

Factors Influencing Utilization of Physiotherapy Service among Children with Cerebral Palsy in Jalandhar District of Punjab

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ABSTRACT

Background: Physiotherapy plays a central role in the management of children with cerebral palsy (CP); however, literature describing the use of physiotherapy service and the factors affecting utilization of physiotherapy service for this group of children in the Indian context remain unexplored. **Aims and Objectives:** To describe the utilization of physiotherapy services and explore the factors affecting utilization of physiotherapy services among children with CP of Jalandhar district of Punjab. **Methodology:** During June 2009 to March 2012 interview of family members of 248 children with CP (male = 159; female = 89) was conducted using a schedule focusing on demography, constraints of resources, expectations, beliefs, awareness, and service utilization. Cross tabulation with Chi-square, univariate, and multivariate logistic regression analysis were the tools of statistical analysis. **Results:** 44.4% children had not received any physiotherapy in their life time. In univariate analysis exposure to physiotherapy was found significantly associated with age of diagnosis (odds ratio [OR] = 2.47), finance constraint (OR = 2.27), personal constraint (OR = 2.54), transportation constraint (OR = 3.01), lack of advice for rehabilitation (OR = 2.36), ignorance about condition (OR = 11.94), and rehabilitation services (OR = 2.88). Multivariate model ($\chi^2 = 57.16$, $df = 15$, $P < 0.001$, pseudo R^2 Cox and Snell = 0.22, Nagelkerke = 0.27) identified two main predictor variables of nonexposure to physiotherapy-ignorance about condition (OR = 7.3) and expectation of normalcy (OR = 0.43). **Conclusion:** The main drivers for the use of physiotherapy among children with CP in Jalandhar district of Punjab were awareness about the condition of CP and expectation of normalcy which demonstrated a complex relationship with sociodemographic factors.

KEYWORDS: Cerebral palsy, physiotherapy, service utilization

INTRODUCTION

Cerebral palsy (CP) describes a group of permanent disorders of movement and posture that are attributed to nonprogressive disturbances in the developing brain and is often accompanied by disturbances of sensation, cognition, communication, perception, behavior, or seizures.^[1] The worldwide incidence of CP is 2–2.5/1000 live births.^[2] After eradication of polio, it is becoming one of the most common causes of childhood disability in India.

The prevention of childhood disability is one of the main focuses of the national policy of disability of India,^[3] which can be approached either by preventing the impairment or by preventing the impairment from becoming a disability.^[4] Advances in neonatal management and obstetric care have not shown a decline in the incidence of CP.^[5] On the contrary, many believe that with a decline in infant mortality rate, there has actually been an increase in the incidence and severity of CP.^[6] In this situation, it becomes imperative that attention is directed toward the second approach that seeks to prevent impairment from becoming disability.

Disability among children with CP is often the product of the interaction of health conditions with contextual environmental and personal factors.^[7] Utilization of rehabilitation services is one such known factor that considerably influences the disability status of an individual. Utilization of health and rehabilitation services in India is a complex phenomenon influenced by several factors. An understanding of these factors is essential for designing context appropriate service delivery method.

Physiotherapy plays a central role in the management of CP and is the most popular therapeutic intervention for CP.^[8] However, limited literature is available on the use of physiotherapy service among CP children.^[9,10] The factors that influence the utilization of physiotherapy service among children with CP

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have largely remained unexplored.^[11] Describing patterns of physical therapy use and identifying factors that contribute to variation in utilization have emerged as an important research agenda of physiotherapy organizations.^[9]

Investigators could not locate any study that described the patterns of physical therapy use and identifies the factors contributing to variation in utilization among children of CP in India. Keeping this in mind, the present study was planned to explore the utilization of physiotherapy services among children with CP in Jalandhar district of Punjab. The specific research objectives were to describe the pattern of physiotherapy use and explore the factors affecting utilization of physiotherapy services.

METHODOLOGY

A cross-sectional survey was conducted on family members of 248 children with CP (male = 159 female = 89) in the Jalandhar district of Punjab from June 2009 to March 2012 as a part of a larger project designed to study the epidemiology of disability in children with CP and approved by BPSAR of Punjabi University Patiala. During 2008–2011, a database of children with CP of age group 3–13 years of Jalandhar district of Punjab was prepared by the investigator. Using records of some hospitals and physiotherapy centers, identification camp organized by a physiotherapy teaching institution and registry of *sarva shiksha abhiyan* as base investigator went to all the 10 blocks of Jalandhar district to register the children with CP for study. Several children were subsequently added to the initial list when brought to the notice of investigator by the local community members and cross referral from the parents of CP children. Each identified child was physically examined by the investigator and was retained in the database only if the following criteria of inclusion were satisfied: (a) diagnosed cases of CP and/or, (b) The presence of motor delay and motor disorder, abnormal muscle tone, abnormal posture or asymmetry, and persistence of primitive reflexes (c) have completed the age of 3–13 years on March 2008, and (d) resident of Jalandhar district.

