

**PERCEPTION OF MOTHERS: TOILET EDUCATION
PROGRAM FOR CHILDREN WITH CEREBRAL PALSY IN
OCCUPATIONAL THERAPY AT IN-PATIENT PAEDIATRIC
UNIT, CRP, SAVAR, DHAKA**

By

Airen Akter

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Faculty of Medicine, University of Dhaka

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Study completed by:

Airen Akter

4th year, B.Sc. in Occupational Therapy

Study Supervisor's name and signature:

Shamima Akter

Lecturer, Department of Occupational Therapy

BHPI, CRP.

Head of department's name and signature:

Nazmun Nahar

Assistant Professor

Head of the department

Department of Occupational Therapy

BHPI, CRP.

Statement of Authorship

Except where is made in the text of the thesis, this thesis contains no materials published elsewhere or extracted in whole or in part form a thesis presented by me for any other degree or diploma or seminar.

No others person's work has been used without due acknowledgement in the main text of the thesis.

This thesis has not been submitted for the aware of any other degree or diploma in any other tertiary institution.

The ethical issues of the study has been strictly considered and protected. In case of dissemination the finding of this project for future publication, it will be duly acknowledged as undergraduate thesis.

Signature: _____ Date: _____

Airen Akter

4th year, B.Sc. in Occupational Therapy

Dedication

*Dedicated to my honorable and beloved parents, younger
brother and sister*

Acknowledgement

All the praise must go to Almighty Allah for blessing and giving me the ability to conduct this study. I would like to express my gratitude to my parents who constantly inspired me to carry out this study. I want to provide my deepest thanks to my fiancé Zabeed Iqbal Piku for giving me mental support during completing the study.

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Abstract

Toileting is a major functional area in activities of daily living. Children with cerebral palsy have problems in self-toileting and their mothers also face difficulty to toilet their child. Thus toilet education program is arranged at inpatient paediatric unit as a part of occupational therapy intervention. However, there is scarcity evidence about toilet education program. This study was focused to know mothers' perception about toilet education program of their children with cerebral palsy at inpatient paediatric unit of Centre for the Rehabilitation of the Paralysed. The objectives were to find out mothers' level of understanding about toilet education program and to find out value of this program from the perspective of mothers. Furthermore, investigator also gathered some suggestions from mothers' perspective about toilet education program. This study was conducted by using qualitative content analysis approach of qualitative method. Participants were selected by using purposive sampling. Data was collected using face to face interview with a semi-structured questionnaire. Data was analyzed by using content analysis. After analyzing data, it was found that mothers of children with cerebral palsy understand all the information clearly and satisfactorily. Mothers of children with cerebral palsy addressed that toilet education program enhance their knowledge about toileting problem of their children with cerebral palsy and about its management. Mothers thought that toilet education program is very important to take care of their children with cerebral palsy. They will utilize their learning from toilet education program at their home environment for their children with cerebral palsy. Mothers thought that showing the toilet training technique by using video clip is better to make information easy to see and remember. Mothers prefer booklet on toilet training technique, which they can use at home to show the techniques and related information to the other family members. Therefore, a video clip can be used for providing information instead of only flashcard of picture about toileting. Overall, the toilet education program is very important for mothers of children with cerebral palsy and they have learned many easy way of toileting which they will use after returning home.

Key words: *Cerebral palsy, Inpatient paediatric unit of CRP, Toileting education program.*

List of Acronyms

ADL: Activities of Daily Living

AOTA: American Occupational Therapy Association

BHPI: Bangladesh Health Professions Institute

CRP: Centre for the Rehabilitation of the Paralyzed

CP: Cerebral Palsy

GO: Government Organization

IADL: Instrumental Activities of Daily Living

MDT: Multi-Disciplinary Team

NGO: Non Government Organization

PWD: Person with Disability

QCA: Qualitative Content Analysis.

RCPP: Rehabilitation Centre for Paralyzed Patient

US: United States

WHO: World Health Organization

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1.1. Introduction

Disability is a major concern in Bangladesh as well as all over the world.(1) Amongst all disability, Cerebral Palsy (CP) is the most common form of chronic disabling condition in children.(2) In Bangladesh, the number of children with CP is approximately 2.8 million among 144,109,214 populations.(3) Children with CP present a variety of clinical presentations and a range of motor impairments and activity limitations.(4) Due to lack of appropriate treatment, children with CP face difficulty in engaging in occupational performance areas such as self-care, productivity and leisure. Toileting is an important part of self-care activities and children with CP often face difficulty in toileting. As a result, children with CP depend on others family members particularly mother. Therefore, CP in a child affects not only the child's life but also the life of the family.(5) Mothers of children with CP are lead a more stressful life and they have lower quality of life compared to fathers of children with CP.(6) Therefore the involvement of mother in treatment of their children with CP is very much important for successful treatment of their child and thus it reduces stress of mother.(7) A well-known organization in Bangladesh called Centre for the Rehabilitation of Paralyzed (CRP) is working for children with CP and their primary caregiver/mother in Multi-Disciplinary Team (MDT). Occupational therapy is a part of MDT and has a great role in the treatment of children with CP. Occupational therapists focus on occupational engagement of children with CP by providing the mother with education about different treatment techniques and different ways of engaging children with CP in Activities of Daily Living (ADL) such as feeding, dressing, toileting etc. In favor of mothers' education, occupational therapists arrange a toilet training class in CRP, although there is no study or evidence on parental thinking, feeling, and understanding of the program and value of the program on mothers' perspectives. Therefore, this study is to find out mothers' perceptions about toilet education program.

1.2. Background

Worldwide over a billion people are estimated to live with some form of disability.(8) This corresponds to about 15% of the world's population.(8) In Bangladesh, the estimated number of persons with disabilities is around 140 million people, which constitutes 10% of its total population.(9) Furthermore, the rates of disability are increasing day by day due to increase in chronic health conditions.(8) CP is an example of such a chronic health condition. CP can be defined as non-progressive but not unchanging disorder of movement and/or posture, due to an anomaly of the developing brain.(10) It occurs in about 2.0–2.5 per 1000 live births.(11) Although CP is a continual condition it doesn't always cause profound disabilities but impaired motor function is the 'hallmark' of the CP syndrome.(12) This is why most children with CP have limitations in self-care functions such as feeding, dressing, bathing, toileting and mobility. Toileting is an important part of personal care and self-care activities.(13) It is easy for a mother to toilet their children with CP when the child is very young, but it become more challenging for mothers when children grow up.(7) Currently, there is no cure for CP. But, there are different treatment options for people who have CP. These options include therapy, medications, surgery, education and support.(14)

For this purpose Centre for the Rehabilitation of the Paralysed (CRP), works for the inclusion of people with disabilities into mainstream society.(15) Children with different conditions get treatment services from inpatient and outpatient department of paediatric unit of CRP. According to statistical report of CRP, July 2010 to June 2011, CP is the most common condition amongst all of the other conditions. In the inpatient paediatric unit, 98% of clients had a diagnosis of CP. The outpatient unit had 1451 client of which 893 client had diagnosed with CP.(16) In the inpatient paediatric unit, children and their primary care givers or mothers are admitted for two weeks residential program. Here, children with CP get treatment from three types of therapy professionals and occupational therapy is one of therapeutic interventions for children with CP that focuses on improving the child's functional performance and ability to interact with his or her physical and social environments.(11) Children with CP and their mother participate in different group therapy, individual therapy and educational program at CRP.(17) Toilet education

program is such an education program which is run by occupational therapist to educate mothers about proper toileting techniques and how the mother will help their children with CP in independent toileting in their home environment. This program runs every Wednesday, every week. The investigator observed the toilet education program in 2nd year basement placement. In that placement, the investigator observed mother's education is necessary for engaging and improving performance in toileting. However, there had not been any study or evidence about mothers' perception of the toilet education program, although this toilet education program is a special area of occupational therapy intervention. Through conducting literature search by manual and online source, it was found that there have conducted numerous studies on CP. Most of these studies are related with prevalence, pathogenesis, cause, medical and therapeutic intervention on CP, effectiveness of various treatments, stress level of mothers having children with CP and satisfaction of the mothers about treatment and child performance. No evidence was found to find out mothers' perception about toilet education program which might be helpful for further recommendation in the toilet education program. There was a gap in knowledge. Therefore, in the 4th year undergraduate research project, the investigator was interested to know mothers' perceptions about the toilet education program. Perception is a way of seeing, understanding or interpreting something.(18) The investigator was interested to know mothers' perception, understanding and learning from the program.

