FAMILY QUALITY OF LIFE WHEN CHILDREN WITH CEREBRAL PALSY

By

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March, 2018

This thesis is submitted in total fulfillment of the requirement for the subject of Research Investigation and partial fulfillment of the requirement for degree:

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Statement of Authorship

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This study has not been submitted for the award of any other degree in any other tertiary institution.

The ethical issue of the study has been strictly considered and protected. In case of dissemination the findings of this research for future publication, Research supervisor will highly concern and it will be duly acknowledged as undergraduate field work.

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Acknowledgement

First of all, I would like to pay my gratitude to the almighty Allah for giving me a passion to go with the research project successfully in time. I am much grateful to my parents and family members for their constant support to continue this study. Heartfelt thanks goes with the persons who helped me to complete my research.

I want to show my gratitude to my honorable supervisor and Head of the Occupational Therapy Department SK. Moniruzzaman helping me by providing instruction, praise and guidance in every step of the study. I am thankful to the in charge Department of Occupational Therapy in Paediatric unit in CRP and also thankful senior Occupational Therapist in William and Marie Taylore School in Savar for theirkind permission for data collection. I give special thanks to Salma Akter Lecturer of Ocuupational Therapy Department and Shamima Akter, Assistant Professor, Department of Occupational Therapy of BHPI for their cordial help during any situation. Also thanks to Md. Anis and Md. Rubel for their cordial help during my work in library.

I am also thankful to junior students for their helping hands in several times during questionnaire translation. I want to convey thanks to those who helped me in critical situation like Moytri, Saddam. Thanks to all my friends for giving their direct and indirect inspiration.

Lastly, my apology goes with the persons if I miss out anyone unintentionally. The author would like to thank all of the children with Cerebral Palsy and their family members who participated in the study.

Dedication

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

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List of the abbreviation

ADL	Activity of Daily Living
AOTA	American Occupational Therapy Association
BHPI	Bangladesh Health Professions Institute
BMRC	Bangladesh medical research council
CRP	Center for the Rehabilitations of the Paralysed
CP	Cerebral Palsy
FQOL	Family Quality of Life
GO	Government Organization
IBR	The Institutional Review Board
NGO	Non-Government Organization
SSC	Secondary School Certificate
QOL	Quality of Life
WHO	World Health Organization

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Abstract

Background:

Study of the family quality of life (FQOL) has been extended as a new field of the developed countries. Family-centered services mean that the needs of all family members should be considered and the involvement of all family members should be encouraged. Parents of disabled children still face huge stigma and it may see continuously in rural areas. This often stops them from seeking help, because they feel ashamed. Main caregiver specially father and mother may lead a painful life because of their children functional limitation.They show higher levels of stress and worse mental health when compared to parents of children without developmental disabilities and the general population. Family Quality of life research indicates that there is little understanding about how family members may differentially perceive and assess their quality of life.

Objectives of the study

This study was intended to the level of Family Quality of life parents of children with Cerebral Palsy. Also explore the relationship and determine the association between age, sex, educational status, employment status, community types, family types & five components of the FQOL.

Methodology

The study was conducted through cross sectional study. Researcher selected convenience sampling technique from the population who meet the inclusion criteria and exclude those who did not meet the criteria. The study area was paediatric unit of CRP, Savar, Dhaka and William and Marie Taylore School, CRP, Savar, Dhaka.

Result and Discussion

After analyzing data, it was found that the fathers' level of satisfaction about FQOL was 3.27 which was neither satisfied or neither dissatisfiedaccording to the FQOL Scale and mothers level of satisfaction was 3.47 which was neither satisfied or neither dissatisfiedaccording to the FQOL Scale.

Conclusion

In closing, this study represents a first step in exploring the level of satisfaction of fathers and mothers with respect to their assessments of FQOL. The results highlight that fathers do not differ from mothers in assessing their overall FQOL.

Kew Words: Perspective, Cerebral Palsy, Quality of Life, Family Quality of Life.

CHAPTER- 1 INTRODUCTION

1.1. Background

Disability is a vital issue all over the world. WHO & World Band suggests that there are One billion people, or 15% of the world's population, experience some form of disability. Among those there are 2–4% of them experience severe difficulties in functioning. GBD 2004 data analysis showed that 15.3% of the world population (approximately 978 million people) had moderate or severe disability, while around 2.9% population (185 million people) experienced severe disabilities. The prevalence of disability is higher in developing countries. Bangladesh is a one of most developing countries in the world. Disability is one of the major issues in Bangladesh (Alam, 2009). Disability rates are increasing day by day. In Bangladesh there are 140 million people are person with disable that means 105 of the total population (Faruque, 2008). In 2004, the prevalence of disability was about 6% among those below the age of 18 and about 14% among those above that age.The current document presents a monograph on prevalence, pattern, and differential of disability using data fromPopulation Census 2011 (Bangladesh Bureau of Statistics, 2011)and Household Income and Expenditure Survey (HIES, 2010). In 2011, The Census gives a data that has put a figure of 1.41% (a total of 101, 585 disables) on the overall disability prevalence in Bangladesh, which is 7.6 percentage points lower than the HIES 2010 estimate of9.01 % for the overall disability prevalence. Disability is more prevalent in rural area compared to urban area. Physical disability and vision disability appeared as the most common forms of disability in the country. Under the physical disability Cerebral Palsy is the most common and chronic disability in the world.

Bangladesh is one of the most densely populated countries in the world. There are 150 million people and 57.5 million children below 18 years of age, and over 31 percent of household's sill live below the poverty. Cerebral Palsy is the most sever disability in Bangladesh. The worldwide prevalence of CP is Approximately 2 to 2.5/ 1000 live births (Surveillance of Cerebral Palsy in Europe, 2000). The Government of Bangladesh (2013) had conducted a survey among children with Autism and neurodevelopmental disorder. According the result of survey the prevalence of cerebral palsy is 4 per thousand. Children with CP have limitation on movement and postural disorders. Many children also experience sensory, communicative and intellectual impairments and may have severe limitations in self-care activities such as feeding, dressing, bathing and mobility (Basaran et al., 2013; Zhang et al., 2015). The children with Cerebral Palsy child totally depend on their Caregiver specially Father & Mother. So the parents of Cerebral Palsy child's parents lead a very poor quality of life.

The family quality of life (FQOL) is an significant extension of QOL in the field of developmental disability (Hoffman et al., 2006).Study of the family quality of life (FQOL) has been extended as a new field of the developed countries (Wang & Brown, 2009; Werner et al., 2009; Brown et al., 2010). Cerebral Palsy is one of the major causes of childhood disability in Bangladesh. The vast majority of babies with Cerebral Palsy in Bangladesh are born in rural areas. Parents of disabled children still face huge stigma and it may see continuously in rural areas. The social value of that family may be decreasing day by day. Peoples are blamed if their child starts showing signs of disability, such as loss of control of their hands and legs or sudden spasms. This often stops them from seeking help, because they feel ashamed. Main caregiver specially father and mother may lead a painful life because of their children functional limitation(Alam, 2009).They show higher levels of stress and worse mental health when compared to parents of children without developmental disabilities and the general population (Byrne et al. 2010).Parents have to cope withmany changing demands which are related to the specific needs of their children. And also in different domains which has to the uniqueness of their process of development. Mental health's of the parents of children with CP are negatively affected and may exhibit depressive symptoms (Manuel et al., 2003; Unsalexhibit depressive et al., 2009).

The work reported in this study is a part of another line of conceptual and instrument development work to define the concept of FQOL and develop a measure (Park et al., 2003; Poston et al., 2003; Summers et al., 2005; Hoffman et al., 2006). The Beach Center FQOL Scale developed through this work contains five sub-scales: family interaction, parenting, emotional well-being, physical/material well-being and disability-related support, and has good psychometric features (Summers et al., 2005; Hoffman et al., 2006). This study continues investigations of the validity of the Beach Center FQOL Scale with respect to the stability of the construct across mothers and fathers.

1.2Justification of the study

Most of the people in Bangladesh have no knowledge about disability and its consequences. The United Nation Convention is highly depended on awareness & service based programs for promoting knowledge, attitude and practices of the whole country including person with disability, parents, family, society and community (Vandamme, 2009). This study recognizes that issues of children with Cerebral Palsy involve father & mother family quality life as the focused of service & supports.

However, services and supports are only focused on children with disabilities and involvement of family members has long been ignored. If people understand the FQOL in Bangladesh, they will be aware of the traditional perspective of disability as a stigma or shame (Wong et al., 2004).Children with CP families have to face discrimination against their children' disabilities from the society and oftentimes have to solve problems for raising their children with disabilities by themselves.These passive or negative social attitudes towards families of children with disabilities become barriers to the design and development of services and supports for families. The results of this study remind that greater improve FQOL outcomes of Bangladeshi families. Although research and intervention models have primarily focused on Mothers &Fathers (Shonkoff et al., 1992; Krauss, 1997).

This research also intends to find out the influence of socio-demographic (age, sex, education, living area). This study makes a correlation between socio-demographic question and components of the FQOL. That will helps the professionals and practitioners will be benefited by developing supports and services from having families' perspectives on their FQOL .All members of interdisciplinary teams, including families themselves, can use a FQOL measure (e.g. the Beach Center FQOL Scale) to identify priority areas for support to address needs and strengths of families during the process of developing and implementing individualized plans.That’s why this study will be useful for understanding family stress, depression & it will be useful for psychosocial perspective (Wang, 2006).

1.3Operational Definition

Cerebral Palsy: Cerebral palsy refers to a group of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination Cerebral palsy (CP) is caused by damage to or abnormalities inside the developing brain that disrupt the brain’s ability to control movement and maintain posture and balance. The term cerebral refers to the brain; palsy refers to the loss or impairment of motor function.(Cerebral Palsy: Hope through Research, 25 May, 2017).

Quality of life: WHO defines Quality of Life 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. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (WHOQOL Group1995).

Family Quality of Life: The most widely definition is that suggested by Park et al. (2003), in which FQOL is defined as “conditions where the family’s needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them” (Zuna et al., 2010).

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CHAPTER- 2 LITERATURE REVIEW

2.1. Cerebral Palsy

Bangladesh is over populated country and Cerebral Palsy is one of the most common developmental disability in Bangladesh.CP is a condition that beginning in early childhood and persisting throughout the lifespan. The definition and classification of cerebral palsy, according to the Executive Committee for the Definition of Cerebral Palsy, states that:

“Cerebral palsy describes a group of permanent disorders of the development of movement and posture that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy, and by secondary musculo-skeletal problems” (Rosenbaum et al. 2007).Therefore cerebral palsy is a disorder of muscle control which results from some damage to part of the brain. The term cerebral palsy is used when the problem has occurred early in life, to the developing brain.Children with cerebral palsy can have problems such as muscle weakness, stiffness, awkwardness, slowness, shakiness, and difficulty with balance. These problems can range from mild to severe. In mild cerebral palsy, the child may be slightly clumsy in one arm or leg, and the problem may be barely noticeable. In severe cerebral palsy, the child may have a lot of difficulties in performing everyday tasks and movements.

Bangladesh has about 5%-15% of total people have some kind of disability (Mahmud, 2005).43% of those people with disability are physically challenged (JICA, 2002). The United states indicate that the incidence of CP is 3.6 per 1000 children (Allosopp, 2008). Bangladesh the prevalence rate of disability in both urban and rural population was estimated 011000 (Khayatzade, 2009).Cerebral Palsy (CP) is the most common cause of severe physical disability in childhood. The Bangladesh Bureau of statistics puts the population of disability of disability people at almost a 10th of the population which is 9.75%. In the U.S, an estimated 746,000 children and adult have CP with a prevalence of 3.3 per 1000.

Cerebral palsy is **caused** by traumatic injury to a developing brain, including the parts of the brain responsible for motor control, coordination and balance. Damage to different parts of the brain's motor control centers causes different types of cerebral palsy. The level of disability depends on the severity and timing of the brain injury. About 70% of cerebral palsy cases are caused by prenatal injuries, 20 % are caused by injuries during birth & 10 % are caused by injuries after birth. Things that can disrupt or hinder the healthy development of a child's brain include:Infections during pregnancy, severe untreated jaundice of the child, birth asphyxiation, Brain injury during or shortly after birth, Brain hemorrhage before birth, Infections after birth etc. There are 10-15% of cases and result of CP is problem during labor pain and delivery. Antepartum hemorrhage or cord prolapsed, compromising the fetus; post neonatal causes of occurring are result of 10% of CP.

Types of Cerebral Palsy: Cerebral Palsy is often classified by severity level as mild, moderate, severe:

Mild – Mild Cerebral Palsy means a child can move without assistance; his or her daily activities are not limited.

Moderate – Moderate Cerebral Palsy means a child will need braces, medications, and adaptive technology to accomplish daily activities.

Severe – Severe Cerebral Palsy means a child will require a wheelchair and will have significant challenges in accomplishing daily activities.

According to **neuro-physically** there are three types of CP: spastic, athetoid and ataxic.

Spastic: spastic is characterized by increase muscle tone. There are different types of spastic CP which is Spastic Monoplegic CP, spastic Diaplegic, spastic Hemiplegic, spastic Tiaplegic, and spastic Quadriplegic. There are 70% to 80% causes of CP are Spastic CP and 10% to 20% causes of athetoid and 5% to 10% causes of ataxic types of CP (Understand of disability, 2012).

Parents of children with CP is usually faced critical situation encountered linked to the often complex process of confirming and disclosing the diagnosis (Baird et al., 2000). Afterwards, parents usually wants to cope with many changing demands related to the specific needs of their children (Gardiner, 2014). Generally, they show higher levels of stress and worse mental health when compared to parents of children without developmental disabilities and the general population (Byrne et al., 2010; Guyard et al., 2011; Rentinck et al., 2007). In other countries the impact of child’s disability on the family seems to be related not only with the child’s characteristics, but also with personal, social and economic variables of the family.

