QUALITY OF LIFE AND ITS ASSOCIATED FACTORS AMONG PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY LIVING IN SARLAHI AND RAUTAHAT DISTRICTS OF NEPAL

By

BINA PANDIT

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(BHPI)

Faculty of Medicine

University of Dhaka

SUPERVISOR'S STATEMENT

As supervisor of Bina Pandit M.Sc. Thesis work, I certify that I consider her thesis **"Quality of Life and its Associated factors among Primary Caregivers of Children with Cerebral Palsy Living in Sarlahi and Rautahat Districts of Nepal"** to be suitable for examination.

Dr. Kamal Ahmed
Associated Professor, IHT
Mohakhali, Dhaka
(Supervisor)

Ahmed
20.05- 2018
Date

We the undersigned certify that we have carefully read and recommended to the Faculty of Medicine, University of Dhaka, for the acceptance of this dissertation entitled "QUALITY OF LIFE AND ITS ASSOCIATED FACTORS AMONG PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY LIVING IN SARLAHI AND RAUTAHAT DISTRICTS OF NEPAL" submitted by **Bina Pandit**, for partial fulfillment of the requirements for the degree of M.Sc. in Rehabilitation Science.

Dr. Kamal Ahmed

Associated Professor, IHT

Mohakhali, Dhaka

Mohammad Anwar Hossain

Associate Professor

Department of Physiotherapy

BHPI

Prof. Dr. Alamgir Kabir

Professor, Department of Statistics

Jahangirnagar University

Muhammad Millat Hossain

Assistant Professor

Department of Rehabilitation Science

BHPI

Date of approval: 06/06/..2018

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Signature:

Name: Bina Pandit

Date: 19.05.2018

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TABLE OF CONTENTS

Page no:

Acknowledgement………………………………………………………… i

Table of Contents……………………………………………………….. ii-iii

List of Tables…………………………………………………………… iv

List of Figures………………………………………………………….. v

Acronyms……………………………………………………………….. vi

Abstract…………………………………………………………………. vii

CHAPTER I: INTRODUCTION…………………………………….. 1-5

1.1 Background ……………………………………………………... 1-2

1.2 Justification of study……………………………………………. 3

1.3 Research question……………………………………………….. 4

1.4 Operational Definition…………………………………………… 4-5

CHAPTER II: LITERATURE REVIEW…………………………… 6-13

CHAPTER III: RESEARCH METHODOLOGY…………………... 14-21

3.1 Conceptual framework………………………………………….. 14

3.2 Study objectives………………………………………………… 15

3.2.1 General objectives………………………………………………. 15

3.2.2 Specific objectives ……………………………………………... 15

3.3 Study design…………………………………………………….. 15

3.4 Study population………………………………………………... 16

3.5 Study site and justification…………………………………….. 16

3.6 Study period …………………………………………………… 16

3.7 Sample size……………………………………………………... 17

3.8 Criteria for selection of sample………………………………… 17

3.8.1 Inclusion criteria………………………………………………... 17

3.8.2 Exclusion criteria……………………………………………….. 17

3,9 Sampling frame ………………………………………………… 18

3.10 Sampling technique……………………………………………... 18

3.11 Data collection Tool/ Material………………………………….. 18-19

3.12 Data collection technique ……………………………………… 19
3.13 Data management and analysis………………………………… 19-20
3.14 Quality control and assurance…………………………………... 20
3.15 Ethical consideration…………………………………………… 20-21

CHAPTER IV: RESULT……………………………………………. **22-56**

4.1 Demographic data of caregivers …………………………………… 22-28
4.2 Demographic data of child with CP……………………………... 29-30
4.3 Characteristic of child……………………………………………… 31-33
4.4 Caregivers Factors………………………………………………… 34-38
4.5 Quality of life of caregivers…………………………………….. 39-41
4.6 Factors associated with QOL of caregivers in rehab group……….. 42-48
4.7 Factors associated with QOL of caregivers in non-rehab group……. 49-54
4.8 Association of QOL with selected variables in rehab group……… 55-56
4.9 Association of QOL with selected variables in non-rehab group…... 56

CHAPTER V: DISCUSSION………………………………………… **57-62**

5.1 Limitation of study……………………………………………….. 62

CHAPTER VI: CONCLUSION AND RECOMMENDATION……. **63-64**

CHAPTER VII: REFERENCES... **65-76**

APPENDIX... viii-xxx

Appendix-A: Informed consent Form in Nepali................................... viii
Appendix-B: Informed consent Form in English.................................. ix
Appendix-C: Questionnaire in Nepali.. x-xvii
Appendix-D: Questionnaire in English... xviii-xxvi
Appendix-E: Assessment of GMFCS level... xxvii
Appendix-F: Approval of the thesis Proposal...................................... xxviii
Appendix-G: Approval letter from Nepal Health Research Council....... xxix
Appendix-H: Permission Letter for data collection from organization.... xxx

LIST OF TABLES

Page no:

Table 4.1 Frequency distribution and comparison of socio demographic data of caregivers in rehab and non-rehab group…………….. 23-24

Table 4.2 Frequency distribution for characteristic of child with CP in rehab and non-rehab group…………………………………… 31

Table 4.2.1 Comparison of child characteristic in two groups……………. 32

Table 4.3 Frequency distribution and comparison of caregivers Knowledge on child condition and rehabilitation in Rehab and Non-rehab group…………………………………....... 34

Table 4.4 Frequency distribution and comparison of availability of service by chi-square in rehab and non-rehab group……….... 35

Table 4.5 Frequency distribution and comparison of perceived stress between two groups………………………………………… 38

Table 4.6 Comparison of the mean score of QOL between caregivers of children with CP in rehab group and non-rehab group……… 39

Table 4.7 Association between Socio demographic of caregiver, child with CP and QOL of caregivers in Rehab group……………. 42

Table 4.8 Child characteristic and QOL of caregivers in Rehab group.... 45

Table 4.9 Caregivers' factors and QOL of caregivers in Rehab group.... 47

Table 4.10 Association of socio demographic data of caregivers and child with QOL of caregivers in Non-rehab group…………... 49

Table 4.11 Child characteristic and QOL of primary caregivers in non-rehab group…………………………………………………..…. 51

Table 4.12 Caregivers factors and QOL of caregivers in Non-rehab group………………………………………………………… 53

Table 4.13 Logistic regression for QOL with selected variables of caregivers of children with CP in Rehab group…… 55

Table 4.14 Logistic regression for QOL with selected variables of caregivers of children with CP in Non-Rehab group……….. 56

LIST OF FIGURES

Page no

Figure 4.1 Age of children with CP in Rehab and Non-rehab group……. 29

Figure 4.2 Gender of children with CP in Rehab and Non-rehab group… 30

Figure 4.3 Financial support for caregivers of children with CP in Rehab and Non-rehab group……………………………………… 37

Figure 4.4 Financial support for caregivers of children with CP in Rehab and Non-rehab group……………………………………… 37

Figure 4.5 Overall Quality of life of primary caregivers of children with CP including both groups…………………………………… 41

ACRONYMS/ SYMBOLS

ADL: Activities of Daily Living.

BHPI: Bangladesh Health Professions Institute

CDWs: Community disability Workers

CP: Cerebral Palsy

ERB: Ethical Review Board

GMFCS: Gross Motor Function Classification System

HRDC: Hospital and Rehabilitation Centre for Disabled Children.

IRB: Institutional Review Board.

NHRC: National Health Research Council.

P&O: Prosthetic and Orthotic

PRC: Prerana Rehabilitation Center.

PT: Physiotherapist

QOL: Quality of Life.

SPSS: Statistical Package for social Science

WHO: World health Organization

χ^2: Chi-Square

n: Number

%: Percentage

ABSTRACT

Background: Cerebral Palsy (CP) is one of the major causes of childhood disability. It appears to be similar in developed and developing countries and theoretically it was estimated that every year around 1116–1675 children are having CP in Nepal (Thapa, 2016). Children with CP need more attention and care from primary caregiver. This can affect Quality of Life (QOL) of primary caregiver.

Objective: The main objective of this study is to determine the QOL and factors associated with QOL among primary caregivers of children with cerebral palsy. **Methodology**: This study was comparative cross-sectional study. Comparison was done between primary caregivers of children with CP in rehab and non-rehab group. Sample was collected through Purposive sampling technique. Face to face interview was done by using well structured questionnaire. Data were analyzed through SPSS 16 version.

Results: Median age of caregivers was 34 years and there was significant difference between age in two groups (*p*=0.028). 83 (86.5%) caregivers were female with significant difference between gender in rehab and non-rehab group (*p*=0.03). Majority of primary caregivers were mother 71 (74%) in both groups. Among all 96 caregivers, 78.1% of caregivers had poor QOL. There was no significant difference between QOL in rehab and non-rehab group (*p*=0.42). Factors associated with QOL in rehab groups was illiteracy (OR=7.33, *p*=0.005), aggressive nature of child (OR=11, *p*=0.050), uncooperative nature of child (OR=9, *p*=0.025), poor knowledge about child condition (OR=15.55, *p*< 0.001), and low financial support (OR=5.2, *p*=0.051). Similarly, factor associated with QOL in non-rehab group was GMFCS level of child (*p*< 0.001) and more perceived stress (OR=5.53, *p*=0.048).

Conclusion: Based on overall result of QOL, majority of primary caregivers was mother and had poor QOL and there was no significant difference between overall QOL of caregivers in Rehab and Non-rehab group. Major factors associated with poor QOL of primary caregivers of children with CP are education level of caregivers, GMFCS level of child, nature of child, knowledge about child condition, financial support and perceived stress. QOL of caregivers must be focused by rehab professionals to achieve adequate functional outcome in children with CP.

Key words: Quality of life, Primary caregivers, Cerebral Palsy.

CHAPTER I: INTRODUCTION

1.1 Background

Cerebral palsy (CP) is a group of neurological disorder that affects body movement, marked by impaired muscle coordination and leading to limitation in activities as well as participation restriction. CP is caused by damage of the brain before, during or after birth (Van Naarden Braun et al., 2015). It is classified as spastic, ataxic and Athetoid and based on the body part involvement- it is classified as hemiplegic, diplegic and quadriplegic (Lakhna, 2013). CP is non-progressive disorder; it means the condition itself does not get worse over time; however secondary complication like spasticity can develop which may get better or worse or remain the same. Gross motor function classification system (GMFCS) is used to classify CP on the basis of the functional level. CP may be accompanied by other disorder like epilepsy, clubfoot, intellectual disability, speech, vision and hearing problem (Okurowska-Zawada, Kułak, Wojtkowski, Sienkiewicz, & Paszko-Patej, 2011).

Globally, CP is one of the major causes of childhood disability with a prevalence estimate ranging from 1.5 to more than 4 per 1000 live birth (Stavsky et al., 2017). Around 15-20% of children with disability are diagnosed with CP in India. The incidence of CP in India is about 3 per 1000 live birth (Vyas, Kori, Rajagopala, & Patel, 2013). Thapa (2016) state that there is no recent study or survey about the prevalence of CP in Nepal but in his study he mentioned that prevalence rate of CP appear similar in developed and developing countries and he theoretically estimated that every year around 1116–1675 children are having CP in Nepal. In Nepal spastic type of CP is most common. At Hospital and Rehabilitation Centre for Disabled Children (HRDC), about 15% of outpatients Children are diagnosed with CP (Banskota, Shrestha, Rajbhandari, & Banskota, 2015).

Around 85% of children with disabilities live in a developing country and also mentioned that CP is one of leading cause of disabilities in children (Khandaker et al. 2015). Children with disabilities required more care compare to normal child (Ahmadizadeh, Rassafiani, Khalili, & Mirmohammadkhani, 2015). Caring child with CP required more time from primary caregiver as well as more resources. Approximately 2.5- 20 time the cost increase while providing care for a child with CP compare to a child without any health condition (Brehaut et al., 2004). The demand of care depends upon the severity of the condition. Taking care of a severely affected child is full-time job and it exerts a great stress on the caregiver (Mohammed, Ali, & Mustafa, 2016). Okurowska-Zawada et al. (2011) state that caregiver of children with CP experience more emotional stress, fatigue, frequent loneliness and health problem which may affect the quality of life of caregiver.

Quality Of Life (QOL) is essential to determine the health status of the individual (Yilmaz, Erkin, & İZKİ, 2013). Measuring QOL of caregivers of children with disabilities provide insight into the challenges faced by the caregiver (Adegoke, Adenuga, Olaleye, & Akosile, 2014). Caregiver QOL is associated with the demand of the care that their child required (Spore, 2004). Identifying factors related to QOL helps to enhance treatment as well as a rehabilitation program, as the main aim of health and rehabilitation service is to improve QOL and well-being of the individuals. Factors that lower QOL of mothers are unemployment status of mothers and having CP child with intellectual disabilities (Ahmadizadeh et al., 2015). Caring children with CP also affect the financial situation of the family, as caring children with CP required extra financial resources as well as time (Davis et al., 2010).

Assessing and addressing QOL and its associated factors of caregivers is useful for the healthcare provider to enhance psychological guidance and information about the condition of the child (Spore, 2004). Raina et al. (2005) mentioned that it is very difficult to understand in details, how some caregivers cope well and other does not. Some of the factors that associated with caregivers stress are the characteristics of the caregiver (age, marital status, coping ability), characteristics of the child (type and the degree of disability), the shared history between the caregiver and the person being cared for social factors, economic factors such as socioeconomic status and cultural context. One of the best ways to ensure appropriate care of the children with CP is to assess coping mechanism and quality of life of their caregiver (Wippermann, 2013).

1.2 Justification of the study

CP is a non-progressive condition which required long-term care as well as rehabilitation services. In order to provide long-term care active involvement of primary caregiver is required. The caregiver can be mother, father, grandparents or any member of a family. Mother is taken as the primary caregiver for children but it depends on culture and family (Ahmadizadeh et al., 2015). The QOL of caregiver of children with CP is often not taken as the main focus by rehabilitation professional/healthcare workers during the process of treating children (Spore, 2004). Therefore, till date, we do not know whether rehabilitation service has any affects on QOL of caregiver or not. The children with CP required long-term care from the primary caregiver. When the child is affected, it affects whole the family and especially caregiver (Gardiner & Iarocci, 2012; Terra et al., 2011). If caregivers fail to provide sufficient care to the child, the improvement in child functional level is not possible (Reinhard, Given, Petlick, & Bemis, 2008). If the caregiver fails child suffer, so it`s important to provide attention on caregiver while planning and providing treatment for a child with CP (Eker & Tüzün, 2004). Physiotherapists working in communities and health institutions are very complicatedly involved in habilitation and rehabilitation of children with CP and should be attentive and supportive to the parents/caregivers (Chiluba, & Moyo, 2017).

There are few quantitative (cross-sectional and case-control) study regarding QOL of mother and parents but in Nepal till date no study has been carried out on the QOL of caregiver of children with CP, as the quality of life depend on social and cultural norms so it is important to measure and assess the QOL of caregivers of children with CP. Davis et al. (2010) state that caring children with a disability have a profound impact on QOL and health of caregiver, however "it's different dimensions and scales must be reviewed in each region or country based on those lifestyles" (Ahmadizadeh et al., 2015, p.16). Close presence and active participation of caregiver is required in all phase of management of children with CP (Ones, Yilmaz, Cetinkaya, & Caglar, 2005). Therefore it is necessary to focus and determine overall QOL of caregiver along with the factors associated with QOL of Caregivers in Nepal.

1.3 Research question

What is the overall quality of life of primary caregivers of children with CP and what are the factors associated with quality of life of primary caregivers of children with CP living in Sarlahi and Rautahat districts of Nepal?

1.4 Operational definition

Quality of life (QOL): Quality of life is defined as an individual's perception about his/ her own life in the context of the culture and value systems in which they live (Nedjat, Montazeri, Holakouie, Mohammad, & Majdzadeh, 2008).

Primary caregiver: Primary caregiver is the main care provider who spends most of the time in caring the child with CP and provides all the support that a child required including support in Activities of Daily Living (ADL).

Cerebral palsy: CP in injury to brain that occurs before, during or after birth resulting in to functional limitation and leading disability.

Characteristic of child: In this study characteristic of child include type of CP, GMFCS level, nature of the child, and participation as well as health condition of the child.

Rehabilitation service: In this study term rehabilitation service means, therapy or Prosthetic & Orthotic (P&O) service received by children with CP by professionals Physiotherapist (PT) or P&O or even by community Disability worker (CDW) at different location of visit and also continuing home therapy.

Rehab Group: In this study, rehab group means caregivers of those children with CP who are getting **continuous rehabilitation** service.

Continue rehabilitation service: In this study, continue rehabilitation means, those children with CP who have received numbers of follow-up session of rehabilitation service by therapist/ P&O or CDW in last 1 year and also continuing home therapy at home.

Non-Rehab Group: In this study, non-rehab group means caregivers of those children with CP who are identified by Prerana but haven’t received rehabilitation service or **discontinued rehabilitation service**.

Discontinue rehabilitation service: In this study, discontinue rehabilitation service means children with CP who have not received any follow-up session by PT/P&O and CDWs and even not home therapy from last 1 Year because of different undefined reason.

Perceived stress: Physical, mental or emotional factors that causes- bodily or mental tension in caregivers. The degree to which caregivers perceives tension in all the way of providing care to child with CP.

Participation of child: In this study, participation of child means whether child goes to school and play with other children or not.

Availability of service: In this study, availability of service means whether children with CP can easily reach toward service and also all the service regarding child care is easily accessible by their caregivers.

CHAPTER II : LITERATURE REVIEW

2.1 Cerebral Palsy

CP describes as a group of disorders that affects movement and posture, causing restriction or limitations in activity attributed to non-progressive disturbances in the developing fetal or infant brain (Hafström et al., 2018). Based on motor function CP is classified into Spastic CP characterized by increase in muscle tone and non-spastic CP which exhibit decrease or fluctuating muscle tone. An injury in the brain inside the pyramidal tract causes spastic and outside the pyramidal tract causes non-spastic CP. Non-spastic CP is divided into two groups, ataxic and athetoid (Gunel, Turker, Ozal, & Kara, 2014).

According to Krigger (2006), 70%-80% of children with CP have spastic clinical features such as increase in muscle tone, increase deep tendon reflex, muscle weakness, muscle contracture, joint deformities. 10%-20% of children with CP have athetoid type of clinical feature such as uncontrolled and slow movements in hands, feet, arms, or legs and, in some cases, the muscles of the face and tongue causing grimacing or drooling, increase in stress, speech problems swallowing difficulty (Gunel et al., 2014) and 5-10% children with CP account for ataxic type of clinical feature such as: hypotonia, tremor, motor control affected, balance problems, unstable and wide gait. Mixed type of the CP account for approximately 10% of all cases (Campagna, 2016).

GMFCS is used to classify CP on the basis of the functional independences and it is based on the child age (Chagas et al., 2008). "The GMFCS measures how much of the action is achieved by the child rather than measure the quality of the motor performance" (Gunel et al., 2014, p.42). GMFCS is based on the age groups. Between the age of four and six years, the children with CP in GMFCS I is able to walk indoors and outdoors independently, climb stairs, and start to run and jump. In GMFCS II, the child can transition into and out of standing without support but unable to run or jump. In GMFCS level III, a child can sit in chair but may required support for functional activities and can walk with handheld mobility device and may required wheeled mobility for long distance. In GMFCS level IV children require support for trunk control to allow sitting and also required assistance to change the positions. And in GMFCS level V the abilities of children are stable with a need for complete assistance with transfers (Paulson, & Vargus-Adams, 2017). For age group between 6 to 12 years, GMFCS level I indicate least limitation where child can walk without limitation and limitations is seen in more advanced gross motor skills. In GMFCS level II, child can Walks without restrictions, limitations in walking outdoors and in the community. In GMFCS level III, child can walks with assistive devices. In GMFCS level IV Self mobility with limitations, children are transported or use power mobility outdoors and in the community. And in GMFCS level V child is totally depended and self mobility is severely limited (Carnahan, Arner, & Hägglund, 2007).

