

Factors Influencing the Utilization of Physiotherapy Services Among the Children with Cerebral Palsy at Protibondhi Seba-O-Sahajjo Kendro in Bangladesh

Md. Rafiqul Islam¹, Ershad Ali², Rasel Howlader³

¹Protibondhi Seba-O-Sahajjo Kendro (PSOSK), Jatiyo Protibondhi Unnayan Foundation (JPUF), Ministry of Social Welfare, Dhaka, Bangladesh

²Walk for Life - The Clubfoot Program of Bangladesh, Dhaka, Bangladesh

³BRAC Education Program (BEP), Dhaka, Bangladesh

Email address

rafiqulphysio@gmail.com (R. Islam), physioershad@gmail.com (E. Ali), howlader.rasel@yahoo.com (R. Howlader)

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Abstract: *Background:* Cerebral palsy (CP) is a non-progressive irreversible lesion either single or multiple areas of the immature brain due to a developmental abnormality of brain or injury of the brain during labor, at the time of birth or during delivery. The prevalence of cerebral palsy is 2.5% per one thousand live births. Children with cerebral palsy required rehabilitation care both at home and rehabilitation center. The study aims to find out the factors affecting adherence to physiotherapy appointment for caregivers of children with cerebral palsy in Bangladesh. *Methods:* A cross-sectional study designed to conduct the research a total of 225 cerebral palsy child from the 14 Protibondhi Seba-O-Sahajjo Kendro (PSOSK) at the different district of the Bangladesh were selected through random sampling techniques by face-to-face interviews. This data collection procedure was completed within one month. Chi square test were used for statistical analysis of data and the significant level set at $p < 0.05$. *Results:* Study shows that among the 225 CP child only 33.8% maintain adherence and 66.2% was non-adherence. Different variables such as numbers of siblings, doctors' consultation, parents' level of education and their awareness, mother health condition and having any savings have a significant association with adherence ($P < 0.005$). *Conclusion:* Adherence of the cerebral palsy child with physiotherapy appointment is out most important for better management. In this study, it is suggested that the quality of life of the CP child is significantly changed by physiotherapy as well as rehabilitation.

Keywords: Cerebral Palsy, Physiotherapy, Caregivers, Adherence, Rehabilitation

1. Introduction

Cerebral palsy is a non-progressive irreversible lesion either single or multiple areas of the immature brain due to a developmental abnormality of brain or injury of the brain during labor, at the time of birth or during delivery [1]. It is the most commonly occurring neurodevelopment disorder beginning in the early stage of the neonatal period and persists for while lifelong [2]. The prevalence of CP is much higher in preterm infants than in full terms infants [3]. Worldwide, the prevalence of cerebral palsy is 2.5% per one thousand live births [4]. Cerebral palsy is 5 to 10-fold more

prevailed in lower economic countries in the globe [5].

Bangladesh is a developing country and the prevalence of Cerebral palsy in Bangladesh was 3.7 per thousand of the children in a live birth [6]. Another study conducted on the prevalence of childhood disabilities and cerebral palsy in the community and recommended that the prevalence of cerebral palsy in Bangladesh was 6.1/1000 in a live birth [7].

The prevalence of disability due to cerebral palsy in a population of children ages 2-9 years from both urban and rural populations was estimated to be 70/1,000 for all grades of severity and 22/1,000 for serious disability in Bangladesh [8].

In the light of international initiatives and quality of service and the right and protection of persons of disabilities declared by the UNCRPD, Bangladesh government form Neuro-developmental Disability protection act 2013, the national disability development foundation was formed in 2009 and it is responsible for the ministry of social welfare. There are 103 Protibondhi Seba-O-Sahajjo Kendro (PSOSK) are operating by this foundation. The main aim of those centers is to provide free disability detection survey activities in all districts and provide free medical and therapy services to all persons with disabilities and persons at the risk of disability to ensure healthy living. In the fiscal year of 2017-2018, nearly 40 lacks and four thousand medical and therapy services and about 34 thousand assistive devices were provided through 103 PSOSK.

