

Utilization of institutional rehabilitation service in pediatric patients with disability in Southwest Rajasthan

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ABSTRACT

Background: Rehabilitating disabled child maximizes functional independence, thereby, enhancing the quality of life and better community participation. Utilization of rehabilitation services is a significant issue in developing countries like India. This study aims to observe the pattern of utilization of institutional rehabilitation services by pediatric patients with disability. **Methods:** This was an observational study (descriptive cross-sectional study) conducted at Department of Physical Medicine and Rehabilitation in a tertiary care set-up. Descriptive data from an ongoing study involving children with and without developmental delay (DD) over 1 year were collected in terms of age, gender, distance from the institute, diagnosis, and frequency of visit. Utilization pattern for rehabilitation services among pediatric patients was analyzed with respect to diagnosis and frequency of visit under each diagnosed category. The demographic variable of age, gender, and distance from the institute was further correlated to frequency of visit. IBM SPSS statistics 22 was used for descriptive statistical analysis and correlation of variables. **Results:** Of 464 disabled children using rehabilitation service, data for 399 (M: 255, F: 144) children were complete with age ranging from 3 months to 18 years and distance from 1 km to 600 km from institute. There were 330 children with DD and 69 in non-DD category. Two hundred and sixty-eight cases used one-time consultancy, 86 preferred intermittent services, and 45 patients were regular. Negligible correlation with a trend toward negative values was observed between frequency of service utilization and distance (Rho = -0.139 Sig. = 0.006, at 0.01 level) and between age and utilization frequency (Rho = -0.074, Sig = 0.140). **Conclusions:** The study showed that children with DD were main utilizers of rehabilitation services. Nearly 67% of disabled children utilized services only once with a trend toward younger age group and those nearer to institute were noted.

Keywords: Children with disability, institutional rehabilitation, service utilization

Introduction

Childhood disability impacts healthcare significantly as these children experience a wide spectrum of issues ranging from medical complications (such as seizures, spasticity, contractures) to functional impairments (such as mobility issues, dependency for daily living activities, poor cognition, behavioral issues, and poor social interaction).^[1-3] A comprehensive rehabilitation started as soon as diagnosed with an impairment helps in maximizing functionality and reducing caregiver burden in

long run.^[1-3] Literature suggests that in India, one in every tenth child is either born with or subsequently acquires a physical, mental, or sensory disability.^[2] With a large percentage of disabled pediatric patients, rehabilitation has become an essential aspect of country's healthcare.^[1] However, recent WHO survey estimated that 76%–85% of disabled people in developing countries receive no care and only 2% of them can access rehabilitation.^[4] Hence, research regarding utilization of pediatric rehabilitation service has emerged in recent years.^[1] Previous studies on disability prevalence in India have reported poor utilization of rehabilitation services. A study done by Kumar and Gupta showed that among 201 neurologically impaired individuals in the rural area of Uttar Pradesh, no one

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was receiving rehabilitation.^[5] In a similar study by Srivastava *et al.* in Mau district of Uttar Pradesh, 82.93% had not availed rehabilitation services.^[4] Padhyegurjar and Padhyegurjar reported poor utility of rehabilitative services among locomotor disabled individuals of urban slums in Mumbai (35.6%). Of these, 50.7% were treated by General practitioners and only few approached specialty rehabilitative services.^[6] Borker *et al.* showed nonutilization of rehabilitation among 75.8% of disabled in rural Goan community.^[7] Sinha and Sharma studied the utilization pattern in cerebral palsy children in Jalandhar district, Punjab and found only 55% had received some form of therapy.^[3] Of the available literature about unmet rehabilitation needs of disabled, only limited evidence is present regarding rehab utilization pattern in disabled children *per se*. More so, most of studies have reported primarily those individuals who have never received any exposure to rehabilitation. The present study, therefore, aimed to investigate the utilization pattern among disabled children in Southwest Rajasthan, who had at least one exposure of rehabilitation at a tertiary care setup and hence were aware regarding its benefits.

