

**SATISFACTION OF PARENTS OF CHILDREN WITH PHYSICAL
DISABILITY ABOUT PHYSIOTHERAPY HOME EXERCISE
PROGRAMME**

Fayrus Fahmida kabir

Bachelor of Science in Physiotherapy (B.Sc. PT)

Roll No. 1616

Registration No. 1928

Session: 2010 -2011

BHPI, CRP, Savar, Dhaka



Bangladesh Health Professions Institute (BHPI)

Department of Physiotherapy

BHPI, CRP, Savar, Dhaka – 1343

Bangladesh

August' 2015

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

**SATISFACTION OF PARENTS OF CHILD WITH PHYSICAL DISABILITY
ABOUT PHYSIOTHERAPY HOME EXERCISE PROGRAM.**

Submitted by- **Fayrus Fahmida Kabir** Bachelor of Science in Physiotherapy (B.Sc. in
Physiotherapy)

.....
Firoz Ahmed Mamin

Assistant Professor
Department of physiotherapy
BHPI, CRP, Savar, Dhaka
Supervisor

.....
Md. Sohrab Hossain

Associate Professor
Department of Physiotherapy, BHPI &
Head of the Programs
CRP, Savar, Dhaka

.....
Mohammad Anwar Hossain

Associate Professor of Physiotherapy, BHPI &
Head, Department of Physiotherapy
CRP, Savar, Dhaka

.....
Md. Shofiqul Islam

Assistant Professor of Physiotherapy
BHPI, CRP, Savar, Dhaka

.....
Md. Obaidul Haque

Associate Professor & Head
Department of Physiotherapy
BHPI, CRP, Savar, Dhaka.

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 declares that for any publication, presentation or dissemination of the study, I would be bound to take written consent from my supervisor and Head of the Physiotherapy Department, Bangladesh Health Profession Institute (BHPI).

Signature:.....

Date:.....

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Acknowledgement

First of all, I am grateful to almighty **ALLAH** for enabling me to complete this dissertation. I am extremely grateful to my honorable and praiseworthy supervisor **Firoz Ahmed Mamin** for his excellent guidance from the very beginning to winding up of this study.

I would like to pay my gratitude to **Md. Obaidul Haque**, Associate professor of physiotherapy department, for giving me information about the qualitative study. I would like to pay my gratitude to **Md. Sohrab Hossain**, Associate professor of physiotherapy department, for giving me information about the qualitative study. I would like to pay my highest gratitude to **Mohammad Anwar Hossain**, Associate Professor of physiotherapy department for providing me excellent guidelines. I would like to pay my gratitude to **Md. Shofiqul Islam**, Assistant Professor of physiotherapy department for providing me excellent guidelines. I would like to offer special thanks to my friends and many others for their valuable time, guidance and help throughout the study. I am thankful to all the library staff of the Bangladesh Health Professions Institute (BHPI) for their cordial help to find out important books and other necessary document.

In fact, no amount of thanks is enough to acknowledge the role played by the study participants in making this dream a reality. Lastly thanks to all who always are my well-wisher and besides me as friend without any expectation.

List of Acronyms

ATNR	Asymmetric Tonic Neck Reflex
BMRC	Bangladesh Medical Research Council
BHPI	Bangladesh Health Profession Institute
CP	Cerebral Palsy
CRP	Centre for the Rehabilitation of Paralysed
IRB	Institutional Review Board
PRST	Progressive Resistance Strength Training
TES	Therapeutic Electrical Stimulation
WHO	World Health Organization

Abstract

Title: Satisfaction of parents of child with physical disability about physiotherapy Home exercise program.

The aim of the study is to find the satisfaction of parents about the home exercise program. The objective of the study is to investigate the satisfaction of physiotherapy home program among the parents of children with disability. The study is conducted by using qualitative approach focus on specific individuals, rather than group of types of individuals. 10 sample were selected using a purposive sampling technique in accordance with inclusion and exclusion criteria. Data was collected by using the Bengali version questionnaire through face to face interview with the participants. As parents are the most significant part of a child's life so their satisfaction level is most important for the service provider. Parents believed practice of home program activities was a part of life, to maximize progress, gain guidance, and manage time. Home programs provided benefits including support, realism, flexibility, motivation, generalizable activities, practice reminders, progress updates, and role clarification. In this study the result shows that the parent's satisfaction 80% cases are positive and 20% cases are negative. 80% parents satisfied about the home exercise program but 20% shows much cause. Here is a problem some participants did not identify the physiotherapy and Occupational therapy due to overlapping or physiotherapist and Occupational therapist not discussed to the parents about their own activities or treatment procedure. Parents used these programs to help parent their child.

Keywords: Cerebral palsy, parent's satisfaction about home program, improvement of home exercise program.

1.1 Background

Bangladesh is one of least developed countries in the world situated in the South Asia as measured in terms of average income, calories consumed per person, high infant mortality (Hosain et al., 2002). The rising numbers of poor and the population boom have been two major challenges facing Bangladesh. The continued stress on national resource potentials caused by increasing population will retard the poverty alleviation efforts. Over population is the major problem in Bangladesh. The literacy rate is increasing but most of the people are less aware about health.

International classification of impairment, disability, and handicap define disability the term disability is defined as “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (Barbottee et al., 2005). According to World Health Organization (WHO) 10% of total population in Bangladesh are disabled (Akter & Rahman, 2006).

In Bangladesh, where life is difficult for many able-bodied people, disabled people are more likely to face much greater problems in the absence of a disabled friendly environment. They are less likely to be educated, employed, or rehabilitated. Social segregation of disabled persons is extremely widespread. As a result disability is going to be matter of concern besides all other major problems in Bangladesh. In Bangladesh every 1minute 6 new children are born. CP is one of type of motor disorder. A recent figures estimate that there are 7 CP (Cerebral palsy) child birth per 1,000,000 births. In developing countries the incidence of CP children is 2 per 1000 children (Hagberg et al., 2001). Cerebral palsy is the most common condition that is responsible for the child disability.

The calculation based on estimations and forecasts of the U.S. Bureau of the census, International data base indicate that in 2010 the number of patients with the infantile cerebral palsy (ICP) were increase to 17340000 people in the world. According to statistics population with cerebral palsy in USA exceeded 75000.

