents had some level of formal education, with primary education being the most common. The occupations of the parents were categorized into three groups: agricultural workers, daily wagers, and those working in the private sector. The results revealed that 38 parents (31.67%) were engaged in agricultural work, 60 (50%) were daily wagers, and 22 (18.33%) were employed in the private sector. This indicates that half of the parents were daily wagers, making it the most common occupation among the group.

On the whole the analysis of the parents of children with disabilities revealed that fathers were more likely to be the primary caregivers compared to mothers. A slightly higher proportion of parents were older than 28 years. Most parents had primary education, and daily wage labor was the most common occupation. These characteristics provide valuable insights into the demographics and socio-economic status of the families involved in the study.

Table 4: Mental health of parents of disabled children

	Depression No. (%)	Anxiety No. (%)	Stress No. (%)
Mothers			
Mild	23(19.16)	19(15.83)	21(17.50)
Moderate	54(45.00)	52(43.33)	48(40.00)
Sever	43(35.83)	49(40.83)	51(42.50)
Fathers			
Mild	33(27.50)	48(40.00)	43(35.83)
Moderate	57(47.50)	43(35.83)	56(46.66)
Sever	30(25.00)	29(24.16)	21(17.50)
χ^2 (df) Sig.	14.61* (4) 0.021		

The mental health assessment of parents of disabled children revealed various levels of depression, anxiety, and stress among mothers and fathers were indicated in Table 4. Among mothers, 19.16% experience mild depression, 45.00% have moderate depression, and 35.83% suffer from severe depression. In terms of anxiety, 15.83% of mothers have mild anxiety, 43.33% experience moderate anxiety, and 40.83% suffer from severe anxiety. Regarding stress, 17.50% of mothers report mild stress, 40.00% have moderate stress, and 42.50% experience severe stress.

Among fathers, 27.50% report mild depression, 47.50% experience moderate depression, and 25.00% suffer from severe depression. When it comes to anxiety, 40.00% of fathers have mild anxiety, 35.83% experience moderate anxiety, and 24.16% suffer from severe anxiety. Regarding stress, 35.83% of fathers report mild stress, 46.66% have moderate stress, and 17.50% experience severe stress. The chi-square test ($\chi^2 = 14.61$, $df = 4$, $p = 0.021$) indicates that there was a statistically significant difference in the levels of depression, anxiety, and stress between mothers and fathers.

Table 5: Mean, Standard Deviation, t value for mental health of parents with child's characteristics of children with disability

Information about children		Depression	Anxiety	Stress
Gender	Male	14.92±1.12	16.23±1.56	15.62±2.03
	Female	17.45± 2.13	14. 46±2.23	19.13±1.04
	t-value (Sign.)	4.41*	3.18*	5.02**
Age (Years)	5years to 7 years	18.16±2.04	17.47±2.12	18.72±1.19
	8 years and 9+ years	12.43±1.23	13.82±2.11	13.68±2.12
	t-value (Sign.)	5.13**	3.12*	3.99*
Birth Order	First born	15.13±1.21	17.36±2.43	18.16±2.71
	Second born and later born	17.23±2.10	12.73±1.07	14.15±1.52
	t-value (Sign.)	2.03 ^{NS}	3.08*	4.03*

