



Assessing the Prevalence of Psychological Distress in Parents of Special Children

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Abstract

Background: Parents of children with intellectual disabilities are constantly under stress due to the challenging nature of raising them. Thus, this study aims to evaluate the psychological stress the parents of special children face.

Methods: This cross-sectional study was carried out in the various schools for special children in and around the city of Hyderabad in March 2023. Abedin's Parenting Stress Index (short form) was used, and the questionnaires were distributed among 265 parents and carers of special children. Descriptive statistics, frequency distribution, Pearson's correlation, and multiple linear regression analysis were done using the collected data.

Results: When categorised under mild, moderate, and high-stress level groups, 90 parents out of 265 were in the low-stress, 87 under moderate stress, and 88 under the high-stress level group. A significant correlation was observed between stress among parents of special children the education status of the parent ($P < 0.05$), and the duration of disease since diagnosis in the child ($P < 0.05$).

Conclusion: The study concluded that the majority of the parents are in psychological distress.

Keywords: Psychological Distress; Parental Distress; Special Kids; Parental Stress Index; Difficult Child; Intellectual Disability

Introduction

Parenting special needs children presents additional complexities, adding to the already arduous journey of parenthood. ¹Parenting a kid with special needs often involves more than typical parenting, as it requires navigating through a range of changing criteria specific to the unique requirements of the child [2]. Parents may experience ambivalent emotions upon learning that their children have disabilities [3].

Parents who are raising children with specific problems such as autism, attention deficit hyperactivity disorder (ADHD), and other diseases are likely to experience heightened psychological symptoms. Parenting special needs children can result in challenges related to family functioning, parenting discomfort, and varying parenting styles, which differ from the experience of parenting typically developing children [4].

Parents may experience emotional and social challenges as a result of their children's disability. They frequently encountered a multitude of adverse emotions, such as tension, anxiety, and sadness, due to heightened apprehension about their own and their children's future, which could have an impact on their well-being. In addition, they were highly susceptible to experiencing psychological anguish in comparison to parents with neurotypical children. Psychological distress is a condition of emotional suffering that is characterised by symptoms of depression and anxiety [5]. The high levels of internalizing and externalizing concerns in youngsters had shown in contribution to the high degree of stress [6]. As the parents face the majority of the increasing daily care burden for young children, they may elevate the likelihood of experiencing high levels of stress and, in certain situations [7]. Consequently, it was imperative to assess the magnitude of psychological anguish experienced by parents with children who have special needs in order to develop effective solutions, interventions, and techniques to aid and assist these parents.

Children with exceptional needs may be referred to as children with neurodevelopmental disorders (NDD). Neurodevelopmental disorders (NDD) encompass a variety of illnesses, including Cerebral Palsy (CP), genetic disorders resulting in brain damage, and other conditions that restrict functional abilities such as vision, hearing, speech, behaviour, motor skills, and cognitive impairments [8]. They were identified as children who needed extra assistance and support from education, health, medical, and social-environmental services to enhance their health, development, learning, quality of life, involvement, and integration into the community, beyond what is typically required for children in general.¹ Oftentimes, they were unable to engage in the activities appropriate for their age due to their inability to effectively use their physical, mental, and social capabilities. In assessing impairment in children, it is generally recommended to evaluate it based on specific measurements or a combination of factors such as physiological functions and structures, developmental aspects, cognitive abilities, and emotional factors.³ In addition, individuals in this group typically encountered numerous obstacles during their early years and continued to face them into adulthood. These challenges included serious health issues, disruptive behaviours, and diagnostic examinations that placed a significant load on their parents [9].

Individuals with specific requirements Children were perceived as a source of psychological, physical, social, and economic strain on the family. The equilibrium of parents' lives was of utmost importance as it would directly impact the growth and maturation of their children. Providing care for children with special needs might create challenges in achieving a balance between work responsibilities and giving them the necessary attention [10]. Parents must effectively manage their various responsibilities with limited resources, including time and energy. This includes finding a balance between employment and caring for their children, which may mean attending medical visits at the hospital. Upon failing to meet their obligations, individuals had a sense of shame for not adequately fulfilling the role of exemplary parents. Parents were required to allocate additional time to attend to their children's needs, such as ensuring proper nutrition, sanitation, washing, and engaging in therapeutic activities [11]. This finding is consistent with a recent study which indicated that parents should allocate additional time to assist their children in activities such as eating, dressing, walking, and other tasks [12].