Currently there are more than 10000 new cases occur each year (Chatterjee, 2010). Stated that the prevalence rate of cerebral palsy is 225 per 1000 children in developing country. Bangladesh has recently seen an increase in the number of children diagnosed with cerebral palsy. According to disability profile, the client assess in the shishu bikash clinic (Rural Clinic) during January to December 1999 showed a report of child disability were 42% of total disability was cerebral palsy, among these spastic 9%. Athetoid cerebral palsy is 2%, Ataxic cerebral palsy is 3% and rest of patient is other type of cerebral palsy (Khan & Rahman, 2005). Also according to data based report of CRP Pediatric Unit from June 2006 to July 2008 showed that types of conditions treated lead to impairment among 1178 patients, 1000 were cerebral palsy, autism 43, erbs palsy 20, down's syndrome 15 and others 86. But from July 2009 to 2011 it is shown that 91% is cerebral palsy patient and 4% is other patient. From this statistics it is clearly seen that cerebral palsy has covered a large area in the field of child disability of Bangladesh (Hinchcliff, 2007). Stated that the majority of children with cerebral palsy are born with abnormalities in parts of the brain that means cerebral palsy primarily characterized by central nervous system abnormalities, such as loss of selective motor control and abnormal muscle tone. As a result of growth of these primary characteristics often lead to secondary deficits, including bone deformity, muscle contracture, poor posture, sitting ability and balance. Cerebral palsy is a catchall term for a variety of disorders that affect a child's ability to move and to maintain posture, sitting ability and balance (Geralis, 2006). All type of cerebral palsy each child has been suffers poor sitting ability and sitting posture.

Exercise programs in cerebral palsy (CP) are lifelong activities that are prescribed for home. Exercise in CP facilitates the children to learn how to use their remaining potential to compensate for the movements that could not have been performed. Regular and appropriate home exercise programs and participation of the caregiver are crucial for the rehabilitation of disabled children. Rehabilitation professionals agree that caregiver involvement is cost-effective for more comprehensive rehabilitation. Programs involving the caregivers have been shown to accelerate the success of the rehabilitation goals and to improve motor function of disabled children.

For this reason, teaching exercises to family members and assessing follow-up for adherence are very important components of treatment. Furthermore, to maximize outcomes, rehabilitation professionals should assure the parents about the effectiveness of caregiver incorporation into rehabilitation.

Current literature about the factors affecting the adherence to conventional home exercise programs is incomplete. Regarding childhood, physical activity and keeping on physiotherapy often decrease in adulthood, and lack of beneficial effects and loss of motivation are some of the causes reported. It has been estimated that the rate of non-adherence to prescribed therapeutic regimens is almost as high as 50 (Basaran et al., 2012).

1.2 Rationale

About 15% of the world's population lives with some form of disability, of whom 2-4% experience significant difficulties in functioning. The global disability prevalence is higher than previous WHO estimates, which date from the 1970s and suggested a figure of around 10%. 5-6% people in Bangladesh have a disability of one kind or another. On the other hand 2% of children in Bangladesh live with severe disability. This study aims to investigate the satisfaction of Physiotherapy home the parents of children with This study will be helpful in making physiotherapist to aware about the children with disability parent's satisfaction about home program. Physiotherapy plays a vital role in the management of disability in children. So it will also be helpful for physiotherapist in working in this area for delivering treatment service. As a result patients become more benefited, and my personal interest to work in this area and to know the satisfaction of physiotherapy home program among the parents of children with disability.

Disability is a state of decreased functioning associated with disease, disorder, injury, or other health conditions, which in the context of one's environment is experienced as an impairment, activity limitation, or participation restriction (Tuomilehto & Wareham, 2006). Disability is also an important development issue with an increasing body of evidence showing that persons with disabilities experience worse socioeconomic outcomes and poverty than persons without disabilities. Disability and poverty are intricately interlinked. Poverty can cause disability with its associated malnutrition, poor health services and sanitation, and unsafe living and working conditions. Conversely, the presence of a disability can trap people in a life of poverty because of the barriers disabled people face to taking part in education, employment, social activities, and indeed all aspects of life (Mont, 2007).

The WHO's global estimate predicts approximately 10% of all people have a disability of one kind or another. This is also considered to be true in Bangladesh with some sources quoting a higher disability rate in rural Bangladesh. The prevalence of disability in Bangladesh is believed to be high because of overpopulation, extreme poverty, illiteracy, lack of awareness, and above all, lack of medical care and services (Titumir & Hossain, 2005).

Physical disabilities have many different causes including: inherited or genetic disorders such as muscular dystrophy, conditions present at birth such as spina bifida, serious illness affecting the brain, nerves or muscles such as meningitis, accidents leading to spinal cord injury, accidents leading to brain injury (Davis, 2014).

Children with disabilities are one of the most marginalized and excluded groups of children, experiencing widespread violations of their rights. Discrimination arises not as a result of the intrinsic nature of children's disability, but rather, as a consequence of lack of understanding and knowledge of its causes and implications, fear of difference, fear of contagion or contamination, or negative religious or cultural views of disability.

It is further compounded by poverty, social isolation, humanitarian emergencies, lack of services and support, and a hostile and inaccessible environment. Too often, children with disabilities are defined and judged by what they lack rather than what they have. Their exclusion and invisibility serves to render them uniquely vulnerable, denying them respect for their dignity, their individuality, even their right to life itself (Unicef, 2013).

To date, two common bipolar models, or approaches to disability have been popularly advanced within the literature, namely, the medical and social models of disability. Disable people are able to know their potential to change their present situation, thereby becoming full and active citizen in the modern societies in which they live (Ang, 2010). The medical model of disability is considered to be predecessor of the social model. This model disability is defined primarily as a disease state and perceived as a deviation or abstraction from normality (Williams, 2004).

The model asserts that the most significant problem that the disable people face in the loss of physical and cognitive impairments as well as occupational ability. Hence the medical model is deficit model which views as essentially a problem focusing upon the individual physical and mental impairments. The model also assumes that disabled people are biologically and physiologically inferiors to those who are able bodied, and by implication, do not have the competence to make decision for them. The social model of disability provides a socio political conceptualization of disability. The social model is the total antithesis to the medical model. Where the primary focus of analysis has shifted from the deficit of the functional, physiological and cognitive abilities of the impaired. Individual to the detrimental and oppressive structure of the society. And the negative social attitude encountered by disables people throughout their live. A central tenet of the social model is that irrespective of the political, economic and religious character of the society in which they live, disable people are subject or oppression and negative social attitude that inevitably undermine their person-hood and status of full citizenship (Ang, 2010).