2.2. Quality of Life

The QOL concept was focused in the early 1990s, but scholars and practitioners in the field of intellectual and developmental disabilities have taken the lead in developing the concept of QOL in a holistic manner (Brown, 1999). Several articles and texts have explored the conceptual basis of QOL and the life domains associated with it, such as physical and material well-being, emotional wellbeing, social belonging and community living(Brown et al., 2000; Schalock &Verdugo, 2002; Brown & Brown, 2003; Schalock, 2004). The QOL is emphasis on examining the perceptions and dynamics of the family unit as a whole. Research has also been conducted into the practical benefits of QOL.

The family is form by constitutes a dynamic, interconnected, and self-regulating system which is influenced by a set of shared, yet also unique, contextual influences. Disability theorists and practitioners have enhance their narrow child-centered perspectives and now seek to understand their multiple levels of analysis which is how child, family, and service characteristics interact and overlap in their contributions to their family functioning. From this perspective, the significant ways in which having a child with a disability impacts all family members, including parents and siblings, can be addressed.

2.3 Family Quality of Life Research

The total well-being of anindividual’sfamily will be support, but services are now seen as contributors, sharing is the responsibility of maintaining QOL(Schippers &Van Boheemen, 2009). An Australian perspective, FQOL is relevant to current disability legislation, policy and practice. There are over 500 000 people with a developmental disability in Australia (approximately 3% of the population) (Australian Institute of Health and Welfare, 2008).Disability not only affect the child's life but also the family's life also the parents, other members of the family, relatives, friends, and even neighbors of a child with disabilities. All are suffer for disability and experience stress to a varying extent.

In developing countries, the pressure is even greater. The majority of families are already living under difficult conditions(McConachie et al., 2001).Bangladesh situation is worst for women, who comprise the poorest and most vulnerable population even among the hard-core poor (Sen and Yurtsever, 2007).Thus, mothers of children with CP are likely to be doubly disadvantaged in developing countries (Understand of Disability, 2012).

In Bangladeshis the perception of disability is remain largely negative. Especially in rural areas, disability is often viewed as a curse brought on by the misdeeds of parents, and is often believed to be contagious. A small number of studies find that to understand the experience of parents with a child with cerebral palsy and how best services might be delivered to families of children with cerebral palsy (Guillamón et. al.,2013).Some studies show that parents' of children with CP had high levels of stress and worse mental pressure and has a relationship problem than other parents of children without developmental disability in Asia (Rentinck et al., 2006). In 40 studies appears similar result in the general population consistently in a more recent review and in many studies (Byrne et al.,2010; Bella et al., 2011; Parkes et al., 2011). Most of the studies have focused on the impact of caring for a child with CP on parents' mental health and less attention has been paid to its effects on their quality of life. According to the available literature, quality of life levels of parents of children with CP are worse than the ones found for the general population and that of parents of healthy children (Kaya et al., 2010).

Family-centered services means that the needs of all family members should be considered and the involvement of all family members should be encouraged (Rosenbaum et al. 2006).FQOL research indicate that there is little understanding about how family members may differentially perceive and assess their quality of life (Brown et al., 2003) and a priority research area is exploring how to measure different family members with perspectives in assessing their FQOL. The responses of different family members (e.g. mother and father) may indicate different areas of emphasis on different domains of FQOL which could have important implications for policy and services.

2.4 Beach Center Family Quality of Life Scale and Measurement

The Beach Center on Disability at the University of Kansas, KS, and USA developed a conceptualization measuring tools which is of FQOL scale. The Beach Center Family Quality of Life Scaleassessesfamily’s perception of their satisfaction as well as Level of satisfaction with different accepts of FQOL. The instrument is used a 5 point liker-type response scale from 1=very dissatisfied to 5= very satisfied. The FQOL scale has 25-items that measures FQOL satisfaction across five domains: Family Interaction, referring to the relationships among and between family members; Parenting, meaning the kinds of activities families engage in to facilitate their child’s development; Emotional Well-Being, involving perceptions of stress and support availability; Physical/Material Well-Being, referring to basic physical needs such as medical support and transportation; and Disability-Related Support, including supports across the community contexts of school, work, and home (Park et al., 2003; Turnbull, 2004; Turnbull et al., 2007). The measure’s demonstrated psychometric validity (Hoffman et al., 2006; Summers et al., 2005; Wang et al., 2006).

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CHAPTER- 3 METHODOLOGY

3.1Research Question

What is the Family Quality of life of the children with Cerebral Palsy?

3.2 Aim & Objectives

Aim of the Study

To identify Fathers & mothers level of satisfaction about Family Quality of Life when children with Cerebral Palsy.

Objectives of the study

1. To identify level of the satisfaction about FQOL.
2. To find out the association between demographical characteristics (gender, age, educational background, employ mental status, types of the community, types of the family) five factor structure of FQOL.

3.3 Conceptual framework

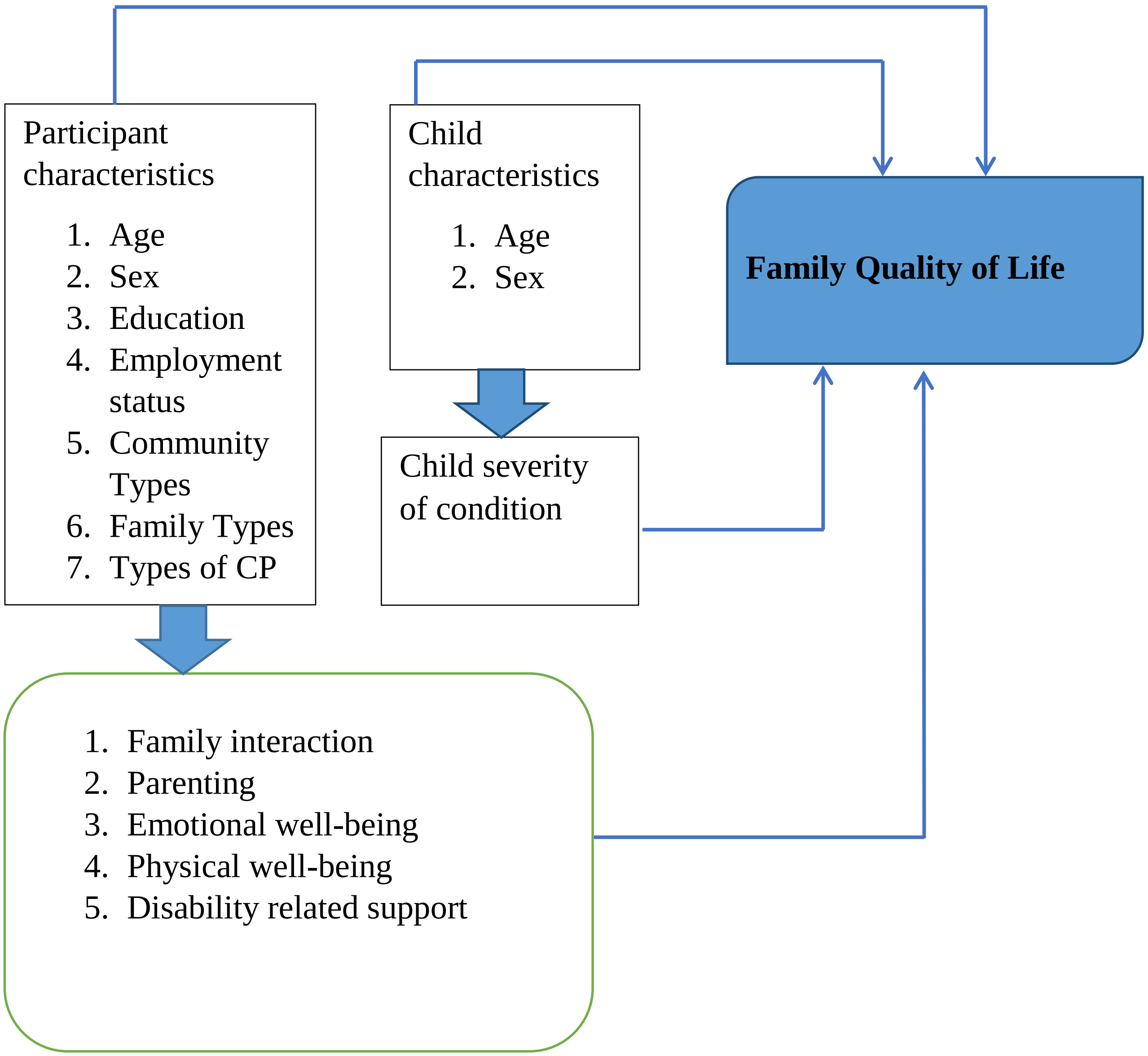


Figure 1: Conceptual framework

3.4 Study Design

The study was conducted through cross sectional study. The researcher used this type of study design because the current study carried out at one point of time over a short period. Data was collected on individual characteristics, including demographic questioner and in this way this study is provided a snapshot of the characteristics which is associated with it. The focus of the study was to identify the association between ages, sex, types of CP, relation to the child, employment status with components of FQOL questioner. It was conducted at one time point where estimate the relation between ages, sex, types of CP, relation to the child and also employment status.

3.5 Study Population

The population consists of father and mother of children with Cerebral Palsy.

3.6 Study Area

The study area was paediatric unit of CRP, Savar, Dhaka and William and Marie Taylore School, CRP, Savar, Dhaka. The Center for the Rehabilitation of paralysed (CRP) is a non-profit non-government organization which treats and rehabilitation disabled people. The researcher has chosen the inpatient paediatric unit CRP, Savar because the paediatric unit which has indoor and outdoor service? The indoor is only for Children with Cerebral Palsy. The children with Cerebral Palsy have been admitted here for 14 days with their mothers. The William and Marie Taylore School, CRP, Savar, Dhaka is an Inclusive school which has all types of children like children with disable and children without disable. There are 110 Children with Cerebral Palsy study in this school and most of the families' children with CP are living near by the school that's why Researcher selected this school.

3.7 Sample size

Sample size Calculation,

$$N=\frac{z^2\times p\times(1-p)}{d^2}$$

Here, N= Sample size

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

P= 0.4 (Prevelence of Cerebral Palsy in Bangladesh)

d=0.05 (Level of Significance/ margin of error)

Putting these values in formula, N= 368

The calculated sample size is 368.

3.8Participation Selation Criteria

Inclusion Criteria:

- A child which ages range is Birth – 18 years old.
- Fathers and Mothers of children with Cerebral Palsy.
- Children with Cerebral Palsy are diagnosed by appropriate Health Professionals.

Exclusion Criteria:

- The child who have multiple disability or impairment, e.g. Blind, Autism, any other syndrome.
- Those who are not within the age range.

3.9Sampling Technique

Researcher selected convenience sampling technique from the population who meet the inclusion criteria and exclude those who did not meet the criteria. Convenience sampling saves time, money and helps to identify participation in a convenience way.

3.10Data collection Materials

The data was collected by FQOL scale (Beach center Family Quality of life, 2006) and self-development demographic questioner. Researcher translates the FQOL scale in Bangla version. It is a five point liker scale. This five point liker scale is used for identify level of satisfaction of the fathers and mothers of the Children with Cerebral Palsy. Investigator also developed information sheet which has aim and objectives of the study. A consent form was also used to take concern from the participants. Investigator also used pencil, paper and eraser.

3.11Data Management and Analysis

Data was analyzed by statistic package for the social Science (SPSS) version of 23.

3.12Quality Control and Quality Assurance

Researcher conducted a pilot survey to evaluate participants understanding level of questionnaires. Researcher selected four families for piloting. After completing the pilot survey researcher modify the questionnaires. Based on their feedback researcher modified one survey item from “My family get dental care when needs” to “My family gets dental treatment when they have problem in teeth”. It is important to carry out a field test before final data collection. By this field test researcher can understood barriers of the study. It helps the researcher to find out difficulties and get a chance to correction the questionnaires to make it more easy and understandable.

3.13Ethical Consideration

Researcher followed the Bangladesh medical research council (BMRC) and WHO research guide line. Researcher received ethical permission from the institutional review board (IRB) of BHPI. In addition for data collection purpose, permission was also obtained from Head of Occupational Therapy Department BHPI, In charge of the paediratic unite of the Savar,CRP and principal of William and Marie Taylore School, CRP, Savar, Dhaka. Researcher maintained the confidentiality of the collected data from the individuals. All the participants were informed about the purpose of the study.

CHAPTER- 4 RESULTS

4.1: Results with Respect to the Socio Demographic Status

Table 4.1: Distribution of Respondents by Age, Sex of the Children with Cerebral Palsy

Socio-demographic characteristic of respondents		
Age of children with CP	N=120 Frequency (n)	Percent (%)
0-5	54	45.0
6-11	44	36.7
12-17	22	18.3
Total	120	100.0
Sex of Children with CP		
Boys	65	54.2
Girls	55	45.8
Total	120	100.0
Types of the CP		
Ataxic	7	5.8
Athetoid	16	13.3
floopy	2	1.7
Spastic Diaplegic	32	26.7
spastic Triaplegic	3	2.5
spastic hemiplegic	21	17.5
spastic quadriplegic	39	32.5
Total	120	100.0

Table 4.1 showed the Demographic data of the children with Cerebral Palsy. The age range of the children's 45% (n=54) was 0-5 years, 36.7% (n=44) was 6-11 years, 18.3% (n=22) was 12-17 years.There was 54.2% (n=65) Male children with CP and 48.8% (n=55) female children with CP.The types of the Children with CP, there was 32.5% (n= 39) Quadriplegic CP, 26.7% (n=32) was spastic Diaplegic CP, 17.5% (n=21) Was spastic hemiplegic CP, 13.3% (n=16) was Athetoid CP, 5.8% (n=7) wasAtaxic CP, 2.5% (n=3) was spastic Triaplegic CP and 1.7% (n=2) was floppy.