As there are not many studies that focus on the stress levels and mental well-being of the parents of a special child, the aim of this study is to evaluate the psychological stress faced by parents of special child in the city of Hyderabad, India.

Methodology

A cross-sectional study was conducted in Hyderabad to ascertain the psychological stress experienced by parents of children with special needs. The current investigation was carried out among the guardians of children enrolled in specialised education-

al institutions in the city of Hyderabad. The city of Hyderabad is geographically separated into five distinct zones: the North, South, Central, East, and West. The DEO provided a comprehensive roster of schools within these zones. Hyderabad city has a total of 110 special schools. Three schools were randomly selected from each zone using a simple lottery procedure to obtain a sample. The assessment of psychological stress experienced by parents of children with special needs was conducted using Abidin's (1995) Parenting Stress Index Short Form (PSI/SF). The PSI/SF is a 36-item scale that exhibits strong correlations with the full-length PSI in measures of overall stress, parent domain (PD), child domain, and P-CDI. The questionnaire comprises three components: parental distress (PD), parent-child dysfunctional interaction (P-CDI), and challenging child (DC). Each of them comprises a collection of 12 questions, respectively. The response was evaluated based on the Likert scale, which includes the following options: strongly disagree (1), disagree (2), neither agree nor disagree (3), agree (4), and strongly agree (5). The socio-economic status was recorded using demographic information such as the child's age, parent's age and gender, parent's education status, marital status, occupation, and the head of the family's marital status. Additionally, information on the total number of family members, total number of siblings, child's order among siblings, child's diagnosis, duration of the disease since diagnosis, any systemic illness in the parent, and the Modified Kuppaswamy Socio-Economic Scale (2022) were also considered.

Inclusion criteria

Parents of children with exceptional needs aged between 4 and 18 years

- Parents who provided written informed consent and agreed to participate in the study.
- Individuals responsible for the care and supervision of children with special needs.

Exclusion criteria

- Parents of children with physical disabilities.
- Parents of non-participating individuals -Parents of exceptional children aged below 4 years and above 18.

The necessary ethical approval was acquired from the institutional review board of a dental institution, Vikarabad (approved number: 05/SSCDS/SS/IRB/2022), and permits were received from the relevant schools. At the outset, a preliminary investigation was carried out with 30 parents of children with special needs from two schools that were not part of the primary study. This was conducted to assess the practicability and clarity of the questionnaire, as well as to ascertain the optimal sample size. The final sample size of 265 was determined based on the mean score obtained from the pilot. The parents were provided with detailed information about the study's purpose and gave their informed consent. The data collection was planned to take place for a duration of 3

months, specifically from January 1 to March 31, 2023. The special schools that granted permission were contacted. The school administrators were asked to organise a parent-teacher meeting on the designated days to ensure the highest possible attendance. The lead investigator gave the questionnaires to the parents, allowing them sufficient time to complete them before collecting them on the same day. The parents who lacked proficiency in reading or writing English were individually questioned by the lead investigator, and their responses to the questionnaire were recorded. The gathered data was examined for completeness and inputted into an Excel spreadsheet. The statistical analysis was conducted using SPSS 20.0. The confidence interval was established with a 95% level of confidence. A P value of 0.05 was deemed to be statistically significant. Analysed were descriptive statistics, frequency distribution, Pearson’s correlation, and multiple linear regression analysis.

