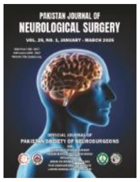

PAKISTAN JOURNAL OF NEUROLOGICAL SURGERY (QUARTERLY) –
OFFICIAL JOURNAL OF PAKISTAN SOCIETY OF NEUROSURGEONS

Original Research

Exploring the Patterns of Childhood Disability in a Tertiary Care Hospital – A Demographic Analysis

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ABSTRACT

Objectives: To identify childhood disability patterns and associated demographic characteristics presenting to a tertiary care center of excellence.

Materials and Methods: This prospective observational cross-sectional study was conducted at the Department of Rehabilitation, Armed Forces Institute of Rehabilitation Medicine (AFIRM), Rawalpindi, from Dec 22 to Nov 23. We included 160 patients in our study. Demographic variables studied were age, weight, physical characteristics, reason for referral and primary diagnoses, family and birth history, access and barriers to rehabilitation services, and overall satisfaction with services provided using a 7-point Likert scale.

Results: Among 160 patients, cerebral palsy was the most common diagnosis (30%), followed by myopathies (18.8%), autism spectrum disorders (13.1%), and musculoskeletal disorders (10%). Other conditions included neurodegenerative diseases (6.9%), intellectual disabilities (6.3%), Down syndrome (4.4%), and spinal dysraphism (3.1%). Comorbidities were common, with 30% of patients showing additional health concerns such as respiratory issues, seizure disorders, and gastrointestinal problems, which further complicate their care and management. Lower-income households showed higher disability rates and early diagnosis was more common for autism and cerebral palsy.

Conclusion: Neurological disorders like cerebral palsy, autism spectrum disorders, and musculoskeletal conditions were the most common childhood disability presentations.

Keywords: Congenital abnormalities, Childhood, Hereditary neurodegenerative disorders, Hospital referrals, Pakistan, Rehabilitation.

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Date of Submission: 15-12-2024
Date of Revision: 27-03-2025

Date of Acceptance: 28-03-2025
Date of Online Publishing: 31-3-2025
Date of Print: 31-3-2025

DOI: 10.36552/pjns.v29i1.1050

INTRODUCTION

The burden of childhood disabilities has been on the rise for the past few decades.[1] The availability of better diagnostic modalities and advancements in the field of pediatrics has enabled clinicians to identify and diagnose childhood diseases and disability. It is estimated that the burden of childhood disabilities is on the rise and a 2020 survey showed that >1 in 10 children and adolescents are diagnosed with physical or intellectual childhood disability with the number projected to be 291.2 million.[2] According to the inclusivity of the childhood disability reforms in the Sustainable Development Goals, estimates are needed for the demographic variations and incidence of the disability patterns in the demographic areas to better understand and come up with interventions for achieving a favorable outcome.[3,4]

The existing crunch on medical resources in the post-COVID pandemic area necessitates the rationalization of allotting resources, and this requires tangible data without which the approach to healthcare would be a practice in futility.[5] The estimates for childhood disability vary considerably worldwide and this is partly due to the way we define disability in a person. The new bio-psycho-social model not only incorporated physical disabilities but also mental health and external and environmental factors that contribute to them.[6] The annual expenditure on childhood disabilities is staggering even in developing countries and it is the need of time to carry out local studies to define patterns of childhood disability to better equip and focus medical setups for their treatment or intervention accordingly.[7] The average annual expenditure for treatment of childhood disabilities is around 4500-70,000 dollars worldwide.[8] With the staggering costs and the disabilities requiring prolonged and sometimes life-long interventions, identification of patterns of disability is mandatory to proceed and intervene for their treatment and prevention.

Minimal work has been done on childhood disability patterns in our setups. This study will define major childhood disability patterns from local demographic regions, which will help to rationalize and prioritize our treatment strategies and hospital resources for those who need them the most.

MATERIALS AND METHODS

Study Design & Setting

This prospective observational cross-sectional study was carried out at the Department of Rehabilitation Medicine, Armed Forces Institute of Rehabilitation Medicine (AFIRM), Rawalpindi from Dec 22 to Nov 23 after approval from the ethical review board vide letter no. 04/2023.

Sampling

The sample size was calculated keeping the confidence interval at 95%, and the margin of error at 5% with the population proportion of childhood disability projected at 10.1% according to WHO estimates[9]. The minimum sample size according to the WHO calculator came out to be 140. We included 160 patients in our study.