As cerebral palsy cannot be fully cured, different therapeutic intervention with a multidisciplinary team approach is used for secondary impairment prevention and ensuring the natural developmental milestone of the cerebral palsy child [9]. Physiotherapy is more frequently used for functional improvement of the cerebral palsy child [10]. Mothers of children with cerebral palsy are usually the primary caregivers of their children, [11]. Typically, in rural and undeveloped areas, these caregivers have had no or limited access to skills and training [12]. Consequently, it is out most important to recognize how parents/caregivers of the children with cerebral palsy manage their children's physiotherapy services and the potential barriers they encounter during the use of the services. Hence knowledge of those factors that affect adherence to physiotherapy appointments among the children with CP has an important association for ongoing efforts directed at proper rehabilitation of those children [13]. So, the aim of this study is to find out the factors affecting adherence to physiotherapy appointments of children with cerebral palsy in Bangladesh.

2. Materials and Methods

A cross-sectional study was carried out at protibondhi seba-o-sahajjo kendro (PSOSK) from the fourteen (14) different districts and Upazila in Bangladesh. 225 participants were assigned randomly. The researcher took data from the principal caregiver's randomly who came at PSOSK. The Inclusion criteria of the study was diagnosed cerebral palsy child's who already registered for physiotherapy treatment at PSOSK. Age is between 1-10 years and who received physiotherapy intervention at least three months.

Prior to collect data the purpose of the study was explain and written consent were taken. Data were collected through a self-developed questionnaire consisting of closed structured question through face-to-face interview. Prior to data collection expert opinion were taken to validate the questionnaire. Data was collected within a short period of time and the total procedure were completed at 30 days.

Adherence is estimated by considering the number of the attendance of prescribed appointments divided by the total

session he or she received treatment (from the first appointment) multiply by one hundred i.e., $\text{Adherence} = \frac{\text{Session of received treatment / prescribed appointments}}{100} \times 100$. Where $\geq 70\%$ score is considered at adherence, while $< 70\%$ considered to be non-adherence.

3. Result

There are 225 children with cerebral palsy enrolled in this study. Among them 44% is quadriplegic CP, 26.7% is hemiplegic CP. Rests of percentage (29.3%) were suffering either Monoplegic or paraplegic type of cerebral palsy.

Table 1. Characteristics of the study participants (n=225).

| | |
|----------------------------------|--------------|
| Age: mean (SD), month | 48.6 (30.55) |
| Sex: boy, n (%) | 114 (54.8%) |
| Schooling (Age>60months) N=63 | |
| No: n (%) | 41 (65.08) |
| Other disease: Yes, n (%) | 62 (27.6) |
| Other disability: Yes, n (%) | 102 (45.3) |
| Assistive device: Yes, n (%) | 103 (45.8) |
| Dependent on others for ADL | |
| Yes, n (%) | 211 (93.8) |
| Principal caregiver: Mother, (%) | (91.6) |
| Rate of Adherence, n (%) | 76 (33.8) |
| Non-Adhere, n (%) | 149 (66.2) |

3.1. Caregiver's Awareness and Spend Time at Home for Exercises

Among the caregiver 44.4% of them had no knowledge/awareness about Physiotherapy, 38.70% had minimal awareness about treatment and 14.20% was known what exercise was performed for physiotherapy treatment for their child and only 2.7% of caregiver had clear image about physiotherapy and they are very optimistic about the health of their child. 51.1% caregiver did not spend time at home for exercising their CP child. The mean times were 35.15 ± 33.90 minutes.

