

# **BARRIERS EXPERIENCED BY CAREGIVERS TO ACCESS TREATMENT OF CLUBFEET PATIENTS AT CRP**

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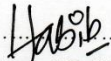
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We the under sign certify that we have carefully read and recommended to the Faculty of  
Medicine, University of Dhaka, for the acceptance of this dissertation entitled

**BARRIERS EXPERIENCED BY CAREGIVERS TO ACCESS  
TREATMENT OF CLUBFEET PATIENTS AT CRP**

Submitted by Kumar Amitav, for the partial fulfillment of the requirement for the  
Degree of Bachelor of Science in Physiotherapy.



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**Declaration**

I declare that the work presented here is my own. All sources used have been cited appropriately. Any mistakes or inaccuracies are my own. I also declare that for any publication, presentation or dissemination of information of the study. I would be bound to take written consent from Head of Physiotherapy Department, Bangladesh Health Professions Institute(BHPI).

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## Abbreviations

**AHA** American Health Association

**BHPI** Bangladesh Health Profession Institute

**BMRC** Bangladesh Medical Research Council

**CRP** Centre for the Rehabilitation of the Paralysed

**IRB** Institutional Review Board

**WHO** World Health Organization



## Abstract

**Purpose:** The purpose of the study is to identify barriers experienced by caregiver of clubfeet patient to accesses treatment at CRP . **Objectives:** The objectives are to identify the barriers of clubfeet patient's caregiver at CRP . To find out the main problem which hinders the accessibility to treatment of clubfeet. . patient who are getting service from CRP Mirpur and Savar ponseti clinic treatment and its actual reason, which may cause severe disability as a consequence.

during clubfoot treatment.. **Methodology:** The study was conducted at the Outpatient department of CRP. The study utilized qualitative descriptive survey. 12 participants were my sample. A structured, self-administered, closed ended questionnaire was used to collect data.. Those results indicated that all parents understood their role in the treatment of clubfoot during the plaster-casting phase and 74% of parents understood the consequences of not following the treatment regimen. Sixty seven percent of parents indicated that they did not know about clubfoot and its treatment before their child was diagnosed. Sixty-seven percent of parents indicated that they had poor communication with the clinicians; and 64% of the parents indicated that the clinicians did not give them a chance to talk about their problems. The factors that affected parents attending regular treatment appointments included: (i) high transport costs; (ii) lengthy travelling distance; (iii) poor social/family support; and (iv) poor communication between the parent and the clinician. **Conclusion:** This study comprehends about the experienced barriers experienced by caregivers of clubfeet to accesses treatment . So, identification of these barriers will help to give emphasize on designing the overcoming strategy of those challenges.

## 1.1 Background

Disability in childhood becoming a challenge day by day in the developed and under developed nations (Kingau, 2012). Increase the incidence of children, born with congenital clubfoot deformity which is linked by loss of ability to perform normal daily living activity (Matthew et al., 2006). Disability has introduced as a significant public pathological state worldwide at present time. However, the burden of childhood disability is a public health problem in developing countries which remains relatively unrecognized.

Clubfeet is a clear, relatively visible birth abnormality. With an estimated incidence of 1:1000 newborns, every year about 100,000–200,000 children are born with a clubfoot worldwide (Owen et al., 2012). Gupta et al. (2008) found that about eighty percent of total clubfoot children are in low- or middle-income countries. Clubfoot was first shown from Archaeological research in ancient Egyptian tombs on mummies by Smith & Warren (1924) reporting clubfoot on the Egyptian Pharaoh Siptah (XII century B.C.).

Disability due clubfoot threatens a person's potential productivity resulting to dependency. This has a great impact on an individual's social economic status that can significantly reduce the standard of living for the family and the community at large. In addition, the structural differences caused by clubfoot causes social stigma and affect the child psychologically (Bedford, 2009).It's subject is physical impairments that result in decreased ambulation and incapacity to perform fundamental business such as carrying water, collecting food and go to school and mainly dynamic activity. Children Living with the pain due to this disability and feeling insult a serious physical disability (Pirani et al., 2009). This induce to subordination for activities of daily vigorous with significant economic impact on the family. In addition, the structural differences in children with clubfoot are associated with social stigma, which has a psychological effect on the child.

Rehabilitation services are internationally recognized as one of the key components of health care (WHO, 2004 ). The goals of rehabilitation program in clubfoot including correction of the impairment which directly improve function, reduce activity limitations, prevent participation restrictions, prevent social and educational disadvantage, and to overall improvement the quality of life of the child. The importance of health care in many developing countries is directed primarily to curative and preventive aspects of disease, whether rehabilitation getting less attention ( Bhatia & Joseph,2001). Scarcity of resources and inappropriate distribution of health care professionals between rural and urban regions add to problems of rehabilitation in developing nations. This resulting, patients in poor rural settings going without treatment or having to travel long journeys to urban areas for treatment. For example, Physicians report up to 30% of patients do not complete treatment in developing country ( Palma, 2013). It has been shown that One out of 750 children born in the world suffers from clubfoot. According to clubfoot cure organization ; Around 2,20,000 babies in developing countries born with clubfoot each year . So several Study shows approximately 80% of total clubfoot is in low and middle income countries where most of these babies have limited access to receive effective treatment for their clubfoot and will grow up with severe disability as a consequence. Palma (2013) mentioned that the more number of trained physicians access in provincial areas , there the more probability of reduction of the financial and travel burden of parents to help increase compliance with treatment.

In America and the United Kingdom the estimated incidence of clubfoot is 1 per 1000 births, where boy children are more affected than girls, the ratio of boys and girl is 2:1 (Moorthi, 2005). However another finding indicate the incidence of 2 to 3 per 1000 births in developed countries (Pandey &Pandey,2003). Additionally the incidence of clubfoot among black South African children is reported to be 3.5/1000 births (Ballantyne,2002). 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. 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

(Shawky,2002). Every year in Bangladesh and Myanmar estimated five thousand to six thousand children are born with clubfoot deformity and among these number approximately one of every 1000 children born in our country (Walk for life, 2017). 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 . Due to lack of awareness and poor access to healthcare system, most children with clubfoot in developing countries have limited access to receive treatment . 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 (Scott & Evans,1997). Patient compliance with treatment procedures is important for the therapeutic regiment, that helps to therapeutic regiment be effective. Without compliance, the therapeutic goals cannot be achieved, resulting in poor patient outcomes (Cameron, 1996).

Physiotherapists has essential role in the rehabilitation team in clubfoot treatment both in developed and developing countries (Shack & Eastwood, 2006). It is not duty of a Physiotherapist, only offer treatment to children with clubfoot, but also ensure the education of parents/caregivers about the diagnosis, the treatment process and the expected outcome (Ireland, 2003). Initially a full diagnosis through a proper assessment of the child's capacity of functioning related to his/her age and initial intervention is important, in line with the consistency of treatment requirements, active parental involvement in the treatment system is also important for achieving good treatment results(Shack & Eastwood,2006).

Patient compliance with treatment procedures is important for the therapeutic regimen to be effective. It is not possible to achieve the therapeutic goals without compliance, which leads to resulting in poor outcomes of clubfeet treatment (Cameroon,1996). Research in recent years on adherence to pediatric treatment regimes has received attention, as sub optimal adherence to medical and other therapeutic procedure which have personal,

social and clinical implications for the child as an adult (De & Dobkins,2005). 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 (Modi, 2006). Therefore, it is important to understand how parents/caregivers manage their children's treatment and the potential barriers these parents solving during the utilization of clubfoot treatment services. It is important to determine the compliance of patients to clubfoot correction treatment in order to identify and target factors that may positively or negatively influence parents/caregivers attending at CRP.

## **1.2 Research question**

How the barriers experienced by caregivers hinders the accessibility of treatment of clubfeet patients in CRP ?

### **1.3 Aim**

The aim of the study is to investigate obstacle to treatment attendance parents of children with clubfoot in complying with clubfoot treatment at CRP Hospital, Savar.

### **1.4 Objectives of the study**

In order to achieve the aim of the study, the following objectives will be identified

- i) Identification of the difficulties parents experience in attending all treatment appointments.
- ii) Identification of associations between compliance to treatment and parent's knowledge about clubfoot, parents' experience of communication with the clinician, and the difficulties parents experience in attending all treatment appointments

## 1.5 Rationale

Nowadays clubfeet is a common type of disabling condition in all developing and poorly developed countries in the world. It is also increasing day by day for different reasons in Bangladesh. Clubfeet that causes the physical disability and psychologically hampered are important health problems in Bangladesh.

