

Parental Stress of Pakistani Families with Children who Have Developmental Disabilities

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ABSTRACT

Background: The goal of this research was to find out what factors were associated with these parenting effects in Pakistani mothers and dads who had children with intellectual disability (ID) or autism spectrum disorders (ASD). A total of 191 parents agreed to take part in the study, 100 of whom had a child with ADS and 91 of whom had a child with ID. Each participant filled out standardized parenting stress scale rating scales and provided demographic data during the interview. Families who have children with Autism and ID have higher emotional state, according to structural equation modelling.

Objective: To find out parental stress of Pakistani families with children who have developmental disabilities.

Methodology: The cross-sectional study was conducted through five different organizations in Lahore, Pakistan (Bases, Rising sun, Dimensions, Autism resource center, Oasis) and from two hospitals (Mayo Hospital Lahore and Sheikh Zaid Hospital). Standardized questionnaire (Parental stress scale) was used. Data was collected through standardized questionnaire after taking informed consent and distributed among the parents with children that have special needs (ASD and ID). Parents were asked to complete a questionnaire. Result scores were recorded for every respondent. The data was analyzed by "Statistical Package for Social Sciences" SPSS (version 22.0).

Results: Using a standardized questionnaire, it was shown that the emotional well-being of families with children with ASD and ID was much worse, with both mothers and fathers reporting emotional exhaustion. Stress was exacerbated by a lack of emotional well-being. ASD parents show high percentage of 72.2% and ID parents show highest percentage of 61.1% so according to the given standardized questionnaire points the higher the percentage the higher the stress level. While raising a kid with neurological disabilities has a roughly comparable effect on Pakistani families as it does on parents in other countries, there is evidence that children with ASD and ID provide particular challenges to these families.

Conclusion: Parents of both children face higher stress level. High level of parent stress needs timely counselling of the parents about the circumstances that they need to be encountered with having an abnormal child. They shall be aware with the techniques to deviate their mind from the most recurring point of stress.

Keywords: Autism spectrum disorder, Intellectual disability, Parental stress, Pakistan, Health, developmental disability

INTRODUCTION

Stress seems to be obvious and it has been regarded as a usual part of the parental obligations. The level of usual stress goes high when we talk about the families with children with ASD. For studies have shown that the families of Autism Spectrum Disorder develop more stress as compared to those having children with other growing disorders.^[1]

Raising a child with physical disabilities is directly proportional to parent's pain. It brings both impediments and prospects for levitation of children that are having Neurodevelopmental Disorder. Until a child becomes self-sufficient, extra care must be made available by linked paternities.

^[2] This anxiety can be defined as the sense of disparity among the requirements of parenting and the possessions that are accessible.

^[3] Raising a kid is kind of a difficult task, and raising a child with other developmental disabilities is significantly more difficult. It is more stressed for the parents of disabilities as compared to those who are normal. For having an incapacitated child can cause a lot of hindrances and problems in one's life. The problems that are very momentous usually relate with up keeping of the disabled children, which typically create influence on their capacity to maintain the children and other household prerequisites.^[4]

The term autism is used to describe a collective state of acute and enduring neurodevelopmental diseases which is featured by discrepancies in public communication, interface and recurring of same activities. (American Psychiatric Association, 2002). Mental disability was often used for person who has less than 70 Intellectual proportion and disability in the skill of adapting things before one reaches the age of eighteen.^[5]

The behavior with constrained and monotonous patterns as well as an extensively growing disability that is clearly manifested

by communication deficiencies is Autism Spectrum Disorder (ASD).^[6]

Proper maintenance of a kid with ASD can cause anxiety states to rise above those experienced by families with normally growing kids and children with other neurological impairments. A comparison of maintaining those children that have Autism Spectrum Disorder and normally developed children, the later one are easier to handle.^[7] Along with the caring difficulties as well as extensive financial damages add upon the already existing emotive stress and lifestyle changes in the parents of the children who get diagnosed with ASD.^[8] Emotional and behavioral symptoms that are accompanied by extra psychopathology have negative consequences that extend beyond ASD's core symptoms. With the principle symptoms of ASD, the emotive a communicative symptoms with psychopathology lead to more negative results.^[9] The parents of ASD's children are under more stress as compared to those having children with other difficulties.^[10] A huge number of studies have recently discovered that families with kids with ASD experience significantly greater emotional states and depression and anxiety symptoms than parents of typically developing children. There are various factors that lead to increase in the stress of parents having children with the problem of autism, this includes the children communal conduct, interaction problems, emotive boredom, dysregulation issues, less uptake of food, and sleeplessness. People feel reluctance in accepting the functional disability of their children. The health status of the main guardian who's providing assistance to the autistic children is critical to define the responsibilities of other family members.^[11]

