

Psychological Stress, The Role Of Caregiving, And Quality Of Life In Parents Of Children With Learning Disabilities In Pakistan

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Abstract:

This study aimed to evaluate the level of psychological stress, burden sentiments, and their impacts on parents in Pakistan caring for kids with learning difficulties. Data were gathered using a correlational study approach from psychiatric institutions and special education schools in Lahore, Pakistan. Using purposive sampling, a total of N=100 individuals (50 men and 50 women) were selected. Parents' levels of stress were measured using the Perceived Psychological Stress (Cohen, 1983), the Family Caregiving Role Scale (FCRS; Schofield et al., 1997), the severity of the burden was assessed using the Family Caregiving Role Scale (FCRS), and the Quality of life (EQ-5D; Van Reenen & Janssen, 2015) was used to assess the effects of having children with learning disabilities on parents' lives. The findings, which were analyzed using SPSS, showed a negative correlation between psychological stress and emotions of burden about parents' life among those parenting children with learning difficulties. Dads reported greater stress levels and loads than mothers, and differences were also seen between mothers and dads. These results highlight the need for parents to have their psychological needs and support requirements met when parenting children with learning impairments in Pakistan and shed light on their difficulties.

Keywords: Psychological stress, Feelings of burden, Learning disabilities, Pakistan.

Place and Duration: this study was conducted at Lahore College for Women University, Lahore, from May 2021 to May 2022.

Introduction

There are many causes of neurodevelopmental disorders, also known as learning difficulties, including genetic and environmental factors. Worldwide, there is a sizable incidence of learning difficulties (Smith et al., 2020). About 10% of children in high-income countries (HICs) are thought to have learning difficulties (CDCP, 2020). The incidence and prevalence of learning difficulties in Low and Middle-Income Countries (LMICs) are poorly characterised. According to research done in Lahore, Pakistan, one in every 300 kids has a learning disability (Siddiqui, 2021). Rehman and Obaid (2005) noted that learning difficulties are more common in Pakistan's rural areas. This demonstrates the necessity of more research into the effects and difficulties experienced by parents in Pakistan who are trying to raise kids with learning problems. Learning disabilities like Down syndrome can significantly affect a child's cognitive, academic, and social functioning. Understanding the specific challenges parents face with children with learning disabilities is crucial to providing appropriate support and interventions. By addressing the unique needs of these parents, we can improve family functioning and enhance the children's and their carers' overall well-being.

Different researchers have suggested that parental stress is not only deleterious to parents but also affects the children and the family's overall functioning, eventually increasing the burden on the family (Daundasekara et al., 2021). A systematic review indicates that quality of life is significantly affected due to parental stress, either from the father or mother, which can be determined as a reduction in life satisfaction (Martin et al., 2019). It has been shown that parental stress is the cause of less stimulation for parents with their children (Miragoli et al., 2018). A study based on the cross-disability approach indicated that the emotional manifestation, particularly the countenance of high criticism, was associated with the parents of children with learning disabilities, ultimately negatively affecting and increasing the family's burden (DePauw S.W., 2020).

In a longitudinal study, it has been revealed that economic and cultural diversity vary in HICs and LMICs (Bryant et al. 2011; Hsiao and Van 2011; Department of Education and Skills 2006; Selway and Ashman 1998). Studies conducted in different Islamic studies also showed that although it has been considered that LD is due to God's will, there is a lot of stress, familial stigma, and societal burden associated with the parents (Ahmed et al., 2006; Bryant et al., 2011). Conversely, almost no research was conducted to explore the parental perspective in Pakistan. Thus, the present study aims to explore parental stress and familial burden and how they affect the quality of life of parents with children with learning disabilities in Pakistan.

The Rationale of the Study

There is a scarcity of research focusing specifically on parents of children with learning disabilities in Pakistan. Most studies in this area have been conducted in high-income countries, and there is a need to explore parents' unique experiences and challenges in a Pakistani context. This study aims to fill this research gap and provide valuable insights into the psychological well-being and

support needs of parents in Pakistan. Parents play a crucial role in supporting and nurturing their children, especially those with learning disabilities. However, raising a child with learning disabilities can be demanding and stressful, potentially adversely affecting parental well-being. Understanding the psychological stress and burden that parents experience can help identify areas where support and interventions are required to promote their well-being and ultimately improve family functioning.

Methods

The current study examined the severity of psychological stress, feelings of burden, and their effects on parents raising children with symptoms of learning disabilities in Pakistan.

Research Design

The co-relational research design examined the severity of psychological stress, feelings of burden, and their effects on parents raising children with symptoms of learning disabilities in Pakistan.

Sampling Strategy and Sample

The correlational research study was conducted through purposive sampling by selecting those parents who had children with learning disabilities in Lahore, Pakistan (N=100), aged between 1 year to 10 years (M = 6.59, SD = 1.88). A total of 100 participants participated in the research, of which fifty-five (N=50) were fathers and fifty (N=50) were mothers, as the formal sample size recommendations by Andy Field Were N=100 (Field, 2013) for good practice. The sample was recruited by administering the inclusion criteria checklist after obtaining written and verbal consent from parents and the institute.