1.3. Significance

The aim of the study was to find out the mothers' perception about toilet education program for their children with CP. According to SK. Moniruzzaman, In-charge of occupational therapy paediatric services (written communication, 8 August 2012) toilet education program for children with CP is a part of occupational therapy intervention. This program works to improve mother's knowledge by providing education about how they can facilitate their children with CP in independent or modified toileting. After providing any treatment or education, it is necessary to know the importance of the specific strategy for a particular group, as success of the treatment session will depend on the level of understanding of an individual.(19) Objectives of the study were to identify level of understanding and learning from this program as well as the value of the education program. Furthermore, if the mothers

provide any suggestions about this program, it was also gathered in this study. If the regarding authority focuses on the positive and negative sides of the toilet education program and take necessary steps accordingly, then it may be beneficial for the further client group. The study findings may be used for the occupational therapists to let them informed about the value of the education program according to the perception of mothers. With the permission of authority, the results of the study can be shared with the paediatric occupational therapists, so this study may help the therapists to know mothers' perception about the program in the form of a written document. This study is also evidence of mothers' perception about the toilet educational program for children with CP. If anyone wants to know about this program then therapists can use this study and will get a snapshot about toilet education program and mothers' perspectives about the program. This study may be helpful for service providers to continue good rapport with the caregivers by sharing and understanding their feelings. Additionally, mothers of children with CP may become motivated to take occupational therapy treatment because they feel that occupational therapists are giving value to their opinions. After returning home, they may motivate other clients to take treatment from occupational therapists.

1.4. Aim of the study

To find out mothers' perception about the toilet education program for their children with CP in the inpatient program of CRP paediatric unit, Savar, Dhaka

1.5. Objectives

- To find out mothers' understanding from the toilet education program
- To find out value of the toilet education program for children with CP from their mothers' perspective
- To gather suggestions from mothers about the toilet education program

2.1. Cerebral Palsy

CP is the most common cause of motor disability in childhood.(20) The latest figures in the United States indicate that the incidence of CP is 3.6 per 1000 children, with males affected to a greater extent than females.(20) According to statistics by country for CP 2011, the prevalence of CP in Bangladesh is 4157 person among 141,340,476 people and the rate is 0.003% among the whole population.(21) CP describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy, and by secondary musculoskeletal problems.(22)

There are several causes of CP: prenatal events are responsible for approximately 75% of all cases of CP and include brain malformations, maternal infections and vascular events such as middle cerebral artery occlusion, metabolic conditions and toxins, Perinatal causes are responsible for approximately 10–15% of cases and result from problems during labour and delivery such as antepartum haemorrhage or cord prolapse, compromising the fetus, Postneonatal causes occurring after 28 days of life are responsible for about 10% of all cases of CP and include infections such as meningitis, accidental and non-accidental injuries.(23) Types of CP are classified neuro-physiologically into three major types: spastic, athetoid, and ataxic. Spasticity is characterized by hypertonicity, athetoid type is characterized by involuntary and uncontrolled movements and ataxic type is characterized by unsteadiness and difficulties with balance, particularly when ambulating. About 70% to 80% of the cases of CP are spastic type, 10% to 20% cases are athetoid and 5% to 10% cases are ataxic type of CP.(24)

CP is a condition that occurs early in life and is present throughout a person's lifetime. Actual brain damage of children with CP does not change but symptoms can become more severe over time.(25) As a result, functional impairment or limitation may change as the child grows up. The ability to live independently with CP varies

widely depending on the severity of each case.(6) Some individuals with CP will require personal assistant for all activities of daily living. Others can lead semi-independent lives, needing support only for certain activities. Still others can live in complete independence. Children with CP may need assistance in everyday activities, overall health, well-being and occupational performance and the need for personal assistance often depends on age and functional limitation.(26)

2.2. Relationship between cerebral palsy and functional limitation

Functional limitation is one of the major impairments of children with CP.(12) Children with CP have limitation in gross motor skills that limit their functional performance such as dressing, toileting, playing and interacting with the environment. They may affect nearly all of the body functions and which body functions are affected depends on the type of CP, the severity of the condition, and presence of associated disorders.(27) Milder forms of CP may have little impact on occupational performance. Some individuals will require physical assistance, additional training, or assistive technology to participate fully in occupational performance areas, while individuals with severe forms of CP will be limited in their performance of all areas of occupation.(27) According to American Occupational Therapy Association (AOTA), occupational performance areas include activities of daily living, work, and leisure.(13) Activities of daily living (ADL) have been defined as the right and responsibility to take care of your physical, emotional and spiritual well-being.(28) Self care tasks and Instrumental Activities of Daily Living (IADL) encompass some of the most important task that children learn as they mature. Basic self care tasks are including grooming, bathing, toileting, dressing, feeding, achieving functional mobility and communicating.(28) Among all self-care activities, toileting is an important part of personal care. Like other ADL tasks, toileting is a complex task that needs various motor skills. A child can perform independent toileting within four to five years old.(28) It may be influenced by child's capacities and environment. Children with CP may find problem to perform toileting activity independently.

2.3. Cerebral palsy and toileting performance

Many children with CP face problems in toileting due to abnormal muscle tone and body coordination or difficulty in controlling their body movement.(29) There are two kinds of problems child may face when learning to use the toilet. The first involves physical problems for example the child is unable to move to the toilet, is unable to squat or even sit on an ordinary toilet seat, and with washing himself after using the toilet. The second problem involves child's lack of understanding. Child may not understand where or when or how should use the toilet.(30) Though toileting is important for child privacy especially for older children with CP, sometimes mothers of children with CP may not aware about toilet training or do not know how to approach toileting problem of their children.(31) Most children enter school at 5 or 6 years of age, they are expected to perform the basic toileting, grooming and personal hygiene tasks needed for school.(13) These activities can be a real challenge to the children with CP and their family. And take care of a child with disabilities at home might be somewhat overwhelming for caregivers. Therefore, it is important that the child is encouraged to try, and given the opportunity to do so in his own way.(7) The ability to develop skills for self toileting is important to maintain child's own personal health.

2.4. Toilet training technique for children with cerebral palsy

To begin toilet training tasks child and mother must be physically and psychologically ready.(28) Toilet training should start when the children with CP is normally age of 2-2 and half. In some children with CP, training should be delayed until the age of three or four.(31) Before beginning toilet training, the child needs to have developed certain physical and social skills such as: the ability to squat over a toilet or sit on a toilet or provision of the appropriate equipment, a bladder that will hold urine for at least one hour, bowel that is not constipated, some awareness of being wet or soiled, some awareness about toilet training and ability to communicate their needs.(32, 33) Then toilet training should be started. After starting, mother can use a diary for collecting the information about the regular time of toileting. If there no particular time can be found then mother can set times in the day for toileting, e.g. immediately after waking: before going to sleep: after eating or drinking.(32) Mother should give lots of praise, some children respond to lots of verbal praise and hugs, other children respond better to a reward system. Gradually, encourage child to

perform toileting with less supervision or independence. Use demonstrations, models, and examples for encouragement. Sometimes accidents can be happened if the child is excited, fearful, unwell or concentrating very hard or something else.(34) Then mother should not be disappointed with the child as disappointment may result making the child anxious. Progress can be slow and require lots of patience and perseverance.(34) Mother and child may be happy and successful by continuing toilet training program.

2.5. Adaptation and modification for toileting activity of children with cerebral palsy

Adaptation and modification should be made on child's clothing, the toilet, or toileting area to meet the child's needs. The following are suggestions for adapting toileting. However, different situations and different surroundings will require different adaptations.(31)

Clothing: For girls, pin up the skirt or dress up out of the way when training. For boys, use shorts or 'training' pants of thick toweling material and with elastic waistbands.

Potties: A simple pot, plastic container or dish can be designated for toileting or a plastic potty. A strong box made of wood with a hole cut into it can be placed over the pot. The potties must be put in a secure place, especially if the child has poor balance.

Commodes: A 'commode' chair can be made from an ordinary chair, with a hole cut into the seat. Commode chairs with wheels can be wheeled over the toilet.

Accessible toilet: Ensure that the child can get into and out of the toilet, make sure that there is a ramp, that the door is wide enough, and that there is enough space inside. Bars can be placed inside the toilet at a level where the child can hold onto them, either in front or at the sides.

Outside: If a child uses the ground, an old inner tube can be placed over a hole in the ground. Strong sticks can be used to build a low 'railing' for the child to hold stick while child sit on the hole for toilet.

Lying down: Some children with severe CP may become independent in toileting if they able to lie down. Use a clean plastic mat that can be washed after each use.(31)

Occupational therapists are specializes in improving child activities of daily living.(23) Therefore, occupational therapists educate mother of children with CP about toilet training technique.

