

Barriers facing by parents during clubfoot treatment of children with clubfoot deformity

Abstract

Background: One out of 750 children born in the world suffers from club foot and among them 80% was in low and middle income countries. Most of these babies had limited access to receive effective treatment for their clubfoot. While receiving treatment, their parents were facing several problems and barriers to complete the treatment regime. Although the majority of clubfoot babies were in developing countries but we actually didn't know how much are dropping from treatment and its actual reason, which may cause severe disability as a consequence. The purpose of this study was to investigate barriers facing by parents who have children with clubfoot during clubfoot treatment.

Methods: This cross sectional study was conducted among 102 parents who had children with clubfoot deformity during its treatment in selected clinics. The samples were selected purposively from the clinics where clubfoot treatment was given and face to face interview was done by using semi-structured questionnaire.

Results: The mean (\pm SD) age of the respondents was 24.7 (\pm 6.0) years where 87.3% respondents were female and 59.8% respondent's educational status was up to primary level. About 44.1% respondents started treatment of their child within 6 months of birth and 33% within 6 to 12 months where 57% respondents were referred by health care professional to clinics. About 69.6% respondents agreed with prolong treatment regime and about 83.4% respondents reported about prolong waiting time where 93.1% were motivated to completion the treatment. On the other hand about 89.3% respondents were able to understand the clinician's information correctly. About 61% respondents told about financial problems where 92.2% respondent's main earning members were paying treatment cost. Additionally 18% respondents had transport problem and about 78% had to come in the clinic for treatment from more than 11 km away.

Conclusion: There is need to improve the communication skills of clinicians offering treatment to children with clubfoot at the Clinics. Need to minimize cost and develop patient friendly service so that parents get service within short possible time. Finally, there is need to decentralize clubfoot treatment services away from referral hospitals to the people in the community through outreach programs.

Keywords: Club Foot, Barriers, Deformity

Introduction

The burden of childhood disability as a public health problem in developing countries remains relatively unrecognized.¹ One out of 750 children born in the world suffers from club foot. Around 2,20,000 babies in developing countries born with clubfoot each year.² Study shows approximately 80% of total clubfoot is in low and middle income countries.^{2,3} Most of these babies have limited access to receive effective treatment for their clubfoot and will grow up with severe disability as a consequence.³ In America and the United Kingdom the estimate incidence of clubfoot is 1 per 1000 births, with males more affected than females in a ratio of 2:1.⁴ However another finding indicates an incidence of 2 to 3 per 1000 births in developed countries.⁵ Additionally the incidence of clubfoot among black South African children is reported to be 3.5/1000 births.⁶ Although it is estimated that 80% of the world's disabled children less than 15 years of age live in developing countries, not much is known about the disabling conditions such as clubfoot in these countries.⁷

In Bangladesh the estimated number of children with clubfoot born per year is about 4373, and an incidence rate of club foot is 1.2/1000 births.¹ Every year in Bangladesh and Myanmar an estimated 5-6000 children are born with clubfoot deformity every year, which is approximately one of every 1000 children born in our country.⁸ Untreated or incorrectly treated clubfoot soon becomes 'neglected clubfoot' as the child grows. A child with neglected clubfoot will have difficulty in wearing normal shoes and as they grow older may experience severe pain. Neglected clubfoot severely restricts ability to walk in some cases, and in others only short distances are manageable. The burden of this disability impacts on society as a whole and as such the problem of untreated clubfoot should be viewed as a public health issue which must be addressed.³ Due to lack of awareness and poor access to healthcare most children with clubfoot in developing countries have limited access to receive treatment.⁹ It has been shown that only 10% of children with clubfoot in East Africa are able to access treatment from a specialist owing to inadequate awareness, poor communication, travel expenses and increased parental

responsibilities of care in the family.¹⁰ Currently, only 2% out of over one million people with disabilities in Uganda receive rehabilitation services.¹¹ Patient compliance with treatment procedures is important for the therapeutic regimen to be effective. Without compliance, the therapeutic goals cannot be achieved, resulting in poor patient outcomes.¹² Research on adherence to pediatric treatment regimes has received attention in recent years as sub optimal adherence to medical and other therapeutic regimens can have personal, social and clinical implications for the child as an adult.¹³ Lack of information regarding reasons for adherence to the regimen makes it difficult for health providers and health planners to determine the impact of treatments on health status or weigh the cost/benefit ratio for prescribing costly treatments to the patients.¹⁴ Therefore, it is important to understand how parents/caregivers manage their children's treatment and the potential barriers these parents encounter during the utilization of clubfoot treatment services. Despite serious consequences of poor compliance to prescribed therapeutic regimens for children with physical and mental impairments, compliance or treatment adherence in this group of children has not been well studied.¹⁵ Socio-economic factors have been shown to be a major hindrance to access to health care services in most resource-poor settings.¹⁶ Studies in developing countries with low-resource settings have shown that multiple barriers affect patient or caregiver's utilization of health care services. In this study we tried to find out the barriers facing by parents during clubfoot treatment of their children with clubfoot deformity.