Table 5 explored how the mental health of parents of children with disabilities is affected by the child's gender, age, and birth order, focusing on depression, anxiety, and stress levels. Parents of female children reported depression levels that were 16.9% higher than those of male children (mean scores: 17.45 vs. 14.92, t -value = 4.41, $p < 0.05$). Conversely, anxiety levels were 10.9% lower for parents of female children compared to those of male children (mean scores: 14.46 vs. 16.23, t -value = 3.18, $p < 0.05$). Stress levels were significantly higher for parents of female children by 22.5% compared to parents of male children (mean scores: 19.13 vs. 15.62, t -value = 5.02, $p < 0.01$). Parents of younger children (aged 5 to 7 years) experienced 46.1% higher depression levels compared to parents of older children (8 years and older) (mean scores: 18.16 vs. 12.43, t -value = 5.13, $p < 0.01$). Anxiety levels were 26.4% higher in parents of younger children compared to older children (mean scores: 17.47 vs. 13.82, t -value = 3.12, $p < 0.05$). Stress levels were 36.8% higher in parents of younger children compared to those of older children (mean scores: 18.72 vs. 13.68, t -value = 3.99, $p < 0.05$). For depression, parents of second-born or later-born children reported levels that were 13.9% higher compared to those of first-born children (mean scores: 17.23 vs. 15.13, t -value = 2.03, not significant). Anxiety levels were 26.7% lower in parents of second-born or later-born children compared to those of first-born children (mean scores: 12.73 vs. 17.36, t -value = 3.08, $p < 0.05$). Stress levels were 22.1% lower in parents of second-born or later-born children compared to first-born children (mean scores: 14.15 vs. 18.16, t -value = 4.03, $p < 0.05$).

On the whole the findings indicate substantial differences in parental mental health based on the child's gender, age, and birth order. Parents of female, younger, and first-born children tend to experience higher

levels of depression, anxiety, and stress. These insights emphasize the need for tailored mental health interventions to support these specific parent groups effectively.

Table 6: Mean, Standard Deviation, t value for characteristics of parents based on mental health

Variables		Mean±SD	t-value	Sig.
Gender	Mothers	16.35±2.31	3.183*	0.032
	Fathers	11.39±1.08		
Age	<30 years	18.63±2.18	5.140**	0.001
	31-35 years	13.36±0.63		
Education	Not-educated	16.76±2.13	4.491**	0.001
	Educated	12.63±1.82		

The study also analyzed the mental health characteristics of parents based on gender, age, and education, reporting the mean and standard deviation for each group. The results show that mothers have a significantly higher mean mental health score (16.35±2.31) compared to fathers (11.39±1.08), with a t-value of 3.183 and a p-value of 0.032, indicating a statistically significant difference. When considering age, parents younger than 30 years have a mean mental health score of 18.63±2.18, which is significantly higher than those aged 31-35 years, who have a mean score of 13.36±0.63. This difference was supported by a t-value of 5.140 and a p-value of 0.001, showing a strong statistical significance. In terms of education, parents who are not educated have a mean mental health score of 16.76±2.13, while educated parents have a lower mean score of 12.63±1.82. The t-value for this comparison was 4.491, with a p-value of 0.001, indicating a statistically significant difference based on education level. These results highlighted that mothers, younger parents, and those who are not educated tend to have higher mental health scores, suggesting greater mental health challenges within these groups. The results were in line with the study conducted by Soni and Jain (2016) represented that parent of intellectually disabled child scored significantly higher on some categories of psycho-neuroses part than the parents of a normal child. It seems that parents of intellectually disabled child suffer from psychoneurotic problems, such as, conversion reaction, phobia, depression, neurasthenia. Another study conducted by Chen et al (2023) found that there was a higher prevalence of mental health problems for parents of children with disabilities compared to those without in all child ages. Regression analyses indicated that parents of children aged 12 to 17 years with disabilities had significantly higher mental health service utilization and costs compared to parents of children without disabilities.

Table 7: Correlations among the analyzed variables

	Depression	Anxiety	Stress
Depression	1	0.56**	0.47*
Anxiety		1	0.61**
Stress			1

Table 7 revealed significant correlations among the variables of depression, anxiety, and stress. Depression was found to have a moderate positive correlation with anxiety ($r = 0.56$, $p < 0.01$) and a somewhat weaker positive correlation with stress ($r = 0.47$, $p < 0.05$). Anxiety also showed a strong positive correlation with stress ($r = 0.61$, $p < 0.01$). These results suggest that higher levels of depression are associated with higher levels of anxiety and stress, and that anxiety is strongly related to stress levels. The finding supported by the finding of Lupu in 2016 reported that there were significant positive correlations between depression, anxiety and stress.