2.6. Occupational therapy and children with cerebral palsy

Occupational therapists play their role in early intervention by focusing on promoting function through remediation, compensation, adaptation and education techniques, while providing family support throughout the entire process.(35) The goal of occupational therapy is to enable individuals to achieve independence in areas of occupational performance. Such independence can be achieved through self-independence or through an individual directing others such as in an assistant care situation.(36) Occupational therapy uses purposeful activity and task analysis to prevent and minimize the impact of disability on functional independence and facilitates the development of those skills and behaviors essential to meeting the demands of everyday life.(37) The focus of occupational therapy is not on the neurologic disease itself, but rather on the impact a disorder has or potentially will have on a child's ability to function in life roles. The primary goal is to facilitate occupational performance and prevent dysfunction by providing the child with opportunities to develop, restore, and maintain those skills and behaviors necessary for independent living. The goal of occupational therapy for CP patients is to help them live as independently as possible. Occupational therapy for CP patients uses the individual's personal strengths to help them overcome their disabilities. It also helps them to learn how to perform daily activities such as dressing, eating, toileting and bathing themselves, all this creates a higher sense of independence and self-confidence.(37) An occupational therapist helps a child master the basic activities of daily living, such as eating, dressing, and using the bathroom alone. They will use exercise, facilitated practice, alternative strategies and adaptive equipment to promote independence.(14) Occupational therapists understand the nature of family occupations can help parents manage and adapt daily living tasks with their children. The therapist asks first about daily routines and tasks that seem the most difficult. After observing the parent self-care techniques of a child, occupational therapists suggest easier ways of bathing, feeding, dressing and toileting. As children become older, occupational therapists help them to become more independent in these self-care tasks.(23)

2.7. Treatment facilities for children with cerebral palsy in Bangladesh

Though children with CP may face many difficulties in ADLs, many can live long, happy, quality lives. Therefore many children go on to enjoy near-normal adult's lives if their disabilities are properly managed. The earlier treatment begins the better improvement and development of new skills which is necessary for accomplishing everyday task.(38) Traditionally, treatment of CP has focused on influencing the primary impairments such as spasticity, or the secondary impairments such as joint contractures. There are many strategies for children with CP like conservative interventions, pharmacological interventions, surgical interventions, neurophysiological interventions etc.(39) Admittedly, their care may involve more visits to health care practitioners, require therapy, medications, and perhaps surgery at some point.(40) Recently, treatment of CP is increasingly focusing on influencing activities, such as ambulation and self-care. Treatment strategies involve task oriented intervention and environmental modification for facilitating independence.(22) For this purpose in Bangladesh, there are many Non-Government Organization (NGO) and Government Organization (GO) working, where treatment for children with CP is available. CRP is a NGO, which has been working for the last 32 years to provide treatment, training, education, and rehabilitation for the disable people in Bangladesh. CRP began as the Rehabilitation Centre for Paralyzed Patient (RCPP) and was founded on December 11, 1979 by dedicated British woman by the name of Valerie A Taylor.(41) The vision of CRP is to ensure the inclusion of disabled people into mainstream society and the mission is to promote an environment where all disabled people can have equal access to health, rehabilitation, education, information, and employment.(15) The Paediatric unit is a section of CRP which is well equipped to provide standard services for all children with disabilities particularly for the children with CP.(41) The CRP Paediatric unit provides two services - an inpatient service and an outpatient service.(17)

2.8. Inpatient paediatric unit

This residential program provides two weeks intensive services for children with disabilities and their primary caregiver, most of whom are children with CP. This program is designed to integrate children with disabilities into their own family and community. The aim of the therapists is to maximize the child's ability to attain

independence in everyday living and to improve quality of life. Therapists educate the mother about the child's condition, and teach them how to take care of the child at home. In these two weeks the mother and child are involved in different group therapy, individual and combined treatment sessions and an educational program. The occupational therapists work with a MDT approach with different professions. Some of the occupational therapy programs include; morning group therapy, hand therapy, feeding, dressing and toileting classes, parents meeting, play therapy, and sensory integration therapy. Within these two weeks, the occupational therapists also prescribe and provide assistive and adaptive devices according to the child's individual needs, such as splints and special seats. On the final day of the program, the occupational therapists provide a booklet of the overall treatment program for the mother.(17) On discharge patients will return to outpatients for follow up although many interventions have been studied in CRP, evidence is still lacking about the toilet education program.

2.9. Toilet Education Program

According to SK. Moniruzzaman, In-charge of occupational therapy paediatric services (written communication, 8 August 2012) occupational therapists work with mothers of children with CP to improve mothers' knowledge by providing education about how they can facilitate their children with CP in using toilet alone or with modification. Therefore, occupational therapists run the toilet education program on every Wednesday from 12.30-01.00 pm (30 min) every week. The toilet education program is a 2 session program. Primary caregivers and their children with CP attend in this program. In this class, all the caregivers and children sit together in a group and a therapist runs the program through demonstration, discussion, showing picture and answering the caregiver's question. The program runs as a group to increase group interaction, motivation, sharing and encouragement among children and caregivers.

The aim of the toilet education program is to educate the mother to help them to make their child as independent as possible in toileting. To achieve this aim occupational therapists work with the following objectives, to provide basic education to mother about importance of independent toileting, to make the mother better understand about how they can help their child according to child's physical status, to educate mother about different positions of toileting, how to engage and encourage child in self toileting, how to make schedule for developing good habit of toileting,

also to educate mother about how to make different modified toilet seat by local materials, to encourage the mother to implement and continue these learning at home and also educate other family member to maximize child's ability in toileting.

The total content of toilet education program is to discuss and describe the purpose of toileting and importance of independence in toileting especially privacy issue for the older and adolescent children with CP. The therapist also address caregiver needs as the child becomes heavier and more difficult to assist with toileting. Therapists discuss different types of problem which may be experienced by children with CP according to body involvement and different positioning of toileting by showing model of doll. How mother can help their children with CP on developing proper habit of toileting in a specific place and specific time is also discussed. Occupational therapists also share how mother can encourage her child in bladder management. Different ways to communicate with their children and ways to provide feedback during toileting and personal hygiene after toileting are also discussed. According to the child's sitting ability, different types of modified toilet chair and ways of making different modified chair in rural and urban area by local materials is discussed by showing picture and practical use of a modified toilet chair which make the major portion of the class. Therapists also teach ways of providing additional support such as grab rail, using bamboo for support in normal toilet, and how child with CP can easily access the hygiene utensils after toileting. In 1st class, therapist completes primary discussion about toileting, showing model of different position of toileting, showing picture of different modified toilet and then in the 2nd class, therapist complete rest of content of the class such as practical demonstration of toilet sitting, and after that therapist takes few superficial feedback for few minutes from mothers and if respondents do any mistake or are unable to perform proper technique, therapist correct this. Therapist also discuss about the problems of their child which are identified by the mothers after first class. At the end, therapists review some key point of information of both classes.

2.10. Mothers' perception

Mothers of the children with CP are the primary caregiver and play an important role in the development of the children. Individuals have their own way of understanding about their environment. A situation may be the same but the interpretation of that situation by two people may be vastly different. Perception can be defined as a process by which individuals organize and interpret their sensory impressions in order to give meaning to their environment.(42) Mothers' perception about toilet education program means their own way of understanding about toilet education program on the basis of their knowledge. From the mothers' perception, the investigator gained information about the mothers' understanding, learning from the program, value of the program and mothers' suggestion to recognize the program for better service. Perception of the mother about toilet education program is important because education programs can change the mothers' attitude towards their children.(43) Mother play an important role as educator and motivator to their children's learning process.(7) It is also possible that mothers can teach their husbands the same procedure that they have learnt from education program. Then husband may help their wife in implementing the learning to develop a good toileting habit of their children with CP. On the other hand, they can also help their wives to make necessary adaptation for their children with cerebral palsy to perform toileting activity independently. Therefore, it is very much important to know mothers' perception about toilet education program for their children with CP.

3.1. Study design

Investigator used qualitative method for this study. This method aims to describe the experiences of people in a particular setting and to understand their perspective. Its purpose is to develop a hypothesis, concepts and theory.(44) The study was conducted by Qualitative Content Analysis (QCA) approach of qualitative method. This method was used for exploring the behaviour, processes of interaction, and the meanings, values and experiences of purposefully sampled individuals and groups.(45) Priest et al quoted Miles work in their article (46) that content analysis facilitates the production of core constructs from textual data through a systematic method of reduction and analysis. Priest et al quoted Bryman's work in their article (46) that it also facilitates contextual meaning in text through the development of emergent themes derived from textual data. The investigator had analyzed themes from mothers' responses about the toilet education program by analyzing data. Therefore the investigator had selected the QCA design to conduct this study.

3.2. Study setting

The study area was the inpatient paediatric unit of CRP, Savar, Dhaka. CRP is a NGO which treats and rehabilitates people with disabilities regardless of their socio-economic status and aims to improve the quality of life of Person with Disabilities (PWD) in Bangladesh. The CRP at Savar is the only rehabilitation centre in Bangladesh that specializes in the treatment of spinal cord injuries.(47) In addition, CRP has outdoor unit facilities for PWD such as, paediatric unit, neuro musculoskeletal unit, stroke rehabilitation unit, and hand therapy unit. The paediatric unit has inpatient and outpatient areas. The inpatient paediatric unit is a residential program which provides two weeks of intensive service for children with disabilities and their caregivers. Here the therapists mainly educate the primary caregiver about basic treatment and management of the child's functional ADLs. The treatment program is designed to integrate children with CP into family and community life. One group stays for two weeks then the next group for another two weeks. Most of the children in the inpatient paediatric unit are children with CP.(17) The two weeks

residential program starts on Saturday, then after having a weekend on Friday, it finishes on next Thursday.

3.3. Population

The investigator observed eight toilet education classes in the preparatory phase of this study and found that the class content is the same for every group. The populations were mothers of children with CP who come for two weeks indoor program with their children and attend the toilet education class of CRP, Savar, Dhaka.