Scheduled interview of parents of all the identified children was conducted by a physiotherapist (RS) having 11 years of experience of working with CP. The schedule of interview consisted of semi-structured questions focusing on demographic information, constraints of resources, expectations, beliefs, awareness, and service utilization. The initial draft of questionnaire prepared after a review of literature and in-depth interview of some family members of children was validated for content by a panel of experts consisting of physiotherapist, pediatrician, and social worker. The schedule was pretested on 25 parents before using for final data collection.

The socioeconomic (SE) status of the family was determined by the SE scale developed by Aggarwal *et al.*,^[12] this scale is a modification of kuppuswamy scale suitable for both rural and urban population. It provides an SE score by totaling the scores assigned to the variables of education, occupation, and monthly income of the head of family in seven-point scales. On the basis of SE score, the family can

be grouped into six SE classes, namely, upper high, high, upper middle class, lower middle class, poor, and very poor. For the purpose of analysis in this study, the two categories (upper high and high) of high, upper and lower of middle and very poor and poor of lower were clubbed to get three categories of SE class. Education status of parents was classified into three categories – educated – education +2 and above, less educated = schooling up to 10th class, and illiterate – unable to read or write

Statistical analysis

On the basis of lifetime exposure to physiotherapy data was categorized into two groups of “not exposed” and “exposed group.” Children of nonexposed group had never received any physiotherapy in their lifetime, whereas the exposed group included those who had received physiotherapy for variable duration in their lifetime. Cross tabulation with Chi-square was used to examine the association of each variable with physiotherapy exposure. A series of univariate regression analyses was conducted on significant factors with each potential variable as independent variable and exposure to physiotherapy as dependent variable to examine the independent effect of variable on physiotherapy use. To investigate how the combination of variables predicted the exposure to physiotherapy, independent variables, which were significant at the 0.05 level in the univariate analyses, were assessed together as a single block in multivariate regression models with entry probability of 0.05 and removal of 0.10. Odds ratio (OR) and 95% confidence interval were calculated for univariate and multivariate models. Data were analyzed using SPSS version 16.0 for windows by Microsoft Corp. NY for windows.

RESULTS

Physiotherapy service utilization

In the cohort of 248 children with CP, 44.4% children have not received any physiotherapy in their lifetime [Figure 1]. In exposed group [Figure 2], majority received physiotherapy at physiotherapy teaching institutions (31.15%), followed by government hospitals (23.91%), private hospitals/clinics

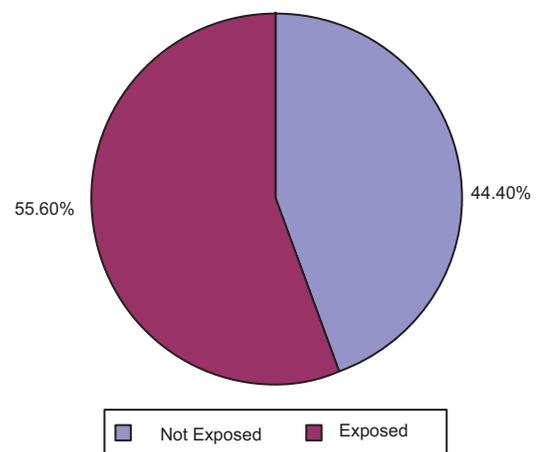


Figure 1: Physiotherapy service utilization of the children with cerebral palsy in Jalandhar district

(23.18%), charitable dispensaries (7.97%), and at home (13.76%). Duration of physiotherapy service utilization demonstrated wide SE divide. Table 1 presents the distributions of duration of physiotherapy according to SE status of family. 61.53% children of higher SE class received physiotherapy for >3 years; the corresponding figures for the middle SE class, and lower SE class was 21.21% and 13.15%, respectively. The majority of children (31.15%) received physiotherapy for 2–3 years.