2.2 Caring children with CP

CP is not a disease; it is conditions associated with lifelong disability resulting into functional limitation and are dependent on parents or caregiver for essential care (Chiluba, & Moyo, 2017). Children with CP may require high level of assistance throughout the life. Providing high level of care can become burdensome for caregiver (Singogo, Mweshi, & Rhoda, 2015). Care giving is normal part of parenting life but managing the child with chronic health condition may be exhausting for some caregivers (Basaran, Karadavut, Uneri, Balbaloglu, & Atasoy, 2013). Caring children with CP may affect daily life of mother as mother is consider as primary caregiver (Ahmadizadeh et al., 2015). Mother of children with CP has more roles compare to mother of healthy child. Huang, Kellet & St John (2010) state that caring child with CP may be overwhelming, resulting in sorrow as it require lots of time and patience from caregiver. Caring children with CP become more difficult as child grow due to increase in their body size and weight that increase the level of care (Dambi, Mlambo, & Jelsma, 2015). CP is a sudden event, parents/caregivers of CP children is forced to accept a large amount of unexpected responsibilities (Chiluba & Moyo, 2017). Caring children with CP put parents in higher level of stress and also worse mental health (Rentinck, Ketelaar, Jongmans, & Gorter, 2007). High level of anxiety is felt by caregiver due to lack of support in caring for the child, physical exhaustion, very low levels of knowledge about CP, and high levels of stigma related to having a disability (Zuurmond, Mahmud, Polack, & Evans, 2015).

2.3 Caregiver of Children with CP

Chiluba, & Moyo (2017) in their study reported that young age people are less involved in care-giving for children with CP compare to any other group. Women have more responsibility in raising children in most part of the world and mother is specially engaged as a primary caregiver of children with disabilities (Ones, Yilmaz, Cetinkaya & Caglar, 2005). Caregivers of children with CP relatively younger with mean age of 30 years and female were most involved as caregiver (Dambi et al., 2015). Grandmother, father and other women of the family were linked in activities of care for children with disabilities, but the mother remains main person involved in the process of child care (Macedo, Silva, Paiva, & Ramos, 2015). Mother role as caregivers consist of wide rand of activities such as lifting and turning child, supporting in activities of daily living and assisting child to move that can put physical strain over caregiver (Eker & Tüzün, 2004).

2.4 QOL of caregivers

QOL has been taken as important aspect of health care system and it's depend upon individual perception about his/ her life position in the context of culture and value system, that is used to determine life sustaining measure, allocation of resource (Spore, 2004). QOL of caregiver is related to health, psychological wellbeing, social support and family relation that can be affected when significant amount of time is committed in caring children with chronic condition (Adegoke et al., 2014). QOL of family member can be high if proper support, coping strategy and family center care are provided, and it is responsibility of health professionals to address issues of family and plan treatment based on family centered approach (Wippermann, 2013). Support service is related with the QOL of caregiver that is when social support is high, QOL of caregiver increases (Browne, 2010). Quality of life found unsatisfactory in both mother and grandmother and the score of grandmother QOL was lower compare to score of the mother (Wu, Zhang, & Hong, 2017). Due to lack of participation in social activities, QOL of caregiver decreases (Ones et al., 2005).

Health professionals should emphasized on the need of the social support and should include it in intervention program in order to maintain psychological support of caregiver and enhance their QOL (Miskam, Juhari, &Yaacob, 2017). Health professionals must focus on process to support caregiver and provide counseling and relaxation technique that may enable caregivers to adopt healthier life and may enhance QOL of caregivers (Basaran et al., 2013; Rone-Adams, Stern, & Walker, 2004).

2.5 Factors associated with QOL of caregivers

Identifying factor associated with QOL enables in recognition of those caregivers who are at the risk of having their physical psychological health adversely affected and supports in the implementation of intervention strategies to reduce the negative impact of caring on parents of children with disability (Muñoz-Marrón et al., 2013).

Older caregiver experienced lower QOL as caregiver age increases, QOL decreases. It is suggested that an increase in age may be associated with depression, which could negatively affect QOL (Shirmard, Seyyedi, Toopchizadeh, & Ghojazadeh, 2017).

QOL is also affected by low socioeconomic condition and lack of basic services or available of the service far from the community (Mohammed, Ali, & Mustafa, 2016). Caregiver’s quality of life also varies according to the information they received as well as depend upon personal resources of the caregivers (Macedo et al., 2015).

QOL of mother is not influenced by educational status and their religious, the main factor that influence QOL of mother is family support through the extended family system. Higher level of emotional support received by the caregiver, lower the probability of impaired QOL (Adegoke et al., 2014).

Caregiver of children with CP does not report any severe disease but have lower health related behaviour like inadequate sleep. Caregiver of children with CP do wide range of activities such as assisting child at ADL, lifting child that put physical strain on caregiver that lower the score of QOL (Eker & Tüzün, 2004). Shirmard et al. (2017) mentioned that burden of caring for children with CP may influence QOL of parents. Caring for these children has a high psychosocial burden on the parents, including financial costs, detrimental effects on physical health, and reduced time for other relationships and activities. Most of the parents of children with CP are less involved in full-time jobs and have lower incomes because caring for their families is their main activity (Brehaut et al., 2004). Okurowska-Zawada et al. (2011) concluded that parents of children with CP have good quality of life as they have accepted and adapted to the situation, the problem especially occurred due to lack of knowledge about disease and financial issue. Mother of children with CP suffers from more stress compare to mother of healthy children and also provide more time in child treatment, exercise and care that gives financial pressure to caregiver (Borzoo, Nickbakht & Jalalian, 2014).

Depending upon the severity of the condition, level of assistance is required, if caregivers have lack of skill in uplifting CP child it may give pain and discomfort in shoulder and back of caregiver leading to musculoskeletal condition affecting health related quality of life of caregiver (Dambi, Chivambo, Chiwaridzo & Matare, 2015).

2.6 Child functioning and QOL of caregivers

The severity of child condition and functional limitation not affect mother but may causes depression. However, social support has profound impact on the mental status of caregiver (Okurowska-Zawada et al., 2011). Shirmard et al. (2017) reported that level of disability in children is correlated with parental stress, which could be a cause for lower QOL of caregivers.

Ones et al. (2005) mentioned that primary caregiver of children with CP have higher level of psychological and physical symptom that alter QOL of caregiver and also state that mother are mostly involved in the role of primary caregiver. The study concluded that there is lack of correlation between GMFCS and QOL of mother as most of children were diagnosed with GMFCS 3rd and 4th level. Severity of the disability and functional level of child measured by GMFCS had no impact on the health of the biological mother but it lower overall score of the QOL of caregiver (biological mother) (Tuna, Ünalan, Tuna, & Kokino, 2004).

Dehghan, Dalvand, Feizi, Samadi, & Hosseini, (2016) reported that mother having children with good gross motor function have higher level of QOL. The parents of children with CP perceive their own health as unsatisfactory, including symptoms of depression, stress, muscle pain, and diminished quality of life (Lima, Cardooso, & Silva, 2016). Rapin (2007) reported that severity of the disabilities affect the QOL of children, it may not affect QOL of caregiver. Prudente, Barbosa, & Porto (2010) in their research shows that after ten months of rehabilitation, the QOL of mother significantly improved only in pain domain along with improvement of GMFCS level of children with CP. QOL of child with CP and their functional level are interrelated and also it depend upon QOL domain that is physical domain is strongly associated with functioning than psychological domain (Shelly et al., 2008).

Poley, Brouwer, van Exel, & Tibboel (2012) had shown that, stress experienced by parents of children with CP is not related to the level of the child functioning nut it is associated with access to resources, nature of the family and social support

2.7 Health of caregiver of children with CP

Health of caregiver is important area need to be focused by health care provider. Poor health of caregiver may not result only decrease in work productivity but also increased in costs associated with provision of services for the care recipient (Brehaut et al., 2004). There is more evidence that shows, caregiver of children with disability suffer more from physical and psychological complication, feel loneliness and more stressed compare to caregiver of healthy children (Laurvick et al., 2006). Caregivers of children with CP often have stressful life due to imbalance between social needs and demand of care. Therefore, many primary caregivers may experience several psycho-social problems (Basaran et al., 2013). Caring for a child with CP has greater impact on the mental health of mothers (Chiluba, & Moyo, 2017). Raina et al. (2005) states that physical and psychological health of caregiver was strongly influenced child behavior and demand of the care required by the child. Therefore, it is important for health care provider to assess how caregiver health is affected by behavioral and functional aspect of the child disability. “Treatment or prevention of depression in mothers of children with CP should be recommended to improve the rehabilitation process and to attain better functioning” (Okurowska-Zawada et al., 2011, p.121). Parents of children with CP generally have worse physical and emotional health. More than 70% of mother of children with disabilities complains of low back pain (Cooley, 2004). Caregivers of children with CP are unable to provide their own social need that why they have lower satisfaction with life (Cheshire, Barlow, & Powell, 2010). The experience of heightened stress and impaired mental health leads to sense of depression and depression rate in mother of children with CP is much higher than the mother of the normal child (Basaran et al., 2013). The main problem reported by the mother were fatigue, depressed mood, anxiety and physical symptom. Depressed mood was associated with social isolation and feeling of guilt (Okurowska-Zawada et al., 2011).

2.8 Social support and QOL of caregiver

Social support refers to psychological resources available to him or her through his or her interpersonal relationship. The birth of a child gives a new social role to their parents and can symbolize the beginning of a new life cycle (Lima et al., 2016). Social support helps to prevent and ease the stressful situation, and if proper social support is not there, it may lead to feelings of abandonment, sadness and anger (Polita & Tacla, 2014). Most powerful predicator of poor quality of life of mother were sleep disturbance, lack of perceived social support, low coping capacity, no adaption to the situation (Macedo et al., 2015). Caring the child with disability throughout the day limits the social participation as well as social functioning of the caregivers (Eker & Tüzün, 2004). Family function played an important role in both the physical and the psychological health of caregivers. Therefore, health care providers should be encouraged to value family functioning in technical aspects of the services that are offered to children with complex disabilities (Raina et al., 2005). QOL of mother of children with CP is lower because less social support from the extended family (Adegoke et al., 2014)

2.9 Health Services and QOL of caregivers.

In order to manage children with disability effectively, it is important to focus on the caregivers and also possible disability of primary caregivers should be considered (Tuna et al., 2004). At present, formal or informal caregivers are considered as an important component pertaining to the management of patients. High quality of health services from social works is one of the most reliable ways to promote caregiver satisfaction and quality of life. Poor quality of life of caregivers not only limits a child, for receiving quality treatment but also increases the health care cost and create economic problem (Sajjadi, Vameghi, Ghazinour, & KhodaeiArdakani, 2013).

“Historically, disability rehabilitation programmes focus only on the adult or child with disability, with little or no attention to the impact of disability on the wider family” (Zuurmond et al., p.12, 2015). Several studies have evaluated the QOL of parents of children with CP and found it to be worse than parents of healthy children and due to worse QOL of caregiver, children with CP does not receive quality health service (Shirmard et al., 2017).

2.10 Rehabilitation service for children with cerebral Pasly

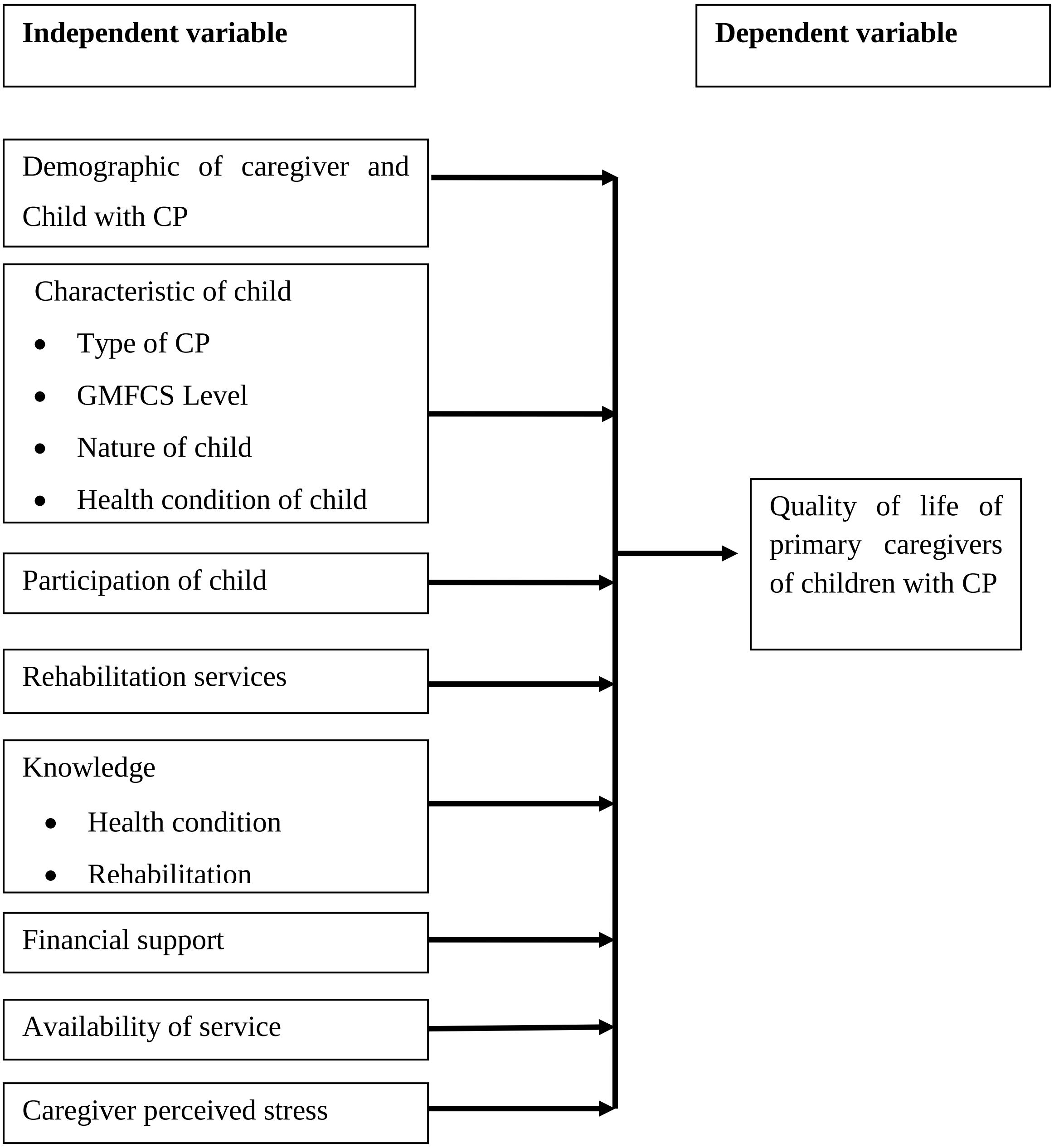
Rehabilitation is key intervention for management of children with CP for achieving successful functional outcome (Yeowell, Al-Mutayliq, & Fatoye, 2016). There are no specific treatments that can remediate the brain damage. However, rehabilitation service can prevent secondary complication and improve functional limitation (Trabacca, Vespino, Di Liddo, & Russo, 2016). The rehabilitation team commonly consists of a PT, orthotist and CDW. For proper management of children with CP, rehabilitation team most focused on family center approach (Morgan & Tan, 2010). Globally, 85% of children with disability are living in developing country, but less than 5% of them have access to rehabilitation service. In country Bangladesh, out of 417 children with CP, 57% of children with CP had never received any rehabilitation service (Khandaker et al., 2015).

2.11 Effect of rehabilitation on QOL of caregivers

Rehabilitation is the cornerstone of treatment in CP, the parents' cooperation with the rehabilitation team is very important for effective management. However, rehabilitation may place additional burdens on caregivers (Yeowell et al., 2016). Caregiver cooperation can be affected by their psychological, physical, and social status (Shirmard et al., 2017). Emotional and informational support positively affected the family members. Depression is significantly decreases in caregivers of those who received rehabilitation educational program (Jung & Kim, 2014). Proper use of assistive technology in children with disability lighten the caregiver's assistance in the area of mobility, self care and social function thus enhance QOL of caregivers (Nicolson, Moir & Millsteed, 2012).

CHAPTER III: RESEARCH METHODOLOGY

3.1 Conceptual framework



3.2 Study objective

3.2.1 General objective

To determine the QOL and factors associated with QOL among primary caregivers of children with CP.

3.2.2 Specific objectives

- To identify overall QOL of primary caregiver of children with CP.
- To compare QOL of primary caregivers of children with CP in rehab group and non-rehab group.
- To identify whether socio-demographic factors of caregiver and child characteristic is associated with QOL of caregivers.
- To find out association between knowledge about child condition, financial support and QOL of caregivers.
- To identify the relationship between perceived stress and QOL of primary caregivers.

3.3 Study design

Comparative cross-sectional study was done to determine QOL of caregivers and factors associated with it. This study was cross-sectional because it is effective design to collect quantitative information about different a variable. A comparative cross-sectional study is a one-point prevalence measurement for multiple risk factors associated with a particular condition and measuring of dependent and independent variable simultaneously (Raja, 2015). In this study, there were two comparison groups.

Rehab group: Caregiver of those children with CP who were getting continuous rehabilitation service.

Non-Rehab group: Caregiver of those children with CP who were identified by Prerana Rehabilitation center (PRC) but had not received rehabilitation service or discontinued rehabilitation service because of different undefined reason.

3.4 Study population

Primary caregivers of those children who were diagnosed with CP and were receiving continuous rehabilitation services from PRC (rehab group) or not received rehabilitation services or discontinue rehabilitation service (non-rehab group) and living in a community of Sarlahi and Rautahat districts of Nepal. Existing database of PRC showed that 446 children were identified from 2012-2016. Only 115 children with CP were continuing rehabilitation service whereas, many had discontinued to rehabilitation service. Therefore, both groups of caregivers were included in this study.

The caregivers providing home therapy and receiving follow-up service from any rehab professionals and community workers were also included in this study.

3.5 Study Site and Justification

This study was done in Sarlahi and Rautahat districts because these districts are one of the rural districts of Nepal and according to the existing database of PRC about 446 children (4-12 years) with CP have accessed service from PRC since 2012-2016. These showed there was large numbers of children with CP in these districts.

Prerana Rehabilitation Center (PRC) situated in Malangwa, Sarlahi district and provides service in 8 districts of Province-2 through- Institutional based service as well as out-reaches service. More clients are serviced on out-reach based; due to lots of barrier, many people cannot access service from center. Children with CP in Rautahat district mainly served through community based service. From last few years, in Sarlahi there is no facility of community based service. Therefore, this study was done in these 2 districts through community visit.

3.6 Study period

This study extended from August 2017 to April 2018.

3.7 Sample size

As the prevalence of CP in Nepal is not studied till date, the sample size was calculated by taking expected proportion 50% since it gives large sample size, level of confidence at 95% and Precision at 5%, by using the formula of cross-sectional study ($n= Z^2 P (1-P)/d^2$)

Here, $P=0.50$ (50% prevalence)

$Z= 1.96$ (level of confidence at 95%)

$d= 0.05$ (precision 5%)

$n= (1.96)^2 \times 0.50(1-0.50) / (0.05)^2$

$n= 384$

The calculated sample size was 384. As this study was carried out through the community visit, so due to time limitation and financial issue, I took 96 sample for this study, 56 respondents were in rehab group and 40 respondents were in non-rehab group.

