

Comparative Analysis of Psycho-Social Stress Among Parents of Children with Mental and Physical Disabilities

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Abstract

The study aimed to explore the parental stress experienced by caregivers of children with disabilities. The sample consisted of 60 parents of disabled children who completed a questionnaire on various aspects of their stress and coping strategies. The data were analyzed using descriptive statistics and analysis of variance (ANOVA) tests. The results showed that most participants were female (70%) and had a monthly income of less than 50,000 PKR (66%). The ANOVA tests revealed significant differences in parental stress levels across different types of disabilities (mental, physical, or both) for three variables: feeling overwhelmed by caregiving responsibilities, feeling isolated and lacking support from family and friends, and taking breaks or respite from caregiving responsibilities. The Duncan test indicated that the parents of children with both mental and physical disabilities had the highest levels of stress for these variables, followed by the parents of physically disabled children and then the parents of mentally disabled children. The study concluded that parenting a disabled child can significantly impact parental stress levels and that the type of disability can influence the degree of stress experienced by parents.

Keywords: Parental Stress, Disabled Child, Mental and Physical Disability, Caregiving.

Introduction

Due to the problems, frustrations, and challenges that parents encounter daily, parenting, while tremendous and gratifying, is frequently accompanied by high-stress levels. Parents are frequently unprepared for the demands and obstacles that come with raising a child with developmental disabilities. The effects of having a kid with developmental difficulties can be profound and endure a lifespan for the entire family (Martin & Colbert 1997; Simmerman, 2001). Numerous studies in this area have shown compared to parents of children with usual development, parents of children with developmental disabilities face more stress (Sanders & Morgan, 1997; Roach et al., 1999). The effects of a kid's challenges with development and the family are nonlinear and not directional. The effects are multifaceted and reciprocal, have an impact on the entire family system, and have an impact on how family members interact with one another (Breslau, 1982; Breslau & Prabucki, 1987; Harris, 1994; Rodrigue et al., 1994). Due to the family's stress, siblings of children with developmental challenges may not be as fortunate (Rossiter & Sharpe, 2001).

The concerns and support needs of carers of children with chronic diseases are similar, according to Stein and Jessop (1989). This essay was written with the understanding that developmental disorders affect families similarly regardless of the diagnosis. A broad variety

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of impairments are called developmental disabilities (DD). To attempt to include every type of DD in this publication would have been unreasonable and beyond the researcher's capabilities. The researcher chose the DD categories already described because there have been several studies on them and their effects on families.

The dynamics and existence of his family are impacted by more than just the child with developmental impairments. The child's growth is also influenced by the family, whether favourably or unfavourably. Early intervention programs According to studies, intervention initiatives for kids with impairments are more successful when family difficulties, such as before beginning, address parental stress. Higher levels of parental stress are also demonstrated by studies associated with less favourable program outcomes Brinker et al., 1994. For this reason, experts must understand and manage parental stress. Finally, it appears that parental stress hinders the parents themselves and has less favourable consequences from initiatives to enhance parental competence Baker et al. (1991); Rhodes (2003). In contrast, intervention programs for kids with DD have been a great success. Brinker et al. (1994), Robbin et al. (1991). The stress that parents of children with DD suffer has been linked to a variety of issues. In this study, they are divided into three groups:

- Stress brought on by the features of the child
- The situation, as seen by the parents
- The resources and support of the family

Global Perspective

Worldwide reports over the past few years have revealed a very remarkable rise in the number of kids with ASD. According to Fitzgerald (2004), the National Autistic Society of the United Kingdom, there may be 91 cases of autistic spectrum disorders for every 10,000 people. A developmental impairment known as autism spectrum disorder (ASD) is marked by challenges with social interaction and communication as well as by restricted interests and repetitive activities (APA, 2000). When autism was believed to be a very severe illness frequently accompanied by intellectual handicaps, the first research on its prevalence was published in the 1960s and 1970s. According to this study, there are typically four to five incidents per 10,000 youngsters. With the release of the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980, which included diagnostic criteria for infantile autism and pervasive developmental disorder, the American Psychiatric Association officially recognized autism as a distinct clinical diagnosis for the first time. It has since become clear that autism is a continuum of behavioural characteristics that results in various degrees of functional impairment (CDC, 2016). According to statistics, there are more and more people developing autism. Over the past few years, it has risen by 10% to 17% yearly. Germany, China, and the United States have the highest rates of autism. However, the frequency of ASD in the general population sample across Asia, Europe, and North America is 1.89%. In these wealthy nations, guys are more likely than girls to have ASD. The total number of autistic children, which is currently close to 4 million, will rise by 7 million by the year 2020, according to a study (Bardhan et al., 2016).