Clubfeet is a life-changing event in case where as that makes the people losing their full mobility power and it can make dependent on assistive device, but it depends on the proper treatment in early life . So the treatment varies from age to age . Treatment and progressive rehabilitation is not a matter for health service provider alone. It is a combination of both health service provider and family member. Physiotherapy goals to prevent the activity limitations and participation restrictions for children with inadequately treated or neglected clubfoot, and quality improvement of life of children with clubfoot developed and developing area. A major implication of the increase in the number of children growing with inadequately or uncorrected clubfoot is the probability of an increase in the prevalence of physical disability in the community. This not only results in a greater number of people requiring a wide range of health services including health promotion and rehabilitation but also results in a large number of these children in the form of basic needs of life such as education and, socialization and, leads to Poor quality of life The results of the study may help in growing the awareness of the benefits of complying with clubfoot treatment regimen among parents / caregivers. It may also be used in planning and implementation of awareness programs about clubfoot and its treatment in CRP, Savar.

This data shows that caregiver of clubfeet patients have to facing barriers to access to the mainstream treatment facility across the country. The rehabilitation program will be unfulfilled without raising awareness among the family and community people about the easy and long term treatment of the person with clubfeet. Therefore, proper medical treatment and rehabilitation only can increase survival expectation. Research makes a profession strongest. So there is no alternative option to do research as a professional to develop the profession. In our country there is no such study about the barriers experienced by caregivers to access treatment of clubfeet patients at CRP.



## **1.6 Operational definition**

In the context of this particular study, namely, barrier of parents/caregivers of children with clubfoot to the treatment during the plaster casting phase in C.R.P, Savar , the terms used are defined below .

### **Barrier**

Barrier with clubfoot treatment, as used in this study, is defined as the patients' negative experiences to access treatment of clubfoot child consistently every session of treatment (manipulations and plaster cast changes) at the CRP , Savar.

### **Parent and caregiver**

In this study, the term 'parent' refers to the child's biological parent whereas 'caregiver' refers to other careers such as grandparents, and other relatives or supporters. These two terms are utilized because the biological parents may not necessarily be the prime caregiver of the child or the person who brings the child for treatment at the CRP .

### **Treatment**

This refers to all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualization. Treatment may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation .

### **Clubfoot**

Clubfoot is a congenital deformity of the lower limb characterized by smaller calf muscles and adduction of the forefoot, cavus (increased longitudinal arch), varus of the heel (heel turned in) and equinus of the foot (foot in plantar flexion).

literature reviews of a research are conducted for a purposeful variation. Review of literature gives an account of the accessible as well as available information (Jesson & Lacey (2006)

It involves the evaluation which includes reviews with current knowledge. The theoretical and practical contribution as a fundamental result through investigation. (Silveira, 2001).

Studies around the world indicate the diversity of Clubfoot events. The variations appear to be due to differences in race, population studied and geographical location of the study (Roye & Roye, 2002).

Clubfoot forms in the early weeks of gestational development, and this may be part of specific syndromes or secondary to neurologic or systemic disease. The majority of cases are termed 'idiopathic' (Werler et al., 2013), the cause of which is not fully understood (Siapkara et al., 2007). Genetic factors have been signified (Dietz, 2002; Dobbs et al., 2009), while environmental factors have been reported in some studies, they stated that seasonal variation and intrauterine immobility having a role (Siapkara et al., 2007; Dobbs et al., 2012). Other risk factors that have been reported are male gender (Byron-Scott et al., 2005; Kancherla et al., 2010), maternal smoking (Kancherla et al., 2010; Cardy et al., 2011; Parker et al., 2009; Dickinson et al., 2008; Honein et al., 2000) and maternal diabetes (Kancherla et al., 2010; Parker et al., 2009). Although there were no strong correlations with any socio-demographic paternal characteristics, a higher percentage of case fathers were younger at the age of conception compared to control fathers (Nguyen et al., 2012). Statistics showing regularly that the idiopathic clubfoot is the most common congenital musculoskeletal deformity and affects about one in 1,000 newborns (Suzanne et al., 2015). Another study said that One out of 750 children born in the world suffers from club foot. Birth prevalence of clubfoot with reports of 0.39 per 1000 births in Chinese populations (Tracey et al., 2017). Again 1.1 per 1000 in Caucasian and 6.8 per 1000 in Polynesian populations (Ching et al., 1969). In Vietnam, the

prevalence of clubfoot is estimated to be one per 1000 births (Evans, 2009). Overall, it is estimated that 80% of children born with clubfoot each year live in low- and middle-income countries (Jowett et al., 2011). 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 (Shawky et al., 2002). In Bangladesh and Myanmar an estimated 5000-6000 children are born with clubfoot deformity every year, which is approximately one of every 1000 children born in our country (Monoarul et al., 2014). In another finding , America and the United Kingdom has estimate incidence of clubfoot is 1 per 1000 births, with males more affected than females in a ratio of 2:1 (Moorthi, 2005). Similar studies in Hawaiian and Maori (New Zealand) estimate the prevalence of clubfoot to be between 6.5 to 7 per 1000 live births (Kruse et al., 2008) . However another finding indicates an incidence of 2 to 3 per 1000 births in developed countries ( Pandey & Pandey, 2003).

Epidemiological studies on clubfoot shows that the main cause of clubfoot is unknown (Chapman et al., 2000 ;Roye & Roye, 2002). The main causes of clubfoot deformity is a combination of environmental factors (Baker et al., 2003) and genetic factors ( Dundar et al., 2009; Alvado et al., 2011) . The environmental factors means the intrauterine environment during pregnancy period which includes abnormal positioning of fetus, uterine pressure, congenital constriction band, alteration of normal temperature , un-stretched of uterus and placental insufficiency ( Hart et al., 2005).

The genetical factor is linked to a defect in genetical composition of the chromosomes which can be inherited (Dietz, 2002; Alvado et al., 2011). Similarly, a study by Chapman et al. (2000) reported that one main gene controls the clubfoot deformity. In another study by Staheli (2009) indicated that there are 3- 4% chance of affected among the children in families where one parent has clubfoot ,there the children may also be affected when both parents are affected and in this case chances are 30%. This congenital deformity may also present with other musculoskeletal disorders, for example, in arthrogryposis, myelodysplasia, and myelomeningocele (Hart et al., 2005). In a study Philippe et al., (2017) reported similar that there may have a association of these deformities with a variety of conditions, including myelomeningocele, arthrogryposis, cerebral palsy, and poliomyelitis.

Clubfoot is characterized by four deformities of the foot. These include rigid equinus of the foot (foot is in plantar flexion), cavus of the mid foot (increased longitudinal arch of foot), varus of the hind foot (heel turned in) and adductus of the forefoot at the mid tarsal joints (fore foot in adduction) (Mocuende, 2006). Roye (2002) mentioned that in a clubfoot characterized by the medially rotation of the talus and calcaneus, and fixed in a plantar flexed position . The plantar flexion is said to cause a larger part of the articular surface of the talus to lie outside the mortise of the navicular bone. Abnormally develops of the hyaline cartilage in this joint because with the rest of the joint it is not articulated. In addition, the anterior surface of the talus grows stonefly and normal growth occurs on the medical side, which articulates with the subluxednavicular bone.

It is easy to identify the structural nature of clubfoot deformity at birth by either traditional birth attendants or health care providers in public and private health facilities (Konde et al., 2005). Additionally, it also can be identify parents/caregivers the condition during their routine observation of the infant (Seedat et al., 2002). However, a few service providers do not diagnose or ignore this condition at birth (Konde et al., 2005). Identification of the problem is the first step in management process; diagnosis is followed by assessment and treatment (Bussing et al., 2003). Studies show that early diagnosis of the condition particularly in paediatrics defines the management and outcome of management (Salako et al., 2001).

Various interventions are used in medical management of clubfoot. These methods are surgical intervention (Dietz et al., 2009) and Pirani (2009) also mentioned about conservative management (non-surgical). The main aim of management is to address the impairment, prevent activity limitations and participation restrictions (Dobbs et al., 2004). Around 1990, the popularity of the non-surgical treatment of clubfoot with the Ponseti method increased worldwide and now a days the Ponseti treatment of clubfeet is considered to be the first choice of primary treatment in most parts of the world, but some feet are still first treated surgically (Besselaarc et al., 2017). Ponseti method should be considered the best treatment modality for all children with clubfeet. In the developing

world, where most neglected clubfeet occur emphasis should continue to the training of practitioners and implementation of program to reach all affected children (Van, 2011). But in a study, Rijal (2015) shown that 92.3% doctors had no formal orthopedic training and these are the persons who basically care; provide advice regarding treatment and referral of the patients.

#### Factors influencing compliance

- i. Socio-economic/financial factors
- ii. Travelling distance
- iii. Social/family support/ Social stigma
- iv. Communication between clinician and parent
- v. Waiting time
- vi. Negative attitudes of health care providers
- vii. Patient/Caregivers' knowledge about treatment
- viii. Missed diagnosis and poor referral

Rehabilitation related research continuously has published that consistent follow up of treatment appointments forms a major role in improving structures and functions of the foot (Pirani et al., 2009). Regular attendance followed by follow—up is also associated with good treatment outcomes, improvement of activity participation and over all good prognosis and better quality of life of the patient (Ponseti, 2005). Here, have a details finding which negatively influences that affect adherence to clubfoot treatment regiment .The section is categorized in subsections which include: socio-economic/financial factors; travelling distance; social/family support; communication between the clinician and the patient; waiting time at the; negative attitudes of health care providers; and patient/caregiver's knowledge about the condition. Lermanet al., (2004) mentioned that, Interactions within the family system, between the patient or caregiver influence the health provider, Patients or caregiver's behaviour during treatment , so there have a moderate influence of health care system and the external environment. On the other hand Kerkorian et al., (2006) suggested that the quality of experience obtained by the patient or caregiver during treatment influences treatment-seeking decisions and keeping

treatment appointments. These findings suggest that compliance to therapeutic interventions can be influenced by many factors that can present as barriers to treatment attendance.