3.8 Criteria for selection sample

3.8.1 Inclusion criteria

- Primary caregivers of children with CP.
- Age of children was in between 4 -12 years.
- Caregivers of those Children with CP who were register in database of PRC.
- GMFCS level II, III, IV, and V.
- Caregivers of children with CP who were willing to response in this study.

3.8.2 Exclusion criteria.

- Primary caregiver below 18.
- Children with CP with other health condition like spina bifida, mental retardation.
- Caregiver unable to communicate.
- Having another patient or disable individual within the family.

3.9 Sampling frame

From the existing database of PRC Sarlahi, list of children with CP was drawn. The caregiver was selected according to inclusion criteria that were also match inclusion criteria of children with CP. As it was difficult to identify and reach toward caregivers of CP children without the available list, therefore sampling frame was drawn.

3.10 Sampling technique

Non-probability purposive sampling technique was chosen to collect data in this study. It is a process in which a sample is drawn from the available subjects purposively (Palinkas, Horwitz, Green, Wisdom, Duan, & Hoagwood, 2015). The reason for choosing this sampling technique was to get respondents for this study according to the study criteria which saved time as well as minimize the financial burden as this study was on done through community visit. This sampling technique provides identification and selection of information-rich cases related to the phenomenon of interest (Palinkas et al., 2015).

3.11 Data collection Tool/ Material

Data was collected by using self-develop well-structured questionnaire. The questionnaire of QOL was developed by taking a reference from WHO-QOL BREF, Ferran and Power Quality of life index questionnaire, Quality of life questionnaire and also focusing on a living scenario of people in Nepal. When functional level of children with CP was not available from the database of PRC (as PRC started keeping record of GMFCS level from year 2015), functional level of children with CP was assessed by using Gross motor classification system Expanded and Revised (GMFCS – E&R). The GMFCS is a reliable and valid system that is used to classify the severity of motor function of children with CP according to their age-specific gross motor activity (Eker & Tüzün, 2004).

For this study, data was collected through face to face interview by using self-developed structured questionnaire. The questionnaire was divided into four parts and it took about 20-25 minutes to complete the entire questionnaire by each respondent. The first part of questionnaire consists of demographic data of caregivers and children with CP. 2nd part of questionnaire consists, questions on all the factors associated with child problem. 3rd part of questionnaire consists, questions on all the factors associated with caregivers and 4th part of questionnaire consists of questions on QOL of caregivers. To ensure the validity and reliability of the questionnaire, linguistic validations and pilot study was done.

3.12 Data collection technique

At first, the ethical approval was taken from Institutional review board (IRB) of Bangladesh Health Professions Institute (BHPI) for the study. This study was conducted in Nepal, and data was collected from caregivers of children with CP who were registered in database of PRC. Therefore, a written permission from managing authority of PRC Nepal was also obtained. Along with all documents, an application for ethical approval was sent to Ethical Review Board (ERB) of Nepal Health Research Council (NHRC) and written approval was taken.

From the existing database of PRC, list of children with CP, their caregiver name, contact number, and address were drawn. Then a phone call was made to ensure the caregiver meet the inclusion criteria. Data was collected through community visit. As this study was done through community visit, data collectors were also involved to collect the data. Data collectors helped researcher to complete the study within the time duration. Firstly, orientation of questionnaire was given to data collectors followed by data collection training.

Community visit was done by researcher and data collectors to those places who meet the inclusion criteria. Researcher and data collectors collected data together from those places which were not easily accessible due to lack of transport facilities. Nepali version of the questionnaire was used for data collection. Before data collection pilot study was carried out.

3.13 Data management and analysis

Firstly, data was entered in Microsoft Excel. Statistical Package for social science (SPSS) software version 16 was used for the data analysis. Data was re-coded as required. Reliability test on SPSS was done to ensure internal validity of the questionnaire. Descriptive analysis was done to calculate frequency and percentage by using custom table and it was presented in tables and figures. Comparison of demographic data and other variables of two groups were done using chi-square test. Comparison of QOL of caregiver of two groups was done by compare mean (independent t-test). Score of each domain of QOL calculated, score of minimum 70% and above was categorized as good and below 70% was categorized as poor. Overall QOL score was also calculated and was categorized as good QOL and poor QOL. Descriptive analysis was done to calculate frequency and percentage of QOL domain and overall QOL and it was presented in figures. Chi-square analysis was done to identify the association between different variables and binary logistic regression was done to analysis odd ratio between variables which were associated.

3.14 Quality control and assurance

In order to improve the quality of the study, first of all the questionnaire was translated into a National language that is Nepali. The questionnaire was translated following the standard procedure of linguistic validation that is, In the first step all questionnaire was translated in to Nepali language by two Nepalese translators, In the second step, two Nepali version of questionnaires were reconciled and in the third step reconciled Nepali version of the questionnaire was translated in to English version questionnaire by the 3rd translator. The translated questionnaire was cross-checked and pilot study was carried out to ensure the validity of the questionnaire. After reviewing the results of pilot study, little changes were made in prepared questionnaires like in question 14 mixed type of CP was added and similarly in question 25, category 1- no barrier I am not sure actually therapy service improve child condition was added.

The entire filled questionnaire is placed safely in order to maintain confidentially of participants. The collected data was reviewed, re-coded and enter into SPSS Program. Analysis of the data was done from computer to minimize the errors.

3.15 Ethical consideration

Study was conducted following the standard guidelines for ethical consideration. The study followed the WHO guidelines. At first, ethical approval was taken from Institutional review board (IRB) of Bangladesh Health Professions Institute (BHPI) for the study. As the study was conducted in Nepal, a written permission from concerning managing authority of Prerana Rehabilitation Center Nepal was obtained. An application for ethical approval was sent to Ethical Review Board (ERB) of Nepal Health Research council (NHRC) and written approval was obtained. The study was done through face to face interview. Before the interviews, clear explanation about the objectives of the study and data collection was provided to respondents. Individual informed consent was taken from respondent before data collection. Respondents were having complete freedom to be involved in the study as they were provided with options to respond or not to respond to the interviewer queries. Respondents were not being forced to answer the questions if they were not willing to. Respondents were having complete freedom to withdraw from the study at any time during an interview. The data collected from respondents was absolutely confidential. There was no physical, psychological and financial harm to the participants.

CHAPTER IV: RESULT

In this study, total 104 caregivers were addressed. Following the inclusion criteria, 96 primary caregivers were selected. Eight were excluded due to the exclusion criteria- five children had signs of puberty, one caregiver was unable to communicate, two caregivers were having another disable person at home.

Finally, 56 (58.3%) primary caregivers of children with CP on rehab group (who are under continue rehabilitation) and 40 (41.7%) primary caregiver of children with CP on non-rehab group (Who have discontinue rehabilitation) were enrolled in the study.

4.1 Demographic data of caregivers

Age of respondents' ranges from 20-70 years, as parents and grandparents both were included in this study.

Median age of caregivers in rehab group was 32.50 years; Median age of caregivers in non-rehab group was 35 years, and median age in both groups was 34 years.

Table 4.1 Frequency distribution and comparison of socio demographic data of caregivers in Rehab and Non-rehab group

Level	Caregivers of children with CP in Rehab Group (n=56)	Caregivers children with CP in Non-rehab group (n=40)	Total (n=96)		
Caregivers	n(%)	n (%)	n (%)	χ^2 value	*p* Value
District					
Sarlahi	13 (23.2)	34 (85.0)	47 (49.0)	36.64	<0.001
Rautahat	43 (76.8)	6 (15.0)	53 (51.0)		
Age (in years)					
20-30	25 (44.6)	15 (37.5)	40 (41.7)	9.12	0.028 Fisher Exact test
31-40	21 (37.5)	12 (30)	33 (34.4)		
41-50	9 (16.1)	5 (12.5)	14 (14.6)		
51+	1 (1.8)	8 (20.0)	9 (9.4)		
Gender				4.70	0.032 Fisher Exact
Male	4 (7.1)	9 (22.5)	13 (13.5)		
Female	52 (92.9)	31 (77.5)	83 (86.5)		
Type of family					
Small	32 (57.1)	19 (47.5)	51 (53.1)	0.87	0.234
Joint	24 (42.9)	21 (52.5)	45 (46.9)		
Marital status					
Married	52 (92.9)	37 (92.5)	89 (92.7)	0.004	0.941 Fisher Exact
Widow	4 (7.1)	3 (7.5)	7 (7.3)		
Education					
Illiterate	36 (64.3)	35 (87.5)	71 (74.0)	7.52	0.05 Fisher Exact
Primary	8 (14.3)	3 (7.5)	11 (11.5)		
secondary	10 (17.9)	1 (2.5)	11 (11.4)		
High school and above	2 (3.6)	1(2.5)	3 (3.1)		
Occupation					
Unemployment	2 (3.6)	5 (12.5)	7 (7.3)	4.73	0.192 Fisher Exact
Housewife	36 (64.3)	26 (65.0)	62 (64.6)		
Agriculture	12 (21.4)	8 (20.0)	20 (20.8)		
Others	6 (10.7)	1 (2.5)	7 (7.3)		

Level	Caregivers of children with CP in Rehab Group (n=56)	Caregivers children with CP in Non-rehab group (n=40)	Total (n=96)		
Caregivers	n(%)	n (%)	n (%)	χ^2 value	*p* Value
No. of children					
1	8 (14.3)	3 (7.5)	11 (11.5)	4.15	0.245
2	19 (33.9)	9 (22.5)	28 (29.2)		Fisher
3	11 (19.6)	14 (35.0)	25 (26.0)		Exact
4 and above	18 (32.1)	14 (35.0)	32 (33.3)		
Relation to children					
Mother	44 (78.6)	27 (67.5)	71 (74.0)	2.58	
Father	3 (5.4)	5 (12.5)	8 (8.3)		
Grandmother	4 (7.1)	5 (12.5)	9 (9.4)		0.46
Others	5 (8.9)	3 (7.5)	8 (8.3)		Fisher Exact
Annual income					
Below 50000	22 (39.3)	25 (62.5)	47 (49.0)	5.45	0.142
51000-100000	18 (32.1)	9(22.5)	27 (28.1)		Fisher
110000-150000	10 (17.9)	3(7.5)	13 (13.5)		Exact
151000 and above	6 (10.7)	3(7.5)	9 (9.4)		
Health problem					
Yes	15 (26.8)	9 (22.5)	24 (25.0)	0.22	0.630
No	41 (73.2)	31 (77.5)	72 (75.0)		

χ^2 test, * Level of significance: $p < 0.05$.

Districts of caregivers

Table 4.1 presents, in rehab group 43 (76.8%) respondents were from Rautahat district and only 13 (23.2%) respondents were from Sarlahi district. In non-rehab group 34 (85%) respondents were from Sarlahi and only 6 (15%) respondents were from Rautaht district. The result of chi-square tests for difference between districts of caregivers in the two groups was χ^2 (1, N=96) =35.64, $p<0.01$. This means, statistically, there was significant difference between districts of caregivers in two groups. More numbers of caregivers of children with CP from rehab group were from Rautahat district.

Age of caregivers

Table 4.1 represents, out of 98 respondents, 40 (41.7 %) respondents were between age of 20-30 years and only 9 (9.4%) of respondents were 51 and above years. In both groups, more numbers of caregivers were in between 20 and 30 years. Looking at the age of respondents (primary caregivers) in rehab group (n=56), 25 (44.6%) were in between age 20-30 years, 21 (37.5%) in between 31-40 years, 9 (16.1%) were in between 41-50 years and only 1 (1.8%) was above 50 years. In non-rehab group (n=40), 15 (37.5%) were in between 20-30 years, 12 (30%) in between 31-40 years, 5 (12.5%) were in between 41-50 years and 8 (20%) were above 50 years. The result of chi-square tests for difference between age of caregivers in the two groups was χ^2 (3, N=96) =9.12, $p=0.028$. This means, statistically, there was significant difference between ages of caregivers in two groups. In non-rehab group, more caregivers were above 50 years whereas only few caregivers were above 50 in rehab group.

Gender of caregivers

Among all 96 respondents, 83 (86.5%) respondent were female and only 13 (13.5%) respondents were male. That means, most of primary caregivers were female. Primary caregivers of children with CP in rehab group (n=56), 52 (92.9%) were female and 4 (7.1%) were male. Primary caregivers of children with CP in non-rehab group (n=40), 31 (77.5%) were female and 9 (22.5%) were male. The result of chi-square tests for difference between gender of caregivers in the two groups was χ^2 (1, N=96) =4.70, $p=0.03$. This shows there was significant difference between genders of caregivers in two groups, (Table 4.1). Male are more in non-rehab group than rehab group.

Type of Family of caregivers

Among the 96 respondents, 51 (53.1%) were living in small family and 45 (46.9%) were living in joint family. Primary caregivers of children with CP in rehab group (n=56), 32 (57.1%) were living in small family and 24 (42.9%) were living in joint family whereas primary caregivers of children with CP in non-rehab group (n=40), 19 (47.5%) were living in small family and 21 (52.5%) were living in joint family. The result of chi-square tests for difference between type of family of caregivers in the two groups was χ^2 (1, N=96) =0.87, p=0.23. There was no statistical significant difference between types of family of caregivers in two groups (Table 4.1).

Marital status of caregivers

Among 96 respondents, 89 (92.7%) respondents were married and 7 (7.3%) respondents were widow. No respondents were single and divorced found in this study. In this study, out of 56 respondents in rehab group, 52 (92.9%) respondents were married and only 4 (7.1%) were widow. Out of 40 respondents in non-rehab group, 37 (92.5%) respondents were married and only 3 (7.5%) were widow. The result of chi-square tests for difference between marital status of caregivers in the two groups was χ^2 (1, N=96) = 0.004, p=0.94. Statistically, there was no significant difference between marital statuses of caregivers in two groups (Table 4.1). More numbers of respondents were married.

Education of caregivers

Among 96 respondents 71 (74%) respondents were illiterate and 25 (26%) respondents were literate. Out of 56 respondents in rehab group, 36 (64.3%) respondents were illiterate, 8 (14.3%) were having primary level of education, 10 (17.9%) were having secondary education and 2 (3.6%) had higher level of education, Out of 40 respondents in non-rehab group 35 (87.5%) respondents were illiterate, 3(7.5%) were having primary level of education, 1 (2.5%) were having secondary education and only 1(2.5%) had higher level of education. In this study, more number of respondents was illiterate. The result of chi-square tests for difference between education level of caregivers in the two groups was χ^2 (3, N=96) =7.52, p=0.05. This shows there was significant difference between educations of caregivers in the two groups (Table 4.1). Majority of respondents were illiterate. More numbers of people are illiterate in non-rehab group.

Occupation of caregivers

Out of all 96 respondents 7 (7.3%) were unemployed and 62 (64.6%) were housewife, 20 (20.8%) were engaged in agriculture and 7 (7.3%) were engaged in other occupation. More number of respondents was housewife. Looking at the occupation of the respondents, out of 56 respondents in rehab group, 2(3.6%) respondents were unemployed, 36 (64.3%) were housewife, 12 (21.4%) were involved in agriculture and 6 (10.7%) were involved in other occupation. Out of 40 respondents in non-rehab group, 5 (12.5%) respondents were unemployed, 26 (65%) were housewife, 8 (20%) were involved in agriculture and only 1 (2.5%) were involved in other occupation. The result of chi-square tests for difference between occupation of caregivers in the two groups was χ^2 (3, N=96) =4.73, *p*=0.19. That means there was no significant difference between occupations of caregivers in the two groups (Table 4.1). Majority of caregivers were housewife.

Number of children of caregivers

Out of 96 respondents among them 11 (11.5%) were having 1 child, 28 (29.2%) were having 2 children, 25 (26%) were having 3 children and 32 (33.3%) were have 4 and more number of children. In rehab group (n=56), respondents 8 (14.3%) were having 1 child, 19 (33.9 %) were having 2 children. 11 (19.6%) were having 3 children and 18 (32.1 %) were having 4 and more children. In non-rehab group (n=40), respondents 3 (7.5%) were having 1 child, 9 (22.5 %) were having 2 children. 14 (35%) were having 3 children and 14 (35 %) were having 4 and more children. The result of chi-square tests for difference between number of children of caregivers in the two groups was χ^2 (3, N=96) =4.15, *p*=0.24. This shows that, there was no significant difference between numbers of children of caregivers in two groups (Table 4.1). In both groups more number of caregivers has more than 4 children.

Relationship to child

Looking at the relationship of child with all 96 respondents, 71 (74%) were mother, 8 (8.3%) were father, 9 (9.4%) were grandmother and 8 (8.3%) were others. This shows maximum respondents were mother, as mother is taken as primary caregivers.

Looking at respondents in rehab group (n=56), 44 (78.6%) were mother, 3 (5.4%) were father, 4 (7.1%) were grandmother and 5 (8.9%) were others. In non-rehab group (n=40), 27 (67.5%) were mother, 5 (12.5%) were father, 5 (12.5%) were grandmother and 3

(7.5%) were others. When two groups were statistically compared, the result of chi-square tests for difference between relationship to child of caregivers in the two groups was χ^2 (3, N=96) =2.58, *p*=0.46. This shows there was no significant difference between relationships to child of caregivers in two groups (Table 4.1). In both group mothers were taken as primary caregivers of children with CP.

Family annual income of Caregivers

Among 96 respondents, 47 (49%) respondents family annual income less than 50000 annually and only 9 (9.4%) respondents family annual income was above 150000 rupees. Out of 56 respondents, 22 (39.3%) respondents in rehab group family annual income was below 50000 and only 6 (10.7%) respondents family annual income was above 150000. And out of 40 respondents in non-rehab group, 25 (62.5%) respondents family annual income was below 50000 and only 3 (7.5%) respondents family annual income was above 150000. The result of chi-square tests for difference between family annual income of caregivers in the two groups was χ^2 (3, N=96) =5.45, *p*=0.14. Statistically, there was no significant difference between family incomes of caregivers in two groups. (Table 4.1). Majority of caregivers had family annual income less than 50000 in both groups.

Health problem of caregivers

Among 96 respondents, 24 (25%) respondents were having health problem and 72(75%) respondents were not having any health problem. Out of all 56 respondents in rehab group, 15 (26.8%) respondents were having health problem and 41 (73.2%) were not having any health problem. In non-rehab group out of 40 respondents, 9 (22.5%) respondents were having health problem and 31 (77.5%) were not having any health problem. The result of chi-square tests for difference between health problem of caregivers in the two groups was χ^2 (1, N=96) =0.22, *p*=0.63. There was no significant difference between healths of caregiver in two groups (Table 4.1). Majority of caregivers does not have any health problem in both groups.

4.2 Demographic data of children with CP

Age of child with CP

Among 96 respondents more numbers of children were between ages of 4 to 6 years that is 51 (53.1 %). Mean age of child is 6.41±2.62 years in rehab group, 7.75±2.85 years age in non-rehab group, over all mean age of child with CP is 6.97±2.78 years. In rehab group out of 56 children with CP, 37 (66.1%) children were in age between 4 to 6 years, 7 (12.5%) children were in age between 7-9 years and 12 (21.4%) children were in age between 10-12 years. In non-rehab group, out of 40 children with CP, 14 (35%) children were in age between 4to 6 years, 13 (32.5%) children were in age between 7-9 years and 13 (32.5%) children were in age between 10-12 years. The result of chi-square tests for difference between age of children with CP in the two groups was χ^2 (2, N=96) =9.819, *p*=0.007. There was statistical difference between ages of children in two groups (Figure 4.1). In rehab group majority of children were between 4-6 years where as in non-rehab group, there was equal numbers of children in all group.