Subjects and Methods

The study was descriptive analysis of data obtained from an ongoing study at a tertiary care setup concerning functional outcomes of children with developmental delay (DD). All pediatric patients (those below 18 years) visiting Department of Physical Medicine and Rehabilitation were registered and the data used comprised of children with and without DD over a span of 1 year. Age group included was 0–18 years with no consideration for sex. Those cases whose records were incomplete were not considered. The variables comprised of age, gender and address of children, diagnosis, and follow-up pattern. The distance from their home to institute was calculated.

The rehabilitation service for disabled children provided at the institute comprised of comprehensive medical rehabilitation provided by a multidisciplinary team of rehab physician/physiatrist, occupational therapist, and physiotherapist. Rehabilitation protocol broadly consisted of consultancy, medication titration, and formulation of goal-directed protocol by rehab physician and implementation of rehab protocol by occupational therapist and physiotherapist. Speech therapy and psychological interventions were availed as referrals on need basis. Functional improvement, noted during subsequent visits, helped in titration of further rehabilitation protocol. Since one session of therapy without any subsequent implementation is futile and optimal rehabilitation of a disabled child requires an intensive practice to maximize functionality, caregivers of disabled children were advised for therapy on a regular basis as an outpatient at least for 2–3 months. In case they were unable to come, they were given a written home program and reviewed on a weekly or biweekly or monthly basis, as feasible for them. This study thus included all the children visiting outpatient department to explore the utilization pattern among those who were aware about benefits of rehabilitation. Children were categorized into

one-time consultancy users, intermittent service users (visited with gaps), and regular service users. The missing data were cleaned, and data analysis was done on IBM SPSS (Statistics for Windows Version 22.0, Armonk, NY, IBM Corp. Released 2013). Both DD and subcategories of diagnosis in the non-DD group were analyzed for frequency and rate of service utilization and its correlation was analyzed with respect to age, gender, and distance from institute using Spearman's rho test.

Results

Descriptive analysis showed that a total of 464 children used outpatient department (OPD) services during the study duration. Of these, 399 children had complete data (255 males and 144 females). Age spanned over 3 months to 18 years. They were reporting from a radius of 15–600 km in and around the city of Jodhpur. There were 4 cases that came from other states.

There were 330 children with DD and 69 in non-DD category as shown in Table 1 and illustrated in Figure 1. The demographic details under each category are specified in Table 2. Of the total, 268 were one time users, 86 used services intermittently, and 45 were regular users. Table 3 illustrates the pattern under each subcategory in terms of frequency of utilization. The correlation between utilization frequency pattern and variables of age, gender, and distance has been mentioned in Table 4 under each category.

Table 1: Rehabilitation utilization pattern according to frequency distribution of diagnosis

Diagnosis	Frequency distribution (n=399)
DD	330
Congenital bone deformity	18
Myopathies	16
Behavioral disorders	15
Spinal dysraphism	9
Erb's palsy	6
ABI sequelae	5

DD: Developmental delay; ABI: Acquired brain injury

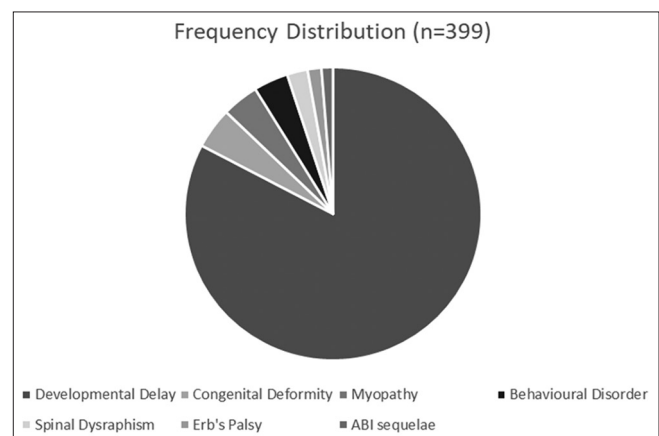


Figure 1: Pie chart illustrating service utilization pattern according to frequency distribution of diagnosis

Table 2: Demographic profile of disabled children according to variables of age, gender, and range of distance traveled for service utilization

