QUALITY OF LIFE AMONG MOTHERS WITH DOWN SYNDROME CHILDREN

By

Shahnaz Munny

April, 2019

This thesis is submitted in total fulfillment of the requirements for the subject RESEARCH 2 & 3 and partial fulfillment of the requirements for degree

Bachelor of Science in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
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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 other 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, research supervisor will highly concern and it will be duly acknowledged as undergraduate thesis.

Signature: ______________________ Date: __________________

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Dedication

Dedicated to my honorable & beloved parents, my respected all teachers of Bangladesh Health Professions Institute (BHPI).

Declaration

I am **Shahnaz Munny** declare that, the study will not be harmful for the participant. Then I would like to ensure that all the data and literature were stated correctly. In that case all discussion of this research project is mine and I am only responsible for any mistake in whole study.

Signature

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Shahnaz Munny

4th year, B. Sc. in Occupational Therapy

Session: 2014-15

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WHO	World Health organization
CRP	Centre for the Rehabilitation of the Paralysed
DS	Down Syndrome
QOL	Quality of Life
WHOQOL	World Health Organization Quality of Life
SPSS	Statistical Package for Social Science

Abstract

Background: Down syndrome is the highest general chromosomal condition. The children with Down syndrome (DS) experience delay in their cognitive and physical development which causes difficulties to perform in self work for the DS children. The mothers of children with DS have to provide more care to their children. They face challenges to maintain her position in life. This study is important to know about the quality of life among mothers with DS children.

Objectives: The objectives of this study to identify the social demographic data of mothers with DS children, identify the percentage among physical, social, environmental and psychological and also identify about how effect their quality of life of mothers with Down syndrome children.

Methodology: This cross sectional study was conducted on 31 participants. The participants have taken from three organizations, the William and Marie Taylor Inclusive School, Faith Bangladesh and Dhaka Proyash. The data was collected by using World health Organization Quality of Life (WHOQOL) with face-to-face interview. The data was analyzed by using SPSS.20 (Statistical Package of Social Science).

Result & Discussion: The results of the study about quality of life among mothers with DS are more satisfied in social relationship skill then orderly environmentally, psychologically and last physically. And most of them reported their quality of life & satisfaction about health was medium level. And found that >35 years olds had higher scores in three domains psychological, social relationship. Whose occupation was employed had higher in three domains physical, psychological and environmental domain. In addition, housewife had higher scores in social domain. Participants those monthly income was more than 60000 taka had higher scores in three domains such as psychological, social and environmental.

Conclusion: The study findings reported that these mothers got enough supports from the family rather than the community. This study is important for the Occupational therapist to work with mothers having children with Down syndrome. When Occupational Therapists come to know the difficulties of a mother with her DS child, then they could provide appropriate interventions, for example: recommendations and suggestions to minimize if they have any challenges, and help them to lead a better quality of life.

Key Words: *Down syndrome, Quality of life.*

Appendix at a Glance

CHAPTER 1: INTRODUCTION

1.1 Background

Bangladesh is one of the world's most densely inhabited countries. The population of Bangladesh is about 166.37 million (World Population Prospects, 2018). There is no accurate information or data on the exact number of persons with disabilities in Bangladesh. Bangladesh is high sufficient to competence particular remark in the number of person with disabilities according to World Bank 2004. According to WHO (2011), Worldwide there are 15.3% people are living with different kind of disability. Globally in developing countries 85% of children live with disabilities, but less than 5% receive rehabilitation service (Maloni et al., 2010). The prevalence of disabilities in children under 18 years can be calculated to 6% and for the age group above 18 years the prevalence to about 14% or corresponding to 3.4 million children with disabilities and 10.2 million adults with disabilities (Disability in Bangladesh, 2014). Every year there are a lot of babies born with disabilities, due to various poor conditions of the country, such as poor maternal health care, lack of nutrition and lack of education. The cross sectional study was carried out in Bangladesh Protibondhi foundation and Society for the welfare of the Intellectual disability from august 2014 to March 2015. The analysis showing that age of most of the mothers of children with disability were between 30 and 39 years and the children with disability were their first baby. Radiation of Down syndrome following to the mother age is 1 in 2000 pregnancies for the mothers about age 20 years and 1 in 100 pregnancies for the mothers about 40 years (National Down Syndrome society, 2012). Into 155 respondents, 27 % had autism and 72.9 % had other disabilities like Cerebral palsy, Down syndrome and intellectual disability (Mondol, Foysol & Shikder, 2016). On average, 1 in every 800 children is born with down syndrome and there are 200000 children with down syndrome in Bangladesh. Growth of a child with Down syndrome is more slowly than other children (The Daily star, 2015). According to the Centers for Disease Control and Prevention, approximately 1 in every 700 babies in the United States is born with Down syndrome, tracing Down syndrome is the highest general chromosomal condition. In regard to 6,000 babies with Down syndrome are born in the United States each year (National Down Syndrome society, 2018). There are many conditions of children with disabilities in Bangladesh, such as Autism spectrum disorder, cerebral palsy, Down syndrome, Deaf blindness, Hearing impairment, Intellectual disability, Physical impairment, Speech impairment, Visual impairment and Multiple disability. Down syndrome is the highest common chromosomal disorder. It involved by an error in cell division those results in an extra 21st chromosome. The cause of extra chromosome is still uncouth. Maternal age is the only factor that has been connected to an increased chance of having a child with Down syndrome. Babies and children with Down syndrome experience some lag in all aspects of their development- physical, social, language, play and emotional. They also have some physical features such as low muscle tone which may impact on their development and fine motor and self-care skills. Children with DS learn to sit walk, talk, and play and toilet train and do most other activities later than their peers without Down syndrome (National Down Syndrome Society, 2012). Down syndrome is a genetic disorder that causes life-long intellectual disabilities, developmental delays and other health problems. A few of the common physical traits of Down syndrome are low muscle tone, small investitute, a pointing tilt to the eyes, and a single dense lap across the inside of the claw – if every individual with DS is an equivalent especial and may reflect these nature to different degrees, or not at all. (National Down Syndrome society, 2018). Down syndrome change in severity. It is proposed (Hsiao, 2013) that Down syndrome founts on not only children but also their families**,** particularly in nonwestern countries such as Nazis, Brazil, Iran etc. Families are usually unperformed for the birth of child with DS and for the impact of it will have on their lives. Caring for a child with special needs can be a stressful job for parents. The parents who have children with special needs face challenges to retain balance among work, leisure and activities of daily living (Wayne & Krishnagiri, 2005). Having a child with Down syndrome has a negative effect on a mother's quality of life like physical, social, environmental, and psychological. These mothers dedicated more time to child care and less time to their own health, ADL's, feelings, personal relationship, freedom, safety and social participation. It has mentioned that these mothers of DS children experience symptom of depression. It is very important for a mother to get support from family and community who have a child with special needs (Shelley, Vivian and Nadia, 2009). There are no studies about how mothers with down syndrome children are thinking, feeling, or understanding about their child’s disability or about the challenges they face therefore, this study is to find out the effect on mothers quality of life due to having a child with Down syndrome.

1.2 Justification of the study

This study helps to identify the quality of life of mothers of children with Down syndrome. Mothers of the children with DS face challenges to maintain their position in life within their cultural and value systems, their objectives, expectations and concerns. They give up other roles in society due to their increased responsibilities for child care. Reeja and Sujatha (2013) conducted study in India and mentioned that in comparison with fathers of DS children, mothers spent more time in providing care, offered more types of support and perceived more care giving burden. The behavior and health of the children had a greater effect on mothers than on fathers. An occupational therapist can use this study as evidence of the effect on the mother quality of life with a DS child. When Occupational Therapists come to know the difficulties of a mother with her DS child, then they could provide appropriate interventions, for example: recommendations and suggestions to minimize if they have any challenges, and help them to lead a better quality of life. According to Ramisch et al. (2005) psychological problems such as depression and anxiety disorders are higher among mothers with special needs children. This study can help other professionals such as psychiatrics or counselors to know about the psychological condition of the mothers of the children with Down syndrome through these mothers’ experience of daily life. Mother is the primary or main care giver of a child. If the mothers have negative experiences in their quality of life this must affect their child caring and their daily life. This research study is particularly necessary for occupational therapists so that they could be able to understand the needs and expectation of mothers and how mothers’ daily life and QOL are impacted after having a Down syndrome child. It will also help therapists to provide effective family education to mother and carer by increasing their knowledge about Down syndrome, and changing their attitudes towards Down syndrome. They also arrange an awareness programs for the mothers, and other people in the community. It could also arrange counseling programs which will help to gain a better life for the mothers and their children. This study can help the new mothers with the children with DS to learn about the living conditions of other mothers of DS children, and this study will help them to know how to prepare or cope with it in future.

1.3 Research Question

What is the quality of life of mothers with Down syndrome children?

1.4 Study aim and Specific objectives

Aim:

To identify the quality of life of mothers with Down syndrome children.

Specific objectives:

The specific objectives of this studies are-

1. To identify the socio-demographic data of mothers with Down syndrome children.
2. To identify the overall quality of life & satisfaction of health level among mothers with DS children.
3. To identify the percentage among physical health, psychological health, social relationship and environmental health.
4. To identify the effects of mothers quality of life for Down syndrome children.

1.5 Operational definition

Down syndrome

Down syndrome is a congenital condition characterized especially by developmental delays, usually mild to moderate impairment in cognitive functioning, short stature, upward slanting eyes, and a flattened nasal bridge, broad hands with short fingers, decreased muscle tone, and by trisomy of the human chromosome numbered 21 called also trisomy 21 (Merriam Webster, 2019).

Mothers' with DS children

A mother is the main caregiver of a child. Children with Down syndrome needs more care because a DS child can't maintain his/her own activities as a child without DS. This is why mothers give their most of the time to look after their children with Down syndrome. After spending a lot of time to look after their child and other works they can't maintain their position in life properly. It has been shown that mothers consider the change in their lives that the event or the child with Down syndrome has brought (Joosa and Berthelsen, 2006).

Quality of Life

The WHO defines QOL as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (WHO, 2014).

Individual and societies general wellbeing is known as QOL. It has some context like international development, healthcare, politics and employment. It is consists of some component like wealth and employment, healthy environment, physical and mental health, education, recreation, leisure time and social relationships (Gregory *et al.*2009).

CHAPTER 2: Literature Review

Down syndrome is an ordinary disorder in Bangladesh. There are a number of children with disabilities in Bangladesh. The children with DS are less in proportion than the other disorders such as autism, cerebral palsy, deaf-blindness, hearing impairment, intellectual disability, physical impairment, speech impairment, visual impairment in Bangladesh. There are some effect on the families who have the DS children; specially, the effect on the quality of life of the mothers of DS children. In this chapter the different studies which are related about Down syndrome and the effects on the quality of life of the mothers of DS children has been used as evidence.

2.1 Down syndrome

Down syndrome is a genetic disorder caused when abnormal cell division results in an extra full or partial copy of chromosome 21. This extra genetic material causes the developmental changes and physical features of Down syndrome. Down syndrome varies in severity among individuals, causing lifelong intellectual disability and developmental delays. It's the most common genetic chromosomal disorder and cause of learning disabilities in children. It also commonly causes other medical abnormalities, including heart and gastrointestinal disorders. Better understanding of DS and early interventions can greatly increase the quality of life for children and adults with this disorder and help them live fulfilling lives (National Down syndrome society, 2016). There is no cure for Down syndrome. Education and proper care have been shown to improve quality of life (Roizen & Patternson, 2003). Some children with Down syndrome are educated in typical school classes, while others require more specialized education (National Association for Down syndrome, 2012). Some individuals with Down syndrome graduate from high school, and a few attend post-secondary education. In adulthood, about 20% in the United States do paid work in some capacity, with many requiring a sheltered work environment (National Association for Down syndrome, 2012). Support in financial and legal matters is often needed. Life expectancy is around 50 to 60 years in the developed world with proper health care (Kliegma & Robert, 2011). Each person with Down syndrome is an individual — intellectual and developmental problems may be mild, moderate or severe. Some people are healthy while others have significant health problems such as serious heart defects.

Children and adults with Down syndrome have distinct facial features. Though not all people with Down syndrome have the same features, some of the more common features include: Flattened face, Small head, Short neck, Protruding tongue, Upward slanting eye lids (palpebral fissures), Unusually shaped or small ears, Poor muscle tone, Broad, short hands with a single crease in the palm, Relatively short fingers and small hands and feet, Excessive flexibility, Tiny white spots on the colored part (iris) of the eye called Brushfield's spots, Short height. Infants with Down syndrome may be average size, but typically they grow slowly and remain shorter than other children the same age. Most children with Down syndrome have mild to moderate cognitive impairment. Language is delayed, and both short and long-term memory is affected. (National Down syndrome Society, 2016). Physical development in children with Down syndrome is often slower than development of children without DS. For example, because of poor muscle tone, a child with DS may be slow learn to turn over, sit, stand, and walk. Because of these delays, they can't learn to participate in physical exercise activities like other children.

It may take them longer than other children to reach developmental milestone. Cognitive impairment, problem with thinking and learning, is common in people with DS and usually ranges from mild to moderate. Only rarely is DS associated with sever cognitive impairment (Martin, 2009)

The cause of the extra full or partial chromosome is still unknown. Older mothers are more likely to have a baby affected by Down syndrome than younger mothers. In other words, the prevalence of Down syndrome increases as the mother's age increases. Incidence of Down syndrome 1 in 2000 births when the mothers' age 20 years, 1 in 900 at the age of 30 years, 1 in 600 at the age of 33 years, 1 in 300 at the age of 36 years, 1 in 100 at the age of 40 years and 1 in 30 births at the age of 45 years of the mothers. However, due to higher birth rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age (National Down syndrome Society, 2012). Human cells normally contain 23 pairs of chromosomes. One chromosome in each pair comes from your father, the other from your mother. (Bunt, 2014). Down syndrome results when abnormal cell division involving chromosome 21 occurs. These cell division abnormalities result in an extra partial or full chromosome 21. This extra genetic material is responsible for the characteristic features and developmental problems of Down syndrome. Any one of three genetic variations can cause Down syndrome (Bunt, 2014). About 95 percent of the time, Down syndrome is caused by trisomy 21 — the person has three copies of chromosome 21, instead of the usual two copies, in all cells. This is caused by abnormal cell division during the development of the sperm cell or the egg cell. In this rare form of Down syndrome, a person has only some cells with an extra copy of chromosome 21. This mosaic of normal and abnormal cells is caused by abnormal cell division after fertilization. Down syndrome can also occur when a portion of chromosome 21 becomes attached (translocated) onto another chromosome, before or at conception. These children have the usual two copies of chromosome 21, but they also have additional genetic material from chromosome 21 attached to another chromosome. There are no known behavioral or environmental factors that cause Down syndrome.

2.2 Experience of family's with Down syndrome children

From a family perspective, the relational life of families provides the central ecological context in which children are nurtured (Hodapp, 2007). The family system is influenced by the attributes each individual brings to family relationships as well as by family members' perceptions of those attributes. The birth of a child with Down syndrome is likely to affect the family system in many ways, from the micro level of dyadic interaction to the macro level of the cultural views guiding parent perceptions about a developmental disability. Much research has indicated that a child with Down syndrome has effects on the family (Silverman, 2007). Some effects relate to the likelihood that a child will display the cognitive and behavioral phenotypes considered to be typical of children with Down syndrome. These include specific patterns of strengths and weaknesses in information processing, social interaction, expressive language, receptive skills, motor skills, and motivation (Van Riper, 2007). Such patterns and/or the expectations of such patterns may influence the behavior of caregivers in dyadic interaction with the child. Other effects may be due to increased difficulties and/or diminished satisfactions in the parental role and to parents' reduced opportunities in other spheres of life such as career success (Van Riper, 2007). In contrast, positive effects are possible through the parents' identification of a particular purpose in life, or the development of particular talents that may not have been called upon in other circumstances (Singer GHS, 2006). Parental adaptation to a child with Down syndrome has also been studied extensively in relation to parental well-being, especially the psychological reactions of parents. Many studies on parental adaptation to a child with Down syndrome have focused primarily on stress. The literature is often unclear about the precise meaning of stress. At least three interpretations have been applied to research on parental adaptation. Some authors use stress to refer to the emotional responses of parents to the demands of the parenting role (e.g., feeling isolated, entrapped, overwhelmed with responsibility). Others focus on the demands brought about by the child's temperament and behaviors (e.g., demandingness, soot ability, activity level). A third approach focuses on parental mental health and psychological functioning (e.g., depression, anxiety, self-acceptance, mastery). This latter approach provides more useful data as it is possible for families to face increased demands but to meet these effectively (Abbeduto L, 2004). Clearly, however, parenting responsibilities, child demands and psychological outcomes are related. While there is some evidence that parents of children with Down syndrome experience similar levels of well-being to those experienced by parents of typically developing children (Pisula E, 2007), most studies suggest that parents of children with Down syndrome experience lower levels of well-being than parents of typically developing children of similar age (Pisula E, 2007)). However, it should be noted that, in these studies, the majority of the parents fell into the non-clinical range on instruments measuring psychological functioning (Stoneman Z, 2007). Nevertheless, as Singer pointed out, even mild levels of depression can have detrimental effects on individuals and on their families (Pisula E, 2007). The same association between behavior problems and parental stress is evident in these parents as in other parents of a child with a disability (Hodapp RM, 2003). Generally, however, children with Down syndrome exhibit fewer behavior problems than children with intellectual disability from other causes, although more than typically developing children and siblings. Both the Hauser-Cram and Eisenhower studies reported that the increase in stress levels were related to the increase in child-related demands experienced by parents (Most DE, 2006).

2.3 Experience of Mothers' with Down syndrome children

Mothers are the main career of their children (Aaron J, 2010) mothers of a child with special needs experience difficulty with their children's care. The care of a child with disabilities is a responsibility on the families, mainly the mothers who are affected by this situation**.** The parents do not always have the same views of their families and the issues which cause stress. The needs of fathers have received much less attention than the needs of mothers for the caring of the children with DS. According to (Ramisch J, 2005) having a child with developmental disability has a negative effect on parent functionality and the quality of life among mother more than the father**.** In this study, the quality of life among mothers contains their ADLs, social participation, acceptance from their families and communities and their financial situation due to have the DS children. A quality life is a person's daily activities, experiences, feelings which depend on individual's living environment, work pattern, social environment and surrounded all things (Bookman E, 2007). It also mention that quality of life means wealth and employment, healthy environment, physical and mental health, education, recreation, leisure time and social relationships (Bookman E, 2007). Daily life also contains a person's social environments. Activities of daily livings (ADLs) of an individual contain self-care, productive works and leisure. Mothers of the children with Down syndrome face challenges to perform their daily activities such as their own self-care activities, productive works, and leisure. Because of the physical and cognitive developmental delay the children with DS can't perform their self-activities and they are totally depended on their mothers. It mentioned that raising a child with special needs is challenging for the mothers in maintaining a balance among their position in life (Wayne and Krishnagiri, 2005)

2.4 Quality of Life (QOL)

The World Health Organization (WHO) defines quality of life as the understanding that individuals have of their place in life within their cultural and worth systems, their objectives, expectations and concerns. These changes in the quality of life of parents are outright related to diverse factors, for example acceptance of their child's deficiency, how they received the news, lack of access to fact and changes in daily routines. Individual and societies ordinary wellbeing is known as QOL (WHO, 2014). It has some affection like international development, healthcare, politics and service. It is consists of some part like wealth and employment, healthy environment, physical and mental health, education, recreation, leisure time and social relationships (Gregory *et al,* 2009). Down syndrome children develop slower; parents, therefore, need to commit themselves importantly to foster their development. These children require provoked stimulus and attention in their everyday activities. Such level of care on the part of parents of Down syndrome children aware everyday routines. Thus, functional, structural and emotional changing happen in all family members, particularly in parents related to their quality of life (WHO, 2014). It well-read that quality of life (QL) usually discuss ideas such as health and illness, influenced by transfers on the morbimortality profile, and its relationship to progresses in medical diagnostics and therapeutics (Seidl & Zannon, 2004). They drop out that health and illness are processes that could be cognized as a continuum, and are directly connected to economic and socio-cultural aspects, as well as to life styles. The presence of a person with special care needs will sense the family structure and its effects will also depend on which family member is affected, the period of permanence on the injury, and its severity (Araujo & Pizzol, 2011). Concerning children with some kind of deficiency, the family has the significant role to animate, provide remark, care, comprehension and defense. There in sense, the family can be described as an organized group of people, influenced by socio-cultural perspective and individual imperious, who participate into relevance, in which each member plays an appointed role (Araujo & Pizzol, 2011).