Methodology

Study design

This cross sectional study was conducted among the parents who had children with clubfoot deformity during its treatment in selected clinics.

Study area and population

The population of this study was the parents who had children with congenital clubfoot deformity attending in the selected clinic for treatment. Both male and female parents were recruited for interview. The study was conducted at 'Nilphamari' and 'Rangpur' general disability clinics and in National Institute of Traumatology and Orthopedics Rehabilitation (NITOR).

Study sample and sampling method

To conduct study 102 samples were selected purposively from the selected clinics from January 2011 to June 2011. The parents who had children with clubfoot age up to 2 years, who were currently receiving treatment and undergoing plaster casting were included in this study. Children who had clubfoot with other additional disabilities and other relatives who were not principle caregivers of children with clubfoot were excluded from this study.

Data collection tools and techniques

Data were collected by face to face interview. On average, 25-30 minutes were spent for each of the patients. A pre-tested semi-structured questionnaire in Bangla was used for data collection. The questionnaire was pre-tested with similar type of patients who were not included in the study sample. Some modifications and corrections were done subsequently using the feedback from pre-testing.

Data analysis

After collection data were checked thoroughly for consistency and completeness. Data were cleaned, edited and verified on daily basis to avoid any error or inconsistency. Incomplete or erroneous data were discarded. SPSS (Statistical Package for Social Sciences) Statistics version 16 was used to analyze the data. After the entry, range, consistency and normal distributions were checked. Descriptive statistics were computed for all categorical variables.

Ethical issues

Purpose of data collection was explained to the respondents and informed written consents were taken from the respondents prior to data collection. Respondents' dignity and respects were maintained and interviews were taken with strict privacy. The respondents were informed clearly that their personal identity would be kept confidential and the data would be used only for study purpose. Moreover, participants were allowed to withdraw themselves at any stage of the study. Neither any drug nor any invasive procedure was applied.

Results

Socio-demographic characteristics of the respondents

Of the 102 respondents, the age ranges were from 14 years to 40 years. The mean \pm SD age was 24.7 \pm 6.0 years. About 58.8 % (60) respondents were in younger age group (20-30 years). Rest of 28.5% (29) was in age group 14 to 20 years and 12.7% (13) are in age group 31 to 40 years. The results showed 87.3% (89) respondents were female and 12.7% (13) were male. In case of occupation, study showed that about 51% (52) were house wife and rest of them were service holder 17.6% (18), business man 13.7 % (14), day labor 11.8 % (12), farmer 4.9 % (5) and one percent was unemployed. About 59.8% (61) respondents's educational status were up to primary level where 28.4% (29) had no formal education. Only 7.8% (8) parents had University level education. Rest of 21.6% (22) of parents had secondary level education and 10.8% (11) had higher secondary school level education. Results showed about 44.1% respondents started treatment of their child within 6 months of birth and 33% within 6 to 12 months. In case of referral to the clinic, about Fifty-seven percent of the children (n=58) were referred by friends or neighbor, 38.2% of children (n=39) were referred by medical professionals, 2% of children (n=2) were referred by traditional birth attendants, parents of 2.9% of children (n=3) referred themselves to the clinic (Table 1).

Barriers related to treatment

About 69.6% (71) respondents opinion was that prolong treatment regime affect the treatment completion. Rest of the parents (30.4%) were not agrees to this compliment. In case of waiting time about 83.4% (85) respondents had to wait more than two hours for receiving treatment. About 15.7 % parents had to wait one hour, 1% had to wait 30 minutes for receiving treatment. In case of motivation to complete treatment, about 93.1% (95) were motivated to completion the treatment of clubfoot deformity where 6.9% respondents were not sure about the completion of treatment program. In case of understanding clinician's instruction, result showed that 89.3% (91) respondents able to understand the clinician's information correctly

and about 10.7% (11) respondents were not able to understand the clinician's information correctly (Table 2).

Table 1 Socio-demographic characteristics of the School children

Items	Frequency	Percentage	Mean \pm SD
Age (Years)			
Up to 20 yrs	29	28.5	
21-30 yrs	60	58.8	
31-40 yrs	13	12.7	24.7 \pm 6
Total	102	100	
Gender			
Male	13	12.7	
Female	89	87.3	
Total	102	100	
Occupation			
Service	18	17.6	
Business	14	13.7	
Unemployed	1	1.0	
House wife	52	51.0	
Farmer	5	4.9	
Day labor	12	11.8	
Total	102	100	
Educational Status			
No formal education	29	28.4	
Primary level	32	31.4	
Secondary School Certificate	22	21.6	
Higher Secondary Certificate	11	20.8	
Graduate level	8	7.8	
Total	102	100	
Age of Treatment Commencement			
0 to <6 months	45	44.1	
6 to <12 months	34	33	
12 to 24 months	23	22.9	
Total	102	100	
Referred to the Clinic			
Friends/Neighbor	58	57	
Medical professional	39	38.2	
TBA	2	2	
Self	3	2.9	
Total	102	100	