Factor influencing exposure to physiotherapy

Exposure to physiotherapy was significantly associated with age, age of diagnosis locality, SE status, and educational status. Children diagnosed at younger age were more likely to receive physiotherapy. The nonexposure to physiotherapy showed a positive relationship with age of child (OR = 1.13). Finance constraint (OR = 2.27), personal constraint (OR = 2.54), transportation constraint (OR = 3.01), lack of advice for rehabilitation (OR = 2.36), lack of awareness about condition (OR = 11.94), and lack of awareness about rehabilitation services (OR = 2.88) increases the likelihood of nonexposure to physiotherapy. Expectation of normalcy (OR = 0.29) reduced the odds of nonexposure [Table 2].

Entering all the significant factors in multivariate analysis created problems of multicollinearity. Therefore, a correlation analysis of variables was conducted and the variables having r value of or more 0.8 with other variables were excluded from the analysis. The financial constraint was strongly correlated related with SE status ($r < 0.84$) with 96% and 100% of families of lower SE class experiencing financial constraint. Lack of awareness about rehab requirement of

child was strongly correlated related with lack of advice for rehab ($r = 0.93$). Close to 99% of parents aware about rehab requirement had received advice for rehabilitation from medical doctor. Thus, advice for rehab was treated as proxy for awareness about rehab services, and SE status was treated as independent variable serving as proxy for financial constraints.

Multivariate model [Table 3] identified three main predictor variables of nonexposure to physiotherapy - ignorance about condition (OR = 7.3), expectation of normalcy (OR = 0.43), and age (OR = 1.10). The proportion of variance explained by the model was 22%–27% (Pseudo R-Square Cox and Snell = 0.22, Nagelkerke = 0.27).

DISCUSSION

Despite the acknowledged need of physiotherapy in management of CP, there exist limited studies^[10,13-15] that describe the use of physiotherapy services among the CP children. There is little research on the use of health and rehabilitation services by PWD in India.^[16] This study provides primary data for with regard to physiotherapy service utilization among children with CP in Jalandhar and might be the first Indian study that attempts to gain an insight of the factors associated with nonutilization of physiotherapy services.

55% of children had received some kind of physiotherapy and only 14.91% had received physiotherapy for >3 years. These findings are in gross variance with those reported from the Western countries.^[10,13,14] In Ireland, service use among families of CP children was very high with 96% receiving physiotherapy at least twice a week for 30 min.^[10,13] In the Canadian study of Majnemer *et al.*,^[15] Physiotherapy and

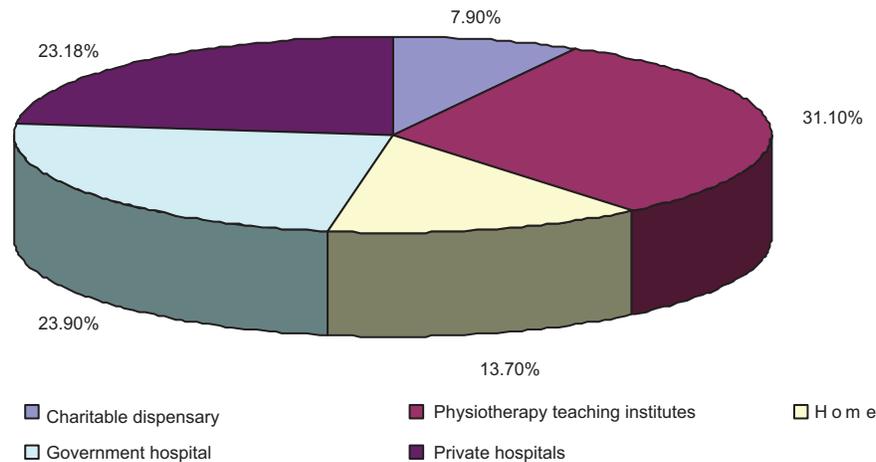


Figure 2: Distribution of place of physiotherapy of children with cerebral palsy of Jalandhar district

Table 1: Distribution of duration of physiotherapy received according to socioeconomic status

Duration (years)	Upper class (26), n (%)	Middle class (74), n (%)	Lower class (38), n (%)	Total (138), n (%)
<1	2 (7.7)	13 (17.6)	5 (13.1)	20 (14.5)
Between 1 and 2	4 (15.4)	19 (25.7)	15 (39.5)	38 (27.5)
Between 2 and 3	4 (15.4)	26 (35.1)	13 (34.2)	43 (31.1)
>3	16 (61.5)	16 (21.6)	5 (13.1)	37 (26.8)