2.4.1 Physical Health

Health is the grand condition of a living creature at a given time. It is the soundness of the body, independency from disease or abnormality, and the condition of good well-being. It is when the body is operate as it was planned to function (Nordfjaern, 2011). Mothers plays a significant role in assisting the person with particular care needs, as well as in rearing her as part of the community, preventing elimination situations. Only, the tasks imputed to the mothers, often without enough move and no health institutions and social support network, and also the changes in routine (Buzatto &Beresin, 2008). In the unilabiate analyses, worse maternal mental health was associated with the child with Down syndrome having current ear problems and current muscle/bone problems.). It is the first study to investigate specific health characteristics in the child with Down syndrome and assess their impact on mothers' mental well-being. Compared with mothers of children with one episode of illness in 2004 those whose children had 4–6 or ≥7 episodes (Abbeduto, Seltzer & Shattuck et al, 2004).

2.4.2 Psychological health:

Psychosocial health considers a range of mental illnesses including anxiety, depression, bipolar disorders and schizophrenia, and relates to an individual's perceptions, emotions and behaviors. Psychosocially healthy people feel good about themselves, feel comfortable with other people, control tension and anxiety, and are able to meet the demands of life, curb hate and guilt, and maintain a positive outlook. Emphasize that the presence of maladaptive behaviors has impact on mothers' psychological health, which is evidenced by the presence of stress. A recent meta-analysis suggested that parenting stress is higher in parents of children with autism spectrum disorders or DS than in parents of typically development children (Hayes & Watson, 2013). Other studies have shown that the stress levels of mothers of children with DS are higher than those of mothers of non-disabled children (Esdaile, 2009). The findings of a study showed that life stress, burnout and depression are closely associated and could share some underling mechanisms (Plieger, Melchers, Montag, Meermann, & Reuter, 2015). The depression and the emotional exhaustation are correlated with the number of life stress events (Plieger et al., 2015).

2.4.3 Environmental health

Environmental health is the science and practice of preventing human injury and illness and promoting well-being by identifying and evaluating environmental sources and hazardous agents and limiting exposures to hazardous physical, chemical, and biological agents in air, water, soil, food, and other environmental media or settings that may adversely affect human health (Hayes & Watson, 2013). Environmental Health is the branch of public health that focuses on the interrelationships between people and their environment, promotes human health and well-being, and fosters healthy and safe communities (Plieger et al., 2015). The mean of environmental health of the mothers had a significant difference with their education level. This means that the higher the education level, the better would be their quality of life. It showed that among all aspects of the quality of life of mothers, there was only a significant difference in environmental health and mothers with severe disability had lower environmental health (Buzatto &Beresin, 2008).

2.4.4 Social relationship

In social science, a social relation or social interaction is any relationship between two or more individuals. Social relations formed from individual agency form the basis of social structure and the basic object for solution by social scientists (Malhotra, 2013). Loss of social relations is one of the problems that children with intellectual disability may reason for parents. Research has displayed that children with intellectual disability reason stress and mental disintegration in the family and their parents have under level of mood (Koohsali, Mirzamani, Karimlo, & Mirzamani, 2008). It showed that mothers with disabled children have several social activities (Keller & Honig, 2004). These restriction may be due to the negative attitude unto certain diseases, little information of the society, cultural conditions, and specific situation of the children. Since the demographic variables in this study explained only 17% of the quality of life of mothers of children with Down syndrome, it seems that other variables could affect the quality of life.

2.5 Mother’s quality of life with Down syndrome children

According to the definition of “quality of life” by WHO, life comprises people’s own understanding of their position in life and in the cultural value system in which they are living. Quality of life involves indicators for example good health, proper housing, employment, personal and family security, education and recreation, mental health, physical health, proper family life, proper social life, job security, and independency (Sadeghi, Alipour, Abedi, & Ghasmi, 2013). Quality of life is a spacious idea that includes notions such as physical health, psychological state, level of independence, quality of social relationships (Bayatiani, Pourmohammadreza Tajrishi, Gangalivand, Mirzamani, & Saleh, 2011) and relation to important environmental aspects. Environmental factors not only sense people’s social cooperation, but also their quality of life and this is far more significant in mentally disabled people than the ordinary population (Glanz et al., 2010). In research studies that have been extensively conducted in various countries on different races and cultures, some issues have been studied such as parental stress, various conflicts, depression, especially in the first months after child’s birth, marital conflict and divorce, and a variety of behavioral disorders (Cunningham, 1996; Hemmati, Asadi, & Mirsepasi, 2005). Parents of children with Down syndrome are fronted with a lot of problems and stress due to their children (Amirmajd & Sareskanrud, 2012). This state is worse in third world countries, where families have narrow resources and parents, especially mothers are unable to adequately address other prospects of life. Additionally, parents of children with disability are manifested to a lot of stressful factors for a long time that puts them in an inconvenient and weedy conditions, leading to problems in their married relationships, career, and relationships of parents with other children and finally can have negative conse- quences for children (Jalili et al., 2013). These mothers display high levels of stress (Paster, Brand- wein, & Walsh, 2009), mental health problems, depression, anxiety, financial difficulties, negative emotions, self-blame, fear of child’s future problems (Zani, Merino, & Marcon, 2013), impaired physical performance, and fatigue or exhaustion. The specific role of the mother for the pregnancy and birth, child care, and education makes them expertise more press. Therefore, they need more assistance (Raina et al., 2005; Yilmaz, Erkin, & İzki, 2013). Many studies have tested the quality of life of various groups in Iran, but a few of them focused on the quality of life of performing mothers with children with Down syndrome. Abdul Hadi et al. (Haimour & Abu-Hawwash, 2012) in a study evaluate quality of life of parents with children with dis- ability. They showed that there are significant differences in quality of life of parents with children with disability.

CHAPTER 3: Methodology

3.1 Conceptual framework

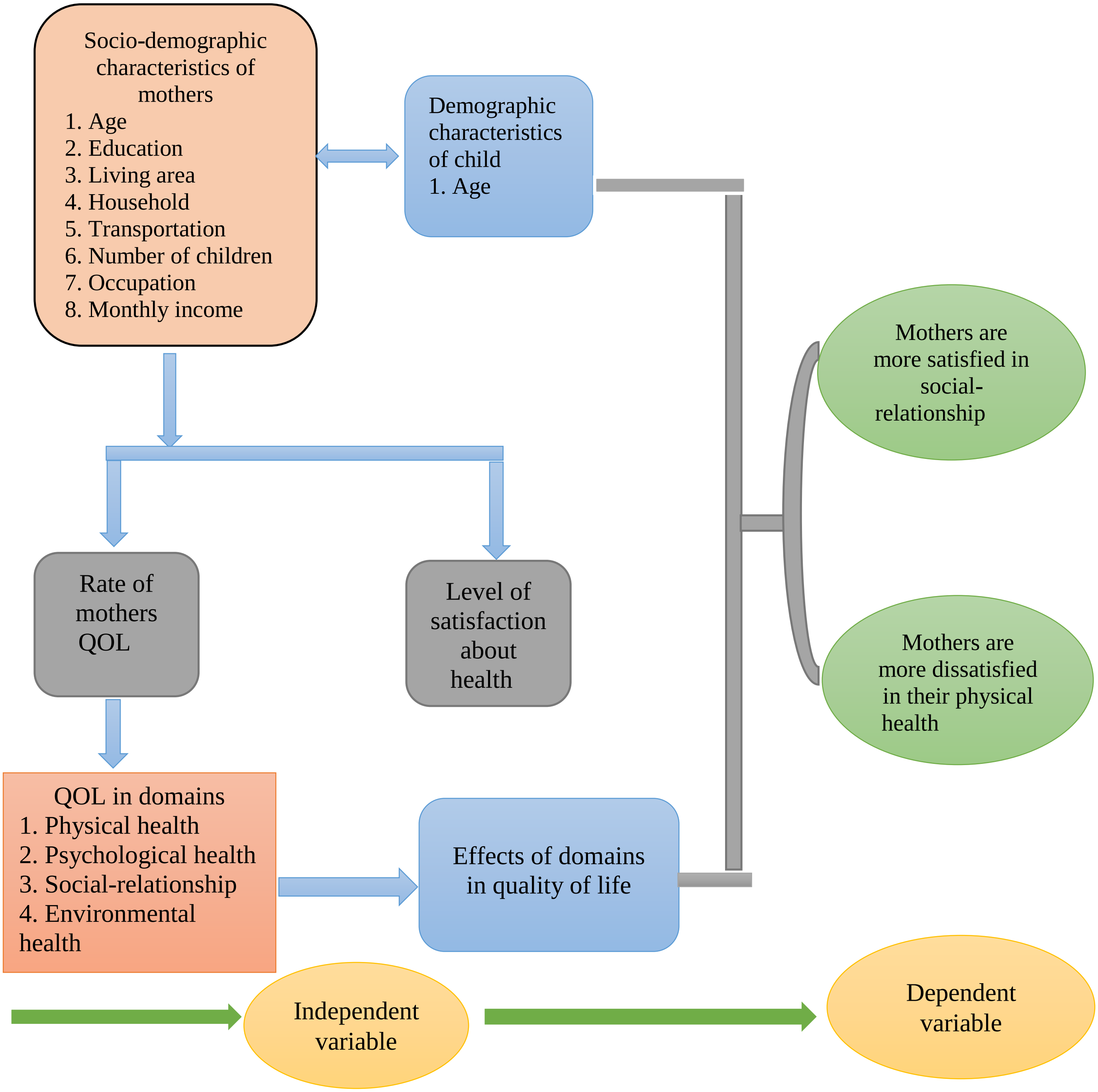

Figure: Conceptual Framework

3.2 Study design:

Study design guides in planning and implementing the process of study in a scientific way to achieve a desire objective. The study is a cross sectional study which was conduct over a short period of time to identify the quality of life among mothers of children with Down syndrome. Cross sectional studies are used to determine prevalence and multiple outcomes. This type of study is relatively quick, cheap and easy to conduct. Cross sectional study allow to collected data by an interview with multiple outcomes from every individual at one point of time and then analysis the outcome (Mann, 2003). Cross-sectional studies provide a snapshot of the characteristics associated with subjects, at a specific point in time and only one group can be used (Alexander et al, 2014 & Dental screts, 2015). So the researcher used Cross sectional study for conducting this study.

3.3 Study population

The mothers of children with Down syndrome are population of this study because mother is the main caregiver of a child who give their most of the time to look after their children and they have been selected from three organization including the William and Marie Taylor School CRP-Savar, Dhaka, Dhaka Proyash, Mirpur, Dhaka and Faith Bangladesh, Iqbal road, Dhaka.

3.4 Study setting

The participants have taken from three organizations, the William and Marie Taylor Inclusive School, Faith Bangladesh and Dhaka Proyash. Participants are selected according to inclusion criteria and excluded from the study according to exclusion criteria.

The William and Marie Taylor Inclusive School

The William and Marie Taylor (WMT) Inclusive School is a school located within The Centre for the Rehabilitation of the Paralyzed. Since 1993 CRP has operated a special needs school. Recognizing the short comings of the segregated educational system, CRP began construction of an inclusive school building in 2003. This new 17 school combines CRP's mainstream school which accommodates children of staff members and local children, with the special needs school. An inclusive educational environment also enables children with special needs to access a level of education suitable for their capabilities and to have the same access to sporting, recreational and extra-curricular activities as those attending mainstream schools. In an interview it has been known that the total students of the school are 298 and 107 of them special needs students. Among them six students are Down syndrome children. There is inclusive classes included class play-class five. There are five special need classes and one vocational training class.

Dhaka Proyash

Proyash– a specialized institute which provides services for holistic development of the children with special educational needs through multidimensional programs. The institute also serves as training and research centre for the development of special education teachers and therapists. In Proyash, for children with Down syndrome have a sector named Intellectual Disability School and Early Child Development Period. Many down syndrome children are studying there and also indoor and outdoor services available for them. Researcher collected data from mothers and also from outdoor services where mothers come. Proyash branches at Savar, Bogra, Sylhet, Ghatail, Chittagong, Comilla, Jessore and Rangpur Cantonment also conduct similar programmes.

Faith Bangladesh

Foundation for Advancement of Innovations in Technology and Health, Bangladesh [faith Bangladesh] is a registered not-for profit organization based in Bangladesh which envisions a planet where people living in resource-poor communities will enjoy advancement of innovations relating to health and technology. Researcher also collected data from Faith Bangladesh. Many parents come there and take services from the organization for their child to improve the occupational performance.

3.5 Study period

The study was conducted from September 18 to April 19.

3.6 Sample Size

Sample size depends on some factors such as; the quality of data, the scope of the study, the nature of the topic, the amount of useful information obtained from each participant, the number of interviews per participant, and the Quantitive method and study design used. A sample size should be as large as the researcher obtains with a reasonable expenditure of time and energy. For conducting the study, investigator took sample according calculated numbers. Sample size could be large or small. Amount of sample size depends on study population and their participants (Bailey, 1997).

According to standard formula, sample size will be-

$$n = \frac{\mathbf{z^2 \times p \times q}}{\boldsymbol{\alpha^2}}$$

$$= \frac{(\mathbf{1.96})^{\mathbf{2}} \times \mathbf{.5} \times \mathbf{.5}}{(\mathbf{.05})^{\mathbf{2}}}$$

$$= 384.16$$

$$= 384$$

Here, n = Sample Size

z = 1.96 (Z-value) (e.g., 1.96 for 95 percent confidence level)

p = 50%=0.5

q = (1-p) = (1-.5) = .5

r = 0.05 (level of significance/ margin of error)

If researcher will use the standard measurement to find out the sample size, it would be 384. Though it is an academic research, data collection period was 2 months. Within two months 384 participant’s data collection was practically not possible. That’s why researcher took 41 Samples.

3.7 Inclusion and exclusion criteria

Inclusion criteria:

- ✓ Mothers with Down syndrome children.
- ✓ Medically stable mothers who could participate in the program.

Exclusion criteria:

- ✓ Medically unstable mother.
- ✓ Unwilling mother.
- ✓ Mother who have cognitive problems.

3.8 Sampling strategy

For this study the researcher collected data by using purposive sampling from the population who met the inclusion criteria. The sampling strategy was purposive sampling because researcher did not simply study whoever was available, but used judgment to select a sample (Frankel & Wallen, 2000). That means the sample was made up of participants who were able to give appropriate information to fulfill the research aims and objectives. Purposive sampling method is used to study the lived experience of a specific population. The purpose is to identify the effects of substance abuse on an individual's QOL. So, the researcher used these sampling strategies

3.9 Data Collection tools

For conducting the study and data collection, the researcher used-

- ✓ Standardized Bangla Questionnaire by using WHOQOL-BREF
- ✓ Consent form & information sheet Bangla
- ✓ Socio-demographic Bangla Questionnaire
- ✓ Paper, pen & pencil

3.10 Data collection method

Data has collected from the participant through face to face interviews. Interviews conducted face- to-face are close and the researcher can contact directly and develop rapport with the participant. At first the researcher took permission from those organization which was choose as study settings. The researcher explained the study's aim and purposes to participants before collecting data. The participants or careers read (if they can) the information sheet and consent form. Who were unable to read researcher explained the information sheet and consent form. All the participants had the opportunities to ask any study related questions and they showed interest to participate in the study they signed in the consent form willingly. The researcher collected data by structured questionnaire, pen, pencil and paper. If any question that was in the questioner difficult to understand for the participants researcher helped to understand indirectly. Data collection procedure took an average 30 minutes to collect one data from one participant. The researcher collected demographic information from the participants.

3.11 Data management and analysis

SPSS is suitable for analysis the Quantitative data. Nominal, Ordinal, & Scale data can be input in SPSS and able to analysis those data in different way. Researcher input the data in statistical package for social science (SPSS) software 20.0 versions. The researcher used statistical analysis to prosthesis user's physical, psychological, social and environmental effects to their quality of life. So researcher used this SPSS to fulfill the objectives.

3.12 Quality control and quality assurance

WHOQOL-BREF

For identifying the effects of mothers with down syndrome children on QOL a valid questionnaire called the World Health Organization Quality of Life (WHOQOL-BREF) was used. It is a questionnaire of 26 items distributed into four domains (physical, psychological, social relationships, and environment). The researcher used this questionnaire in order to classify the individuals of the sample as having lower or higher QOL (Moreira et al. 2013).

Development of demographic questionnaire

The researcher developed a demographic questionnaire related to the research question by reviewing different literature related to QOL of users. This questionnaire helped to identify the demographic variables of patients.

Field test of the questionnaire

A field test was conducted with 3 mothers with Down syndrome children. Field test conducted to refine the question according to participants' perception. From the field test the researcher became aware of which parts the participants found difficult to understand. However, finally field test data was not analyzed. This helped the researcher to ensure that the data collection was going in the right way.

3.13 Ethical Consideration

The investigator maintained ethical consideration in all aspects of the study. At first, the investigator took approval from supervisor and course coordinator, Department of occupational therapy, Bangladesh Health Professions Institute (BHPI) an academic institute of CRP. The researcher maintained some ethical consideration like: After getting the permission of doing this study from the academic institute the researcher started to do it. Then researcher went to the In-charge of Faith Bangladesh and the Principle of Dhaka

Proyash and William and Marie Taylor Inclusive School with an application letter from BHPI to conduct the data collection. Then researcher got permission from the In-charge of Faith Bangladesh and Principle of Dhaka Proyash and William and Marie Taylor Inclusive School for data collection. The researcher has informed participants before to invite participation in the study and ensure that all participants were informed about their rights and reserves and about the aim and objectives of the study. Before starting the interview the researcher has used a written consent to take the permission of each participants of the study. It has been also ensured that all kinds of confidentiality highly maintained. The researcher ensured not to leak out any type of confidentialities and the participant had the rights to leave the study when she wants. Researcher had no right to force the participants to give information if they does not want to give. A written information sheet and consent form was signed by each participant who participated in this study. There are all rights of the participant reserved and researcher was accountable to the participant to answer any type of study related question. The researcher also ensured that the organization is not hampered by this study.

CHAPTER 4: Expected outcome/ Result

This section provides statistical analysis in a systematic way and interpretation of analyzed findings with the aim and objectives of the study. The aim of the study was to find out the quality of life among mothers with Down syndrome children by domain of physical health, psychological health, social relationship and environmental health. Findings of the study are presented by table and bar chart.

4.1 : Socio-demographic characteristics of the mothers with Down syndrome children

In this study the researcher used many socio-demographic components these are age, educational status, religion, living area, household, transportation, age of the child, child's number, siblings, other child have any disability, occupation, approximately income in each month. The researcher categorized all the demographic characteristics.

Table 1: Distribution of respondents by mother's age, educational status, household, transportation, occupation and monthly income.

		Frequency (n)	**Percent**
Age of the mother	16-25 years	1	3.2%
	25-35 years	18	43.5%
	>35 years	22	61.3%
	Total	41	100.0%
Educational status of mother	S.S.C	16	38.7%
	H.S.C & above	23	56.8%
	Illiterate	2	6.5%

	Total	41	100.0%
Household	Own	20	51.6%
	Rented	21	48.4%
	Total	41	100.0%
Transportation	Car	13	35.5%
	Motorbike	2	3.2%
	Bus	17	41.7%
	Rickshaw	8	19.4%
	C.N.G	1	3.2%
	Total	35	100.0%
Occupation of mother	Employee	8	19.4%
	Business	1	3.2%
	Housewife	32	77.4%
	Total	41	100.0%
Monthly income	1000-20000	8	22.6%
	21000-40000	12	25.8%
	41000-60000	8	12.9%
	More than 60000	13	38.7%
	Total	41	100.0%

Among those 41 participants about 3.2% (n=1) were 16 to 25 age group, 43.5% (n=18) respondents were 25 to 35 age group, 61.3% (n=22) were > 35 age group. Among those 41 participants about 38.7% (n=16) were educated to S.S.C, 56.8% (n=23) had education H.S.C and above, 6.5% (n=2) were illiterate. In addition all of the participants religion are Muslim 100.0% (n=41) and all of the participants lived in town 100.0% (n=41). From 41 participants 51.6% (n=20) lived in their own house and 48.4% (n=21) lived in rented house. Most of the participants 38.7% (n=13) were used bus for transportation, 35.5% (n=17) were used car, rickshaw 19.4% (n=8), motorbike 3.2% (n=2) and C.N.G 3.2% (n=1). Most of the participants77.4% 9 (n=32) were housewife, 19.4% (n=7) were employed, 3.2% (n=1) were business. Of the participants monthly income 38.7% (n=13) had more than 60000 taka, 25.8% (n=12) had 21000 to 40000 taka, 22.6% (n=8) had 1000 to 20000 taka and 12.9% (n=8) had 41000 to 60000 taka.

Table 2: Demographic characteristics of children with Down syndrome

		Frequency (n)	**Percent**
Age of the child	1-3 years	5	12.9%
	4-6 years	13	29.0%
	7-9 years	13	32.3%
	10-12 years	8	19.4%
	More than 12 years	2	6.5%
	Total	41	100.0%
	First	17	38.7%
	Second	19	48.4%

Child's number	Third	4	9.7%
	Fourth	1	3.2%
	Total	41	100.0%
Other Child have any disability	Yes	3	4.9%
	No	39	95.1%
	Total	41	100.0%

Out of 41 participants age of the child 32.3% (n=13) were within 7-9 years old, 29.0% (n=13) were within 4-6 years old, 19.4% (n=8) were within 10-12 years old, 12.9% (n=5) were within 1-3 years old and 6.5% (n=2) were more than 12 years old. From 41 participants child's number 48.4% (n=19) were second, first 38.7% (n=17), 9.7% (n=4) were third and 3.2% (n=1) were fifth. Overall participants are 74.2% (n=30) had siblings and 25.8% (n=11) had no siblings. Among those 41 participants 95.1% (n=39) other child had no any disability, 4.9% (n=2) other child had any disability.