3.2. Traveling Time, Waiting Time and Cost Required for Receiving Services

Table 2. Socio-cultural information of the participants.

| Variables | Frequency | % | Frequency | % |
|---|-----------|------|--|------|
| Father attitude towards CP child | | | Neighborhood view with CP | |
| Strong Positive | 59 | 26.3 | 29 | 12.9 |
| Positive | 133 | 59.4 | 142 | 63.1 |
| Negative | 03 | 1.3 | 09 | 4.0 |
| Strongly negative | 29 | 12.9 | 45 | 20 |
| Family member help to take care | | | Other child meet & play | |
| Yes | 49 | 73.1 | 152 | 67.6 |
| No | 18 | 26.9 | 73 | 32.4 |
| Family member interrupts for receiving PT treatment | | | Who interrupt for receiving PT treatment | |
| Yes | 18 | 8.0 | Father=11 (61.1) | |
| No | 207 | 92.0 | GM+GF=5 (27.9) | |

Almost every participant has to wait for some time to get treatment, maximum waiting time was 180 minutes and mean waiting time was 28.63 ± 24.19 minutes. Minimal 10 minutes and maximum 210 minutes were required to reach the center.

Minimum travelling cost was 10 and maximum was 500 takas, the mean cost was 87.98 ± 78.95 taka.

Here, GM-grandmother, GF-grandfather

There are (Table 2) 67 number of families were combined among them 26.9% cases others family member didn't help to take care the disable child. 67.6% of other child of the

family regularly meet and play with the disable child and 32.4% didn't play and meet with the CP child. Only 8% of family members interrupted for receiving Physiotherapy treatment among them 61.1% interruption was provided by father and 16.7% provided by grandmother.

Table 3. Characteristic of CP children and adherence.

| Variables | ADHERENCE | | df | x2 | P-Value |
|--|---------------------|--------------------------|----|--------|---------|
| | Adhere N=76 (33.8%) | Non-adhere N=149 (66.2%) | | | |
| Siblings | | | | | |
| No sibling | 42 (18.7) | 52 (23.1) | 1 | 8.580 | .003** |
| Siblings | 34 (15.1) | 97 (43.1) | | | |
| Doctor consultancy | | | | | |
| Yes | 67 (29.8) | 107 (47.6) | 1 | 7.671 | .006** |
| No | 09 (4.0) | 42 (18.7) | | | |
| characteristics of parents and Adherence | | | | | |
| Mother's education | | | | | |
| Below SSC | 39 (17.3) | 111 (49.3) | 1 | 12.17 | .000** |
| Above SSC | 37 (16.4) | 38 (16.9) | | | |
| Mother illness | | | | | |
| Yes | 18 (8.0) | 18 (8.0) | 1 | 5.042 | .025* |
| No | 58 (25.8) | 131 (58.2) | | | |
| Father Education (One father was left due to dead) | | | | | |
| Below SSC | 36 (16.0) | 104 (46.4) | 1 | 11.237 | .001** |
| Above SSC | 40 (17.8) | 44 (19.6) | | | |
| Family members | | | | | |
| Three | 28 (12.4) | 36 (16.0) | 1 | 3.976 | .046 * |
| >Three | 48 (21.3) | 113 (50.2) | | | |
| Family savings | | | | | |
| Yes | 30 (13.3) | 30 (13.3) | 1 | 9.626 | .002 ** |
| No | 46 (20.4) | 119 (52.9) | | | |
| Expenditure for physiotherapy treatment (Taka) | | | | | |
| Upto1000 taka | 50 (22.2) | 124 (55.1) | 1 | 8.725 | .003 ** |
| Above 1000taka | 26 (11.6) | 25 (11.1) | | | |

(* = Level of significant, * P < .05)

In this study (Table 3) 58.2% of CP child had siblings, among them 43.1% showed non-adherence. 77.4% of CP child consult with doctor among them 47.6% showed non-adherence with treatment, on the other hand 22.7% of CP child did not consult with doctors and among these percentage comparatively higher 18.7% of participant showed non-adherence with treatment.

3.3. Parents and Adherence

Mother's illness has also significant relation with adherence with Physiotherapy treatment (Table 3), 73.3% of families had no savings that indicate they lived in low economic condition and the rate of non-adherence was 52.9%.