Table 2: Bivariate regression analysis of demographic and environmental factors associated with nonexposure to physiotherapy

Factors	B	SE	Wald	df	Exp (B)	95% CI	
						LB	UB
Lack of therapy facility in vicinity	0.99	0.26	13.60	1	2.69***	1.59	4.57
Finance constraint	0.82	0.26	9.36	1	2.27**	1.34	3.85
Personal constraint	0.93	0.26	12.06	1	2.54***	1.50	4.31
Transport constraint	1.10	0.26	17.30	1	3.01***	1.79	5.07
Ignorance about condition	2.48	0.74	11.02	1	11.94***	2.76	51.66
Ignorance about rehab requirement	1.05	0.36	8.54	1	2.88***	1.41	5.86
Expectation of normalcy	-1.23	0.30	16.13	1	0.29***	0.15	0.53
Lack of advice for rehabilitation	0.86	0.36	5.48	1	2.36***	1.15	4.86
Female children	-0.24	0.26	0.85	1	0.78	0.46	1.32
Rural locality	0.93	0.28	10.67	1	2.53***	1.45	4.44
Age at diagnosis	0.90	0.21	17.46	1	2.47***	1.61	3.79
Age	0.12	0.04	10.29	1	1.13***	1.05	1.22
High SES	-1.66	0.47	12.23	1	0.19***	0.07	0.48
Middle SES	-0.76	0.28	7.40	1	0.47**	0.27	0.81
Lower SES	0 ^b	-	-	0	-	-	-
Educated	-1.22	0.33	12.88	1	0.30***	0.15	0.58
Less educated	-0.38	0.38	0.99	1	0.69	0.33	1.44
Illiterate	0 ^b	-	-	0	-	-	-

^aThe reference category is: Yes, * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$, CI: Confidence interval, LB: Lower bound, UB: Upper bound, SE: Standard error, SES: Socioeconomic status

occupational therapy were most common services provided predominantly in the school setting, and 84.6% children were receiving at least one rehabilitation service. In Hong Kong^[14] approximately 38% of children with CP attended a mainstream school, and 61% received outpatient therapy support.

There are major differences in the physiotherapy service delivery structure between developed countries and India. Unlike developed countries where therapy interventions are provided to children on statutory basis in mainstream and special schools, Indian CP children do not have such benefit. Physiotherapy is just one of the many treatment options as besides allopathic treatment (modern medicine and surgery), homeopathy, ayurvedic treatment, massage, and even magical remedies are often sought by the patient of chronic disabling conditions. This makes utilization of health, and rehabilitation services a complex phenomenon which is influenced by a plethora of personal, demographic, and environmental factors.

Availability and affordability of service remain the key major determinants of use of rehabilitation services in India, as the facility for comprehensive multidisciplinary rehabilitation does not exist in most of the places. In the present study also, physiotherapy was the main rehab service available to children with CP. Speech therapy was provided to just 4%, and none of the children had received occupational therapy. Nonavailability

Table 3: Multivariate logistic regression analysis (final model) of factors predicting the nonexposure to physiotherapy

Variables	B	SE	Wald	df	Exp (B)	95% CI	
						LB	UB
Intercept	-3.02	1.34	5.06	1			
Age	0.096	0.05	3.48	1	1.10	0.99	1.22
Age of diagnosis	0.48	0.27	3.17	1	1.61	0.95	2.74
Lack of facility of therapy	0.01	0.49	0	1	1.00	0.39	2.62
Personal constraint	0.05	0.52	0.01	1	1.04	0.38	2.88
Transport constraint	0.47	0.44	1.15	1	1.60	0.68	3.80
Ignorance about condition	1.61	0.82	3.84	1	5.00*	1.00	25.06
Expectation of normalcy	-1.02	0.42	5.92	1	0.35*	0.16	0.82
Lack of advice for rehabilitation	0.57	0.44	1.66	1	1.76	0.74	4.18
Rural locality	0.24	0.39	0.40	1	1.27	0.60	2.73
Educational status							
Educated	-0.49	0.47	1.08	1	0.61	0.24	1.55
Literate	-0.53	0.44	1.43	1	0.58	0.25	1.40
Illiterate	0 ^b	-	-	0	-	-	-
SES							
High	-0.074	0.81	0.01	1	0.92	0.19	4.57
Middle	-0.472	0.51	0.86	1	0.62	0.23	1.69
Low	0 ^b	-	-	0	-	-	-

2 LL=332.89, $\chi^2=61.70.16$, $df=15$, $P < 0.001$. Pseudo R^2 : Cox and Snell=0.19, Nagelkerke=0.29, Percentage correct (n)=65.5%, Percentage correct yes=74.6%, Overall percentage correct=70.6%. aReference category is yes, * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$, CI: Confidence interval, SES: Socioeconomic status, LB: Lower bound, UB: Upper bound, SE: Standard error

of treatment facility in the vicinity was a constraint expressed by 56.9% among them 54.6% could not receive physiotherapy. Constraint of therapy facility in the vicinity was also felt by 46.37% parents whose children received physiotherapy.