4.2 : Rate of Quality of Life (Participant Reported)

In case of overall quality of life among mothers with Down syndrome children (n=41), only 3.2% (n=1) participant had very good QOL and 32.3% (n=17) had good quality of life whether most of the participant 54.8% (n=20) reported neither poor nor good QOL. 9.7% (n=3) participant reported poor QOL and not found any participant which had very poor QOL.

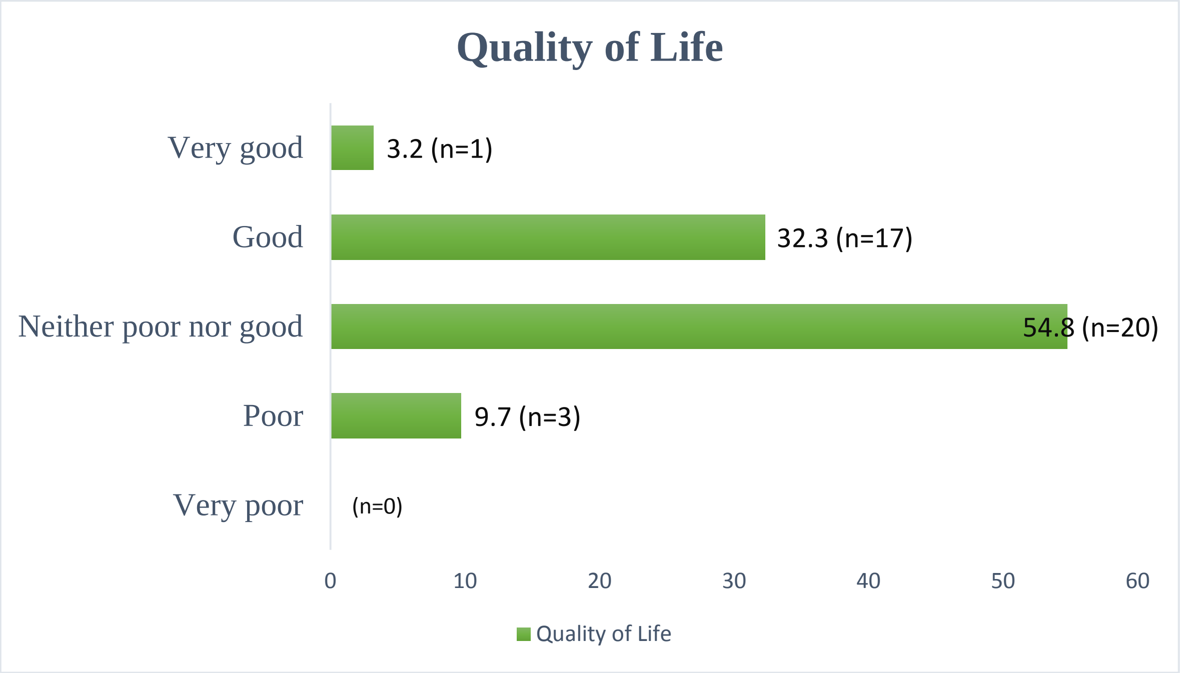

Fig 1: Rate of participant's Quality of Life

Table 3: Overall quality of Life for mothers with Down syndrome children

			Rate of Mothers QOL				
			Very poor	Poor	Neither poor nor good	Good	Very good
Age of mother	16-25 years	Count (n)	0	1	0	0	0
		Percent	0.0%	100.0%	0.0%	0.0%	0.0%
	25-35 years	Count (n)	0	1	8	8	0
		Percent	0.0%	9.1%	45.5%	45.5%	0.0%
	>35 years	Count (n)	0	1	12	9	1
		Percent	0.0%	5.3%	63.2%	26.3%	5.3%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.2%
Educational status of mother	S.S.C	Count (n)	0	1	10	4	0
		Percent	0.0%	8.3%	75.0%	16.7%	0.0%
	H.S.C & above	Count (n)	0	1	7	8	1
		Percent	0.0%	5.9%	41.2%	47.1%	5.9%
	Illiterate	Count (n)	0	1	2	0	0
		Percent	0.0%	50.0%	50.0%	0.0%	0.0%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.25

Living area	Town	Count (n)	0	3	19	12	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.2%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.2%
Household	Own	Count (n)	0	0	8	7	1
		Percent	0.0%	0.0%	50.0%	43.8%	6.2%
	Rented	Count (n)	0	3	9	3	0
		Percent	0.0%	20.0%	60.0%	20.0%	0.0%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.2%
Transportation	Car	Count (n)	0	1	4	5	1
		Percent	0.0%	9.1%	36.4%	45.5%	9.1%
	Motorbike	Count (n)	0	0	2	0	0
		Percent	0.0%	0.0%	100.0%	0.0%	0.0%
	Bus	Count (n)	0	2	9	4	0
		Percent	0.0%	16.7%	66.7%	16.7%	0.0%

	Rickshaw	Count (n)	0	0	3	3	0
		Percent	0.0%	0.0%	50.0%	50.0%	0.0%
	C.N.G	Count (n)	0	0	1	0	0
		Percent	0.0%	0.0%	100.0%	0.0%	0.0%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.2%

Child's age	1-3 years	Count (n)	0	1	3	1	0
		Percent	0.0%	25.0%	50.0%	25.0%	0.0%
	4-6 years	Count (n)	0	1	5	3	0
		Percent	0.0%	11.1%	55.6%	33.3%	0.0%
	7-9 years	Count (n)	0	0	5	4	1
		Percent	0.0%	0.0%	50.0%	40.0%	10.0%
	10-12 years	Count (n)	0	1	4	2	0
		Percent	0.0%	16.7%	66.7%	16.7%	0.0%
	More than 12 years	Count (n)	0	0	2	2	0
		Percent	0.0%	0.0%	50.0%	50.0%	0.0%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.2%
	First	Count (n)	0	2	6	4	0
		Percent	0.0%	16.7%	50.0%	33.3%	0.0%
	Second	Count (n)	0	1	7	6	1
		Percent	0.0%	6.7%	46.7%	40.0%	6.7%
	Third	Count (n)	0	0	3	0	0

Child’s number		Percent	0.0%	0.0%	100.0%	0.0%	0.0%
	Fourth	Count (n)	0	0	1	0	0
		Percent	0.0%	0.0%	100.0%	0.0%	0.0%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.2%
Other Childs disability	Yes	Count (n)	0	0	1	0	0
		Percent	0.0%	0.0%	100.0%	0.0%	0.0%
	No	Count (n)	0	3	14	9	1
		Percent	0.0%	11.1%	51.9%	33.3%	3.7%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	10.7%	54.8%	32.3%	3.2%
	Employee	Count (n)	0	1	1	4	0

Occupation of Mother		Percent	0.0%	16.7%	16.7%	66.7%	0.0%
	Business	Count (n)	0	0	1	0	0
		Percent	0.0%	0.0%	100.0%	0.0%	0.0%
	Housewife	Count (n)	0	2	15	6	1
		Percent	0.0%	8.3%	62.5%	25.0%	4.2%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.2%
Income in each month	1000-20000	Count (n)	0	1	4	2	0
		Percent	0.0%	14.3%	57.1%	28.6%	0.0%
	21000-40000	Count (n)	0	1	5	2	0
		Percent	0.0%	12.5%	62.5%	25.0%	0.0%
	41000-60000	Count (n)	0	0	3	1	0
		Percent	0.0%	0.0%	75.0%	25.0%	0.0%
	More than 60000	Count (n)	0	1	5	5	1
		Percent	0.0%	8.3%	41.7%	41.7%	8.3%
Total		Count (n)	0	3	20	17	1
		Percent	0.0%	9.7%	54.8%	32.3%	3.2%

4.3 : Level of Satisfaction about Health (Participant Reported)

This figure shows the degree of participants satisfaction about their health after caring their children among participant (n=41), 6.5% (n=2) participant was very satisfied, 12.9% (n=7) reported neither satisfied nor dissatisfied and 3.2% (n=1) very dissatisfied about their health. However most of the participant 45.2% (n=20) reported was satisfied. 32.3% (n=11) participant reported they were dissatisfied about their health, show in figure 2.

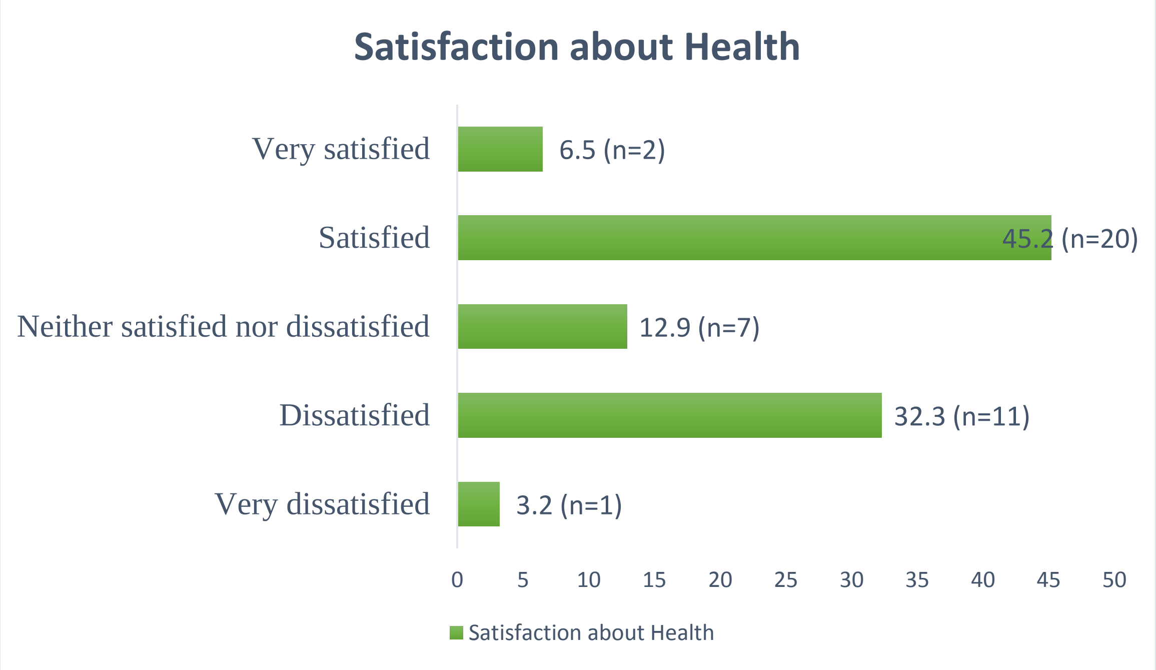

Fig 2: Level of Satisfaction about Health

Table 4: Level of Health satisfaction among mothers with Down syndrome children

			How satisfied are you with your health				
			Very dissatis-fied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
Age of the mother	16-25 years	Count (n)	0	0	0	1	0
		Percent	0.0%	0.0%	0.0%	100.0%	0.0%
	26-35 years	Count (n)	0	3	2	6	0
		Percent	0.0%	27.3%	18.2%	54.5%	0.0%
	>35 years	Count (n)	1	7	2	7	2
		Percent	5.3%	36.8%	10.5%	36.8%	10.5%
Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%
Educational Status of mother	S.S.C	Count (n)	0	4	1	7	0
		Percent	0.0%	33.3%	8.3%	58.3%	0.0%
	H.S.C & above	Count (n)	1	5	3	6	2
		Percent	5.9%	29.4%	17.6%	35.3%	11.8%
	Illiterate	Count (n)	0	1	0	1	0
		Percent	0.0%	50.0%	0.0%	50.0%	0.0%
Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%

Religion	Muslim	Count (n)	1	11	6	15	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%
Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%
Living area	Town	Count (n)	1	11	6	15	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%
Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%
Household	Own	Count (n)	1	7	0	6	2
		Percent	6.2%	43.8%	0.0%	37.5%	12.5%
	Rented	Count (n)	0	3	4	8	0
		Percent	0.0%	20.0%	26.7%	53.3%	0.0%
Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%
Transportation	Car	Count (n)	1	4	0	4	2
		Percent	9.1%	36.4%	0.0%	36.4%	18.2%
	Motorbike	Count (n)	0	1	0	0	0
		Percent	0.0%	100.0%	0.0%	0.0%	0.0%
	Bus	Count (n)	0	2	4	6	0
		Percent	0.0%	16.7%	33.3%	50.0%	0.0%
	Rickshaw	Count (n)	0	2	0	4	0
		Percent	0.0%	33.3%	0.0%	66.7%	0.0%
	C.N.G	Count (n)	0	1	0	0	0

		Percent	0.0%	100.0%	0.0%	0.0%	0.0%
Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%

Child’s age	1-3 years	Count (n)	0	3	0	1	0
		Percent	0.0%	75.0%	0.0%	25.0%	0.0%
	4-6 years	Count (n)	0	3	0	5	1
		Percent	0.0%	33.3%	0.0%	55.6%	11.1%
	7-9 years	Count (n)	1	1	3	4	1
		Percent	10.0%	10.0%	30.0%	40.0%	10.0%
	10-12 years	Count (n)	0	2	1	3	0
		Percent	0.0%	33.3%	16.7%	50.0%	0.0%
	More than 12 years	Count (n)	0	1	0	1	0
		Percent	0.0%	50.0%	0.0%	50.0%	0.0%
Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%
Child’s number	First	Count (n)	0	3	2	6	1
		Percent	0.0%	25.5%	16.7%	50.0%	8.3%
	Second	Count (n)	1	6	2	5	1
		Percent	6.7%	40.0%	13.3%	33.3%	6.7%
	Third	Count (n)	0	0	0	3	0
		Percent	0.0%	0.0%	0.0%	100.0%	0.0%
	Fourth	Count (n)	0	1	0	0	0
		Percent	0.0%	100.0%	0.0%	0.0%	0.0%
Total		Count (n)	1	11	7	20	2

		Percent	3.2%	32.3%	12.9%	45.2%	6.5%
Siblings	Yes	Count (n)	1	8	3	10	1
		Percent	4.3%	34.8%	13.0%	43.5%	4.3%
	No	Count (n)	0	2	1	4	1
		Percent	0.0%	25.0%	12.5%	50.0%	12.5%
Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.3%	12.9%	45.2%	6.5%
Other child have any disability	Yes	Count (n)	0	1	0	0	0
		Percent	0.0%	34.8%	0.0%	0.0%	0.0%
	No	Count (n)	1	10	5	20	2
		Percent	3.7%	29.6%	14.8%	44.4%	7.4%
Total		Count (n)	1	11	7	20	2
		Percent	3.6%	32.1%	14.3%	42.9%	7.1%
Occupation Of Mother	Employee	Count (n)	0	2	0	4	0
		Percent	0.0%	33.3%	0.0%	66.7%	0.0%
	Business	Count (n)	0	0	0	0	1
		Percent	0.0%	0.0%	0.0%	0.0%	100.0%
	Housewife	Count (n)	1	8	4	10	1
		Percent	4.2%	33.3%	16.7%	41.7%	4.2%

Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.2%	12.9%	45.2%	6.5%
Income in each month	1000-20000	Count (n)	0	2	1	4	0
		Percent	0.0%	28.1%	14.3%	57.1%	0.0%
	21000-40000	Count (n)	0	1	3	4	0
		Percent	0.0%	12.5%	37.5%	50.0%	0.0%
	41000-60000	Count (n)	0	2	0	2	0
		Percent	0.0%	50.0%	0.0%	50.0%	0.0%
	More than 60000	Count (n)	1	5	0	4	2
		Percent	8.3%	41.7%	0.0%	33.3%	16.7%
Total		Count (n)	1	11	7	20	2
		Percent	3.2%	32.2%	12.9%	45.2%	6.5%

4.4 : Quality of Life (According to WHOQOL Domain)

Results indicate that the qualities of life among mothers with down syndrome children are decreased in all four domains of life. The social relationship domain had the highest score, while the physical domain had the lowest score. Quality of life with domain 3 (social relationship) obtaining the highest which score is 5.71 ± 0.95. Domain 1 (physical health) acquired the least score among all the domains which is 3.34 ± 0.52. The environmental domain obtains 4.00 ± 0.89 & the psychosocial health domain score are 3.70 ± 0.61, show in (Table 4). The overall findings of the study about quality of life among mothers with down syndrome children in Bangladesh estimated that they are more satisfied in social relationship skill then orderly environmentally, psychically and last physically.

Table 5: Quality of Life (WHOQOL-BREF domain)

Statistics				
	Physical health domain	Psychological health domain	Social relationship domain	Environmental Domain
N	41	41	41	41
Mean	3.34	3.70	5.71	4.00
Std. Deviation	0.52	0.61	0.95	0.89

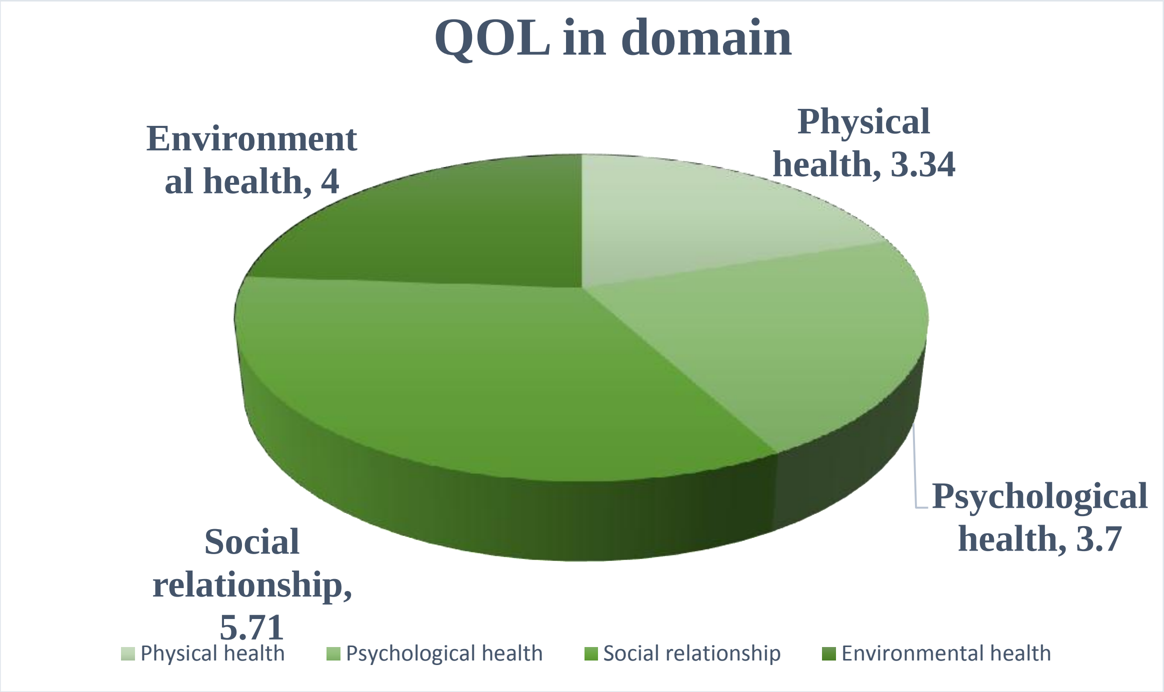

Fig 3: Quality of Life (WHOQOL-BREF domain)

4.5: Effect of mothers quality of life (physical health, psychosocial health, social relationship and environmental health) for Down syndrome children

As for the domain scores on the WHOQOL-BREF, the researcher observed that different ages participants' scores are different. At the same time the researcher also found that scores are different (higher or lower) on the basis of demographic factors in all domain of WHOQOL-BREF. Table-6 describes the mean values and standard deviation of the WHOQOL-BREF domains, classified by some socio-demographic variables (age, educational status, occupation and monthly income). The researcher found that 26-35 year olds had lower scores in two domains psychological (3.70 ± .581), social-relationship (5.09 ± .970) and >35 years olds had higher scores in three domains psychological (3.76±.647), social-relationship (6.07±.786) and environmental (4.22±.907). H.S.C & above educated participants domains such as physical (3.42±.325), psychological (3.71±.689), environmental domain (4.34±1.01) and social (5.76±1.17) higher scores than the S.S.C and illiterate participants domain scores.