Disable people should have access to all services, which are available to other people in community such as community health service, child health program, social welfare and education (Thomas, 2007).

The terminology to describe any aspect of impairment, disability or handicapped has not yet been developed in most developing countries the terms impairment, disability and handicap are just knows the starting to be understood (Krafting & Krefting, 2013). World health organization (WHO) developed international classification system that define disability. Impairment is any loss of abnormality of psychological, physiological, or anatomical structure of function.

A disability is any restriction or lack of ability in activity in the manner or within the range considered normal for a human being. A handicap is disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfillment of a role that is normal. A physical disability is any condition that permanently prevents normal body movement and/or control. There are many different types of physical disabilities. Some of the main muscular dystrophies include, Acquired brain and spinal injuries, Spina bifida, Multiple disabilities.

Cerebral palsy is primarily a disorder of movement and posture. It is defined as an “umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development”. It may be stated as a static encephalopathy in which, even though the primary lesion, anomaly or injury is static, the clinical pattern of presentation may change with time due to growth and developmental plasticity and maturation of the central nervous system (Sankar & Mundkur, 2005).

Clinical types of CP are most commonly classified according to neurological symptoms. Generally we can summarize the problems based on clinical types; Spastic cerebral palsy-Spasticity is a major clinical feature of over 75% of cases with CP. The most important problems in children with spastic CP are spasticity in extremity muscles, hypo

tonus in trunk muscles, insufficiency in protective and equilibrium reactions, stereotype movement patterns, slow and firm movements, combined reactions, joint deformities due to muscle strength inequality, posture and gait disorders Spastic CP is further classified by the region of the body affected. These include: Spastic hemiplegic (One side affected).Spastic diplegia (The legs are affected with little to no upper-body spasticity).

Spastic quadriplegia (All four limbs affected). People with spastic quadriplegia are the least likely to be able to walk. Some children with quadriplegia also have hemi paretic tremors, an uncontrollable shaking that affects the limbs on one side of the body and impairs normal movement (Tirosh & Rabino, 2007). Athetoid cerebral palsy-Main problems include fluctuations in muscle tone, involuntary extremity and trunk movements, insufficiency of stabilization of the trunk and extremities, insufficiency of muscle co-contraction, and insufficiency of correction, equilibrium and protective reactions.

Ataxic cerebral palsy- It generally presents with hypo tonus, weak co-contraction, postural stabilization insufficiency, dissymmetry, and coordination disorders of movement. In children with hypotonic cerebral palsy, weak head control, weakness in trunk stabilization and control, insufficiency of correction, equilibrium and protective reactions, joint hyper mobility are seen as the main problems (Gunel, 2009). Mixed Cerebral Palsy-Children with CP can have a combination of all the above. This is called mixed Cerebral Palsy.

Some risk factors for cerebral palsy have been identified. These include: premature birth, birth weight, clotting problems, inability of the placenta to provide the developing fetus with oxygen and nutrients, RH or A-B-O blood type incompatibility between mother and baby, infection of the mother with German measles or other viral diseases in early pregnancy, bacterial infection of the mother, fetus or baby that directly or indirectly attacks the infant's central nervous system, prolonged loss of oxygen during

the pregnancy or birthing process, or severe jaundice shortly after birth (Kuker et al., 2015).

Signs and symptoms can vary greatly. Movement and coordination problems associated with cerebral palsy may include: Variations in muscle tone, such as being either too stiff or too floppy, stiff muscles and exaggerated reflexes (spasticity), stiff muscles with normal reflexes (rigidity), lack of muscle coordination (ataxia), tremors or involuntary movements, slow writhing movements (athetosis), delays in reaching motor skills milestones, such as pushing up on arms, sitting up alone or crawling, favoring one side of the body, such as reaching with only one hand or dragging a leg while crawling, walking, such as walking on toes, a crouched gait, a scissors-like gait with knees crossing or a wide gait, excessive drooling or problems with swallowing, difficulty with sucking or eating, delays in speech development or difficulty speaking , difficulty with precise motions, such as picking up a crayon or spoon (Miller, 2015).

Observation of slow motor development, abnormal muscle tone, and unusual posture are common initial clues to the diagnosis of cerebral palsy. Assessment of persistent infantile reflexes is important. In infants who do not have cerebral palsy, the moro reflex is rarely present after six months of age, and hand preference rarely develops earlier than 12 months of age. Hand preference may occur before 12 months of age if spastic hemiplegia is present. The testing strategy is based on the clinical picture, pattern of development of symptoms, family history, and other factors influencing the probability of specific diagnoses. Targeted laboratory tests and cerebral imaging using computed tomography, magnetic resonance imaging, and ultrasound are useful physical diagnostic tools. Surveillance for associated disabilities such as hearing and vision impairment, seizures, perception problems with touch or pain, and cognitive dysfunction can help complete the clinical assessment and determine the diagnosis (Siewk, 2015).

Cerebral palsy not a new disorder. There have probably been children with cerebral palsy as long as there have been children. But the medical profession did not begin to study cerebral palsy as distinct medical condition until 1861. In that year an English orthopedic surgeon Dr. William john little published first paper describing the

neurological problem of children with spastic diplegia. Spastic diplegia is still sometimes called little disease. The term cerebral palsy comes into use in the late 1800s. Sir William Osler, a British medical doctor, is believed to have coined the term.

Dr. Sigmund Freud, the Austrian neurologist better known for his work in psychiatry, published some of the earliest medical papers on cerebral palsy. In the early years, Dr. Little believed that most cases of cerebral palsy were caused by obstetrical complications at birth. He suggested that children born with cerebral palsy were born following complicated deliveries, and that their condition was a result of lack of oxygen to the brain. He said this oxygen shortage damaged sensitive brain tissue controlling movement. But in the late 1800s Freud disagreed (Zisock, 2003).