Table 2 Barriers related to treatment

Barriers	Frequency	Percent
Prolong Treatment Regime		
Agree	71	69.6
Disagree	31	30.4
Total	102	100
Prolong Waiting Time		
Up to 30 minutes	1	1
Up to 1 hour	16	15.7
Up to 2 hours	43	42.2
More than 2 hours	42	41.2
Total	102	100
Motivation for Treatment Completion		
Motivated	95	93.1
Not-motivated	7	6.9
Total	102	100
Understanding the Clinician's Advice		
Yes	91	89.3
No	11	10.7
Total	102	100

Barriers to regular treatment attendance

The barriers that were assessed include: financial, social and family support, travelling distance from the disability Clinics. About 96.1% respondents said that they were facing some problem to take these services and that was financial problem, one of them saying about social stigma. Very few 3.9% respondents (n=4) were not bothering with any type of problem. The result showed that, about 24% came from more than 15 kilometers by using rickshaw or van. Eleven patients took treatment by walking from the clinic (distance less than 15 km). Maximum (n=34) came from more than twenty kilometers and using bus (n=22). Maximum respondents (n=94) were financed by their earning member. Very few (n=2) were financed by community leader (Table 3).

Table 3 Barriers to regular treatment attendance

Barriers to Regular Treatment Attendance					
	Yes		No		
	Frequency (n)	Percent (%)	Frequency (n)	Percent (%)	
Financial	61	59.8			
Transport	18	17.6			
Social support	1	1.0			Total
Family support	5	4.9	4	3.9	
Time	13	12.7			
Total	98	96.1	4	3.9	102
Transport to Come in to Clinic					
Distance	Frequency (n)	Percent (%)	Bus	Rickshaw/van	Walking
0-10 km	22	21.6	1	17	4
11-15 km	27	26.5	3	17	7
16-20 km	19	18.6	7	12	0
>20 km	34	33.3	22	12	0
Total	102	100.0	33	58	11
Financial Support for Treatment					
	Frequency (n)	Percent (%)			
Father/Earning member	94	92.2			
Friends/neighbors	3	2.9			
Community leader	2	2.0			
Health worker	3	2.9			
Total	102	100.0			

Discussion

Study showed about more than two third respondents was agreed that the treatment regime of clubfoot was too long. That's why they faced problem in continuing treatment regime. Although most parents did not report it as a major barrier to adherence to the treatment requirement, it is important to discuss the duration of waiting time for treatment at the Clinics. In this study, 85% of parents waited for two or more hours for treatment. This was a very long a period to wait for treatment for children who easily tired and get hungry after an excessive wait and, for the mothers who had other responsibilities at home including caring for other children. This long wait could be due to the heavy case loads these clinics experience as these hospitals were the only public health facilities in the districts which offered treatment of clubfoot at no cost under special care of experts. It was possible that decentralizing treatment services for clubfoot could eliminate many of these barriers such as parents experience including the long hours parents had to wait to access the services at these hospitals.¹⁷ On the other hand almost majority (95%) of the respondents were motivated or wished to complete the treatment, where in this study about 91%

respondents reported that they were able to understand the clinicians information where 11% claimed that they did not able to understand them. Research had shown that relationships between the health care provider and patient or caregiver determine the patient/caregivers behavior during treatment. Good relationships were said to be vital for mutual understanding and are strongly correlated with compliance to the prescribed treatment,¹⁸ a good health provider-caregiver communication involved exchange of information and required the health provider to interpret explanations, define or clarify issues and procedures and also to be prepared prior to the actual explaining. It is said that if the treatment process was explained to patients or caregivers, they would be more knowledgeable, had more positive beliefs about their treatment, feel more satisfied with care, and more likely to comply with the treatment requirements.¹⁹⁻²² In this study found, about 61% respondents reported that financial problem was their main reason for receiving and attending for treatment where 18% respondents reported transport was their main barriers for treatment receiving and 13% reported about time problem and rest of 5 reported family problems for receiving treatment. Study also found that almost majority of the respondents came to the clinic from more than 10 km

away where about one third respondents came to the clinic from more than 20 km away. Study also found that about 94% respondents had to pay their own cost of treatment. It is reported that in developing countries the effect of distance became stronger when combined with lack of transportation and poor roads, which contributed towards indirect costs of visits to health care facilities. In USA, distance travelled to the treatment centre, was associated significantly with treatment retention and completion.²³ Clients who travelled less than one mile were much more likely to complete treatment as compared to clients who travelled greater distances. This indicates that as the economic costs of treatment attendance increased with distance, the ability diminishes for clients to stay in treatment longer.^{24,25}

Conclusion

The study identified some difficulties in adhering to the required treatment program. These may have been barriers to attendance for other parents. These included financial constraints to meet transportation costs, travelling distance and inadequate parent-clinician communication.

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Conflicts of interest

The author declares that there is no conflict of interest.

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