Table 6: Effects of mothers quality of life for down syndrome children

Demographic Variables			**Domain in Quality of Life**			
			Physical health	**Psychological health**	**Social-relationship**	**Environment health**
Age of the mother	26-35 years	Mean	3.42	3.70	5.09	3.72
		Std. Deviation	±.491	±.581	±.970	±.767
	>35 years	Mean	3.19	3.76	6.07	4.22
		Std. Deviation	±.554	±.647	±.786	±.907
Educational Status of mother	S.S.C	Mean	3.13	3.70	5.70	3.63
		Std. Deviation	±.535	±.404	±.655	±.486
	H.S.C and above	Mean	3.42	3.71	5.76	4.34
		Std. Deviation	±.325	±.689	± 1.17	± 1.01
	Illiterate	Mean	2.99	3.60	5.25	3.25
		Std. Deviation	±.233	± 1.41	±.353	±.353
Occupation of mother	Employee	Mean	3.58	3.80	5.41	4.60
		Std. Deviation	±.442	±.521	±.861	±.841

	Housewife	Mean	3.22	3.65	5.70	3.80
		Std. Deviation	±.538	±.641	±.931	±.830
Income in each month	1000-20000	Mean	3.01	3.54	5.07	3.25
		Std. Deviation	±.604	±.550	± 1.17	±.439
	21000-40000	Mean	3.16	3.62	5.62	3.49
		Std. Deviation	±.461	±.549	±.517	±.591
	41000-60000	Mean	3.45	3.65	5.00	3.95
		Std. Deviation	±.549	±.443	±.408	±.158
	More than 60000	Mean	3.39	3.76	6.37	4.78
		Std. Deviation	±.550	±.761	±.778	±.791
Child’s age	1-3 years	Mean	3.37	3.75	5.62	4.04
		Std. Deviation	±.656	±.525	±.853	±.209
	4-6 years	Mean	3.33	3.66	6.11	4.16
		Std. Deviation	±.364	±.741	±.781	±.757
	7-9 years	Mean	3.52	3.85	5.62	4.09
		Std. Deviation	±.580	±.566	±1.15	±1.20
	10-12 years	Mean	3.06	3.44	5.50	3.59
		Std. Deviation	±.448	±.654	±.707	±.862
	More than 12 years	Mean	3.25	3.60	5.25	3.49
		Std. Deviation	±1.06	±.282	±1.06	±.223

Participants whose occupation was employed had higher in three domains physical (3.58±.442), psychological (3.80±.521) and environmental domain (4.60±.841). In addition, housewife had higher scores in social domain (5.70±.931). Participants those monthly income was more than 60000 taka had higher scores in three domains such as psychological (3.76±.761), social (6.37±.778) and environmental (4.78±.791) compared to those who had monthly income 21000-40000 and 41000-60000. On the other hand, users those monthly income was within 1000-20000 taka had lower scores in physical (3.01±.604), psychological (3.54±.550), social (5.07±1.17), and environmental (3.25±.439) domain. Mothers whose children age between 7-9 years, they have great impact on physical and psychological domain and whose children age between 4-6 years, they have great impact on social relationship and environmental domain.

CHAPTER 5: Discussion & Conclusion

5.1 Discussion

A mother is the main caregiver of a child. Children with Down syndrome needs more care because a DS child can't maintain his/her own activities as a child without DS. This is why mothers give their most of the time to look after their children with Down syndrome. After spending a lot of time to look after their child and other works they can't maintain their position in life properly. It has been shown that mothers consider the change in their lives that the event or the child with Down syndrome has brought (Joosa and Berthelsen, 2006). A mother with a special need child faces many challenges to make a proper balance in productive works like house hold activities and employment. Some studies stated that (Wayne and Krishnagiri, 2005) a mother of a child with Down syndrome have to spend her most of the time to look after the child and less time to productive work. According to Joosa and Berthelsen (2006) many mothers of the DS children described their family relationship as similar to all families. Their husbands provide enough support in take care of family and they work together. It is also mentioned (Hsich and Puymbroeck, 2013) that the support from the husband is the most important factor in reduction anxiety. In a family the supports from one's spouse is the most important source of emotional support for caregivers of children with special needs. Many mothers reported that they get physical support also from their family members. According to WHO health is a broad term include physical, mental and social, environment and quality of life also a holistic term which also related to the health so measuring of those domains is essential for find out the quality of life. Their experience of life against those barriers is effect on QOL. Experience is the term that varies person to person. It depends of some factor such physical, emotional, environmental & social and together that factor is quality of life. (Poljak-Guberina et al., 2005).

In this present study most participants are aged more than 35 years old, 18 participants are aged between 26-35 years and 1 participant age 16-25 years. The mean ±SD of age range is (2.58±.56). According to Carswell and Borsatto the age of parents with Down syndrome children ranged from 24 to 47 years, and most parents are aged over 30 years as in the present study. Their age ranged from 28 to 49 years (mean of 37 years) (Silva NLP and Dessen MA, 2006). In other studies the mothers' age ranged 22–65 years old, and the mean age (in years) was 43.67±8.49. The inverse correlation of maternal age and mothers' overall QOL could be related to the needs to meet the various child-related care demands which were straining physically, especially as mothers grew more advanced in age. Furthermore, care demands were apparently not decreased as their child gradually grew and progressed to their teenage years and beyond, with their physiological and social-related needs as an individual. In addition to this, sources of family support and assistance available to mothers may be gradually reduced with age (Lam LW and Mackenzie AE, 2008).

The study found that many of the participant had completed H.S.C and above more rather than others because most of the mothers lived in urban location. There were about 38.7% participants is S.S.C pass. And participant were 6.5% of illiterate. Others studies shows that significantly large percentage of them (41%, n=66) attained education until primary school level or below because large number of mothers lived the rural location (Glidden LM and Schoolcraft SA, 2003).

In addition all of the participant's religion are Muslim 100.0% and all of the participants lived in town 100.0%. From all participants 51.6% lived in their own house and 48.4% lived in rented house In Malaysian studies show that the majority of them embraced one of the three main religions in Malaysia, 84% namely Islam, 55% of Christianity and 17% of Buddhism (Gatford A, 2001). In other studies found that a little over half of the sample practiced 56% were catholic. And the same studies show in the sample, 80% resided in flats or houses with their families; most parents (60%) reported owing their houses (Wayne DO, 2005).

In this studies the investigated found that most of the participants 38.7% were used bus for transportation, 35.5% were used car, rickshaw 19.4%, motorbike 3.2% and C.N.G 3.2%. In other research show that 66.67% used public transport (buses) as their means of transportation. Almost half of the group did not have the means to have a car to move around, but had to depend on motorcycles or public transport (Japan Bank for International Cooperation, 2012).

In this research among those participants age of the child 32.3% were within 7-9 years old, 29.0% were within 4-6 years old, 19.4% were within 10-12 years old, 12.9% were within 1-3 years old and 6.5% were more than 12 years old. Malaysian studies found that most of the participant's age of the child 60.2% were within more than 10 years old (Wayne DO, 2005). The results of the study shows that 77.4% 9 of participant has housewife, 19.4% of has employed, 3.2% has own business. In another studies Malaysian mother reported that 72% of mother has housewife because of taking care of their children and also their low education level (Mugno D, 2007). This present study found that of the participants monthly income 38.7% had more than 60000 taka, 25.8% had 21000 to 40000 taka, 22.6% had 1000 to 20000 taka and 12.9% had 41000 to 60000 taka. The Malaysian study in Malaysia found that in relation to household income, nearly half of the group (40.4%; n= 65) reported income of < RM 500. This is considered as below the poverty line income of RM 830 household income in 2009 (Mugno D, 2007).

Quality of life is affected by factors such as beliefs, attitudes; as well as cultural, economic, social, and religious values. Results indicate that the qualities of life among mothers with Down syndrome children are decreased in all four domains of life. The social relationship domain had the highest score, while the physical domain had the lowest score. Quality of life with domain 3 (social relationship) obtaining the highest which score is 5.71 ± 0.95. Domain 1 (physical health) acquired the least score among all the domains which is 3.34 ± 0.52. The overall findings of the study about quality of life among mothers with Down syndrome children in Bangladesh estimated that they are more satisfied in social relationship skill then orderly environmentally, psychically and last physically.

In Malaysian studies indicate some variations among QOL of the four life domains. The highest and lowest domain scores were found for the DOM 3 (social relationship, Mean = 14.9± 2.1) and DOM 4 (environmental support, Mean = 13.3±2.1) respectively. The higher domain score which was obtained for DOM 3 (social relationship) indicated mothers' level of satisfaction in this domain. Lower domain score of the DOM 4 (environmental support) denoted mothers' relative dissatisfaction (Hsieh RL, 2009).

In Brazil, the investigated found that the social domain had the highest score, while the psychological domain had the lowest score. When comparing these results with those reported in a study of mothers with autistic children, we find that in this case the physical domain had the highest score (69.4) and the environmental score had the lowest score (60.8) (Iervolino SA, 2005). A low score in the psychological domain of the parent's quality of life confirms the conclusions of Carswell and Grossi. They state that the birth of a child with Down syndrome may result in psychological pain for their parents. This psychological impact is responsible for generating confused feelings that may persist throughout life (Grossi R, 1999). Further aspects possibly related with lower scores in the psychological domain in the quality of life assessment of parents are: social, psychological and financial overburden and the need for taking care of the child, which may cause feelings of anxiety and uncertainty in parents. There are also feelings of insecurity about the survival, development and long-term care of the child, as well as the effect of such care on the parent's personal lives. For the majority of the sample, caring for their Down syndrome child affected their quality of life. There were some explanations given for this, of which the majority reported the existence of major involvement with their child's education and care which brought satisfaction to the parents themselves, however. According to Carswell, the need for special attention requires that parents involve themselves in every activity and care of their Down syndrome child. Other studies reported the increased responsibility and workload that these parents have in caring for Down syndrome children (Silva NLP, 2006). This level of involvement in the care and in the activities of Down syndrome children requires more time from parents, as reported by Parazzi and Dupas,(14), Saraiva and Nobrega. Grossi, Barnett and Boyce, among others, however, stated that time for involvement is the main difficulty parents face daily (Silva NLP, 2006).

In Iran, this result shows that mothers gained the highest scores on the physical aspect (Amirmajd and-Sareskanrud, 2012). It also studied parents of children with Down syndrome and normal children, which showed no significant difference between the qualities of their lives (Khanjani, Hatamizade, Hoseinian, Rahgozar, and Arjmand, 2010). It studied the impact of training on taking care of children with cerebral palsy and concluded that the quality of life of caregivers in all subscales and total score of the two general physical and mental areas improved, and the highest score was gained by the physical aspect (Khanjani, Hatamizade, Hoseinian, Rahgozar, & Arjmand, 2010). This finding is consistent with our results. The results of this study can be explained, however, in the sense that taking care of children with Down syndrome brings along fatigue, time consumption, and stress for the parents. However, research shows that parents of these children more easily get used to this condition, because children with Down syndrome have positive features and less behavioral problems than children with other disabilities (Amirmajd & Sareskanrud, 2012; Oliveira & Limongi, 2011).

Other findings showed that environmental health had the lowest mean score in "quality of life". This finding is consistent with findings (Oliveira & Limongi, 2011). Also, the mean of environmental health of the mothers had a significant difference with their education level. This means that the higher the education level, the better would be their quality of life. In eastern societies, with different cultures, attitudes, and attention on individuals' lives, environmental factors should be assessed along with other related factors. Providing more convenience to hold workshops and courses and augmenting educational parental self-esteem programs lead to social connection of these parents. The results of studying the quality of life in the caregivers can be used to evaluate the humane and financial costs caused by Down syndrome, the effects of the new programs and measures, psychophysical changes, and social functioning conditions of the caregivers (Oliveira & Limongi, 2011).

The present study identifies that 26-35 year olds had lower scores in two domains psychological (3.70 ± .581), social-relationship (5.09 ± .970) and >35 years olds had higher scores in three domains psychological (3.76±.647), social-relationship (6.07±.786) and environmental (4.22±.907). Those with an education level H.S.C and above had higher scores in all domains such as physical (3.42±.325), psychological (3.71±.689), environmental domain (4.34±1.01) and social (5.76±1.17) than the S.S.C and illiterate participants domain scores.

Others studies showed that the mean of environmental health of the mothers had a significant difference with their education level. This means that the higher the education level, the better would be their quality of life (Amirmajd and Sareskanrud, 2012).

Participants whose occupation was employed had higher in three domains physical (3.58±.442), psychological (3.80±.521) and environmental domain (4.60±.841). In addition, housewife had higher scores in social domain (5.70±.931). Participants those monthly income was more than 60000 taka had higher scores in three domains such as psychological (3.76±.761), social (6.37±.778) and (4.78±.791) compared to those who had monthly income 21000-40000 and 41000-60000. On the other hand, users those monthly income was within 1000-20000 taka had lower scores in physical (3.01±.604), psychological (3.54±.550), social (5.07±1.17), and environmental (3.25±.439) domain. Mothers whose children age between 7-9 years, they have great impact on physical and psychological domain and whose children age between 4-6 years, they have great impact on social relationship and environmental domain.

5.2 Limitations of the study

This study has conducted due to fulfillment of the course curriculum. The current study has some potential limitations that should be kept in mind when interpreting the results. Firstly the data was collected on QOL but the sample size of the research was small, this may affect the generalizability of the findings. The researcher has got very few times with the mothers at the school. Therefore, it becomes difficult to build rapport with them. Most of the participants were not interested to give actual information beside they wants researcher will help them to answer those question that was very challenging to the investigator to collect data but some of the participants were very co-operative to share all of information. There was no study has been conducted related to the topic in Bangladesh. There have been found some information related to this study on global perspective from manual searching by books and journals from online database such as Google scholar, Google web page, PubMed, Hinari etc. A related article was found but it regarded different countries; and it important to remember that Bangladeshi culture and what QOL means to them is different to other countries.

5.3 Conclusion

QOL is a vast aspect for every human being. It is subjective and indefinable. This concept depends on some factor such as physical and psychological, social, environmental and activities of daily life, productivity, leisure, and personal factor. Mother is the primary caregiver of a child. The child with Down syndrome can't maintain their position in life within their cultural and value systems, their objectives, expectations and concerns as a typically developed child due to their developmental delay. The children with DS are dependent on their mothers. The mothers have to provide more care to their DS children. The behavior and health of the children had a greater effect on mothers than on fathers. The findings of the study show that the mothers of the DS children face challenges to maintain time for their quality of life and daily life. They have to spend a lot of time to look after their children. The result has also showed that these mothers got enough supports from the family rather than the community. The study found that the quality of life of among mothers with Down syndrome is good at social relationship & poor in physical health. And they are satisfied about their general health and medium level satisfied about their overall quality of life. This study is important for the Occupational therapist to work with mothers having children with Down syndrome. When Occupational Therapists come to know the difficulties of a mother with her DS child, then they could provide appropriate interventions, for example: recommendations and suggestions to minimize if they have any challenges, and help them to lead a better quality of life. This study can help other professionals such as psychiatrics or counselors to know about the psychological condition of the mothers of the children with Down syndrome through these mothers' experience of daily life. This research study is particularly necessary for occupational therapists so that they could be able to understand the needs and expectation of mothers and how mothers' daily life and QOL are impacted after having a Down syndrome child. The OT could also promote the mothers' coping strategies in managing children with DS.

5.4 Recommendation

This study was covered small number of participant additional larger studies are needed. More studies are needed to compare the QOL of mothers. In future, further studies can be conducted in relation to this study such as the experience of care giving both parents of the children with DS compare with the parents of children with other intellectual disabilities. Arrange an awareness programs for the mothers, and other people in the community. Arrange counseling programs which will help to gain a better life for the mothers and their children.

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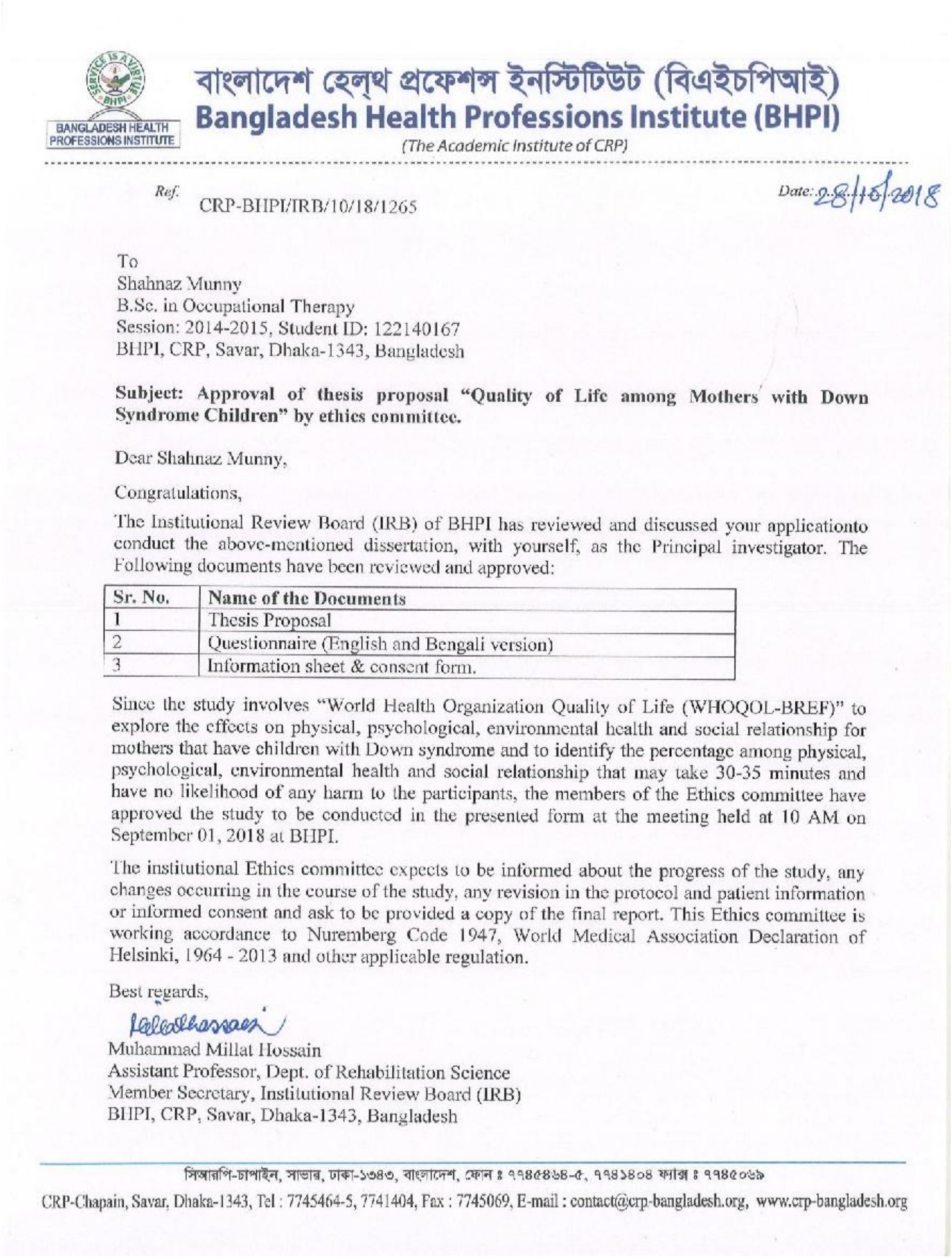
Appendix 1
Approval letter of Institutional Review Board (IRB).



বাংলাদেশ হেল্‌থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)
BANGLADESH HEALTH PROFESSIONS INSTITUTE

Ref. CRP-BHPI/IRB/10/18/1265

Date: 28/10/2018

To
Shahnaz Munny
B.Sc. in Occupational Therapy
Session: 2014-2015, Student ID: 122140167
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of thesis proposal "Quality of Life among Mothers with Down Syndrome Children" by ethics committee.

Dear Shahnaz Munny,

Congratulations,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your applicationto conduct the above-mentioned dissertation, with yourself, as the Principal investigator. The Following documents have been reviewed and approved:

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

Since the study involves "World Health Organization Quality of Life (WHOQOL-BREF)" to explore the effects on physical, psychological, environmental health and social relationship for mothers that have children with Down syndrome and to identify the percentage among physical, psychological, environmental health and social relationship that may take 30-35 minutes and have no likelihood of any harm to the participants, the members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 10 AM on September 01, 2018 at BHPI.