Prognosis for independent ambulation depends in large part on the type of motor impairment. Ambulation status, intelligence quotient, quality of speech, and hand function together are predictive of employment status. For example, cerebral palsy: intelligence quotient ≥ 80 , and understandable speech, who were ambulatory and independent of the need for “significant assistance”, 90% were employed in a “competitive job”. Mortality also is strongly associated with both the level of functional impairment as well as associated non-motor impairments. In one study of over 2014 individuals with cerebral palsy, the strongest predictor of mortality was intellectual disability. For example, among those with profound intellectual disability (i.e., IQ < 20), only one half survived into adulthood; whereas among those with IQ > 35 , 92% survived to adulthood. More generally, mortality risk increases incrementally with increasing number of impairments, including intellectual, limb function, hearing, and vision. In a recent population-based study, the shortest life expectancy was observed among those individuals who were unable to lift their head in prone, who had a life expectancy of 20 years (Thomas, 2007).

Physiotherapy plays a central role in managing the condition; it focuses on function, movement and optimal use of the child's potential. Physiotherapy uses physical approaches to promote, maintain and restore physical, psychological and social well-

being (Damiano, 2008). Children with CP's interventions have lifelong effects, and can be efficient and cost effective. Rehabilitation team members provide services that will help them reach their full potential in their homes and communities. The rehabilitation influence is not restricted to the medical Centre and treatment gymnasium, but frequently includes the child's functioning settings within the home, school, recreation, and community environments (Verschuren, 2008). The physiotherapist focuses on gross motor skills and functional mobility in the management for the motor deficits in CP. Positioning, sitting, transition from sitting to standing, walking with or without assistive devices and orthoses, wheelchair use and transfers, are areas that the physiotherapist works on. Physiotherapists emphasize the need for the practice to be evidence-based whenever possible (Kunz, 2006).

Recently, reviews have addressed the effectiveness of physiotherapy interventions for children with CP focusing on neuro-developmental therapy (NDT), strength training, conductive education various physiotherapy interventions and orthotic management methods such as biofeedback and electrical stimulation, behavioral and educational approaches such as conductive education, were not included as physiotherapies but were accepted as an adjunct therapy (Msall & Park, 2008).

While there is some evidence that particular physiotherapy techniques for children with cerebral palsy are effective, evidence for other techniques is not consistent.

- a. An exercise program comprised primarily of passive stretching delivered by a therapist. Parents or patients can be instructed to carry out these exercises themselves.
- b. Passive-reflexive (massage) techniques.
- c. Therapeutic Electrical Stimulation (TES) to increase function.
- d. Classical Bobath and Neuro-developmental therapy (NDT) where the emphasis is on "normalization" of muscle tone through passive handling techniques such as the use of reflex inhibiting patterns. Emerging scientific evidence suggests that the following interventions can be recommended for clinical practice

- e. Exercise activities that include active participation of the child to attain functional goals.
- f. Progressive Resistance Strength Training (PRST).
- g. Use of assistive technology to promote mobility such as orthoses, wheelchairs, walkers or crutches.
- h. There is uncertainty about the efficacy and effectiveness of the following interventions which require systematic evaluation, preferably in a research context:
 - i. Partial Body Weight Supported Treadmill training.
 - j. Robotic assisted walking (e.g. Lokomat).
 - k. Night splinting (Morris and Condie, 2008).

Exercise programs in cerebral palsy (CP) are lifelong activities that are prescribed for home. Exercise in CP facilitates the children to learn how to use their remaining potential to compensate for the movements that could not have been performed. Regular and appropriate home exercise programs and participation of the caregiver are crucial for the rehabilitation of disabled children. Programs involving the caregivers has been shown to accelerate the success of the rehabilitation goals and to improve motor function of disabled children. (Basaran, 2012).

The goals of physical therapy are to-

- a. Improving functional mobility.
- b. Strengthen and encourage the growth of muscles.
- c. Improve the ability to move all parts of the body.
- d. Prevent joints from becoming tight or permanently bent (contracted).
- e. Physiotherapy techniques are aimed to assist child with:
 - f. Normalization of their muscle tone
 - g. Maintaining range in muscles affected by hypertonic
 - h. Improved balance and coordination
 - i. Development of gross motor skills
 - j. Strengthening of muscles

- k. Experience of normal movement through play and functional activities
- l. Strengthening and stretching
- m. Physical therapy also may include the use of:
- n. Special positions, exercises, and cushions to help keep a child in a more natural position.
- o. Braces, casts, and splints to help straighten and support the child's joints. These devices also may help manage uncontrolled limb movements
- p. Wheelchairs, walker and other devices for increased mobility.

Parents of children with cerebral palsy believe that home programs make an important contribution to their children's development and progress (Novak, 2011). Parents satisfaction fundamentally concerns how care is viewed and valued by the parents it is an important determinant of a quality health service. However, medicine and health service have been concern principally with biomedical aspect care, which have precluded any concern for the patients view (Fitzpatrick, 2005).

A concern for the quality of health services is one reason to conduct patient satisfaction studies for instance. Identified 6 dimension through which the quality of health service should be evaluated, Access, Relevance to need, Effectiveness, Equality, Efficiency, Social acceptability. The six dimension encompass patient satisfaction. Thus satisfaction sites within the complex of different needs that will help to ensure the quality of health services (Majnemeer, 2007).

In more developed countries parents satisfaction are seen as important indication of the quality of health service. Developing countries influenced by movement in core developed countries, are paying more attention assessing quality of health care and with outcome of measure of quality (Helen, 2014)

There was one study found in the literature that addressed client satisfaction in Bangladesh. This was a study of client satisfaction with health service in rural area in Bangladesh. The major finding of the study revealed that the most powerful predictor for client satisfaction with government service was provider behave or especially respected politeness. However, the finding of this study must be considered in light of the nature of service provision, which was consultative rather than in a more long term

setting such as hospital. Furthermore, satisfaction may simply reflect passive acceptance, rather than be result of action evaluation (Avis, 2006). Although the theoretical basis of what patient satisfaction represents is still controversial, it has been though to include cognitive evaluation and emotional reaction to their care (Fitzpatrick, 2005) has proposed a pragmatic model of patient satisfaction in general practical involving the following component:

- a. An evaluation judgment or reaction to care
- b. A continuous, not dichotomous variable
- c. Multidimensional thus a measure of general satisfaction may be insensitive to
- d. Different aspect of care, and different patient may have different priorities
- e. Variety in different clinical settings. patient characteristic may influence priorities and attitude
- f. Requirements for personal care (Stephen, 2009).