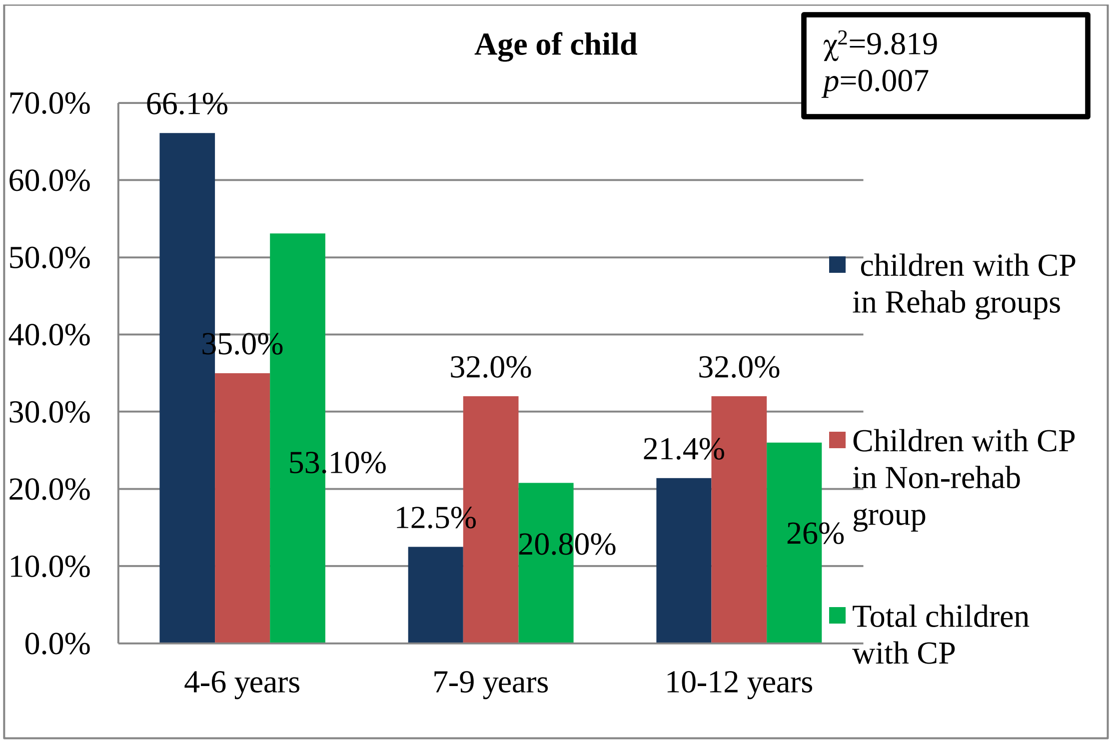


Figure 4.1 Age of children with CP in Rehab and Non-rehab group

Gender of child with CP

In rehab group, out of 56 children with CP, 38 (67.9%) children were male and 18 (32.1%) children were female, where as in non-rehab group out of 40 children, 24 (60%) children were male and 16 (40%) children were female. The result of chi-square tests for difference between gender of children with CP in the two groups was χ^2 (1, N=96) =0.63, *p*=0.42. There was no significant difference between genders of children in two groups. More number of children with CP was male in both the group that is 62 (64.6%) (Figure 4.2). In both groups male children with CP were more.

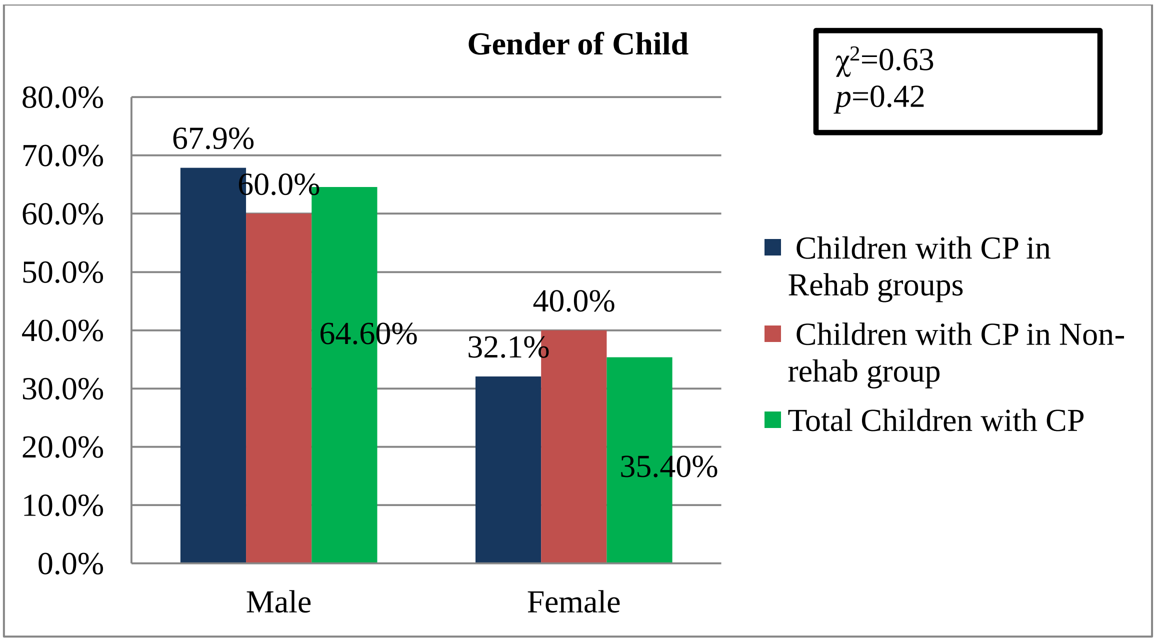


Figure 4.2 Gender of children with CP in Rehab and Non-rehab group

4.3 Characteristic of child

Table 4.2 Frequency distribution for characteristic of child with CP in rehab and non-rehab group

Children with CP	**Level**	Primary caregivers of children with CP in Rehab Group (n=56)	Primary caregivers children with CP in Non-Rehab group (n=40)	Total (n=96)
		n (%)	n (%)	n (%)
Type of CP				
	Spatic	51 (91.1)	28 (70.0)	79 (82.3)
	Ataxic	3 (5.4)	2 (5)	5 (5.2)
	Athetoid	2 (3.6)	4 (10)	6 (5.2)
	Mixed	0 (0)	6 (15)	6 (5.2)
GMFCS level				
	II	19 (33.9)	19 (47.5)	38 (39.6)
	III	16 (28.6)	5 (12.5)	21 (21.9)
	IV	19 (33.9)	8 (20.0)	27 (28.1)
	V	2 (3.6)	8 (20.0)	10 (10.4)
Nature of child				
	Aggressive	12 (21.4)	13 (32.5)	25 (26.0)
	Uncooperative	20(35.7)	7 (17.5)	27 (28.1)
	friendly	14 (25.0)	11(27.5)	25 (26.0)
	Helpful within possibilities	10 (17.9)	9 (22.5)	19 (19.8)
Health condition of child				
	Other health problem	18 (32.1)	6 (15.0)	24 (25.0)
	No other problem	38 (67.9)	34 (85.0)	72 (75.0)
Participation of child				
	No participation	14 (25.0)	14 (35.0)	28 (29.2)
	Participation	42 (57.0)	25 (65.0)	68 (70.8)

Table 4.2.1 Comparison of child characteristic in two groups

	Chi-square value	*p* value
Type of Cp	11.208 (Fisher exact test)	0.011
GMFCs level	11.496 (Fisher exact test)	0.009
Nature of child	4.161	0.24
Health condition	3.657	0.05
Participation	1.129	0.28

χ^2 test, * Level of significance: $p < 0.05$.

Type of CP

In rehab group, out of 56 children with CP, 51 (91.1%) children were spastic, 3 (5.4%) were ataxic and 2 (3.6%) were athetoid. Where as in non-rehab group among 40, 28 (70%) children were spastic, 2 (5%) were ataxic, 4 (10%) were athetoid and 6 (15%) were mixed. Most of children were diagnosed with spastic type of CP (Table 4.2). The result of chi-square tests for difference between types of CP in two groups was χ^2 (3, N=96) =11.20, *p*=0.001 (Fisher exact test). That shows that there was statistical significant difference between types of CP in the two groups (Table 4.2.1). Mixed type of CP was only in non-rehab group.

GMFCS level

Out of 56 respondents- in rehab group, 19 (33.9%) children were having GMFCs level II, 16 (28.6%) were having GMFCs level III, 19 (33.9%) were having GMFCs level IV and 2 (3.6%) were having GMFCs level V. In non- rehab group out of 40, 19 (47.5%) children were having GMFCs level II, 5 (12.5%) were having GMFCs level III, 8 (20%) were having GMFCs level IV and 8 (20%) were having GMFCs level V. In both group, more children 38 (39.6%) are having GMFCS level II and less number of children are in GMFCs V that is 10 (10.4 %) (Table 4.2). The result of chi-square tests for difference between GMFCS level in the two groups was χ^2 (3, N=96) =11.49, *p*=0.009 (Fisher exact test). This shows there was statistical significant difference between GMFCS level in the two groups (Table 4.2.1). In non-rehab group more number of children was in GMFCS level IV and V.

Nature of child

Out of 56 respondents- in rehab group, most of child 20 (35.7%) were uncooperative in nature, 14 (25%) were friendly in nature, 12 (21.4%) were aggressive in nature, and only 10 (17.9%) were helpful in nature. In Non-rehab group out of 40 children, 13 (32.5%) were aggressive in nature, 11 (27.5%) friendly in nature, 9 (22.5%) were helpful in nature and 7 (17.5%) uncooperative in nature (Table 4.2). The result of chi-square tests for difference between nature of child in the two groups was χ^2 (3, N=96) =4.161, p=0.24.This shows statistically, there was no significant difference between nature of child in the two groups (Table 4.2.1). More numbers of children with CP were uncooperative and aggressive.

Health condition of child

Among 96 children of respondents, 72 (75%) were not having any other health problem, 24 (25%) were having other health problem associated with CP. In rehab group, 38 (67.9%) were not having any health problem and 18 (32.1%) were having other health problem associated with CP. In non-rehab group, 34 (85%) were not having any health problem and 6 (15%) were having other health problem associated with CP (Table 4.2). The result of chi-square tests for difference between health condition of child in the two groups was χ^2 (1, N=96) =3.67, p=0.05. There was significant difference between health conditions of children in two groups (Table 4.2.1).

Participation of child

Among 96 children of respondents, 68 (70.8%) were actively participant, 28 (29.2%) were not participant in activities and remains at home. In rehab group, 42 (57%) were actively participant, 14 (25%) were not participant in activities and remains at home. In rehab group, 25 (65%) were actively participant, 14 (35%) were not participant in activities and remains at home (Table 4.2). The result of chi-square tests for difference between participation of child in the two groups was χ^2 (1, N=96) =1.129, p=0.28. There was no significant difference between participation of children in the two groups (Table 4.2.1).

4.4 Caregivers Factors

Table 4.3 Frequency distribution and comparison of caregivers Knowledge on child condition and rehabilitation in Rehab and Non-rehab group

Variable	**Level**	Caregivers of children with CP in Rehab group (n=56)	Caregivers of children with CP in Non-rehab group (n= 40)	Total (n=96)		
		n (%)	n (%)	n (%)	χ^2value	*p* value
Caregiver`s knowledge on child health	Poor Good	43 (76.8) 13 (23.2)	37 (92.5) 3 (7.5)	80 (83.3) 16 (16.7)	4.14	0.04
Knowledge on rehabilitation	Poor Good	29 (51.8) 27 (48.2)	39 (97.5) 1 (2.5)	68 (70.8) 28 (29.2)	23.6	0.01

χ^2 test, * Level of significance: $p < 0.05$.

Caregiver's knowledge on child health

Among 96 respondents, most of respondents 80 (83.3%) were having poor knowledge on child health and only 15 (16.7%) respondents were having good knowledge. Caregivers in rehab group, 43 (76.8%) were having poor knowledge and only 13 (23.2%) were having good knowledge on child health. Caregivers in non-rehab group, 37 (92.5%) were having poor knowledge and only 3 (7.5%) were having good knowledge on child health. This shows there caregivers in rehab group have more knowledge than non-rehab group. The result of chi-square tests for difference between caregivers knowledge on child health in the two groups was χ^2 (1, N=96) =4.14, *p*=0.04. Statistically, there was significant difference between caregivers' knowledge among two groups (Table 4.3). More numbers of caregivers in rehab group had good knowledge than non-rehab group

Caregiver's knowledge on Rehabilitation

Among 96 respondents, most of respondents 68 (70.8%) were having poor knowledge on rehabilitation and only 28 (29.2%) respondents were having good knowledge on rehabilitation. Caregivers in rehab group, 29 (51.8%) were having poor knowledge and 27 (48.2%) were having good knowledge on rehabilitation. Caregivers in non-rehab group, 39

(97.5%) were having poor knowledge and only 1 (2.5%) were having good knowledge on rehabilitation. The result of chi-square tests for difference between caregivers knowledge on rehabilitation in the two groups was χ^2 (1, N=96) =23.60, *p*=0.01. Statistically, there was significant difference between caregivers knowledge among two groups (Table 4.3). More numbers of caregivers in rehab group caregivers had good knowledge than non-rehab group caregivers.

Table 4.4 Frequency distribution and comparison of availability of service by chi-square in rehab and non-rehab group

Variable	**Level**	Caregivers of children with CP in Rehab group (n=56)	Caregivers of children with CP in non-rehab group (n= 40)	Total (n=96)		
		n (%)	n (%)	n (%)	χ^2 value	*p* value
Service available	Not available	27 (48.2)	24 (60.0)	51 (53.1)	1.30	0.25
	Available	29 (51.8)	16 (40.0)	45 (46.9)		
Barrier toward service	Financial.	4 (7.1)	6 (15.0)	10 (10.4)	7.84	0.02
	Lack of support.	11 (19.6)	16 (40.0)	27 (28.1)		Fisher exact
	Others	41 (73.2)	18 (45)	59 (61.5)		
	No barriers	0	0	0		

χ^2 test, * Level of significance: $p < 0.05$.

Availability of service

Among 96 respondents, for 51 (53.1%) respondents’ services was not easily available and for 45 (46.9%) respondents’ services was easily available. Caregivers of children with CP in rehab group, for 27 (48.2%) respondents, services were not easily available and for 29 (51.8%) respondents service was easily available. Caregivers of children with CP in non-rehab group, for 24 (60%) respondents, services were not easily available and for 16 (40%) respondents, service was easily available. The result of chi-square tests for difference between service available in the two groups was χ^2 (1, N=96) =1.30, *p*=0.25.

Statistically, there was no significant difference between caregivers in the two groups regarding availability of service for their child (Table 4.4). Majority of caregivers had not easy access to service.

Barrier toward service

Among 96 respondents, 10 (10.4%) respondents were having financial issue, 27 (28.1%) respondents were having lack of support from family and 59 (61.5%) respondents were having other barriers to reach toward service for their child. In rehab group, 4 (7.1%) respondents were having financial issue, 11 (19.6%) respondents were having lack of support from family and 41 (73.2%) respondents were having other barriers to reach toward service for their child. In non-rehab group, 6 (15%) respondents were having financial issue, 16 (40%) respondents were having lack of support from family and 18(45%) respondents were having other barriers to reach toward service for their child. The result of chi-square tests for difference between barrier toward service in the two groups was χ^2 (2, N=96) =8.84, *p*=0.02 (Fisher exact test). There was significant difference between caregivers in the two groups regarding barrier toward service for their child (Table 4.4). Caregivers in rehab group had lack of support from family whereas in non-rehab group financial issue was main barrier.

Financial support

Among 96 respondents, most of respondents 56 (58.3%) were having moderate financial support, 34 (35.4%) respondents were not having any financial support and only 6 (6.2%) respondents were having full financial support for the treatment of their child(Figure 4.3).

In rehab group, out of 56 respondents most of respondents 28 (50%) respondents were not having any financial support, 25 (44.6%) respondents were having moderate financial support and only 3 (5.4%) respondents were having full financial support for the treatment of their child. In non- rehab group out of 40 respondents, 31 (77.5%) were having moderate financial support, 6 (15%) respondents were not having any financial support and only 3 (7.5%) respondents were having full financial support for the treatment of their child. The result of chi-square tests for difference between financial support in the two groups was χ^2 (1, N=96) =12.56 *p*=0.002 (Fisher exact test). There was significant difference between caregivers in the two groups regarding financial support (Figure 4.4). Caregivers in non-rehab group had more financial support than caregivers in rehab group.

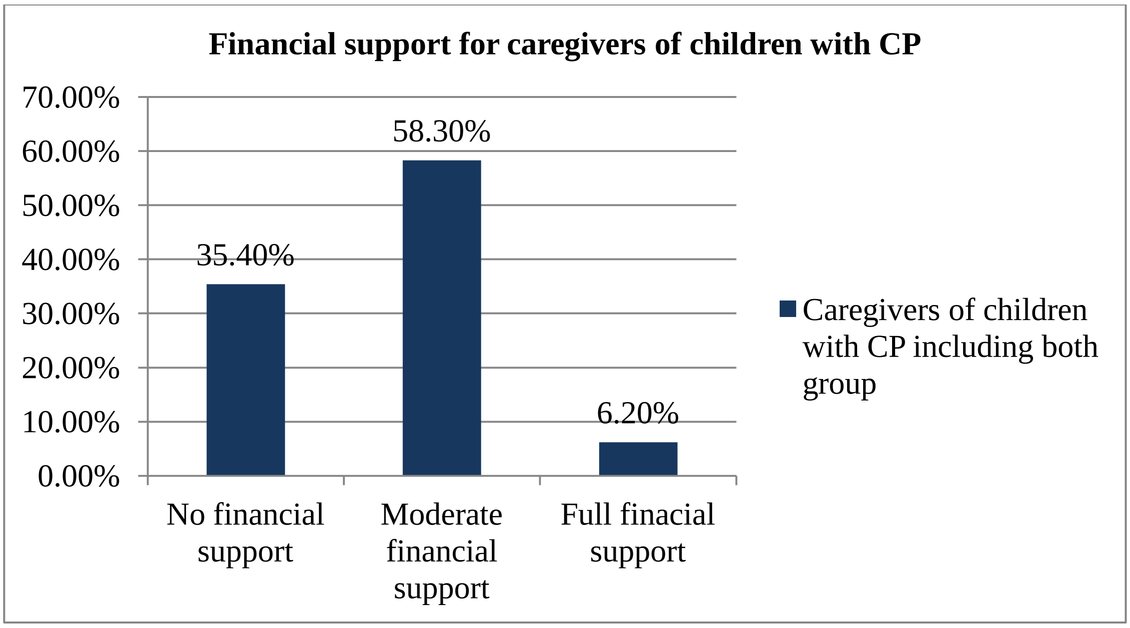


Figure 4.3 Financial supports for caregivers of children with CP in Rehab and Non-rehab group

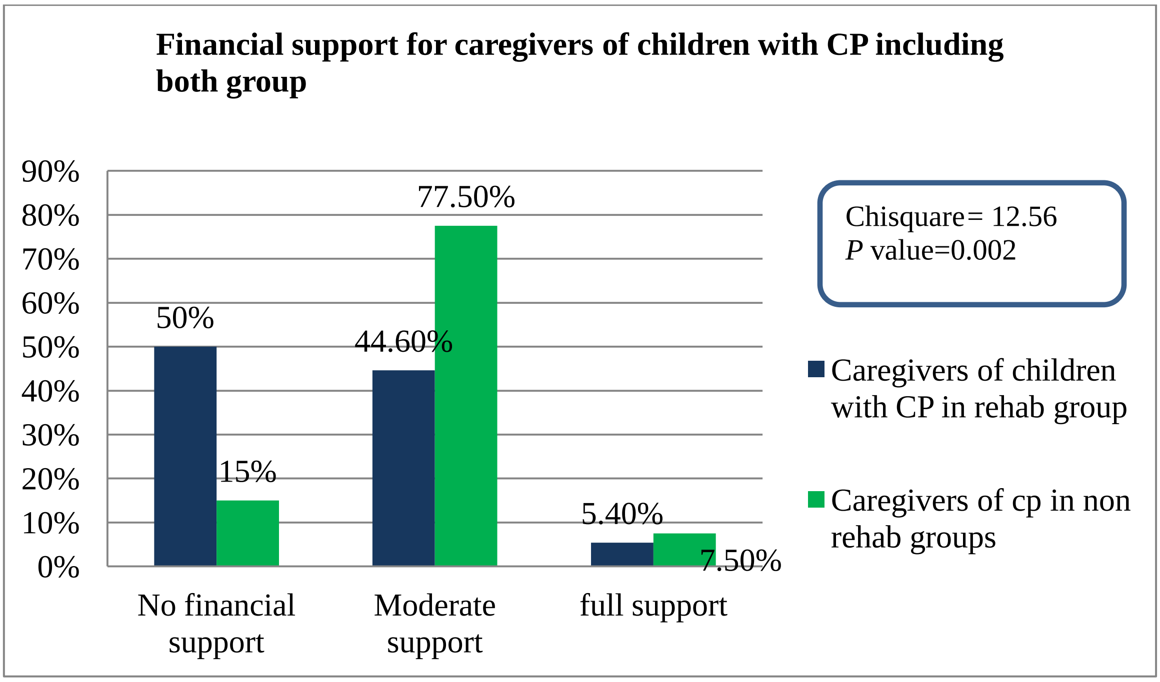


Figure 4.4 Financial supports for caregivers of children with CP in Rehab and Non-rehab group

Perceived stress

For perceived stress, 4 questions were asked to respondents. These 4 items were first tested for its reliability using SPSS 16.0 version scale reliability test and it was found that Cronbach's Alpha equal to 0.661 which is near to standard Cronbach's alpha which is 0.7. It means that these 4 items are nearly homogenous and a reliable scale to measure the perceived stress of respondent. Then, the frequency distribution of caregiver perceived stress was calculated using descriptive statistics. And comparisons of perceived stress in two groups were done by chi-square.