Demographic profile	Frequency distribution	
Age group		
Overall	11 months to 23 years	
DD	11 months to 17 years	
Congenital bone deformity	11 months to 18 years	
Myopathies	2 years to 17 years	
Behavioral disorders	3 years to 18 years	
Spinal dysraphism	9 months to 18 years	
Erb's palsy	5 months to 5 years	
ABI sequelae	6 months to 15 years	
Gender		
	Frequency distribution	
	Male	Female
Demographic profile		
Overall	255	144
DD	213	117
Congenital bone deformity	8	10
Myopathies	13	3
Behavioral disorders	11	4
Spinal dysraphism	5	4
Erb's palsy	4	2
ABI sequelae	1	4
Range of distance traveled (km)		
Overall	1-1783	
DD	1-1783	
Congenital bone deformity	5-260	
Myopathies	3.7-252	
Behavioral disorders	6.8-518	
Spinal dysraphism	6-263	
Erb's palsy	6-162	
ABI sequelae	4-21	

ABI: Acquired brain injury; DD: Developmental delay

Table 3: Pediatric rehab service pattern according to frequency of utilization under each diagnosis

Diagnosis	Follow-up pattern/service frequency rate		
	One time visit	Intermittent	Regular
DD	224	72	34
Congenital bone deformity	8	6	4
Myopathies	13	3	0
Behavioral disorders	12	2	1
Spinal dysraphism	5	1	3
Erb's palsy	4	2	0
ABI sequelae	2	0	3
Overall (n=399), n (%)	268 (67)	86 (22)	45 (11)

ABI: Acquired brain injury; DD: Developmental delay

Discussion

This study investigated the utilization pattern of rehabilitation service for pediatric patients with disabilities in a tertiary care setup located in Jodhpur city in Southwest Rajasthan; the city having an estimated population of 1.056 million spreading over area of 78.6 km².

The study highlighted a spectrum of conditions leading to pediatric disability and that were encountered in the pediatric rehabilitation setup at the institute. Majority of cases were of DD. Non-DD category primarily consisted of congenital bone deformity, behavioral disorders, myopathy, spinal dysraphism, Erb's palsy, and acquired brain injury (ABI) sequelae. Very few studies have explored utilization in such a vast spectrum. Kumar and Gupta in their study found polio followed by cerebral palsy as major cause of neurological disability.^[5] This is in contrast to the current study, probably because polio is now eradicated from country and those inflicted before are now in adult age group. On the other hand, incidence of cerebral palsy, most common cause of DD disorder, is on a rise due to increased survival rates of high risk infants predisposing them to DD later on.^[1] In another study by Suganthi and Kandaswamy in rural Puducherry, congenital deformity and residual palsy were main reasons of locomotor disability, irrespective of age groups.^[8] Congenital bone deformities was the second most common condition for availing rehabilitation in the present study. In a study by Saloojee *et al.* in South African disabled children, cerebral palsy related DD was the most common condition.^[9]

The current study showed only 33% disabled children utilized rehab services and remaining 67% discontinued services, though their caregivers had been explained regarding need and benefits of rehabilitation. This is in concordance with study by Padmamohan *et al.* in rural Kerala where poor acceptability of services was one of the prime reasons for nonutilization of rehab services.^[10] A similar trend was noted by Borker *et al.* in rural Goa where 77.9% disabled had knowledge about rehab services and service was accessible in 44.2%; still only 24.2% utilized services (i.e., 55% of accessible category and 31% of disabled under knowledge category).^[7]

The correlation analysis of follow-up pattern with age revealed a low negative correlation in behavioral disorder and ABI category. Only for Myopathy category, low positive correlation was observed, possibly due to the condition being progressive, with functional difficulties worsening with increasing age. In remaining categories, the coefficient values were negative but <0.3 indicating a negligible correlation of age with service utilization. A negligible correlation with a trend toward negative values implies that disabled children in the current study utilized rehabilitation, irrespective of age, and of them, chances of utilizing were slightly higher in younger children. The possible reason of negligible correlation could be a good referral system from pediatric department in the institute where all children are routinely screened for any deformity or developmental lag and referred for rehab if disability noted. The compliance was enhanced because whenever these children would visit OPD for any medical issues, they were advised to follow-up for rehab services in order to avail a revised protocol based on functional improvement achieved previously. Study by Sinha and Sharma found that advice for rehabilitation by treating primary physician is an important influencer for service utilization and a poor referral system, not fully utilizing expertise available within

Table 4: Correlation between frequency of service utilization and age, gender, and distance profile under each diagnosis