Research on barriers to treatment attendance has classified these influencing factors into different groupings. McCohachie et al., (2001) categorizes these factors into economical factors which intercept journey and usage charged; natural constituent which insist of journey coldness and receptibility of health facilities; psychological factors that family member or caregiver's beliefs (both cultural and religious) and knowledge of patient throughout management. Similar study of Leventhal et al., (2005) differentiates these factors into social-economic, health care setting and system related factors, condition related factors, treatment related factors and patient related factors. Taylon et al., (2004) categorizes these factors into environmental and personal factors. The environmental factors include family support, complexity of the follow up program, relationship between the caregivers and health service provider , and support from the health care provider . On other side, the personal factors include the caregiver's decision to participate and follow the prescribed treatment.

Socio-economic factors have been shown to be a major hindrance to access to health care services in most resource-poor settings. In a study Meremikwu (2009), published that less availability of effective treatment interventions and the high cure rate, the outcome of treatment in many parts of Africa remains sub-optimal due to poor socio-economic conditions and poor health seeking behaviours. Meremikwu et al., (2009) also documented that in most poor countries where Burkitts Lymphoma is endemic, many affected families cannot afford the cost of basic diagnostic tests, causing this treatable condition to be a cause of considerable distress and early death in the affected children. Sharkawy, Newton &Hartley (2006) found that poor socio-economic situations in families affected the parents' use of medical services for their sick children at health facilities. This led them to resort to the least costly services such as religious or traditional treatments. In a study on options of care seeking in South America found that financial access by the parents/caregivers was a major barrier to appropriate health care

seeking for their sick children ( Hill et al., 2003). Wilson et al., (2006) document that accessing health care services for children is affected by monetary issues on a number of different levels. Likewise, travel expenses have been shown to increase the costs of providing and obtaining health care. Bodydell, Pong, Volpe, Tilleczeck, Wilson et al argue that patients/caregivers especially those in rural communities travel long distances to access care which entails high transport costs and this creates more difficulties with keeping appointments and adhering to therapeutic regimens.

Many Studies have found that location of the health facility and geographical accessibility to these facilities remains a central determinant of participation and continuation of the follow up treatment

by the patient or caregiver. It is said that the distance needed to travel to and from treatment imposes costs on patients/caregivers in the form of both greater time commitment and increased economic expenses that affects compliance with the required prescribed treatment (Beardsley et al., 2003). There have some evidence which indicates that there is a relationship between distance to treatment and the length of stay in the treatment regimen. For example in a cross-sectional study on factors associated with treatment adherence among patients with tuberculosis in Thailand found that the longer the distance a patient had to travel to a health facility, the lower the adherence to the treatment regimen (Tornee et al.,2005).

Similarly, Reif (2005) mentioned in a study on barriers to accessing HIV/AIDS care in North Carolina USA, found that 58% of participants indicated long travelling distance and lack of transportation services as their main barrier to adhering to the required treatment protocol. In another study on access and discontinued mental health care among adolescents in Minnesota USA, Samargia et al., (2006) found inability to pay for the health services and lack of transport as perceived barriers that hindered adolescents from utilizing and complying with the treatment requirements of mental health. Results from these studies indicate that the location of a health facility from the homes of patients/caregivers can determine the utilization of medical services from the health facility. On the other hand, transit time may also affect compliance to treatment. A study on compliance of patients to tuberculosis treatment in Brazil, found that poor patients who experienced longer transit time to reach health facilities, reported symptoms that had

lasted significantly longer and had more high rates of previous defaulting than those of their wealthier counterparts(Bero,2006). Studies in developing countries with low-resource settings have shown that multiple barriers affect patient or caregiver's utilization of health care services. In another study in Ghana. Tolhurst et al., (2006) found that distance travelled to health facilities, cost of treatment, long waiting times and negative attitudes of health care providers were major barriers to utilization of health care services.

According to Letvak (2002), social support is a multidimensional process operationalised on the basis of who is providing the support, quantity and quality of support, availability of support and satisfaction with the support. In this regard, Letvak defines social support as support volunteered by family members and friends. However, Cunningham &Barbee (2000) ; Letvak (2002) describes social support as a set of people from whom an individual can reasonably expect to receive help in a time of need. This help may be financial assistance or physical assistance during the time of care. Hanneman & Blacher (1998) mentioned that one of the ways in which families with children that have physical and mental impairments buffer stress is through the use of support systems for instance friends, immediate family members, other relatives or professionals such as social workers, counselors and others. They suggest that the purpose of support systems is to alleviate strain related to care giving, strengthen or improve family functioning and to improve the quality of life of the parents/caregivers and that of the patient. Again Letvak (2002) indicates that people with high levels of social support experience less stress when in stressful situations and are able to cope more successfully during difficult times than those without social support.

In a research by Kadzin & Wassell (2000) ; Letvak (2002) both has shown that the development of strong social support networks within the family is a strong predictor of well-being and health within the family and facilitates follow up for the required treatment. For example, in a study in Hong Kong on stress appraisal and social support of Chinese mothers of children with intellectual disability demonstrated that mothers who received tangible, emotional and informational support from family members and training centre staff were more likely to cope with the stress of caring for a child with intellectual disability and follow up with treatment sessions than those parents who did



not receive this support (Chen & Tang 1997). Similarly in a study on health care utilization in twelve Western North Carolina counties in USA, Arcury (2005) found that respondents with a family or friends who could provide support with transportation attended the prescribed treatment regimen more often than those who did not. In summary, these findings indicate that family support in form of financial or physical support during care, which results in family well being and functioning, is a strong predictor of adherence to treatment requirements.

One of the factors that can contribute to defaulting treatment appointments is the way patients or caregivers perceive health care providers (Buck et al .,1997). Buck et al argue that if a health provider is perceived as concerned, and prescribes treatment as a reflection of that concern, then the compliance of patients to the prescribed treatment is likely to be higher than if the prescription is seen as an indication that the health provider has no time for or interest in the patient or caregiver. Furthermore, the amount of contact patients have with their health provider may also be an influential factor in enhancing compliance with the prescribed treatment. For example in one study conducted on patients with epilepsy in USA, Buck et al (1997) found that patients who had a regular arrangement to see their physician about epilepsy had a better compliance with the treatment regimen than those who saw the physician irregularly.

According to Iroch (2007), explaining about the problem is a component of communication that requires clarification about the problem, procedures and statements and also the health worker being prepared prior to actual explaining. Postulates that good communication skills, listening to patient's needs and tailoring treatments to the needs of the patient helps to establish a two-way flow of information that enables the negotiation of a contract of management between the health provider and the patient or caregiver. Similarly, Bultman &Svarstad (2002) assert that proper clinician communication does not only influence patient or caregiver's knowledge about treatment but also changes his or her initial beliefs about the effect of treatment. According to Van Wieringen et al. (2002) Health providers and patients/caregivers hold different views and models for illness or disease. They suggest that it is vital to explore the patient/caregiver's explanatory model for illness during consultations and, to try and bridge the gap between the

patient/caregiver's and health provider's conception of the health problem, which can only be achieved through effective communication with the patient/caregiver. For example, in a study in New York USA on delayed or forgone care for children with special health care, Smaldone et al. (2005) found that parents whose health care provider never or only sometimes spent adequate time with them, or listened to their concerns were more likely to forgo care than parents whose health care provider spent adequate time with them or listened to their concerns.

Studies have shown that behaviors of health care providers during treatment can influence patient or caregiver's adherence to the prescribed treatment program. According to Duong et al. (2004) Health provider-patient interaction has a major impact on the perception of the quality of services rendered and in turn the utilization of health services. Good health provider attitudes towards patients have been found to act as an enabling environment that enhances health provider-client relationship that results in satisfaction with the treatment given and more committed clientele (Ambruso et al., 2005). On the other hand, poor provider-patient interaction is reported to be a barrier to accessibility and utilization of health care services in many African countries (Grossmann et al., 2001). For example in a study in Kenya, Sharkawy et al. (2006) found that parents of children with epilepsy who had unpleasant or unsuccessful experiences with health care providers in health care facilities stopped taking their children to these health centres for treatment. Similarly, Izugbara et al., (2005) found that the negative attitudes of health care providers towards patients in public health facilities in Nigeria that arose from frustration, lack of incentives and inadequate materials to use as well as poor remuneration, demoralised patients and caregivers and resulted in them defaulting for treatment appointments. In another study, in Benin & Grossmann (2001) mentioned that abusive behaviours of health providers in public health care facilities stopped women utilizing and attending to antenatal check ups in public health facilities.