Frequency distribution by custom table shows, out of 96 respondents, 56 (58.3%) respondents were always stressed and only 40 (41.75) respondents were not stress while providing care to child. In rehab group, 38 (67.9%) of respondents always stressed and 18 (32.1%) not stress while in non-rehab group among 440 respondents, 18 (45% always stressed and 22 (55%) not stress at all. When two groups are compared statistically, the result of chi-square tests for difference between perceived stress in the two groups was χ^2 (1, N=96) =5.01, *p*=0.025. This shows there was significant difference between perceived stresses in both groups (Table 4.5). More numbers of caregivers in rehab group were more stressed than non-rehab group.

Table 4.5 Frequency distribution and comparison of perceived stress between two groups

	Caregivers of children with CP in Rehab group.	Caregivers of children with CP in non-rehab group	Total		
	n (%)	n (%)	n (%)	χ^2value	*p* value
Perceived stress					
Always stressed	38 (67.9)	18 (45.0)	56 (58.3)	5.01	
Not stress at all	18 (32.1)	22 (55.0)	40 (41.7)		0.025
Total	56 (100)	40 (100)	96 (100)		

χ^2 test, * Level of significance: $p < 0.05$.

4.5 Quality of life of respondents

For quality of life, 25 questions were asked to respondents. 25 questionnaires were divided in 5 different domains. These 25 items were first tested for its reliability using SPSS 16.0 version scale reliability test and it was found that Cronbach's Alpha equal to 0.835 which is more than standard Cronbach's alpha 0.7. It means that these 25 items are homogenous and a reliable scale to measure the QOL of respondent.

Table 4.6 Comparison of the mean score of QOL between caregivers of children with CP in rehab group and non-rehab group

Quality of life domain	Caregiver of children with CP in rehab group Mean ±SD	Caregiver of children with CP in Non-rehab group. Mean ±SD	t	*P* value
Health Domain	21.84±4.17	22.72± 4.11	-1.03	0.30
Psychological	21.79 ±4.10	21.18±4.61	0.68	0.49
Family Relationship	12.59 ±3.10	12.48±3.63	0.16	0.86
Social participation	11.21±3.70	8.95±2.63	3.31	0.001
Environmental	12.62±3.43	12.67±3.62	-0.06	0.94
Overall QOL	80.05±12.08	78.00± 12.45	0.81	0.42

Independent t test * Level of significance: *p* < 0.05

Health domain

For caregiver of children with CP in rehab group, mean score in health domain was 21.84±4.17 and for caregivers of children with CP in non-rehab group mean score on health domain was 22.72± 4.11. Statistically, there was no significant difference between health domain in Rehab group (M=21.84, SD= 4.17) and Non-rehab group (M=22.72, SD= 4.11) condition; t = -1.03, *p*=0.30 (Table 4.6)

Psychological domain

For caregiver of children with CP in rehab group, mean score in psychological domain was 21.79 ±4.10 and for caregivers of children with CP in non-rehab group mean score on psychological domain was 21.18±4.61. Statistically, there was no significant difference between psychological domain in Rehab group (M=21.79, SD= 4.10) and non-rehab group (M=21.18, SD= 4.61) condition; t = 0.68, *p*=0.49 (Table 4.6).

Family Relationship

For caregiver of children with CP in rehab group, mean score in family relationship domain was 12.59 ±3.10 and for caregivers of children with CP in non-rehab group mean score on family relationship domain was 12.48±3.63. Statistically, there was no significant difference between family relationship domain in rehab group (M=12.59, SD= 3.10) and non-rehab group (M=12.48, SD= 3.63) condition; t = 0.16, *p*=0.86 (Table 4.6)

Social participation

For caregiver of children with CP in rehab group, mean score in social participation domain was 11.21±3.70 and for caregivers of children with CP in non-rehab group mean score on social participation domain was 8.95±2.63. Statistically, there was significant difference social participation domain in rehab group (M=11.21, SD= 3.7) and non-rehab group (M=8.95, SD= 2.63) condition; t = 3.31, *p*= 0.001 (Table 4.6)

Environmental

For caregiver of children with CP in rehab group, mean score in environmental domain was 12.62±3.43 and for caregivers of children with CP in non-rehab group mean score on environmental domain was 12.67±3.62. Statistically, there was no significant difference between environmental domain in rehab group (M=12.62, SD= 3.43) and non-rehab group (M=12.67, SD= 3.62) condition; t = -0.06, *p*=0.94) (Table 4.6)

Overall QOL

For caregiver of children with CP in rehab group, mean score in Overall QOL was 80.05±12.08 and for caregivers of children with CP in non-rehab group mean score on over all QOL was 78.00± 12.45. Statistically, there was no significant difference between overall QOL in rehab group (M=80.05, SD= 12.08) and non-rehab group (M=78.00, SD= 12.45) condition; t = 0.81, *p*=0.42 (Table 4.6).

Quality of life of all respondents

Among all 96 respondents who were included in this study, Overall QOL of caregivers of children with CP, 75 (78.1%) respondents scored poor quality of life and only 21 (21.9%) scored good quality of life. This show most of respondents were having poor Quality of life. When quality of life was analyzed by each domain, in environmental domain 91 (98.4%) respondents scored poor and only 5 (5.2%) respondents scored good, in social participant domain 78 (81.2%) respondents scored poor and only 18 (18.8%) respondents scored good, in psychological domain 73 (76%) respondents scored as poor and only 23 (24%) respondents scored as good. In health domain, 28 (29.2%) respondents rated poor health and 68 (70.85%) respondents rated good health. In family relationship domain 22 (22.9%) respondents scored poor family relationship and 74 (77.1%) respondents score good family relationship (Figure 4.5).

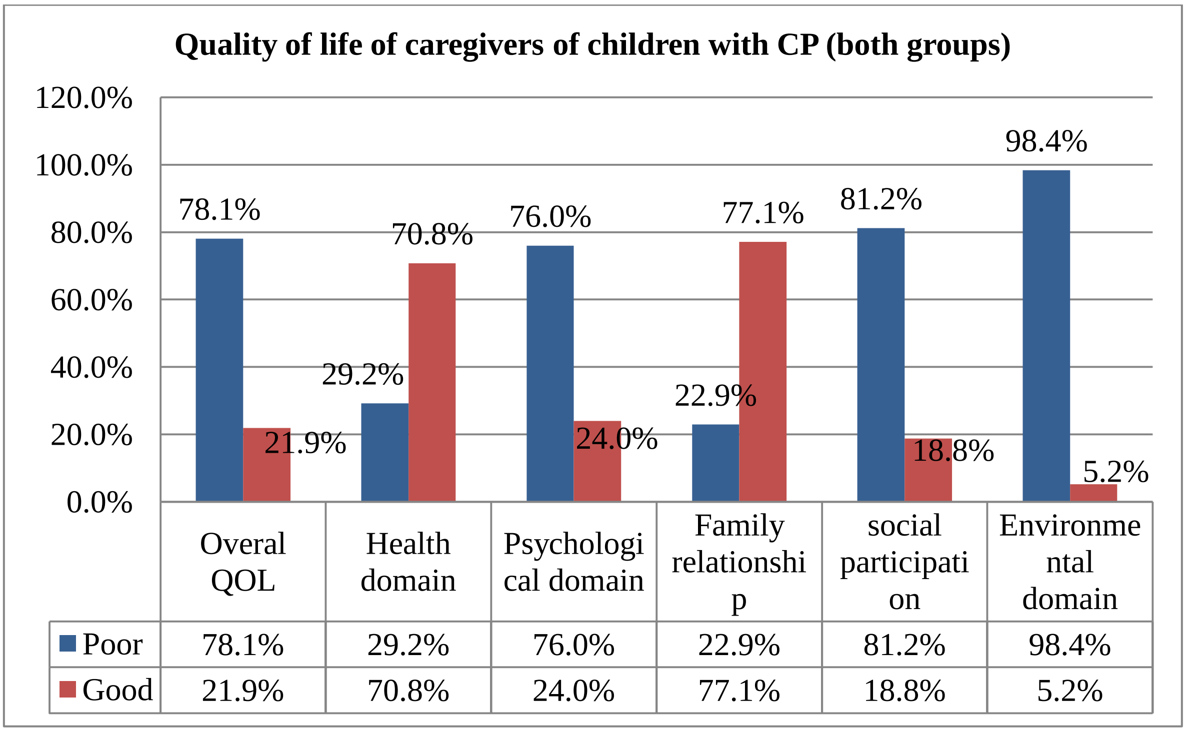


Figure 4.5 Overall Quality of life of primary caregivers of children with CP including both groups

4.6 Factors associated with QOL of caregivers in rehab group

Table 4.7 Association between Socio demographic of caregiver, child with CP and QOL of caregivers in Rehab group

Variable	**Level**	Quality of life of caregivers	
		Chi-square value	*P* value
Caregivers			
Age (in years)	20-30		
	31-40	6.517	0.089
	41-50		
	51+		
Gender	Male		
	Female	0.150	0.699
Type of family	Small		
	Joint	0.041	0.840
Marital status	Married		
	Widow	0.936	0.333
Education	Illiterate		
	Primary	12.44	0.006*
	Secondary		
	High and above		
Occupation	Unemployment		
	Housewife	1.461	0.691
	Agriculture		
	Others		
Annual income			
	Below 50000	1.902	0.593
	51000-100000		
	110000-150000		
	151000 and above		
Health problem	Yes		
	No	0.286	0.593
Child with CP			
Age of child (in years)	4-6		0.560
	7-9	1.160	
	10=12		
Gender of child	Male	0.026	0.873
	Female		

χ^2 test, * Level of significance: $p < 0.05$

Age of caregivers and QOL

Assessing association between age of caregivers and QOL, the result of chi-square tests was χ^2 (3, N=56) =6.517, *p*=0.089 (*p*=<.05). Hence, it was concluded, there was no significant association between age of caregivers and QOL of caregivers in this study (Table 4.7).

Gender of caregivers and QOL

The result of chi-square tests for association between gender of caregivers and QOL was χ^2 (1, N=56) =0.150, *p*=0.699. This shows, the test was not statistically significant at 5% level of significance. Therefore, there was no significant association between gender of caregivers and QOL of caregivers in this study (Table 4.7).

Type of family and QOL

The result of chi-square tests for association between type of caregivers and QOL provides χ^2 (1, N=56) =0.041, *p*=0.840 (*p*=<.05). This shows, there was no evidence to conclude association between type of family of caregivers and QOL of caregivers was significant in this study (Table 4.7).

Marital status and QOL

Looking at the result of chi-square tests for association between marital status of caregivers and QOL, the provided result was χ^2 (1, N=56) =0.936, *p*=0.33 (*p*=<.05). This shows that, there was no significant association between marital status of caregivers and QOL of caregivers in this study (Table 4.7).

Education of caregivers and QOL

Assessing the association between education level of caregivers and QOL by chi-square, the obtain result was χ^2 (3, N=56) =12.44, *p*=0.006. Therefore, the test was statistically significant at 5% level of significance. This shows that, there was strong evidence to conclude association between education level of caregivers and QOL of caregivers was significant in this study (Table 4.7).

Occupation

The result of chi-square tests for association between occupation of caregivers and QOL was χ^2 (3, N=56) =1.46, *p*=0.691. This shows that, there was no significant association between occupation of caregivers and QOL of caregivers in this study (Table 4.7).

Family Annual income

As shown in Table 4.7, the result of chi-square tests for association between family annual income of caregivers and QOL was χ^2 (3, N=56) =1.90, *p*=0.593 (*p*=<.05). This shows that, there was no significant association between family annual income of caregivers and QOL of caregivers in this study.

Health problem of caregivers and QOL

The result of chi-square tests for association between health problem of caregivers and QOL was χ^2 (1, N=56) =0.286, *p*=0.593. This shows that, there was no significant association between health problem of caregivers and QOL of caregivers in this study (Table 4.7).

Age of child and QOL

Assessing the association between age of child and QOL of caregivers, the result of chi-square tests was χ^2 (1, N=56) =1.16, *p*=0.560 which shows the test was not significant at 5% level of significance. Therefore it was concluded, there was no significant association between age of child and QOL of caregivers in this study (Table 4.7).

Gender of child and QOL

The result of chi-square tests for association between age of children with CP and QOL was χ^2 (1, N=56) =0.026, *p*=0.873 which shows the test was not significant at 5% level of significance. Therefore it was concluded, there was no significant association between gender of child and QOL of caregivers in this study (Table 4.7).

Table 4.8 Child characteristic and QOL of caregivers in Rehab group

		Quality of life of caregivers	
Variable	**Level**	Chi-square value	*P*-value
Child with CP			
Type of CP	Spastic Ataxic Athetoid Mixed	1.194	0.551
GMFCs level	II III IV V	2.246	0.523
Nature of child	Aggressive Uncooperative friendly Helpful within possibilities	8.749	0.033*
Health condition of child	Other health problem No other problem	0.823	0.364
Participation of child	No participation Participation	0.162	0.687

χ^2 test, * Level of significance: $p < 0.05$

Type of CP and QOL

The result of chi-square tests for association between types of CP and QOL was χ^2 (3, N=56) =1.194, *p*=0.551. This shows that, there was no significant association between types of CP and QOL of caregivers in this study (Table 4.8).

GMFCs level and QOL

The result of chi-square tests for association between GMFCS and QOL of caregivers was χ^2 (3, N=56) =2.246, *p*=0.523 Therefore it was concluded, there was no significant association between GMFCS level of child and QOL of caregivers in this study (Table 4.8).

Nature of child and QOL

Association between nature of child and QOL of caregivers was analyzed by chi-square tests. The obtain result of association was χ^2 (3, N=9=56) =8.749, *p*=0.03. This shows the test was significant at 5% level of significance. Therefore, it was concluded that there was strong evidence to show association between nature of child and QOL of caregivers was significant in this study (Table 4.8).

Health condition of child and QOL

The result of chi-square tests for association between health condition of child and QOL was χ^2 (1, N=56) =0.823, *p*=0.364 (*p*=<.05). This shows that, there was no significant association between age of child problem of caregivers and QOL of caregivers in this study (Table 4.8).

Participation of child and QOL

Over viewing the result of chi-square tests for association between participation of child and QOL was χ^2 (1, N=56) =0.162, *p*=0.687. This shows the test was not significant at 5% level of significance. Therefore, it was concluded there was no significant association between participation of child and QOL of caregivers in this study (Table 4.8).

Table 4.9 Caregivers factors and QOL of caregivers in Rehab group

Variables	**Level**	Quality of life of caregivers	
		Chi-square value	*p*-value
Knowledge about child condition	Poor knowledge		
	Good Knowledge	14.94	0.001*
Knowledge about rehabilitation	Poor knowledge		
	Good Knowledge	2.31	0.128
Availability of service	Not available	0.016	0.901
	Available		
Barrier toward service	Financial issue		
	Lack of family support	1.552	0.460
	Others		
Financial support	No support	6.25	0.044*
	Moderate support		
	Full support		
Perceived Stress	Always stressed	0.345	0.557
	Not stressed		

χ^2 test, * Level of significance: $p < 0.05$

Knowledge about child condition

Table 4.9 presents, association between knowledge about child condition and QOL of caregivers by chi-square. The obtain result of test was χ^2 (1, N=56) =14.94, p=0.001. Therefore, the test was significant at 5% level of significance. This shows that, there was significant relationship between knowledge about child condition and QOL of caregivers in this study.

Knowledge about rehabilitation

Looking at chi-square result for association between knowledge about rehabilitation and QOL of caregivers was χ^2 (1, N=56) =2.31, p=0.128. This shows that, there was no significant relationship between knowledge about rehabilitation and QOL of caregivers in this study (Table 4.9).

Availability of service

The result of chi-square tests for association between availability of service and QOL of caregivers was χ^2 (1, N=66) =0.016, *p*=0.901. Therefore, the test was significant at 5% level of significance. This shows that, there was no significant association between availability of service and QOL of caregivers in this study (Table 4.9).

Barrier toward service

The result of chi-square tests for association between barrier toward service and QOL of caregivers was χ^2 (2, N=56) =1.552, *p*=0.46. Therefore, the test was not significant at 5% level of significance. This shows that, there was no statistically significant association between barrier toward service and QOL of caregivers in this study (Table 4.9).

Financial support

The association between financial support and QOL of caregivers was analyzed using chi=square test. The calculated result for association between financial support and QOL of caregivers was χ^2 (2, N=56) =6.25, *p*= 0.04. Therefore, the test was significant at 5% level of significance which shows there was strong evidence to conclude association between financial support and QOL of caregivers was significant in this study (Table 4.9).

Perceived Stress

The chi-square tests for association between perceived stress and QOL of caregivers was χ^2 (1, N=56) =0.345, *p*= .557. This means, the test was significant at 5% level of significance. Therefore, there was strong evidence to conclude the association between perceived stress and QOL of caregivers in this study was significant (Table 4.9).