Intellectual impairment is the term that is mostly used to show declining of both mental efficiency as cognitive, knowledgeable with critical thinking ability and interactive

performance which include all the public and real problems.^[12] It has published by the Diagnostic and Statistical Manual of Mental Abnormalities in its Fifth version that the diagnosis lie in all the intangible, societal, as well as applied areas of a disorder. It is getting usual for the parent of an autistic children to get sensitive, indecisive, astounded, grieve, faulty, disdain and skeptical of the reliability of every diagnosis.^[13]

The parents who are under the bad stimulus of raising the children with intellectual impairment are facing two problems initially as a start, many children are considered at the ground of various functionality where the abnormalities of the functionality are ignored most of the time.^[14]

Literature Review: The purpose of this study with Iranian mothers and fathers who might have kids with intellectual impairments (ID) or autistic spectrum disorders was to see if there were any correlations between these parental factors and their children's outcomes (ASD). The study enrolled 121 parents of children with ADS (69 women and 52 males from 94 households) and 115 families of children with ID (101 families, out of which 83 were mothers and 32 were dads). Each participant filled out conventional scoring system for parental stress, psychological health, family characteristics, and fulfillment with caregiving role, and also demographics details and information of unstructured resources, during an interview. Parental involvement was substantially weaker in families with an ASD kid, according to measurement model, both mothers and fathers reported greater stress levels. Higher emotional levels were linked to worse emotional well-being amongst mothers, single parents, and parents of children with developmental disabilities.^[15]

Parents in the IMAGINE-ID study (n = 888) reported significantly more psychological stress than the general population in the UK (Cohen's d = 0.546). In between deviation were connected to current life experiences and the perceived effect of children's concerns. Age of the child, physical handicap, autistic traits, and other behavioral issues all predicted the impact. Kid and family factors influence parents' psychological health when looking after children with a mental retardation, which converge on parental evaluation of impact. We discovered that genetic etiologies, in general, influence impact and thus family hazards. Families of people with autism spectrum disorder (ASD) are much more likely to suffer from stress than caregivers of children who are growing normally (TD).^[16]

The goal of this research was to look at whether or not Parents of children with special needs and their child's negativity (environmental precursors), and also opinions of their child, to better understand their subjective wellness and physiological stress. The subjective wellness of 37 families of ASD kids and 41 families of TD children was evaluate, and physically stress was assessed. Additionally, toddler's pessimism was detected, as well as families' impressions of their kid's issues. Parents reported autistic features, emotion management ability, and liability/negativity, among other things and their application of reassessment. Parents of children with ASD reported lower subjective outcomes than caregivers of children with usual development also well enough and higher stress response. Parents' judgments of their children's liability/negativity, as well as their use of reassessment, were better predictors of subjective health than ASD, and parents' opinions of their children's liability/pessimism attributed equally more to families' physiological stress as ASD. Working with parents at the level of perceptual constructs and reappraisal capacity will help prevention and intervention strategies aimed at parental wellness and their mental health.^[17]

In Africa, no such research has yet been carried out. The focus of this thesis is to investigate how frequent mental harm is among Malawian parents of intellectually disabled children, as well as what variables contribute to it. In January and February of 2015, a quantitative cross-sectional investigation was conducted. A number of 177 mothers and dads of children with intellectual impairments were recruited at random from two child impairment clinics. "As a measure of psychological discomfort, questions on

socio-demographic factors were presented to all consenting individuals," according to the study. Families of kids with mental retardation reported psychological anguish in 70/170 (41.2%) of cases. In Malawi, there is a significant amount of psychological suffering amongst families of intellectually impaired children.^[18]

This study looked at a framework that suggested (a) familial pressure and the family environment used by families of kids with ASD are linked; (b) ASD symptoms, family functioning, and style of parenting all clarify deviation inside the demonstration of externalizing and internalizing signs within and between individuals with Disabilities; and (c) after attempting to control for particular demographic factors, style of parenting moderates the affiliation among ASD intensity as well as the demonstration of externalizing and internalizing symptoms among children with ASD. . A self-report measure was completed by 70 primary caregivers of children diagnosed with ASD varying in age from three to eighteen years. Externalizing behaviors were found to be influenced by ASD severity and parenting style, but not by internalizing behaviors, according to statistical studies. Parental stress was found to be the strongest with both characterized by strong and emotion dysregulation behavior of children are influenced by this variable. The relationship between ASD severity and internalizing and externalizing behavior was not found to be mitigated by parenting style, nor was it linked to the emotional state of families with children with ASD.^[19]