Inclusion Criteria

The study included all children aged less than 18 years of age presenting to the in-patient or out-patient department of the hospital and diagnosed with any congenital or acquired abnormality according to the international criteria of ICF-CY (International Classification of Functioning, Disability and Health for Children and Youth).[10,11]

Exclusion Criteria

Patients with visual and/or hearing impairment and those to whom the parents or next of kin didn’t consent were excluded.

Clinical Management and Data Collection

The study method included data collection after individuals were added to the study group as per the inclusion criteria furnished. Data collection was carried out on a pre-approved institutional proforma and was given to all residents and consultants seeing patients in the in-patient and out-patient department but were kept unaware of the study protocol for which the data was being collected. The primary consultants responsible for the study explained in detail the collection of data from the patient and the next of kin or parents to all consultants and residents appointed to fill the proformas and submit every day to the research department. Data collection included history, detailed examination, and medical records of the patient. Both the patient and the next of kin were interviewed in detail in the language of their convenience using interpreters where needed regarding barriers to services of re-habilitation, whether they were satisfied with the services or interventions provided, and detailed family history of any other disabilities in any other adults or siblings in the family or immediate relatives. The data forms once submitted were anonymized and the patient's name was kept confidential. Once de-identified they were analyzed by a statistician blinded to the study protocol.

Data Analysis

The demographic variables studied were age, weight, physical characteristics, reason for referral and major diagnoses, family and birth history, access and barriers to rehabilitation services, and overall satisfaction with services provided using a 7-point Likert scale. The Data were statistically described in terms of mean and SD, frequencies, and percentages when appropriate. All statistical calculations were performed using Statistical Package for Social Sciences (SPSS)26.0.

RESULTS

One hundred and sixty (n=160) patients were included in the study protocol according to the inclusion and exclusion criteria furnished.

Age Distribution

Frequency distribution according to age showed that 20 (12.5%) patients in the 1-5 years age group, 78 (43.75%) patients in the 6-10 years age group, and 33 (20.62%) in the 16-18 years age group as shown in Table 1.

Weight Distribution

Patients' mean weight showed 7.152.05 kg in the 1-5 years age group, 13.402.17 kg in the 6-10 years age group, and 32.582.94 kg in the 16-18 age group. Details are shown in Table 1.

Gender Distribution

The sample's age distribution is predominantly concentrated in the 6-10 years group (43.75%), with other age groups also represented. The sample consists of 66.9% males and 33.1% females, with a higher proportion of participants

Table 1: *Basic characteristics of the sample population (n=160).*

Variable	n(%)
Age Distribution (Years)	
1-5 years	20 (12.52%)
6-10 years	78 (43.75%)
11-15 years	29 (18.13%)
16-18 years	33 (20.62%)
Mean Weight (Kg)	
1-5 years	7.15±2.05
6-10 years	13.40±2.17
11-15 years	23.41±1.61
16-18 years	32.58±2.94
Gender	
Male	107 (66.9%)
Female	53 (33.1%)
Rural/Urban	
Rural	112 (70%)
Urban	48 (30%)

from rural areas (70%). Details are shown in Table 1.

Table 2: *Disability characteristics in sample population (n=160).*

Variable	n(%)
Age of Disability Onset	
Under 01 year	20 (12.5%)
Under 03 years	44 (27.5%)
Under 05 years	68 (42.5%)
More than 05 years	28 (17.5%)
History of Any Previous Rehabilitation by a PMR Spec in the Last 1 Year	
Yes	32 (20%)
No	128 (80%)
Reasons for Referral	
Speech delay	76 (47.5%)
Motor delay	46 (28.8%)
Global development delay	18 (11.3%)
Amputation	03 (1.9%)
Cognitive impairment	09 (5.6%)
Traumatic brain injury	08 (5%)
Birth History	
Pre-term	76 (47.5%)
Term	77 (48.1%)
Post-term	07 (4.4%)
Mode of Delivery	
Vaginal	89 (55.6%)
Caesarian	71 (44.4%)
Marriage	
Consanguineous	111 (69.4%)
Non-consanguineous	49 (30.6%)
History of Disabilities	
In siblings	62 (38.8%)
In immediate family	71 (44.4%)
None	27 (16.9%)
Socioeconomic Status	
Very modest	90 (56.3%)
Modest	43 (26.9%)
Stable	27 (16.9%)