4.7 Factors associated with QOL of caregivers in non-rehab group

Table 4.10 Association of socio demographic data of caregivers and child with QOL of caregivers in Non-rehab group

Variable	**Level**	Quality of life of caregivers	
		Chi-square value	*P* value
Caregivers			
Age (in years)	20-30		
	31-40	0.376	0.89
	41-50		Fisher exact
	51+		
Gender	Male		
	Female	0.198	0.656
Type of family	Small		
	Joint	0.775	0.385
Marital status	Married		
	Widow	2.495	0.114
Education	Illiterate		
	Primary	6.467	0.091
	Secondary		
	High and above		
Occupation	Unemployment		
	Housewife	4.312	0.230
	Agriculture		
	Others		
Annual income	Below 50000		
	51000-100000	1.569	0.666
	110000-150000		
	151000 and above		
Health problem	Yes		
	No	2.80	0.08
Child with CP			
Age of child (in years)	4-6		0.345
	7-9	2.079	
	10=12		
Gender of child	Male		0.873
	Female	0.188	

χ^2 test, level of significance. *p*<0.05

Table 4.10 presents association between socio demographic of caregivers, children with CP and QOL of caregivers. The result of chi-square tests for association between age of caregivers and QOL was χ^2 (1, N=40) =0.376, *p*=0.89. The result of chi-square tests for association between gender of caregivers and QOL was χ^2 (1, N=40) =0.198, *p*=0.656. The result of chi-square tests for association between type of family of caregivers and QOL was χ^2 (1, N=40) =0.775, *p*=0385. The result of chi-square tests for association between marital status of caregivers and QOL was χ^2 (1, N=40) =2.492, *p*=0.114. The result of chi-square tests for association between education of caregivers and QOL was χ^2 (1, N=40) =6.467, *p*=0.09. The result of chi-square tests for association between occupation of caregivers and QOL was χ^2 (1, N=40) =4.312, *p*=0.23. The result of chi-square tests for association between annual family income of caregivers and QOL was χ^2 (1, N=40) =1.56, *p*=0.66. The result of chi-square tests for association between health problem of caregivers and QOL was χ^2 (1, N=40) =2.80, *p*=0.08. The result of chi-square tests for association between age of child and QOL was χ^2 (1, N=40) =2.07, *p*=0.34. The result of chi-square tests for association between gender of child and QOL was χ^2 (1, N=40) =0.188, *p*=0.87. This shows all the test of socio demographic of caregivers and children with CP were not significant at 5% level of significance. Therefore, it was concluded that there was no significant association between socio demographic of caregiver, demographic of child with CP and QOL of caregivers in this study

Table 4.11 Child characteristic and QOL of caregivers in non-rehab group

Variable	**Level**	Quality of life of caregivers	
		Chi-square value	*p*-value
Child with CP			
Type of CP	Spastic Ataxic Athetoid Mixed	5.24	0.154
GMFCs level	II III IV V	16.77	<0.001*
Nature of child	Aggressive Uncooperative friendly Helpful within possibilities	5.557	0.135
Health condition of child	Other health problem No other problem	0.416	0.519
Participation of child	No participation Participation	2.477	0.09

χ^2 test, level of significance. $p<0.05$

Characteristic of child and QOL of caregivers

The result of chi-square tests for association between types of CP and QOL was χ^2 (3, N=40) =5.24, *p*=0.154. Association between nature of child and QOL of caregivers was analyzed by chi-square tests. The obtain result of association was χ^2 (3, N=40) =5.55, *p*=0.135. The result of chi-square tests for association between health condition of child and QOL was χ^2 (1, N=40) =0.416, *p*=0.519. Over viewing the result of chi-square tests for association between participation of child and QOL was χ^2 (1, N=40) =2.47, *p*=0.09. Therefore, the test was not significant at 5% level of significance. Hence it was concluded that, there was no significant association between participation of child characteristic and QOL of caregivers in this study (Table 4.11).

Child characteristic (GMFCs level) and QOL

The result of chi-square tests for association between GMFCS and QOL of caregivers was χ^2 (3, N=40) =16.77, $p<0.001$. Therefore it was concluded, there was significant association between GMFCS level of child and QOL of caregivers in this study (Table 4.11).

Table 4.12 Caregivers factors and QOL of caregivers in Non-rehab group

Variables	**Level**	Quality of life of caregivers	
		Chi-square value	p-value
Knowledge about child condition	Poor knowledge		
	Good Knowledge	2.495	0.114
Knowledge about rehabilitation	Poor knowledge		
	Good Knowledge	2.70	0.10
Availability of service	Not available	0.188	0.665
	Available		
Barrier toward service	Financial issue		
	Lack of family support	1.964	0.374
	Others		
Financial support	No support	2.679	0.262
	Moderate support		
	Full support		
Perceived Stress	Always stressed	4.409	0.036*
	Not stressed		

χ^2 test, level of significance. $p<0.05$

Table 4.12 presents the result of chi-square tests for association between knowledge about child condition and QOL of caregivers was χ^2 (1, N=40) =2.49, p=0.114. Looking at chi-square result for association between knowledge about rehabilitation and QOL of caregivers was χ^2 (1, N=40) =2.70, p=0.10. The result of chi-square tests for association between availability of service and QOL of caregivers was χ^2 (1, N=40) =0.188, p=0.665. The result of chi-square tests for association between barrier toward service and QOL of caregivers was χ^2 (2, N=40) =1.964, p=0.374. The association between financial support and QOL of caregivers was analyzed using chi-square test. The calculated result for association between financial support and QOL of caregivers was χ^2 (2, N=40) =2.67, p=

0.262 ($p>0.05$). This shows there was no evidence to conclude association between financial support and QOL of caregivers was significant in this study (Table 4.12).

Perceived Stress

The tests for association between perceived stress and QOL of caregivers was χ^2 (1, N=40) =4.409, p= 0.03. This means the test was significant at 5% level of significance. Therefore, there was strong evidence to conclude the association between perceived stress and QOL of caregivers was significant in this study (Table 4.12).

4.8 Association of QOL with selected variables in rehab group.

Table 4.13 Logistic regression for QOL with selected variables of caregivers of children with CP in Rehab group

Variable	**Level**	Quality of life of caregivers			
		p value	OR	(95% CI) for EXP(B)	
				Lower	Upper
Education	Illiterate	0.005*	7.33	2.10	56.02
	Literate		Reference		
Nature of child	Aggressive	0.050	11.00	1.005	120.43
	uncooperative	0.025	9.00	1.325	61.13
	Friendly	0.071	6.0	0.85	41.90
	Helpful within possibilities	0.056	Reference		
Knowledge about child condition	Poor knowledge	<0.001	15.55	3.13	77.18
	Good Knowledge		Reference		
Financial support	Not at all	0.051	5.200	0.99	27.22
	Moderate support		Reference		

Binary logistic regression*Level of significance p<0 .05

Education of caregivers

Primary caregivers who were illiterate had 7.33 (*p*= 0.005, 95% CI: 2.10-56.02) times poor QOL compare to primary caregiver who were literate (Table 4.13).

Nature of child

Primary caregivers of children with CP who had aggressive child had 11.00 (*p*= 0.050, 95% CI: 1.00-120.4) times poor QOL than primary caregivers who had child they are helpful in all possibilities. Similarly Primary caregivers who had uncooperative child had

9 (*p*= 0.025, 95% CI: 1.32-61.13) times poor QOL than primary caregivers who had child helpful in nature in all possibilities (Table 4.13).

Knowledge about child condition

Viewing knowledge about child health, primary caregivers who had poor knowledge had 15.55 (*p*< 0.001, 95% CI: 3.13-77.18) times poor QOL than primary caregivers of children with CP who have good knowledge about condition (Table 4.13).

Financial support

Logistic regression result on financial support shows, primary caregivers who are not receiving any type of financial support had 5.20 (p= 0.051, 95% CI: 0.99-22.2) times poor QOL than primary caregivers who receive different type of financial support (Table 4.13).

4.9 Association of QOL with selected variables in non-rehab group.

Table 4.14 Logistic regression for QOL with selected variables of caregivers of children with CP in Non-Rehab group

Variable	Level	Quality of life of caregivers			
		P value	OR	(95% CI) for EXP(B)	
				Lower	Upper
Perceived Stress					
	Always stressed	0.048	5.53	1.014	30.25
	Not stressed		Reference		

Binary logistic regression*Level of significance *p*< 0.05

Table 4.14 presents logistic regression for QOL with perceived stress by primary caregivers of children with CP. While analysis perceived stress found to be associated with QOL of caregivers in non-rehab group. Primary caregivers of children with CP who are always stressed had 5.53 (*p*= 0.048, 95% CI: 1.01-30.25) times poor quality of life than primary caregivers who are not stressed.

CHAPTER V: DISCUSSION

The purpose of this study was to determine the quality of life and factors associated with QOL among primary caregivers of children with CP living in Sarlahi and Rautahat districts of Nepal. Majority of primary caregivers in rehab groups (76.8%) were from Rauthat district whereas majority of caregivers and in non-rehab group were from Sarlahi district (85%). Young women are especially responsible for caring children. This study shows that median age of primary caregivers was 34 years, and there was little difference in median age of caregivers in rehab (32.5 years) and non-rehab group (35 years). Rehab group caregivers were younger than non-rehab group. This study also found, majority of caregivers were female that is 86.5%. This result also shows difference in gender of caregiver in rehab and non-rehab group. The result of this study found that, relatively younger age females were mostly involved in the process of caring children with CP. This result is supported by Dambi et al., (2015) caregivers of children with CP relatively younger with mean age of 30 years and female were most involved as caregiver. Chiluba, & Moyo (2017) result shows that median age of primary caregivers was 33.6 years, and dominant young age people are less involved as primary caregiver, though they provide support and assistance in caring process. Ones et al. (2005) revealed that women have more responsibility in raising children and caring children with disabilities. Different studies have reported that majority of caregivers had low education status and were house wife (Neves et al., 2015; Ahmadizadeh et al., 2015). This study also support same fact, that majority of primary caregivers were illiterate (74%) and 64.6 % were housewife. This study found that, among 96 participants, 74% were mothers who were involved as primary caregivers of children with CP and there was no significant difference between 2 groups. Similarly other study revealed that all other family members are involved in support caring, but mother is specially engaged as a primary caregiver of children with disabilities (Ones et al., 2005). Majority of primary caregivers family annual income was low and only 9.4% had annual income above 150000 and there was no significant difference between annual incomes in 2 groups. This finding is also supported by several researchers, children with CP and their caregivers had low socio-economic condition, as parents of children with CP were less involved in full time job and have less income (Brehaut et al. 2004; Dambi et al., 2015).

Many study on QOL of primary caregivers shows that, QOL of caregivers is significantly lower than caregivers of normal child (Ones et al., 2005; Ahmadizadeh et al., 2015). The result of this study is consistent with other research, among all respondents (n=96), majority of caregivers had poor QOL (78.10%) and reason of low QOL was poor score in environmental domain (98.40%), 81.20% primary caregivers had low score in social participation domain and 76% had poor psychological aspect. The result of Neves, Pietrovski, & Claudino (2015) showed that, environment domain present lower score of 50.63% significantly differ from other domain. Caregivers of children with CP often have imbalance between social needs and demand of care. Caring the child with disability throughout the day limits the social participation (Eker & Tüzün, 2004). Therefore, many primary caregivers may experience several psycho-social problems (Basaran et al., 2013). Caring children with CP throughout day affect psychological aspect of caregivers and have more negative feeling and also feeling of loneliness. Similar result was found by different researcher Raina et al. (2005); Laurvick et al., (2006), they reported that psychological health of caregiver is strongly influenced by demand of the care required by the child.

The result of this study found that, there was no statistically significant difference between overall QOL of primary caregivers in rehab group and non-rehab group that is mean score of rehab group was 80.05±12.08 and non-rehab group was 78.00 ±12.45. Both groups had poor QOL and rehabilitation service does not have any effects on QOL caregivers. This finding is also supported by Prudente et al. (2010), rehabilitation service does not significantly influence overall quality of life of caregivers, some improvement is seen only in pain domain of caregivers and GMFCS level of children with CP. Zuurmond et al. (2015) mentioned that rehabilitation program is only focused in children with disabilities, it does not have any impact on quality of life of caregivers. Caregivers received enough support from their immediate family but are unhappy from the support they received from health professions (Kilonzo, 2004). Yeowell et al. (2016) also reported that rehabilitation have no significant effect on the caregivers' psychological aspect.

Over viewing the result of study domain wise, there was significant difference between mean score of social participation in rehab and non-rehab group. Caregivers of rehab group have more opportunity for social participation than non-rehab group. Similar result was revealed by Kilonzo, (2004), caregivers who are involved in CBR program, had good QOL as social participation of caregiver can be increased by providing support service such as counseling, support group service through rehabilitation. Comans, Currin, Brauer, & Haines (2011) found similar result, rehabilitation service improve participation of people with disabilities as well as participation of caregivers.

QOL of caregivers is always associated with different factors. In this study, 74% caregivers were illiterate and 26% caregivers were literate. There was statistical difference in education level in two groups. In rehab group 64.34% were illiterate and in non-rehab group 87.5% were illiterate. The result of this study found that, poor QOL of primary caregivers was associated with education level of caregivers only in rehab group. This result is also supported by Gutierrez-Angel., Martinez-Juarez, Hernandez-Vanegas, & Crail-Melendez (2018) more year of education of caregivers was associated with better QOL in primary caregivers with epilepsy. There was no association between education and QOL in non-rehab group. Ahmadizadeh et al. (2015) found that, education status of caregivers is not associated with QOL of caregivers.

Most of children in this study were diagnosed with GMFCS level II (39.6%), III (21.9%) and IV (28.1%). There was significant difference between GMFCS level in rehab and non-rehab group. The specific characteristic of child like GMFSC level was found to be associated with QOL in non-rehab group. This study reported, majority of caregiver in non-rehab group have poor QOL due to increase in severity of child condition. This result is supported by Shirmard et al. (2017) level of disability in children was correlated with parental stress, which directly lower QOL of caregivers. Tuna et al. (2004) mentioned that severity of the disability and functional level of child measured by GMFCS had no impact on the health of the biological mother but it lower overall score of the QOL of caregiver. Dehghan et al. (2016) reported that mother having children with good motor function have higher level of QOL. In rehab group, GMFCS was not associated with QOL of caregivers. Ones et al. (2005) concluded that there is lack of correlation between GMFCS and QOL of mother as most of children were diagnosed with GMFCS 3rd and 4th level.

Among 96 caregivers, 26% caregivers were having aggressive child and 28.1% caregivers were having uncooperative child. Nature of child was found to be associated with poor QOL in rehab group. Primary caregivers of children with CP who had aggressive and uncooperative child have poor QOL than primary caregivers who had child helpful in nature in all possibilities. Gutierrez-Angel et al. (2018) reported that aggressive and uncooperative behaviour was clearly associated with lower QOL and increased level of burden in caregivers. Ahmadizadeh et al. (2015) mentioned that CP children are more aggression in nature compare to normal child, aggression nature of child lower QOL of caregivers.

In this study, 83.3 % caregivers had poor knowledge among 96 respondents. There was statistical difference between knowledge in rehab and non-rehab group. Caregivers in rehab group (23.2%) had good knowledge than non-rehab group (7.5%). This finding is supported by Dambi et al. (2017); Reinhard et al. (2018) rehab counseling, education workshop organized through rehabilitation service increase caregiver's knowledge about child condition. The result of this study revealed knowledge about child condition is associated with QOL in rehab group. Primary caregivers who had poor knowledge had poor QOL than the primary caregivers of children with CP who had good knowledge about condition in rehab group. Okurowska-Zawada et al. (2011); Reinhard et al. (2018) reported similar result; due to inadequate knowledge about disease and knowledge to deliver proper care, caregivers had increases in financial pressure that ultimately lower QOL of caregivers. Basic knowledge about child health helps caregivers to make decision and solves problem associate with care giving.

In this study result, 35.4% caregivers were not having any financial support. There was significant difference between caregivers in the two groups regarding financial support. 60% of caregivers in rehab group were receiving some financial support and it was less than non-rehab group. In non-rehab group, severity of disability was more and Hanass-Hancock & McKenzie (2017) mentioned based on severity social grant is provide by government. In rehab group financial support was strongly associated with poor QOL of caregivers in this study. In rehab group, primary caregivers who were not receiving any type of financial support have poor QOL than primary caregivers who receive different type of financial support from different organization. Similar result were found in study of Vellone, Piras, Venturini, Alvaro & Cohen (2011); Zacharopoulou, Zacharopoulou &

Lazakidou (2015) low income is associated with worst QOL, while the financial support from government and assistance from another person relieve caregivers and thus improve QOL.

The finding of this study shows, 58.3% caregivers were always stressed and 41.7% of caregivers did not perceive stress in providing care to child. Yuen Shan Leung & Wai Ping Li-Tsang (2003) reported parents of children with severe disability experience higher level of stress. Assessing statistically, there was statistical difference between perceived stresses by caregivers in 2 groups. Caregivers in rehab group perceived more stress than non-rehab group. Rehabilitation is the cornerstone of treatment in CP, and for effective management parents cooperation is required. However, rehabilitation may place additional burdens on caregivers (Yeowell et al., 2016). Perceived stress was associated with poor QOL in non-rehab group. Caregivers of children with CP who were always stressed have poor quality of life than primary caregivers who are not stressed. Poley et al. (2012) reported, stress in caregiver was not associated with functioning of child but also associated with nature of family and social support. The result of this study is supported by Borzoo et al. (2011), caregiver of children with CP had more psychological stress compared to caregiver of normal child. Lima et al. (2016) also reported caregivers of children with CP perceive poor health and had symptoms of depression and more stress that diminished QOL of caregivers.

5.1 Limitation of study

- First limitation of study was inability to randomly select primary caregivers
- Inability to match the characteristic of caregivers in rehab and non-rehab group, both groups is not totally homogenous; majority of respondents in rehab group were from Rautahat district, education level of caregivers was different.
- Details information on overall QOL is not noted in this study, as this study was done through quantitative method.
- This study found that female caregivers were not comfortable to talk on family relationship matter directly.
- The study was done through community visit, therefore only 96 respondents were interviewed.
- Lack of time and resources.

CHAPTER V I: CONCLUSION AND RECOMMENDATION

6.1 Conclusion

According to research objective, it was determined that majority of primary caregivers were mother and had poor QOL and there was no significant difference between QOL in of caregivers in Rehab and Non-rehab group as QOL of caregivers in neglected area for rehab professional. Majority of rehab group caregivers had good knowledge, less financial support, and more perceived stress than non-rehab group.

Based on overall result of QOL in this study, the major factors associated with poor QOL of caregivers of children with CP are education level of caregivers, GMFCS level of child, nature of child, knowledge about child condition, financial support and perceived stress. Illiteracy, uncooperative and aggressive nature of child, poor knowledge about child condition, and low financial supports are main factors associated with poor QOL of caregivers in rehab group. Similarly, severity of child disability and more perceived stress are most predominating factor that is associated with QOL of primary caregivers in children with CP in non-rehab group. Information about caregivers' QOL and its associated factors is important in order to identify and address modifiable factors. QOL of caregivers must be focused by rehab professionals to achieve adequate functional outcome in children with CP as proper rehabilitation and habilitation of children with CP depends of care and support received from caregivers.

6.2 Recommendation

Like other country, CP is one of major cause of disability seen in children in Nepal, but till prevalence CP is not studied. Further study is recommended to study the prevalence of CP in Nepal. The study also recommended to-do longitudinal study, to see impact of rehabilitation service on QOL of life of primary caregivers. The study also recommended to-do qualitative study, to know in details about factors associated with QOL of caregivers. When primary caregivers had poor QOL, caregivers cannot provide appropriate and sufficient care to child, thus child functional level may more affected, resulting in increased in functional limitation in child. Home therapy is important part of rehabilitation of children with CP, until we focus on caregivers, we cannot ensure proper home therapy. Therefore, this study recommended for rehab professional to focus on QOL of caregivers and design treatment protocol for children with CP focusing on caregiver that is caregiver centered approach.