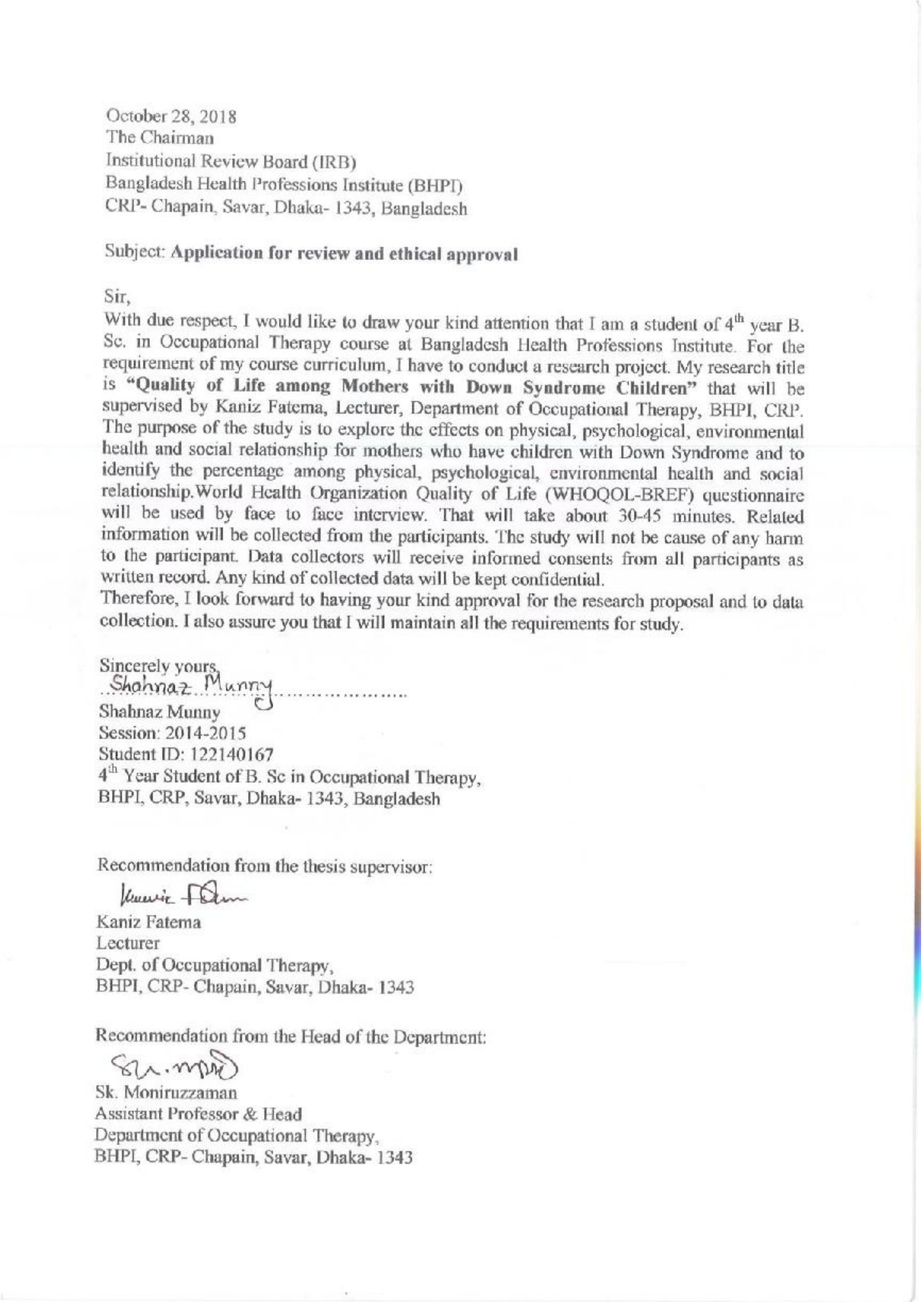
The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance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

Best regards,

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

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ, ফোন ঃ ৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ ফ্যাক্স ঃ ৭৭৪৫০৬৯
CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404, Fax : 7745069, E-mail : contact@crp-bangladesh.org, www.crp-bangladesh.org

Appendix 2
Permission letter for conducting study



October 28, 2018
The Chairman
Institutional Review Board (IRB)
Bangladesh Health Professions Institute (BHPI)
CRP- Chapain, Savar, Dhaka- 1343, Bangladesh

Subject: **Application for review and ethical approval**

Sir,

With due respect, I would like to draw your kind attention that I am a student of 4th year B. Sc. in Occupational Therapy course at Bangladesh Health Professions Institute. For the requirement of my course curriculum, I have to conduct a research project. My research title is **"Quality of Life among Mothers with Down Syndrome Children"** that will be supervised by Kaniz Fatema, Lecturer, Department of Occupational Therapy, BHPI, CRP. The purpose of the study is to explore the effects on physical, psychological, environmental health and social relationship for mothers who have children with Down Syndrome and to identify the percentage among physical, psychological, environmental health and social relationship.World Health Organization Quality of Life (WHOQOL-BREF) questionnaire will be used by face to face interview. That will take about 30-45 minutes. Related information will be collected from the participants. The study will not be cause of any harm to the participant. Data collectors will receive informed consents from all participants as written record. Any kind of collected data will be kept confidential.

Therefore, I look forward to having your kind approval for the research proposal and to data collection. I also assure you that I will maintain all the requirements for study.

Sincerely yours,
Shahnaz Munny……………………
Shahnaz Munny
Session: 2014-2015
Student ID: 122140167
4th Year Student of B. Sc in Occupational Therapy,
BHPI, CRP, Savar, Dhaka- 1343, Bangladesh

Recommendation from the thesis supervisor:

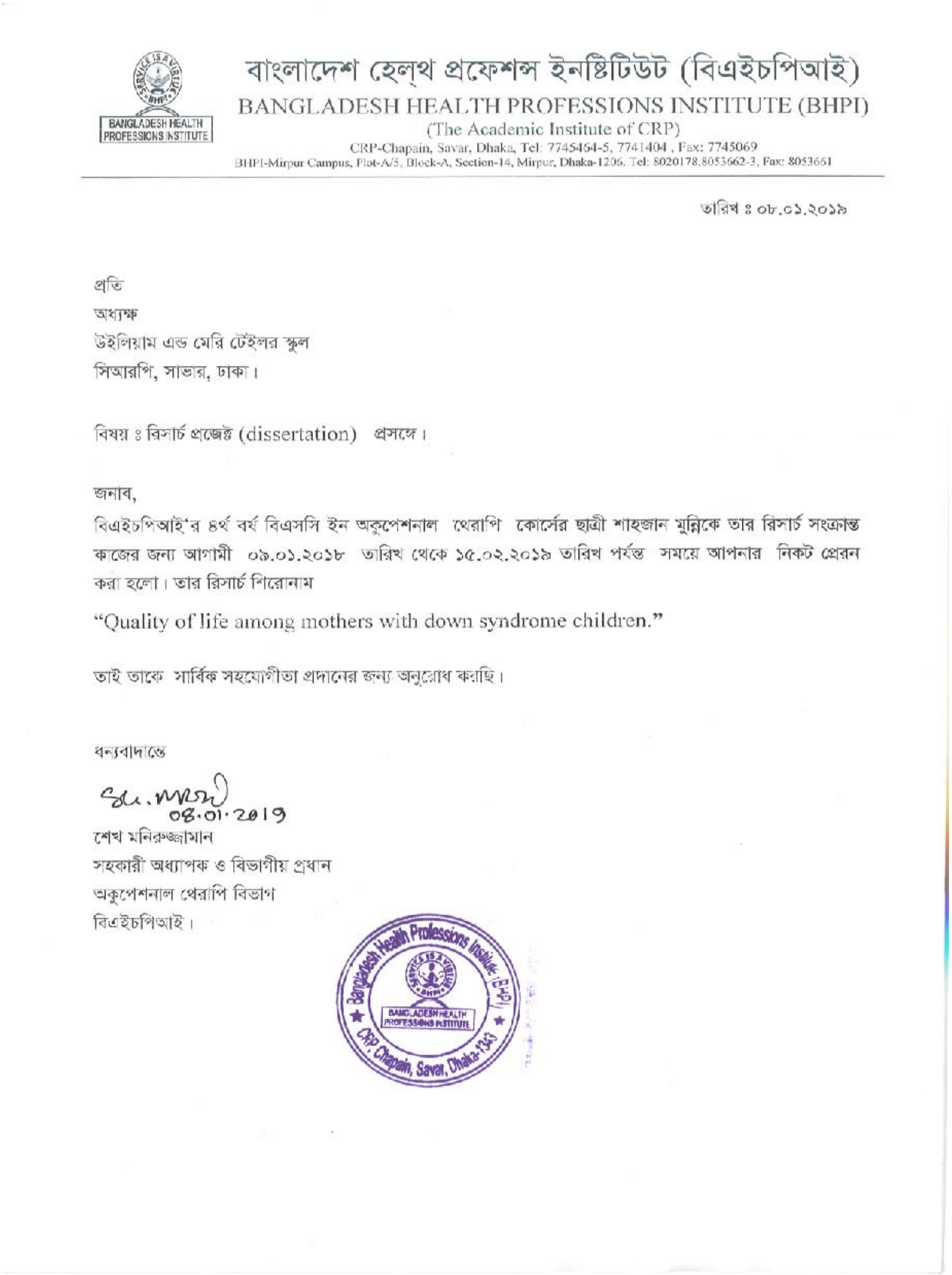
Kaniz Fatema
Lecturer
Dept. of Occupational Therapy,
BHPI, CRP- Chapain, Savar, Dhaka- 1343

Recommendation from the Head of the Department:

Sk. Moniruzzaman
Assistant Professor & Head
Department of Occupational Therapy,
BHPI, CRP- Chapain, Savar, Dhaka- 1343

Appendix 3

Permission letter for data collection



বাংলাদেশ হেল্থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)
CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404 , Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178,8053662-3, Fax: 8053661

তারিখ ঃ ০৮.০১.২০১৯

প্রতি
অধ্যক্ষ
উইলিয়াম এন্ড মেরি টেইলর স্কুল
সিআরপি, সাভার, ঢাকা।

বিষয় ঃ রিসার্চ প্রজেক্ট (dissertation) প্রসঙ্গে।

জনাব,

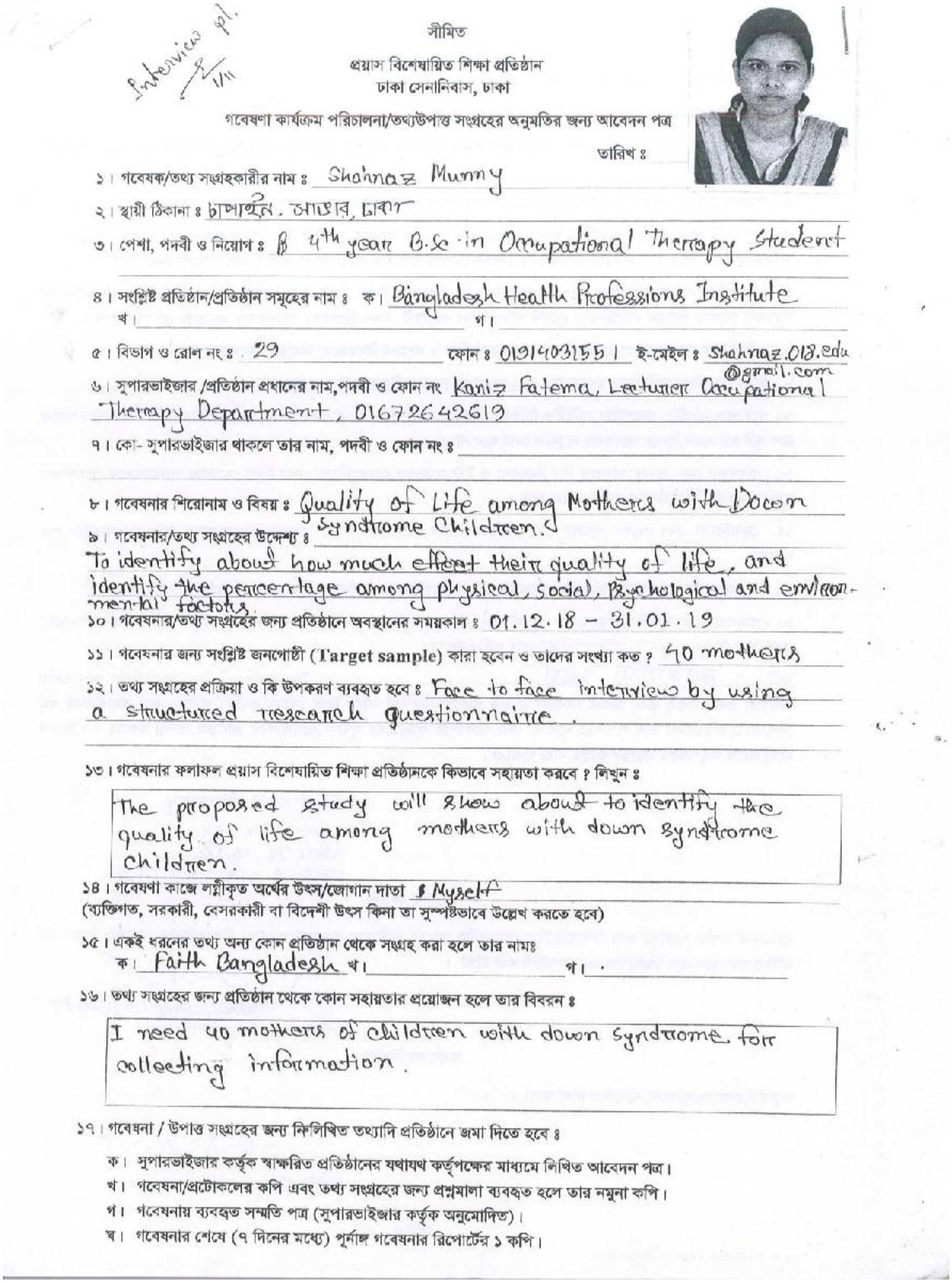
বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী শাহজান মুন্নিকে তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ০৯.০১.২০১৮ তারিখ থেকে ১৫.০২.২০১৯ তারিখ পর্যন্ত সময়ে আপনার নিকট প্রেরন করা হলো। তার রিসার্চ শিরোনাম

“Quality of life among mothers with down syndrome children.”

তাই তাকে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করাছি।

ধন্যবাদান্তে

08·01·2019
শেখ মনিরুজ্জামান
সহকারী অধ্যাপক ও বিভাগীয় প্রধান
অকুপেশনাল থেরাপি বিভাগ
বিএইচপিআই।



Interview pl.
1/11

সীমিত

প্রয়াস বিশেষায়িত শিক্ষা প্রতিষ্ঠান
ঢাকা সেনানিবাস, ঢাকা

গবেষণা কার্যক্রম পরিচালনা/তথ্যউপাত্ত সংগ্রহের অনুমতির জন্য আবেদন পত্র

তারিখ :

১। গবেষক/তথ্য সংগ্রহকারীর নাম : Shahnaz Munny

২। স্থায়ী ঠিকানা : চাপাইন, সাভার, ঢাকা

৩। পেশা, পদবী ও নিয়োগ : 4th year B.Sc in Occupational Therapy Student

৪। সংশ্লিষ্ট প্রতিষ্ঠান/প্রতিষ্ঠান সমূহের নাম : ক। Bangladesh Health Professions Institute
খ। গ।

৫। বিভাগ ও রোল নং : 29 ফোন : 01914031551 ই-মেইল : shahnaz.018.edu@gmail.com

৬। সুপারভাইজার /প্রতিষ্ঠান প্রধানের নাম,পদবী ও ফোন নং Kaniz Fatema, Lecturer Occupational Therapy Department, 01672642619

৭। কো- সুপারভাইজার থাকলে তার নাম, পদবী ও ফোন নং :

৮। গবেষনার শিরোনাম ও বিষয় : Quality of Life among Mothers with Down Syndrome Children.

৯। গবেষনার/তথ্য সংগ্রহের উদ্দেশ্য :
To identify about how much effect their quality of life, and identify the percentage among physical, social, Psychological and environmental factors.

১০। গবেষনার/তথ্য সংগ্রহের জন্য প্রতিষ্ঠানে অবস্থানের সময়কাল : 01.12.18 – 31.01.19

১১। গবেষনার জন্য সংশ্লিষ্ট জনগোষ্ঠী (**Target sample**) কারা হবেন ও তাদের সংখ্যা কত ? 40 mothers

১২। তথ্য সংগ্রহের প্রক্রিয়া ও কি উপকরণ ব্যবহৃত হবে : Face to face interview by using a structured research questionnaire.

১৩। গবেষনার ফলাফল প্রয়াস বিশেষায়িত শিক্ষা প্রতিষ্ঠানকে কিভাবে সহায়তা করবে ? লিখুন :

The proposed study will show about to identify the quality of life among mothers with down syndrome children.

১৪। গবেষণা কাজে লগ্নীকৃত অর্থের উৎস/জোগান দাতা : Myself
(ব্যক্তিগত, সরকারী, বেসরকারী বা বিদেশী উৎস কিনা তা সুস্পষ্টভাবে উল্লেখ করতে হবে)

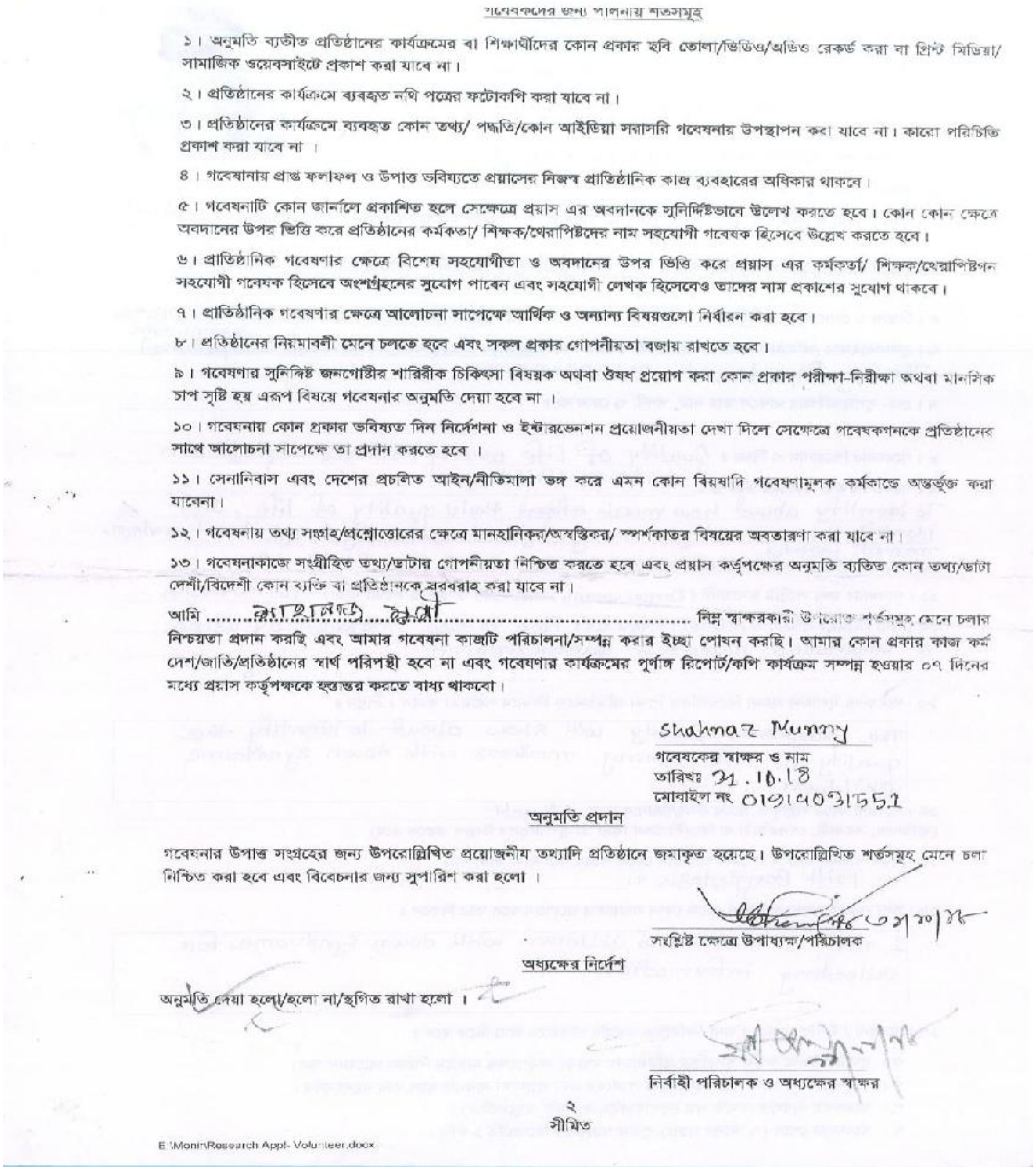
১৫। একই ধরনের তথ্য অন্য কোন প্রতিষ্ঠান থেকে সংগ্রহ করা হলে তার নামঃ
ক। Faith Bangladesh খ। গ।

১৬। তথ্য সংগ্রহের জন্য প্রতিষ্ঠান থেকে কোন সহায়তার প্রয়োজন হলে তার বিবরন :

I need 40 mothers of children with down syndrome for collecting information.