Disability Distribution

When the disability characteristics were analyzed, it showed that disability onset was within 1 year in 20 (12.5%) patients, under 3 years in 44 (27.5%) patients, and 28 (17.5%) patients had the onset of disability of more than 5 years duration. When asked about providing any rehabilitation services by a rehabilitation specialist in the last year, 32 (20%) patients sought help, whereas 128 (80%) patients did not. Previous personal history taken for gestational age of delivery showed 76 (47.5%) patients were born pre-term, 77 (48.1%) at term, and 07 (4.4%) were born post-term. Parents' Family history showed an increased frequency of consanguineous marriages in parents of 111 (69.4%) parents versus 49 (30.6%) parents with non-consanguineous marriages. History of disabilities in siblings or immediate family showed 62 (38.8%) patients had one or more siblings with a disability, 71 (44.4%) patients had a disability in the immediate family, and 27 (16.9%) patients had no history of disability in siblings or the immediate family. Details are shown in Table 2.

Access to Hospital Services

History taken for access, provision, and quality of rehabilitation and hospital services showed that 47 (29.4%) patients had been admitted to a hospital and/or rehabilitation center in the last 01 year. Median satisfaction scores of the care and services provided by the healthcare services and physicians taken from parents, next of kin, and children who could properly articulate were 4.00 (3.00-4.00). Significant barriers in the provision of rehabilitation services revealed financial constraints in 75 (46.9%) cases, transportation difficulties in 43 (26.9%) cases, and non-access to a treatment center due to distance in 10 (6.3%) cases (Table 3).

Major disabilities diagnosed after evaluation and workup showed cerebral palsy in 48 (30%) of patients, myopathies in 30 (18.8%) patients, musculoskeletal in 16 (10%) patients, autism spectrum of diseases in 21 (13.1%) cases, neurodegenerative diseases in 11 (6.9%) cases, intellectual disabilities in 10 (6.3%) cases, acquired mononeuropathy in 07 (4.4%) cases, spinal dysraphism in 05 (3.1%) cases, down syndrome in 07 (4.4%) cases, traumatic brain injury in 01 (0.6%), hereditary polyneuropathies in 01 (0.6%) and amputation in 03 (1.9%) cases.

DISCUSSION

Table 3: *Provision of hospital and rehabilitation services (n=160).*

Variable	Values
Mean frequency of hospital/rehab admission in the last 1 year	47 (29.4%)
Median satisfaction scores of cares and services provided during admission	4.00 (3.00-4.00)
Currently Receiving Any Rehabilitation Services	
Physical therapy	36 (22.5%)
Occupational therapy	36 (22.5%)
Rehabilitation psychological services	36 (22.5%)
Orthotic services	10 (6.3%)
Pain medicine interventions	09 (5.6%)
None	33 (20.6%)
Major Barriers in the Provision of Rehabilitation Services	
Financial constraints	75 (46.9%)
Transportation difficulties	43 (26.9%)
Lack of awareness	32 (20%)
Treatment centers far away	10 (6.3%)

The study was carried out in our institute to better understand the prevailing patterns of childhood disabilities in our demographic setup to better understand and allocate resources according to the burden of diseases presented to us. We also aimed to find out the associated family dynamics, socioeconomic histories, and problems faced to receive hospital and rehabilitation services to better understand and advocate improvement in the infrastructure to better address and improve patient care for disabilities, some of which may require lifelong treatment.

Our study identified the 6–10-year age group as the one with the highest presentation to the center with referrals for workup for childhood disabilities. Details taken from the parents showed that this was the approximate age for starting school and these disabilities manifested themselves as poor learning and/or behavioral changes picked up by the teachers and recommended to be shown for further evaluation. A study done by Connor et al, also identified childhood disabilities as being identified in the 7-15 year bracket when school and early social interactions manifested these disabilities.[12] Local studies done for disabilities in early childhood in Punjab, Pakistan by Malik et al, also identified the 8-12 year age group as the most common to have childhood disabilities identified due to stunted intellectual and social behaviors requiring workup and evaluation.[13] Mean weight seen for all age group strata showed that the mean weight calculated for age was below the percentile for children of the same age without childhood disabilities. These children had issues with feeding, physical activity, and weight gain which are all contributing to their deteriorating health. Studies done by Foster et al[14] and Magana et al,[15] also confirmed the same findings of childhood disabilities and their association with decreased weight gain for age for the percentile.