In summary, good communication between the patient/caregiver and the health provider during clinical encounters and consultations is important for mutual understanding and agreement and is a good predictor of compliance to the prescribed care.

Patients and caregivers like to wait for treatment for as short a time as possible. According to Lonrothand (2001), treatments regimens with repeated visits and long waiting times at each visit are inconvenient for the patient and caregiver and are less likely to be attended to as required. Health economy studies have shown that short and long-term absences from work as a result of an excessive treatment wait may result in production losses and this may be a cost to the individual's family and the employer. Terricone (2006) stated that the value of lost production as a result of time spent attending treatment at the health facility affects the family in terms of loss of time from paid work and unpaid work and the value (to the caregiver) of leisure activities forgone in terms of quality of life. In a addition Waseem et al., (2003) stated that evaluating waiting time for pediatric treatments may be important because caregivers may become unduly stressed and intolerant of what may seem as an excessive wait. Lengthy waiting times tend to cause dissatisfaction with the care, which may lead to poor compliance with the treatment recommendations. These arguments indicate that the time spent by patients and caregivers in health facilities waiting for treatment is a social cost in terms of lost productivity to the family and may influence the adherence of patients/caregivers to the required treatment.

Caregivers can get misconception from treatment appointments and at times discontinue treatment due to their poor understanding of the required treatment protocol or not understanding how the treatment works (Bultman & Svarstd, 2002). Many studies suggest that when health care consumers understand interventions and how these interventions lead to improved health, they are more likely to seek care and adhere to recommended a treatment protocol. O'Callaghan et al., (2005) argues that increasing health knowledge and awareness among patients/caregivers about their patients conditions enables them to make informed decisions regarding their health needs.

Similarly, Weiss et al.(2003) stated that knowledge about the condition may be a motivation to abide by the treatment regimen in that a person who makes an effort to learn about an illness, will also make an effort to control it. In a clubfeet related study in Peru has shown ,twenty-seven out of 32 (75%) believed that lack of knowledge among the parents or caregivers about the Ponseti method, was a barrier to achieve the success in

Peru, (Palma ,2013). In same study Palma (2013) also mentioned that the parents with low education levels thinking the treatment will complete within a single visit , from this thinking they do not come after the casting phase is over and when the parents see a corrected foot, then do not come in follow-up session and in a result of this poor knowledge , abduction brace use are not properly monitored .

In a study on knowledge of diabetes and adherence to diabetes control measures in France, Fediaevsky et al., (2005) stated that all caregivers who were knowledgeable about glycaemia control adhered to the recommended treatment regimen unlike those caregivers who were less knowledgeable. Similarly, in another study on HIV related knowledge and adherence to antiretroviral therapy in New York, USA, Weiss et al (2003) stated that all the caregiver that participated in their study had good knowledge about HIV and complied well with the treatment regimen. In conclusion it could be argued that knowledge about clubfoot and the nature of its treatment interventions may play a role in the compliance with rehabilitation interventions. This could be attained through health education sessions for the caregiver at the CRP structured in form of talks/discussions about clubfoot and its treatment in local languages for parents.

### 3.1 Study Design

A qualitative approach was chosen to conduct my study. This method was found suitable for this study on barriers experiences by caregiver of clubfeet patients to access treatment in CRP. By adopting this method, the researcher was able to achieve a greater breath and depth of understanding the participants' experiences and views. A semi-structured questionnaire was used and face to face interview was conducted. Interview were recorded. The participants was given freedom to express their view and feelings. That's why researcher selected the qualitative research approach, which help to gain understanding and exploring the feelings, opinion and barriers to access treatment in CRP.

### 3.2 Study setting

The study was conducted at CRP outpatient department (Savar and Mirpur). In this department, they provide clubfeet treatment under a project named "walk for life". The researcher chose this area because it is a referral tertiary level hospital for the province with a multidisciplinary rehabilitation unit. Patients that attend there, are sent from other hospitals, health centers as well as clinics over the country. The service providers at this clubfeet service center includes two physiotherapists. Center for the Rehabilitation of the Paralysed (CRP) is a non government organisation that works for cure and removing clubfeet from Bangladesh under a project and provides resources for management. This service is open every Tuesday at Savar and every Monday at Mirpur. The researcher observed and interacted with the individual in their own contexts.

### 3.3 Study population

Clubfeet patient's caregiver who are getting service from CRP outpatient department Savar and Mirpur.

### **3.4 Participant selection procedure**

The inclusion criteria for participation in this study were the persons are involving to take care of clubfeet child , who being the child to the treatment center, and who are coming at CRP for clubfeet treatment. The researcher selected the participant by purposive sampling because researcher had specific requirements and chose those who met the selection criteria. At first permission was sought from my research supervisor then Ethical review board and Head of CRP medical wings and had a discussion about the study was held with the responsible physiotherapist. 9 participants from Savar CRP and 3 participants from Mirpur . Total 12 participants were finally selected for this study.

### **3.5 Inclusion criteria**

- Caregivers both male and female . (mother or father or uncle or aunty)
- Subject who are willing to participate.
- Patients age must between 1day to 2 years

### **3.6 Exclusion criteria**

- Subject who are not willing to participate.
- Subject who have psychological problem ( May reply inappropriately )

### **3.7 Sample size**

9 participants from Savar CRP and 3 participants from Mirpur . Total 12participants were finally selected for this study.

### **3.8 Data collection procedure**

Researcher conducted face to face interview with a open ended question for data collection. With open ended question, participants get more freedom to explain their opinions. That face to face interview helps the researcher to observe the participants facial expression and non verbal expression during interview period (Depoy&Gitlin, 2015). Before starting the formal interview, researcher ensured a quiet place by contacting with the regarding authority and built connection with the participants and made them comfortable for interview. The interviewer explained the research question

and aim of the study. Then the interviewer used information sheet and consent form to take the permission of the participants. Next interviewer asked questions. All question and information sheet was developed into Bangla. Interview was conducted in Bangla and recorded by recorder of mobile phone. The interview conducted during daytime and the duration was approximately 10 minutes for each participant. Venue of interview was outpatient department of CRP, Savar and Mirpur but the place of interview depended on situation and permission of regarding authority.

### **3.9 Data collection tools and material**

A phone recorder was used to record the interview of the participants. Pen, paper and clip board was used to write down observation notes. An information sheet and consent form was used for taking permission from the participants. A open ended question sheet was used to conduct the interview

### **3.10 Questionnaire**

For data collection a semi-structured questionnaire is used. The questionnaire is formed based upon the related literature, determine of the study title and also pilot study.

### **3.11 Duration of data collection**

Data were collected from 10<sup>th</sup> May 2017 to 20<sup>th</sup> June 2017. Each participant provided time to collected data. Each interview took approximately 20-30 minutes to complete.

### **3.12 Data Analysis**

At first in data analysis, the researcher listened to the interviews several times from the tape recorder and then the interviewed data was transcribed in Bangla. The researcher checked the transcript to make sure that all the data was available in the transcript. Then three copies were made from the transcript and were given to seven people for translation from Bangla to English. Data was analyzed by 3 stages: coding, categorizing and generating theme.

After that, the investigator read all data repeatedly to find out the actual meaning of the participants' expressions of what they wanted to say and organized them. Then major categories were found from the interview questions. The researcher was arranging all the

information according to the categorization. Under these categories, the researcher coded all the information from the interviewed transcript. After finishing the tabulation of coding, the researcher detected some important codes that made the themes of the study. At last, themes were identified and emerged as a process of interpretation

### **3.13 Field test**

After getting approval for conducting the research and before starting the final data collection, researcher accomplished the field test with two participants. Field test was necessary as it helped the investigator to develop a final question and to collect data from participants easily. This test was performed to find out the difficulties that exist in the question. By this test, the researcher re-arranged and modified the question as required for the participants, so they can understand the question clearly

### **3.15 Ethical Consideration**

The research proposal was submitted to the ethical committee that is institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI), Bangladesh Medical Research Council (BMRC) and World Health Organisation (WHO) guideline were followed also to conduct this study. Informed consent was used to take permission from all participants. Participants' rights and privileges were ensured. All the participants were aware about the aim and objectives of the study. Findings of the study were disseminated with the approval of regarding authority. IRB permission was obtain.

### **3.16 Rigor of the study**

Researcher always tried to maintain trust worthiness and honesty in this study. The study was conducted in a clear & systematic way to reducing the sources of error and bias. During conduct the study every section of the study is checked & re – checked by the research supervisor. All the raw data was collected from appropriate sources and maintained referencing system.



## CHAPTER-IV RESULTS

A qualitative study results were analyzed by content analysis. By using this analysis process, the researcher organized collected data according to categories, coding and themes. The aim of the study is to identify the barriers experienced by caregivers to access treatment of clubfeet patients in

Centre for the Rehabilitation of the Paralyzed (CRP). Participants respond according to their perception. In this section coding is used to understand the participants' statement and to generate the themes.