3.4. Participant selection procedure

Participants were selected by purposive sampling. “Purposive Sampling means that a researcher does not simply study whoever is available, but uses judgment to select a sample that they believe, based on prior information, will provide the data they need”.(48) The investigator selected participants the following way, after taking permission from the in-charge of paediatric unit; the investigator discussed the study with the responsible occupational therapists of the inpatient paediatric unit. The investigator then observed the toilet education class for selecting the participants. The investigator made a list of mothers who fulfill the inclusion criteria, then invited them to become a participant in the study. For this study 6 participants were selected. The consent and level of interest of each participant was confirmed prior to inclusion in the study. For participant selection the inclusion criteria was as follows:

- Mothers of cerebral palsy children who attended both toilet education classes.

3.5. Ethical consideration

The investigator maintained ethical consideration in all aspects of the study. At first, the investigator took approval (Appendix-1) from supervisor and course coordinator, Department of occupational therapy, Bangladesh Health Professions Institute (BHPI) an academic institute of CRP. Then permission was taken from the In-charge of paediatric unit (Appendix- 2) for data collection from the participants. The investigator took information sheet and consent form in Bangla (Appendix 4- 4.1 and 4.2) to the participants who were interested to participate in the study and informed them verbally about topic and purpose of study. The investigator ensured

that the paediatric unit will not be harmed by this study. It was informed that there would be no risk or direct benefit to participate in the study. The participants were not deprived from any therapy sessions because of this study. Each participant had the right to refuse to answer any question or withdraw from the study. It was also ensured that all information that was provided by participants will be confidential only investigator and supervisor have access to them.

3.6. Field test

Prior to starting the data collection, the investigator completed a field test with three participants. It is important to carry out a field test before collecting the final data as it helps the researcher to refine the data collection plan.(49) This test was performed to identify any difficulties that exist in the questionnaires. By finding any difficulties, the investigator rearranged the questionnaires to make it more understandable, clear and enough for the participants and the study.

3.7. Data collection tools and materials

During the interview time, the investigator used audio tape recorder to collect the interview data. Because to write down every question's answer in details was very hard during the interview session. Audio taping is a fundamental data collection tool while researcher use face to face interview by open-ended question in a natural setting.(49) Pen and clip board were used to write down participants general information. Information sheet and consent forms were used for gaining permission from the participants, for details Please see appendix 4- 4.1, 4.2 for Bangla copy and appendix 5-5.1, 5.2 for English translated copy. A semi-structured questionnaire was used to conduct the interviews (please see appendix 4- 4.3 for Bangla copy and appendix 5-5.3 for English translated copy).

3.8. Data collection procedure

The aim of the study was to explore mothers' perceptions about the toilet education program. The investigator collected data from mothers after completing two classes. The investigator used face-to-face interview with a semi-structured questionnaire for data gathering. Face-to-face interview are more intimate and allow the interviewee to interact directly in the interview and develop it.(50) The

investigator collected the data by own self. At first, the investigator arranged a quiet place by communicating with the regarding authority, and spent some time building rapport and a trusting therapeutic relationship with participants. The investigator explained the study question and aim of the study. The investigator then took the opinion of the participants by using an information sheet and consent form. After completing these primary steps, the investigator asked questions to identify the understanding, learning, and importance of this program. All questionnaires and information sheets were translated into Bangla. Interviews were conducted in Bangla and recorded by MP3 recorder. Duration of interview was approximately 20 minutes for each participant. Venue of interview was inpatient paediatric unit of CRP, Savar. Appointment of interview time was the last two days (Wednesday and Thursday) of the two week program (after both toilet education classes in both weeks) during the data collection period of the study.

3.9. Data analysis process

The investigator used qualitative content analysis to analyze data of mothers' perception about toilet education program. The aim of data analysis was to find out actual meaning of information, which was collected according to the participant's opinion. Priest et al. also quoted Bryman's work in his research (46) that it also facilitates contextual meaning in text through the development of emergent themes derived from textual data. Data was analyzed by 3 stages: coding, categorizing and generating themes. First level coding was started with line-by-line analysis, where phrases, sentences or whole sections were pasted into categories. Then second level analysis was done by indexing more detail and pieces of codes with similar meaning or insights will be grouped together to form a category. In third level, progressing reduction was done through a process of interpretation to generate themes.(46)

At the first step of analysis the investigator listened to the recorded interviews several times. After that the interview was transcribed into Bangali by the investigator, the investigator reviewed the interviews with the transcript to ensure all the data was presented within the text. After formulating the transcription, it was given to 6 individuals who were competent in English to translate the data from Bangla to English. Investigator has completed three copies of data where one set was translated by the investigator and two copies were translated by the volunteer group.

After that, the investigator verified those three data sets and also read it several times to recognize what the participants wanted to say in the interviews. At the same time, the investigator listened to the MP3 recorder to ensure the validity of data. Then the investigator categorized the data. In the 2nd step, after categorizing the investigator started content analysis. Then investigator tried to find out the codes from participants' answer. Investigator organized data according to the categories. Under those categories, the investigator coded all the information from participants' interview. The coding was different from each participant and after finishing the coding; the investigator detected some important codes that reflected the themes of the study findings.

Rigor of the study

The rigorous manner was maintained to conduct the study by the investigator. This study was conducted in a systemic way by following the steps of research under supervision of an experienced supervisor. During the interview session and analyzing data, the investigator never tried to influence the process by own value, perception and biases. The investigator accepted the answer of the questions whether they were of positive or negative impression. During asking question, the investigator always tried to avoid leading. The transcripts were translated by another 6 individuals to avoid biasness and investigator checked it several the times with his own translation and recording to reduce any mistake and compared it with the Bangla transcript. The participants' information was coded accurately and checked by the supervisor to eliminate any possible errors. Investigator tried to keep all the participants' related information and documents confidential. At last in the result section, the investigator used scientific manner and didn't interpret the outcomes of the result.

In the result section, it has been possible to understand the mothers' opinions by content analysis, where some categories have been found. Under the different categories, mothers' different opinions are expressed by different codes. Five major categories were found these are: mothers' understanding of the toilet education program, mothers' learning from the toilet education program, importance of the program to mothers' of children with CP, utilization of learning from toilet education program after returning home and suggestions for the toilet education program. Under these categories four themes emerged which are as follows:

4.1 Findings at a glance

Theme-1: Mothers of children with CP understand all the information clearly and satisfactorily.

Theme-2: Mothers of children with CP addressed that the toilet education program enhanced their knowledge about toileting problem and its management.

Theme-3: Mothers thought that toilet education program is very important for them and their children with CP.

Theme-4: Mothers will utilize their learning from toilet education program in their home environment for their children with CP.

Theme-5: Mothers suggest that to use booklet and showing the toilet training techniques by using video clip in a small group is better to make information easy to remember and program more valuable.

4.2. Discussion

Below there is the description of the theme according to its category and coding. For details about the categories and codes of the study, please see the appendix 6- 6.1, 6.2, 6.3, 6.4, and 6.5.

Theme-1: Mothers of children with cerebral palsy understand all the information clearly and satisfactorily.

(Emerged from category-1, for details please see the appendix 6-6.1)

Occupational therapists designed the toilet education program to improve mother's knowledge by providing education about how mothers can facilitate their children with CP in using toilet alone or with modification. One of the objectives of the study was to find the understanding from toilet education program. Investigator graded this category (understanding of information) into a five point measure scale: very clearly, clearly, satisfactorily, not clearly, and can't understand anything. During the interviews, the most participants claimed that they have clear understanding all the information presented in the toilet education program and only two participants reported that they understood satisfactorily all the information presented in the toilet education program. In interview one participant said-

"I understood clearly all information from the toilet education program"

Occupational therapists use pictures of different modified toilets and also demonstrate practical use of modified toilet for educating participants. Literature suggested that different people understand information in different ways. Some people understand information when it is written down; others understand better when it is explained verbally or demonstrated practically.(51) Another participant said:

"I could understand all the information satisfactorily from toilet education program"

Therapists provide information in such language that is easy to understand for participants. Therapists try to provide information by using local terms as much as possible. It is also discussed in literature that professionals should begin with positive points and then explain problem and deficit and avoid using technical terms. If they use technical terms then it should be explained in ways that everyone understands.(52) Occupational therapists teach the mothers of children with CP about different easy ways of toileting in toilet education program in local language without using technical term and in such a way by using various techniques, demonstration, verbal instruction, practical session etc. Therefore, mothers can understand provided information during the educational program without facing difficulty.

Theme-2: Mothers of children with cerebral palsy addressed that the toilet education program enhanced their knowledge about toileting problem and its management.