Conclusion

The study concluded that there were notable differences in the personal and socio-demographic characteristics of the children and their caregivers. It was found that 60% of the children were male, and 40% were female. In terms of age distribution, 37.5% of the children were between 5 to 7 years old, while 62.5% were 8 years and older. The types of disabilities among the children included multiple disabilities (40%), motor disability (29.12%), learning disability (17.34%), and cognitive disability (14.53%). Among the caregivers, 58.33% were fathers, and 41.67% were mothers. Parents aged between 23-27 years accounted for 46.67%, while those older than 28 years constituted 53.33%. Regarding educational attainment, 32.5% of the parents were not educated, 45% had primary education, and 22.5% had secondary education. In terms of occupation, 31.67% of the parents worked in agriculture, 50% were daily wagers, and 18.33% were employed in the private sector. The mental health assessment revealed significant differences between mothers and fathers. Among mothers, 19.16% experienced mild depression, 45.00% had moderate depression, and 35.83% suffered from severe depression. For anxiety, 15.83% of mothers experienced mild anxiety, 43.33% had moderate anxiety, and 40.83% had severe anxiety. Regarding stress, 17.50% of mothers reported mild stress, 40.00% had moderate stress, and 42.50% had severe stress. Fathers reported 27.50% mild depression, 47.50% moderate depression, and 25.00% severe depression. For anxiety, 40.00% of fathers experienced mild anxiety, 35.83% moderate anxiety, and 24.16% severe anxiety. Regarding stress, 35.83% of fathers reported mild stress, 46.66% moderate stress, and 17.50% severe stress. The chi-square test indicated a statistically significant difference in the levels of depression, anxiety, and stress between mothers and fathers. Additionally, it was found that mothers had a significantly higher mean mental health score (16.35 ± 2.31) compared to fathers (11.39 ± 1.08). Parents younger than 30 years had a higher mean mental health score (18.63 ± 2.18) compared to those aged 31-35 years (13.36 ± 0.63). Furthermore, not-educated parents had a higher mean mental health score (16.76 ± 2.13) compared to educated parents (12.63 ± 1.82). These results suggested that mothers, younger parents, and those who were not educated faced greater mental health challenges.

Implications and recommendations

Implications of these findings extend beyond the immediate context of the study, pointing to broader systemic issues surrounding the care and support provided to children with disabilities and their families. It is evident that caregiving responsibilities, coupled with the challenges of managing a child's disability, can take a toll on parents' mental health, particularly among mothers and those who are younger or less educated. As such, there is a pressing need for comprehensive support systems that address the emotional and psychological needs of parents, including access to mental health services, respite care, and peer support networks.

Recommendations stemming from these findings should prioritize the development and implementation

of targeted interventions aimed at promoting the mental well-being of parents, particularly mothers, who may be disproportionately affected. This may involve providing education and training on stress management techniques, offering counseling services tailored to the unique needs of parents and fostering community-based support networks. Additionally, initiatives aimed at enhancing parent's resilience and coping strategies should be integrated into existing disability support programs, ensuring that parents have the resources and support they need to navigate the challenges of caring for a child with disabilities effectively. Moreover, efforts to improve parents access to education and employment opportunities can have a significant impact on their overall well-being, as higher levels of education and stable employment are associated with better mental health outcomes. This underscores the importance of implementing policies that promote inclusive education and employment practices, as well as providing vocational training and financial support to caregivers who may face barriers to accessing education and securing stable employment.

Disclosure statement

The author declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Informed consent

Informed consent was taken from all the participants involved in the study.

Data availability statement

In adherence to the APA ethical guidelines, the dataset analyzed in this study is unavailable for public viewing to protect privacy and maintain confidentiality with the participants.

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