Diagnosis	Correlation of variables with frequency of service utilization					
	Age		Gender		Distance traveled	
	ρ	Significant	ρ	Significant	ρ	Significant
Overall data	-0.074	0.140	+0.086	0.087	-0.139	0.006
DD	-0.030	0.583	+0.078	0.155	-0.150	0.006
Congenital bone deformity	-0.403	0.097	-0.111	0.662	-0.233	0.351
Myopathy	+0.048	0.861	+0.092	0.733	+0.407	0.118
Behavioral disorder	-0.434	0.106	-0.018	0.951	-0.169	0.547
Spinal dysraphism	-0.233	0.546	-0.027	0.945	-0.540	0.134
Erb's injury	-0.123	0.804	+0.250	0.633	+0.023	0.965
ABI sequelae	-0.363	0.548	-0.408	0.495	+0.266	0.665

ρ : Spearman's rho test correlation value; ABI: Acquired Brain Injury; DD: Developmental delay

system, adversely affects it.^[3] Previous studies done by Kaminker *et al.* and Chiarello *et al.* showed that service frequency decreases with age and becomes more consultative and episodic with increasing age.^[11-13] This probably accounts for the negative trend in the present study as well.

Previous studies conducted one-two decades ago had deduced that referral of a child was based on the severity of disability, i.e., those with severe impairments were referred for rehab and those with milder impairments may or may not be referred. Campbell *et al.* had found two decades ago that a child was referred for therapy only if a physician perceived the child's disability as severe.^[1,14] Bailey *et al.* suggested one decade back that referral time to rehabilitation could be influenced by diagnosis since pediatricians were reluctant to refer children with DDs or less severe disabilities to early intervention services.^[1,15] This is in contrast to the trend seen at this institute where children with all types of disabilities are referred for rehabilitation. This, therefore, reflects an improved understanding among the health-care professionals regarding the need of rehabilitation for functional improvement in chronic impairments.

Correlation of distance with different diagnosis showed a mixed picture. A moderate negative association was found between distance traveled and availing of rehabilitation service in spinal dysraphism category and a negligible correlation with negative trend in DD, congenital bone deformity, and Erb's palsy categories. This suggests a negative trend for conditions often diagnosed at birth or in subsequent visits, such as for developmental lag. A low positive correlation was observed for myopathy and negligible correlation with trend toward positive values for ABI and behavioral disorders, probably because these are acquired at later stages and child at birth is normal or does not have any high predisposing risk factors. Thus, care-givers are willing to take any amount of effort to help child reach pre-

morbid status and hence, travel even from far distance, to utilize the service. Previous studies have mentioned environmental factors including transportation and area of residence as one of the significant barriers for rehab utilization, though none of them have specifically looked at distance as a measure.^[3,7,16] Studies in South African areas have found distance as one of the prime reasons for nonutilization in disabled.^[9]

Negligible correlation with a mixed pattern of positive and negative trends was observed with gender as well. Only a low positive correlation was observed for ABI which was possibly due to unequal sample distribution of males and females. This indicates equality in terms of usage of rehabilitation services, suggesting that caregivers are equally concerned regarding impairment in a child irrespective of gender.

Although a negative trend was observed for age and distance, none of these factors had a significant correlation values with service utilization in spite of only one-third of caregivers continuing with services. This highlights the role of other barriers in availing the services. Previous studies have shown financial constraints, low socioeconomic status, ignorance about condition, family negligence, parental education, false family beliefs and unrealistic expectation of normalcy and poor perceptions about disease and disability as different reasons for nonutility of rehabilitative services.^[3,7,10,16]