### **Participant's socio-demographic information**

This study aimed to investigate barriers experienced by caregivers of clubfeet patients to access clubfoot treatment at CRP outpatient department. Nine caregivers were from Savar and three caregivers were from Mirpur . A total of 12 caregivers participated in the study from the two area.

In this study three male and nine female caregivers of clubfeet patients. The average age of the patient's caregivers is 27.83 years with age range 18-35 years. 8 caregivers were biological mothers, two caregivers were biological fathers and one caregiver was uncle, one caregiver was aunty. Four participants lived in urban areas which were about one fourth and eight participants lived in rural areas. The academic level in the participants are 16.67% (n = 2) Illiterate. More than eighty percent of participant (n = 10) are secondary level .Among the secondary completed participant some of them are s.sc completed and some of them didn't appear in S.S.C examination. May some of them are class eight passed , but they got shame to share this, for this they reported not clearly. . There no one was (n = 0) honors degree graduated.

This section presents information on the caregiver's ages, Relation with Patients, Living area , Travelling Distance , employment status, and educational level.

**Socio-demographic information    Number of the participant (n)**

Table -1: Socio-demographic information of the participants

---

<b>Caregiver Age</b>	
18-27	5
28-35	7
<b>Relation with Patients</b>	
Mother	8
Father	2
Uncle, aunty	1,1
<b>Treatment place</b>	
Savar	9
Mirpur	3
<b>Living area</b>	
Rural area	8
Urban area	4
<b>Employment status</b>	
Housewife	5
Doing a job	4
<b>Education level</b>	
Illiterate	2
Primary	0
S.S.C, Class 10	10
H.S.C	0
Honors	0

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## Duration of from treatment started

Table -2: Duration of from treatment started

Participant	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Month (from which month treatment started )	1 <sup>st</sup>	3 <sup>rd</sup>	1 <sup>st</sup>	24 <sup>th</sup>	1 <sup>st</sup>	3 <sup>rd</sup>	1 <sup>st</sup>	2 <sup>nd</sup>	14 <sup>th</sup>	3 <sup>rd</sup>	14 <sup>th</sup>	2 <sup>nd</sup>

Here table showing that one third of patient's caregivers started treatment at first month of child birth . In tabulated form we can see that a little ratio of caregiver had a extremed delay of treatment access. So data analysis show that , Less than half number of participant reported that they have a history of late Diagnosis. But more than half of participant says they diagnosed early.

## Distance of Treatment center from home

Table -3: Distance of treatment center from home.

Participant	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Distance of Treatment center from home	½ Hour	3-4 hour	1/2 hour	4-5 hour	2-3 hour	8-10 hour	1-1.5 hour	½ hour	8-9 hour	4-5 hour	1-2 hour	1-2 hour

From tabled data , a few number of Patient traveling a extreme long distance on average 8 to 9.5 hours. Which explained that it is so tough to continue the treatment for a long period . Other side near to fifty percent of patient are coming from the less far distance. Here data analysis showing that the average time requirement of traveling from home to CRP is 2.58 hours to 3.167 hours . which is long period for a parents or caregiver to access the treatment.

It has been possible to understand the participant opinions by content analysis, where some categories have been found. Under the different categories, patient different opinions are expressed by different codes. Six major categories were found these are

Theme that emerged from data analysis are given below

Theme -1: Half of number of participant have long travelling distance .

Subtheme 1.1: Fifty percent participant says long traveling distance creates barrier to access the treatment.

Subtheme 1.2 : More than eighty percent participant says they have to consider their working day for long distance travelling.

(emerged from category 1)

Category -1: Participant have travelling a long distance .

Table -4: Participants long distance travelling.

<b>Coding</b>	<b>P1</b>	<b>P2</b>	<b>P3</b>	<b>P4</b>	<b>P5</b>	<b>P6</b>	<b>P7</b>	<b>P8</b>	<b>P9</b>	<b>P10</b>	<b>P11</b>	<b>P12</b>	<b>Total</b>
Difficulty to move for a long distance (in past or present)	√	√		√	√	√						√	<b>6</b>
Consider working hours			√	√	√	√	√	√	√	√	√	√	<b>10</b>

Here among six participants, reported that Long distance is a problem or barrier for them to accesses to treatment . And six participant , reported that their home are not so far from treatment center .

Theme -2 : More than fifty participant says they got family support and positive attitude . Only five participants face negative attitude from family members . But in case of information getting the ratio is equal. Fifty percent participant are getting wrong information from their society and neighbor about the clubfeet treatment .

(emerged from category 2)

Category -2: Family support and social stigma.

Table -5 : Family support and social stigma.

<b>Coding</b>	<b>P1</b>	<b>P2</b>	<b>P3</b>	<b>P4</b>	<b>P5</b>	<b>P6</b>	<b>P7</b>	<b>P8</b>	<b>P9</b>	<b>P10</b>	<b>P11</b>	<b>P12</b>	<b>Total</b>
Family support	√	√			√	√	√		√			√	<b>7</b>
Positive attitude and right information From relative or neighbor or family member.	√	√	√		√		√			√			<b>6</b>

Here one fourth number of caregiver shared that they had no family support and didn't get right information about the clubfeet treatment from relative and neighbor. A few number of caregiver saying they got information or positive attitude from their relative but their own family member doesn't help them. So most of participants were satisfied about their family support and family member attitude. But most of the patient didn't get right information about the clubfeet treatment.

Less than fifty percent caregiver get positive attitude and right information about the treatment from their relative and neighbor.

Theme -3 : Equal percent participant reported their opinion differently . The Fifty percent of Participant says waiting time in CRP for getting treatment is not unusual . Because either their home are near to CRP or neither they are housewife. Fifty percent of the participant say, If it is possible to minimize the waiting time , it will be helpful for them surely .

(emerged from category 3)

Category -3: Waiting time of participant in CRP

Table -6: Waiting time of participant in CRP

<b>Coding</b>	<b>P1</b>	<b>P2</b>	<b>P3</b>	<b>P4</b>	<b>P5</b>	<b>P6</b>	<b>P7</b>	<b>P8</b>	<b>P9</b>	<b>P10</b>	<b>P11</b>	<b>P12</b>	<b>Total</b>
Facing problem	√		√	√			√	√	√				6
Not facing problem		√			√	√				√	√	√	6

Table showing that caregivers explained different opinion in case of waiting time. Who are saying they facing problem, they add details that either they had a job or business . So this study say that most participants experienced a long waiting time as a barrier to reach the treatment of clubfeet to CRP . But less then fifty percent of caregiver experienced these waiting time as usual.

Theme -4 : Except one participant all participant reported that there have a necessary to know how to care properly of a clubfeet patient in home and out of home.

(emerged from category 4)

Category -4: Acknowledgement of participant about clubfeet

Table -7: Acknowledgement of participant about clubfeet

<b>Coding</b>	<b>P 1</b>	<b>P 2</b>	<b>P 3</b>	<b>P 4</b>	<b>P 5</b>	<b>P 6</b>	<b>P 7</b>	<b>P 8</b>	<b>P 9</b>	<b>P1 0</b>	<b>P1 1</b>	<b>P1 2</b>	<b>Tota l</b>
Acknowledgement of caregivers	√	√	√	√	√		√	√	√	√	√	√	11

Table shows that all most participant reported that they must need to know about clubfoot , for betterment of their child and early prognosis. But they all have no enough knowledge about clubfeet. Most of them shared that they have lack of knowledge about their child condition and treatment .



Theme -5 : Less than half number of participant reported that they have a history of late Diagnosis. But more than half of participant says they diagnosed early .

(emerged from category 5)

Category -5: late diagnosis of clubfeet .

Table -8: Late diagnosis of clubfeet .

<b>Coding</b>	<b>P1</b>	<b>P2</b>	<b>P3</b>	<b>P4</b>	<b>P5</b>	<b>P6</b>	<b>P7</b>	<b>P8</b>	<b>P9</b>	<b>P10</b>	<b>P11</b>	<b>P12</b>	<b>Total</b>
Late diagnosis				√					√		√	√	4
Early diagnosis	√	√	√		√	√	√	√		√			7

In table we see that maximum patients caregiver were able access to treatment in early age of child . A little less than fifty percent of participant says their child diagnosed in late. And more than fifty percent of participant says their child diagnosed early.

Theme -6 : The majority of participant says treatment cost is managed by patient’s father and patients uncle or with the family support and they reported that they must need financial support from CRP, or some of them are getting financial support from CRP at present. Most of participant says they need mild financial support to continue the treatment regularly. Only one participant says she has no need any financial support. (emerged from category 6)

**Category -7:** Treatment cost of participant

Table -9: Treatment cost of participant .