The peripheral areas were our major referral demographic with more than 70% of patients in our study belonging to the country's rural areas. Most of these people belonged to a very modest socioeconomic class (in more than 50% of the cases). Most of them were unaware of the disease process but the majority were told about it by the local general practitioner but didn’t have the resources to travel or afford medical services at larger centers for diagnoses and subsequent treatment. Studies done by Hussain et al[16] and N Singal et al,[17] identified the rural areas with the highest incidence of childhood disabilities. This is especially true for developing countries where access to food, water, hygiene, and healthcare services are scarce and the trend of consanguineous marriage is still prevalent propagating these genetic diseases to run unchecked from generation to generation. Local studies by Ibrahim et al,[18] showed that 60% of the population in rural areas in Punjab, which were in line with findings from our study as well, had consanguineous marriages and were having a major impact on genetic diseases being transferred from parents to children. This was also concluded by studies done by Ahmad et al, who found consanguineous marriages to be prevalent and the cause of major childhood disabilities, especially neurological and intellectual disorders.[19] Moreover, most of the patients in our study have a sibling or an immediate family member suffering from a childhood disability as well. The prevalence in both cases was around 40% in our study population. Boehm et al, also concluded similar results with more than 30% of patients with neurological or intellectual disabilities having a sibling and/or near relative suffering from the same.[20]

When asked about the rehabilitation services being provided in the past or currently for the disabilities, patients or their parents reported that the majority were receiving physical, occupational, and other interventions but upon detailed history, most of them were either very rudimentary being provided by a technician or a nursing assistant in the rural areas in a local clinic with no exact knowledge of the disease itself.

When evaluated and a detailed workup was done, confirmatory results showed cerebral palsy to be the dominant disease in our local demographic setup affecting more than 30% of the patients in our study group. The disease also overlapped with patients presenting with intellectual disabilities, delayed milestones, and neurodegenerative diseases. With low birth weight and problems during delivery as the main causes implicated as concluded by local studies carried out by Mughal et al,[21] various studies are needed to co-relate these factors in various demographics in Pakistan. Low birth weight and more incidence of caesarian (around 40%) in our study may well contribute to these findings and the high overall percentage. Myopathies and musculoskeletal disorders, along with neurological and intellectual disabilities, form the top five diagnoses in our setup for childhood disabilities.

The study recommends allocating and providing resources according to the specific disease burden of childhood disabilities in the local demographic areas to further improve and enhance the facilities and resources. It also recommends better rehabilitation services in rural areas, which form a significant proportion of the patients presenting for evaluation and intervention.

CONCLUSION

The findings from this study highlight the predominant patterns of childhood disability in our local demographic, with cerebral palsy, myopathies, and autism spectrum disorders being the most common diagnoses. Our study also emphasizes the significant impact of socioeconomic factors, particularly in rural areas, where access to rehabilitation services remains a significant barrier. The high prevalence of consanguineous marriages and the presence of family histories of disability further underline the genetic factors contributing to childhood disabilities in our population.

REFERENCES

1. Olusanya BO, Wright SM, Nair MKC, Boo NY, Halpern R, Kuper H, et al. Global Burden of Childhood Epilepsy, Intellectual Disability, and Sensory Impairments. Pediatrics. 2020;146(1):e20192623. DOI:10.1542/peds.2019-2623.
2. Vawter-Lee M, McGann PT. The Increasing Global Burden of Childhood Disability: A Call for Action. Pediatrics. 2020;146(1):e20201119. DOI: 10.1542/peds.2020-1119.
3. Abualghaib O, Groce N, Simeu N, Carew MT, Mont D. Making Visible the Invisible: Why Disability-Disaggregated Data is Vital to “Leave No-One Behind”. Sustainability. 2019; 11(11):3091. DOI: 10.3390/su11113091.
4. Avelar ABA, da Silva-Oliveira KD, da Silva Pereira R. Education for advancing the implementation of the

Sustainable Development Goals: A systematic approach. The international journal of management education. 2019;17(3):100322.
Doi: 10.1016/j.ijme.2019.100322