Providing physiotherapy service to CP child is a costly affair. Besides the cost of service, several indirect expenses such as travel to treatment center, loss of working hours leading to loss of wages of parents are also involved as child has to be brought regularly to the physiotherapy center for relatively long period. In developed countries also where health insurance coverage for meeting the cost of treatment and rehab is available for a majority of the population.^[17] Parents find it difficult to provide therapy services if they are not covered under insurance plan.^[11] Dusing *et al.*^[18] reported that in USA children with disability without insurance coverage were significantly more likely to have a reported unmet need for therapy services.

Indian health services operated in fee for service mode. Just 10% of the Indian population is covered by any form of social or voluntary health insurance.^[19] And these schemes do not cover the expenses of rehab of CP. The Government of India does offer income tax rebate on the expenses rendered to a child with disability. However, these benefits

are applicable only to the taxpayers which constitute a very small proportion of Indian population. For the majority of Indian population, there is no financial support for meeting the expenses of rehabilitation of disabled members of family. Charges for physiotherapy are high for private hospital and clinic. Physiotherapy teaching institution and government hospitals provide relatively less costly services, but there is a long waiting time in these centers. Transportation of child to physiotherapy center also involves considerable expenses and for a poor family, it becomes a major barrier even when therapy services are provided for free or at nominal cost. Most of the families (96%) belonged to lower SE class admitted that they were not financially sound to get treatment for their child.

This variation in cost of service and transportation difficulty coupled with financial capability to bear the cost is reflected in physiotherapy utilization pattern of SE classes where a wider SE divide is evident. In comparison to lower SE class, likelihood of exposure to physiotherapy was much higher for high (5 times) and middle SE class (3 times). The place and duration of physiotherapy also showed remarkable variation among social classes. The majority of higher classes received physiotherapy from private hospitals/clinics, whereas majority of the lower class received treatment from government hospital. The majority of middle classes received treatment from physiotherapy teaching institutions. The duration of physiotherapy also showed remarkable variation among social classes indicating an increase in duration of physiotherapy with the improvement of SE status. Majority of children of higher class received physiotherapy for >3 years; the corresponding figures for the middle class, and lower class were 21.21% and 13.15%, respectively.

Poverty and resource constraints are the known factors for nonaccess of health and rehabilitation services in developing countries.^[20-23] Financial constraint and difficulty in transportation as the barriers for rehabilitation of neurological disability has been reported from other part of India as well.^[24,25] Finding of this study confirms this for the children with cerebral in Jalandhar district.

However, financial and resource constraint lost their significance in multivariable model where ignorance about condition and expectation of normalcy emerged as the main predictor variable. Nonexposure to physiotherapy showed positive relation with ignorance and negative relation with expectation of normalcy. The children whose parents were ignorant about the nature of CP were 7 times more likely not to receive physiotherapy. On the other hand, expectation that “my child will be completely normal” enhanced the chance of physiotherapy exposure.

Ignorance was also reported as a major reason for nonutilization of rehab services in other parts of India.^[24-26] Kumar and Gupta^[24] reported ignorance as the major barrier to neurological rehabilitation in rural areas of Uttar Pradesh. Padhyegurjar and Padhyegurjar^[26] reported that in urban slum of Mumbai 87.1% attribute the lack of knowledge of rehabilitative services as the reason for not taking treatment. Study of Srivastava *et al.*^[25] conducted in Mau district of Uttar Pradesh reported unawareness as the main reason for not availing rehabilitation services.

It was observed that if parents were aware about the prognosis and therapy requirement; then, irrespective of SE status they managed against all odds to ensure that child receives some service. On the other hand, ignorance fostered other negative beliefs and gave rise to nonutilization of services. Close to 43.54% parent in the present study did not believe that child condition would improve with physical exercises and most of them had not utilized physiotherapy services.