Research Tools

The researcher filled out the demographic form for those who fulfilled the inclusion criteria or consented to participate in the study. The demographic form, which includes age, socioeconomic status, mother's occupation, family system, age of diagnosis, the reaction of the family upon diagnosis, changing reaction, and future concerns (Inclusive schooling, Mainstream Education, Vocational training), was asked by parents before starting the interview.

Parents and researchers each completed a different psychological assessment form. These were;

1. Perceived Psychological Stress (Cohen, 1983)

Sheldon Cohen (1983) developed a perception of psychological stress. Amna Tahir and Prof. Rukhsana Kausar (Institute of Applied Psychology, University of the Punjab, Lahore, Pakistan) translated the scale in 2013. The 14-item scale rates from "0 to 4", in which 0 means Never, 1= rarely, 2= sometimes, 3 means almost frequently, and 4 means very frequently. The higher score on the scale shows higher stress levels in the participants. The reliability of the scale in the present study was .61.

2. **The Family Caregiving Role Scale** (Schofield et al.,1997)

The Family Caregiving Role Scale (FCRS), developed by Schofield et al. (1997), is widely used to measure burden severity among family care-givers. The scale assesses the care-giver's perception of the demands and challenges associated with their caregiving role. It is specifically designed to capture the multidimensional aspects of the burden experienced by caregivers. The FCRS consists of items that tap into various dimensions of caregiver burden, including emotional, role, financial, social, and physical strain. Caregivers rate each item on a Likert scale, indicating the extent to which they agree or disagree with the statements. The scale encompasses items such as "I feel emotionally drained from caregiving" and "I have difficulty managing my responsibilities due to caregiving demands."

3. **Quality of Life** (EQ-5D-5L) (van Reenen & Janssen, 2015)

A standardised instrument to measure health status and associated population utility weights. It consists of a self-report questionnaire covering five dimensions of health, such as mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. The Urdu version of the scale will be used, which has already been used in Pakistan (Husain et al., 2017; 2020).

Ethical Considerations

To start the study, the first step was to get approval from the ethical board of the university. The research proposal was presented, and the ethics board recommended some changes. After making appropriate changes, permission was finally granted by the university board to conduct the research. The second step was to approach the authors of all the instruments we planned to use during the research. An official email was sent with the objective of the study to the respective authors of instruments for permission to use their scales. After getting the authors' written permission, the work on the ground started. At the third level, permission was obtained from different special education schools and Psychiatry OPDs of hospitals to obtain data. The information leaflet has been designed for the participants in hard copy so they can understand the study's objectives and receive an invitation to participate. The information leaflet was provided in English and Urdu for their understanding. Written consent has been obtained before starting the study. The participants have been informed that confidentiality will be maintained during the research.

Results

The current study explored the severity of psychological stress, feelings of burden, and their effects on the lives of parents raising children with symptoms of learning disabilities in Pakistan. Descriptive and inferential statistics were both used to analyse the data accordingly, including to determine the reliability of the Cronbach's alpha of the scales, the skewness and kurtosis of the variables and their scales, and the values of means, standard deviations, and percentiles in the case of the demographic characteristics of the participants. Pearson's Correlation Coefficient, Multiple Linear Regression, and independent sample t-test were conducted to execute the results and outcomes of the gathered data using "Statistical Package for Social Science (SPSS) version 21".

Table 1.1 The table shows the Psychometric Properties of psychological instruments (N=100)

Instruments	K	M	SD	α	Skewness	Kurtosis
Perceived Psychological Stress	100	45.46	4.6	0.83	.285	-.501
The Family Caregiving Role Scale	100	32.14	2.5	0.90	-.244	-.639
Quality of Life	100	69.05	4.06	0.94	.296	-.297

Note. k=No of items; α =Cronbach's alpha; SD =Standard Deviation

The result concluded that psychometric properties of variables have significant skewness and kurtosis values, i.e., all assessment scales used in the study had good reliability to use in the current study. The distribution of the assessment ranges was normal. Psychological stress, familial burden and family quality of life values are 0.83, 0.90 and 0.94, respectively.

Table 1.2 The table shows the characteristics of the sample (N=110)

Variables	M(SD)	f(%)
Age	6.59(1.88)	-----
Socioeconomic Status	2.1(.62)	-----
Lower	-----	6(16.9)
Middle	-----	38(69.1)
Upper	-----	11(20.1)
Mother's Occupation	1.67(.48)	-----
Working	-----	18(32.7)
Housewives	-----	37(67.3)
Family System	1.40(.49)	-----
Nuclear	-----	18(32.7)
Joint	-----	37(67.3)
Reaction upon diagnosis	2.36(.70)	-----
Denial	-----	15(27.3)
Hard to accept	-----	13(23.6)
Acceptance	-----	27(49.1)
Age of Diagnosis	1.47(.66)	-----
At birth	-----	34(61.8)
Within one year	-----	16(29.1)
Within two years	-----	5(9.1)
Future Concerns	2.05(.83)	-----
Inclusive Education	-----	17(30.9)

Mainstream	-----	18(32.7)
Vocational Training	-----	20(36.4)

Note. M=Means, SD=Standard Deviations, f=frequencies and % Percentages

Results revealed that most of the participants belonged to middle socioeconomic status with a mean of (M=2.1, SD=.62), and belonged to the nuclear family system (M=1.40, SD=.49). The percentage of working women was higher (M=1.67, SD=.48). The acceptance of having special children, i.e. learning disability was very difficult for the parents (M=2.05, SD=.83). Furthermore, majority of the parents were willing to make their children study at mainstream schools (M=2.05, SD=.83) rather than inclusive education or vocational training.

