

Economic Burden of Rehabilitation Services Among Parents of Children with Autism Spectrum Disorder in Pakistan: A Cross-Sectional Study

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Abstract

Background: This study quantifies the economic burden of rehabilitation services on families of children with autism spectrum disorder (ASD) in Karachi, Pakistan, and identifies associated socioeconomic factors.

Methods: A cross-sectional study was conducted with 30 parents of children (aged 3-14 years) diagnosed with ASD. Data were collected through structured interviews assessing sociodemographic characteristics, direct rehabilitation costs (physiotherapy, occupational therapy, speech therapy, special education), indirect costs (transportation, assistive devices, caregiver support), and perceived financial stress. Data were analyzed using SPSS version 26.0.

Results: The average monthly total cost was PKR $37,900 \pm 10,600$, with direct service costs averaging PKR $28,500 \pm 8,200$ and indirect expenses PKR $9,400 \pm 4,600$. Seventy percent of parents reported moderate to high financial stress. Monthly household income significantly predicted financial burden ($p = 0.01$), with lower-income families experiencing disproportionate strain. Nearly all costs were paid out-of-pocket due to minimal public funding.

Conclusion: This study provides critical baseline evidence on ASD rehabilitation costs in Pakistan, where such data are scarce. Findings highlight significant socioeconomic inequities and support policy recommendations for subsidized therapy programs and financial assistance mechanisms.

Keywords: Autism Spectrum Disorder, Economic Burden, Financial Stress, Rehabilitation Services, Pakistan.

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1. INTRODUCTION

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by persistent deficits in social communication and interaction, alongside restricted, repetitive patterns of behaviour or interests (Harm et al, 2013). Globally, the prevalence of ASD in children is estimated to be around 0.6% to 0.7% (Issac et al 2025). In Asia the reported prevalence of ASD as stated in metanalyses is estimated in between 0.4 to 0.5% (Salari et al 2022). In Pakistan, reliable nationwide epidemiological data are lacking; however, non-governmental estimates suggest that approximately 350,000 children may live with ASD, and the limited diagnostic infrastructure, social stigma, and variable awareness about autism contribute to under-reporting and delayed diagnosis (Singhi et al 2023 & Bukhari et al 2025).

Children with ASD frequently require intensive, long-term rehabilitation services such as physiotherapy (Haque et al 2025), occupational therapy, and speech and behavioral interventions (Haque et al 2025) alongside special educational supports and standard medical care (Maini 2025). These services are resource-intensive and often require repeated sessions, specialist staff, and active family involvement (Mazza et al 2021). As such, the financial implications for families can be substantial. Internationally, studies have documented high direct and indirect costs associated with caring for children with ASD (Matin et al 2022). For instance, a national cost-of-illness study in China estimated that the lifetime cost per individual with ASD ranged from approximately USD 2.65 million (for those without intellectual disability) to USD 4.61 million (for those with intellectual disability), and the total societal cost in 2020 was estimated at USD 41.8 billion (Zhao et al, 2024). A regional study in China reported the annual burden of families of children with ASD at RMB 86,700 (\approx USD 13,596), with non-medical rehabilitation and educational costs constituting a large portion of the total (Zhao et al., 2024).

In Pakistan, research specifically quantifying the economic burden of rehabilitation services for children with ASD remains extremely limited (Abbasi et al 2025). Available reports point to the fact that most families pay out-of-pocket for therapies and services, while public funding and insurance coverage for autism rehabilitation are minimal or absent (Haider et al., 2024). Private rehabilitation packages in major urban centers are reported to cost tens of thousands of Pakistani rupees per month, representing a significant expense relative to many families' incomes. Service availability tends to be concentrated in urban areas, creating access inequities for families in peri-urban or rural settings (Haider et al., 2024).

Given this gap in the literature, a cross-sectional assessment of the economic burden borne by parents of children with ASD receiving rehabilitation services in Pakistan is both timely and important. Quantifying both rehabilitation service costs (including therapy, education, transport, and assistive devices) and indirect costs (such as caregiver support and related expenses) will provide critical evidence. Such evidence can inform policymakers, practitioners, and advocacy groups about the magnitude of financial stress, identify socioeconomic factors associated with higher burden, and underpin recommendations for policy interventions—such as subsidized therapy, insurance coverage, rural outreach programs, and inclusive service development.