১৭। গবেষনা / উপাত্ত সংগ্রহের জন্য নিম্নলিখিত তথ্যাদি প্রতিষ্ঠানে জমা দিতে হবে :

ক। সুপারভাইজার কর্তৃক স্বাক্ষরিত প্রতিষ্ঠানের যথাযথ কর্তৃপক্ষের মাধ্যমে লিখিত আবেদন পত্র।
খ। গবেষনা/প্রটোকলের কপি এবং তথ্য সংগ্রহের জন্য প্রশ্নমালা ব্যবহৃত হলে তার নমুনা কপি।
গ। গবেষনায় ব্যবহৃত সম্মতি পত্র (সুপারভাইজার কর্তৃক অনুমোদিত)।
ঘ। গবেষনার শেষে (৭ দিনের মধ্যে) পূর্নাঙ্গ গবেষনার রিপোর্টের ১ কপি।



গবেষকদের জন্য পালনীয় শর্তসমূহ

১। অনুমতি ব্যতীত প্রতিষ্ঠানের কার্যক্রমের বা শিক্ষার্থীদের কোন প্রকার ছবি তোলা/ভিডিও/অডিও রেকর্ড করা বা প্রিন্ট মিডিয়া/ সামাজিক ওয়েবসাইটে প্রকাশ করা যাবে না।

২। প্রতিষ্ঠানের কার্যক্রমে ব্যবহৃত নথি পত্রের ফটোকপি করা যাবে না।

৩। প্রতিষ্ঠানের কার্যক্রমে ব্যবহৃত কোন তথ্য/ পদ্ধতি/কোন আইডিয়া সরাসরি গবেষনায় উপস্থাপন করা যাবে না। কারো পরিচিতি প্রকাশ করা যাবে না ।

৪। গবেষানায় প্রাপ্ত ফলাফল ও উপাত্ত ভবিষ্যতে প্রয়াসের নিজস্ব প্রাতিষ্ঠানিক কাজ ব্যবহারের অধিকার থাকবে।

৫। গবেষনাটি কোন জার্নালে প্রকাশিত হলে সেক্ষেত্রে প্রয়াস এর অবদানকে সুনির্দিষ্টভাবে উলেখ করতে হবে। কোন কোন ক্ষেত্রে অবদানের উপর ভিত্তি করে প্রতিষ্ঠানের কর্মকর্তা/ শিক্ষক/থেরাপিষ্টদের নাম সহযোগী গবেষক হিসেবে উল্লেখ করতে হবে।

৬। প্রাতিষ্ঠানিক গবেষণার ক্ষেত্রে বিশেষ সহযোগীতা ও অবদানের উপর ভিত্তি করে প্রয়াস এর কর্মকর্তা/ শিক্ষক/থেরাপিষ্টগন সহযোগী গবেষক হিসেবে অংশগ্রহনের সুযোগ পাবেন এবং সহযোগী লেখক হিসেবেও তাদের নাম প্রকাশের সুযোগ থাকবে।

৭। প্রাতিষ্ঠানিক গবেষণার ক্ষেত্রে আলোচনা সাপেক্ষে আর্থিক ও অন্যান্য বিষয়গুলো নির্ধারন করা হবে।

৮। প্রতিষ্ঠানের নিয়মাবলী মেনে চলতে হবে এবং সকল প্রকার গোপনীয়তা বজায় রাখতে হবে।

৯। গবেষণার সুনির্দিষ্ট জনগোষ্টীর শারিরীক চিকিৎসা বিষয়ক অথবা ঔষধ প্রয়োগ করা কোন প্রকার পরীক্ষা-নিরীক্ষা অথবা মানসিক চাপ সৃষ্টি হয় এরূপ বিষয়ে গবেষনার অনুমতি দেয়া হবে না ।

১০। গবেষনায় কোন প্রকার ভবিষ্যত দিন নির্দেশনা ও ইন্টারভেনশন প্রয়োজনীয়তা দেখা দিলে সেক্ষেত্রে গবেষকগনকে প্রতিষ্ঠানের সাথে আলোচনা সাপেক্ষে তা প্রদান করতে হবে ।

১১। সেনানিবাস এবং দেশের প্রচলিত আইন/নীতিমালা ভঙ্গ করে এমন কোন বিষয়াদি গবেষণামূলক কর্মকান্ডে অন্তর্ভূক্ত করা যাবেনা।

১২। গবেষনায় তথ্য সংগ্রহ/প্রশ্নোত্তোরের ক্ষেত্রে মানহানিকর/অস্বস্তিকর/ স্পর্শকাতর বিষয়ের অবতারণা করা যাবে না।

১৩। গবেষনাকাজে সংগ্রীহিত তথ্য/ডাটার গোপনীয়তা নিশ্চিত করতে হবে এবং প্রয়াস কর্তৃপক্ষের অনুমতি ব্যতিত কোন তথ্য/ডাটা দেশী/বিদেশী কোন ব্যক্তি বা প্রতিষ্ঠানকে সরবরাহ করা যাবে না।

আমি ....শাহনাজ মুন্নী.. নিম্ন স্বাক্ষরকারী উপরোক্ত শর্তসমূহ মেনে চলার নিশ্চয়তা প্রদান করছি এবং আমার গবেষনা কাজটি পরিচালনা/সম্পন্ন করার ইচ্ছা পোষন করছি। আমার কোন প্রকার কাজ কর্ম দেশ/জাতি/প্রতিষ্ঠানের স্বার্থ পরিপন্থী হবে না এবং গবেষণার কার্যক্রমের পূর্ণাঙ্গ রিপোর্ট/কপি কার্যক্রম সম্পন্ন হওয়ার ০৭ দিনের মধ্যে প্রয়াস কর্তৃপক্ষকে হস্তান্তর করতে বাধ্য থাকবো।

Shahnaz Munny

গবেষকের স্বাক্ষর ও নাম

তারিখঃ 31.10.18

মোবাইল নং 01914031551

অনুমতি প্রদান

গবেষনার উপাত্ত সংগ্রহের জন্য উপরোল্লিখিত প্রয়োজনীয় তথ্যাদি প্রতিষ্ঠানে জমাকৃত হয়েছে। উপরোল্লিখিত শর্তসমূহ মেনে চলা নিশ্চিত করা হবে এবং বিবেচনার জন্য সুপারিশ করা হলো ।

৩১/১০/১৮

সংশ্লিষ্ট ক্ষেত্রে উপাধ্যক্ষ/পরিচালক

অধ্যক্ষের নির্দেশ

অনুমতি দেয়া হলো/হলো না/স্থগিত রাখা হলো ।

নির্বাহী পরিচালক ও অধ্যক্ষের স্বাক্ষর

২

সীমিত

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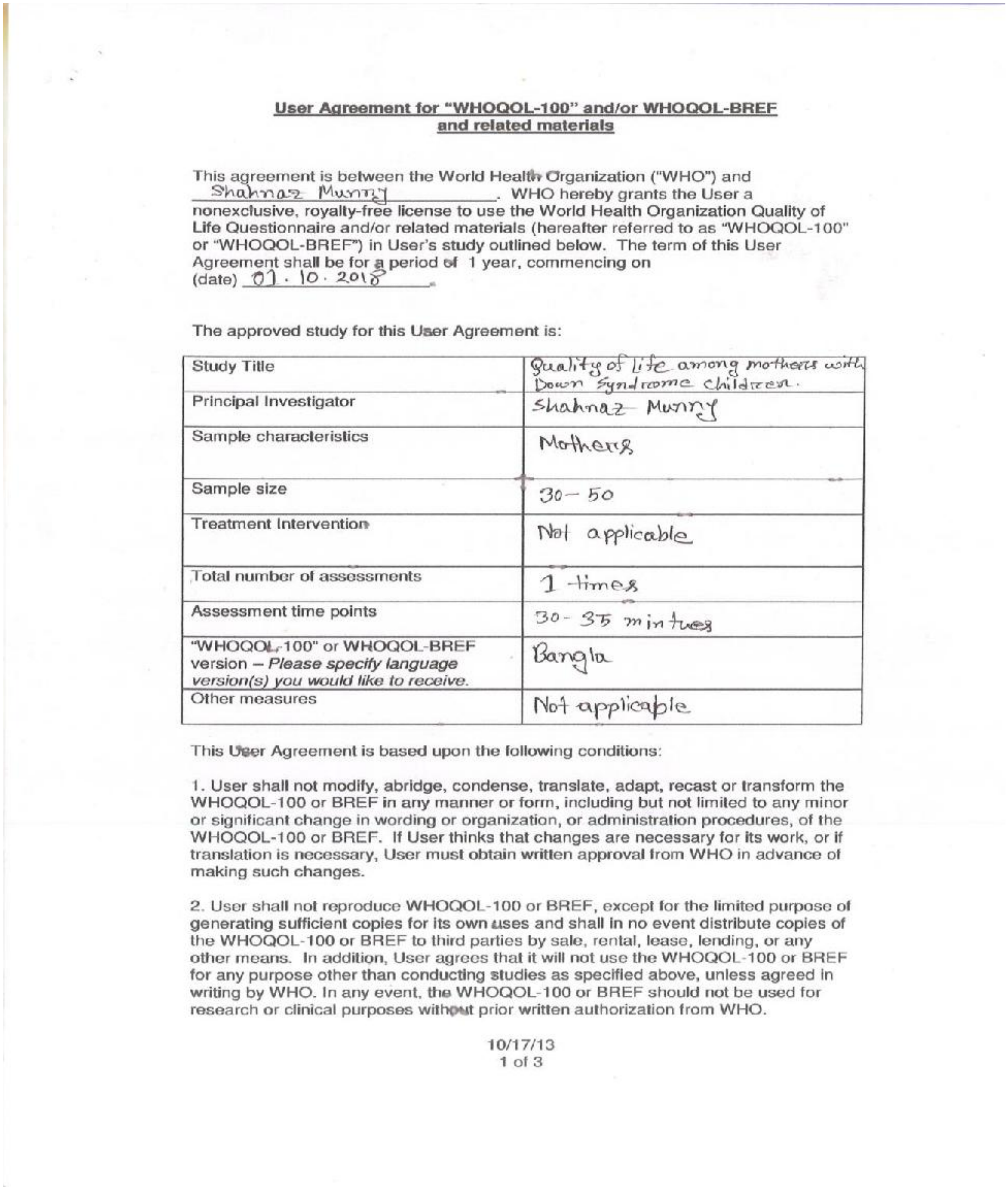
Appendix 4
Permission to Use WHOQOL-BREF Bangla



User Agreement for "WHOQOL-100" and/or WHOQOL-BREF and related materials

This agreement is between the World Health Organization ("WHO") and Shahnaz Munny. WHO hereby grants the User a nonexclusive, royalty-free license to use the World Health Organization Quality of Life Questionnaire and/or related materials (hereafter referred to as "WHOQOL-100" or "WHOQOL-BREF") in User's study outlined below. The term of this User Agreement shall be for a period of 1 year, commencing on (date) 01. 10. 2018.

The approved study for this User Agreement is:

Study Title	Quality of Life among mothers with Down Syndrome children.
Principal Investigator	Shahnaz Munny
Sample characteristics	Mothers
Sample size	30 – 50
Treatment Intervention	Not applicable
Total number of assessments	1 times
Assessment time points	30 - 35 mintues
"WHOQOL-100" or WHOQOL-BREF version – *Please specify language version(s) you would like to receive.*	Bangla
Other measures	Not applicable

This User Agreement is based upon the following conditions:

1. User shall not modify, abridge, condense, translate, adapt, recast or transform the WHOQOL-100 or BREF in any manner or form, including but not limited to any minor or significant change in wording or organization, or administration procedures, of the WHOQOL-100 or BREF. If User thinks that changes are necessary for its work, or if translation is necessary, User must obtain written approval from WHO in advance of making such changes.

2. User shall not reproduce WHOQOL-100 or BREF, except for the limited purpose of generating sufficient copies for its own uses and shall in no event distribute copies of the WHOQOL-100 or BREF to third parties by sale, rental, lease, lending, or any other means. In addition, User agrees that it will not use the WHOQOL-100 or BREF for any purpose other than conducting studies as specified above, unless agreed in writing by WHO. In any event, the WHOQOL-100 or BREF should not be used for research or clinical purposes without prior written authorization from WHO.

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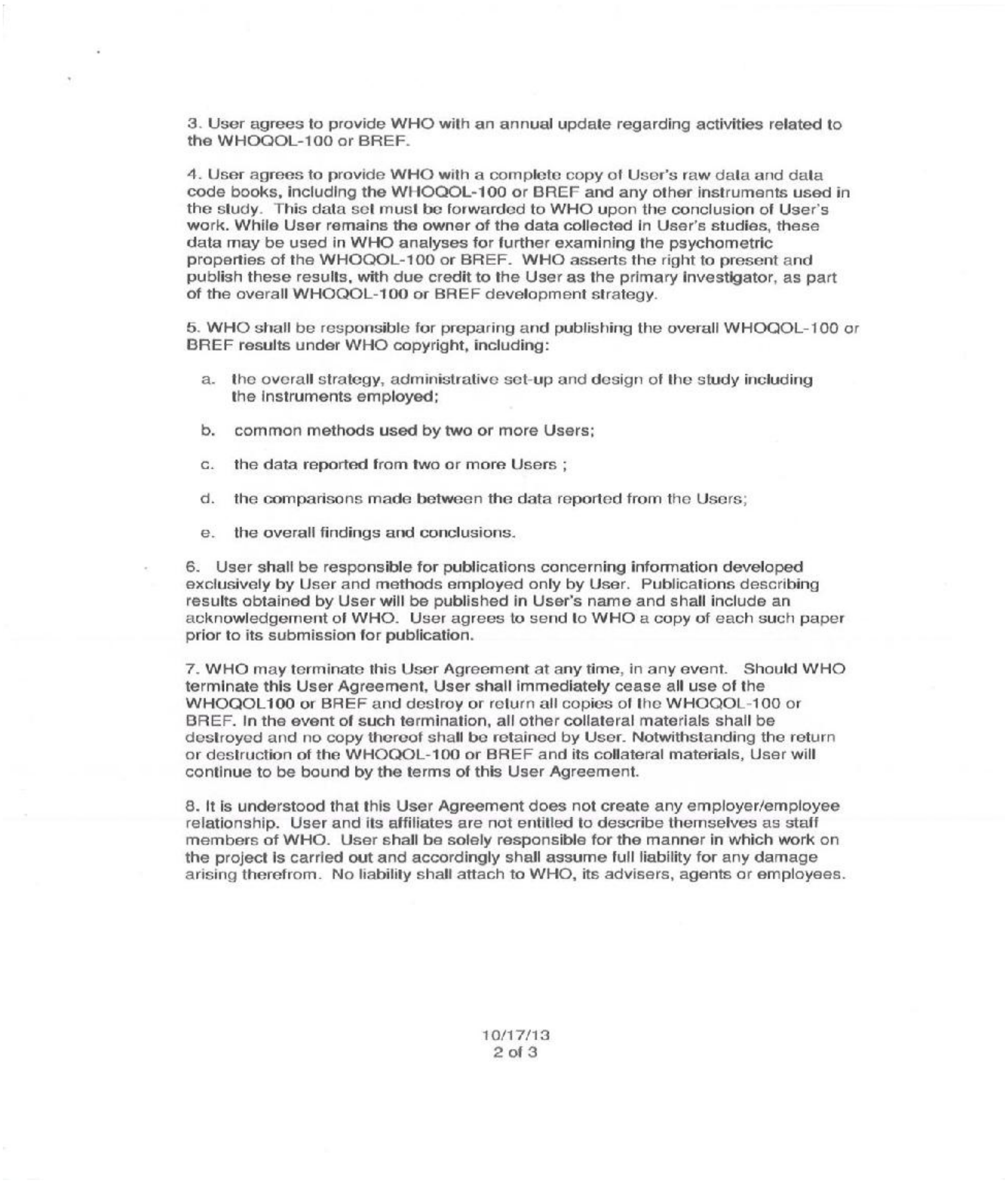
1 of 3



3. User agrees to provide WHO with an annual update regarding activities related to the WHOQOL-100 or BREF.

4. User agrees to provide WHO with a complete copy of User's raw data and data code books, including the WHOQOL-100 or BREF and any other instruments used in the study. This data set must be forwarded to WHO upon the conclusion of User's work. While User remains the owner of the data collected in User's studies, these data may be used in WHO analyses for further examining the psychometric properties of the WHOQOL-100 or BREF. WHO asserts the right to present and publish these results, with due credit to the User as the primary investigator, as part of the overall WHOQOL-100 or BREF development strategy.

5. WHO shall be responsible for preparing and publishing the overall WHOQOL-100 or BREF results under WHO copyright, including:

a. the overall strategy, administrative set-up and design of the study including the instruments employed;

b. common methods used by two or more Users;

c. the data reported from two or more Users ;

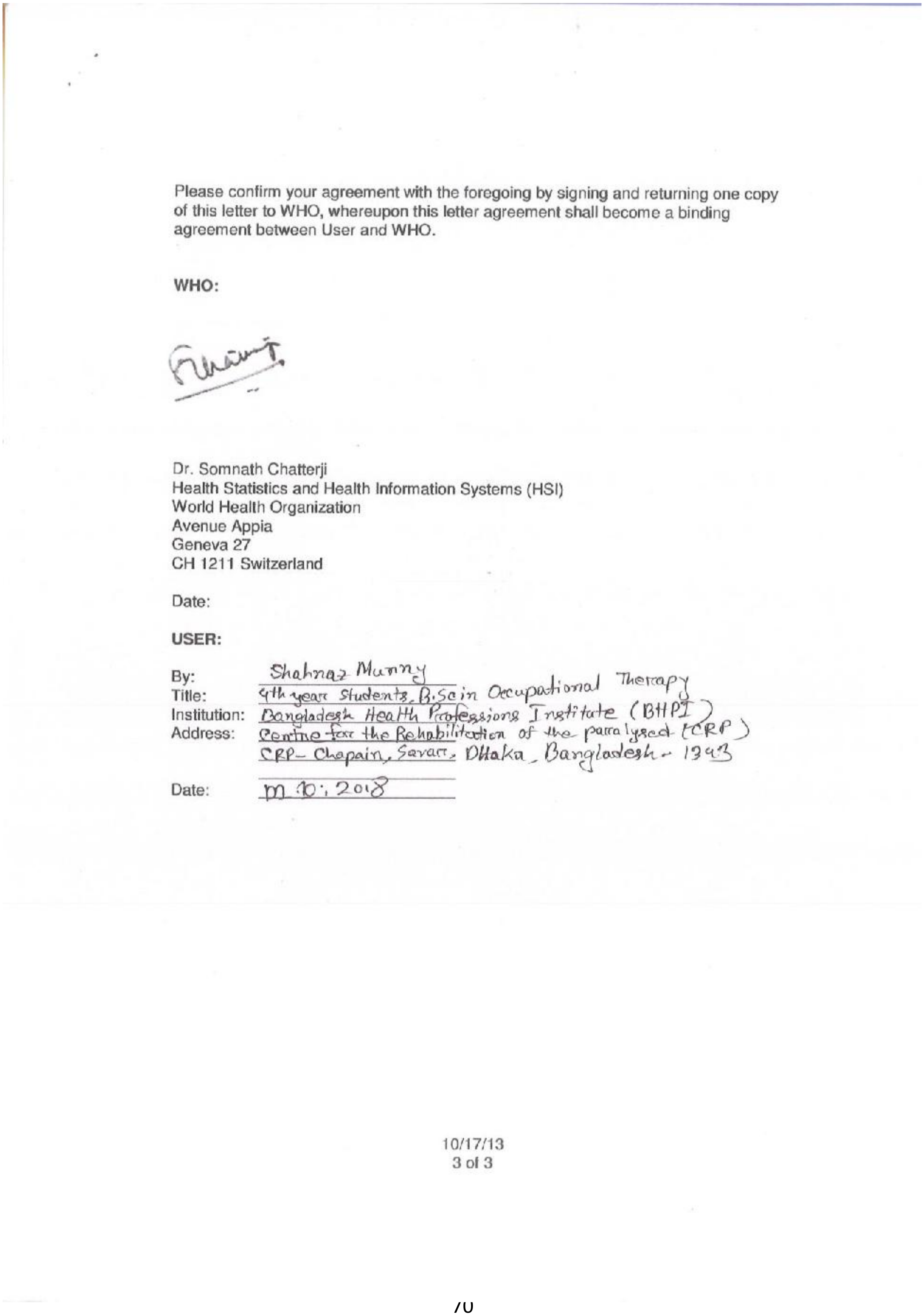
d. the comparisons made between the data reported from the Users;

e. the overall findings and conclusions.

6. User shall be responsible for publications concerning information developed exclusively by User and methods employed only by User. Publications describing results obtained by User will be published in User's name and shall include an acknowledgement of WHO. User agrees to send to WHO a copy of each such paper prior to its submission for publication.

7. WHO may terminate this User Agreement at any time, in any event. Should WHO terminate this User Agreement, User shall immediately cease all use of the WHOQOL100 or BREF and destroy or return all copies of the WHOQOL-100 or BREF. In the event of such termination, all other collateral materials shall be destroyed and no copy thereof shall be retained by User. Notwithstanding the return or destruction of the WHOQOL-100 or BREF and its collateral materials, User will continue to be bound by the terms of this User Agreement.