Results

Component	n %
Child’s age	
<9 years	86 (32.5%)
>9 years	179 (67.5%)
Child’s gender	
Boy	161 (60.8%)
Girl	104 (39.2%)
Parent’s age	
<30 years	46 (17.4%)
>30 years	219 (82.6%)
Parent’s gender	
male	67 (25.3%)
female	198 (74.7%)
Parent’s educational status	
Illiterate	23 (8.7%)
Primary school	32 (12.1%)
Secondary school	74 (27.9%)
PUC	16 (6.0%)
Graduate	85 (32.1%)
Post graduate	35 (13.2%)
Marital status	
Married	240 (90.6%)
Single parent	11 (4.2%)
Divorced	5 (1.9%)
Widow	6 (2.3%)
Widower	3 (1.1%)

Parents occupation	
Legislator/senior official/manager	6 (2.3%)
Technician/associate professional professional	14 (5.3%)
Skilled worker,Shop and market sales workers	28 (10.6%)
Craft and related trade	4 (1.5%)
Elementary occupation	24 (9.1%)
Professionals	15 (5.7%)
Skilled agricultural and fishery workers	4 (1.5%)
Plant and machine operator	2 (0.8%)
Unemployed	168 (63.4%)
Socio-economic status of the family	
Upper	11 (4.2%)
Upper middle	89 (33.6%)
Low middle	97 (36.6%)
Upper lower	61 (3.05)
Lower	7 (2.6%)
Marital status of the head of the family	
Married	249 (94.0%)
Single parent	3 (1.1%)
Divorced	3 (1.1%)
Widow	4 (1.5%)
Widower	6 (2.3%)
Total number of family member	
2	2 (0.8%)
3	44 (16.6%)
4	130 (49.1%)
5	41 (15.5%)
6	18 (6.8%)
More than 7	30 (11.5%)
Total number of siblings	
0	58 (21.1%)
1	117 (44.2%)
2	72 (27.2%)
More than 3	18 (6.9%)
Child’s order among siblings	
0	58 (21.1%)
1	95 (35.8%)
2 and above	112 (43.1%)

Table 1: Demographic details of the participants.

A cross-sectional study was conducted to evaluate the psychological stress among 265 parents of children with special needs in the city of Hyderabad. Among all the parents, a majority of 82.6% were over 30 years old, most of them were female (74.4%), and about 90.6% of them were married, while very few (4.2%–1.9%) were either single parents or divorced, respectively. Among the parents, 32.1% were graduates and 10.6% were in professional occupations, but 63.4% of them were unemployed. Majority of them belonged to lower middle-class families (36.6%), and the least of them, 2.6%, were from low socio-economic groups. A majority of children belonged to the age group above 9 years (67.5%), and most of them were boys (60.8%). In the order of the child’s birth, 40.4% of them were second born (Table 1).

Component	n %
Diagnosis of the child	
Autism spectrum disorder	63 (23.8%)
Down’s syndrome	41 (15.5%)
ADHD	33 (12.5%)
Others/combination of above	128 (48.3%)
Duration of disease since diagnosis in child	
1-3 years	53 (20.0%)
3-5 years	49 (18.5%)
5-10 years	52 (19.6%)
>10 years	111 (41.9%)
Any systemic illness of the parent	
None	171 (64.5%)
Diabetes	24 (9.1%)
Hypertension	30 (11.3%)
Others	44 (15.1%)

Table 2: Medical history of the child and the parent.

Regarding the medical history of the child, 23.8% of them suffered from autism spectrum disorder, 15.5% from Down’s syndrome, and 12.5% from ADHD, while most of the children (48.3%) suffered from a combination of the above or other conditions such as cerebral palsy, hearing deficit, anxiety disorder, etc. Around 41.9% of the children were diagnosed more than 10 years ago. Among the parents, 64.5% did not give any history of any systemic illness, whereas only a few, 11.3%, had hypertension (Table 2).

Table 3 shows distribution of the participants based on their stress levels experienced. 34% of parents experienced mild stress, 32.8% of parents experienced moderate stress and 33.2% of parents experienced high stress levels.

Stress levels	Frequency	Percent
Mild stress	90	34.0
Moderate stress	87	32.8
Severe stress	88	33.2
total	265	100.0

Table 3: Distribution of the parents based on the level of stress.

Discussion

A cross-sectional study was conducted to evaluate the psychological stress among 265 parents of children with special needs in the city of Hyderabad. Among all the parents, 82.6% were over 30 years old, most were female (74.4%), and about 90.6% were married, while very few (4.2%-1.9%) were either single parents or divorced, respectively. One argument against the study’s findings is that it may not accurately reflect the psychological stress that all parents of children with special needs experience because it only focused on a narrow demographic (parents in the city of Hyderabad) and did not include participants from various backgrounds and experiences.