2. LITERATURE REVIEW

Recent years have seen renewed attention to both the prevalence of autism spectrum disorder (ASD) and the multifaceted burden it places on families and health systems. Several large meta-analyses and surveillance reports document increasing identification and variable prevalence across regions. A three-level meta-analysis estimated global prevalence rates that vary by region and age groups and emphasized heterogeneity in study methods and detection (Talantseva et al., 2023). U.S. surveillance data similarly showed rising identification in multiple sites, underscoring that prevalence estimates depend heavily on screening, diagnostic practices, and service availability (Maenner et al., 2023). Country-specific work from China further documented increasing prevalence and highlighted the scale of service needs in populous settings (Jiang et al., 2024). Taken together, these epidemiologic studies imply a growing population requiring long-term rehabilitative and educational supports, increasing the policy relevance of economic-burden research. A growing body of literature has examined the economic dimensions of ASD. While the heaviest cost-burden studies have come from high-income settings, emerging research shows that non-medical rehabilitation and special education are major cost drivers internationally (Salari et al., 2022). In contexts where health insurance and public supports are limited, these costs are most commonly paid out-of-pocket, creating substantial financial strain for families and leading to unequal access to care. These patterns have important implications for low- and middle-income countries where formal social protection is weaker and services concentrate in urban centers.

Caregiver- and family-centered research has consistently documented high psychosocial strain associated with caring for a child with ASD. Recent cross-sectional studies across diverse settings have reported elevated caregiver stress, depression, and reduced life satisfaction among parents, with mothers often bearing the majority of caregiving responsibilities (van Niekerk et al., 2023; Mumtaz et al., 2022). Predictors of greater caregiver strain include lower household income, greater care intensity, and limited access to formal supports (Nighat et al., 2022). Studies in South Asia and Pakistan specifically note pervasive stigma, limited trained personnel, and fragmented service provision, which amplify both economic and psychological burdens on families (Khan et al., 2021).

Pakistan-specific studies, while still limited in number, echo regional findings. Local work has described high levels of caregiver strain and psychological distress, and highlighted service concentration in urban areas as a barrier for many families (Pasha et al., 2021). Research examining psychosocial functioning among parents found reduced life satisfaction and significant concerns about long-term financial sustainability of therapy regimens (Sajjad et al., 2022). These domestic studies underline that the dual problems of high out-of-pocket costs and uneven geographic distribution of rehabilitation services create both access and equity challenges in Pakistan.

Finally, several studies call for actionable policy responses: expansion of subsidized or publicly funded rehabilitation, strengthening of community-based and school-based interventions to reduce travel and caregiver burden, development of caregiver support programs, and integration of ASD services into primary care and educational systems to improve early detection and continuity of care (Talantseva et al., 2023; Maenner et al., 2023). The literature therefore suggests that quantifying rehabilitation-related expenditures and their distribution by

socioeconomic status remains essential for designing local policy solutions that reduce inequities and support family well-being.

3. METHODOLOGY

3.1 Study Design

This study employed a cross-sectional descriptive design to assess the economic burden of rehabilitation services among parents of children diagnosed with autism spectrum disorder (ASD).

3.2 Study Setting

The study was conducted in the Institute of Physical Medicine and Rehabilitation Sciences and Ziauddin University Boat Basin location Karachi, Pakistan. Participants were recruited from multidisciplinary services, including physiotherapy, occupational therapy, and speech therapy.

3.3 Study Population and Sample Size

The target population consisted of parents or primary caregivers of children (aged 3–14 years) diagnosed with ASD who were receiving any form of rehabilitation service. A sample size of n=30 participants was calculated based on the prevalence of ASD 0.7% calculated in the study conducted in China titled as: "Prevalence, incidence, and characteristics of autism spectrum disorder among children in Beijing, China" and after applying attrition rate by 50% (Zhao et al. 2024).

3.4 Inclusion and Exclusion Criteria

Parents of children who had a formal diagnosis of ASD and had been receiving rehabilitation services for at least three months were included in the study. Only those willing to participate and able to provide cost-related information were considered. Parents of children with comorbid severe intellectual disabilities or other neurological disorders, as well as those not attending regular therapy sessions, were excluded to maintain data uniformity.

3.5 Data Collection Procedure

Data were collected using a structured, pre-tested questionnaire. The questionnaire consisted of five sections: (1) sociodemographic information (age, gender, education, occupation, and household income), (2) child-related characteristics (age, gender, duration since ASD diagnosis, and type of therapies received), (3) rehabilitation service costs including fees for physiotherapy, occupational therapy, speech therapy, and special education, (4) indirect costs such as transportation to rehabilitation centers, purchase or maintenance of assistive devices, and expenses related to caregiver support, and (5) perceived financial stress, measured using a five-point Likert scale ranging from "no burden" to "extreme burden." The questionnaire was reviewed by experts in physiotherapy, rehabilitation sciences, and public health to ensure content validity. Data were obtained through face-to-face interviews conducted by trained researchers at the participating centers after obtaining written informed consent.

Each interview lasted approximately 15–20 minutes, and all responses were recorded anonymously to maintain confidentiality.