MATERIALS AND METHODS

The cross-sectional study was conducted through five different organizations in

Lahore, Pakistan (Bases, Rising sun, Dimensions, Autism resource center, Oasis) and from two hospitals (Mayo Hospital Lahore and Sheikh Zaid Hospital). The study was conducted in 6 months after the approval of synopsis from November 2021 to February 2022. The inclusion criteria was both Mother and Father of children with developmental disabilities (ASD and ID) were included. And parents of children with other co-morbid disabilities were excluded. Purposive sampling technique was selecting to collect the data. Standardized questionnaire (Parental Stress Scale) consist of 18 questions was used. Parents were requested to fill the questionnaire. Results score were recorded for every respondent. After the completion of data, frequencies of each question were calculated through statistical package for social sciences (SPSS) to evaluate final results of research. 191 parents of children with disabilities (ASD and ID) were participated. Out of which 100 were parents of ASD and 91 were parents of ID. Sample size were calculated by estimated population mean.

RESULTS

Table 1: Shows the characteristics

Demographic	Features	N (%)
Age Mean 5.33 SD + 2.054	3-5	126(63.5)
	5-7	41(20.8)
	7-11	19(11.5)
	11-13	7(3.6)
Gender	Male	120(63)
	Female	71(37)
Current Diagnosis	Autism	100(52)
	Intellectual Disability	91(48)
Birth Order	1 st Order	97(51)
	2 nd order	60(31)
	3 rd order	23(12)
	4 th order	9(5)
	5 th order	2(1)
Number Of Siblings	0-2	119(62.3)
	2-4	64(33.5)
	4-6	8(4.2)

The higher the score the higher the measured level of parental stress

18- Low stress level

90-high stress level

The above mentioned figures point out that parents who participated have higher stress level. Using a standardized questionnaire, it was shown that the emotional well-being of

families with children with ASD and ID was much worse, with both mothers and fathers reporting emotional exhaustion and higher stress level.

Table 2: Show the frequency and percentage of each question.

No	Statement	Strongly disagree	Disagree	Undecided	Agree	Strongly Agree
1.	I am happy in my role as a parent	6(3.1%)	29(15.2%)	40(20.9%)	74(38.7%)	42(22.0%)
2.	There is little or nothing I wouldn't do for my children if it was necessary	120(6.3%)	6(3.1%)	45(23.6%)	102(53.4%)	26(13.6%)
3.	Caring for my children sometimes takes more time and energy than I have to give	19(9.9%)	19(9.9%)	22(11.5%)	99(51.8%)	32(16.8%)
4.	I sometimes worry whether I am doing enough for my children	8(4.2%)	22(11.5%)	25(13.1%)	106(55.5%)	30(15.7%)
5.	I feel close to my children	3(1.6%)	43(22.5%)	36(18.8%)	60(31.4%)	49(25.7%)
6.	My children is an important source affection for me	5(2.6%)	2(1.0%)	31(16.2%)	96(50.3%)	57(29.8%)
7.	Having children gives me a more certain and optimistic view for the future	4(2.1%)	15(7.9%)	39(20.4%)	82(42.9%)	51(26.7%)
8.	I enjoy spending time with my children	4(2.1%)	42(22.0%)	40(20.9%)	57(29.8%)	48(25.1%)
9.	The major source of stress in my life is my children	22(11.5%)	48(25.1%)	35(18.3%)	72(37.7%)	14(7.3%)
10.	Having children leaves little time and flexibility in my life	12(6.3%)	41(21.5%)	36(18.8%)	87(45.5%)	15(7.9%)
11.	Having children has been a financial burden	20(10.5%)	32(16.8%)	34(17.8%)	60(31.4%)	45(23.6%)
12.	It is difficult to balance different responsibilities because of my children	16(8.4%)	18(9.4%)	22(11.5%)	113(59.2%)	22(11.5%)
13.	The behavior of my children is often embarrassing or stressful to me	30(15.7%)	27(14.1%)	36(18.8%)	60(31.4%)	38(19.9%)
14.	If I had to do over again, I might decide not to have children	34(17.8%)	60(31.4%)	56(29.3%)	36(18.8%)	5(2.6%)
15.	I feel overwhelmed by the responsibility of being a parent	9(4.7%)	37(19.4%)	27(14.1%)	75(39.3%)	43(22.5%)
16.	Having children has meant having too few choices and too little control over my life	2(1.0%)	50(26.2%)	45(23.6%)	82(42.9%)	12(6.3%)
17.	I am satisfied as a parent	12(6.3%)	60(31.4%)	50(26.2%)	38(19.9%)	31(16.2%)
18.	I find my children enjoyable	29(15.2%)	62(32.5%)	48(25.1%)	23(12.0%)	29(15.2%)