8. It is understood that this User Agreement does not create any employer/employee relationship. User and its affiliates are not entitled to describe themselves as staff members of WHO. User shall be solely responsible for the manner in which work on the project is carried out and accordingly shall assume full liability for any damage arising therefrom. No liability shall attach to WHO, its advisers, agents or employees.



Please confirm your agreement with the foregoing by signing and returning one copy of this letter to WHO, whereupon this letter agreement shall become a binding agreement between User and WHO.

WHO:

Dr. Somnath Chatterji
Health Statistics and Health Information Systems (HSI)
World Health Organization
Avenue Appia
Geneva 27
CH 1211 Switzerland

Date:

USER:

By: Shahnaz Munny
Title: 4th year Students, B.Sc in Occupational Therapy
Institution: Bangladesh Health Professions Institute (BHPI)
Address: Centre for the Rehabilitation of the paralysed (CRP)
CRP- Chapain, Savar, Dhaka, Bangladesh - 1343

Date: 11.10.2018

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3 of 3

Appendix 5 (A)

Consent form & Information sheet (English)

BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)

Department of Occupational Therapy

CRP- Chapain, Savar, Dhaka-1343. Tel: 02-7745464-5, 7741404, Fax: 02-774506

Code No:

Participants' Information and Consent sheet

Title: Quality of life among mothers with Down syndrome children

Investigator: Shahnaz Munny, Student of B.Sc. in Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP- Savar, Dhaka- 1343.

Supervisor: Kaniz Fatema, Lecturer in Occupational Therapy Department, Bangladesh Health Professions Institute (BHPI), CRP- Savar, Dhaka- 1343.

Place: Faith Bangladesh, Iqbal road, Dhaka, Dhaka Proyash, Dhaka, William and Marie Taylor school at CRP, Dhaka.

Part 1- Information Sheet:

Introduction:

I am Shahnaz Munny, B.Sc. in Occupational Therapy student of the Bangladesh Health Professions Institute (BHPI), have to conduct a thesis as a part of this Bachelor course, under thesis supervisor, Kaniz Fatema. You are going to have details information about the study purpose, data collection process, ethical issues. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. If this consent form contains some words that you do not understand, please ask me to stop. I will take time to explain.

Research background and objectives:

You are being invited to be a part of this research because In Bangladesh there are no findings about the quality of life of mothers with DS children. There are no studies about how mothers with down syndrome children are thinking, feeling, or understanding about their child's disability. This study has identified mothers' quality of life because of have a child with Down syndrome. To identify the percentage among physical, social, environmental and psychological. To identify about how much effect their quality of life of mothers with Down syndrome. Mother is the primary or main care giver of a child. If the mothers have negative experiences in their quality of life this must affect their child caring and their daily life. This research study is particularly necessary for occupational therapists so that they could be able to understand the needs and expectation of mothers and how mothers' daily life and QOL are impacted after having a down syndrome child. It will also help therapists to provide effective family education to mother and carer by increasing their knowledge about down syndrome, and changing their attitudes towards down syndrome.

Let's know about the topic related to participation in this research work:

Before signing the license from you, the details of managing the research project will be presented to you in detail through this participation note. If you want to participate in this study, you will have to sign the agreement. If you do not complete literacy knowledge, or if you fail to provide a signature for another reason, then your thumb impression will be taken in a consent sheet in presence of a witness. If you ensure the participation, a copy of your consent will be given. After a representative of collection data team by the researcher will go to you. At any given time taken from you by a question paper information will be collected. Your participation in this research project is optional. If you do not agree then you do not have to participate. Despite your consent, you can withdraw your participation at any time without giving any explanation to the researcher.

What are the benefits and risks of participation?

You will not get any benefit directly to participate in the research project. Participation in this study can lead to many difficulties in your daily work. However, we are hopeful that the benefits derived from the results of this research will remove the disadvantages. Do not worry about the questions that others may know about your identity, it’s a request. Patients name, address will not be included in the data analysis software to reduce the risk of uncover identity.

Confidentiality of information:

By signing this agreement, you are allowing the research staff to study this research project to collect and use your personal resources. Any information gathered for this research project, which can identify you, will be confidential. The information collected about you will be mentioned in a symbolic way. Only the concerned researchers and their supervisor will be able to access this information directly. Symbolic ways identified data will be used for the next data analysis. Information sheets will be kept into a locked drawer. Electronic version of data will be collected in BHPI’s Occupational Therapy department and researcher’s personal laptop. It is expected that the results of this research project will be published and presented in different forums. In any publication and presentation, the information will be provided in such a way that you cannot be identified in any way without your consent. Data will be initially collected in papers.

Information about promotional results:

The results of this study will be published in various social media, websites, conferences, discussions and reviewed journals.

Participants' fees:

There is no stimulus and remuneration arrangement for participation in this study.

Source of funding to manage research:

The cost of this research will be spent entirely by researchers own funds. This study will be done in small areas and no money will come from external source

Information about withdrawal from participation:

Despite your consent, you can withdraw your participation at any time without giving any explanation to the researcher. If the information can be used after the cancellation, its permission will be mentioned in the participant's withdrawal letter (Applicable only for voluntary withdrawal).

Contact address with the researcher:

If you have any questions about the research project or if you have any questions about the research project, you can ask it anytime now or later. In that case, you can contact the number assigned to the researcher 01914031551 (ShahnazMunny).

Complaint:

If there is any complaint regarding the conduct of this research project, contact this number with the Association of Ethics (7745464-5). This research project has been reviewed and approved by the CRP-BHPI / IRB / 10/18/1265 from the Bangladesh Health Professions Institute, Savar's Educational Ethics Council.

Participant’s Withdrawal letter

(Applicable only for voluntary withdrawal)

Participant’s Name:

Reason for Withdrawal:

Whether permission to previous information is used?

Yes/Not

Participant’s Name:

Participant’s Signature & Date:

*If illiterate

Participant fingerprint

Witness's Name:

Witness’s Signature & Date:

Part 2- Consent form:

I have been invited to participate in the research titled **Quality of Life among Mothers with Down Syndrome Children**. I have read the previous letter or it has been read to me. There was an opportunity to ask my questions about this and I got a satisfactory answer to all the questions. I voluntarily agree to be a participant in this study.

Participant Name:

Participant Signature: Date:

*If illiterate

Participant fingerprint

Witness's Name:

Witness's Signature: Date:

Researcher & Consenting person's statement:

I have read the participant's information form to the participant and according to my maximum capacity; the participants understand that the following topics will be done:

1) All the information will be used in research work
2) Information will be totally confidential
3) Participant's name and identity will not be published

I am sure that the participant has been given the opportunity to ask questions about this topic and the accurate answer to these questions has been given as per my maximum capacity. I am convinced that no person has been compelled to give consent. He or she has freely or voluntarily agreed.

A copy of Participant's information and consent sheet has given to the participant

Researcher Name:

Researcher Signature: Date:

Appendix 5 (B)

Consent form & Information sheet (Bangla)

বাংলাদেশ হেল্থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)

অকুপেশনাল থেরাপি বিভাগ

সিআরপি– চাপাইন, সাভার, ঢাকা–১৩৪৩. টেলি: ০২-৭৭৪৫৪৬৪–৫ ,৭৭৪১৪০৪, ফ্যাক্স: ০২-৭৭৪৫০৬

কোড নং:

অংশগ্রহণকারীদের তথ্য এবং সম্মতিপত্র

গবেষনার বিষয়: “ডাউন সিন্ড্রোম বাচ্চাদের মায়ের জীবন যাত্রার মান”।

গবেষক: শাহানাজ মুন্নী, বি.এস.সি ইন অকুপেশনাল থেরাপি (৪র্থ বর্ষ), সেশন: ২০১৪-২০১৫ ইং, বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), সাভার, ঢাকা- ১৩৪৩

তত্ত্বাবধায়ক: কানিজ ফাতেমা, শিক্ষিকা, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেল্ প্রফেশন্স ইনস্টিটিউট।

গবেষনার স্থান: ফেইথ বাংলাদেশ, ইকবাল রোড, ঢাকা, ঢাকা প্রয়াস, ঢাকা এবং উইলিয়াম এন্ড মেরী টেইলর স্কুল, সি.আর.পি, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ।

পর্ব ১: তথ্যপত্র

ভূমিকা:

আমি শাহানাজ মুন্নী, ঢাকা বিশ্ববিদ্যালয়ে চিকিৎসা অনুষদের অধীনে বাংলাদেশ হেল্ প্রফেশনস ইনস্টিটিউটে বি.এস.সি.ইন অকুপেশনাল থেরাপি বিভাগে ৪র্থ বর্ষের ছাত্রী হিসেবে স্নাতক শিক্ষাকার্যক্রম (২০১৪-২০১৫ ইং) সেশনে অধ্যয়নরত আছি। বিএইচপিআই থেকে অকুপেশনাল থেরাপি বি.এস.সি শিক্ষাকার্যক্রমটি সম্পন্ন করার জন্য একটি গবেষনা প্রকল্প পরিচালনা করা বাধ্যতামূলক। এই গবেষণা প্রকল্পটি অকুপেশনাল থেরাপি বিভাগের শিক্ষিকা কানিজ ফাতেমা এর তত্ত্বাবধায়নে সম্পন্ন করা হবে। এই অংশগ্রহনকারী তথ্যপত্রের মাধ্যমে গবেষণার প্রকল্পটির উদ্দেশ্য, উপাত্ত সংগহের প্রণালী ও গবেষণাটির সাথে সংশ্লিস্ট বিষয় কিভাবে রক্ষিত হবে তা বিস্তারিতভাবে আপনার কাছে উপস্থাপন করা হবে। যদি এই গবেষণায় অংশগ্রহন করতে আপনি ইচ্ছুক থাকেন, সেক্ষেত্রে এই গবেষণার সম্পৃক্ত বিষয় সম্পর্কে স্বচ্ছ ধারনা থাকলে সিদ্ধান্ত গ্রহন সহজতর হবে। অবশ্য এখন আপনার অংশগ্রহন আমাদের নিশ্চিত করতে হবে না। যে কোন সিদ্ধান্ত গ্রহনের পূর্বে, যদি চান তাহলে আপনার আত্মীয়-স্বজন, বন্ধু অথবা আস্থাভাজন যেকারো সাথে এই ব্যাপারে আলোচনা করে নিতে পারেন। অপরপক্ষে, অংশগ্রহনকারী তথ্যপত্রটি পড়ে, যদি কোন বিষয়বস্তু বুঝতে সমস্যা হয় অথবা যদি কোন কিছু সম্পর্কে আরো বেশি জানার প্রয়োজন হয়, তবে নির্দ্বিধায় প্রশ্ন করতে পারেন।

গবেষনার প্রেক্ষাপট ও উদ্দেশ্য:

এই গভেষনায় সকল ডাউন সিড্রোম বাচ্চার মায়েদের অন্তর্ভূক্ত হবার জন্য আমন্ত্রন জানানো হবে। এর অংশ হিসাবে, আপনাকেও উক্ত গবেষনা প্রকল্পে অংশগ্রহনের জন্য আমন্ত্রণ জানানো হলো। কারণ, বাংলাদেশে ডাউন সিড্রোম শিশুর মায়েদের জীবন যাত্রার মান সম্পর্কে কোনো তথ্য নেই। ডাউন সিড্রোম শিশুদের অক্ষমতা সম্পর্কে তাদের মায়েদের চিন্তা-ভাবনা, অনুভূতি বা তাদেরকে বোঝার বিষয়ে কোন গবেষনা হয়নি। এই গবেষনাটি ডাউন সিড্রোম শিশুদের মায়ের জীবন মাত্রার মান নিয়ে করা হয়েছে। ডাউন সিড্রোম শিশুদের জন্য তাদের মায়েদের জীবন যাত্রার মান কতটা প্রভাবিত হবে তা সনাক্ত করবে। মায়েদের জীবন যাত্রার মানে যদি কোন নেতিবাচক অভিজ্ঞতা থাকে তাহলে সেটা তাদের সন্তানের যত্ন এবং তাদের দৈনন্দিন জীবনে প্রভাব ফেলে থাকে। এই গবেষনাটি অকুপশেনাল থেরাপিস্টদের জন্য বিশেষভাবে প্রয়োজনীয় যাতে তারা মায়েদের প্রয়োজনীয়তা এবং প্রত্যাশা বুঝতে পারে এবং কিভাবে ডাউন সিড্রোম বাচ্চাদের জন্য মায়েদের দৈনন্দিন জীবনযাপনে প্রভাবফেলে। আপনার কার্যকারী অংশগ্রহণ গবেষণার উদ্দেশ্য পূরণে সহায়তা করবে বলে আমরা আশাবাদী।

এই গবেষনা কর্মটিতে অংশগ্রহনের সাথে সম্পৃক্ত বিষয়সমূহ কি সে সম্পর্কে জানা যাকঃ

আপনার থেকে অনুমতিপত্রে স্বাক্ষর নেবার আগে, এই অংশগ্রহনকারী তথ্যপত্রের মাধ্যমে গবেষনা প্রকল্পটির পরিচালনা করার তথ্যসমূহ বিস্তারিত ভাবে আপনার কাছে উপস্থাপন করা হবে। আপনি যদি এই গবেষনায় অংশগ্রহন করতে চান, তাহলে সম্মতিপত্রে আপনাকে স্বাক্ষর করতে হবে। আপনি যদি স্বাক্ষর জ্ঞান সম্পন্ন না হন বা অন্য কোন কারনে স্বাক্ষর প্রদানে ব্যর্থ হন, সেক্ষেত্রে আপনার কাছ থেকে একজন স্বাক্ষীর উপস্থিতিতে বৃদ্ধাঙ্গুলির ছাপ সম্মতি পত্রে নেওয়া হবে। আপনি অংশগ্রহন নিশ্চিত করলে, আপনার সংরক্ষনের জন্য সম্মতিপত্রটির একটি অনুলিপি দিয়ে দেয়া হবে। পরবর্তীতে গবেষক কর্তৃক গঠিত তথ্য-উপাত্ত সংগ্রহের একটি দলের প্রতিনিধি আপনার কাছে যাবে। আপনার থেকে চেয়ে নেওয়া যে কোন একটি নির্দিষ্ট সময়ে একটি প্রশ্নপত্রের মাধ্যমে তথ্য সংগ্রহ করা হবে। এই গবেষনার প্রকল্পে আপনার অংশগ্রহণ ঐচ্ছিক। যদি আপনি সম্মতি প্রদান না করেন তবে আপনাকে অংশগ্রহন করতে হবে না। আপনি সম্মতি প্রদান করা স্বত্ত্বেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন।

অংশগ্রহনের সুবিধা ও ঝুঁকিসমূহ কি ?

গবেষনা প্রকল্পটিতে অংশগ্রহনের জন্য আপনি সরাসরি কোন সুবিধা পাবেন না। এই গবেষণায় অংশগ্রহনে আপনার দৈনিন্দন কাজে সাময়িক অসুবিধা কারন হতে পারে। তবে আমরা আশাবাদী যে, এই গবেষনার ফলাফল থেকে প্রাপ্ত উপকারীতা এই অসুবিধাকে অতিক্রম করবে। যেসমস্ত প্রশ্নের মাধ্যমে আপনার পরিচয় সর্ম্পকে অন্যরা জানতে পারে, সেই বিষয়ে উদ্বিগ্ন না হবার জন্য অনুরোধ করা হচ্ছে। অংশগ্রহণকারীর নাম, ঠিকানা উপাত্ত বিশ্লেষণের সফটওয়্যারে উল্লেখ না করে পরিচয় উন্মুক্ত হবার ঝুঁকি কমানো হবে।

তথ্যের গোপনীয়তা কি নিশ্চিত থাকবে?

এই সম্মতিপত্রে স্বাক্ষর করার মধ্য দিয়ে, আপনি এই গবেষনা প্রকল্পে অধ্যয়নরত গবেষনা কর্মীকে আপনার ব্যক্তিগত তথ্য সংগ্রহ ও ব্যবহার করার অনুমতি দিয়েছেন। এই গবেষনা প্রকল্পের জন্য সংগৃহীত যেকোন তথ্য, যা আপনাকে

সনাক্ত করতে পারে তা গোপনীয় থাকবে। আপনার সম্পর্কে সংগৃহীত তথ্যসমূহ সাংকেতিক উপায়ে উল্লেখ থাকবে। শুধুমাত্র এর সাথে সরাসরি সংশ্লিষ্ট গবেষক ও তার তত্ত্বাবধায়ক এই তথ্যসমূহে প্রবেশাধিকার পাবেন। সাংকেতিক উপায়ে চিহ্নিত উপাত্ত সমূহ পরবর্তী উপাত্ত বিশ্লেষনের কাজে ব্যবহৃত হবে। তথ্যপত্রগুলো তালাবদ্ধ ড্রয়ারে রাখা হবে। বিএইচপিআই এর অকুপেশনাল থেরাপি বিভাগে ও গবেষকের ব্যক্তিগত ল্যাপটপে উপাত্তসমূহের ইলেকট্রনিক ভার্সন সংগৃহীত থাকবে।

প্রত্যাশা করা হচ্ছে যে, এই গবেষণা প্রকল্পের ফলাফল বিভিন্ন ফোরামে প্রকাশিত এবং উপস্থাপিত হবে। যে কোন ধরনের প্রকাশনা ও উপস্থাপনার ক্ষেত্রে তথ্যসমূহ এমন ভাবে সরবরাহ করা হবে, যেন আপনার সম্মতি ছাড়া আপনাকে কোন ভাবেই সনাক্ত করা না যায়। তথ্য-উপাত্ত প্রাথমিক ভাবে কাগজপত্র সংগ্রহ করা হবে ।

ফলাফল প্রচার সর্ম্পকিত তথ্য

এই গবেষনার ফলাফল বিভিন্ন সামাজিক মাধ্যম, ওয়েবসাইট, সম্মেলন, আলোচনাসভায় এবং পর্যালেচিত জার্নালে প্রকাশ করা হবে।

অংশগ্রণকারীর পারিশ্রমিক

এই গবেষণায় অংশগ্রহনের জন্য কোন উদ্দীপনা ও পারিশ্রমিক দেবার ব্যবস্থা নেই।

গবেষণা পরিচালনার ব্যয়কৃত অর্থের উৎস

এই গবেষণাটির খরচ সম্পূর্ণ গবেষকের নিজস্ব তহবিল থেকে ব্যয় করা হবে। এই গবেষণাটি ছোট পরিসরে করা হবে এবং এখানে কোন অর্থ বহিরাগত উৎস থেকে আসবে না।

অংশগ্রহণ থেকে প্রত্যাহার সর্ম্পকিত তথ্যসমূহ

আপনি সম্মতি প্রদান করা স্বত্তেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন। বাতিল করার পর তথ্যসমূহ কি ব্যবহার করা যাবে কি যাবেনা তার অনুমতি অংশগ্রহণকারীর প্রত্যাহারপত্রে (শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য) উল্লেখ করা থাকবে।

গবেষকের সাথে যোগাযোগের ঠিকানা

গবেষনা প্রকল্পটির বিষয়ে যোগাযোগ করতে চাইলে অথবা গবেষনা প্রকল্পটির সর্ম্পকে কোন প্রশ্ন থাকলে,এখন অথবা পরবর্তীতে যে কোন সময়ে তা জিজ্ঞাসা করা যাবে। সেক্ষেত্রে আপনি গবেষকের সাথে উল্লেখিত ০১৯১৪০৩১৫৫১ (শাহনাজ মুন্নী) নাম্বারে যোগাযোগ করতে পারেন।

অভিযোগ

এই গবেষনা প্রকল্প পরিচালনা প্রসঙ্গে যেকোন অভিযোগ থাকলে প্রাতিষ্ঠানিক নৈতিকতা পরিষদের সাথে এই নাম্বারে (৭৭৪৫৪৬৪-৫) যোগাযোগ করবেন। এই গবেষনা প্রকল্পটি বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট, সাভারের প্রাতিষ্ঠানিক নৈতিকতা পরিষদ থেকে সিআরপি-বিএইচপিআই/আইআরবি/১০/১৮/১২৬৫ পর্যালোচিত ও অনুমোদিত হয়েছে।

অংশগ্রহণকারীর প্রত্যাহার পত্র

(শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য)

অংশগ্রহনকারীর নাম: ……………………………………………………………

প্রত্যাহার করার কারন:

………
………
………
………
……………………………………………………………………

পূর্ববর্তী তথ্য ব্যবহারের অনুমতি থাকবে কিনা?