3.6 Data Analysis

All data were entered and analyzed using the Statistical Package for the Social Sciences (SPSS) version 26.0. Descriptive statistics such as frequencies, means, and standard deviations were used to summarize demographic variables and cost components. Inferential statistics, including independent t-tests and one-way ANOVA, were applied to compare the economic burden across different socioeconomic groups and types of rehabilitation services. A p-value of less than 0.05 was considered statistically significant.

3.7 Ethical Considerations

Ethical approval was obtained from the Institutional Review Board (IRB) of the participating university and from the administrations of all included centers. Participants were informed about the purpose of the study, the voluntary nature of participation, and the assurance of confidentiality before data collection. Written informed consent was obtained from each participant. No identifiable personal data were recorded, and all responses were kept confidential and used solely for research purposes.

4. RESULTS

A total of 30 parents of children diagnosed with autism spectrum disorder (ASD) participated in the study. The mean age of the respondents was 35.6 ± 6.8 years, and the majority were mothers (70%). Most participants (60%) reported a monthly household income below PKR 100,000, reflecting a predominantly middle-to-lower socioeconomic group. The average age of children with ASD was 7.8 ± 2.9 years, with males comprising 73.3% of the sample. Nearly all children were receiving multidisciplinary rehabilitation, including physiotherapy, occupational therapy, and speech therapy (Table 1).

Table 1. Sociodemographic Characteristics of Parents (n = 30)

Variable	Category	Frequency (n)	Percentage (%)
Gender of parent	Male	9	30.0
	Female	21	70.0
Age group (years)	25–34	11	36.7
	35–44	13	43.3
	≥45	6	20.0
Education	Below graduate	10	33.3
	Graduate	15	50.0
	Postgraduate	5	16.7

	<100,000	18	60.0
Monthly income (PKR)	100,000–200,000	9	30.0
	>200,000	3	10.0

Most children were attending regular therapy sessions (≥ 3 times per week), and a significant proportion (80%) were enrolled in special education programs. The duration since diagnosis varied, with 40% of children diagnosed within the last three years (Table 2).

Table 2. Child-Related Characteristics (n = 30)

Variable	Category	Frequency (n)	Percentage (%)
Gender of child	Male	22	73.3
	Female	8	26.7
Age group (years)	3–6	11	36.7
	7–10	13	43.3
	11–14	6	20.0
Duration since diagnosis	<3 years	12	40.0
	≥ 3 years	18	60.0
Type of services received	Physiotherapy	25	83.3
	Occupational therapy	24	80.0
	Speech therapy	22	73.3
	Special education	20	66.7

The average monthly rehabilitation service cost per child was PKR $28,500 \pm 8,200$, covering fees for physiotherapy, occupational therapy, speech therapy, and special education. In addition, the average indirect cost was PKR $9,400 \pm 4,600$, including transportation, assistive devices, and caregiver expenses. Parents from higher-income groups reported significantly greater total expenditures ($p = 0.03$), reflecting access to private centers with higher fees. (Table 3).

Table 3. Monthly Cost Distribution of Rehabilitation Services (PKR)

Cost Component	Mean \pm SD	Range (PKR)
Rehabilitation service cost	$28,500 \pm 8,200$	15,000 – 45,000
Transportation	$3,200 \pm 1,400$	1,000 – 6,000
Assistive devices	$2,800 \pm 1,900$	500 – 7,000

Caregiver-related expenses	3,400 ± 2,100	1,000 – 8,000
Total monthly cost	37,900 ± 10,600	20,000 – 58,000

In terms of perceived financial stress, 70% of parents reported a moderate to high level of burden. A significant association ($p = 0.01$) was observed between monthly household income and perceived financial stress, suggesting that lower-income families experienced greater economic strain. However, no statistically significant differences were found based on the child's age or duration of therapy (Table 4).

Table 4. Association Between Socioeconomic Factors and Perceived Financial Stress

Variable	Category	Mean Stress Score ($\pm SD$)	p-value
Monthly income (PKR)	<100,000	4.3 ± 0.7	
	100,000–200,000	3.6 ± 0.8	0.01
	>200,000	2.8 ± 0.5	
Education level	Below graduate	4.1 ± 0.9	0.09
	Graduate or above	3.6 ± 0.8	
Type of center	Public	3.5 ± 0.6	0.07
	Private	4.0 ± 0.8	

5. DISCUSSION

This study assessed the economic burden of rehabilitation services among parents of children diagnosed with autism spectrum disorder (ASD) in Karachi, Pakistan. Findings revealed that families experience a considerable financial strain, with the mean total monthly cost of rehabilitation reaching approximately PKR 38,000, a figure that constitutes a substantial proportion of the average household income in urban Pakistan. The results align with regional and international evidence indicating that rehabilitation and educational expenses for children with ASD pose a significant challenge for families, particularly those from lower socioeconomic strata (Haider et al., 2024; Zhou et al., 2020).