CRP is an organization which treats and rehabilitates of people regardless of their economic means. The holistic approach of CRP attempts to consider the patients physical emotional, social and economic needs during and following treatment. CRP was found in 1979 and continues to be only center of its kind in Bangladesh (CRP leaflet, 2012).

What are the facilities of CRP many patient has taken treatment from pediatric unit in CRP. Two facilities are available in this pediatric unit. These are outpatient facilities and inpatient facilities. After two weeks of indoor program patient return their home. During going to home therapist gives parents of patient name of book Akivuto Prithibir Pothe. Involving in this book which exercises is need for patient at home. This book is bangla version so all parents understand properly. Some patients are coming from another district. They cannot take treatment daily so therapist teaches parents about all exercise so that parents doing all exercise her child properly at home. Patient benefits this program.

3.1 Study design

The purpose of this study is to find out the satisfaction of parents of children with disabilities about physiotherapy home exercise program. The study is conducted by using qualitative approach focus on specific individuals, rather than group of types of individuals.

The researcher used a qualitative study design to collect depth information about patient satisfaction. Qualitative research is suitable for exploring a new area and understanding individual attitude and behaviors. That's why the researcher selected the qualitative research approach, which helps to gain understanding and explore the feelings, attitude, opinions, fear and behavior of parents of children with cerebral palsy. The research design utilized semi structured and face to interviews because this was suitable for collecting research description in this topic. This methodology is appropriate when there is only a small number of participants.

3.2 Study Site

The study site was the outdoor program of pediatric unit of the Centre for the rehabilitation of the paralyzed (CRP). This was used because of time constraint and availability of population limited resources.

3.3 Study Pupolation

Children with cerebral palsy parents who come at CRP outpatient unit.

3.4 Sample Size

The sample size was only ten (10) parents of children with Cerebral Palsy (CP).

3.5 Data collection tools

Some questions were designed to contact the interviews; during the interview instrument were papers and pen to write field notes. Audiotape recorder was used to

tape the interviews. It was appropriate to use a tape recorder because it is difficult to write and think at the same time in the interview and as a result some small but important things miss. It was also easier for the researcher to translate into English by English facilities as it gives access of hearing whenever the researcher needed. The advantage of using tape record was having full transcript of interview and accessibility to independents analysis.

3.6 Data collection technique

Data were collect by using the Bengali version questionnaire through face to face interview with the participants. During the interview the researcher ensured the environment is quiet so that the participant feel comfortable to talk with researcher. The researcher will address client about confidentiality by consent.

3.7 Data analysis

The interviews followed a semi structured questionnaire and all participants were asked the same questions. After transcript of the entire interview, the data was organized according to the interview questions. All transcripts were read several times to discover the themes and to find out what the participants actually wanted to say. The researcher at first accumulated a category to question number one. The researcher identified similarities from all participants interview, question number one. Themes were developed from a list of category. This procedure was repeated for all the questions. Using the topic analysis the researcher then did the second step data analysis. During data analysis the interviews were read several times and the important categories identified. The categories were outcome of outdoor home program, exploring expectations of clients regarding this program, satisfaction levels of the participants of parents and child were considered to explore. All themes were listed before they were placed into these categories according to their definition. Also some sub themes were listed under main themes and analysis it according to participants interview. The result obtained from these themes and sub themes were written on a separate page.

3.8 Ethical consideration

The ethical guideline of WHO IRB and BMRC was strictly followed. The research proposal was submitted to the ethical review committee of Bangladesh Health Profession Institute (BHPI) for approval and to CRP's ethical committee for getting permission for Data collection. After proposal was approved to carry out with the study the researcher had moved the study.

The research approved by the ethical committee of center for the rehabilitation of the paralyzed (CRP). At first the researcher got the permission from CRP pediatric unit. Then she got permission from the participants and assured them regarding the confidentiality of their names and address. All the information and tape was kept in a locker. It was explained that there were no risks whatever for participants who agree to take part in this research. To take part in this research study on "Satisfaction of parents of child with physical disability about physiotherapy home exercise program". The researcher is a 4th year B. Sc. student of physiotherapy and doing this research, which is a part of partial fulfillment of her bachelor degree, the participants in the study was parents of cerebral palsy of pediatric unit of CRP and had to prepared participate in a face to face interview with tape recorder. The interview looks approximately 20-30 minutes with each participant by semi-structured question.

3.9 Inclusion criteria

The participants were chosen from those who were attending the follow up session after receiving treatment from indoor program at home. Child age: 3-10 years. Mother who were minimum able to read and write her name because they were able to understand and perform at home.

3.10 Exclusion criteria

Children with other types of disability, e.g.- muscular dystrophy, down syndrome, because the aim of the study was to find out perspective of the mothers of cerebral palsy. Children of age group below 2 and above 10 years because they are not available in CRP pediatric patient. Children who don't have mother or constant career because the career will not constant she cannot able to give appropriate information about child.

3.11 Reflexivity

There was possibility of researchers own biases, example he might have interest on a group of mother and less interest another group which might affect the result. Making the result other without interviewing etc. To avoid the ease he needs to be 100% honest on continuing the actual research process, not worried about the positive result. He need to give same attention to all participants equally and worked hard throughout the whole time to complete a good, honest research project and at last the researcher tried to minimize biases.

3.12 Positionality of the Researcher

The researcher did the research as apart of course curriculum of 4th year B. Sc in physiotherapy. It was the first attempt for the researcher. As a trance physiotherapist researcher was arranged of researcher's own ideas about value of the home program. The parents were unaware about work of the student and therefore they were free to share their views. Researcher did not try to influence their views in any way. Researcher built a friendly relationship and tries to capture their views and not allows researcher own ideas to interview, The researcher become aware that some of the uneducated

parents were not interested in other families and were anxious to return home quickly. However all participants new points but aware of the researcher own research. Researcher had no emotional expression during taking interview though all mothers were very sensitive about their children. Participants were empowered in this project.

Researchers attitude was professional neither too rigid not too much friendly and completed the interview process successfully. All participants understood all questions. They were able to express their own feelings without any hesitation. Researcher did not ware white coat.