হ্যাঁ/না

অংশগ্রহনকারীর স্বাক্ষর: তারিখঃ
*নিরক্ষর হয় যদি
অংশগ্রহনকারীর আঙ্গুলের ছাপ

স্বাক্ষীর স্বাক্ষর ঃ
তারিখঃ

সম্মতি পত্র ০২ঃ পর্ব

“ডাউন সিন্ড্রোম বাচ্চাদের মায়ের জীবন যাত্রার মান”- আমি পূর্বলিখিত তথ্য পত্রটি পড়েছি বা এটা আমাকে পড়ে শোনানো হয়েছে। এই বিষয়ে আমার প্রশ্ন জিজ্ঞাসা করার সুযোগ ছিল এবং যে কোন প্রশ্নের আমি সন্তুষ্টজনক উত্তর পেয়েছি। এই গবেষনায় একজন অংশগ্রহনকারী হবার জন্য আমি স্বেচ্ছায় সম্মতি দিচ্ছি।

অংশগ্রহনকারীর স্বাক্ষর: তারিখঃ
*নিরক্ষর হয় যদি
অংশগ্রহনকারীর আঙ্গুলের ছাপ

স্বাক্ষীর স্বাক্ষর ঃ
তারিখঃ

গবেষক ও সম্মতিকারীর বিবৃতি:

আমি অংশগ্রহনকারীকে অংশগ্রহনকারীর তথ্যপত্রটি পড়ে শুনিয়েছি এবং আমার সর্বোচ্চ সামর্থ অনুযায়ী নিশ্চিত করেছি যে, অংশগ্রহনকারীর বোধগম্য হয়েছে যে, নিম্নোক্ত বিষয়সমূহ করা হবে।

১) সকল তথ্য গবেষণার কাজে ব্যবহৃত হবে।
২) তথ্যসমূহ সম্পূর্ণভাবে গোপনীয় করা হবে।
৩) অংশগ্রহনকারীর নাম ও পরিচয় প্রকাশ করা হবে না।

আমি নিশ্চিত করেছি যে, এই বিষয় সর্ম্পকে অংশগ্রহনকারীকে প্রশ্ন জিজ্ঞাসা করার সুযোগ দেয়া হয়েছে এবং অংশগ্রহনকারী যে সকল প্রশ্ন জিজ্ঞাসা আমার সর্বোচ্চ সামর্থ অনুযায়ী, সেগুলোর সঠিক উত্তর প্রদান করা সম্ভব হয়েছে। আমি নিশ্চিত করেছি যে, কোন ব্যক্তিকে সম্মতি দান করতে বাধ্য করা হয়নি। তিনি অবাধে অথবা স্বেচ্ছায় সম্মতি দিয়েছেন।

অংশগ্রহনকারীকে অংশগ্রহনকারীর তথ্য ও সম্মতিপত্রের একটি অনুলিপি দেওয়া হয়েছে।

গবেষকের নাম:

গবেষকের স্বাক্ষর : তারিখ:

Appendix 6 (A)

Socio-demographic questionnaire (English)

Participant Code no:
General questions
Please read the explanation on the previous page before answering the questions below!

- What is your age range?

1. 16-25 years.
2. 26-35 years.
3. > 35 years.

- How old his/her is father?

1. 16-25 years.
2. 26-35 years.
3. > 35 years.

- Educational background?

1. Primary.
2. UP to S.S.C
3. H.S.C and above
4. Illiterate

- Educational background of his/her father?

1. Primary.
2. UP to S.S.C
3. H.S.C and above
4. Illiterate

- Religion?

1. Muslim
2. Hindu
3. Others

- Where do you live?

1. Village
2. Town

- Household:

1. Own
2. Rented

- What type of transportation used?

1. Car
2. Motorbike
3. Bus
4. Rickshaw

5. CNG

- How old is your child?

1. 1-3 years
2. 4-6 years
3. 7-9 years
4. 10-12 years
5. More than 12 years

- What is your child's number?

1. First
2. Second
3. Third
4. Fourth
5. More

- Does he/she have any other siblings?

1. Yes
2. No

- Does your other child have any disability?

1. Yes
2. No

- What is your occupation?

1. Employee
2. Business
3. Study
4. Housewife
5. Others

- What is child father's occupation?

1. Employee
2. Business
3. Day labor
4. Farmer
5. Others

- Monthly income?

1. 1000-20000
2. 21000-40000
3. 41000-60000
4. More than 60000

Appendix 6 (B)

Socio-demographic questionnaire (Bangla)

অংশ গ্রহনকারীদের কোড নম্বরঃ

সাধারন প্রশ্ন

নিম্নের প্রশ্নের উত্তর দেওয়ার আগে, দয়া করে পূর্ববর্তী পৃষ্ঠার বিবরণী পড়ুন

- আপনার বয়স কত?

  ১। ১৬-২৫ বছর

  ২। ২৬-৩৫ বছর

  ৩। >৩৫ বছর
- শিশুর বাবার বয়স কত?

  ১। ১৬-২৫ বছর

  ২। ২৬-৩৫ বছর

  ৩। >৩৫ বছর
- আপনার শিক্ষাগত যোগ্যতা কি?

  ১। প্রাথমিক

  ২। মাধ্যমিক

  ৩। উচ্চ মাধ্যমিক এবং তার উপরে

  ৪। অশিক্ষিত
- শিশুর বাবার শিক্ষাগত যোগ্যতা কি?

  ১। প্রাথমিক

  ২। মাধ্যমিক

  ৩। উচ্চ মাধ্যমিক এবং তার উপরে

  ৪। অশিক্ষিত
- ধর্মঃ-

  ১। মুসলিম

  ২। হিন্দু

  ৩। অন্যান্য
- আপনি কোথায় বাস করেন?

  ১। গ্রাম

  ২। শহর
- বাসস্থানঃ-

  ১। নিজের

  ২। ভাড়াটে
- কোন ধরনের পরিবহন ব্যাবহার করে?

  ১। গাড়ী

  ২। মোটর সাইকেল

  ৩। বাস

৪। রিক্সা

- বাচ্চার বয়স কত?

  ১। ১-৩ বছর

  ২। ৪-৬ বছর

  ৩। ৭-৯ বছর

  ৪। ১০-১২ বছর

  ৫। ১২ বছরের বেশি
- আপনার এটা কততম বাচ্চা?

  ১। প্রথম

  ২। দ্বিতীয়

  ৩। তৃতীয়

  ৪। চতুর্থ

  ৫। আরও অধিক
- শিশুর অন্য কোন ভাইবোন আছে?

  ১। হ্যাঁ

  ২। না
- আপনার অন্য কোন বাচ্চার অক্ষমতা আছে?

  ১। হ্যাঁ

  ২। না
- আপনি বর্তমানে কি কাজ করছেন?

  ১। চাকুরী

  ২। ব্যবসা

  ৩। পড়ালেখা

  ৪। গৃহিণী
- শিশুর বাবা বর্তমানে কি কাজ করছেন?

  ১। চাকুরী

  ২। ব্যবসা

  ৩। দিন মজুর

  ৪। কৃষক
- পারিবারিক মাসিক আয় কত টাকা?

  ১। ১০০০-২০০০০

  ২। ২১০০০-৪০০০০

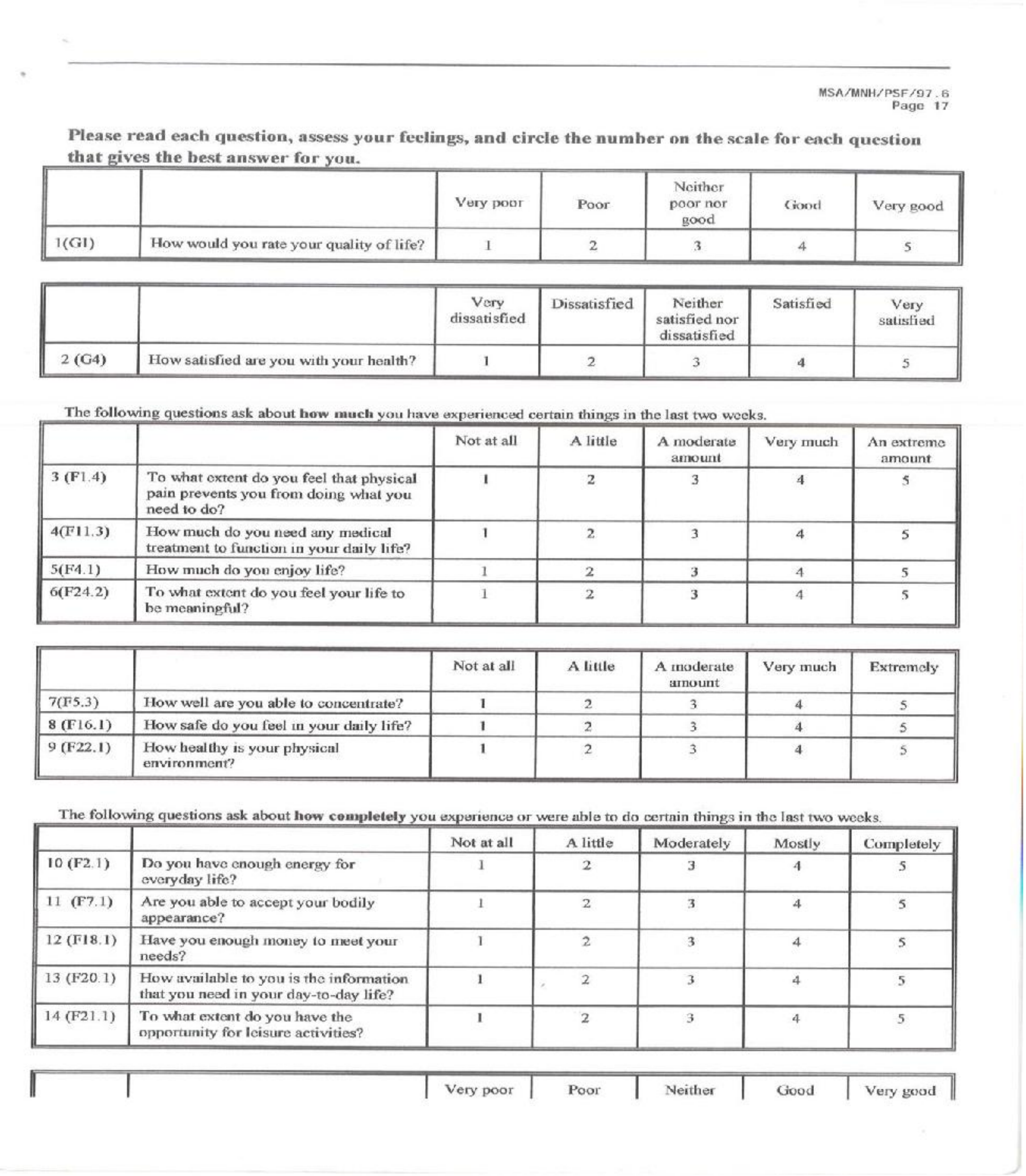
  ৩। ৪১০০০-৬০০০০

  ৪। ৬০০০০ এর বেশি

  ৫। কোন আয় নাই

Appendix 7 (A)

WHOQOL-BREF (English)



Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither	Good	Very good

				poor nor good		
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?..

How long did it take to fill this form out?..

Do you have any comments about the assessment?

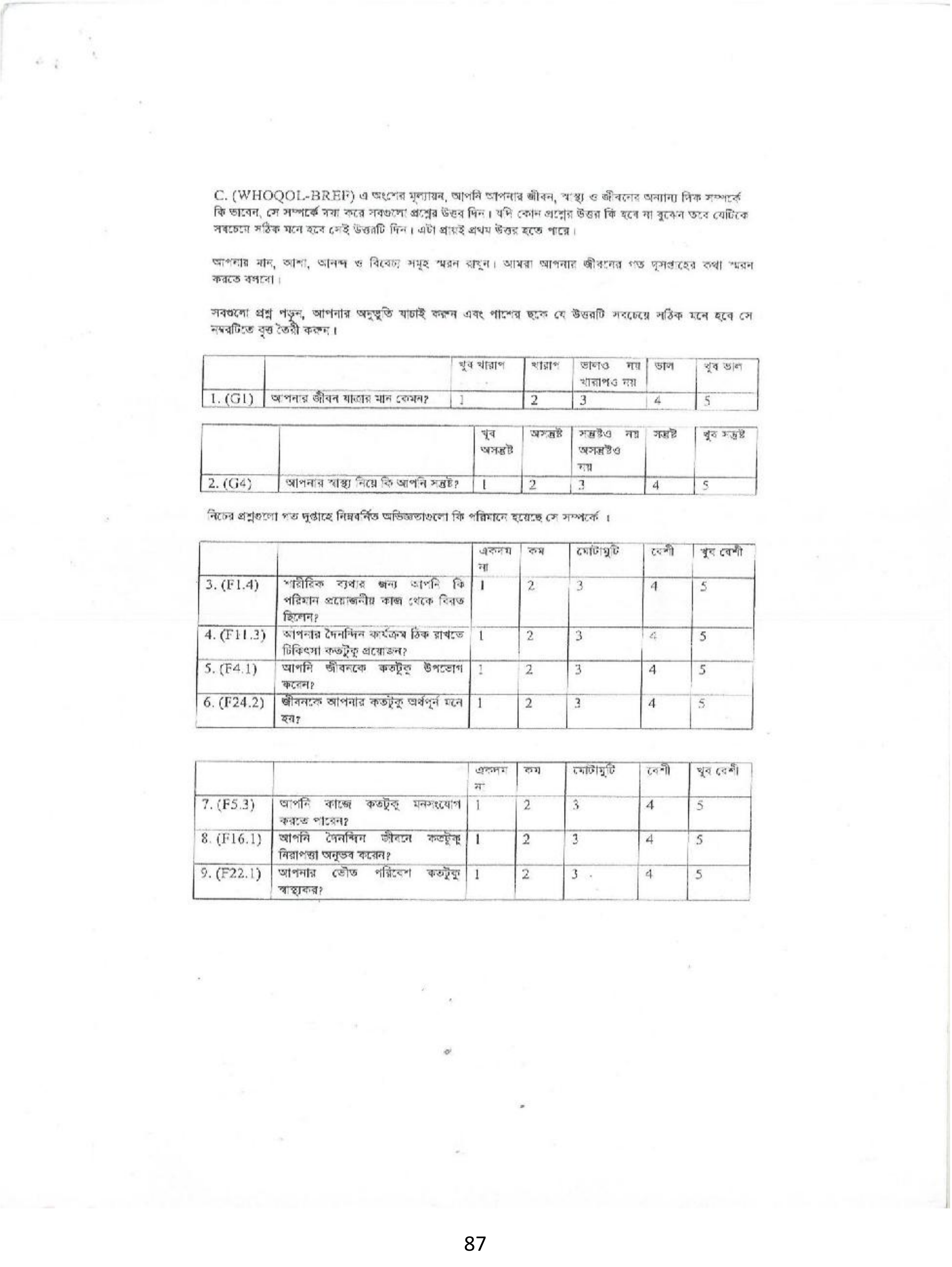
....

....

THANK YOU FOR YOUR HELP

Appendix 7 (B)

WHOQOL-BREF (Bangla)



C. (WHOQOL-BREF) এ অংশের মূল্যায়ন, আপনি আপনার জীবন, স্বাস্থ্য ও জীবনের অন্যান্য দিক সম্পর্কে কি ভাবেন, সে সম্পর্কে দয়া করে সবগুলো প্রশ্নের উত্তর দিন। যদি কোন প্রশ্নের উত্তর কি হবে না বুঝেন তবে যেটিকে সবচেয়ে সঠিক মনে হবে সেই উত্তরটি দিন। এটা প্রায়ই প্রথম উত্তর হতে পারে।

আপনার মান, আশা, আনন্দ ও বিবেচ্য সমূহ স্মরন রাখুন। আমরা আপনার জীবনের গত দুসপ্তাহের কথা স্মরন করতে বলবো।

সবগুলো প্রশ্ন পড়ুন, আপনার অনুভূতি যাচাই করুন এবং পাশের ছকে যে উত্তরটি সবচেয়ে সঠিক মনে হবে সে নম্বরটিতে বৃত্ত তৈরী করুন।

		খুব খারাপ	খারাপ	ভালও নয় খারাপও নয়	ভাল	খুব ভাল
1. (G1)	আপনার জীবন যাত্রার মান কেমন?	1	2	3	4	5

		খুব অসন্তুষ্ট	অসন্তুষ্ট	সন্তুষ্টও নয় অসন্তুষ্টও নয়	সন্তুষ্ট	খুব সন্তুষ্ট
2. (G4)	আপনার স্বাস্থ্য নিয়ে কি আপনি সন্তুষ্ট?	1	2	3	4	5

নিচের প্রশ্নগুলো গত দুসপ্তাহে নিম্নবর্নিত অভিজ্ঞতাগুলো কি পরিমানে হয়েছে সে সম্পর্কে।

		একদম না	কম	মোটামুটি	বেশী	খুব বেশী
3. (F1.4)	শারীরিক ব্যথার জন্য আপনি কি পরিমান প্রয়োজনীয় কাজ থেকে বিরত ছিলেন?	1	2	3	4	5
4. (F11.3)	আপনার দৈনন্দিন কার্যক্রম ঠিক রাখতে চিকিৎসা কতটুকু প্রয়োজন?	1	2	3	4	5
5. (F4.1)	আপনি জীবনকে কতটুকু উপভোগ করেন?	1	2	3	4	5
6. (F24.2)	জীবনকে আপনার কতটুকু অর্থপূর্ন মনে হয়?	1	2	3	4	5

		একদম না	কম	মোটামুটি	বেশী	খুব বেশী
7. (F5.3)	আপনি কাজে কতটুকু মনসংযোগ করতে পারেন?	1	2	3	4	5
8. (F16.1)	আপনি দৈনন্দিন জীবনে কতটুকু নিরাপত্তা অনুভব করেন?	1	2	3	4	5
9. (F22.1)	আপনার ভৌত পরিবেশ কতটুকু স্বাস্থ্যকর?	1	2	3	4	5

নিচের প্রশ্নগুলোতে জানতে চাওয়া হয়েছে - গত দুই সপ্তাহে আপনি কতটুকু সম্পূর্ণভাবে কোন কাজ করতে বা অভিজ্ঞতা লাভ করতে পেরেছেন।

		একদম না	কম	মোটামুটি	অধিকাংশ	পরিপূর্ণভাবে
10. (F2.1)	আপনার কি প্রতিদিন কাজ করার মত শক্তি আছে?	1	2	3	4	5
11. (F7.1)	আপনি কি আপনার শরীরের গড়ন নিয়ে সন্তুষ্ট?	1	2	3	4	5
12. (F18.1)	আপনার কি প্রয়োজন মেটাতে যথেষ্ট টাকা আছে?	1	2	3	4	5
13. (F20.1)	আপনি কি দৈনন্দিন জীবন-যাপনের জন্য প্রয়োজনীয় তথ্য পান?	1	2	3	4	5
14. (F21.1)	অবসর কাটানোর/বিনোদনের সুযোগ আপনার কতটুকু আছে?	1	2	3	4	5

		খুব খারাপ	খারাপ	ভালও না মন্দও না	ভাল	খুব ভাল
15. (F9.1)	আপনি কতটা ভালভাবে চলাফেরা করতে পারেন?	1	2	3	4	5

নিচের প্রশ্নতে জানতে চাওয়া হয়েছে - গত দুসপ্তাহে আপনার জীবনের বিভিন্ন দিক নিয়ে আপনি কতটুকু সন্তুষ্ট?

		খুব অসন্তুষ্ট	অসন্তুষ্ট	সন্তুষ্টও নয় অসন্তুষ্টও নয়	সন্তুষ্ট	খুব সন্তুষ্ট
16. (F3.3)	আপনার ঘুম নিয়ে আপনি কতখানি সন্তুষ্ট	1	2	3	4	5
17. (F10.3)	দৈনন্দিন কাজ করার ক্ষমতা নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
18. (F12.4)	আপনার কাজ করার ক্ষমতা/দক্ষতা (ক্যাপাসিটি) নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
19. (F6.3)	নিজেকে নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
20. (F13.3)	অন্যদের সাথে আপনার ব্যক্তিগত সম্পর্কসমূহ নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
21. (F15.3)	আপনার যৌন জীবন নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
22. (F14.4)	বন্ধুদের কাছ থেকে পাওয়া সাহায্যে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
23. (F17.3)	আপনি আপনার বাসস্থানের অবস্থা নিয়ে কতটুকু সন্তুষ্ট?	1	2	3	4	5
24. (F19.3)	আপনি যে স্বাস্থ্যসেবা পান তাতে কি সন্তুষ্ট?	1	2	3	4	5
25. (F23.3)	আপনি যাতায়াত ব্যবস্থা নিয়ে কতটুকু সন্তুষ্ট?	1	2	3	4	5

নিচের প্রশ্নগুলোতে জানতে চাওয়া হয়েছে - গত দুসপ্তাহে ঐ নির্দিষ্ট বিষয়সমূহ আপনি কতবেশী/ঘনঘন অনুভব করেছেন?

		কখনো না	কখনো কখনো	মাঝে মাঝে	প্রায়শঃই	সব সময়
26. (F8.1)	আপনার হতাশা, উদ্বেগ, অবসন্নতা এই সব নেতিবাচক অনুভূতি কত ঘন ঘন হয়?	1	2	3	4	5

(নিশ্চিত হোন যে সব প্রশ্নের উত্তর দেয়া হয়েছে।)