Table 4. Residence, Transportation and adherence.

| Variables | ADHERENCE | | df | x2 | P-Value |
|--|---------------------|--------------------------|----|--------|---------|
| | Adhere N=76 (33.8%) | Non-adhere N=149 (66.2%) | | | |
| Location of the residence | | | | | |
| Village | 45 (20.0) | 116 (51.6) | 2 | 10.647 | .005** |
| Thana | 09 (4.0) | 15 (6.7) | | | |
| District | 22 (9.8) | 18 (8.0) | | | |
| Distance from PSOSK to residence of the participants | | | | | |
| Upto10000meters | 57 (25.3) | 79 (35.1) | 1 | 10.170 | .001** |
| Above10000meters | 19 (8.4) | 70 (31.1) | | | |
| Time required for reaching PSOSK | | | | | |
| Up to30 min | 45 (20.0) | 59 (26.2) | 1 | 7.789 | .005** |
| Above30 min | 31 (13.8) | 90 (40.0) | | | |

(* = Level of significant, * P < .05)

As nearly two third of the participants lived in village (Table 4), 60.4% of participants required travel up to 10 Km,

among them 35.1% showed non-adherence, 46.2% of participants required up to 30minutes of traveling to reach

the PSOSK and among them 26.2% was non-adherence.

Table 5. Socio-cultural characteristics of the participants and adherence.

| Variables | ADHERENCE | | df | x2 | P-Value |
|---|---------------------|--------------------------|----|--------|---------|
| | Adhere N=76 (33.8%) | Non-adhere N=149 (66.2%) | | | |
| Father's attitude towards CP child | | | | | |
| Positive | 73 (32.4) | 119 (52.9) | 1 | 10.040 | .002** |
| Negative | 03 (1.3) | 29 (12.9) | | | |
| Neighborhood view to the CP child | | | | | |
| Positive | 66 (29.3) | 106 (47.1) | 1 | 6.890 | .009** |
| Negative | 10 (4.4) | 43 (19.1) | | | |
| Caregiver level of awareness about Physiotherapy | | | | | |
| No knowledge | 22 (9.8) | 78 (34.7) | 1 | 11.163 | .001** |
| Knowledgeable | 54 (24.0) | 71 (31.6) | | | |
| Caregiver spent time at home exercise | | | | | |
| Yes | 49 (21.8) | 61 (27.1) | 1 | 11.155 | .001** |
| No | 27 (12.0) | 88 (39.1) | | | |
| characteristics of services provided by the institute and adherence | | | | | |
| Therapy providing times | | | | | |
| < 30 minutes | 35 (15.6) | 105 (46.6) | 1 | 12.765 | .000** |
| >30 minutes | 41 (18.2) | 44 (19.6) | | | |
| Providing therapy regularly as per prescription | | | | | |
| Yes | 66 (29.3) | 108 (48.0) | 1 | 5.920 | .015* |
| No | 10 (4.4) | 41 (18.2) | | | |
| Physiotherapist's attitude towards the caregiver of CP child | | | | | |
| Positive | 74 (32.9) | 133 (59.1) | 1 | 4.494 | .034* |
| Negative | 02 (0.8) | 16 (7.1) | | | |
| Condition of the CP child changed after receiving treatment | | | | | |
| Yes | 71 (31.6) | 79 (35.1) | 1 | 36.967 | .000*** |
| No | 05 (2.2) | 70 (31.1) | | | |

(* = Level of significant, * P < .05)

Study result (Table 5) showed that among the fathers of 224 CP child 192 fathers showed positive attitude and their adherence rate was high. On the other hand, 32 father showed negative attitude, among them 29 CP child showed non-adherence. Above table also showed that 23.5% of neighbor showed negative view towards the CP child among them 19.1% was non-adherence.