Table 4.2: Demographic Information of the Participants

Age of the participants	Frequency (n)	Percent (%)
16-20	3	2.5
21-30	40	33.3
31-40	53	44.2
41-50	22	18.3
>50	2	1.7
Total	120	100.0
Sex of the Participant		
Male	60	50
Female	60	50
Total	120	100
Education Background		
Illiterate	3	2.5
signature	5	4.2
primary	14	11.7
Secondary	37	30.8
SSC	39	32.5
Hsc	13	10.8
B.Sc/ BA/ Honors	7	5.8
M.Sc/ MA/ Masters	2	1.7
Total	120	100.0

Table 4.2 showed that among 120 were participants, there were 50% female (n=60) and 50% were male (n=60). The above table shows that The most of the participants age ranges was from 31-40 years that means 44.2% (n=53). The Table described 2.5% (n=3) were of 16-20 years,

33.3% (n=40) were of 21-30 years, 18.3% (n=22) were of 41-50 years, 1.7% (n=2) participants‟ age were from more than 50.

In table 2, also showed that, among all the participants (n=120) education background was, 32.5% (n=39) were SSC, 30.8% (n=37) were secondary, 11.7% (n=14) were primary, 10.8% (n=13) were HSC, 5.8% (n=7) were B.SC/BA/BBA/Honors, 4.2% (n=5) were signature, 2.5% (n=3) were Illiterate and 1.7% (n=2) were MSC/MA/MBA/Masters .

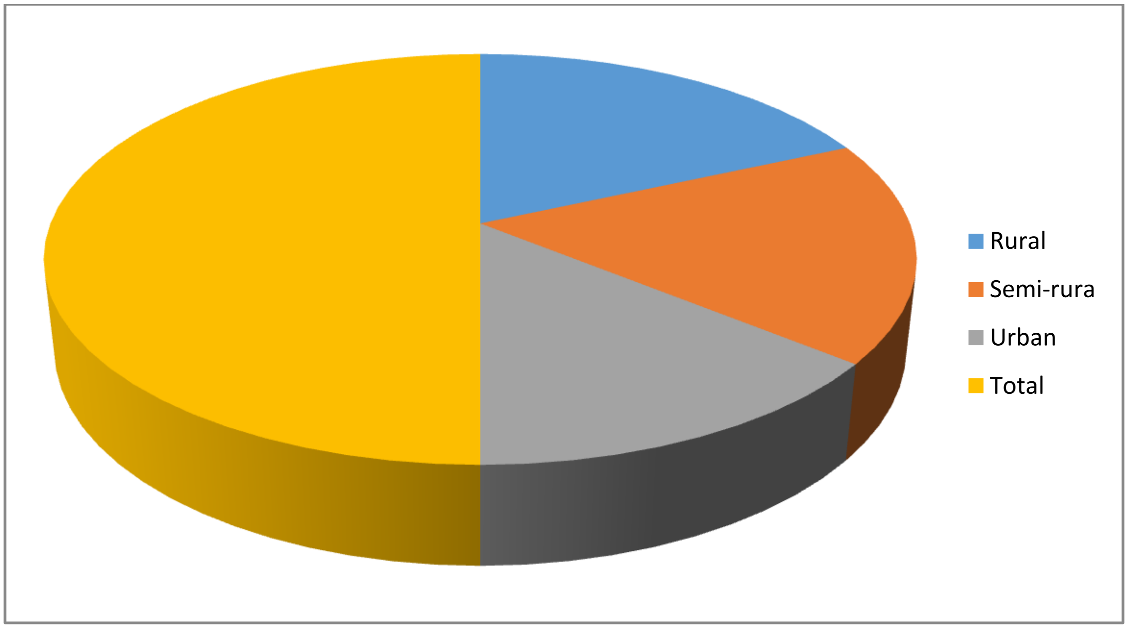


Figure 2: Community types of the Participants

Community types of the participants was 36.7% (n=44) rural, 35% (n=42) semi-rural, 28.3% (n=34) was urban.

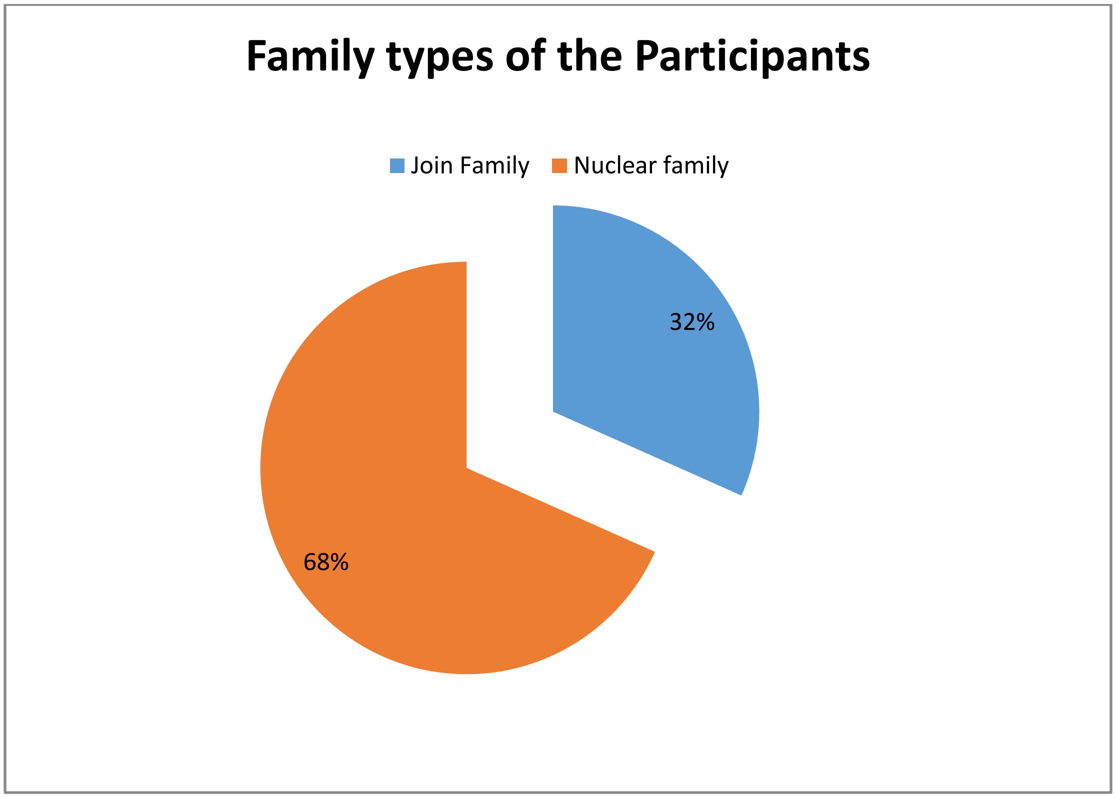


Figure 3: Family types of the participants

This figure shows that there were 68% (n= 82) nuclear family and 32% (n=38) were join family.

4.2 Level of Family Quality of Life

This study has two groups of participate one was child's fathers group and another was child's mothers group. Researcher finds out both fathers and mothers levels of satisfaction about Family Quality of life

Table 4.3: Fathers Level of satisfaction about family Quality of life

Dimension of family quality of life (Mean & SD) (Possible Score range 1 to 5)	
Family Interaction	3.3585 (o.59)
Parenting	3.4658 (0.67)
Emotional Well-Being	2.8125 (0.73)
Physical/ Material Well-being	3.3775 (0.74)
Disability Related Support	3.3750 (0.74)
Mean (± SD) 3.27 (± 0.69)	

Participants were asked to rate overall (globally) how satisfied they are with their FQOL using a 5-point scale (1 = very dissatisfied to 5 = very satisfied). Overall satisfaction ratings that were equivalent to a rating of satisfied.

Family interaction (mean = 3.35, SD= 0.59) were found to be consistent with the mean of the total of satisfaction ratings for the individual domains. This Mean describe the Family Interaction was neither satisfied nor dissatisfied because its Mean is 3 to 4.

Parenting Mean 3.46 (0.67) were found which describe to the neither satisfied nor dissatisfied.

Emotional Well-being was Mean 2.81 and SD 0.73 which describe Dissatisfaction because its mean is 2 to 3.

Physical Well-being / Material Well-being Mean was 3.37 and SD 0.74 which describe neither satisfied nor dissatisfied because its Mean is 3 to 4.

Disability Related Support was Mean 3.37 and SD 0.74 which describe neither satisfied nor dissatisfied because Mean is 3 to 4.

The fathers' overall level of satisfaction about FQOL was 3.27 which was neither satisfied or neither dissatisfiedaccording to the FQOL Scale.

Table 4.4: Mothers Level of satisfaction about family Quality of life.

<u>Dimension of family quality of life (Mean & SD)</u> **<u>(Possible Score range 1 to 5)</u>	
Family Interaction	3.4495 (0.85578)
Parenting	3.4933 (0.794)
Emotional Well-Being	2.8442 (1.08873)
Physical/ Material Well-being	4.0967 (4.491)
Disability Related Support	3.4833 (0.700)
Mean (± SD) 3.47 (± 1.58)	

Family interaction mean (±) (3.44, ±0.85) were found to be consistent with the mean of the total of satisfaction ratings for the individual domains. This Mean describe the Family Interaction, So it was neither satisfied nor dissatisfied because its Mean is 3 to 4.

Parenting Mean 3.49 (±0.79) were found which describe to the neither satisfied nor dissatisfied.

Emotional Well-being was Mean 2.844 and SD 1.08 which describe Dissatisfaction because its mean is 2 to 3.

Physical Well-being / Material Well-being Mean was 4.09 and SD 4.491 which describe satisfied because its Mean is 4 to 5.

Disability Related Support was Mean 3.48 and SD 0.70 which describe neither satisfied nor dissatisfied because its Mean is 3 to 4.

Overall family Quality of life of mothers was 3.47 which was indicating neither satisfied or neither dissatisfied.

4.3 Comparison by t-Test between Demographic characteristics and Family Quality of life Components

Table 4.5 Comparison between Demographic characteristics with Family Quality of life Components by T-test

Components	Gender of children with CP	N	Mean	P-vale
D-2	Boys	38	20.8684	.001****
	Girls	22	20.6364	
Components	Types of the family	N	Mean	P-Vale
D-1	Join family	26	18.8846	.026*
	Nuclear family	34	22.2353	
D-2	Join family	26	62.2677	.003***
	Nuclear family	34	76.2729	
D-5	Join family	26	71.5385	.016**
	Nuclear family	34	69.1765	

P< 0.05 (Significant level)

Table 4.5 show the two groups are significantly different from each other and focus on the result by t-test. So researcher concludes that four mean are significant from each other.Domain-2 (Parenting component) & in the group of gender of children with Cerebral Palsy was statistically significant. The P-vale was .001 which was less than significant level (0.05)

Domain-1 (Family interaction), Domain-2 (Parenting), & Domain-5 (Disability related support) with in the group of types of family was significant relation. The P-value was .026, .003,& .016 was less than significant level (0.05).

4.4The association between Demographic characteristics and five factors of Family Quality of life of Fathers'

Table 4.6 Group mean difference regarding overall level of satisfaction of physical well-being/ Material well-being & Disability related support using ANOVA.

Researcher was conducted ANOVA test with all demographic characteristics of the participant (Fathers of children with CP) with five domain of FQOL. But below table show which was found significant relation between them.

Father								
Group		N	D-4 Mean ± SD	D-4 F	D-4 P-Value	D-5 Mean ± SD	D-5 F	D-5 P-Value
Age Group of the participants	21-30	11	56.36 ± 14.136	3.438	.023	61.36 ± 10.26	3.841	.014**
	31-40	27	67.70 ± 17.397			67.03 ± 14.82		
	41-50	20	72.00 ± 6.988			68.50 ± 14.69		
	>50	2	80.00 ± 22.627			97.50 ± 3.53		
	Total	60	67.46 ± 15.065			67.50 ± 14.91		

**P< 0.05 (Significant Level)

Table 4.6 show the groups are significantly different from each other and focus on the result by ANOVA test. Researcher conduct it demographic characteristics of the participants with five domains of FQOL. Researcher was found significant relation between Age group of the participants with Domain-4 (Physical well-being/ Material well-being), Domain-5 (Disability related support). The P-vale was .014 which was less than significant level (0.05). This table only shows the fathers significant relation.

Table 4.7 Group mean difference regarding overall level of satisfaction of Parenting & Disability related support using ANOVA.

Father								
Group		N	D-2 Mean ± SD	D-2 F	D-2 P-Value	D-5 Mean ± SD	D-5 F	D-5 P-Value
Employment status of the participants	Worker/ Day labor	13	59.84 ± 13.15	4.280	.009	62.69 ± 12.68	3.657	.018*
	Government job	3	86.66 ± 8.821			91.66 ± 10.40		
	Non-Government job	13	69.74 ± 12.05			65.00 ± 16.07		
	Business	31	70.21 ± 12.99			68.22 ± 13.81		
	Total	60	68.68 ± 13.72			67.50 ± 14.91		

P< 0.05 (Significant level)

This table also shows the fathers significant relation. Researcher was found significant relation between employment status of the participants with Domain-2 (Parenting), Domain-5 (Disability related support). The P-vale was .018 which was less than significant level (0.05).

4.5The association between Demographic characteristics and five factors of Family Quality of life of Fathers'

Table 4.8 Group mean difference regarding overall level of satisfaction of physical well-being/ Material well-being uses ANOVA.

Researcher was conducted ANOVA test with all demographic characteristics of the participant (Mothers of children with CP) with five domain of FQOL. But below table show which was found significant relation between them.