Most parents, other relatives, and ultimately the entire family system face challenges as a result of the initial diagnosis of hearing impairment, including mental stress from time and financial constraints. It becomes challenging to communicate, especially when the illness has a speech delay, an intellectual disability, and delayed communicative development with such kids. This can result in social stigma and isolation, which causes the children to experience negative emotions like sadness, disappointment, helplessness, and aggressiveness. Along with adjusting to the first diagnosis' shocking order to properly care for the affected child, families must gain complete awareness of the use of hearing aids, sign language, educational practices, student placement, and legal matters.

Due to its complex legal, social, educational, psychological, and medical elements, intellectual disability, which affects nearly 156 million people worldwide, is said to be a significant problem. As a result, it is difficult to describe, appreciate, instruct about, and administer to everyone's satisfaction on various degrees of impairment in society. A developmental disease called intellectual impairment comprises scholarly and functional anomalies inside the cognitive areas, communal interaction, and practical implementation. According to DSM 5, intellectual disability affects about 1% of the general populace, 0.12 % of three to five-year-olds and 0.62% of younger males aged six to twenty-one have an intellectual disability.

Status in Pakistan

To investigate the caregiver load, a cross-sectional study was done among those who have children who were intellectually challenged and hearing-impaired. One hundred sixty-two parents of kids with hearing loss and intellectual disabilities were all taken into account. Data were gathered using a non-probability handy sampling strategy. After receiving consent, the information was given by the National Institute of Rehabilitation Medicine executive director and the principal of Al-Farabi Special Education Institute both in Islamabad. The seven-month study took place between July 2018 and February 2019. Parents of kids with intellectual disabilities and hearing loss were also included., but parents of children with any other systemic co-morbidity or disability were not between the ages of 1 and 16. Forms for gathering demographic data were used. They asked questions about the kid and caregiver's age, gender, education, occupation, income, family structure, and handicap level.

A cross-sectional study including 310 moms of disabled children from infancy to age 18 was conducted in Karachi's ten rehabilitation facilities (2019). Thirty-one mothers completed a pretested questionnaire that was used to collect data. Each rehabilitation centre was interviewed as part of a convenience sample. The Maslach Burnout Inventory (MBI) was utilized to evaluate burnout. The correlations between the different characteristics of the research participants and Utilizing linear regression modelling, the scores of its three sub-dimensions—Emotional Exhaustion (EE), Depersonalization (DP), and Personal Accomplishment (PA)—were examined.

Child Features, Behavior and Stress Connected to Children

According to a study, the primary diagnosis of a kid has a considerable effect on the parents' psychological well-being. Parents' typical responses under these circumstances include shock, denial, disbelief, and grief Martin and Colbert (1997). A significant number of literature demonstrates that parents initially struggle with their diminished hopes, and aspirations for their ideal kid and that this grieving process causes them emotional anguish (Martin & Colbert, 1997; McCubbin et al., 1982). However, after the diagnosis, some parents feel relieved because it finally all but ends their questions and gives them answers, according to Martin and Colbert (1997).

According to Waisbren (1980), parents of children with DD must redefine their responsibilities as parents and embrace new identities. This could lead to ambivalence and anxiety, which would only serve to heighten stress levels. Other research raises the possibility that the child's qualities and behaviours connected to the diagnosis may be the source of stress for parents rather than merely the diagnosis itself. They claim that the degree of a child's impairment, It takes time to adjust to the child's characteristics and his demanding actions away from the parents—may be substantially correlated with parental stress (Simmernan, et al. 2001).

Parents may experience significant stress as a result of the problematic behaviours, self-mutilation, and maladaptive behaviours of children with DD. Children need regular monitoring for their own safety and that of their siblings (Cole, 1986). Numerous parents link their children's persistent need for attention to their stress according to Minnes (1988). Many

children with DD may struggle to care for themselves or display actions that are harmful to others, typical for kids their age and developmental stage. Therefore, parents must devote more time and effort to their child and commit more significantly to him. Parents' stress may be reduced as a result (Martin & Colbert, 1997).

Caregiving for an infant with DD affects not just how intensely it is done but also how long it takes. The handicap may hinder or postpone the child's development of autonomy. According to Frey et al. 1989 and Quine and Pahl (1991) certain child-related qualities, such as communication abilities or the degree of difficulty a kid experiences when completing a practice, are all substantially associated with increasing the stress levels that parents go through. Special medical needs and the need for parents to constantly be with their children or to supervise them conflict with the daily tasks of parents. Their limited opportunities to relax, have fun, or take some time for themselves due to a shortage of time lead to fatigue, burnout, and distress (Martin & Colbert, 1997; Cole, 1986). Parental mental health issues and low levels of self-efficacy are linked to children's irrational behaviour (Herring et al., 2006).