3.13 Rigor

The researcher did not influence the participation in any way. During the interview, the researcher did not interrupt participant while answering questions. No leading question was asked and judgments were avoided on interviewees talk. The researcher mostly asked open questions.

Results

The main objective of the study is to explore the satisfaction of parents of child with physical disability about physiotherapy home exercise program. 10 participants were selected for this study. Out of 15 individuals who were invited two participate in this research project, 10 were agree to attend then record the participant speech and summarized the main theme after identified the main theme, the recorded data was reviewed to ensure validity of data. Content analysis has been done to identify core consistencies and meaning then data was coded in to the broad category as dictated by the research question and all the category were listed and grouped into categories. This section explores the major theme and categories that emerged from analysis of the data. The main themes and categories are flowing:

Theme 1 Perception among child with cerebral palsy of parents about home exercise program.

Code 1.1 Normalize muscle tone of the child.

In this study 10 participants were participated. Most of the parents said that it helps to normalize their child's muscle tone after receiving treatment from CRP. One parents said that "before receiving treatment their child have more spasticity but after receiving treatment their children decrease spasticity

Code 1.2 Satisfaction of parents about therapy services.

Maximum subject are satisfied with their service by home exercise program because they are benefited from this service, subject also gets benefited. Child is improved as subject expectation is fulfill because child improved his condition.

One participant said, I satisfied to come here. I think every home exercise is well organized. Before receiving treatment child muscle power was very poor and child did not talk properly.

Another participant said, I satisfied because before taking treatment her child was unable to grip any object but due to home exercise program now her child can grip any object. Therapist advised mother to practice the griping activities at home.

Other participant said, I satisfied to come here because I have live far away from CRP, so home program is effective and efficient for my child, I am very glad to get home program.

Another participant said that, before getting therapy my child could not do sit, walk, and toilet by himself but after having therapy my child does the work properly. So I am very satisfied to get the home program.

Another participant said that before getting therapy my child was one side of hemiplegic. After two weeks indoor program, therapist advised the patient AFO during at home. Now he goes to school by wearing AFO. My child continues her study. So I am happy to get the home program.

Code 1.3 Satisfaction with behavior of the staff

Home exercise is a program where parents have to be close contact with the therapist. So behavior of the therapist is another part of satisfaction. One subject said, I am satisfied because the therapist behavior is good.

When therapist gives exercise my child at the home, I cannot catch all exercise and this time I asked therapist, he reviews it. Therapist was not feel bore.

Another subject said, therapist behavior is good, when I practiced exercise with my child at the home and I do some mistake anything or I forget some activities. So I contact with the therapist through mobile. Therapist listens to carefully.

Participants no.	Age	Sex	Occupation	Educational back ground	Area
P1	30	Female	House wife	Class eight	Rural
P2	35	Female	House wife	SSC	Urban
P3	22	Female	House wife	Class five	Urban
P4	26	Female	House wife	SSC	Urban
P5	28	Female	House wife	Literate	Rural
P6	35	Female	House wife	Literate	Rural
P7	34	Female	House wife	HSC	Urban
P8	23	Female	House wife	Illiterate	Urban
P9	21	Female	House wife	Class five	Urban
P10	30	Female	House wife	Illiterate	Urban

Among the ten participants all were female. The participant was all aged between 21 to 35. This means they could easily understand the research questions, because it is appropriate age, not too old or young.

Theme 2 Learning from this home program.

Code 2.1 How to do exercises for the child

Most of the participant said that they learned how to do exercise. Like exercise of arm and leg. How to do the bridging exercise. To keep it normal most of them are said they will do it at home. As an answer to the question the maximum said the things that they learned the exercise and that they will do it at home.

Another participant said, I have learned many information from physiotherapy. I will do everything that exercise need for my child at home.

One participant said, in this home program I think arm and leg exercise is best because it prevent the limitation of movement of the joint of the my child exercise through play as much I can.

One participant said, Here I have learned the exercise for arm and legs and the body which will do regularly at home.

One participant said, I learned How do I keep my child in standing position and I learned where should I give support during standing position. This home program I get better result.

Code 2.2 How to maintain ADL

During therapy the physiotherapist explain to the parents how to ADL of the child that means about dressing, toileting, feeding, brushing, sitting, standing maintain, walking. They also learn this thing from health education. From that mother can learn a lot about her child.

Two participant said they learned about how to ADL at home such as how to sit, how to toilet sit, how to feed on lap of mother, how to dress up etc.

One participant said, I have learn exercise for arm and leg how to make bridge, how to sit the baby, how to do exercise of the body keeping in the lap, also how to feed it. I will do this at home.

From that quotation the researcher could easily find what the participant's achievement was or what they learned from that program. The participant thought such things very important for their child. They will do all things at home and they believe their child will be improved.

Code 2.3 Effective exercise for the child

Maximum participant said that, all exercise is need for her child. But one participant said that all exercise is good but I think arms and leg exercise are better because it helps to movement the joint.

Other participant said that, balance practice is better because no dynamic sitting balance of my child now improve the dynamic sitting balance my child.

Another participant said that, ball throwing practice is good because my child cannot catch any object but now my child able to catch any objects.

Theme 3 Barrier of home program

Most of the participant's response was no problem. Sometimes they answered the question. There is no problem but when asked sub question, Are you sure you have no problems? Then they started to speak about some problem.

Code 3.1 Lack of attention child

One participant said that she cannot able to applying the home program appropriately at home. Because during therapeutic time child carried out. Sometimes child feel pain in his arms and leg .For taking anti epileptic drug patient get seeped all over the time.

Code 3.2 Poor educational background of the parents

One participant said that she cannot able to applying the home program appropriately at home. Because of most of the time she forgets the home program given by individual's therapist and participants also said that she and her husband are illiterate. So after finishing the two weeks indoor program every participants got a book named "Ekivuto Prithibr Pothe" although they are illiterate they could not able to read the book through. For the reason they could not provide appropriate therapy to the child.

Code 3.3 Amount of exercise

One participant reported that they initially wanted to perform the recommended amount of exercises, but they tended to reduce these over time. They reported two reasons. The first reason was that participants felt that doing a lot of exercises was problematic, as this either required excessive time taken from their daily activities or it restricted their time for recreational or affective relationships with their children.