Mother					
Group		N	D-4 Mean ± SD	D-4 F	D-4 P-Value
Educational status of the participants	Signature	4	76.00 ± 11.77	4.280	.009**
	Primary	6	72.00 ± 7.15		
	Secondary	22	68.36 ± 10.46		
	SSC	22	71.63 ± 11.70		
	Hsc	5	72.80 ± 5.21		
	B.Sc/ BA/ Honors	1	32.0000		
	Total	60	70.20 ± 11.44		

P< 0.05 (Significant level)

Table 4.8 show the groups are significantly different from each other and focus on the result by ANOVA test. Researcher conduct it demographic characteristics of the participants with five domains of FQOL. Researcher was found significant relation between educational status of the participants with Domain-4 (Physical well-being/ Material well-being). The P-vale was .009 which was less than significant level (0.05).

Table 4.9Group mean difference regarding overall level of satisfaction of Parenting uses ANOVA.

Mother					
Group		N	D-2 Mean ± SD	D-2 F	D-2 P-Value
Community types of the participants	Rural	23	69.08 ± 12.80	4.970	.010*
	Semi-rural	23	65.07 ± 18.30		
	Urban	14	80.47 ± 9.32		
	Total	60	70.20 ± 15.52		

P< 0.05 (Significant level)

Table 4.8 show the groups are significantly different from each other and focus on the result by ANOVA test. Researcher conduct it demographic characteristics of the participants with five domains of FQOL. Researcher was found significant relation between community types groups of the participants with Domain-2 (parenting). The P-vale was .010 which was less than significant level (0.05).

CHAPTER-5 DISCUSSION & CONCLUSION

5.1: Discussion

The Major purpose of this study was to assess Fathers and Mothers Family Quality of Life .The current study provides further insight to the measurement of FQOL, and to the issues affecting family members that have a member of Cerebral Palsy Child. Investigator was used psychometric such as Beach Center Family Quality of Life Scale (FQOL), which assess families perceptions of their satisfaction of different aspects of family quality of life (Beach Center Family Quality of Life , 2006). A total of 120 samples were studied, among of them 60 of fathers and 60 of mothers were respondents of the child that suffer from CP.

1.1 Socio-Demographic Characteristic of Children with Cerebral Palsy

Researcher added 9 demographic questions with respect to the objective aspects of Bangladeshi Family .These demographic questions include: (1) gender of the children with CP; (2) age of the children with CP; (3) Types of the Cerebral Palsy (4) Age of the Participant (5) Sex of the Participant (6) Educational background of the participants (7) relationship to the child; (8) family structure; (9) community type (e.g. urban and rural); In addition, there were three demographic questions about the gender, age and types of the CP were the children with Cerebral palsy.

Socioeconomic and Demographic characteristics of the participant showed that the 54 children (45%) age group were 0-5 years, 44 children (36.7%) age groups were 6-11. Also 22 children (18.3%) age groups were 12-17. There were 65 (54.2%) child parents was participate in this study and 55 (45.8%) child parents was participant in this study. Most of the Children with CP was Quadriplegic CP 32.5% and very rare was floppy 1.7% (n=2).

1.2 Socio-Demographic Characteristic of the Participants

There were 120 participants, which had 50% female (n=60) and 50% were male (n=60). The study shows that The most of the parents age ranges were from 31-40 years that means 44.2% (n=53). The study also described that, 2.5% (n=3) were of 16-20 years, 33.3% (n=40) were of 21-30 years, 18.3% (n=22) were of 41-50 years, 1.7% (n=2) participants‟ age were from more than 50.

Among the 120 respondents 32.5% (n=39) had SSC and 49.2% (n=59) has below SSC (no Certificate educational level) and only 18.3% (n=22) had above SSC education. Among 120 participants, there were 36.7% (n=44) lived in rural, 35% (n=42) lived in semi-rural, 28.3% (n=34) lived in urban.

1.3 Fathers Level of satisfaction about Family Quality of Life

This important issue on FQOL research is a valuable step forward in recognizing the central role of the family in the lives of persons with disabilities. Universally, families have always found ways to care for persons with disabilities; although the literature appears to be dominated by studies highlighting the negative aspects of caregiving (Senel & Akkök, 1995; Datta et al., 2002; Webster et al., 2008).In fact, much of the research on families in general has also focused on dysfunctions of the family unit. According to DeFrain (1999), most 20th century researchers have been asking 'Why do families fail?' and therefore have been finding many family problems. Alternatively, he argues that when we start asking 'How do families succeed?' we aremore likely to identify strengths in a family, which in turn can lead to the foundation for continued growth and positive change in a family and a society.

Discussed in terms of the FQOL domains that were found to be at the higher and lower ends of the scales. This reporting is designed to provide a more in-depth understanding of the quantitative results. Family Quality of Life measured by the Beach Center Family Quality of Life Scale. It is 5-point liker scale which indicated 1 = very dissatisfied to 5 = very satisfied.

There were five domains in this scale. The Family Interaction Mean (±SD) was 3.35 (± 0.59) , Parenting Mean (±SD) was 3.46 (± 0.67) , Emotional Well-being Mean (±SD) was 2.81 (± 0.73), Physical Well-being/Material Well-being Mean (±SD) was 3.37 (± 0.74)and Disability related support Mean (±SD) was 3.37 (± 0.74).

Australian family quality of life literature conduct a study about developmental disability, the study found the overall family quality of life neither satisfied or neither dissatisfied (Rillotta et al., 2012). Another study in china focuse that the mental health of primary caregivers were remarkably poorer than the general population, which was consistent with the findings of previous researches abroad (Mobarak et al., 2000; Hamzat and Mordi, 2007;Byrne et al., 2010; Mehmedinovic et al., 2012; Basaran et al., 2013). In the study of Ones et al. (2005), all domains of quality of life in mothers of children with CP were significantly lower than that of control mothers.

The researcher found satisfaction level in this study was that the father's level of satisfaction was neither satisfied or neither satisfied.Another study in caregiver FQOL in china found a result,the caregivers of children with CP had to overcome the difficulties and complications arising from their children's impairments, they were unable to provide for their own social needs; therefore,they had lower satisfaction with life (Ones et al. 2005, Jeong et al. 2013).

1.3 Mothers Level of satisfaction about Family Quality of Life

Family Quality of Life measured by the Beach Center Family Quality of Life Scale. It is 5-point liker scale which indicated 1 = very dissatisfied to 5 = very satisfied.

At first researcher assess the individual domains of the Family Quality of Life (FQOLS-2006). Researcher was finding out the Mean and SD of the individual components.

The Family Interaction Mean (±SD) was 3.4495 (±0.85578), Parenting Mean (±SD) was 3.4933 (±0.794), Emotional Well-being Mean (±SD) was 2.8442 (± 1.08873), Physical Well-being/Material Well-being Mean (±SD) was 4.0967 (±4.491), and Disability related support Mean (±SD) was 3.4833 (±0.700).

In the family quality of life literature evidence suggests that mothers of children with disabilities may experience more stress and depression (Bristol et al., 1988; Trute, 1995; Olsson & Hwang, 2001), and that mothers reported more time demands and negative impacts on their personal well-being (McLinden, 1990). Perceptive of father and mother FQOL literature say that fathers do not differ from mothers in assessing their overall satisfaction of FQOL (Wang et. al., 2006). Fathers may experience more impacts when the child with a disability is male (Trute, 1995), while mothers may experience greater stress with younger children and/or children with behaviour problems (Trute, 1995). Further, fathers may feel greater stress associated with their perceptions of their child's social acceptance (Saloviita & Leinonen, 2003).

In this study show that the overall level of satisfaction of mother was neither satisfied and neither dissatisfied. This study also found that the father and mothers satisfaction level was same. There was no difference between their level of satisfaction.

1.4 Comparison between Demographic characteristics and Family Quality of life Components by T-test

Table 4.5 show the two groups are significantly different from each. The result was focus by t-test. Researcher was conducted the comparison between two groups of demographic characteristics such as sex of children with CP & the participantsand types of family with five components of the FQOL. But Researcher found only four results that are significant from each other.

Domain-2 (Parenting component) & in the group of gender of children with Cerebral Palsy was high significant relation. The Male mean was 20.8684 and female mean was 20.6364. The P-vale was .001 which was less than significant level (0.05).

Than Domain-2 (Parenting) & types of family has significant relation. The P-vale was .003 which was less than significant level (0.05). The join family mean was 62.2677 and nuclear family mean was 76.2729.

Domain-1 (Family interaction) & in the group of types of family of the participants was significant relation. Becausethe join family mean was 18.8846 and nuclear family mean was 22.2353. The P-vale was .026 which was less than significant level (0.05).

Domain-5 (Disability related support) & in the group of types of family was significant relation. The P-value was .016 was less than significant level (0.05). The join family mean was 71.5385 and nuclear family mean was 69.1765.

In the family literature, studies of role allocations in families find that mothers and fathers tend to allocate different priorities to work and family life, but no gender differences have been found in definitions of ‘ideal’ role participation (Perrone et al. 2005), which is consistent with the findings of this study.

In this study also found no gender differences of father and mother in role of the family quality of life.

1.5 Group mean difference regarding overall level of satisfaction of family quality of life components using ANOVA (Fathers)

Researcher was conducted ANOVA test with all demographic characteristics of the participant (Fathers & mothers of children with CP) with five domain of FQOL. But this study found some relationships between them.

Table 4.6 & 4.7 show the groups are significantly different from each other and focus on the result by ANOVA test. Researcher conduct it demographic characteristics of the participants with five domains of FQOL. Researcher was found significant relation between Age group of the participants with Domain-4 (Physical well-being/ Material well-being)Domain-5 (Disabilityrelated support). The P-vale was .014 which was less than significant level (0.05). The mean (± SD) was 67.46 (± 15.06).

Researcher was also found significant relation between employment status of the participants with Domain-2 (Parenting), Domain-5 (Disability related support). The P-vale was .018 which was less than significant level (0.05).The mean (± SD) was 68.68(± 13.72).

1.6 Group mean difference regarding overall level of satisfaction of family quality of life components using ANOVA (Mothers)

Table 4.8 & 4.9 show the groups are significantly different from each other and focus on the result by ANOVA test. Researcher conduct it demographic characteristics of the participants with five domains of FQOL. Researcher was found significant relation between educational status of the participants with Domain-4 (Physical well-being/ Material well-being). The P-vale was .009 which was less than significant level (0.05). The mean (± SD) was 70.20(± 11.44).

Researcher was found significant relation between community types groups of the participants with Domain-2 (parenting). The P-vale was .010 which was less than significant level (0.05). The mean (± SD) was70.20(± 15.52).

Study in caregiver FQOL in china found a result, as a person ages, morphology, functionandmetabolismofthephysiologicalfunctionundergoa series of changes, such as weakened immunity and decreased activity. These directly affect an older person’s daily activities, social function and mental status (Jiang and Zhang 1999). In the study of Mao et al. (2004), it was reported that age and educational level can affect physical and mental health. They found a significant relation between age educational relation & family quality of life (Wu, Zhang & Hong, 2017). In another literature of FQOL in china suggest that community types of the participants & severity types of the CP significant predictors of satisfaction rating of FQOL (Hu, Wang & Fei, 2012). In addition, Feng &Yi (2002) noted the social-economic status of families is a key indicator of family wellbeing and happiness.The findings in this study confirm their results.

5.2 Limitation:

- The representativeness of the sample in this study is limited as the data were only collected in the Savar and Dhaka area in Bangladesh. There was Limited diversity of families in the sample.
- Lack of variance in response.
- It was difficult to collected data from fathers of the family because they weren't always present in the home.
- The investigator calculated sample size was 368 but the sample size was 120 just a few more respondents could have been collected if more data collectors would be possible to assign. Nevertheless, the parent's availability and their willingness to participate, inclusion criteria, the time margin and costs involved with data collections compelled the investigators to stick with the current sample size.
- Another limitation of the study relates to the lack of data collection on some other important family demographic variables such as: family dynamics, family support services and family coping patterns. These variables are potential influential factors of the relationships between the family demographics and their perceived satisfaction with their FQOL and should be incorporated in the future studies.
- The present study has suggested that the FQOLS-2006 has the potential, with some modifications, to provide a reliable and comprehensive assessment of FQOL in Bangladeshi context.

5.3Conclusion

In closing, this study represents a first step in exploring the level of satisfaction of fathers and mothers with respect to their assessments of FQOL. The results highlight that fathers do not differ from mothers in assessing their overall FQOL. Furthermore, the finding of measurement invariance of the FQOL construct across the groups of fathers and mothers suggests that the FQOL Scale is a useful and reliable tool that can similarly measure the underlying FQOL construct across fathers and mothers in early childhood programs. Its capacity to discriminate between families with different levels of FQOL in different domains and concepts also suggests that it could be a useful practical measure for service delivery. Service providers will be able to use the expert opinions expressed from within the family to identify specific areas of need and then assist families to access the same places and resources that are available within the wider community. FQOL research plays a key role in ensuring that children with Cerebral Palsy and their families have an opportunity to describe what they need to improve their FQOL. Moreover, if the outcomes of the research are taken seriously by support service providers, then they will be better placed to implement programs to support families that have a member with Cerebral Palsy child.

5.4 Recommendation

From this study it is clearly seen that the parents perceived of Family Quality of life. The researchers have drawn some recommendation based on the findings of the research.

- The researcher recommends that in future similar research might be conducted in this area should use with larger scale of sample size.

- A further research in this area might contribute to understand the factors of Family quality of life (Brach Center Family Quality of life Scale, 2006).

- To ensures effective treatment and rehabilitation to the parents who have children with Cerebral Palsy.

- It is necessary to ensure caregiver physical, mental and socio-economic wellbeing.