5. Sabatello M, Burke TB, McDonald KE, Appelbaum PS. Disability, Ethics, and Health Care in the COVID-19 Pandemic. Am J Public Health. 2020;110(10):1523-1527.
DOI: 10.2105/AJPH.2020.305837.
6. Barak S, Elad D, Gutman D, Silberg T. Using a biopsychosocial approach to examine parental sense of burden and competency associated with raising a child with a physical disability. Child Care Health Dev. 2023;49(3):518-528.
DOI: 10.1111/cch.13066.
7. Shahat ARS, Greco G. The Economic Costs of Childhood Disability: A Literature Review. Int J Environ Res Public Health. 2021 Mar 29;18(7):3531.
Doi: 10.3390/ijerph18073531.
8. Lavelle TA, Weinstein MC, Newhouse JP, Munir K, Kuhlthau KA, Prosser LA. Economic burden of childhood autism spectrum disorders. Pediatrics. 2014;133(3):e520-9.
DOI: 10.1542/peds.2013-0763.
9. Olusanya BO, Kancherla V, Shaheen A, Ogbo FA, Davis AC. Global and regional prevalence of disabilities among children and adolescents: Analysis of findings from global health databases. Front Public Health. 2022;10:977453.
DOI: 10.3389/fpubh.2022.977453.
10. Organization WH. International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY: World Health Organization; 2007.
11. Abdi S, Spann A, Borilovic J, de Witte L, Hawley M. Understanding the care and support needs of older people: a scoping review and categorisation using the WHO international classification of functioning, disability and health framework (ICF). BMC Geriatr. 2019;19(1):195.
DOI: 10.1186/s12877-019-1189-9.
12. Connors C, Stalker K. Children's experiences of disability: Pointers to a social model of childhood disability. Childhood and disability: Routledge; 2020;22(1):102-16.
DOI: 10.1080/09687590601056162.
13. Malik R, Raza F, Rose P, Singal N. Are children with disabilities in school and learning? Evidence from a household survey in rural Punjab, Pakistan. Compare: A Journal of Comparative and International Education. 2022;52(2):211–31.
DOI: 10.1080/03057925.2020.1749993.
14. Foster BA, Reynolds K, Callejo-Black A, Polensek N, Weill BC. Weight outcomes in children with developmental disabilities from a multidisciplinary clinic. Res Dev Disabil. 2021;108:103809.
DOI: 10.1016/j.ridd.2020.103809.
15. Magaña S, Errisuriz VL, Yu AP, Heydaria N, Zeng W, Mirza M, Vanegas S, Brown S, Parra-Medina D, Suarez-Balcazar Y. Associations between parenting strategies and BMI percentile among Latino children and youth with intellectual and developmental disabilities. Front Pediatr. 2023 Jul 27;11:1189686. DOI: 10.3389/fped.2023.1189686.
16. Hussain S, Munir A, Ibrar M. Children with disability: Problems and challenges in Pakistan. The Journal of Humanities & Social Sciences. 2020;28(1):87-99.
17. Singal N, Sabates R, Aslam M, Saeed S. School enrolment and learning outcomes for children with disabilities: findings from a household survey in Pakistan. International Journal of Inclusive Education. 2020;24(13):1410-30.
DOI: 10.1080/13603116.2018.1531944
18. Ibrahim SH, Rizvi A, Ahmed AM, Bhutta ZA. Association of Risk Factors for Early Childhood Disability in Rural Pakistan. Asia Pac J Public Health. 2022;34(1):143-147.
DOI: 10.1177/10105395211048318.
19. Ahmad N, Abbas S, Hafeez S, Ahmad N, Qayyum R, Mujahid S, et al. Prevalence of Congenital Defects among Consanguineous Marriages in Pakistan. Journal of Society of Prevention, Advocacy and Research KEMU. 2023;2(1).
20. Boehm TL, Carter EW. Family Quality of Life and Its Correlates Among Parents of Children and Adults With Intellectual Disability. Am J Intellect Dev Disabil. 2019;124(2):99-115.
DOI: 10.1352/1944-7558-124.2.99.
21. Mughal M, Rizva SMA, Malik S. Cerebral Palsy in Pakistan: A Review of Study Approaches, Status of Research and Trends. Pak Pediatr J. 2022;47(1):3-10.

Additional Information

Disclosures: None to disclose by any author.
Ethical Review Board Approval: The ethical approval was taken vide certificate: 04/2023.
Human Subjects: Informed written consent was taken all participants or from their guardians/ parents.
Conflict of Interest: In compliance with the ICMJE uniform disclosure form, all authors declare the following:
Financial Relationships: All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work.
Other Relationships: All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.
Data Availability Statement: For data sharing, interested researchers can contact the corresponding authors.
Funding: None.

AUTHORS CONTRIBUTION

Sr. #	Authors Full Name	Intellectual contribution in terms of:
1.	Danish Ali Mir	Study design, analysis, acquisition of data, and manuscript writing.
2.	Muhammad Tawab Khalil	Acquisition and interpretation of data, critical review, and manuscript writing.
3.	Farooq Azam Rathore	Acquisition and interpretation of data, and manuscript writing.
4.	Asma Rauf	Data collection and analysis, and critical review of the article.
5.	Imran Irshad	Study design and data analysis, manuscript writing, and critical review of the article.
6.	Muhammad Ammar Khan	Study concept and data collection, and critical review of the manuscript.