(Emerged from category-2, for details please see the appendix 6-6.2)

Occupational therapist worked with family members to support the needs and goals of the parents during therapy. From toilet education program, mothers can learn so many easy ways or techniques of toileting that are beneficial for them when handling their children with CP. Most of the participants have learned much new information about toileting. They have learned different things from toilet education program, they mentioned that they have learned proper toilet sitting position, how to make proper habit of toileting, how to make different modified toilet, how to provide additional support of toileting, different way of hygiene after toileting etc. One participant said:

“I have learnt much new information, before join in the class I have no idea about this. Now I am knowledgeable about the problem of my child and how to solve this problem”

Another participant said that she has learnt how to solve her child’s problem related with toileting and has got much new information. Occupational therapists provide information for mothers related to handling their children with CP. In one studies, it is suggested that parents’ needs and goals should be supported by therapy services which can be beneficial for parents.(53)

To meeting mothers’ needs at the start of program, occupational therapists discuss different type of problem related with toileting which are common in children with CP. Then therapists show squatting position practically with children with CP. All participants reported that they have learnt proper toilet sitting position or squatting position after completing both toilet education classes. One participant said:

“I have learnt how to sit my child in toilet sitting position and benefit of toilet sitting position”

Another participant said that she has learnt how to help her child practice squatting position or toilet sitting position. Squatting position is necessary for performing

toileting activity, as it is suggested that, with handicapped children: choosing a position which enables them to use the toilet with minimum or no help is very important. If one can start seating child correctly from the beginning, it will be easier to teach him to use the toilet.(30)

Besides toilet sitting practice, habituation is very important for performing activities of daily living. Children become proficient at the role of self-care when they can perform ADL tasks automatically and do them habitually.(13) During observation of the toilet education program, the investigator found that therapists teach ways how to create an appropriate routine or habit for toileting. Therapist discussed that after feeding in the morning; mothers should take her child at toilet and wait for 10 min for toileting. One participant said like-

“Therapist said after feeding we should bring our child in toilet in a particular time everyday and remember the timing of toileting. Then by practicing it will be a habit of our child for toileting in a particular time”

Literature also suggested that, before beginning toilet training mother should notice at what times over several days the child toilet. Begin to put child on the pot or latrine about 15 - 30 minutes after one meal is finished, the child is placed on the toilet for 15 to 30 minutes. Choose either breakfast or dinner and stick with it, since the point of a bowel training program is to train the child to produce a bowel movement at the same time every day or every other day.(54)

As occupational therapists main focus is to enable the child to be independent in activities of daily living. To become independent in toileting Occupational Therapist use many additional supports in toileting such as grab rail, ring, and cloth etc. If a child has sitting ability or need minimum support in sitting then above additional support can be used. After completing both toilet education classes one participant said-

“I have learnt how to provide additional support such as using a bamboo in front of child in toilet and child can hold this bamboo for support in toileting”

Another participant said that she has learnt how to provide support in high commode such as a foot rest which can be used for foot support and a hand rail can be used for hand support. Literature prefers that if a house has an Asian toilet and child has a

problem squatting over it, one may attach a rail on the side wall so that child can hold on to it and squat safely and comfortably. If toileting area is out in the open, one can fix a bamboo pole into the ground to be used as support to hold bamboo. If a house has western type toilet, one can attach a bar on the side wall to assist child to get on and off the seat and hold steady while sitting. If child's feet are not flat on the floor, then put a low stool for him to rest on.(30)

In addition, with support different types of adaptation and modification are needed for children with CP. Occupational therapists also discuss different types of modified toilets and how mothers can develop modified toilet with local materials. Therapists also teach ways of making a modified toilet more stable. All participants reported that they have learnt how to make different modified toilet for their children with CP. Among them one participant said:

“There are many toilet chairs which are available in market. We can also make this at home by using an old wooden chair and cut a hole on the seat and place a bucket or tin under it.”

Another participant said that she has learnt how to make toilet chair such as she can make a hole on the centre of a chair and hole should be large enough for washing by hand and then the toilet chair can place upon Asian toilet. Literature suggested that so many handicapped children can be helped to become independent in their toileting if special aids or adaptations are made. Different children will require different adaptations.(55) By this way child who are unable to sit or need more support for sitting can easily perform toilet.

At the ending of the toilet education program, occupational therapists discuss personal hygiene after toileting. Hygiene after toileting is very important for good health. After completing toilet education class, mothers become knowledgeable how to help child in washing hands and cleaning self. One participant also said-

“I have also learnt about cleaning after toileting, equipment for cleaning need to be placed within child's reachable area and child can easily take and use after toileting.”

Another participant said that she can arrange a bucket of water near the child during toileting to give an opportunity of self washing. It is also discussed in literature that

many handicapped children find it as a problem to wash themselves after using the toilet.(30) In order to become as independent as possible, it is important that we start teaching the child to wash himself as early as possible. Young children need help in cleaning themselves after using the toilet. But allow child to participate in the washing is also important.(30)

For achieving above activities related with toileting, encouragement plays an important role to participation of all activity. Occupational therapists also discuss about how to encourage a child in toilet training. Like other children, the children with CP should be encouraged from an early age to help them in toileting. If children with CP become failure to perform toileting, then mother should not be disappointed they should train child with encouragement and praise. One participant said:

“Occupational therapist advised to encourage the child; I should praise child by clapping hands or giving a kiss or saying you are a good boy or girl.”

Literatures suggest that Positive reinforcement should be given for any output into the toilet and also dry diapers. Use simple descriptive common words to describe the desired activity.(56) As well as, encourage the children when they perform any activity and give them lots of praise for every achievement.

Theme-3: Mothers thought that toilet education program is very important for them and their children with cerebral palsy.

(Emerged from category-3, for details please see the appendix 6-6.3)

Most of participants said toilet education program is very important for them and their child for proper handling of children with CP in toileting. From this program, mothers learn many techniques that they can teach their child at home. If they do not attend this program, they could not learn the techniques or not be able to teach their child correct techniques. One participant said:

“Yes, these learning are very important for my child.”

A study was done to evaluate service provision to young children with cerebral palsy in Bangladesh. This study was conducted using randomized controlled trial design;

they had conducted this study on 85 children with their mothers. They had conducted a training program of parents of children with CP. In this training, they provided health advice with minimal intervention, handling techniques etc. In the result of the study, it was seen that 58 children were successfully followed up. Researcher found that this program increase maternal knowledge and skills in handling their children with CP.(57) One more study related to the effectiveness of self-care training (dressing) by occupational therapists on five children with CP showed that four children improved their ability to dress, and three of them needed more time to dress after ten weeks of occupational therapy intervention.(58) In another study, it was shown there was significant change in function of children with CP and parent satisfaction after an occupational therapy health program.(59)

Toilet education program is very important for mothers and children with CP, because mothers gain knowledge about toilet training techniques that are important for their child to become independent in toileting, helpful for maintaining child's privacy and adjustment with society. Also mothers feel less stress for their children with CP. One participant said:

“This program is very important because, if I do not know proper technique then what I will teach my child and this information were unknown to me before coming here.”

Caregiver education is an important part of all therapy for children because this education helps the caregiver and parent to learn specific techniques.(28) Education is also a basic need of caregiver and occupational therapists are working to meet the need. It was also found in a study that occupational therapists have the responsibility to ensure the need of caregivers and children with disabilities are addressed during intervention.(60)

This program is also important for making the children with CP independent in toileting as much as possible. One participant said –

“Very important because, my child is growing day by day and I want she will complete her toileting by herself. I think if I can teach my child properly then she will be able to toilet without my help.”

Literature also supports that independent toileting is an important aspect of a child's overall development that allows him to maintain independence and dignity.(31)

Toilet education program is also important for maintaining privacy. Privacy issue is equal for all humans; whether he or she is child or adult.(55) It is also necessary for children with CP because sometimes mothers are not aware about child's privacy. They cannot understand that it is also necessary to maintain privacy of children with CP. After toilet education class one participant said:

“My child has disability and she cannot go to toilet alone as she is growing up, it will be discomfoting for her if I stay beside her during toileting. So, teach proper toileting technique is important for her.”

It is also suggested in literature, as the disabled child grows, he/she will fell the same need of privacy as any child would for toileting and other personal acts. Help the child to obtain the privacy he/she needs.(55)

Toilet education program also plays an important role in personal hygiene as well as social acceptance. It is very important for child psychosocial development. If a child cannot maintain personal hygiene, then his peer may disallow him in play or interacting with them. One participant said-

“Everyone hates my child for his disability. If my child will toilet here and there he will look dirty and everyone hates him more and society do not allow him any gathering. If I teach him clean and wash after toileting that I learn from class, he will maintain his personal hygiene. So, this class is very important for my child.”

Literature also suggests that; independent toileting is often a requirement for schooling and peer interaction.(31) If the child has poor toilet hygiene, he may be ridiculed by his peers. And it is also necessary for the child's social acceptance.(31)

If the child becomes independent in toileting and can maintain his or her own hygiene and privacy, mother becomes stress free with the child. In Bangladesh mothers are the primary caregiver of children with CP. Mothers lead more stressful life than other family members. They also face various physical problems due to poor handling skills such as stress in back, neck etc. One participant said with satisfaction about the importance of the program-

“I think this program is important for my child. Because now I do his work but he would be older in future. Then it will be more stressful for me to do his activity. If I practice this technique from now she will be able to do his work as well as my stress will be reduced in future.”

Literature also supports this, occupational therapists need to show caregivers how to handle or carry a child in a way that will help him develop the best possible control over his body, and prevent caregiver back strain or injury.(61) Parents may require support and respite, as well as education, to care for the child with CP and to meet the needs of the family as a whole.(62)

Theme-4: Mothers will utilize their learning from toilet education program in their home environment for their children with cerebral palsy.