- The current study also recommends that health professionals might contribute to minimize the parents Psychological problems and to increase family interaction by providing proper education, supportive therapy, couple therapy occupational training, counseling, information for maintaining own health (Shonkoff , 1992).

- Research and intervention models have primarily focused on mothers (Krauss, 1997)family-centered assessment and intervention must consider other family members by addressing the family as a whole (Bailey et al.,1998).

- Professionals and practitioners in early childhood programs can benefit from having families' perspectives on their FQOL when developing supports and services (Dunst & Bruder., 2002).

- To include other family members such as- sisters, brothers, grandparents, aunty, uncle in further study.

REFERENCE LIST

Alam, K. J., (2009). Bangladesh and persons with Disabilities [Internet]. Asia-pacific Human Rights Information Center; [accessed 01 Feb 2018]. Available at: http://www.hurights.or.jp/archives/focus/section2/2009/03bangladesh-and-persons-with-disability.html.

Allsopp, M., Braun, N., Doernberg, N., Benedict, R., Kirby, R., Durkin, M. (2008). Prevalence of Cerebral Palsy in 8-year-old children in three areas of the United stated in 2002: a multisite collaboration. Paediatrics, vol 121, no3, pp547-54 [Accessed 17 Feb 2018]. Available at : http://hinari-gw.who.int/whalecompaediatrics.aappublications.org/whalecom0/content/121/3/547.full.pdf+html?sid=e7c21lab0-88bf-4344-8721-411916ca11e6

Australian Institute of Health andWelfare (AIHW) (2008). Disability in Australia:Intellectual Disability. Bulletin no. 67. Cat. no. AUS110. Australian Institute of Health and Welfare, Canberra.

Bangladesh Bureau of Statistics, B. C., (2011). Population and Housing Census. Dhaka, Bangladesh Bureau of Statistics.

Bangladesh Bureau of Statistics, B. H, (2010). Household Income and Expenditure Survey (HIES),Bangladesh Bureau of Statistics.

Basaran, A., Karadavut, K.l., Uneri, S. O., Balbaloglu, O., & Atasoy, N., (2013). The effect of having a children with CP on quality of life, burn-out, depression and anxiety scores : a comparative study. European journal of physical and rehabilitation medicine, 49, 815-822.

Bailey D. B., McWilliam R. A., Darkes L. A., Hebbeler K., Simeonsson R. J., Spiker D. & Wagner M. (1998). Family outcomes in early intervention: a framework for program evaluation and efficacy research. Exceptional Children 64, 313–18.

Byrne, M. B., Hurley, D. A., Daly, L.,& Cunningham, C. G., (2010) .Health status of caregivers of children with CP. Child: Care, Health and Developmental, 36, 696-702.

Brown I., Anand S., Fung W. L., Isaacs B. & Baum N., (2003). Family quality of life: Canadian results from an international study. Journal of Developmental and Physical Disabilities 15, 209–30.

Brown I., (1999). Embracing quality of life in times of spending restraint. Journal of Intellectual & Developmental Disability 24, 299–308.

Brown I. & Brown R., (2003). Quality of Life and Disability: An Approach for Community Practitioners. Jessica Kingsley Publishers, London.

Brown I., Neikrug S.,& Brown R. I., (2000). Family Quality of Life Survey. Faculty of SocialWork, University of Toronto, Toronto.

Brown I., Anand S., Fung W. L. A., Isaacs B.,& Baum N., (2003) Family quality of life: Canadian results from an international study. Journal of Developmental and Physical Disabilities 15, 207–30

Cerebral Palsy: Hope through Research, (25 May, 2017). National Institute of Neurological and stroke ;[Accessed 01 Feb 2018]. Available from:https://www.ninds.nih.gov/Disorders/All-Disorders/Cerebral-Palsy-Information-Page.

Cerebral Palsy: A Complete Guide for Caregiving 2nd ed. Freeman Miller, M.D. and Steven J. Bachrach, M.D. The Johns Hopkins University Press. Baltimore, MD. 2006.

Children with Cerebral Palsy: A Parent’s Guide 2nd ed. Edited by Elaine Geralis. Chapter 1: What is Cerebral Palsy? by Dr. Elliot S. Gersh. Chapter 3: Medical Concerns and Treatment by Dr. Gersh. Woodbine House, Inc. Bethesda, MD. 1998.

Dunst C. J.,& Bruder M. B., (2002). Valued outcomes of service coordination, early intervention, and natural environments. Exceptional Children 68, 361–75.

DeFrain J., (1999). Strong families. Family Matters 53, 6–13.

Dunst C., Trivette C., Hamby D.,& Bruder M., (2006). Influences of contrasting natural learning environment experiences on child, parent and family well-being. Journal of Developmental and Physical Disabilities 18, 235– 50.

Datta S. S., Russell P. S. S.,& Gopalakrishna S. C., (2002). Burden among the caregivers of children with intellectual disability: associations and risk factors. Journal of Intellectual Disabilities 6, 337–50. doi: 10.1177/ 146900470200600401.

Faruque, A. A., (2008). Plight of persons with disabilities: towards effective legal framework. The daily star.net;[Accessed 01 Feb 2018]. Available at: http://www.thedailystar.net/law/2008/04/03/index.htm

Gardiner, E. C., (2014). Quality of life in families of children with autism spectrum disorder: considerations of risk and resilience (Doctoral dissertation, Arts & Social Sciences:).

Government of Bangladesh.,(2013). Survey of Autism and Neurodevelopmental Disorder in Bangladesh .

Guillamón, N., Nieto, R., Pousada, M., Redolar, D., Muñoz, E., Hernández, E.,& Gómez-Zúñiga, B., (2013). Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. *Journal of clinical nursing*, *22*(11-12), 1579-1590.

Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A., (2006). Assessing family outcomes: psychometric evaluation of the Beach Center Family Quality of Life Scale. *Journal of marriage and family*, *68*(4), 1069-1083.

Hu, X., Wang, M., & Fei, X., (2012). Family quality of life of Chinese families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, *56*(1), 30-44.

Jokinen, N. S., & Brown, R. I., (2005). Family quality of life from the perspective of older parents. *Journal of Intellectual Disability Research*, *49*(10), 789-793.

Kaya, K., Unsal-Delialioglu, S., Ordu-Gokkaya, N. K., Ozisler, Z., Ergun, N., Ozel, S. & Ucan, H., (2010). Musculo-skeletal pain, quality of life and depression in mothers of children with CP. Disability and Rehabilitation, 32, 1666–1672.

Khayatzade Mahani M., (2009).A comparative Study about quality of life in mothers of children with cerebral palsy, mental retardation and mothers of normal children [Persian]. Bimonthly Official Publication Medical Daneshvar 17: 49–58.

Krauss M. W.,(1997).Two generations of family research in early intervention. In: The Effectiveness of Early Intervention (ed. M. Guralnick), pp. 6–24. Paul H. Brookes, Baltimore, MD.

Manuel, J., Naughton, M. J., Balkrishnan, R., Paterson Smith, B. & Koman, L. A., (2003). Stress and adaptation in mothers of children with CP. Journal of Pediatric Psychology, 28, 197–201.

Park, J., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., Mannan, H., Nelson, L. L., (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. Journal of Intellectual Disability Research, 47, 367384. doi:10.1046/j.1365-2788.2003.00497.x

Rillotta, F., Kirby, N., Shearer, J., & Nettelbeck, T., (2012). Family quality of life of Australian families with a member with an intellectual/developmental disability. *Journal of Intellectual Disability Research, 56*(1), 71-86.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., Dan, B. & Jacobsson, B., (2007). A report: the definition and classification of CP April 2006. Developmental Medicine and Child Neurology. Supplement, 109,8 –14.

Shonkoff J. P., Hauser-Cram P., Krauss M. W. & Upshur C. C., (1992). Development of infants with disabilities and their families. Monographs of the Society for Research in Child Development 57 (6, Serial No. 230).

Surveillance of Cerebral Palsy in Europe, (2000) Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Dev Med Child Neurol. 42:816–824.

Schippers, A., & van Boheemen, M., (2009). Family quality of life empowered by familyoriented support. Journal of Policy and Practice in Intellectual Disabilities, 6, 1924. doi:10.1111/j.1741-1130.2008.00195.x

S¸enelH.G., &AkkökF.,(1995). Stress levels and attitudes of normal siblings of children with disabilities. International Journal for the Advancement of Counselling 18, 61–8.

Sen E, and Yurtsever S., (2007). Difficulties experienced by families with disabled children. Journal for Specialists in Pediatric Nursing 12: 238–252.

Shonkoff J. P., Hauser-Cram P., Krauss M. W.,& Upshur C. C., (1992) Development of infants with disabilities and their families. Monographs of the Society for Research in Child Development 57 (6, Serial No. 230).

Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., & Wang, M., (2005). Conceptualizing and measuring family quality of life. Journal of Intellectual Disability Research, 49, 777-783. doi:10.1111/j.13652788.2005.00751.x

Turnbull, A. P., (2004). President's address 2004: 'Wearing two hats': Morphed perspectives on family quality of life. Mental Retardation, 42, 389-399. doi:10.1352/0047-6765(2004)42<383:PAWTHM>2.0.CO;2

Turnbull, A. P., Poston, D. J., Minnes, P., & Summers, J. A., (2007). Providing supports and services that enhance a family's quality of life. In I. Brown & M. Percy (Eds.), A comprehensive guide to intellectual & developmental disabilities (pp. 561-571). Baltimore, MD: Paul H. Brookes.

Understanding the Lives of Caregivers of Children with Cerebral Palsy in rural Bangladesh: Use of Mixed Methods (PDF Download Available). Available from:https://www.researchgate.net/publication/281548746_Understanding_the_Lives_of_Caregivers_of_Children_with_Cerebral_Palsy_in_rural_Bangladesh_Use_of_Mixed_Methods [accessed Feb 17 2018].

Understanding Cerebral Palsy: A Guide for Parents and Professionals. Marion Stanton. Jessica Kingsley Publishers. London and Philadelphia. 2012.

Vandamme, E., (2009). Concepts and challengs in the use of knowledge, attitude-practice surveys: literature review.

Wang, M., Summers, J. A., Little, T., Turnbull, A., Poston, D., & Mannan, H., (2006). Perspectives of fathers and mothers of children in early intervention programmes in assessing family quality of life. *Journal of Intellectual Disability Research, 50*(12), 977-988. doi:10.1111/j.1365-2788.2006.00932.x.

Wang M. & Brown R., (2009). Family quality of life: a framework for policy and social service provisions to support families with children with disabilities. Journal of family Social work I2, I44-67.

Webster R. I., Majnemer A., Platt R.W.,& Shevell M. I., (2008). Child health and parental stress in school-age children with a preschool diagnosis of developmental delay. Journal of Child Neurology 23, 32–8.

WHOQoL Group, (1995). The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social science & medicine*, *41*(10), 1403-1409.

Wong S.Y., Wong T. K. S., Martinson I., Lai A. C., Chen W. J. & He Y. S., (2004) Needs of Chinese parents of children with developmental disability. Journal of Learning Disabilities 8, 141–58.

Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S., (2010). Theorizing about family quality of life. In R. Kober (Ed.), Enhancing the quality of life of people with intellectual disabilities: From theory to practice (pp. 241-278). Dordrecht, the Netherlands: Springer.

Hamzat, T. K. & Mordi, E. L., (2007). Impact of caring for children with CP on the general health of their caregivers in an African community. International Journal of Rehabilitation Research, 30, 191–194.

Jeong, Y. G., Jeong, Y. J. & Bang, J. A., (2013).Effect of social support on parenting stress of korean mothers of children with CP. Journal of Physical Therapy Science, 25, 1339–1342.

Jiang, J. M. & Zhang, C. X.,(1999). Satisfaction and influencing factors on quality of daily life of city old people. Chinese Journal of Public Health, 15, 856–857.

Mao, Q., He, X. M., Zhen, Y. R. & Ke, Z. H., (2004.) Study on the quality of life of the aged in urban areas in middle and southern part of Fujian province. Chinese Journal of Nursing, 42, 165–168.

Mehmedinovic, S., Sinanovic, O. & Ahmetovic, S., (2012). Depression in parents of children with CP in Bosnia and Herzegovina. Acta Medica Iranica, 50, 819–821.

Feng X.T. & Yi S. G., (2002) Family quality of life for citizens: indicators and structure. Research on Sociology 24, 107–18.

Bristol M. M., Gallagher J. J. & Schopler E., (1998). Mothers and fathers of young developmentally disabled and nondisabled boys: adaptation and spousal support. Developmental Psychology 24, 441–51.

McLinden S. E., (1990). Mothers’ and fathers’ reports of the effects of a young child with special needs on the family. Journal of Early Intervention 14, 249–59.