Parents' involvement in their children's educational process is crucial. Parents must be more involved with special needs children than typically developing kids (Westling, 1997). There is less time for other activities since they have to take on new obligations for which they are frequently unprepared, attend special training and instruction sessions for parents, communicate frequently and frequently with teachers, etc. When their children fail academically, parents might quickly become demoralized. Stress results from all of this (Martin & Colbert, 1997).

Insights Towards Parenting

Parents' levels of stress are influenced by their cognitive evaluations of their child's handicap. Having a child with impairments will either lead to stress or positive coping and adaptation, depending on how the family perceives the child's handicap, their explanations for why things happen, and their understanding of what they can do to alleviate stress. Numerous research studies have looked into how parental cognitive assessments affect stress. Parental stress levels may be affected by a confluence of kid features and parental views, according to Mash and Johnston (1990). Other research suggests that cognitions may, in some circumstances, predict parental stress more accurately than the kid's unsuitable behaviour Hastings and Brown (2002), Plant and Sanders (2007) and Lustig's (2002) research indicates that it helped families adjust when the disabled person could reframe their disability in a positive light and felt capable rather than helpless. Parents' self-esteem, self-efficacy, and locus of control have been the subject of studies on how parental cognitions affect stress (Hagekull et al., 2001; Hassall et al., 2005; Hastings & Brown, 2002).

Parental thoughts reportedly serve as a mediator between a number of variables that influence parents' burden. Quine and Pahl (1991) discovered that psychological assessments mediate the child's behavioural problems. According to Hasting and Brown (2002), self-efficacy serves as a barrier between the child's maladaptive behaviour and the stress and hopelessness that mothers of autistic children experience. Hassall et al. (2005) discovered that Parental locus of control, parenting satisfaction, and concerns about children's behaviour accounted for most of the variation in parenting stress they evaluated. They also discovered that parental locus of control acted as a mediator in the significant relationship between parental stress and family support.

Methodology

The current study is being conducted under the broader framework of quantitative research technique, which involves statistical methods to analyze data. This enables researchers to identify data patterns, trends, and relationships and make statistically supported conclusions.

Quantitative studies often aim to generalize findings to a large population. The location of the study is District Okara of Punjab province in Pakistan.

This study was conducted in Punjab, Pakistan's District Okara. Parents of children in Okara City who were mentally and physically retired made up the population for this study. The parents are locals whether they came for employment or are otherwise dwelling in Okara.

The sample size of the current study was 60 parents of mentally and physically disabled children. In this investigation, the non-probability sampling method was used. This study adopts the face-to-face interview schedule of the field survey method for data collection. The researcher in this study uses snowball sampling techniques. The non-probability sampling technique known as snowball sampling is widely used in social science research when the target group is difficult to contact or identify. Chain referral sampling and network sampling are other names for it. Snowball sampling relies on the referrals of early participants to find and recruit new participants. The researcher uses interviews, surveys, or other research techniques to gather data from the initial participants. The data may be qualitative or quantitative, depending on the research goals.

Organized questionnaires with closed-ended responses and questions are used as data collecting methods to gather pertinent data for achieving the research's aims and objectives. According to the study's objectives, the questionnaires were created to collect interval, numerical, and nominal data for descriptive and inferential statistics.

Tools for Data Collection

A stress level scale called businesses and professionals of all stripes frequently utilize the Perceived Stress Scale (PSS). The PSS is a self-report stress meter that gauges how much people believe their lives are unpredictable and overwhelming. The Likert scale, which has ten questions and is scored from 0 (never) to 4 (very often), has a maximum of 10 questions. Higher scores represent higher perceived stress levels. The total score goes from 0 to 40.

The Perceived Stress Scale scoring guidelines are as follows:

0 to 13: Low Anxiety

14 to 26: Mild stress

27 to 40: Very stressful

It is crucial to remember that, depending on the person and the circumstance, degrees of stress can vary significantly, and the PSS and other self-report tools are only one method of measuring stress levels.

Study Variable

Parental Stress

This variable focuses on the stress level of parents of children who have retired from the physical and mental workforce. It could be assessed using instruments like the Perceived Stress Scale (PSS) or particular stress measures designed for parents of kids with disabilities.

Physiological Well-being

This variable examines the psychological well-being of parents and looks at things like overall mental health, happiness, and life satisfaction. Psychological health could be evaluated using tools like the SWLS or the General Health Questionnaire (GHQ) to measure general health.