<b>Coding</b>	<b>P1</b>	<b>P2</b>	<b>P3</b>	<b>P4</b>	<b>P5</b>	<b>P6</b>	<b>P7</b>	<b>P8</b>	<b>P9</b>	<b>P10</b>	<b>P11</b>	<b>P12</b>	<b>Total</b>
Need financial support	√	√	√	√	√	√		√	√	√	√	√	11
No need of financial support							√						1

In table , data showing all most patient caregivers need financial help , amount may some or more . All most all participant reported that they need financial support to continue their children’s treatment. Only one participant reported that he has no need of financial support .

Clubfoot is congenital structural impairment that, if untreated or inadequately treated leads to deformity. Overall the establishment of a nationwide clubfoot treatment program will be of benefit to a large number of children with clubfeet and the families. In a developing country with much demand on health funding, many challenges remain. The cost of plaster of Paris and splints, treatment cost, time spent by the parents to attend the hospital, and patient compliance are vital factors for adequate treatment. In this chapter the study results are discussed in relation to the research questions and objectives of the study. This study shows that if effective clubfoot program is available near to their home, parent will attend the hospital regularly and treat their children. Other barriers highlighted include the need to improve the communication skills between clinicians offering treatment to children with clubfoot and their parents. Informed parents could assist with compliance to treatment. It has been possible to understand the Barriers experienced by caregivers to access treatment of clubfeet patients in CRP. By content analysis different categories are found under which different opinions are expressed by different codes. Six major categories were found under which six themes were emerged. This part is carried out on the basis of analysis of acquired data and its relevance with other published literature related to the study.

**Theme -1:** Maximum participant have long travelling distance .

Subtheme 1.1: Maximum participant says long traveling distance creates barrier to access the treatment.

Subtheme 1.2 :Maximum participant says they have to consider their working day for long distance travelling.

In case of clubfeet treatment , long travelling distance has a effect on the accessibility to treatment . During interview , most of participants claimed about their distance .

Participant -1,2,4,5,6,12 said similar , “ It is a long distance for my family , it took too more time, which cause loss of daily income .

Participant -3,7,8,9,10,11 said, ‘I have no problem, it snormal to wait in a hospital for treatment purpose.

Participant -4 said,“ It take five to six hours to reach here. May be 300 or 350 mile . We facing problem for coming from a long distance . sometimes I could not get any income for coming here. if there have CRP service in my town , it would be be better.”

Participant -1 said, “I think it’s a long distance for me. But I don’t need to consider any of my working hour . I am a housewife.

Participant -5 said, “ it takes a long journey time. And her father ( patients father ) have to miss his daily base work or business which hamper daily income.

Participant 6said, “ we have to consider a prolong time. I have to stop my daily work.it take 8 to 10 hours to reach here. Muddy road in my village, it’s a problem at all.

Participant -2 said,“ At frist it seemsto a problem for long traveling distance. But now it is ok for me. Nothing to do now for despite of treatment.

Participant -3 said, “I think , distance is not aproblem for me.

Participant –9 said, ‘no , not at all. Its not a ling distance for me.

Participant -10 said, “it hinders my husband daily activity.

Participant -11 said, “Distance is really a serious issue to continue the treatment.

Participant -12 said, “ when I come to crp , I can not go to my job

From this transcripts among six participants, reported that Long distance is a problem or barrier for them to accesses to treatment . And six participant , reported that their home are not so far from treatment center ,

Again, 3 participant among the serial no. 3,7,8,9,10,11 reported that at frist they also experience problem , but now they are used to with this.

Again , 6 perticipant reported that long distance from crp is also causes loss of income on these schedule treatment date.

There have some evidence which indicates that there is a relationship between distance to treatment and the length of stay in the treatment regimen. For example in a cross-sectional study on factors associated with treatment adherence among patients with tuberculosis in Thailand (Tornee et al .,2005) found that the longer the distance a patient had to travel to a health facility, the lower the adherence to the treatment regimen .

So my study say that most of the participants experienced barriers to accesses treatment of clubfeet to CRP due to long distance.

**Theme -2** :Maximum participant says they got family support and positive attitude . Only one forth participant faces negative attitude from family members . But maximum participant are getting wrong information from their society and neighbor about the clubfeet treatment

In case of clubfeet treatment , family support has a effect on the accessibility to treatment . During interview , most of participants were satisfied about their family support and family member attitude. But most of the patient didn't get right information about the clubfeet treatment.

Participant -1 said, “ At first my family was not show any possiitive attitude , at the beginning of the treatment they were change, they support me to get full treatment for my child . but after my child born , my neighbor my husband forced me to receive traditional treatment .

Participant -2 said, “ My husband and his family always support me.”

Participant -3 said, “ no , my support is me own.

Participant -4 said, “ Father of child always want his baby's full cure. And he want to continue treatment.

Participant -5 said, “ no , I never fell any lack of support from my family. But thay did not know about the clubfeet.

Participant -6 said, “ yes, my family always concern aobout my child treatment.

Participant -7 said, “ My family member help me by providing money.”

Participant -8 said, “ yes, my family support me a little .

Participant -9 said, “ I think family support is so much important to strat and continue this treatment. I miss it.

Participant – 10 said, “ My family my husband were so angry when this child born. My brother help me only to get this treatment.

Participant - 11 said, “ I didn’t get my family support to continue this treatment.

Participant -12 said, “ child’s father always concern , I never felt any lack of support from him .

Most of patient caregiver reported that they are not facing any obstacle from their family. A small number of participant reported that ; at beginning of the treatment they face various negative attitude from their neighbor .

Less than fifty percent caregiver get positive attitude and right information about the treatment from their relative and neighbor.

Letvak (2002) indicates that people with high levels of social support experience less stress when in stressful situations and are able to cope more successfully during difficult times than those without social support.

So my study say that all most participants didn’t experience any incooperation from family to reach the treatment of clubfeet to CRP . But morethen fifty percent of caregiver experienced lack of positive attitude from their relative and neighbor.

**Theme -3** : Equal percent participant reported their opinion differently . The Fifty percent of Participant says waiting time in CRP for getting treatment is not unusual . Because either their home are near to CRP or neither they are housewife. Fifty percent of the participant say, If it is possible to minimize the waiting time , it will be helpful for them surely .

In case of clubfeet treatment , waiting time has a effect on the accessibility to treatment . During interview , most of participants were unsatisfied about the waiting time before getting treatment.

Participant -2,5,6,10,11,12 said similar : I think its usual, it true that treatment is necessary to us, but if there any fixed time of own schedule.

Participant -2 said : its unusual, it happened when we go to the other hospital.

Participant -1,3,4,7,8,9 said: I think , waiting time some so long , then we can't do other activity of that day.

Participant -4said : I think it is usual.

Participant -7said : it is problem , there have a fixed date. It will be better , if we could know the fixed time.

Participant -8 said : it just took our full day.

Participant -5 said : Hospital work take some more time, I think its happened. I want to cure my child .

Participant -9 said : Waiting time is too long someday, but it normally happened to other hospital or treatment center.I think , waiting time may hamper caregiver working hour.

Participant -10said : it is usual

Participant -11said : Waiting time must not be more than half or one hour, cause child under 2 year , need to breast feeding. Sometime its not possible in here.



Participant -12said : no, I have no problem to wait here for treatment. Because , who come from long distance, they need more time reach crp , but if there any fixed time , they frequently miss their schedule time.

Patient career reported that they facing any obstacle by long waiting time. So my study say that more than fifty percent of participants experienced a long waiting time as a berrier to reach the treatment of clubfeet to CRP . But lessthen fifty percent of caregiver experienced these waiting time as usual.

**Theme -4** : Except one participant all participant reported that there have a necessary to know how to care properly of a clubfeet patient in home and out of home.

In case of clubfeet treatment , Acknowledgement of participant about clubfeet has a effect on the accessibility to treatment . During interview , all participant express their opinion as like that.

Participant -1said : yes, its really necessary.

Participant -2 said : If we have a right concept at least , then we can care our child properly

Participant -3said : I think it is very much important to know about my child condition .

Participant -4said : yes, its my duty to get a clear knowledge about clubfoot

Participant -5said : all caregiver must know about what problem his or her child have , what is the treatment , what is the prognosis ,

Participant -6 said : yes, its important . but I have poor knowledge about it .

Participant -7 said : All parents want to cure their child, for this reason thay must acknowledge about clubfoot.

Participant 8 said : its important for caregiver.

Participant -9 said : I think it has a necessity .

Participant -10 said : If we have lack of proper knowledge , then we can't care our child properly

Participant -11 said : Yes , it is important for our child health.

Participant - 12said : it helps to cure child condition directly.

All most participant reported that they must need to know about clubfoot , for betterment of their child and early prognosis.

Caregivers can get miss concept from treatment appointments and at times discontinue treatment due to their poor understanding of the required treatment protocol or not understanding how the treatment works (Bultman & Svarstd, 2002).

So my study show that Acknowledgement of patient career about clubfeet is important .

**Theme -5** : Half amount of participant says they have a history of late Diagnosis. But half of participant says they diagnosed early .

Participant -1, 2, 3,5,6,7,8,10 reported similar : Their children have a history of early diagnosis

Participant -4,9,11,12reported similar : Their children have a history of late diagnosis.