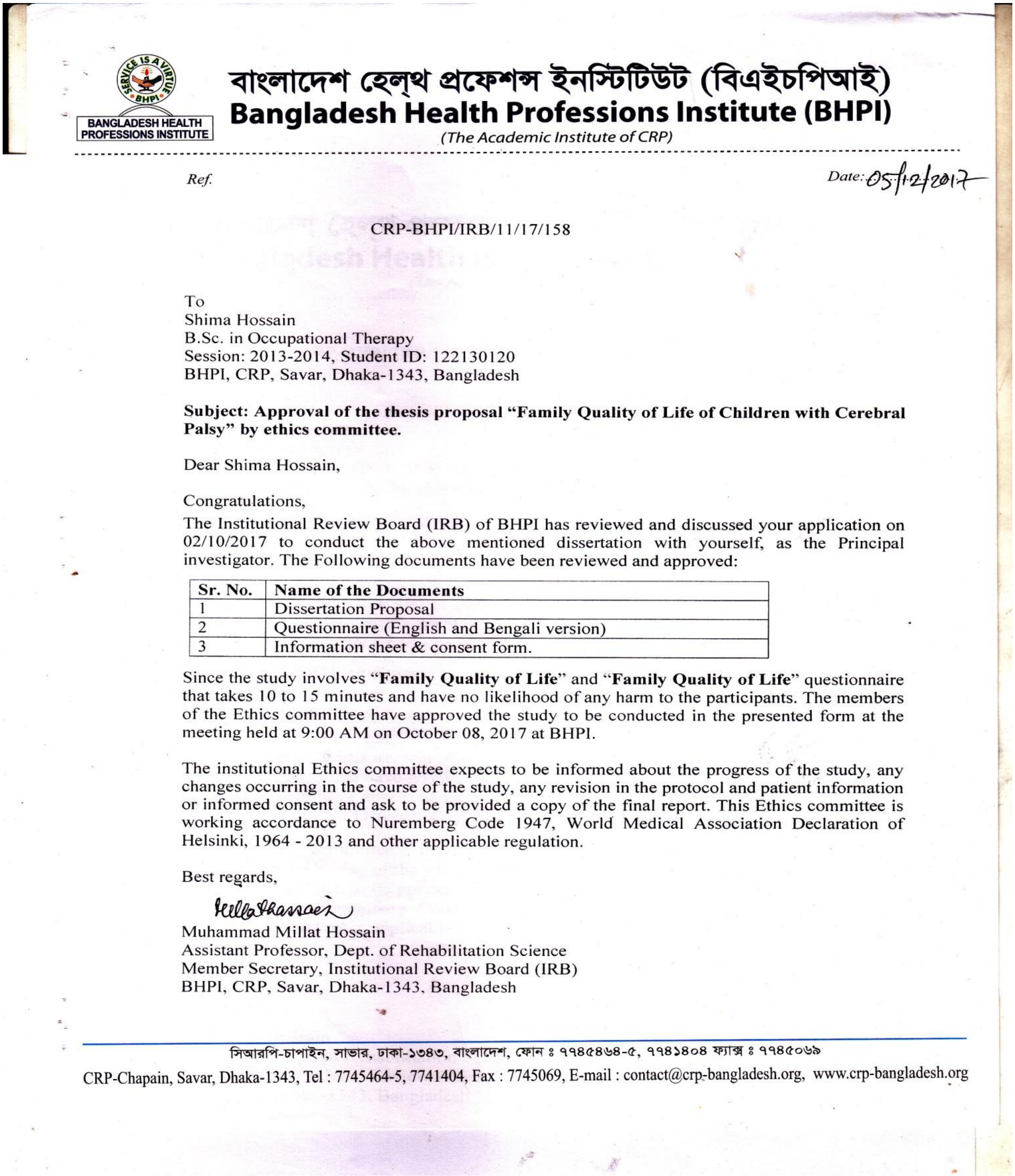
Perrone K. M., Webb L. K. & Blalock R. H., (2005). The effects of role congruence and role conflict on work, marital, and life satisfaction. Journal of Career Development 31, 225–38.

Saloviita. M. I. & Leinonen E., (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX model. Journal of Intellectual Disability Reearch 47, 300–12.

Trute B., (1995). Gender differences in the psychological adjustment of parents of young, developmentally disabled children. Journal of Child Psychology and Psychiatry 36, 1225–42.

APPENDIX-I

(IBR permission Letter)



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

Ref. Date: 05/12/2017

CRP-BHPI/IRB/11/17/158

To
Shima Hossain
B.Sc. in Occupational Therapy
Session: 2013-2014, Student ID: 122130120
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "Family Quality of Life of Children with Cerebral Palsy" by ethics committee.

Dear Shima Hossain,

Congratulations,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on 02/10/2017 to 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	Dissertation Proposal
2	Questionnaire (English and Bengali version)
3	Information sheet & consent form.

Since the study involves "**Family Quality of Life**" and "**Family Quality of Life**" questionnaire that takes 10 to 15 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 9:00 AM on October 08, 2017 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.

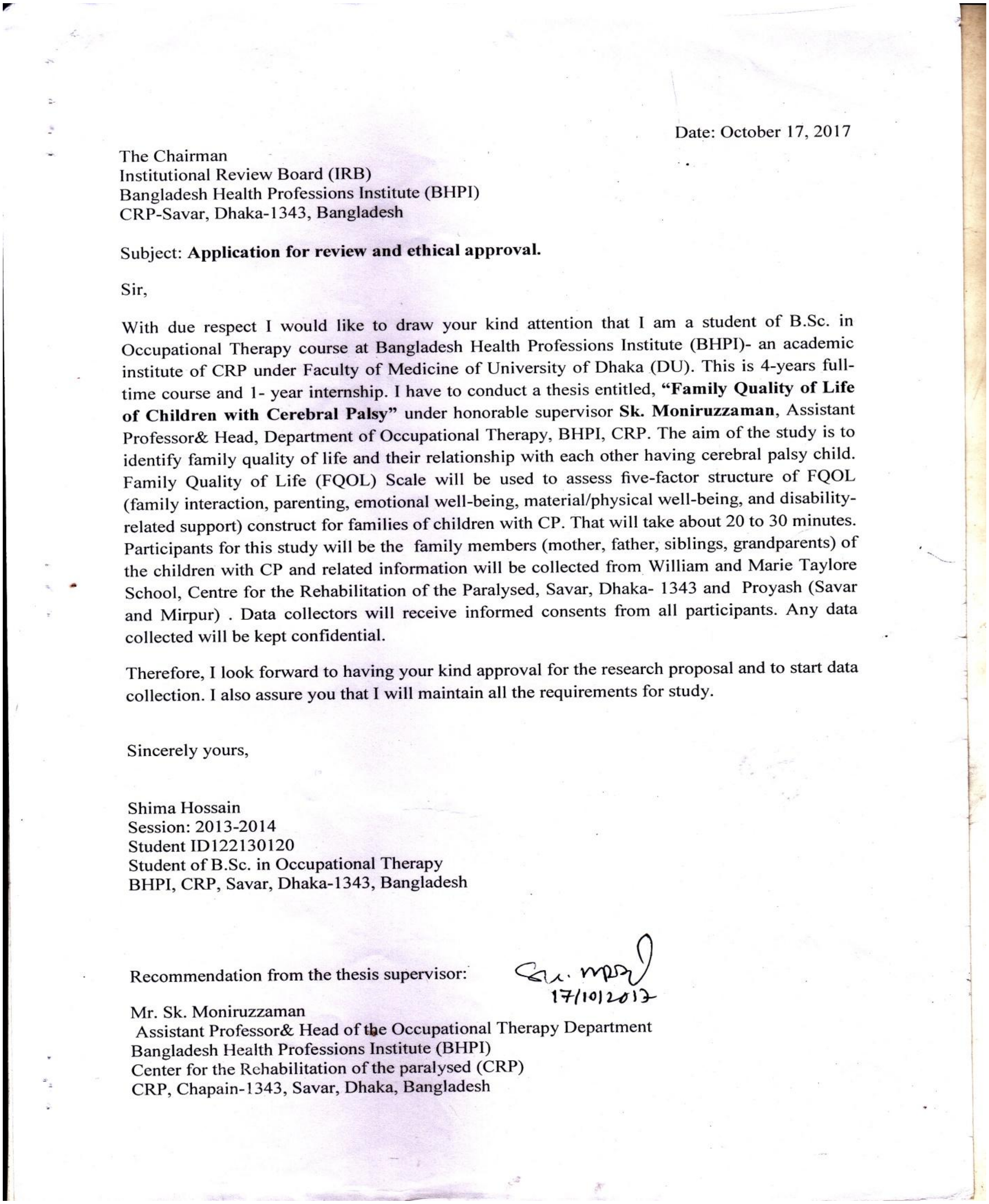
Best regards,

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-II

(Permission letter)



Date: October 17, 2017

The Chairman
Institutional Review Board (IRB)
Bangladesh Health Professions Institute (BHPI)
CRP-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 B.Sc. in Occupational Therapy course at Bangladesh Health Professions Institute (BHPI)- an academic institute of CRP under Faculty of Medicine of University of Dhaka (DU). This is 4-years full-time course and 1- year internship. I have to conduct a thesis entitled, **“Family Quality of Life of Children with Cerebral Palsy”** under honorable supervisor **Sk. Moniruzzaman**, Assistant Professor& Head, Department of Occupational Therapy, BHPI, CRP. The aim of the study is to identify family quality of life and their relationship with each other having cerebral palsy child. Family Quality of Life (FQOL) Scale will be used to assess five-factor structure of FQOL (family interaction, parenting, emotional well-being, material/physical well-being, and disability-related support) construct for families of children with CP. That will take about 20 to 30 minutes. Participants for this study will be the family members (mother, father, siblings, grandparents) of the children with CP and related information will be collected from William and Marie Taylore School, Centre for the Rehabilitation of the Paralysed, Savar, Dhaka- 1343 and Proyash (Savar and Mirpur) . Data collectors will receive informed consents from all participants. Any data collected will be kept confidential.

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

Sincerely yours,

Shima Hossain
Session: 2013-2014
Student ID122130120
Student of B.Sc. in Occupational Therapy
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Recommendation from the thesis supervisor:

17/10/2017

Mr. Sk. Moniruzzaman
Assistant Professor& Head of the Occupational Therapy Department
Bangladesh Health Professions Institute (BHPI)
Center for the Rehabilitation of the paralysed (CRP)
CRP, Chapain-1343, Savar, Dhaka, Bangladesh

APPENDIX-III

(Information sheet)

The name of the researcher is Shima Hossain. She is a student of 4th year B.Sc. in Occupational Therapy in Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). As a part of his academic issues, she has to conduct a research project in this academic year. So researcher would like to invite you to participate in this study. The title of the study is "Family Quality of Life When Children with Cerebral Palsy"**.**

Your participation is voluntary in the study. You can withdraw your participation in anytime. There is not the facility to get any pay by this participation. The study will never be any harm to you but it will help the service user to know your experience, which is very important for the service provider to plan for their future activities.

Confidentiality of all records will be highly maintained. The gathered information from you will not be disclosed anywhere except the researcher and supervisor. The study will never publish the name of participant anywhere.

If you have any query regarding the study, please feel free to ask to the contact information.

Stated below:

Shima Hossain
Student of 4th year B.Sc. in Occupational Therapy
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI),
Centre for the Rehabilitation of the Paralysed (CRP),
Chaplain, Savar, Dhaka-1343

APPENDIX-VI

(Information sheet)

তথ্যপত্র

গবেষণাকারীর নাম ঃ সিমা হোসেন । সে পক্ষাঘাত পূনর্বাসন কেন্দ্র (সি আর পি) এর অধিনস্থ বাংলাদেশ হেলথ্ প্রফেশন্স্ ইনস্টিটিউটের অকুপেশনাল থেরাপি বিভাগ এ ৪র্থ বর্ষের ছাত্রী । তার প্রাতিষ্ঠানিক কার্যের অংশ হিসেবে চলন্ত শিক্ষাবর্ষে তাকে একটি গবেষণামূলক কাজ করতে হবে । গবেষণাটির শিরোনাম “ পারিবারিক গুনগত মান সম্পর্কে ধারণা ।

গবেষণায় আপনার অংশ গ্রহণসম্পূণ রুপে স্বেচ্ছায় । আপনি যে কোন সময় গবেষণা থেকে আপনার অংশগ্রহণ প্রত্যাহার করতে পারবেন । এই গবেষনায় অংশগ্রহণে গবেষক আপনাকে কোন ভাবে আর্থিক সাহায্য প্রদান করবেন না । এই অংশগ্রহণ কখনোই আপনার জন্য ক্ষতির কারণ হয়ে দাড়াবে না কিন্তু এই গবেষণার মাধ্যমে সেবাপ্রদানকারী সদস্যগণ আপনার অভিজ্ঞতার কথা জানতে পারবেন এবং প্রাপ্ত তথ্য সমূহ সেবার মান উন্নয়নে সাহায্য করবে ।

আপনার কাছ থেকে প্রাপ্ত তথ্য সমূহের সর্বোচ্চ গোপনীয়তা রক্ষা করা হবে । গবেষক এবং অংশগ্রহনকারীর নাম প্রকাশ হবে না ।

গবেষণা সর্ম্পকিত যে কোন ধরনের প্রশ্নের জন্য নিম্নলিখিত ব্যক্তির সাথে যোগাযোগ করার জন্য অনুরোধ করা যাচ্ছে ।

সিমা হোসেন
বিএসসি ইন অকুপেশনাল থেরাপি (৪র্থ বর্ষ)
অকুপেশনাল থেরাপি বিভাগ
বাংলাদেশ হেলথ্ প্রফেশন্স্ ইনস্টিটিউট
পক্ষাঘাতগ্রস্তদের পূনর্বাসন কেন্দ্র (সি আর পি)
চাপাইন , সাবার, ঢাকা-১৩৪৩

APPENDIX-V

(Consent Form)

This research is part of Occupational Therapy course and the name of the researcher is Shima Hossain. Shee is a student of 4th year B.Sc. in Occupational Therapy in Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). The study was entitled as **“**Perspectives of Fathers and Mothers Family **Quality of Life** When Children **with** Cerebral Palsy **”**. The purpose of the study is to know theLevel of Family’ssatisfactions with FQOLhaving Cerebral Palsy Child.

In this study I am ………………………………………………………. a participant and I have been clearly informed about the purpose and aim of the study. I will have the right to refuse in taking part any time at any stage of the study. I will not be bound to answer to anybody. This study has no connection with me and there will be no impact on my treatment at present and in future.

I am also informed that, all the information collected from the interview will be only used for study purpose and would be kept safety and confidentiality will be maintained. My name and address will not be published anywhere. Only the researcher and supervisor will be eligible to access in the information for his publication of the research result. I have been informed about the above-mentioned information and I am willing to participate in the study withgiving consent.