(Emerged from category-4, for details please see the appendix 6-6.4)

Learning will be fulfilled when mothers utilize these learning at home for their children with CP that is the aim of toilet education program. Occupational therapists also expect this from mothers and according to their expectation all participants claimed that they will use these learning at home for their children with CP. Different participants will use their learning in different ways these are: practicing proper toilet sitting, providing additional support for stability, using modified toilet chair, practicing hygiene etc. As it is discussed in literature that a program will be valuable when participants give importance to it and do it in a meaningful way.(63)

Practice is an important thing to become success at any work. During practicing any activity, mothers need to give some extra time to learn techniques to the child. The mother was unknown about the information of how to practice a child toileting activity. After learning this information from this program, they said they will use these learning by practicing at home with their children with CP. One participant said:

“At first I will practice my child proper toilet sitting which called squatting position and then I will make a comfortable modified toilet chair for my child.”

As it is discussed in literature, practice is necessary for a child to improve his performance. So it is essential to give opportunity to the child to practice. In the beginning, child will need extra time to learn. So, mothers have to choose a time for practicing when they are not in hurry and child can practice easily.(30)

Most participants said they will provide some additional supports for toileting in their village toilet. Among them one participant said:

“I can use these learning by two ways, one is tying cloth in two sides for support or another way is using a bamboo in front of my child. So that, he can hold the bamboo and it will provide additional support.”

Some participants reported in their interview that, they will buy a modified toilet chair which is available in the market. One participant said:

“I will buy a toilet chair in front of this hospital which will be most suitable for my child. I will place a bucket under the chair.”

It has been also found in the literature that many physically disabled children are greatly advantaged by properly fitting and supportive seating.(61) If caregivers implement techniques properly at home, they may get the improvement. However, it needs continuous effort of caregivers. Value of a program depends on how they will use this learning at home and how much it will promote child development in activities of daily living. Literature also supports that those services are highly valuable to the caregivers that promotes their child’s development. This is very natural that caregivers found this service satisfactory as it promotes child’s development in toileting.(64)

Theme-5: Mothers suggest that to use booklet and showing the toilet training technique by using video clip in a small group is better to make information easy to remember and program more valuable.

(Emerged from category-5, for details please see the appendix 6-6.5)

After taking opinions from participants about toilet education program, the investigator found that occupational therapists use flashcard of different technique of toileting and different modified toilet, demonstrating a modified toilet chair etc.

Mothers can understand information clearly and all participants said that provided information is enough for their children with CP but it is very difficult to remember all information. Therefore, they provided some suggestions about program such as increase duration of class, giving booklet which mothers will take at home, and showing video clip instead of only using flashcard, provide education in small group etc. One participant said-

“It will be easier if the picture, flash card or some information is given us in a form of a booklet which we can bring at home with us. We can also show this to our family member it will also helpful for our support when family members will be knowledgeable about this information.”

It is also found in literature that booklets are a highly valued and successful way for parents to keep important information and to have a regular, reliable method for expressing concern to the therapist and other team members.(52)

In interviews, most participants provided suggestions to improve the program such as to use video or by showing television. Participant said that it is very hard to see one picture with all members. Other participant said:

“I think provided information is very important for us but remember all information is so hard. If we can see the information by video then it will be easier to remember.”

Literature also supports that video tapes are helpful for parents to learn particular handling skills, to teach them new techniques and to remember it for a long time. It is also preferable that to teach the parent handling and positioning skills by using video tape might be an effective way.(52)

During interview the participants reported that they sit together in a room. For this reason, some participant sit near the therapist and some sit further back. Therapist used picture to show the handling technique of toileting. Therapists provide lots of information at a time in a large group. It will be more helpful if therapists provide information in a small group. One participant said:

“If the information is provided in a small group then it will be more helpful to understand and remember all information easily.”

Another study related to mothers’ perceptions about home treatment of occupational therapy found mothers become overwhelmed when occupational therapists provide lots of information in a large group.(65)

5.1. Limitation of the study

Investigator has tried to follow best systematic way to conduct the study. Through searching information from different source such as manual searching on BHPI library, online database such as pub med, Hinari, Google scholar, Google, OT Seeker etc., it has been seen that there was no study has been conducted related to toilet education program in Bangladesh. For more specification, investigator searched on above all source by related key points with this study these are CP and ADL, parental education, parental perception about ADL training, self-care training, occupational therapy role in self-care training, mother's perception about occupational therapy intervention, etc. Then investigator found some information related to this study on global perspective. Therefore, investigator had tried best to relate this study with that information. As there is no available related study in Bangladesh or in similar context, so it was not possible to compare the study findings with other study.

5.2. Recommendation

After completing the study, the investigator found some recommendations like professionals can make the toilet education program more structured and resourceful by educating in a small group; can show the toilet training techniques by using video clip according to mothers' need. Mothers can remember information easily if it is possible to show toilet sitting and toilet modification techniques by using video clip. A booklet on toilet training strategies for children with CP can be provided to the mothers or caregivers after toileting class. Mother or primary caregiver can show the techniques to their husband and other family members. The family members can help mother during toilet training of their children with CP in developing appropriate toileting habits.

It will be better if it is possible to conduct the same study by using different method and also a large number of participants. Further study can be done about effectiveness of this toilet education program.

5.2. Conclusion

Cerebral Palsy is the most common condition that is responsible for disability and often affects a child's ability to perform self-care independently. For this reason, children with CP often depend on their mother for toileting. Therefore, occupational therapists run a toilet education program as a part of occupational therapy intervention to educate mothers on how they can help their children with CP.

The study has been conducted to find out mothers' perception about the toilet education program for their children with CP in the inpatient program of CRP paediatric unit. From the result of the study, it is found that mothers have a clear understanding about toilet education program. It was also found that mothers feel toilet education program is very important for their child and they will use these learning at home. It is also true that some mother understood provided information not very clearly and could not remember provided all information. That's why they provided some suggestions for further improvement of toilet education program. Suggestions were: increase duration of class, giving a booklet which mothers will take at home, and showing video clip instead of only flashcard, provide education in small group.

So, this study may be helpful for the occupational therapist to find strength and limitation of the toilet education program and find out some efficient strategies to make the program more effective and valuable for children with CP.

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According to Vancouver referencing style in EndNote X4

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Appendix-1: Permission letter for conducting study

Date: August 12, 2012

To

The Course Coordinator,
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralyzed (CRP)
Chapain, Savar, Dhaka-1343

Subject: Prayer for seeking permission to conduct the research project.

Sir,

With due respect and humble submission I beg most respectfully to state that I am a student of 4th year of B. Sc. In Occupational Therapy course of Bangladesh Health Professions Institute, the academic institute of (CRP). I am sincerely seeking permission to conduct my research project as it is the fulfillment of the requirements of degree of B. Sc in Occupational Therapy. The title of my research is- "The perception of mothers of children with Cerebral Palsy (CP) about the toilet education programme at inpatient pediatric unit of CRP, Savar, Dhaka" The aim of the study is to explore the mother's perception about toilet education program for their CP child in indoor program CRP pediatric unit, Savar.

So, I therefore, pray and hope that you would be kind enough to grant me the permission of conducting the research and which will help me to complete a successful study as a part of my course.

Your most obedient pupil,

Airen Akter

12.08.12

Airen Akter

4th year, Roll-10, Session: 2008-09,

B. Sc. in Occupational Therapy

Department of Occupational Therapy

Bangladesh Health Professions Institute (BHPI)

CRP-Chapain, Savar, Dhaka-1343

Approved by	Comments and Signature
Course Coordinator Mohammad Mosayed Ullah Assistant Professor and Course Coordinator Department of Occupational Therapy BHPI, CRP-Chapain, Savar, Dhaka	<p><i>This project may be permitted with due process of data collection of CRP. Good luck with the project.</i></p> <p style="text-align: right;"><i>Mosayed Ullah</i> 12.08.12</p>
Research Supervisor Shamima Akter Lecturer Department of Occupational Therapy BHPI, CRP-Chapain, Savar, Dhaka-1343.	<p><i>Good luck with your project</i></p> <p style="text-align: right;"><i>Shamima Akter</i> 12.08.12</p>

Mohammad Mosayed Ullah
Course Coordinator &
Dept of Occupational
Therapy, CRP Savar, Dhaka

Appendix-2: Permission letter for data collection

Date: 30.09.2012

To
The In-Charge
Paediatric Unit
Centre for the Rehabilitation of the Paralyzed (CRP)
Chapain, Savar, Dhaka-1343

Subject: Prayer for seeking permission to collect data from pediatric unit, CRP.

Madam,

I beg most respectfully to state that, I am a student of 4th year occupational therapy department of Bangladesh Health Professions Institute (BHPI). I am interested to conduct a qualitative study on paediatric unit. My research title is "Perception of mothers of children with Cerebral Palsy (CP) about the toilet education programme at inpatient pediatric unit of CRP, Savar, Dhaka." The aim of the study is to find out mother's perception about the toilet education programme for their Child with CP in the inpatient programme of CRP paediatric unit, Savar, Dhaka. Mothers of children with cerebral palsy who completed both toilet education classes are the participants of my research project. Now I am looking for your kind approval to start my data collection and I would like to assure that anything of my research period will not be harmful for the participants and also for the pediatric unit. Informed consent will be filled up by the mother for their ethical consideration.