3.4. Characteristic of Caregivers and Adherence

There are (Table 5) 44.5% of caregiver had no knowledge about physiotherapy among them 34.7% were non-adhered with treatment and 55.6% had some knowledge about what treatment was provided to their child, among them 24% adhered with treatment. 51.1% of participant did not spent time at home for exercise, among them 39.1% were non-adhered with treatment and 48.9% of participants spent time at home for exercise, also among them 27.1% were non-adhered with treatment.

3.5. Characteristics of Services Provided by the Institute and Adherence

Result (Table 5) shown that 62.2% of participants received treatment less than 30 minutes among them maximum 46.5% were non-adhered with treatment on the other hand 77.3% of cases therapy was provided regularly, among them 48% were non-adhered and 22.6% of cases therapy was provided

irregularly, among them 18.2% were non-adhered with treatment. There is a significant relationship with the physiotherapist attitude towards the caregiver and adherence and also how much the conditions changed after receiving the physiotherapy, 33.3% of cases the condition of the CP child was unchanged after receiving the treatment and among them 31.1% showed non-adherence.

4. Discussion

The result of this study shows that the mean age of the CP child was 49.90±29.50 months, which was comparable with a study in India (2018) in about the clinical profile of cerebral palsy in which, overall mean age was 48.84 months. The maximum number 56 (24.9%) of CP child presentation were in the age group of 12-24 months in both sex and this study 71.9% of child age within five years, this result was similar with the study of [14] Makwana.

This study showed that the number of siblings had a significant relationship with adherence (P < .003), 58.2% of CP children had siblings, among them 43.1% showed non-adherence. Those families have more than one child, traveling to and from for therapy appointment as per the schedule and their need for childcare assistance, sometimes required schooling the aged siblings that become great barriers for this caregiver for maintaining adherence to

treatment [1]. Among the 225 CP children, only 76 (33.8%) maintain adherence and 149 (66.2%) was non-adherence. Similarly, a classical study [13] shows that 28 (46.7%) of the participant was adherence and 32 (53.3%) was non-adherence. According to the WHO, there are five factors influencing adherence thus include social and economic factors, health system-related factors, therapy-related factors, disease-related factors, and patient-related factors [15].

Majority of the principal caregivers are the biological mother (91.6%) of the CP child and their non-adherence rate was high (60.0%). In this study, three mothers were divorced and one mother was widowed, all of them were non-adhered with treatment, similar findings were observed in a study where the high rate of non-adherence was recorded among the divorced caregiver [13].

Result also shows that non-adherence rates were more than two times greater than adherence in parent's education level below SSC, on the other hand parents whose education level were above SSC their rate of adherence nearly 50% and had a strong relationship with the adherence ($P < 0.05$). This result is similar to the study conducted in the Kano metropolis who found that the education level of caregivers has a strong relationship with adherence to PT appointment [13]. Although PSOSK provided physiotherapy services for the CP children free of cost rural people required high traveling costs due to long-distance, so it becomes a major barrier for a poor family in Bangladesh. This constraint also found in India the researcher found that transportation to the CP child to physiotherapy center involves considerable expenses for a poor family and thus became major barriers even though services provided free of the cost [16].

Service duration and physiotherapist attitude towards the patient has a significant relationship with adherence, Caregivers be satisfied and confident on their therapist resulting in they made more adhere to treatment. Literature showed that a longer duration of treatment period might influence the adherence of chronic ill patients with treatment for the prolog period [17]. There was a significant association between the home exercise program and adherence (P -value 0.001). Non-adherence to home exercise programs is documented as one of the factors affecting treatment outcomes [18].

5. Conclusion and Recommendations

Considering the results of this study, and the difficulties parents experienced in adherence to all treatment appointment at the PSOSK. There is a need to decentralize services from district to Union health centers in the community that are accessible to most patients/caregivers. This can be implemented through outreach clinics in communities that are located far away from the district. This strategy would shorten the distance for parents, increase the accessibility of these services to the very poor families those are unable to meet transportation costs and would be an effective strategy of taking services nearer to the people.

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