Signature/Finger print of the Participant:	Date:
Signature of the Researcher:	Date:
Signature/Finger print of the witness:	Date:

APPENDIX-VI

(Consent Form)

সম্মতিপত্র

এই গবেষনাটি অকুপেশনাল থেরাপির কোর্সেও একটি অংশ এবং গবেষণাকারীর নাম সিমা হোসেন । সে পক্ষাঘাত পূনর্বাসন কেন্দ্র (সি আর পি) এরঅধিনস্থ বাংলাদেশ হেলথ্ প্রফেশন্স্ ইনস্টিটিউটের অকুপেশনাল থেরাপি বিভাগ এর ৪র্থ বষের্র ছাত্রী। এই গবেষনাটির শিরোনাম “পিতা ও মাতার পারিবারিক গুনগত মান সম্পর্কে ধারণা।

এই গবেষনাতে আমি..................একজন অংশগ্রহনকারী এবং পরিষ্কারভাবে এই গবেষনার উদ্দেশ্য সম্পর্কে অবগত। আমার যে কোন সময়ে এই গবেষনা থেকে নিজেকে প্রত্যাহার করার অধিকার আছে। এজন্য আমি প্রশ্নের উত্তর প্রদান করার জন্য কারো কাছে দায়বদ্ধ না। এই গবেষণাটির সাথে আমার কোন সম্পৃক্ততা নেই|এই গবেষণাটি র্বতমানে এবং ভবিষ্যতে আমার চিকিৎসার ক্ষেএে কোন রকম প্রভাব ফেরবে না ।

আমি আরও অবগত আছি যে, এই কথোপকথন থেকে নেওয়া সমস্ত তথ্যাবলি নিরাপদে এবং গোপনীয়তার সাথে শুধু মাত্র গবেষণার কাজেই ব্যবহার করা হবে । আমার নাম এবং ঠিকানা কোথাও প্রকাশ হবে না। শুধু মাত্র গবেষণাকারীর এবং তার গবেষণার সমন্বয়কারীর সাথে এই গবেষণার পদ্ধতি সম্পর্কে অথবা যে কোন প্রশ্নের উত্তর জানার জন্য কথা বলতে পারবে ।

আমি উপরোক্ত তথ্যগুলো ভালোভাবে জেনে নিজ ইচ্ছায় এই গবেষনায় অংশগ্রহন করছি।

অংশগ্রহনকারীর স্বাক্ষর/টিপসই	তারিখঃ
গবেষণাকারীর স্বাক্ষর	তারিখঃ
সাক্ষ্য প্রধানকারীর স্বাক্ষর/ টিপসই	তারিখঃ

APPENDIX-VII

(Questionnaire)

General Information

Name of the Children with CP: Code/ID:

Gender of the children with CP: Age:

Socio-Demographic Information

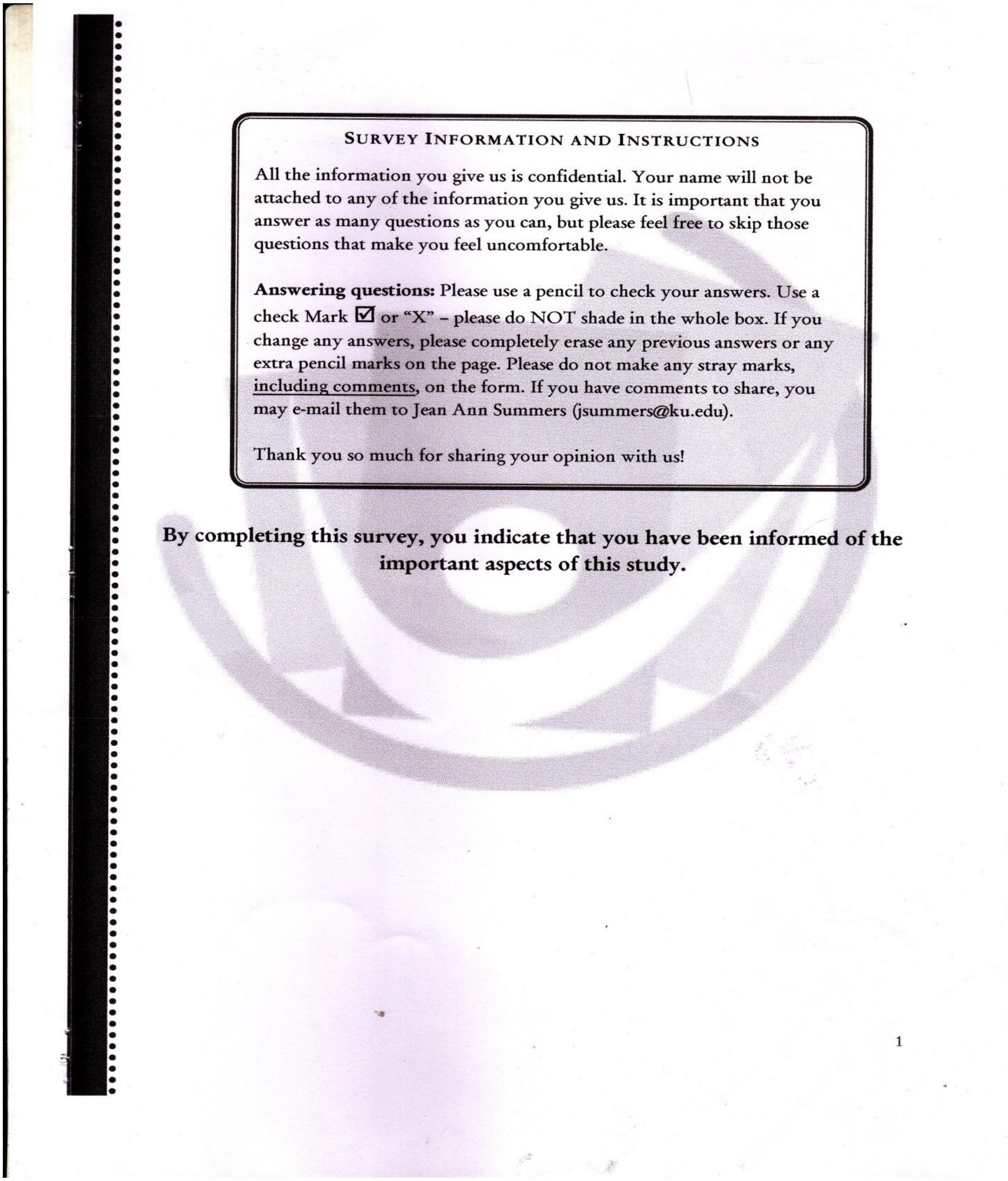
Age of the Participant	1= 16-20 2=21-30 3=31-40 4=41-50 a5= >50	☐
Sex of the Participant	1= Male 2= Female	☐
Education Background	1= Illiterate 2= signature 3= primary	☐

	4= Secondary 5= SSC 6= HSC / Diploma 7= B.Sc./ BA/ Honors 8=M.Sc. / MA/ Masters 9=Others p	
Relationship to the children	1= Father 2= Mother	☐
Employment status of the Participant	1= House wife 2= Worker/ Day labor 3= Government job 4= Non- Government job 5= Business 6= Immigrant	☐
Community Types	1= Rural 2= Semi-Urban 3= Urban	☐

Types of CP	1= Ataxic 2= Athetoid 3= Floppy 4= Spastic Monoplegic 5= Spastic Diaplegic 6= Spastic Triaplegic 7= Spastic Hemiplegic 8= Spastic Quadriplegic	☐
Types of family	1= Join Family 2= Nuclear Family	☐
Marital Status	1= Married 2= Polygamies/Divers married 3= Divorced 4= Widowed	☐
Mobile Number		

APPENDIX-VIII

Family Quality of Life Questioner



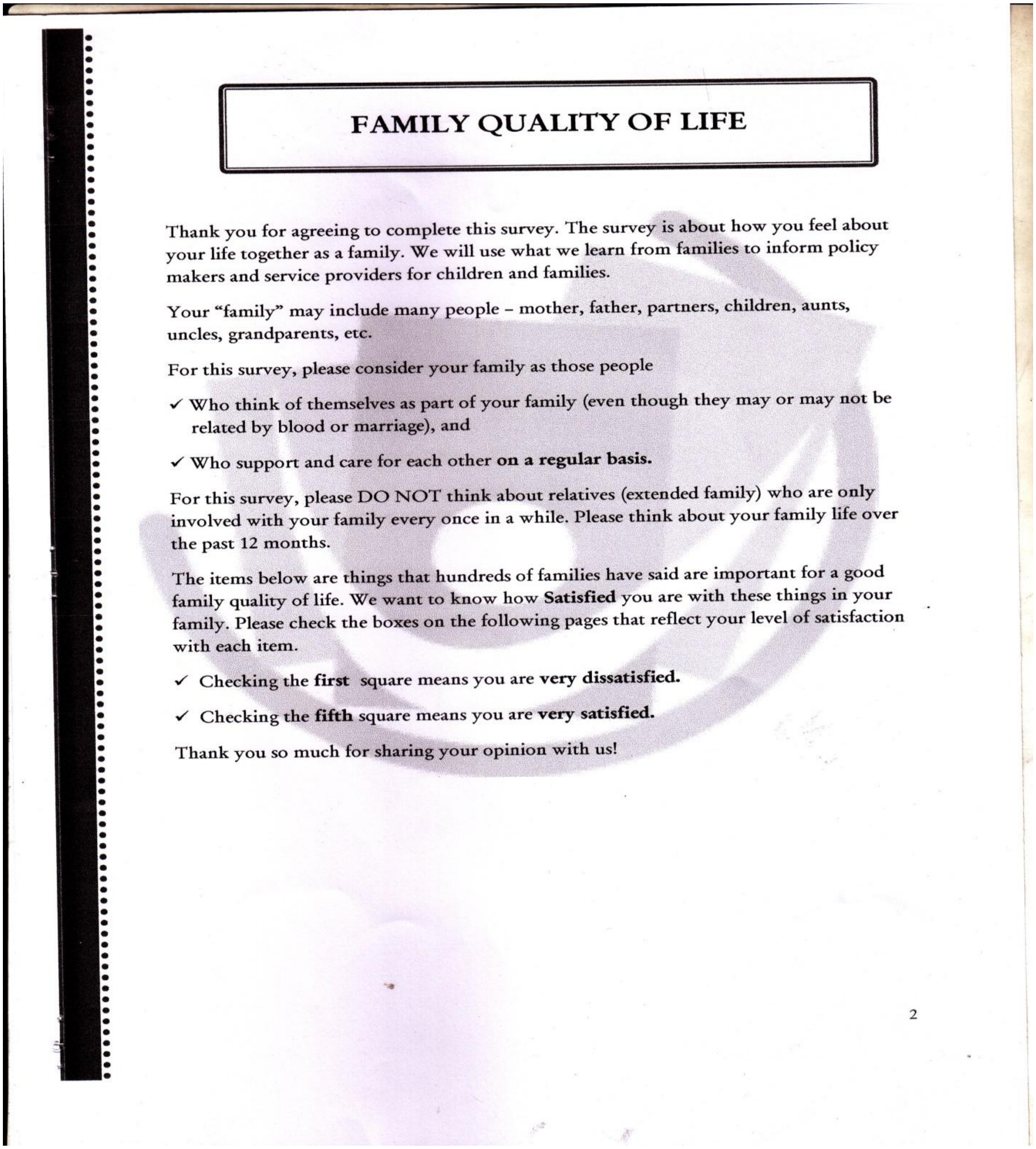
SURVEY INFORMATION AND INSTRUCTIONS

All the information you give us is confidential. Your name will not be attached to any of the information you give us. It is important that you answer as many questions as you can, but please feel free to skip those questions that make you feel uncomfortable.

Answering questions: Please use a pencil to check your answers. Use a check Mark ☑ or "X" – please do NOT shade in the whole box. If you change any answers, please completely erase any previous answers or any extra pencil marks on the page. Please do not make any stray marks, including comments, on the form. If you have comments to share, you may e-mail them to Jean Ann Summers (jsummers@ku.edu).

Thank you so much for sharing your opinion with us!

By completing this survey, you indicate that you have been informed of the important aspects of this study.



FAMILY QUALITY OF LIFE

Thank you for agreeing to complete this survey. The survey is about how you feel about your life together as a family. We will use what we learn from families to inform policy makers and service providers for children and families.

Your "family" may include many people – mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people

✓ Who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and

✓ Who support and care for each other **on a regular basis.**

For this survey, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items below are things that hundreds of families have said are important for a good family quality of life. We want to know how **Satisfied** you are with these things in your family. Please check the boxes on the following pages that reflect your level of satisfaction with each item.