So, I therefore, pray and hope that you would be kind enough to grant me the permission of collecting the data and will help me to conduct a successful study as a part of my course.

I remain madam,
Airen Akter
30-09-2012
Airen Akter
4th year, B. Sc. in Occupational Therapy
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP-Chapain, Savar, Dhaka-1343

*She is permitted for
data collection
Please help her
Thanks
30-09*

Appendix-3: Details about toilet education program

Personal communication document with in-charge of Occupational Therapy pediatric unit, CRP, Savar, Dhaka

Occupational Therapy

In-charge of Pediatric unit, CRP, Savar

Date: 08-08-12

Toilet Education Programme

Occupational therapists are worked with mother of children with cerebral palsy (CP) to improve mothers' knowledge by providing education about mothers can facilitate their children with cerebral palsy in using toilet alone or with modification. Therefore occupational therapist runs toilet education programme/class on every Wednesday from 12.30-01.00 pm (30 min) every week. Toilet education program is a 2 session's program. Primary caregiver and her child with CP attend in this program. In this class all the caregiver and children sit together in a group who has common problem and therapist run the program through demonstration, discussion, showing picture and answering the caregiver's question. The program is run in a group to increase the group interaction, motivation, sharing and encouragement among children and caregiver.

The aim of the toilet education programme is to educate the mother to make their child maximum independence in toileting. To achieve this aim occupational therapists work with some objectives. The objectives of toilet education program are to provide basic education to mother about importance of independent toileting, to make the mother better understand about how they can help their child according to child physical status, to educate mother different position of toileting, how to engage and encourage child in self toileting, how to make schedule for developing good habit of toileting, also to educate mother about how to make different modified toilet seat by local materials, to encourage the mother to implement and continue these learning at home and also educate other family member to maximize child's ability in toileting.

The total content of toilet education programme is to discuss and describe about purpose of toileting class and importance of independence in toileting specially privacy issue for the older and adolescent with children with CP. The therapist also address caregiver needs as the child

St. M. P.
08/08/12

becomes heavier and more difficult to assist with toileting. Therapist is discussed different type of problem which may have children with CP according to body involvement and different positioning of toileting by showing model of doll. How mother can help their children with CP on developing proper habit of toileting in a specific place and specific time every day is also discussed and educates how mother can encourage her child in bladder management. Different ways to communicate with their children and ways to provide feedback during toileting and personal hygiene after toileting is discussed. Positioning of toileting is also discussed. According to child sitting ability different type of modified toilet chair and ways of making different modified chair in rural and urban area by local materials is also discussed by showing picture, practical use of a modified toilet chair and this is the major portion of the class. Therapist also teaches ways of providing additional support such as grab rail, using bamboo for support in normal toilet. How child with CP can easily access the hygiene utensils after toileting is also discussed. In 1st class therapist completes primary discussion about toileting, showing model of different position of toileting, showing picture of different modified toilet and then in the 2nd class therapist complete rest of content of the class such as practical demonstration of toilet sitting, and then takes few superficial feedback for few minutes from mothers and if respondents do any mistake or are unable to perform proper technique, therapist correct this. Therapist also discuss about the problems of their child which are identified by the mothers after first class. At the end therapist review some key point of information of both classes.

Therapists provide some suggestion for teach the child about toileting in toilet education class these are following below:

- Make a list about how many times the child go in toilet in a day or 1 week.
- Make an idea from the list that how many times the child in toilet. Next keep the child in toilet and encourage to toilet. Make habits to keep the child in toilet after wake up from sleep.
- If child cannot want to go in toilet then shout with child and tell him that's it bad habit.
- Teach sign language before going to toilet may use flash chart.
- Encourage child to go to toilet own self.

San. M.D.
08/08/12

Therapist teaches different position for using toilet in toilet education class these are following below:

- Use local materials to make toilet seat. Using it by making a hole and keep bucket under the hole.
- If the child has poor balance, make tie with chair with long cloths.
- Hand rail can be adjusted beside the commode.
- If need to do toilet in outside, then make in outside of the home.
- In case of high commode, a footrest can be used to place the child feet.
- A wheelchair can be placed over the commode by pushing the wheelchair.
- Teach the child how to wash himself after toileting.

*Above information
collected with my
career.*

*Bu. M. D.
08/08/12*

Appendix-4: Information sheet, consent form and questionnaire in Bangla

Appendix-4.1: তথ্য পত্র

আমি আইরিন আক্তার, বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) এর ছাত্রী যা পক্ষাঘাতগ্রস্থদের পুনর্বাসন কেন্দ্র (সিআরপি) এর একটি শিক্ষা প্রতিষ্ঠান। আমি অকুপেশনাল থেরাপী বিভাগের বি.এস.সি. ইন অকুপেশনাল থেরাপীর ৪র্থ বর্ষে অধ্যয়নরত আছি। এই কোর্সের অংশ হিসাবে চূড়ান্ত বর্ষে আবশ্যিকভাবে একটি গবেষণা কর্ম সম্পন্ন করতে হয়। আমি আপনাকে এই গবেষণায় অংশগ্রহণ করার জন্য আমন্ত্রণ করছি। গবেষণার বিষয় হচ্ছে “শিশু সেবা অন্তঃবিভাগ, সিআরপি, সাভার, ঢাকা এর টয়লেট শিক্ষা ক্লাশ সম্পর্কে সেরিব্রাল পাল্‌সি বাচ্চাদের মায়েদের ধারণা”। এই গবেষণার উদ্দেশ্য হলো টয়লেট শিক্ষা ক্লাশ সম্পর্কে সেরিব্রাল পাল্‌সি বাচ্চাদের মায়েদের ধারণা কিরূপ তা জানতে পারা।

এই গবেষণায় অংশগ্রহণ সম্পূর্ণ আপনার ইচ্ছাকৃত। আপনি যে কোন সময় আপনার অংশগ্রহণ প্রত্যাহার করতে পারবেন। ইহা আপনার শিশুর চিকিৎসা সেবায় কোনরূপ ব্যাঘাত ঘটাবে না। গবেষণায় অংশগ্রহণের জন্য কোন উপহারের ব্যবস্থা নেই। আপনি এবং আপনার শিশু গবেষণা থেকে সরাসরি উপকৃত নাও হতে পারেন। তবে গবেষণা থেকে প্রাপ্ত ফলাফল কর্তৃপক্ষকে তাদের ক্লাশ সম্পর্কে আপনার ধারণা জানতে সাহায্য করবে।

গবেষণার সাথে সম্পর্ক যুক্ত কিছু প্রশ্ন নিয়ে আপনার একটি সাক্ষাৎকার নেয়া হবে যা অডিও টেপ দ্বারা সংরক্ষণ করা হবে। আপনার কাছ থেকে প্রাপ্ত তথ্য গোপনীয়তার সাথে রাখা হবে, শুধু গবেষক এবং তার তত্ত্বাবধায়ক তথ্য গুলো ব্যবহার করতে পারবেন। আপনার এবং আপনার শিশুর পরিচয় গবেষণার কোথাও প্রকাশ করা হবে না। গবেষণা সংক্রান্ত আপনার যদি কোন রূপ প্রশ্ন থাকে তাহলে আমাকে দ্বিধাহীনভাবে জিজ্ঞাসা করতে পারেন। গবেষণা বিষয়ক সকল প্রশ্নের উত্তর দেবার জন্য আমি সচেষ্ট থাকব।

আইরিন আক্তার

বি.এস.সি. ইন অকুপেশনাল থেরাপী

অকুপেশনাল থেরাপী বিভাগ

বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩।

Appendix-4.2: সম্মতিপত্র

অংশগ্রহণকারীর জন্য:

দয়া করে নিচের তথ্য গুলো পড়ে হ্যাঁ অথবা না তে টিক () দিন। নিম্নলিখিত তথ্য গুলো প্রকাশ করবে আপনি এই পত্রের তথ্যগুলো বুঝতে পেরেছেন এবং উপরের গবেষণায় আপনার অংশগ্রহণের মতামত।

১. আমি নিশ্চিত করছি যে আমি গবেষণার তথ্য পত্রটি পড়েছি এবং

বুঝতে পেরেছি অথবা তথ্য পত্রটি আমার কাছে ব্যাখ্যা করা হয়েছে

এবং আমার প্রশ্ন করার সুযোগ আছে।-----হ্যাঁ / না

২. আমি এই গবেষণা বিষয়ক সকল প্রশ্নের সন্তোষজনক উত্তর পেয়েছি।-----হ্যাঁ / না

৩. আমি বুঝতে পেরেছি যে গবেষণায় অংশগ্রহণ সম্পূর্ণ ঐচ্ছিক এবং যে

কোন সময় অংশগ্রহণ প্রত্যাহার করতে পারব কারণ পরবর্তীতে তথ্যগুলো

নষ্ট করে দেয়া হবে।-----হ্যাঁ / না

৪. প্রশ্নমালা এবং সাক্ষাৎকার থেকে গবেষক কর্তৃক সংগৃহীত তথ্য তত্ত্বাবধায়ক

দ্বারা নিরীক্ষণ করা হবে। ব্যক্তিগত তথ্য অত্যধিক গোপনীয় থাকবে।

আমি গবেষক ও তত্ত্বাবধায়ককে আমার তথ্য জানার অনুমতি প্রদান করছি।-----হ্যাঁ / না

৫. অংশগ্রহণের ব্যাপারে সিদ্ধান্ত নেয়ার জন্য আমি পর্যাপ্ত সময় পেয়েছি।-----হ্যাঁ / না

৬. আমার সাক্ষাৎকার থেকে প্রাপ্ত তথ্যাদি গবেষণায় ব্যবহারের ক্ষেত্রে আমি রাজি।-----হ্যাঁ / না

৭. আমি গবেষণায় অংশগ্রহণ করতে রাজি।-----হ্যাঁ / না

অংশগ্রহণকারীর স্বাক্ষর.....তারিখ.....