A little less than fifty percent of participant says their child diagnosed in late. And more than fifty percent of participant says their child diagnosed early.

**Theme -6 :** The majority of participant says treatment cost is managed by patient's father. One participant says she is getting service at free cost. Most of participant says they need mild financial support to continue the treatment regularly

Participant -1,2,3,4,5,6,7,9,10,11,12said similar : Need financial support

Participant -8 said different : No need financial support

All most all participant reported that they need financial support to continue this treatment. Only one participant reported that he has no need of financial support .

Meremikwu (2009), published that less availability of effective treatment interventions and the high cure rate, the outcome of treatment in many parts of Africa remains sub-optimal due to poor socio-economic conditions and poor health seeking behaviours.

Raises adequate funds for health, in ways that ensure people can use needed services, and are protected from financial catastrophe or impoverishment associated with having to pay for them. It provides incentives for providers and users to be efficient ( WHO , 2010)

Patient age only 1day to 2 years. But adult patients may need to include in further research.

Data collected from CRP Savar and Mirpur only, it need to study in a borad aspect, as other district hospital.

Cross sectional research on this area may provide more deep information and help to find the depth of the problem. So, it will better if there a further research on this problem.

Due to Ramadan month , patient from long distance were not attending to receive treatment . If the data collection period may elongated after Ramadan month , it will be better for data collection.

The results of the study will be useful in improving service delivery of clubfoot at the outpatient department of CRP Savar and Mirpur . In addition, the results will be useful in developing effective interventions aimed at enhancing utilization of services. These results can be used by the hospital management to identify gaps in the delivery of health care services among health providers in the hospital, so that interventions are sought to improve the health care delivery, for instance improving the communication skills of health providers through refresher courses. It is recommended to do further research on large group of people from various districts and geographical areas in a quantitative approach and also find out the overcoming strategies of barriers faced among caregiver of clubfeet children patient. It is also recommended that there have a necessity to do afurther research on condition and rehabilitation of the adult patients of clubfoot deformity .

From the results of this study, it can be seen that most caregiver who were attending the outpatient department of CRP at the time of the study were compliant. However, the majority of parents had poor knowledge and lacked information on clubfoot and its treatment, and were concerned with some aspects of treatment, in particular communication with the clinician regarding explanation of the treatment process. On the other hand, despite their inadequate knowledge on clubfoot and the treatment process, all parents knew of their role in clubfoot treatment, and most of them knew of the consequences of not adhering to the treatment regimen. In addition, the study identified some difficulties parents experienced in adhering to the required treatment program. These may have been barriers to attendance for other parents. These include financial constraints to meet transportation costs, travelling distance and waiting time.



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Consent sheet ( English )

Assalamualaikum/ Namaskar,

I am Kumar Amitav , a fourth year student of B.Sc. in Physiotherapy in Bangladesh Health Professions Institute (An educational institution of the CRP) affiliated to the Faculty of Dhaka University. As part of the study, I have to perform a research and this is a part of my academic work.. After reading the following information, participants are requesting to participate in the study..

My research topic is " Barrier experienced by caregivers of clubfeet to access treatment in C.R.P ". The purpose of this experimental research to determine the barriers experienced by the caregivers of clubfeet to access to the medical service and to continue it.. To perform the research, I need to collect my information.. Considering the field of research, your child has noticed the necessary features to participate in my research., For this reason, you can be a noble participant of my research and I would like to request you to participate in our study. It is approximately 20-30 minutes since.

I promise that this research will not be hazardous for you or will not harm you. If you feel any hesitation or risk during research work , without hesitation at any time, you can omit this consent sheet. This information is completely confidential, and research participants ' personal data will not be published anywhere else.

As participants of this study if you have any questions, you will find me or my research supervisor Mohammad Habibur Rahman, Assistant Professor, Department of physiotherapy, BHPI, CRP, Savar, Dhaka-1343 can be contacted.

Do you have any questions before we start ?

I can start ?

Yes  No

The child's parent/guardian signature and date ... ..

Receives information of the signature and date ... ..

Researcher's signature and date ... ..



**TITLE: “Barriers Experienced By Caregivers To Access To The Treatment Of Clubfeet Patients in CRP”**

Questionnaire (English)

This question is developed to identify the barriers experienced by caregivers to access to the treatment of clubfeet .

1. Patient’s name:

6. Identification number:

2. Patient’s age:

7. Phone number :

3. Caregiver’s name :

8. Place of receiving treatment :

4. Caregiver’s age :

5. Relationship between caregiver and patient :

9. Caregiver’s sex:

Male

Female

10. What are your educational qualifications:

Illiterate

Primary

Secondary

Higher secondary

Graduate

.11 Where are you living now :

12. what is your employment status :

13 .What do you think , the degree of distance between the CRP and your home is high, and is it somehow preventing to starting or continue this treatment ?

14. How much support your family provide to start or continue this treatment ?

15. What do you think , are you awaiting for a long period after reaching in CRP for this treatment purpose ?

16. What do you think , have you enough knowledge as a caregiver about your children condition ?

17. When was your first visit to this clinic? How long you are receiving treatment here ?  
What do you think is it necessary to diagnosis early ?

18. how you are managing / will manage regular treatment cost ?

19 .Do you facing any challenge to communicate with health care providers ?

20. May the lack of communication can hinders your child health condition indirectly ?

## সম্মতিপত্র

আসসালামুয়ালাইকুম / নমস্কার,

আমি কুমার অমিতাভ, ঢাকা বিশ্ববিদ্যালয়ের চিকিৎসা অনুষদের অধিভুক্ত বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (সিআরপি এর একটি শিক্ষা প্রতিষ্ঠান) এর বি. এস. সি ইন ফিজিওথেরাপিকোর্সের চতুর্থ বর্ষের একজন শিক্ষার্থী। অধ্যয়নের অংশ হিসেবে আমাকে একটি গবেষণা সম্পাদন করতে হবে এবং এটা আমার প্রাতিষ্ঠানিক কাজের একটা অংশ। নিম্নোক্ত তথ্যদি পাঠ করার পর অংশগ্রহণকারীদের গবেষণায় অংশগ্রহনের জন্য অনুরোধ করা হলো।

আমার গবেষণার বিষয় হল “ সিআরপিতে আসা ক্লাবফীট রোগীর যত্নকারীর ক্লাবফীট চিকিৎসাসেবা গ্রহণে প্রতিবন্ধকতা”। আমার এই গবেষণার উদ্দেশ্য হলো সিআরপি তে চিকিৎসা করতে আসা রোগীদের যত্নকারী এই চিকিৎসা সেবা পেতে এবং তা চালিয়ে নিতে যে সকল প্রতিবন্ধকতার সম্মুখীন হোন তা নির্ণয়। গবেষণাটি সম্পাদনের জন্য, আমার তথ্য সংগ্রহ করার প্রয়োজন হবে। গবেষণার ক্ষেত্র বিবেচনা করে আপনার বাচ্চার মাঝে আমার গবেষণায় অংশগ্রহণ করার জন্য প্রয়োজনীয় বৈশিষ্ট্য লক্ষ্য করা গেছে। এজন্য, আপনি আমার গবেষণার একজন সম্মানিত অংশগ্রহণকারী হতে পারেন এবং আমি আপনাকে আমার গবেষণায় অংশগ্রহন করতে অনুরোধ জানাচ্ছি। এতে আনুমানিক ২০- ৩০ মিনিট সময় নিবো।

আমি প্রতিজ্ঞা করছি যে, এই গবেষণা আপনার জন্য ঝুঁকিপূর্ণ হবে না অথবা আপনার কোন ক্ষতি করবে না। গবেষণা চলাকালীন সময়ে কোন রকম দ্বিধা বা ঝুঁকি ছাড়াই যেকোন সময় আপনি এই সম্মতিপত্র বাদ দিতে পারবেন। এই গবেষণার প্রাপ্ত তথ্য সম্পূর্ণভাবে গোপনীয় থাকবে এবং অংশগ্রহণকারীর ব্যক্তিগত তথ্য অন্য কোথাও প্রকাশ করা হবে না।

এই অধ্যয়নে অংশগ্রহণকারী হিসেবে যদি আপনার কোনো প্রশ্ন থাকে তাহলে আপনি আমাকে অথবা আমার গবেষণার সুপারভাইজার মোহাম্মদ হাবিবুর রহমান, সহকারী অধ্যাপক, ফিজিওথেরাপি বিভাগ, বিএইচপিআই, সিআরপি, সাভার, ঢাকা- ১৩৪৩ ঠিকানায় যোগাযোগ করতে পারেন।

শুরু করার আগে আপনার কি কোন প্রশ্ন আছে ?

আমি কি শুরু করতে পারি ?

হ্যাঁ

না

বাচ্চার অভিভাবকের স্বাক্ষরও তারিখ .....

তথ্যগ্রহণকারীর স্বাক্ষরও তারিখ .....

গবেষকের স্বাক্ষরও তারিখ .....