Knowledge, education, and information strongly influence beliefs and perceptions of illness, health-seeking behavior and compliance with therapy,^[27] and the factors that affect the knowledge can significantly alter the service utilization pattern.^[28] Educational levels of parents and advice for rehabilitation of child by treating medical doctor were such factors emerged in univariate analysis. These two factors were significantly associated with awareness about condition and rehab requirement of child and exerted greater influence on the utilization of physiotherapy service. The proportion of children exposed to physiotherapy was much higher among educated families, and they also received physiotherapy for longer duration. Children not advised for rehab by medical doctors were 2.63 times more likely not to receive physiotherapy.

This observation provides support to the notion that poor referral system that does not fully utilize the expertise available within the system is one of the main factors that influence the access to rehab services in India.^[16] It is imperative that extra efforts are made to sensitize the medical community about the need of timely referral for physiotherapy to CP children.

Expectation of normalcy – a facilitator of physiotherapy use as observed in this study – stems from ignorance about the condition. The movement and posture dysfunction in CP are permanent and even with best rehabilitation efforts functional and physical recovery in CP is rarely complete.^[29] Therefore, the aim of the intervention is not complete cure but habilitation. This truth is often emotionally not acceptable to parents, and they tend to lure toward all sorts of treatment options.^[30] The emergence of expectation of normalcy as one of the main drivers of physiotherapy use in this study underscores this point. A closer examination data revealed that this unrealistic expectation was associated with higher utilization of other health services as well.

Although nonsignificant in final model, age of diagnosis and chronological age of child were found significantly associated with exposure to physiotherapy in univariate models. Children diagnosed at younger age had relatively better chance of exposure to physiotherapy, and this supports the value of early identification. The chance of nonexposure was high for children with older age. This positive relationship of age of child with nonexposure to physiotherapy should be interpreted with caution. This may reflect changing pattern of physiotherapy use attributed to the availability of physiotherapy services which has increased in the recent decade in the district. In the last 10 years, number of physiotherapy teaching institution offering bachelor and master degree education in physiotherapy were opened up in Jalandhar district which contributed to increase in the numbers of physiotherapy service providers in the district as well as improving the community awareness about

physiotherapy. *Sarva shiksha abhiyana* - a flagship program of the Government of India - also increased the coverage of physiotherapy to the disadvantaged group of society. This may partly explain the more exposure of physiotherapy service in younger age group. However it does not explain why even with the availability of service older children were not exposed to physiotherapy? We are not sure if this could be an indication of loss of hope of normalcy with the growing age of child.

The multivariate model explained only 25% of the variance in nonexposure to physiotherapy. This strongly suggests the existence of other factors contributing to nonexposure which were not captured in this study. For example, psychological and religious beliefs, interpersonal relationships within family, attitude of service providers, etc., may affect rehab service utilization. It is imperative that these should be explored in future studies.

The findings of this study have important implications for policy formulation and service delivery. The need of improving awareness among the parents of children with CP about the condition and services required for improving the quality of life is apparent. Lots of information on the rehabilitation of CP children is available, nowadays, on the Internet but most of this material is in English. There is scarcity of literature on management of CP in Hindi and Punjabi and other local languages. For person familiar with English, it is easy to access and use information available in English. However, for a majority language barrier prevents independent access of information. A closer examination of data reveals that just 4.9% of educated families who were not provided with advice for rehab were aware about the condition, but the less educated and illiterate remained ignorant when not provided with advice for rehabilitation. The only source of information for them was the health professional and community. In view of the fact that only 17% children were provided advice for rehabilitation making available information in Punjabi and Hindi language seems to be the need of hour. Such efforts would contribute to improve family and community awareness and facilitate physiotherapy service utilization. A mechanism should be evolved to ameliorate the financial and transportation constraints to make physiotherapy affordable to every child with CP irrespective of SE status and locality.

The study was delimited to one district of a prosperous state of India. Conducting similar studies in other parts of country would bring out the true picture. Data for this study were based on the self-reported information of respondents and validation of the provided information from other objective sources was not possible which may be construed as the limitations of this study.

CONCLUSION

This study identified a constellation of complex and interrelated relationship between factors associated with nonexposure to physiotherapy. Awareness and expectation of normalcy were the main drivers for the use of physiotherapy among children with CP in Jalandhar. It is imperative that efforts are made to educate the parents about the nature of condition and the lifelong rehab requirements of the child.

This would create the demand for physiotherapy services and facilitate the establishment of proper mechanism of service delivery.

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Conflicts of interest

There are no conflicts of interest.

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