Perceived stress affect QOL of caregivers in non-rehab-group. Therefore awareness program should be designed for those caregivers who have discontinued rehab service. Proper awareness and knowledge about child condition is important for management of children with CP.

CHAPTER VII: REFERENCES

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APPENDIX

Appendix-A: Informed consent form in Nepali

सुचना र सहमति फारम

नेपालको सर्लाही र रौतहट जिल्लामा बसोबास गर्ने मस्तिष्क पक्षघात भएको बच्चाहरुको प्रमुख हेरचाहकर्ताको जीवनको गुणस्तर र त्यस सम्बन्धित कारकहरु

नमस्कार,

म बिना पंडित हाल बांग्लादेश हेल्थ प्रोफेसन्स इन्स्टिच्युट, ढाका विश्वविधालयबाट “पुनर्स्थापना विज्ञान” विषयमा मास्टर्स गदैछु । डा.कमल अहमदको प्रत्क्षय पर्यवेक्षणमा यो अनुसन्धान गदैछु । म तपाईलाई मेरो अध्ययनमा भाग लिन साथै मेरो खोज **“नेपालको सर्लाही र रौतहट जिल्लामा बसोबास गर्ने मस्तिष्क पक्षघात भएको बच्चाहरुको प्रमुख हेरचाहकर्ताको जीवनको गुणस्तर र त्यस सम्बन्धित कारकहरु”** मा सहभागी हुन अनुरोध गदैछु।

यो अनुसन्धानको मुख्य उदेशय मस्तिष्क पक्षघात (सी.पी) भएको बच्चाहरुको प्रमुख हेरचाहकर्ताको जीवनको गुणस्तर कस्तो छ , साथै तपाई बस्ने समुदायको संस्कृति र मूल्य प्रणालीको सन्दर्भमा तपाई को जीवनको गुणस्तर संग कुन कुन कारकहरु सम्बन्धित छ र कुन कारकहरु तपाईको जीवनको गुणस्तरलाई असर पारेको छ भनेर पत्ता लगाउने हो । यदि तपाई, यो अध्ययनमा भाग लिनुहुन्छ भने, तपाईलाई केहि प्रश्नहरु सोधिनेछ साथै तपाईको बच्चाको समस्या विस्तारमा बुझ्नको लागि तपाईको बच्चालाई हेरिनेछ र जाचँ पनि गरिनेछ । यो अनुसन्धान तपाईको लागि लाभदायी हुनेछ, किनकि यसले तपाईले सामना गरेका समस्याहरु पत्ता लगाउने साथै समाधान गर्न काम तिर सहयोग गर्नेछ । तपाई आफनो पुरा इच्छाले यो अध्ययनमा सहभागी हुनुहोस भन्ने म चाहनछु । कृपया जवाफहरु यथार्थमा दिने् प्रयास गर्नुहोला । यदि तपाईलाई प्रश्नको जवाफ दिन असहज हुनछ भने, तपाई जवाफ नदिन या रद्व गर्न सकनुहुन्छ साथै अध्ययनको समयमा कुनै पनि समस्या आईपरेमा अध्ययनमा बाट हट्ने पुरै स्वतन्त्र रह्नुहुनेछ ।

तपाईले दिनुभएको जानकारीहरु अध्ययन प्रयोजनको लागि मात्र प्रयोग गरिनेछ, तपाईलाई चिन्न सक्ने जानकारीहरु कतै खुलासा वा प्रकाशित हुनेछैन। यदि तपाईसँग अनुसन्धान र प्रश्नवलि सम्बन्धी कुनै पनि प्रश्न छ भने तपाई अनुसन्धानकर्तालाई सोध्न सक्नुहुन्छ । यस अध्ययनमा तपाईले दिनुभएको सहमतिले जानकारीहरु प्रयोग गर्न अनुसन्धानकर्तालाई अनुमति दिन्छ र यो अनुसन्धानको लागि अनिवार्य छ ।

मैले माथिको सबै जानकारी राम्ररी पढेँ र यो अनुसन्धानमा आफनो इच्छाले सहभागी भएको छु । म सबै प्रश्नहरुको सन्तुष्ट जवाफ दिनेछु ।

सहभागीको नाम : .... मिति : ....

सहि : ....

अनपढ भएमा: म सहमति फारमको सहि पढाइको साक्षी छु र म व्यक्तिलाई प्रश्न सोध्ने अनुमति दिनछु ।

म पुष्टि गर्दछु कि यस व्यक्तिले सहमति दिइएको छ ।

सहभागीका सहि

साक्षीको नाम.............. सहि: .... मिति : ....

Appendix-B: Informed consent form in English

Consent Form to Participate in Research

"Quality of Life and its Associated factors among Primary Caregivers of Children with Cerebral palsy living in Sarlahi and Rautahat districts of Nepal"

Namaskar,

I am Bina Pandit currently pursuing my Master`s in Rehabilitation science from Bangladesh Health Profession Institute, Dhaka University. I am conducting research under direct supervision of Dr. Kamal Ahmed. I request you to participate in my research study to find out the **"Quality of life and its Associated Factors among Primary Caregivers of children with Cerebral palsy living in Sarlahi and Rautahat Districts of Nepal"**.

The purpose of this study is to identify QOL and factors associated with it and the main factors that you perceive affected your quality of life being as a main caregiver of children with Cerebral palsy in the context of the culture and value systems in which you live. If you participate in the research study, you will be asked few questions and the researcher will also observe your child to collect information about your child problem. The research will be directly beneficial for you, as it deals with acknowledgment of problems faced by you and will help to work towards solving the problems. I want you to participate in this study with your full desire. Please try to give true answers as much as possible. If you are uncomfortable to answer to any question, you can refuse or not give answer and even you will be having complete freedom to withdraw from study anytime during the interview.

The information will be used for study purpose but the information that can identify you will not be disclosed or published. If you have any queries regarding the survey and questionnaire you may ask to the researcher. Agreeing to this study gives researcher permission to use the information given by you for study and it is mandatory for the research.

I have read all the above information and agree to take part in this study. I will provide all answer to my satisfaction.

Name of Participant___________________

Signature of Participant ____________________ Date ____________________________

If illiterate

I have witnessed of the accurate reading of the consent form and I allow an individual to ask a question. I confirm that the individual has given consent freely.

Thumb print of participant

Name of witness_____________

Signature of witness _____________Date ____________________

Appendix-C: Questionnaires in Nepali

प्रश्नावली

नेपालको सर्लाही र रौतहट जिल्लामा बसोबास गर्ने मस्तिष्क पक्षघात भएको बच्चाहरुको प्रमुख हेरचाहकर्ताको जीवनको गुणस्तर र त्यस सम्बन्धित कारकहरु

नमस्ते, म बिना पंडित हाल ढाका विश्वविधालय अन्तर्गत बांग्लादेश हेल्थ प्रोफेसन्स इन्स्टिच्युटमा “पुनर्स्थापना विज्ञान” विषयमा मास्टर्स गदैछु । म यो अनुसन्धान मेरो पाठयक्रमको भागको रुपमा सञ्चालन गदैछु। मेरो अध्ययनको शीर्षक “नेपालको सर्लाही र रौतहट जिल्लामा बसोबास गर्ने मस्तिष्क पक्षघात भएको बच्चाहरुको प्रमुख हेरचाहकर्ताको जीवनको गुणस्तर र त्यस सम्बन्धित कारकहरु” हो । मेरो यो अध्ययनको परिणामले मस्तिष्क पक्षघात (सी.पी) भएको बच्चाहरुको उपचार योजनामा, बच्चाहरुको हेरचाहकर्तालाई केन्द्रित गरी उपचार योजना बनाउने र परिवार केन्द्रित उपचारमा जोडदिने छ जसले निश्चित रुपमा हेरचाहकर्ताको जीवनमा गुणस्तर बढाउनेछ ।

मस्तिष्क पक्षघात (सी.पी) भएको बच्चाहरुको प्रमुख हेरचाहकर्ताको जीवनको गुणस्तर बुझ्नलाई मैले केहि प्रश्नहरु तयार पारेको छु । यो सबै प्रश्नहरु सकाउन २०-२५ मिनेट लाग्ने छ । कृपया मेरो यो अध्ययनमा तपाई सहभागी भई प्रश्नहरुको सहि जवाफ, प्रश्नावली मा दिइएको उत्तर अनुसार गरिदिनु होला ।

सहभागी प्रश्नावली

पुर्व-अर्न्तवार्ता

अर्न्तवार्ता लिने व्यक्तिको नाम : ....

बच्चाको नाम : ....

स्थान:.........................   मिति :.........................

सहभागी क्रम संख्या :........................

निरन्तर पुनर्स्थापना सेवा: पाएको छ ☐ पाएको छैन☐ (पि.आ. सी बाट प्राप्त जानकारी अनुसार

कृपया उपयुक्त उत्तरमा चिन्ह (☑) लगाउनुहोस् ।

भाग १: सामाजिक डेमोग्राफिक जानकारी

प्रमुख हेरचाहकर्ताको जानकारी

१.	जिल्ला	☐ १. सर्लाही ☐ २. रौतहट
२	हेरचाहकर्ताको उमेर	________________वर्ष
३	लिंङ्ग	☐ १. पुरुष ☐ २. महिला
४	परिवारको प्रकार	☐ १. सानो परिवार ☐ २. संयुक्त परिवार
५	वैवाहिक स्थिति	☐ १. विवाहिक ☐ २. अविवाहिक ☐ ३. विधवा ☐ ४. तलाख भएको
६	शैक्षिक स्तर	☐ १. अनपढ ☐ २. प्राथमिक ☐ ३. माध्यमिक ☐ ४. उच्च विधालय र माथि
७	व्यवसाय	☐ १. बेरोजगार ☐ २. गृहिणी ☐ ३. कृषि ☐ ४. व्यापार ☐ ५. अन्य (...............)
८	बच्चाहरुको संख्या	☐ १. १ ☐ २. २ ☐ ३. ३ ☐ ४. ४ भन्दा बढि
९	बच्चा सँगको सम्बन्ध	☐ १. आमा ☐ २. बुवा ☐ ३. हजुरआमा ☐ ४. अरु (................)
१०	वार्षिक परिवारको आमदानी	....
११	के तपाईलाई कुनै स्वास्थ्य समस्या छ ?	☐ १. छ , पुरानो अवस्था

		☐ २. छ , भरखरको अवस्था ☐ ३. छैन

मस्तिष्क पक्षघात (सी.पी) भएको बच्चाको डेमोग्राफिक डाटा

१२	बच्चाको उमेर	………… वर्ष
१३	बच्चाको लिंङ्ग	☐ १. केटा ☐ २. केटी

भाग २: बच्चाको अवस्था सँग सम्बन्धित कारकहरु माथि प्रश्नावली

अवलोकन / पि.आ. सी बाट प्राप्त जानकारी

१४	मस्तिष्क पक्षघात (सी पी)को प्रकार	☐ १. स्पास्टिक (spastic) ☐ २. अटाक्सिक (Ataxic) ☐ ३. एथेटोइड् (Athetoid) ☐ ४. मिश्रित (Mixed)
१५	बच्चको जि.एम.यफ.सि.यस को स्तर	☐ १. २ ☐ २. ३ ☐ ३. ४ ☐ ४. ५
१६	निरन्तर पुनर्स्थापना सेवा:	☐ १. पाएको छ । ☐ २. पाएको छैन

मस्तिष्क पक्षाघात भएको बच्चाको स्वभाव, स्वास्थ अवस्था र सहभागी माथि प्रश्नवाली

स्वभाव

१७	तपाईको बच्चाको स्वभाव कस्तो छ ?	☐ १. रिसाहा । ☐ २. भनेको कुरा नमान्ने । ☐ ३. मिलनसार । ☐ ४. आफ्नो सिमित घेरा भित्र सहयोगी ।

बच्चाको स्वास्थ को अवस्था

१८	के तपाईको बच्चालाई अरु पनि कुनै स्वास्थय सम्बन्धी समस्या छ ?	☐ १. लगातार बिरामी पर्छ । ☐ २. श्वासको समस्या । ☐ ३. चपाउन र निल्न कठिनाई । ☐ ४. छैन ।
१९	तपाईले आफ्नो बच्चालाई उपचारको लागि कति पटक अस्पताल लगनुभएको छ ?	☐ १. नियमित रुपमा। । ☐ २. धेरै पटक । ☐ ३. दुई पटक। ☐ ४. एक पटक।

बच्चाको सहभागी

२०	के तपाईको बच्चा अरु बच्चाहरु सँग खेल्छ ?	☐ १. नाई, ऊ अरु सँग खेल्न सक्दैन । ☐ २. नाई, अरु बच्चाहरु ऊ सँग खेल्न रुचाउदैन । ☐ ३. हो, तर घर भित्र मात्र । ☐ ४. हो, ऊ अरु बच्चाहरु सँग खेल्छ ।
२१	के तपाईको बच्चा स्कुल जान्छ ?	☐ १. जादैन, ऊ पढ्न सक्दैन । ☐ २. जादैन , यँहा कुनै स्पेशल स्कुल छैन । ☐ ३. जादैन, उसलाई स्कुलमा भर्ना लिदैन । ☐ ४. जान्छ , ऊ ......कक्षा पढ्छ ।

भाग ३: हेरचाहकर्ता सँग सम्बन्धित कारकहरु माथि प्रश्नावली

बच्चाको स्वास्थ्य समस्या र पुनर्स्थापना सेवा बारे ज्ञान

२२	के तपाईलाई आफ्नो बच्चाको समस्या बारे थाहा छ ?	☐ १. छैन । ☐ २. छ ,ऊ अपाङ्ग हो । ☐ ३. छ , उसको कमर र मांशपेशी मा कमजोरी छ । ☐ ४. छ ,ऊ मस्तिष्क पक्षघात (सी.पी) भएको बच्चा हो ।
२३	के तपाईलाई लाग्छ पुनर्स्थापना सेवाले तपाईको बच्चाको अवस्था सुधार गर्न मदत गर्छ ?	☐ १. होइन् , यो जन्मे देखि नै भएकोले ,केहिले पनि मदत गर्न सक्दैन । ☐ २. मलाई थाहा छैन् , पुनर्स्थापना सेवाको बारेमा ☐ ३. हो, मान्छेहरुले थेरापीले काम गर्छ भन्छन्, त्यसैले म पनि गराउछु। ☐ ४. हो, थेरापी पछि केहि सुधार देखिएको छ ।

सेवाको उपलब्धता

२४	के पुनर्स्थापना सेवा र अन्य स्वास्थय सम्बन्धी सेवा तपाईका लागि सजिलै उपलब्ध छ ?	☐ १. छैन। ☐ २. छ , तर कहिले काहि । ☐ ३. छ , तर स्वास्थ्य सेवा मात्र । ☐ ४. छ , सबै सेवा सजिलै उपलब्ध छ ।
२५	पुनर्स्थापना सेवामा पुग्न तपाईको मुख्य वाधा के हो ?	☐ १. कुनै बाधा छैन , थेरापी सेवाले मेरो बच्चाको अवस्था मा सुधार गर्छ भन्ने कुरामा म निश्चित छैन। ☐ २. आर्थिक समस्या । ☐ ३. परिवारबाट सहयोग को कमीले । ☐ ४. अन्य .... ☐ ५. कुनै वाधा छैन ।

आर्थिक सहयोग

१= पटक्कै नाई २= अलिकति, ३= ठिक्क, ४= धेरै जस्तो, ५= पूरै

		पटक्कै नाई	अलिकति	ठिक्क	धेरै जस्तो	पूरै
२६	आर्थिक रुपमा के तपाईको परिवारले तपाईको र तपाईको बच्चाको उपचार सहितको सबै आवश्यकता पुरा गर्छ ?					
२७	तपाईले आफ्नो बच्चाको उपचार र हेरचाहको लागि सरकार / संस्था बाट कुनै पनि आर्थिक सहयोग प्राप्त गर्द हुनुहुन्छ ?					

हेरचाहकर्ताको तनाव बारेमा प्रश्नहरु

१= सधै, २= धेरै जसो ३= कहिले काहि , ४= अलिकति, ५= पटक्कै नाई

		सधै	धेरै जसो	कहिले काहि	अलिकति	पटक्कै नाई
२८	के तपाई आफ्नो काम र जिमेवारीहरुले गर्दा प्राय थकित र तनाव महसुस गर्नुहुन्छ ?					
२९	के तपाईको परिवारको बिचमा हेरविचारको निर्णयलाई लिएर कुनै विवाद छ ?					
३०	के तपाईलाई आफ्नो बच्चाको हेरविचार गर्ने कुरामा आत्मविश्वासको कमी भएको महसुस हुन्छ ?					
३१	के तपाईलाई आफ्नो बच्चाको भविष्यमा चाहिने हेरचाह माथि चिन्ता छ ?					

भाग ४: हेरचाहकर्ताको जीवनको गुणस्तर बारेमा प्रश्नहरु

स्वास्थ्य डोमेन

१= अत्यधिक मात्रा २= धेरै छ ३=ठीक्कै छ, ४= अलिकति छ, ५= पटक्कै छैन

		अत्यधिक मात्रा	धेरै छ	ठीक्कै छ	अलिकति छ	पटक्कै छैन
३२	के तपाईको स्वास्थ्य समस्याले तपाईको दैनिक जीवनमा हस्तक्षेप गरेको छ ?					
३३	के तपाईलाई लाग्छ कि बच्चाको अवस्थाले तपाईको स्वास्थ्यमा असर पारेको छ ?					
३४	तपाईलाई आफ्नो दैनिक जीवनको कार्यमा कतिको औषधि उपचारको आवश्यकता छ ?					

१= पटक्कै छैन् २= अलिकति छ, ३=ठीक्कै छ, ४= धेरै छ ५= अत्यधिक मात्रा मा

		पटक्कै छैन्	अलिकति छ	ठीक्कै छ	धेरै छ	अत्यधिक मात्रा मा
३५	प्रमुख हेरचाहकर्ताको रुपमा तपाई सँग दैनिक जीवनको लागि पर्याप्त तागत छ ?					
३६	के तपाईले राती पर्याप्त निन्द्रा पाउनुहुन्छ ?					

१= साह्रै खराब, २= नराम्रो, ३= ठिक छ ४=राम्रो, ५= धेरै राम्रो

		साह्रै नराम्रो	नराम्रो	ठिक छ	राम्रो	धेरै राम्रो
३७	तपाई आफ्नो स्वास्थ्य लाई कसरी मुल्याङ्कन गर्नु हुन्छ ?					

मनोविज्ञान डोमेन

१= पूरै लाग्छ , २= धेरै जस्तो, ३= ठिक्क, ४= अलिकति ५= पटक्कै लाग्दैन

		पूरैं लाग्छ	धेरै जस्तो,	ठिक्क,	अलिकति	पटक्कै लाग्दैन
३८	के तपाईलाई आफ्नो जिम्मेवारीहरु वा हेरविचार को माग मा फसेको जस्तो लाग्छ ?					
३९	के यो बच्चाको हेरविचार तपाईको मात्र जिम्मेवारी हो जस्तो लाग्छ ?					

१= पटक्कै नाई २= अलिकति, ३= ठिक्क, ४= धेरै जस्त, ५= पूरै

		पटक्कै नाई	ऋलिर्कात	ठिक्क	धेरै जस्तो	पूरै
४०	तपाईलाई कति को लाग्छ , कि तपाइको जीवन अर्थपूर्ण छ ?					
४१	के तपाईलाई लाग्छ , तपाई आफ्नो बच्चाको हेरविचार संगै अरु सम्पूर्ण जिम्मेवारीहरु मिलाउन सक्षम हुनुहुन्छ?					
४२	आफ्नो सबै जिम्मेवारीको साथमा के तपाईले आफ्नो काम माथि ध्यान दिन सक्नु भएको छ?					