Among the parents, 32.1% were graduates, 10.6% were in professional occupations, and 63.4% were unemployed. This could be because many parents of children with special needs may have to prioritise their caregiving responsibilities over their careers. Therefore, these statistics may not reflect the employment rates of parents of children with special needs on a larger scale. Most belonged to lower-middle-class families (36.6%), and the least of them, 2.6%, were from low socio-economic groups. Additionally, the high unemployment rate among the parents surveyed suggests that financial stress may also contribute to their overall well-being and should be considered in future research.

A majority of children belonged to the age group above nine years (67.5%), and most of them were boys (60.8%). In the order of the child’s birth, 40.4% of them were second-born. These findings suggest that parents of children with special needs may face unique challenges and responsibilities, especially if they have multiple children with special needs. Further research should explore the impact of birth order and family dynamics on the well-being and employment rates of parents in this population. Additionally, it is important to consider the specific needs and support required for children in different age groups, as this may impact the parents’ ability to balance employment and caregiving responsibilities.

Regarding the medical history of the child, 23.8% of them suffered from autism spectrum disorder, 15.5% from Down’s syndrome, and 12.5% from ADHD, while most of the children (48.3%) suffered from a combination of the above or other conditions such as cerebral palsy, hearing deficit, anxiety disorder, etc. Understanding the medical history of the children in this population is

crucial for providing appropriate support and resources for their specific needs. It is important to recognize that each child may require different interventions and accommodations based on their individual conditions, which can further impact the parents' ability to balance work and caregiving responsibilities. Therefore, a comprehensive approach that takes into account both the well-being of parents and the specific needs of children across different age groups is necessary for effectively addressing the challenges faced by this population.

Around 41.9% of the children were diagnosed more than 10 years ago. Among the parents, 64.5% did not give any history of any systemic illness, whereas only a few, 11.3%, had hypertension. This suggests that most parents in this population are generally healthy, but may still face challenges in balancing their work and caregiving responsibilities due to the specific needs of their children. It is important for interventions and accommodations to not only address the medical needs of the children, but also provide support and resources for parents to manage their own well-being while caring for their children effectively.

34% of parents experienced mild stress, 32.8% of parents experienced moderate stress and 33.2% of parents experienced high stress levels. These stress levels indicate that a significant portion of parents in this population are facing considerable challenges in managing their work and caregiving responsibilities. It is crucial for interventions and accommodations to prioritize providing effective stress management strategies and resources to help these parents cope with the demands of their situation. Additionally, implementing measures to reduce stress levels can have a positive impact on both the parents' well-being and their ability to care for their children effectively.

In part 2 of this research paper, we will provide a comprehensive description of the questionnaire used to assess the stress levels of working parents and their caregiving responsibilities. Additionally, we will present an in-depth analysis of the collected data to identify patterns and trends related to stress management strategies utilised by this population. This information will contribute to a better understanding of the challenges faced by working parents and inform future interventions and accommodations to support their well-being.

Conclusion

The findings of our study enhance the comprehension that having a child with special needs does not impact the level of stress experienced by the parent. While the results were not statistically significant, it is essential to protect the psychological well-being of these parents through various means, particularly through government organisations such as the Department of Special Education and the Department of Social Welfare. These organisations should develop and implement programmes aimed at assisting parents by

providing services such as family counselling, coping strategies, and early intervention to ensure a high quality of life. These programmes could offer parents the essential assistance and tools to manage the difficulties associated with raising a kid with special needs. In addition, community support groups and non-profit organisations could play a pivotal part in establishing a network of assistance for these parents, enabling them to interact with others who comprehend their distinct experiences. To provide optimal care for their exceptional kid, society may prioritise the mental well-being of these parents by equipping them with the necessary tools and support.

In addition, mental health experts have the capacity to provide counselling and therapy services that are specifically customised to meet the unique requirements of parents who are parenting children with special needs. This would assist them in managing the emotional and psychological strain that frequently accompanies this position. Furthermore, the introduction of policies that offer monetary aid and adaptable work schedules for these parents might alleviate a portion of the economic hardships they could encounter, enabling them to devote more time and effort to the care of their child.

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