I do not do all exercises every day, it's too much and I'm not able to find enough time in my daily routine. (Mother of a 20-month-old boy)

My son receives a lot of physiotherapy at the centre. I believe my job is to be a mum first and not a physiotherapist. (Mother of a 2-year-old boy)

The second reason was that participants felt that executing the whole program could be an excessive burden for the children.

I do not do all the exercises every day because I think it's too much effort and stimulation for my child. (Mother of a 10-month-old girl)

Discussion

In this study the result shows that the parent's satisfaction 80% cases are positive and 20% cases are negative. From home exercise program they learned many things like how to maintain ADL, which position is better for sitting and lying. These kinds of things will be beneficial for their child. CRP can set up this program district level or division level because there is a big percentage of disable children all over the Bangladesh. But there are no proper services for this disabled child. There is a world level physiotherapy, occupational therapy and speech and language therapy services. So this is more beneficial treatment for their child, Occupational therapy, speech and language therapy all are seems very effective for their child. If they maintain at home this treatment would be beneficial for their child. Here is a problem some participants did not identify the physiotherapy and Occupational therapy due to overlapping or physiotherapist and Occupational therapist not discussed to the parents about their own activities or treatment procedure. This is problem because parents can confuse the treatment. So physiotherapist and Occupational therapist could explain to the parents.

Home programs are a form of guidance and advice, which become a way of life for parents and children. Through regular practice of activities at home, parents maximize their child's potential. Parents use the guidance and support that they gain from home programs to build confidence about how to help their child.

Previous research on home programs suggested that parents of children with cerebral palsy take on the vocation of fostering their child's development by striving to be the best parent that they can be (Piggot et al., 2011).

The parents described home programs as a form of "guidance for the journey," which had been alluded to before (Washington & Schwartz, 1996).

Limitation

Sample size is so small that's why it is not possible to generalize the result all over the population. Researcher took the sample only from CRP. So result is not so much valid. During follow the home program patient also took therapy from outside. So confounding variable fall impact.

The research project was done by an undergraduate student and it was first research project for her. So the researcher had limited experience with technique and strategies in term of the practical aspects of research. As it was the first survey of the researcher so might be there were some mistakes that overlooked by the supervisor and the honorable teacher.

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Appendix-1
CONSENT FORM

(Please read out to the participants)

Assalamualaikum / Namasker,

My name is Fayrus Fahmida Kabir, I am conducting this study for a B.Sc. in Physiotherapy project study dissertation titled **“Satisfaction of parents of child with physical disability about physiotherapy home exercise program”** under Bangladesh Health Professions Institute (BHPI), University of Dhaka. I would like to know about some personal and other related information regarding cerebral palsy. You will perform some tasks which are mention in this form. This will take approximately 30 minutes.

I would like to inform you that this is a purely academic study and will not be used for any other purpose. The researcher is not directly related with study, so your participation in the research will have no impact on your present or future treatment in this area (Pediatric unit). All information provided by you will be treated as confidential and in the event of any report or publication it will be ensured that the source of information remains anonymous and also all information will be destroyed after completion of the study. Your participation in this study is voluntary and you may withdraw yourself at any time during this study without any negative consequences. You also have the right not to answer a particular question that you don't like or do not want to answer during interview.

If you have any query about the study or your right as a participant, you may contact with me, researcher and/or **Firoz Ahmed Mamin**, Assistant Professor, department of physiotherapy, CRP, Savar, Dhaka.

Do you have any questions before I start?

So, may I have your consent to proceed with the interview or work?

Yes

No

Name of the participant _____

Signature of the Caregiver _____

Signature of the Interviewer _____

Appendix-2

সম্মতিপত্র

(অংশগ্রহনকারীকে পড়ে শোনাতে হবে)

আসসালামুআলাইকুম / নমস্কার,

আমার নাম ফায়রুজ ফাহিমদা কবির, আমি এই গবেষণা প্রকল্পটি বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)-এ পরিচালনা করছি যা আমার ৪র্থ বর্ষ বি এসসি ইন ফিজিওথেরাপী কোর্সের অধিভুক্ত। আমার গবেষণার শিরোনাম হল : "সেরিব্রাল পালসি শিশুদের বাসায় করানো ফিজিওথেরাপি চিকিৎসা সম্পর্কে পিতামাতার সন্তোষটি"। আমি এক্ষেত্রে আপনাকে কিছু ব্যক্তিগত এবং আনুষঙ্গিক প্রশ্ন করতে চাচ্ছি। এতে আনুমানিক ২০-৩০ মিনিট সময় নিবো।

আমি আপনাকে অনুগত করছি যে, এটা আমার অধ্যয়নের অংশ এবং যা অন্য কোন উদ্দেশ্যে ব্যবহৃত হবেনা। গবেষক সরাসরি এই অধ্যয়নের সাথে অন্তর্ভুক্ত নয়। তাই এই গবেষণায় আপনার অংশগ্রহণ বর্তমান ও ভবিষ্যৎ চিকিৎসায় কোন প্রকার প্রভাব ফেলবেনা। আপনি যে সব তথ্য প্রদান করবেন তার গোপনীয়তা বজায় থাকবে এবং আপনার প্রতিবেদনের ঘটনাপ্রবাহে এটা নিশ্চিত করা হবে যে এই তথ্যের উৎস অপ্রকাশিত থাকবে।

এই অধ্যয়নে আপনার অংশগ্রহণ স্বেচ্ছা প্রণোদিত এবং আপনি যে কোনসময় এই অধ্যয়ন থেকে কোন নেতিবাচক ফলাফল ছাড়াই নিজেকে প্রত্যাহার করতে পারবেন। এছাড়াও কোননির্দিষ্ট প্রশ্নঅপছন্দ হলে উত্তর না দেয়ার এবং সাক্ষাৎকারের সময় কোন উত্তর না দিতে চাওয়ার অধিকার ও আপনার আছে।

এই অধ্যয়নে অংশগ্রহনকারী হিসেবে যদি আপনার কোন প্রশ্ন থাকে তাহলে আপনি আমাকে অথবা / এবং, ফিরোজ আহমেদ মামিন, সহকারী অধ্যাপক, ফিজিওথেরাপি বিভাগ, সিআরপি, সাভার, ঢাকা-১৩৪৩-তে যোগাযোগ করতে পারেন।

সাক্ষাৎকার শুরু করার আগে আপনার কি কোন প্রশ্ন আছে?