Table 1.3 The table shows the correlation coefficient of learning disability parents (N=110)

Variables	1	2	3	M	SD
1. Parental Stress	—	.378***	-.207*	45.46	4.61
2. The Family Caregiving Role Scale	—	—	-.060	32.13	2.52
3. Quality of Life	—	—	—	78.84	4.06

“Note. *p<0.05, **p<0.01, ***p=0.001”

Results concluded that a significant positive relationship exists between parental stress and the family caregiving burden $r = .37, p < .0001$. Thus, parental stress increase with the enhancement of familial burden among parents.

Table 1.4 Linear Regression Analysis for the variables Parental Stress, Familial Burden Predicting Family Quality of Life among Learning Disability parents (N=110)

Variables	B	SE(B)	β	R ²	ΔR^2
				.334	.321
1. Parental Stress	.202	.04	.433***		
2. The family caregiving role scale	.119	.04	.252**		

Note. ΔR^2 = Adjusted R²; B= Unstandardized Coefficients; SE(B) = Standard error of unstandardized coefficients; β =Standardized Coefficient Beta. *p<0.05, **p<0.01, ***p<.001

The results showed two predictors: 33.48% of the adjustment $R = .58, F(2,107) = 26.81, p < 0.005$. Parental stress significantly predicts quality of life in the family ($\beta = .43, p < .001$). Furthermore, the familial burden also positively predicts quality of life from the family perspective ($\beta = .25, p < .005$) among the parents of children with Learning disabilities. Both predictors, parental stress and familial burden, were tested against the family quality of life among the parents of children with Learning disabilities; both of them positively predicted the family quality of life, which shows that

parental stress and familial burden majorly influence the family quality of life among the parents of the children with Learning disabilities.

The present study investigated the severity of parental stress and familial burden and their impact on the quality of life of parents raising children with learning disabilities in Pakistan. The study's findings revealed that parental stress was prevalent among parents of children with learning disabilities and had detrimental effects on the family's overall physical and psychological well-being. This is consistent with previous research highlighting the negative consequences of parental stress on the family system (Staunton et al., 2020). Moreover, the literature supports the correlation between stress and its effects on an individual's physical and psychological health and the disruption of their overall quality of life (Lappe et al., 2018). In accordance with this, it is well known that parents of kids with special needs and neurodevelopmental problems are more stressed than average (Lohaus et al., 2020). In our study, significant levels of stress were reported by both mothers and fathers. Nevertheless, men looked to be under more stress than mothers owing to their numerous obligations, including difficulties with money, relationships, jobs, and psychiatric issues; a lack of professional help for their kids; and cultural shame.

Intriguingly, the study discovered that dads of kids who had been diagnosed with learning difficulties had a higher quality of life than mothers. This may be explained by the fact that women are likely to experience emotional strain more easily than dads do and may also have a lower tolerance for stress and load. Given that their experiences are frequently understudied, the cultural environment also has a substantial impact on the psychological stress felt by mothers of children who have common psychiatric or developmental issues (Nordstrom et al., 2020).

The results of this study are in line with earlier research, which found that parents of kids without neurodevelopmental issues had greater levels of marital closeness than parents of kids with Down syndrome (Carrada et al., 2020). In addition, healthy parents often enjoy a greater quality of life than parents of Down syndrome kids (Sheridan et al., 2020). Additionally, our study found that parenting kids with learning difficulties had a considerable impact on the parents' quality of life.

Implications:

This study adds to the body of knowledge on parental caregiving, stress, and quality of life among parents of children with learning impairments, particularly in Pakistan. For clinical psychologists and other professionals dealing with families in this demographic, the findings have significant ramifications. The findings can guide the creation of specialized management strategies to solve the difficulties experienced by parents while taking Pakistan's cultural environment into consideration. Professionals may create effective treatments and support methods to reduce parental stress and enhance general wellbeing by studying the reasons for parental stress and its influence on quality of life. In order to reduce the negative effects of parental stress and provide a higher quality of life for families raising children with learning difficulties, early detection and intervention can be extremely important.

In conclusion, this study provides insight into Pakistani parents of children with learning impairments in terms of psychological stress, the importance of caring, and quality of life. In order to address the particular difficulties faced by these parents and enhance the wellbeing of both parents and children with learning impairments, it emphasises the necessity for specific assistance and interventions.

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