গবেষক: আমি উপরের অংশগ্রহণকারীকে গবেষণা সম্পর্কে প্রয়োজনীয় বিবরণ দিয়েছি এবং

অংশগ্রহণকারী স্বেচ্ছায় গবেষণায় অংশগ্রহণের মতপ্রকাশ করেছেন।

গবেষকের স্বাক্ষর.....তারিখ.....

Appendix-4.3: প্রশ্ন পত্র

কোড নং:

টয়লেট শিক্ষা ক্লাশে অংশগ্রহণ করেছেন: হ্যাঁ / না

উভয় ক্লাশ পূর্ণ করেছেন: হ্যাঁ / না

১। আপনি কি টয়লেট শিক্ষা ক্লাশের সব তথ্যাবলী বুঝতে পেরেছেন-

ক. খুব ভালভাবে খ. ভালভাবে গ.মোটামুটি ঘ.খারাপভাবে ঙ. একদম বুঝি নাই

২। দয়া করে বর্ণনা করে বলুন আপনি টয়লেট শিক্ষা ক্লাশ থেকে কি কি শিখেছেন।

৩। আপনি কি মনে করেন এই শিক্ষাগুলো আপনার বাচ্চার জন্য-

ক.খুব দরকারি খ. দরকারি গ.মোটামুটি ঘ.না করলেও হয়

ঙ.পুরো সময় অপচয়

(দয়াকরে আপনার উত্তরের সপক্ষে বুঝিয়ে বলুন)।

৪। আপনি কি মনে করেন এই শিক্ষাগুলো বাড়িতে গিয়ে আপনার শিশুর ক্ষেত্রে ব্যবহার করতে পারবেন? হ্যাঁ/ না, যদি করেন তাহলে কি ভাবে করবেন এবং যদি না করেন তাহলে কেন করবেন না দয়া করে বুঝিয়ে বলুন।

৫। আপনি কি মনে করেন ক্লাশে প্রদত্ত তথ্যাবলী যথেষ্ট? হ্যাঁ/ না, টয়লেট শিক্ষা ক্লাশ সম্পর্কে আপনার উপদেশ থাকলে দয়া করে বর্ণনা করে বলুন।

Appendix-5: English translated copy of information sheet, consent form and questionnaire

Appendix 5.1: Information Sheet

I am Airen Akter, student of the Bangladesh Health Professions Institute (BHPI) which is the academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka. I am studying B.Sc. in Occupational Therapy, (4 year course) under the Occupational Therapy department of BHPI. In regards to the fulfillment of B.Sc. Degree, it is mandatory to conduct a research in final or 4th year of study. I would like to invite you to take part in my research study, and the title “Perception of mothers of children with Cerebral Palsy (CP) about the toilet education program at inpatient paediatric unit of CRP, Savar, Dhaka” The aim of the study is to find out mothers’ perceptions about the toilet education program for their children with CP in the indoor CRP paediatric unit, Savar.

It is up to you whether or not you want to participate in this study. If you do not wish to take part then there is an opportunity to withdraw your participation at any time. This will not hamper access to services and will not affect the treatment of your child. There is no incentive for participation in the study. May be there is no direct benefit for you and your child at present. However, it is very important to know your thinking, understanding and learning from the toilet education class for acknowledgement of the positive side or any aspects lacking in this class.

An interview will be conducted with some questions regarding the study that will be recorded by tape recorder. Confidentiality of all records will be highly maintained and all details will be kept on a confidential database that is only accessible to me and my supervisor. The identity of you and your child will not be disclosed in any presentation or publication without your agreement. If you have any queries now regarding this study please feel free to ask. I am accountable to answer all questions regarding this study.

Airen Akter

B Sc. in Occupational Therapy

Department of Occupational Therapy

BHPI, CRP-Chapain, Savar, Dhaka-1343

Appendix-5.2: Consent Form

For mothers taking part in interviews

Please read the following statements and put tik () on yes or no to say that you understand the content of the information sheet, your involvement, and that you agree to take part in the above named study.

1. I confirm that I have read and understood the information sheet for the study or that it has been explained to me and I have had the opportunity to ask questions.-----Yes / No
2. I have satisfactory answers to my questions regarding with this study.-----Yes / No
3. I understand that participation in the study is voluntary and that I am free to end my involvement at any time, or request that the data collected in the study be destroyed without giving a reason.-----Yes / No
4. Information from interview and questionnaire, those will be collected by the investigator might be examined by research supervisor. However, all personal details will be treated as highly confidential. I have permitted the investigator and supervisor to access my recorded information.-----Yes / No
5. I have sufficient time to come to my decision about participation-----Yes / No
6. I agree for quotations from my interviews to be used in the above study----Yes / No
7. I agree to take part in the above study-----Yes / No

Participant's signature_____

Date_____

Investigator

I have explained the study to the above participant precisely and he/she has indicated a willingness to take part.

Investigator's signature_____

Date_____

Appendix-5.3: Questionnaire

Code no:

Participated in the toilet education class: Yes/No

Completed or not completed both classes: Yes/No

1. Did you clearly understand the provided information in the toilet education program like:

a) Very clearly b) Clearly c) Satisfactorily d) Not clearly e) Can't understand anything

2. Would you please explain what you have learned from this toilet education program?

3. Do you feel this learning is :

a) Very important b) Important c) Satisfactory d) Not really e) Totally waste of time

(Would you please explain how?)

4. Do you think you can use this learning for your child in your home environment after you return? Yes/No, would you please explain how?

5. Do you think provided information is enough for your child? Yes/No. Is there any further recommendation about toilet education program, please explain?

Appendix-6: Categories and codes of the study

Each table describes the interview findings. The tick was given only for those columns where the mothers spoke about those issues. Here ‘P’ was used for participant.

6.1. Category-1: Mothers’ understanding of the toilet education program

Code	P1	P2	P3	P4	P5	P6
Very clearly						
Clearly	✓		✓	✓	✓	
Satisfactorily		✓				✓
Not clearly						
Can’t understand anything						

Table 1: Understanding of toilet education program

6.2. Category-2: Mothers’ learning from the toilet education program

Code	P1	P2	P3	P4	P5	P6
Learned many new information about toileting		✓		✓		✓
Proper toilet sitting technique	✓	✓	✓	✓	✓	✓
How to create proper habit		✓				✓
Treatment based on child needs/problem	✓	✓	✓			
How to provide support during toileting	✓		✓	✓	✓	✓
Introduce with different modified toilet	✓	✓	✓	✓	✓	✓
Making modified toilet	✓	✓	✓	✓	✓	✓
Way of hygiene after toileting		✓	✓		✓	✓
Encouragement is necessary for child		✓	✓			✓

Table-2: Learning of mothers from toilet education program

6.3. Category-3: Importance of the program to mothers' of children with CP

Code	P1	P2	P3	P4	P5	P6
Very important		✓	✓	✓	✓	
Important	✓					✓
Satisfactorily						
Not really						
Totally waste of time						

Table-3(A): Importance of toilet education program

Code	P1	P2	P3	P4	P5	P6
Being knowledgeable about toilet training technique	✓	✓	✓	✓	✓	
Being independent in toileting	✓	✓	✓	✓	✓	
For maintaining privacy		✓				✓
Help to adjust with society					✓	✓
Reducing stress among mother	✓		✓		✓	

Table-3(B): Why the toilet education program is important

6.4. Categories-4: Utilization of learning from toilet education program after returning home.

Code	P1	P2	P3	P4	P5	P6
Practicing proper toilet sitting position	✓		✓		✓	✓
Providing additional support for stability	✓	✓		✓	✓	
Using modified toilet chair			✓		✓	
Practicing proper hygiene technique				✓		✓

Table-4: Way of utilization of the learning from toilet education program at home

6.5. Categories-5: Suggestions for the toilet education program

Code	P1	P2	P3	P4	P5	P6
Giving booklet		✓	✓	✓		✓
Showing video clip		✓	✓	✓	✓	
Educating in more small group			✓	✓		
Increase duration of class						✓

Table-5: Suggestions from mothers about toilet education program