Social Support

This variable examines the availability and perception of social support networks for parents. Support from friends, family, and support groups may be among the contributing elements. Social support can be measured with the (MSPSS) or the Social Support Questionnaire (SSQ).

Parent-child Affiliation

This variable investigates the nature of the bond between parents and their physically and mentally disabled children. Different aspects of the parent-child connection can be evaluated using tools like the Parenting Stress Index (PSI) or the Parent-Child Connection Inventory (PCRI).

Result and Analysis

Socio-Demographic of the Respondents

Table 1: Parents gender

	Frequency	Percent	Valid Percent	Cumulative Percent
Male	15	28.3	30.0	30.0
Female	35	66.0	70.0	100.0
Total	50	94.3	100.0	
Total	50	100.0		

Table 1 showed that the Male Out of the total 50 participants, 15 (30.0%) identified themselves as male. The majority of participants, 35 (70.0%), identified themselves as female. Total: When considering the entire sample of 50 participants, 30.0% were male, and 70.0% were female. It's important to note that there are 3 cases (5.7%) that were not specified or categorized under any gender category. These findings provide an overview of the gender distribution among the parents who participant in the study.

Table 2: Parents monthly income

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	less than 50,000	50	78.1	83.3	83.3
	50,000 – 100,000	6	9.4	10.0	93.3
	100,000 – 200,000	3	4.7	5.0	98.3
	more than 200,000	1	1.6	1.7	100.0
	Total	60	93.8	100.0	
Total		60	100.0		

Table 2 shows the distribution of parents' monthly income among the participants. The table provides information on the frequency, percent, valid percent, and cumulative percent of each income category. The table also indicates that there are 4 cases (6.2%) with missing or unspecified income information. Here is a possible interpretation of the table: Out of the total 60 valid responses, 50 (83.3%) reported a monthly income less than 50,000 PKR. Only 6 participants (10.0%) reported a monthly income in the range of 50,000 to 100,000 PKR. Only 3 participants (5.0%) reported a monthly income in the range of 100,000 to 200,000 PKR. Only 1 participant (1.7%) reported a monthly income more than 200,000 PKR. The cumulative percentages indicate the proportion of participants falling within each income category. For example, 83.3% of participants had a monthly income less than 50,000 PKR, while 98.3% had a monthly income less than or equal to 200,000 PKR. The results suggest that the majority of the participants had a low monthly income, and that there was a wide variation in the income levels among the parents.

Table 3: ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
I often feel overwhelmed by the responsibilities of caring for my disabled child?	Between Groups	5.118	2	2.559	3.211	.049
	Within Groups	37.462	47	.797		
	Total	42.580	49			
I frequently experience fatigue and exhaustion due to demand of parenting a disabled child	Between Groups	2.855	2	1.428	2.578	.087
	Within Groups	26.025	47	.554		
	Total	28.880	49			
I often feel anxious about the future and the challenges my child face.	Between Groups	3.125	2	1.562	.664	.520
	Within Groups	110.655	47	2.354		
	Total	113.780	49			
I frequently feel isolated and lackin support of my family and friends	Between Groups	8.130	2	4.065	4.509	.016
	Within Groups	42.370	47	.901		
	Total	50.500	49			
I often worry about the financial burden associated with my childs disability	Between Groups	2.312	2	1.156	1.179	.317
	Within Groups	46.108	47	.981		
	Total	48.420	49			
Frequently experience disruptions in my sleep patterns due to the stress of parenting a disabled child	Between Groups	2.968	2	1.484	3.028	.058
	Within Groups	23.032	47	.490		
	Total	26.000	49			
Participating in suppot groups or counselling	Between Groups	.280	2	.140	.643	.530
	Within Groups	10.220	47	.217		
	Total	10.500	49			
Engaging in physical exercise or relaxation techniques	Between Groups	.873	2	.436	.541	.586
	Within Groups	37.947	47	.807		
	Total	38.820	49			
Allocating time for hobbiesor objective activities	Between Groups	.130	2	.065	.119	.888
	Within Groups					

	Within Groups	25.790	47	.549		
	Total	25.920	49			
Utilizing problem solving strategies to address challenges related to your child disability	Between Groups	.624	2	.312	.218	.805
	Within Groups	67.376	47	1.434		
	Total	68.000	49			
Taking break or respite from care giving responsibilities	Between Groups	2.270	2	1.135	5.309	.008
	Within Groups	10.050	47	.214		
	Total	12.320	49			

The analysis conducted ANOVA (Analysis of Variance) tests to examine the differences in parental stress levels across various factors related to caring for a disabled child. The variables analyzed include feeling overwhelmed by caregiving responsibilities, experiencing fatigue and exhaustion, feeling anxious about the future challenges the child may face, feeling isolated and lacking support from family and friends, worrying about the financial burden, experiencing disruptions in sleep patterns, participating in support groups or counselling, engaging in physical exercise or relaxation techniques, allocating time for hobbies or enjoyable activities, utilizing problem-solving strategies, and taking breaks or respite from caregiving responsibilities.