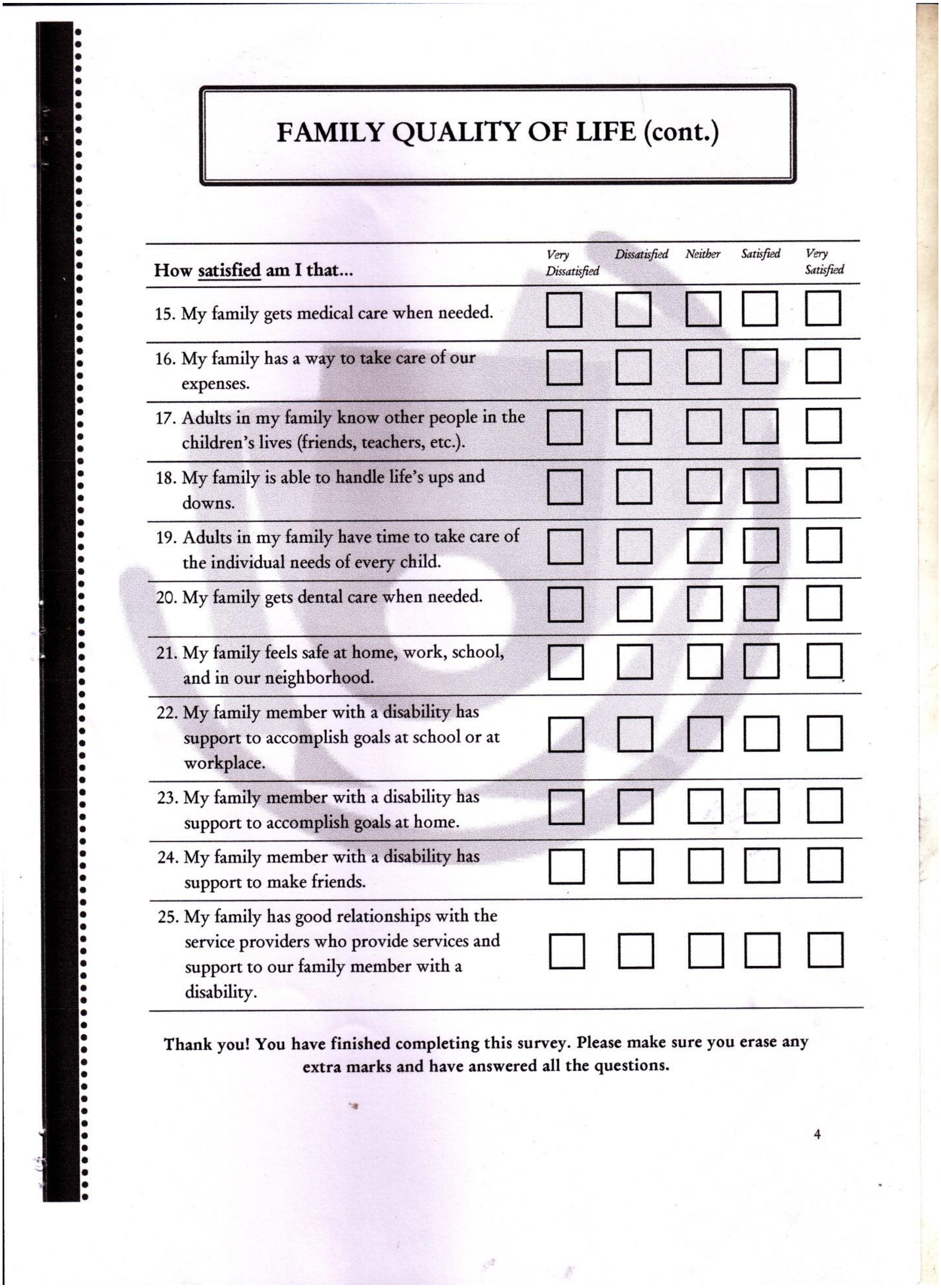
✓ Checking the **first** square means you are **very dissatisfied.**

✓ Checking the **fifth** square means you are **very satisfied.**

Thank you so much for sharing your opinion with us!

FAMILY QUALITY OF LIFE (cont.)

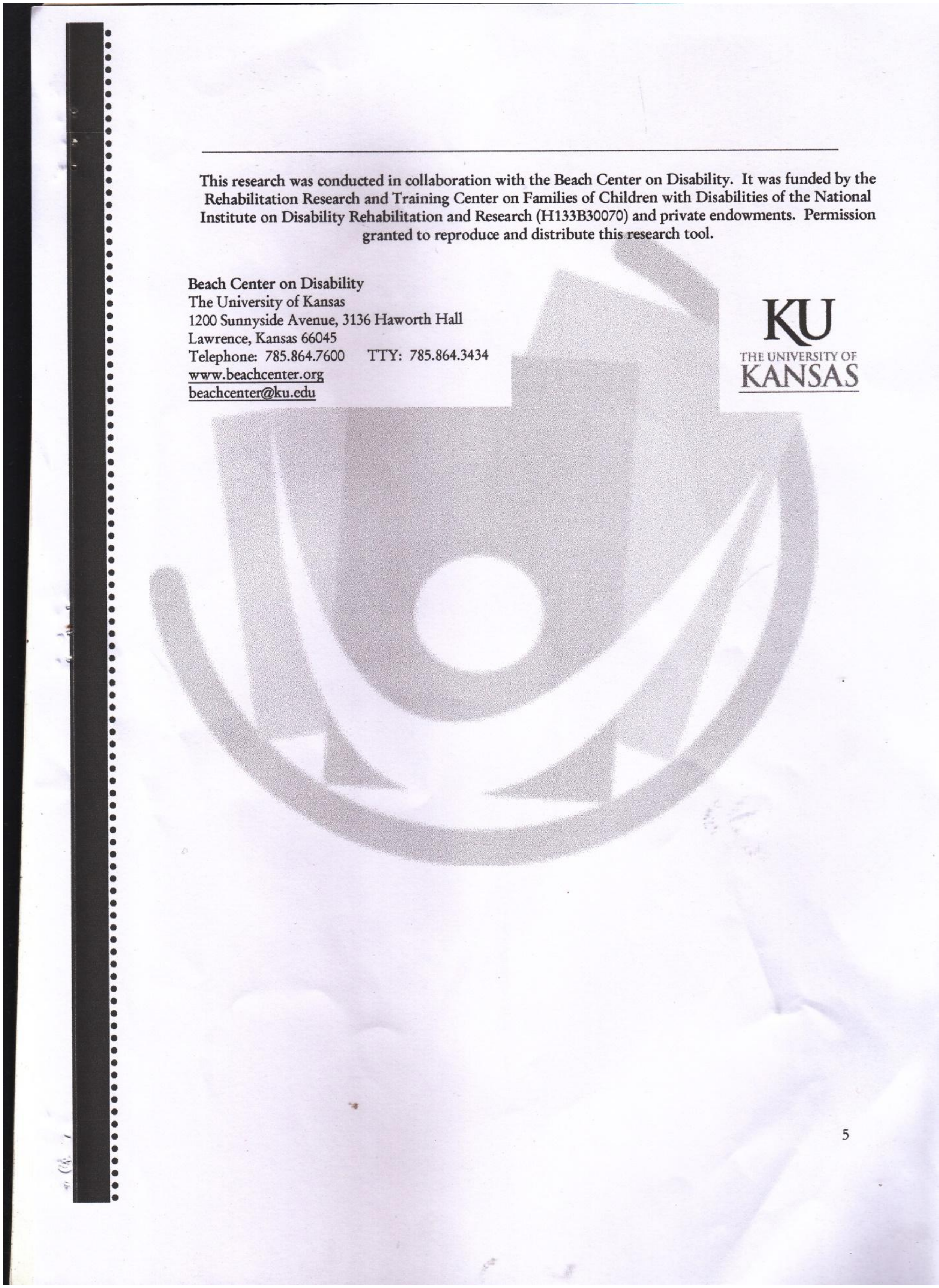
How satisfied am I that...	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
1. My family enjoys spending time together.	☐	☐	☐	☐	☐
2. My family members help the children learn to be independent.	☐	☐	☐	☐	☐
3. My family has the support we need to relieve stress.	☐	☐	☐	☐	☐
4. My family members have friends or others who provide support.	☐	☐	☐	☐	☐
5. My family members help the children with schoolwork and activities.	☐	☐	☐	☐	☐
6. My family members have transportation to get to the places they need to be.	☐	☐	☐	☐	☐
7. My family members talk openly with each other.	☐	☐	☐	☐	☐
8. My family members teach the children how to get along with others.	☐	☐	☐	☐	☐
9. My family members have some time to pursue our own interests.	☐	☐	☐	☐	☐
10. Our family solves problems together.	☐	☐	☐	☐	☐
11. My family members support each other to accomplish goals.	☐	☐	☐	☐	☐
12. My family members show that they love and care for each other.	☐	☐	☐	☐	☐
13. My family has outside help available to us to take care of special needs of all family members.	☐	☐	☐	☐	☐
14. Adults in our family teach the children to make good decisions.	☐	☐	☐	☐	☐



FAMILY QUALITY OF LIFE (cont.)

How **satisfied** am I that...	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
15. My family gets medical care when needed.	☐	☐	☐	☐	☐
16. My family has a way to take care of our expenses.	☐	☐	☐	☐	☐
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	☐	☐	☐	☐	☐
18. My family is able to handle life's ups and downs.	☐	☐	☐	☐	☐
19. Adults in my family have time to take care of the individual needs of every child.	☐	☐	☐	☐	☐
20. My family gets dental care when needed.	☐	☐	☐	☐	☐
21. My family feels safe at home, work, school, and in our neighborhood.	☐	☐	☐	☐	☐
22. My family member with a disability has support to accomplish goals at school or at workplace.	☐	☐	☐	☐	☐
23. My family member with a disability has support to accomplish goals at home.	☐	☐	☐	☐	☐
24. My family member with a disability has support to make friends.	☐	☐	☐	☐	☐
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	☐	☐	☐	☐	☐

Thank you! You have finished completing this survey. Please make sure you erase any extra marks and have answered all the questions.



This research was conducted in collaboration with the Beach Center on Disability. It was funded by the Rehabilitation Research and Training Center on Families of Children with Disabilities of the National Institute on Disability Rehabilitation and Research (H133B30070) and private endowments. Permission granted to reproduce and distribute this research tool.

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APPENDIX-IX

পরিবারের পারিবারিক গুনগত মান

আমি সন্তুষ্ট যে.......		অত্যন্ত অসুন্তুষ্ট	অসুন্তুষ্ট	কিছুইনা	সন্তুষ্ট	খুবই সন্তুষ্ট
1. Family Interaction						
১.১	আমার পরিবার একসাথে সময় কাটাতে পছন্দ করে।					
১.২	আমার পারিবারের সদস্যরা একে অপরের সাথে খুলাখুলি ভাবে কথা বলে।					
১.৩	আমার পরিবার একসাথে সম্যার সমাধান করে।					
১.৪	আমার পরিবারের সদস্যরা তাদের লক্ষ্য অর্জনের জন্য একে অপরকে সাহায্যকরে।					
১.৫	আমার পরিবারের সদস্যরা দেখায় যে তারা একে অপরকে ভালবাসে এবং তারা একে অপরের প্রতি যত্নশীল।					
১.৬	আমার পরিবার জীবনের উত্থান পতন সামলাতে সক্ষম।					
2. Parenting						
২.১	আমার পরিবারের সদস্যরা শিশুদের স্বনির্ভরশীলতা শিখাতে সাহায্য করে।					
২.২	আমার পরিবারের সদস্যরা শিুদের স্কুলের কার্যক্রম করতে সাহায্য করে।					
২.৩	আমার পারিবারের সদস্যরা শিশুদের শিখায় কিভাবে					

	অন্যদের সাথে মিশতে হয়।					
২.৪	আমার পরিবারের প্রাপ্ত বয়স্করা শিশুদের সঠিক সিদ্বান্ত নিতে শিক্ষা দেয়।					
২.৫	আমার পরিবারের প্রাপ্ত বয়স্করা পরিবারের শিশুদের যে শিক্ষক ও বন্ধুবান্ধব আছে তাদের চিনেন।					
২.৬	আমার পরিবারের প্রাপ্ত বয়স্করা পরিবারের প্রত্যেক শিশুদের নিজস্ব চাহিদা পুরনের জন্য প্রয়োজনীয় সময় রয়েছে।					
3. Emotional Well-being						
৩.১	দুশ্চিন্তা থেকে মুক্তি পেতে আমার পরিবার সাহায্যকরে।					
৩.২	আমার পরিবারের সদস্যদের এমন কিছু বন্ধুবান্ধব ও আশেপাশে লোক আছে যারা আমদের সাহায্যকরে।					
৩.৩	আমার পরিবারের সদস্যদের তাদের নিজস্ব ইচ্ছাগুলো খুঁজে বের করার মত সময় রয়েছে।					
৩.৪	আমার পরিবারের সকল সদস্যদের বিশেষ চাহিদার যত্ন নেওয়ার জন্য আমরা পরিবারের বাইরেও সাহায্যপেয়ে থাকি।					
5.Physical/ Material Well-being						
৫.১	আমার পরিবারের সদস্যদের এক জায়গা থেকে অন্য জায়গায় যাওয়ার জন্য প্রয়োজনীয় গাড়ির ব্যবস্থা রয়েছে।					
৫.২	প্রয়োজন হলে আমরা পরিবার দাঁতের চিকিৎসামূকলক সেবা পেয়ে থাকে।					
৫.৩	প্রয়োজন হলে আমরা পরিবার চিকিৎসা সেবা পেয়ে					

	থাকে।					
৫.৪	আমার পরিবারের সদস্যরা আমাদের ব্যয় বহন করার মত উপায়/পন্থা আছে।					
৫.৫	আমার পরিবার বাড়িতে,কর্মক্ষেত্রে,বিদ্যালয়ে এবং আমাদের আশেপাশে নিরাপদ বোধ করে।					
6. Disability Related support						
৬.১	পরিবারে অক্ষম সদস্যকে বিদ্যালয় এবং তার কর্মক্ষেত্রে লক্ষ্য অর্জনের জন্য আমার পরিবার সাহায্যকরে।					
৬.২	পরিবারে অক্ষম সদস্যকে তার নিজ বাড়ি লক্ষ্য অর্জনরে জন্য আমার পরিবার সাহায্যকরে।					
৬.৩	পরিবারে অক্ষম সদস্যদের বন্ধু তৈরী করতে আমার পরিবার সাহায্য করে।					
৬.৪	আমরা পরিবারের সাথে তাদের ভালো সম্পর্ক রয়েছে যারা প্রতিবন্ধি ব্যক্তিদের সেবা প্রদান করে এবং আমাদের পরিবারকে সমর্থন করে।					