আমি আপনার অনুমতি নিয়ে এই সাক্ষাৎকার শুরু করতে যাচ্ছি।

হ্যাঁ

না

১। অংশ গ্রহনকারীর নাম

২। পালনকারীর স্বাক্ষর

৩। সাক্ষাৎ গ্রহনকারীর স্বাক্ষর.....

Appendix-3

Questionnaire

Demographic Information:

Name:

Age:

Sex:

Address:

Phone No:

Parent's occupation:

- Housewife
- Student
- Garments worker
- Teacher
- Farmer
- Other

Residential area:

- Rural: In general, a rural area is a geographic area that is located outside cities and the centers of towns.
- Semirural: Having the both urban and rural characteristics is called semirural area.
- Urban: An urban area is a location characterized by high human population density and vast human-built features in comparison to the areas surrounding it.

Parent's educational status:

- Illiterate
- Literate
- Primary school certificate (PSC)
- Junior school certificate (JSC)
- Secondary school certificate (SSC)
- Higher secondary certificate (HSC)

- Bachelor
- Masters
- Others

Average monthly income in Bangladesh:

- Average (7,990)
- Below average
- Above average

Diagnosis:

- Spastic diplegic CP
- Spastic quadriplegic CP
- Spastic hemiplegic CP
- Ataxic CP
- Athetoid CP

Research question:

- 1 .What do you think about home exercise program of the mother and child care unit of CRP?
2. Which treatment are beneficial for your child or which are not? Please explain?
3. Are you satisfied of this home exercise program? Please explain?
4. What did you learn from that program?
5. What problem did you face in that program? Please explain?
6. Parents Comments –

Appendix-4

প্রশ্নাবলী

অবস্থানগত তথ্য :

নাম:

বয়স:

লিঙ্গ:

ঠিকানা:

ফোন নং:

পিতামাতার পেশা:

- গৃহিণী
- ছাত্র/ছাত্রী
- পোষাক শ্রমিক
- শিক্ষক
- কৃষক
- অন্যান্য

আবাসিক এলাকা:

- গ্রাম: সাধারণত গ্রাম্য এলাকা বলতে বুঝায় এমন একটি ভৌগলিক এলাকা যা শহর থেকে দূরে অবস্থিত।
- মফস্বল এলাকা: এমন একটি এলাকা যা শহর ও গ্রাম এর সমন্বয় এ গঠিত।
- শহর এলাকা: সাধারণত শহর এলাকা বলতে বুঝায় এমন একটি ভৌগলিক এলাকা যা ঘনবসতিপূর্ণ ও অসংখ্য দালানকোঠা দ্বারা সজ্জিত থাকে।

পিতামাতার শিক্ষাগত যোগ্যতা :

- অশিক্ষিত
- শিক্ষিত
- প্রাইমারি স্কুল সার্টিফিকেট
- জুনিয়র স্কুল সার্টিফিকেট
- মাধ্যমিক স্কুল সার্টিফিকেট

- উচ্চ মাধ্যমিক স্কুল সার্টিফিকেট
- স্নাতক
- স্নাতকোত্তর
- অন্যান্য

বাংলাদেশের গড় মাসিক আয়

- গড় (৭৯৯০ টাকা)
- নিম্ন আয়
- উচ্চ আয়

রোগ নির্ণয়:

- স্পার্সটিক ডায়াপ্লিজিক
- কোয়াডিপ্লিজিক
- হেনিপ্লিজিক
- এটাজিক
- এথেন্টয়েড

প্রশ্ন:

১. সি. আর. পি. মা ও শিশু বিভাগ এ বাড়িতে করণীয় কাজ সম্পর্কে আপনি কি মনে করেন?
২. কোন চিকিৎসা টি আপনার বাচ্চার জন্য কার্যকর বা কার্যকর নয়? ব্যাখ্যা করুন?
৩. আপনি বাড়িতে করণীয় কাজের উপর সন্তুষ্ট? ব্যাখ্যা করুন?
৪. আপনি এই কর্মসূচি থেকে কি শিখেছেন?
৫. আপনি এই কার্যক্রম করতে গিয়ে কি সমস্যা সম্মুখীন হয়েছেন? ব্যাখ্যা করুন?
৬. পিতামাতার মন্তব্য-

Appendix-5
Permission letter

Permission letter

The Head of the department
Department of physiotherapy
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka-1343.

Through: Head, Department of Physiotherapy, BHPI.

Subject: Seeking permission of data collection to conduct my research project.

Dear Sir,

With due respect and humble submission to state that I am Fayrus Fahmida kabir student of 4th Professional B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). The ethical committee has approved my research project entitled on "Satisfaction of parents of child with physical disability about physiotherapy home exercise program" under the supervision of Firoz Ahmed Mamin assistant professor, Department of Physiotherapy, CRP. Conducting this research project is partial fulfillment of the requirement for the degree of B.Sc. in Physiotherapy. I want to collect data for my research project from the patients of CRP. So, I need permission for data collection from the Pediatrics unit of Physiotherapy department of CRP-Savar and Mirpur campus. I would like to assure that anything of my study will not be harmful for the participants.

I, therefore, pray & hope that you would be kind enough to grant my application & give me permission for data collection and oblige thereby.

Sincerely

Fayrus Fahmida Kabir
4th Professional B.Sc. in Physiotherapy
Roll-34, Session: 2010-2011
Bangladesh Health Professions Institute (BHPI)
(An academic Institute of CRP)
CRP, Chapain, Savar, Dhaka-1343.

she will collect data from this unit. Please
5-10-15

HOSNEARA PERVEEN
Incharge Paediatric Unit
CRP, Savar, Dhaka

she may be allowed for data collection
06/10/15

Firoz Ahmed Mamin
BSP1 (DU), MSc in Clinical Neuroscience (London)
Assistant Professor
Department of Physiotherapy
BHPI, CRP, Savar, Dhaka

*Approved
Contact with Rehana Begum
Clinical PT, Savar, as a counter
part of the data collection process.*

Mohammad Anwar Hossain
Associate Professor & Head of Physiotherapy Dept.
CRP, Chapain, Savar, Dhaka-1343

Obaidul Haque
Associate Professor & Head of the Department of Physiotherapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343