The results of the ANOVA tests are as follows:

- Feeling overwhelmed by caregiving responsibilities: The groups differed significantly from one another ($p = .049$), indicating that the levels of feeling overwhelmed varied across different groups.
- Experiencing fatigue and exhaustion: There was no significant difference between groups ($p = .087$), suggesting that the levels of fatigue and exhaustion were similar across different groups.
- Feeling anxious about the future and the challenges the child may face: There was no significant difference between groups ($p = .520$), indicating that anxiety levels were comparable across different groups.
- Feeling isolated and lacking support from family and friends: The groups differed significantly. ($p = .016$), suggesting that feeling isolated and lacking support varied across different groups.
- Worrying about the financial burden: No discernible difference existed between the groups. ($p = .317$), indicating that the levels of financial burden-related worries were similar across different groups.
- Experiencing disruptions in sleep patterns: No discernible difference existed between the groups. ($p = .058$), suggesting that the levels of sleep pattern disruptions were comparable across different groups.
- Participating in support groups or counselling: No discernible difference existed between the groups. ($p = .530$), indicating that the levels of participation in support groups or counselling were similar across different groups.
- Engaging in physical exercise or relaxation techniques: No discernible difference existed between the groups. ($p = .586$), suggesting that the levels of engagement in physical exercise or relaxation techniques were comparable across different groups.

- Allocating time for hobbies or enjoyable activities: No discernible difference existed between the groups. ($p = .888$), indicating that the levels of time allocation for hobbies or enjoyable activities were similar across different groups.
- Utilizing problem-solving strategies: No discernible difference existed between the groups. ($p = .805$), suggesting that the levels of utilizing problem-solving strategies were comparable across different groups.
- Groups taking breaks or respite from caregiving responsibilities differed significantly from one another ($p = .008$), indicating that the levels of taking breaks or respite from caregiving responsibilities varied across different groups.

Table 4: Analysis of variance by parental Stress across physical, mental and both disable children

Variable		Sum of Squares	df	Mean Square	F	Sig.
I often feel overwhelmed by the responsibilities of caring for my disabled child?	Between Groups	5.118	2	2.559	3.211	.049
	Within Groups	37.462	47	.797		
	Total	42.580	49			
I frequently feel isolated and lacking support of my family and friends	Between Groups	8.130	2	4.065	4.509	.016
	Within Groups	42.370	47	.901		
	Total	50.500	49			
Taking break or respite from care giving responsibilities	Between Groups	2.270	2	1.135	5.309	.008
	Within Groups	10.050	47	.214		
	Total	12.320	49			

The above table comprises the result of the one-way analysis of variance. The table showed that the overwhelmed responsibilities of caring for a disabled child significantly differ across the parental stress, $F(2,49) = 3.211$, $p = .049$. The table also showed that the lack of support from family and friends is significant across the parental stress $F(2, 49) = 4.509$, $p = .016$. The table also showed that the respite from the caregiving responsibilities is significant across the parental stress $F(2,49) = 5.309$, $p = .008$.

Conclusion

In conclusion, the analysis of parental stress among caregivers of disabled children reveals essential insights into the experiences and challenges faced by these caregivers. The findings indicate that caregivers often feel overwhelmed by their caregiving responsibilities and may experience isolation and lack of support from family and friends. Additionally, the availability of breaks or respite from caregiving duties varies among caregivers.

These findings emphasize the need for targeted interventions and support systems to address the specific needs of caregivers of disabled children. Providing resources and assistance to help caregivers manage their responsibilities, cope with stress, and access social support can contribute to their children's well-being and ability to provide quality care.

Healthcare professionals, policymakers, and support organizations must recognize the unique needs of caregivers of disabled children and develop comprehensive support programs that address their physical, emotional, and social well-being. By implementing strategies to reduce caregiver stress, enhance support networks, and promote self-care, we can improve the overall quality of life for both caregivers and disabled children.

Further research is needed to gain a deeper understanding of the specific factors contributing to parental stress among caregivers of disabled children and to evaluate the effectiveness of different interventions and support programs in alleviating this stress and improving caregiver well-being. By prioritizing the well-being of caregivers, we can create a more supportive and inclusive environment for families with disabled children.

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