The investigators in the present study observed that caregivers of children receiving limited rehabilitation services were well adjusted to living with a chronic disabled child. In India, where family bonds are important, the disabled child was often taken care of and made dependent with a view that child cannot perform anything, and hence, it was moral obligation of parents to perform his/her daily tasks.^[17,18] This was often marred with the belief that condition is incurable with deficits persisting in majority of these children either completely if unrehabilitated or at least to some extent, even after best rehabilitation efforts. For example, in a child with spinal dysraphism, use of assistive devices could improve child's mobility, but it cannot alter the actual power of limbs. Thus, the concept of independent living and functional improvement had less weightage in such a scenario. Breaking this viewpoint with one visit of rehabilitation was difficult, and hence, no further follow-up was often expected. Another barrier noted was that if a child did not improve significantly over a short period and showed a slow improvement graph, the effectiveness of service became questionable in opinion of caregivers. Moreover, a lack of support systems in community providing schooling, recreational, and vocational options to these disabled children was noted, and hence, translation of functional improvement achieved at the institute into improved community participation was difficult for them. Thus, the caregivers foresaw the attempt to achieve functional independence as futile, and the necessity of rehabilitation service utilization became questionable in their viewpoint. A possible solution thought was addressing these viewpoints and beliefs during the first visit at rehabilitation set-up itself. Sessions must explain the benefits of functional

improvement, need for this functional independence for subsequent years; when parents are not there or have become old, and the importance of being self-reliant for any individual. The session must help care-givers understand the expected outcome in view of disability to assist in formulation of realistic rehab goals along with health care professional, so that rehab program is more individualized and beneficial in child's community setting. It was noted that group session with those children and caregivers who were already receiving service on a regular basis was helpful in few of these children. Another observation was that rehabilitation protocol for older children had to be based specifically on the felt needs and required frequent titration of goals keeping the activity limitation profile in mind to enhance compliance in them.

Although the above mentioned beliefs and barriers were noted in the current study, they were not objectively explored for the present study. Thus, the study had its own limitations in terms of other barriers and facilitators for utilization not being looked at, exploring the pattern in context to only a specific region, small sample size in non-DD subcategories, and nonexploration of variation in disability severity.

Further studies addressing these limitations would add to the current findings and will have long-term implications since it would further bring out the gaps in the current practice in the particular setting and at the same time, open doors for possible solutions that can address those gaps. This would also help policy and decision makers of the region and the institute to enhance their efforts for uniform utilization of rehab services. A scientific exploration of health service utilization on a regular basis would help titrate rehabilitation resources required to support children with disability and also guide clinical practice and rehabilitation services models in future.

Conclusion

As evident by the current study, rehabilitation service is definitely used by a significant proportion of children, mainly with developmental lag; though continued by one-third of disabled children, with a trend toward younger age group and those nearer to the institute. The need arises to optimize this pattern in a more uniform way across the age and distance.

Appendix

DD disorders involve inability of child to reach important developmental milestones within an expected period of time in 1 domain or more, developmental domains being gross motor, fine motor, language domain, and social domain. It leads to permanent disability and includes nonprogressive conditions such as cerebral palsy (most common), developmental coordination disorder, or other progressive motor delay disorders.

Congenital bone deformity disorder describes alterations in one or multiple sites of skeletal system condition occurring in various combinations, existing either at or even before birth.

Erb's palsy is a condition where paralysis of arm is caused by injury to upper trunk (C5–C6) of brachial plexus. It most commonly occurs due to shoulder dystocia seen during a difficult birth and accounts for 80% congenital brachial plexopathy.

Myopathy is a diverse group of disorders primarily affecting skeletal muscle producing weakness, fatigue, decreased endurance, and musculoskeletal deformities. They are often associated with other systems dysfunctions, such as the cardiac and pulmonary systems.

Spinal dysraphism involves a spectrum of congenital anomalies resulting in a defective neural arch through which meninges or neural elements are herniated. They are divided into *aperta* (visible lesion) with skin defects and *occulta* (with no external lesion) with normal skin cover. Neurological deficits depend on location and severity of lesion and manifest as motor, sensory, or urinary dysfunction and lead to pain, spasticity, gait abnormality, and scoliosis in child.

An ABI sequelae comprise of issues related to brain injury sustained after perinatal period and can result from traumatic brain injury such as falls or nontraumatic brain injury such as epilepsy, infection such meningitis/encephalitis, low oxygen/hypoxia, tumors, and vascular abnormalities.

Behavioral disorder is an emotional disability characterized by inability of child to build or maintain satisfactory interpersonal relationships with peers and/or teachers and with caregivers in preschool-age children. The child's disability cannot be adequately explained by intellectual, cultural, sensory, general health factors and is characterized by excesses, deficits or disturbances of behavior. Common examples being attention deficit hyperactivity disorder and conduct disorder.

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Conflicts of interest

There are no conflicts of interest.

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