## সম্মতিপত্র

আসসালামুয়ালাইকুম / নমস্কার,

আমি কুমার অমিতাভ, ঢাকা বিশ্ববিদ্যালয়ের চিকিৎসা অনুষদের অধিভুক্ত বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (সিআরপি এর একটি শিক্ষা প্রতিষ্ঠান) এর বি.এস.সি ইন ফিজিওথেরাপিকোর্সের চতুর্থ বর্ষের একজন শিক্ষার্থী। অধ্যয়নের অংশ হিসেবে আমাকে একটি গবেষণা সম্পাদন করতে হবে এবং এটা আমার প্রাতিষ্ঠানিক কাজের একটা অংশ। নিম্নোক্ত তথ্যদি পাঠ করার পর অংশগ্রহণকারীদের গবেষণায় অংশগ্রহনের জন্য অনুরোধ করা হলো।

আমার গবেষণার বিষয় হল “ সিআরপিতে আসা ক্লাবফীট রোগীর যত্নকারীর ক্লাবফীট চিকিৎসাসেবা গ্রহণে প্রতিবন্ধকতা। আমার এই গবেষণার উদ্দেশ্য হলো সিআরপি তে চিকিৎসা করতে আসা রোগীদের যত্নকারী এই চিকিৎসা সেবা পেতে এবং তা চালিয়ে নিতে যে সকল প্রতিবন্ধকতার সম্মুখীন হোন তা নির্ণয়। গবেষণাটি সম্পাদনের জন্য, আমার তথ্য সংগ্রহ করার প্রয়োজন হবে। গবেষণার ক্ষেত্র বিবেচনা করে আপনার বাচ্চার মাঝে আমার গবেষণায় অংশগ্রহণ করার জন্য প্রয়োজনীয় বৈশিষ্ট্য লক্ষ্য করা গেছে। এজন্য, আপনি আমার গবেষণার একজন সম্মানিত অংশগ্রহণকারী হতে পারেন এবং আমি আপনাকে আমার গবেষণায় অংশগ্রহন করতে অনুরোধ জানাচ্ছি। এতে আনুমানিক ২০- ৩০ মিনিট সময় নিবো।

আমি প্রতিজ্ঞা করছি যে, এই গবেষণা আপনার জন্য ঝুঁকিপূর্ণ হবে না অথবা আপনার কোন ক্ষতি করবে না। গবেষণা চলাকালীন সময়ে কোন রকম দ্বিধা বা ঝুঁকি ছাড়াই যেকোন সময় আপনি এই সম্মতিপত্র বাদ দিতে পারবেন। এই গবেষণার প্রাপ্ত তথ্য সম্পূর্ণভাবে গোপনীয় থাকবে এবং অংশগ্রহণকারীর ব্যক্তিগত তথ্য অন্য কোথাও প্রকাশ করা হবে না।

এই অধ্যয়নে অংশগ্রহণকারী হিসেবে যদি আপনার কোনো প্রশ্ন থাকে তাহলে আপনি আমাকে অথবা আমার গবেষণার সুপারভাইজার মোহাম্মদ হাবিবুর রহমান, সহকারী অধ্যাপক, ফিজিওথেরাপি বিভাগ, বিএইচপিআই, সিআরপি, সাভার, ঢাকা- ১৩৪৩ ঠিকানায় যোগাযোগ করতে পারেন।

শুরু করার আগে আপনার কি কোন প্রশ্ন আছে ?

আমি কি শুরু করতে পারি ?

হ্যাঁ

না

বাচ্চার অভিভাবকের স্বাক্ষর ও তারিখ .....

তথ্যগ্রহণকারীর স্বাক্ষর ও তারিখ .....

গবেষকের স্বাক্ষর ও তারিখ .....



গবেষণা শিরোনাম : সিআরপিতে আসা ক্লাবফীট রোগীর যত্নকারীর ক্লাবফীট চিকিৎসাসেবা গ্রহণে প্রতিবন্ধকতা

### প্রশ্নাবলী :

- ১। রোগীর নামঃ
- ২। রোগীর বয়সঃ
- ৩। রোগীর যত্নকারীর নামঃ
- ৪। রোগীর যত্নকারীর বয়সঃ
- ৫। আপনার সাথে রোগীর সম্পর্কটা কী ?
- ৬। সনাক্তকরণনাম্বারঃ
- ৭। মোবাইলনাম্বারঃ
- ৮। চিকিৎসা নেবার স্থান :

৯। রোগীর যত্নকারীর লিঙ্গঃ

- পুরুষ
- মহিলা

১০। শিক্ষাগত যোগ্যতাঃ

- অশিক্ষিত
- প্রাথমিক
- মাধ্যমিক
- উচ্চমাধ্যমিক
- স্নাতক

১১। আপনি কোথায় বসবাস করেন ?

১২। আপনার পেশা কী ?

১৩। আপনার বাসা থেকে সিআরপি এর দূরত্ব কত ? এই দূরত্ব এর জন্য, চিকিৎসা গ্রহণ করতে আপনার কী ধরনের অসুবিধা হয় ?

- ১৪। চিকিৎসার বেপার এ আপনার পরিবার থেকে আপনি কেমন সহযোগিতা এবং সমর্থন পেয়েছেন অথবা পাচ্ছেন ?
- ১৫। সি আর পি তে চিকিৎসা গ্রহন করতে এসে , চিকিৎসা গ্রহন এর পূর্বে যে সময়টা অপেক্ষা করতে হয় আপনাদের , সে ক্ষেত্রে আপনার মতামত কী ?
- ১৬। আপনার শিশুর সঠিক যত্ন নেয়ার জন্য , শিশুর ক্লাবফীট সম্পর্কে যত্নকারীরও পর্যাপ্ত ধারণা থাকার কী ধরনের প্রয়োজনীয়তা আছে বলে আপনি মনে করেন ?
- ১৭। আপনি কতদিন ধরে চিকিতসা নিচ্ছেন ? এই রোগের চিকিতসা শুরু করতে অবহেলা করলে বা দেরি করলে , কী ধরনের সমস্যা হতে পারে ?
- ১৮। আপনার শিশুর চিকিৎসার ব্যয়ভার আপনি কীভাবে ব্যাবস্তা করছেন ?
- ১৯। আপনার শিশুর চিকিৎসকের সাথে আপনার সম্পর্ক এবং যোগাযোগ কেমন ?
- ২০। আপনি চিকিৎসা সেবা গ্রহন করতে এসে কী ধরনের অসুবিধার সম্মুখীন হয়েছেন ?



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)  
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তারিখ : ০৩.০৫.২০১৭

প্রতি  
হেড অব মেডিকেল কেয়ার উইং  
সিআরপি, সাভার, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) প্রসঙ্গে।

জনাব,  
বিএইচপিআই'র ৪র্থ পেশাগত বিএসসি ইন ফিজিওথেরাপি কোর্সের ছাত্র কুমার অমিতাভকে তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ১০.০৫.২০১৭ তারিখ থেকে ২০.০৬.২০১৭ তারিখ পর্যন্ত সময়ে আপনার নিকট প্রেরণ করা হলো। তার রিসার্চ শিরোনাম  
“Barriers experienced by caregivers to access to the treatment of clubfoot patients at CRP.”

তাই তাকে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

মোঃ ওবায়দুল হক  
সহযোগী অধ্যাপক ও বিভাগীয় প্রধান  
ফিজিওথেরাপি বিভাগ  
বিএইচপিআই।



Noted to  
Dr. Usmeh, Registrar, BHPI  
for N/A.  
DR. SAYEED UDDIN HELAL  
MEd, MPH, MS (Neurosurgery)  
Consultant & Instructor  
Head of Neuro-Physiotherapy Wing, CRP





বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)  
**Bangladesh Health Professions Institute (BHPI)**  
(The Academic Institute of CRP)

Ref.

CRP-BHPI/IRB/10/17/144

Date: 15/oct/2017

To  
Kumar Amitav  
B.Sc.in Physiotherapy  
Session: 2012-2013, Student ID 112120031  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

**Subject:** "Barriers Experienced by Caregivers to Access Treatment of Clubfeet Patients at CRP "

Dear Kumar Amitav,

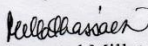
The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on 15/08/2016 to conduct the above mentioned thesis, with yourself, as the Principal investigator. The Following documents have been reviewed and approved:

Sr. No.	Name of the Documents
1	Thesis Proposal
2	Questionnaire (English and Bengali version)
3	Information sheet & consent form.

Since the study involves a self-administered structured Questionnaire on factors affecting compliance on patients of children with clubfeet deformity will take 20 to 25 minutes and have no likelihood of any harm to the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 09:00 AM on August 17, 2016 at BHPI.

The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance to Nuremberg Code 1947, World Medical Association Declaration of Helsinki, 1964 - 2013 and other applicable regulation.

Best regards,

  
Muhammad Millat Hossain  
Assistant Professor, Dept. of Rehabilitation Science  
Member Secretary, Institutional Review Board (IRB)  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ, ফোন : ৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ ফ্যাক্স : ৭৭৪৫০৬৯

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