The majority of the participants in this study were mothers, consistent with prior research identifying women as the primary caregivers of children with ASD in South Asia (Haider et al., 2024). The predominance of mothers in caregiving roles underscores the gendered aspect of caregiving, which often contributes to psychological distress and limits women's ability to maintain employment (Zhou et al., 2020). Although this study did not quantify psychological outcomes, the reported financial burden suggests a potential association between economic strain and caregiver stress, as observed in similar studies from China and India (Li et al., 2022; Zhou et al., 2020).

Rehabilitation costs—including physiotherapy, occupational therapy, speech therapy, and special education—were found to be the major contributors to total expenses. This pattern mirrors findings from China, where non-medical rehabilitation and educational costs constitute nearly 75% of the total ASD-related expenditure (Li et al., 2022). In

Pakistan, where healthcare coverage and insurance systems are underdeveloped, nearly all rehabilitation costs are paid out-of-pocket, making consistent therapy difficult for middle- and low-income families (Haider et al., 2024). The concentration of rehabilitation centers in urban areas such as Karachi, Lahore, and Islamabad further exacerbates inequities, as families from peri-urban or rural regions often travel long distances to access services, increasing indirect costs such as transportation and caregiver support.

Indirect expenses in the current study—transportation, assistive devices, and caregiver costs—averaged PKR 9,400 per month, confirming that non-service-related expenditures also add to the financial burden. These findings are consistent with those of Zhou et al. (2020), who reported that indirect costs in China accounted for nearly 40% of the total annual ASD-related expenditure. The absence of government subsidies, specialized insurance programs, or community-based rehabilitation services in Pakistan amplifies this problem.

Income level was found to be a significant predictor of financial stress, with lower-income parents reporting higher stress scores. Similar socioeconomic gradients in perceived burden have been documented internationally (Li et al., 2022; Zhou et al., 2020). Notably, higher-income families in Pakistan often have access to premium private centers, whereas middle- and lower-income families are constrained to public or less specialized facilities (Haider et al., 2024). This financial disparity reinforces the need for equitable policy responses.

The implications of these findings extend beyond economic hardship. Research increasingly shows that financial strain among caregivers is closely linked to emotional distress, reduced family functioning, and limited treatment adherence (Imran et al., 2025; Li et al., 2022). The psychological toll on caregivers can in turn affect the quality and continuity of care for the child. Addressing these challenges requires a multisectoral approach, integrating health policy, social welfare, and education systems. Subsidized rehabilitation services, tax relief, or public-private insurance programs could alleviate direct financial pressure, while parent training and community support networks may mitigate psychological stress.

Despite its valuable insights, the present study had certain limitations. The relatively small sample size and convenience sampling from urban centers limit the generalizability of the findings. Self-reported cost data may be subject to recall bias, and the study did not differentiate between varying severities of ASD, which could influence the intensity and cost of required therapies. Future large-scale, multi-city studies with longitudinal follow-up are recommended to better capture variations in economic burden and explore its impact on family well-being and treatment continuity.

6. CONCLUSION

The study concludes that families of children with ASD in Karachi face a substantial economic burden associated with rehabilitation services, driven primarily by therapy and special education costs and compounded by indirect expenses such as transportation and caregiving. Lower-income households experience disproportionate financial stress, highlighting socioeconomic inequities in access to necessary rehabilitation. These findings echo international evidence that the financial impact of ASD often exceeds families' income levels, threatening both economic stability and caregiver well-being. Policy interventions such as subsidized therapy programs, community-based rehabilitation centers, and financial support mechanisms are urgently needed to reduce disparities and promote inclusive, affordable ASD care in Pakistan.

AUTHOR'S CONTRIBUTION AND DECLARATIONS

Conception or Design: Iqbal Ahmed, Akbar Mughal

Data Collection and Processing: Bazeen Gulzar, Muhammad Bilal Muhammad Ismail

Analysis or Interpretation of Data: Malaika Imtiaz, Akbar Mughal

Manuscript Writing & Approval: Iqbal Ahmed, Akbar Mughal, Bazeen Gulzar, Muhammad Bilal Muhammad Ismail, Malaika Imtiaz, All Authors

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Furthermore, this research did not involve the use of animals, plants, or any biological specimens requiring ethical approval. Therefore, ethical clearance from an institutional review board, prior informed consent (PIC) from respondents, or animal/plant welfare approvals are not applicable to this study.

The author(s) affirm full compliance with international ethical standards for research and publication.

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