Table 3: Cumulative percentage

Categories	Cumulative frequency ASD	Cumulative frequency ID
Higher stress level	72.2%	61.1%
Lower stress level	27.7%	38.8%

DISCUSSION

The majority of the youngsters that took part in research were male. The current diagnosis of children were Autism and ID. The study was held extensively on a group 191 parents out of which 91 were the families of intellectually handicapped children and the remaining 100 with children of parents who have developmental disabilities. The goal of this research was to find out more about learn more about the parental stress among these parents. The result of research has shown that the families of children with both abnormalities are under stress. The objective of this study was to observe the parental behavior. As most of the parents find the behavior of their children embarrassing and stressful. They are not even in the state to have babies in the future again. They feel the responsibility linked with the disabling of their children so much overwhelming.

First study was conducted in 2014 by Samadi SA et, al. on Parental wellbeing of Iranian families with children who have developmental disabilities. This study provides a lot of benefits. It contributes to a growing corpus of knowledge on raising a kid with neurodevelopmental disorders by contrasting the experiences of people whose families were diagnosed with ASD against those with ID, and both dads and mothers participated as informants. The study included 121 parents who have children with ASD (69 mothers and 52 dads of 94 households) and 115 families of children with intellectual disability (out of 101 families 83 were mothers and 32 were fathers). When in an interview, each participant completed rating scale scales of parental stress, psychological health, family characteristics, and fulfillment with caregiving role. According to structural equation modelling, family support was much lower in households with an ASD child, and both parents reported greater states of anxiety. [15]

Second study was conducted in 2021 by Kate Baker et, al. on Childhood intellectual disability and parents' mental health: integrating social, psychological and genetic influences. This is the first study to look at genetic diagnosis as a possible risk factor in

the context of juvenile intellectual impairment. As in previous research, there is a large range of parental emotional well-being, but among families who care their child with intellectual impairment, this range was drastically pushed toward heightened risk. The emotional discomfort of ID parents (n = 888) was substantially higher (Cohen's d = 0.546). For between variations was connected to current life experiences and the perceived effect of children's concerns. Child age, physical impairment, autistic features, and other behavioral issues all had an impact. As a result, families of ID adolescents are much more worried than families of non-ID adolescents. [16]

Third study was conducted in 2018 by Yun Ju Hasio on parental stress on families of children with disabilities. The influence of parent descriptive statistics and parental support on the standard of living in families with children who have ASD were investigated in this study. 236 families of individuals with Disabilities were gathered among 4 autistic healthcare professionals inside a southwest state in the United States for the study. The Family Quality of Life Scale and the Parental Stress Scale were used to gather data for this study. According to the data, families who have children with ASD are more stressed and have a worse quality of living. The latest findings add to the growing body of evidence supporting Treatment and assistance are critical in reducing parenting stress and financial constraints, as well as tailoring treatments and provide assistance to each family's particular requirements in aims to enhance the quality of life of families with individuals having ASD. [3]

Fourth study was conducted in 2020 by E Staunton et, al. families under pressure: Stress and quality of life in parents of children with an intellectual disability. Almost majority of the children in the research were male, nonverbal, and also had modest developmental disabilities as well as other health issues. Nearly three-quarters of the individuals had been diagnosed with ASD. The goal of this study was to up the tension and standard of living in families of children with moderate-severe-profound intellectual disabilities who participate a Child and Adolescent Mental Health Intellectual Disability Service (CAMHS ID), and also to approximate participants experienced of behavioral issues and satisfaction with support systems. The anxiety of parents PSI 4 is a 120-item questionnaire that evaluates the parental method and

detects defects that might contribute to behavioral disorders in either the child or the parent. The Beach Center Family Quality of Life Scale is a 25-item survey that assesses how satisfied families are with various aspects of family quality of life on a 5-point scale range between "very unhappy" to "very satisfy". FQOL is defined as a set of five domains. Parents face significant amounts of mental stress in addition to the difficulty of caring for a child with an intellectual disability, according to the study. Family quality of life is negatively related to intellectual disability, ASD diagnosis, and parent self-reported stress, implying that the more difficult a child's presentation is and the more stress a parent endures, the less likely the family will have a good quality of life.^[20]

As a conclusion of this discussion, the mental state of the parents has highly affected due to the abnormality in the behavior of their children

CONCLUSION

The overall study of the parental behavior towards the abnormality of their children shows high level of stress among both parents. This study can be highly related with the support providers of family career development in Pakistan and at the international level also. High level of parent stress needs timely counselling of the parents about the circumstances that they need to be encountered with having an abnormal child. They shall be aware with the techniques to deviate their mind from the most recurring point of stress.

Conflict of Interests: The authors declare that they have no conflict of interests with any organization regarding the materials discussed in this manuscript.

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