१= साह्रै असन्तुष्ट, २= असन्तुष्ट, ३= ठिक्क, ४= सन्तुष्ट ५= साह्रै सन्तुष्ट

		साह्रै असन्तुष्ट	असन्तुष्ट	ठिक	सन्तुष्ट	साह्रै सन्तुष्ट
४३	के तपाई आफ्नो जीवनको अवस्थाबाट सन्तुष्ट हुनुहुन्छ ?					

१= पटक्कै लाग्दैन २= अलिकति दिन्छ ३=ठीक्कै दिन्छ, ४= धेरै दिन्छ ५= अत्यधिक मात्रा मा दिन्छ

		पटक्कै लाग्दैन	अलिकति दिन्छ	ठीक्कै दिन्छ	धेरै दिन्छ	अत्यधिक मात्रा मा दिन्छ
४४	के बच्चाको हेरचाहले तपाईलाई धेरै सन्तुष्टि दिन्छ ?					

पारिवारिक सम्बन्ध

१= पटक्कै लाग्दैन २= अलिकति ३=ठीक्कै , ४= धेरै ५= पूरै

		पटक्कै नाई	अलिकति	ठिक्क	धेरै	पूरै
४५	के तपाईले आफ्नो आवश्यकता साथै बच्चाको हेरचाहमा आफ्नो परिवारबाट पर्याप्त सहयोग पाउनु हुन्छ ?					
४६	के तपाई आफ्नो पारिवारसँग को सम्बन्ध बाट सन्तुष्ट हुनुहुन्छ ?					
४७	तपाईले धेरै समय बच्चाको हेरविचारमा विताउँदा, के तपाई आफुलाई परिवारको महत्वपूर्ण सदस्यको रुपमा मान्नु हुन्छ ? (हेरचाहकर्ता मात्रै होइन्)?					

सामाजिक सहभागिता

१= पटक्कै छैन् २= अलिकति छ, ३=ठीक्कै छ, ४= धेरै छ ५= अत्यधिक मात्रा मा

		पटक्कै छैन्	अलिकति छ	ठीक्कै छ	धेरै छ	अत्यधिक मात्रा मा छ
४८	तपाईको सबै जिमेवारी बाहेक कतिको मात्रामा तपाईले अन्य कियाकलापको लागि गर्ने मौका पाउनु हुन्छ?					
४९	के तपाईलाई आफ्नो बच्चासँग यात्रा गर्न सजिलो लाग्छ ?					

५०	तपाईले आफ्नो नातेदारको ठाउँमा घुम्न कतिको मौका पाउनुहुन्छ ?					

१= पटक्कै नाई   २= अलिकति,   ३= ठिक्क,   ४= धेरै जस्तो,   ५= पूरै

		पटक्कै नाई	अलिकति	ठिक्क	धेरै जस्तो	पूरै
५१	तपाईले आफ्नो सामाजिक जीवनमा कुनै राम्रो परिवर्तन देख्नु भएको छ ?					

वातावरण डोमेन

१= पटक्कै नाई   २= अलिकति,   ३= ठिक्क,   ४= धेरै जस्तो,   ५= पूरै

		पटक्कै नाई	अलिकति	ठिक्क	धेरै जस्तो	पूरै
५२	तपाईले आफ्नो दैनिक जीवनमा कतिको सुरक्षित महसुस गर्नु भएको छ?					
५३	तपाईले आफ्नो दैनिक जीवनमा चाहिनै सबै जानकारी पाउनु हुन्छ ?					
५४	तपाईसँग आफ्नो आवश्यकताहरु पुरा गर्न पर्याप्त पैसा छ?					

१= अत्यधिक, २= प्राय ३= ठिक्क, ४= अलिकति,   ५= पटक्कै छैन्

		अत्यधिक	प्राय	ठीक्कै छ	अलिकति छ	पटक्कै छैन्
५५	के तपाईलाई हेरविचार सँग सम्बन्धि कुनै आर्थिक कठिनाइ छ?					

१= साह्रै नराम्रो, २= नराम्रो,   ३= ठिक छ,   ४=राम्रो,   ५= धेरै राम्रो

		साह्रै नराम्रो	नराम्रो	ठिक छ	राम्रो	धेरै राम्रो
५६	समग्रमा तपाई आफ्नो जीवन को गुणस्तरलाई कसरी मुल्याङ्कन गर्नुहुन्छ ?					

Appendix-D: Questionnaires in English

QUESTIONNAIRE

SURVEY ON

Quality of Life and its Associated Factors among Primary Caregivers of Children with Cerebral palsy living in Sarlahi and Rautahat Districts of Nepal

Namaste, I am Bina Pandit currently enrolled at Bangladesh Health Professions Institute under the Dhaka University for a course of master`s in Rehabilitation Science. I am conducting this research as a part of my course. The title of my study is “Quality of Life and its Associated Factors among Primary Caregivers of Children with Cerebral palsy living in Sarlahi and Rautahat districts of Nepal”. The result of my study will guide a treatment plan of children with CP focusing on their caregiver and also emphasize to practice on family center care that will definitely enhance quality of life of caregiver.

To assess the quality of life of primary caregivers of children with CP, I have prepared few questionnaires. It will take around 20-25 minutes to complete the entire questionnaire. I kindly request your participation in this study and answer truly according to given statement of questions.

PARTICIPANT QUESTIONNAIRE

Pre-interview

Name of Interviewer…………………….

Name of child……………………..

Location……………………….. Date …………………….

Participant Serial Number:…………………

Continue Rehabilitation service: Yes ☐ No ☐(On basis of Information obtained from PRC).

Please put tick mark (☑) in appropriate answer

Part I: Socio-Demographic Information

Primary caregiver information

1.	District	☐ 1. Sarlahi ☐ 2. Rautahat
2.	Age of caregiver:	____________Years
3.	Gender	☐ 1. Male ☐ 2. Female
4.	Type of family	☐ 1.Small family ☐ 2. Joint Family
5.	Marital status:	☐ 1.Married ☐ 2. Single ☐ 3. Widow ☐ 4. Divorced
6	Educational level:	☐ 1.Illitrate ☐ 2.Primary ☐ 3. Secondary ☐ 4. High school and Above
7	Occupation:	☐ 1.Unemployed ☐ 2.Housewife ☐ 3. Agriculture ☐ 4. Business ☐ 5. Others (…………………..)
8	Number of children:	☐ 1. 1 ☐ 2. 2 ☐ 3. 3 ☐ 4. 4 and above
9	Relationship to child:	☐ 1. Mother ☐ 2. Father ☐ 3. Grandmother ☐ 4. Others (______________)
10	Annual Family Income:	__________________
11	Do you have any Health Problem?	☐ 1. Yes, Chronic Condition ☐ 2. Yes, Acute condition ☐ 3. No

Demographic data of child with CP

12	Age of Child	______________Years
13	Gender of Child	☐ 1. Male ☐ 2. Female

Part II: Questionnaire on Factors associated with Child condition

On observation/ Information obtained from PRC.

14	Type of CP:	☐ 1. Spastic ☐ 2. Ataxic ☐ 3. Athetoid ☐ 4.Mixed
15	GMFCS level of child:	☐ 1. II ☐ 2. III ☐ 3. IV ☐ 4. V
16	Continue Rehabilitation service	☐ 1. Yes ☐ 2. No

Questionnaire on nature, health condition, and participation of child with CP.

Nature:

17	How is the nature of your child?	☐ 1. Aggressive ☐ 2. uncooperative ☐ 3. Friendly ☐ 4. Helpful within his/her possibilities.

Health condition of child

18	Does your child have any other health related Problem?	☐ 1. Frequent Illness ☐ 2. Breathing Problem ☐ 3. Chewing and Swallowing difficulty ☐ 4. No
19	How many times have you taken your child to any hospital for treatment?	☐ 1. On a regular basis ☐ 2. Many times ☐ 3. Twice ☐ 4. Once

Participation of child

20	Does your child play with other children?	☐ 1. No, he/she can not play with others. ☐ 2. No, other children doesnot like to play with him/her ☐ 3. Yes, but inside home only ☐ 4. Yes, he/ she play with other children.

21	Does your child go to school?	☐ 1. No. He /She cannot study ☐ 2. No. there is no special school ☐ 3. No. school does not take admission for him/her ☐ 4. Yes, He / She studies in ………...class

Part III: Questionnaire on Factors associated with caregivers

<u>Knowledge about the condition of child and rehabilitation</u>

22	Are you known about your child problem?	☐ 1. No ☐ 2. Yes. He/she is Disable ☐ 3. Yes. He/she having trunk and muscle weakness ☐ 4. Yes. He/she is Cerebral palsy child
23	Do you think rehabilitation service helps to improve your child condition?	☐ 1. No, it`s by birth so, nothing can help him/her ☐ 2. I don know, everyone refer him/her for therapy ☐ 3. Yes. People say therapy work, so I do ☐ 4. Yes. Some improvement is seen after therapy

<u>Availability of service:</u>

24	Is rehabilitation service and other health related service is easily available for you?	☐ 1. No ☐ 2. Yes, but very rarely ☐ 3. Yes, but only health service. ☐ 4. Yes. All service easily available for me.
25	What is a main barrier you face to reach rehabilitation service?	☐ 1. No Barrier, I am not sure that actually therapy service can improve my child condition ☐ 2. Financial issue ☐ 3. Lack of support from family. ☐ 4. Others (_______________) ☐ 5. No barrier.

Financial support:

1= Not at all, 2= A little, 3= A moderate amount, 4=Mostly, 5 = fully

		Not at all	A little	Moderately	Mostly	Fully
26	Financially, does your family fulfill all yours and your child need including treatment?					
27	Are you getting any financial support from the government/ organization for the treatment or care of your child?					

Questionnaire on caregiver stress:

1= Always, 2= Very Often, 3= quite often, 4= A little, 5 Not at all.

		Always	Very Often	Quite often	A little	Not at all
28	Do you often feel tired and stress of your work and all your responsibilities?					
29	Are you having any conflicts within your family over care decisions?					
30	Do you have feel lack of confidence in your ability to provide care to your child?					
31	Do you have concerns regarding the future care needs of your child?					

Part IV: Questionnaire on QOL of caregiver:

Health domain

1= An extreme amount, 2= Very Much, 3= A moderate amount, 4= A little, 5 =Not at all.

S.N		An extreme amount	Very Much	A moderate amount	A Little	Not at all
32	Does your health problem interfere with your work of daily living?					
33	Do you feel that your child condition has affected your health?					

34	How much do you need any medical treatment to function in your daily life?					

1= Not at all, 2= A little, 3= A moderate amount, 4= very Much, 5 an extreme amount

		Not at all	A little	A moderate amount	Very Much	An extreme amount
35	As primary caregiver do you feel you have enough energy for everyday life?					
36	Do you get enough sleep at night?					

1= Very poor, 2= poor, 3= neither poor nor Good, 4= Good, 5= Very good

		Very Poor	Poor	Neither poor nor good	Good	Very Good
37	How do you rate your health?					

<u>Psychology domain</u>

1= completely, 2 = Mostly, 3= A moderately amount, 4= A little, 5=Not at all

		Completely	Mostly	Moderately	A little	Not at all
38	Do you have feelings of being trapped by the responsibilities or demands of care?					
39	Do you think that caring this child is only your responsibility?					

1= Not at all, 2= A little, 3= A moderate amount, 4=Mostly , 5 = Completely

		Not at all	A little	A moderate amount	Mostly	Completely
40	To what extent do you feel your life is meaningful?					
41	Do you feel that you are able to manage all your other responsibilities along with care giving?					
42	Along with your all responsibility are you able to concentrate on your work?					

1= Very Dissatisfied, 2= Dissatisfied, Neither dissatisfied nor satisfied 4= satisfied, 5=Very satisfied

		Very Dissatisfied	Dissatisfied	Neither Dissatisfied nor satisfies	satisfies	Very satisfies
43	Are you satisfied with your living condition?					

1= Not at all, 2= A little, 3= A moderate amount, 4= very Much, 5= An extreme amount

		Not at all	A little	A moderate amount	Very Much	An extreme amount
44	Do you think caring for your child give you a lot of satisfaction?					

Family relationship:

1= Not at all, 2= A little, 3= A moderate amount, 4=Mostly , 5 = Completely

		Not at all	A little	A moderate amount	Mostly	Completely
45	Do you get enough support from your family when you need including your child care?					
46	Are you satisfied with your relationships with your family?					
47	As you spend your more time in providing care to child. Do you think yourself as important member of your family (Not only caregiver)?					

Social participation

1= Not at all, 2= A little, 3= A moderate amount, 4= very Much, 5= An extreme amount

		Not at all	A little	A moderate amount	Very Much	An extreme amount
48	Beside all your responsibilities to what extent do you have the opportunity for leisure activities?					
49	Do you feel comfortable to travel with your child?					
50	To what extent you get an opportunity to visit your relatives place?					

1= Not at all, 2= A little, 3= A moderately, 4=Mostly , 5 = Completely

		Not at all	A little	Moderately	Mostly	Completely
51	Have you noticed any pleasant change in your social life?					

<u>Environment factor</u>

1= Not at all, 2= A little, 3= A moderate amount, 4=Mostly, 5 = Completely

		Not at all	A little	Moderately	Mostly	Completely
52	How safe do you feel in your daily life?					
53	Do you get all the information in your daily life that you need?					
54	Do you have enough money to meet your needs?					

1 = An extreme amount, 2=Mostly, 3= A moderately, 4= A little, 5= Not at all,

		An extreme	Mostly	Moderately	A little	Not at all
55	Are you having any financial difficulty associated with care giving?					

1= Very Poor, 2= Poor, 3= Neither Poor Nor Good, 4= Good, 5= Very Good

		Very Poor	Poor	Neither Poor Nor Good	Good	Very Good
56	How do you rate your overall QOL?					

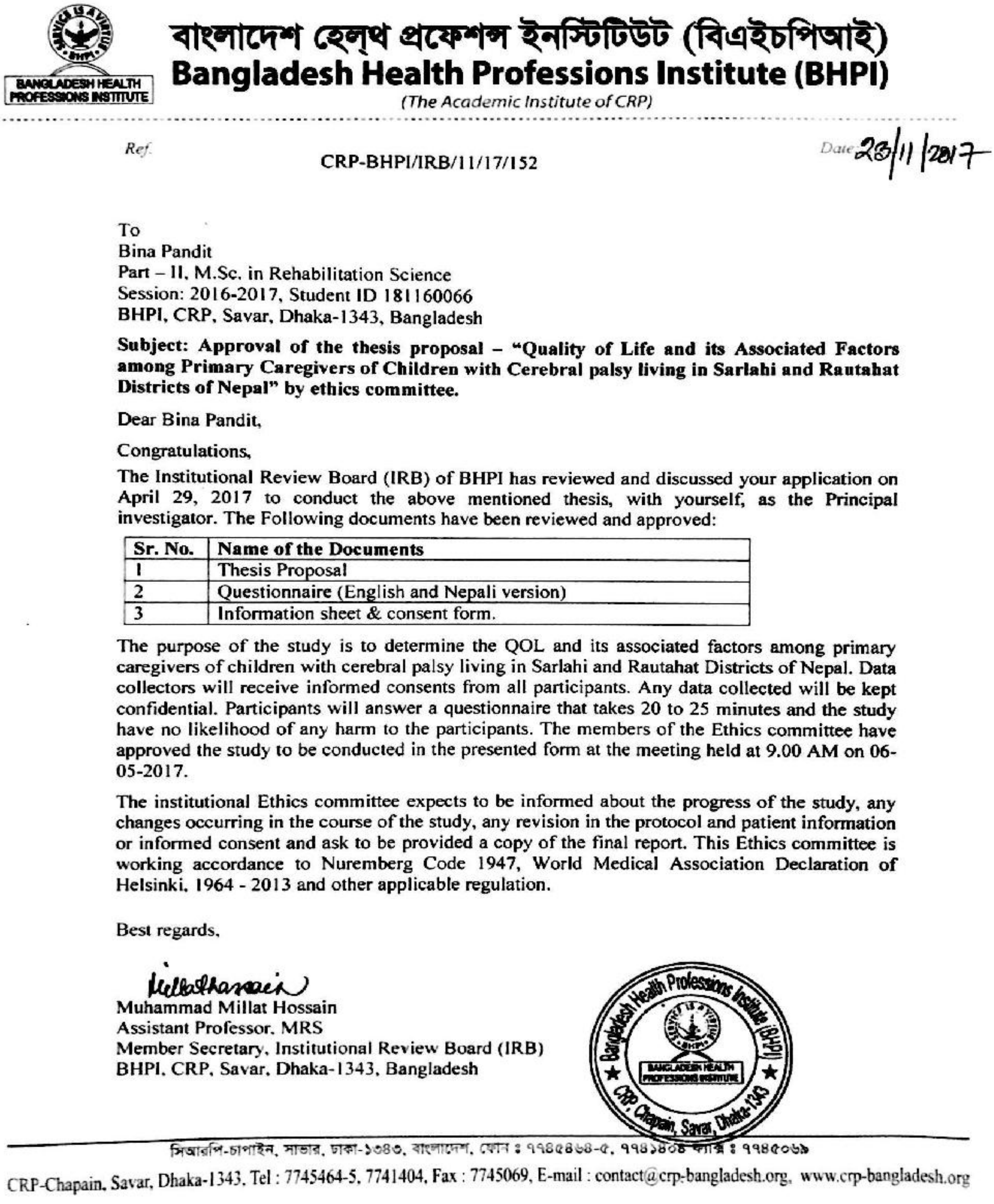
Appendix-E: Assessment of GMFCS level.

Gross Motor Classification System Expanded and Revised (GMFCS – E&R).

Assessment of GMFCS of children with CP from age 4-12 years.

LEVEL I	Child able to walk at home, school, outdoors and in the community. Child can climb stairs without the use of a railing. Child can perform activities such as running and jumping, but speed, balance and coordination are limited.
LEVEL II	Child walk in most settings and climb stairs holding onto a railing. Child may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces.
LEVEL III	Child walk using a hand-held mobility device in most indoor settings. Child may climb stairs holding onto a railing with supervision or assistance. Child use wheeled mobility when traveling long distances and may self-propel for shorter distances.
LEVEL IV	Child use methods of mobility that require physical assistance in most settings. Child may walk for short distances at home with physical assistance or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair.
LEVEL V	Child is transported in a manual wheelchair in all settings. Child has limited in their ability to maintain head and trunk postures and control leg and arm movements.

Appendix-F: Approval of the thesis Proposal



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

Ref. CRP-BHPI/IRB/11/17/152

Date 23/11/2017

To
Bina Pandit
Part – II, M.Sc. in Rehabilitation Science
Session: 2016-2017, Student ID 181160066
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal – "Quality of Life and its Associated Factors among Primary Caregivers of Children with Cerebral palsy living in Sarlahi and Rautahat Districts of Nepal" by ethics committee.

Dear Bina Pandit,

Congratulations,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on April 29, 2017 to conduct the above mentioned thesis, with yourself, as the Principal investigator. The Following documents have been reviewed and approved:

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

The purpose of the study is to determine the QOL and its associated factors among primary caregivers of children with cerebral palsy living in Sarlahi and Rautahat Districts of Nepal. Data collectors will receive informed consents from all participants. Any data collected will be kept confidential. Participants will answer a questionnaire that takes 20 to 25 minutes and the study 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 06-05-2017.

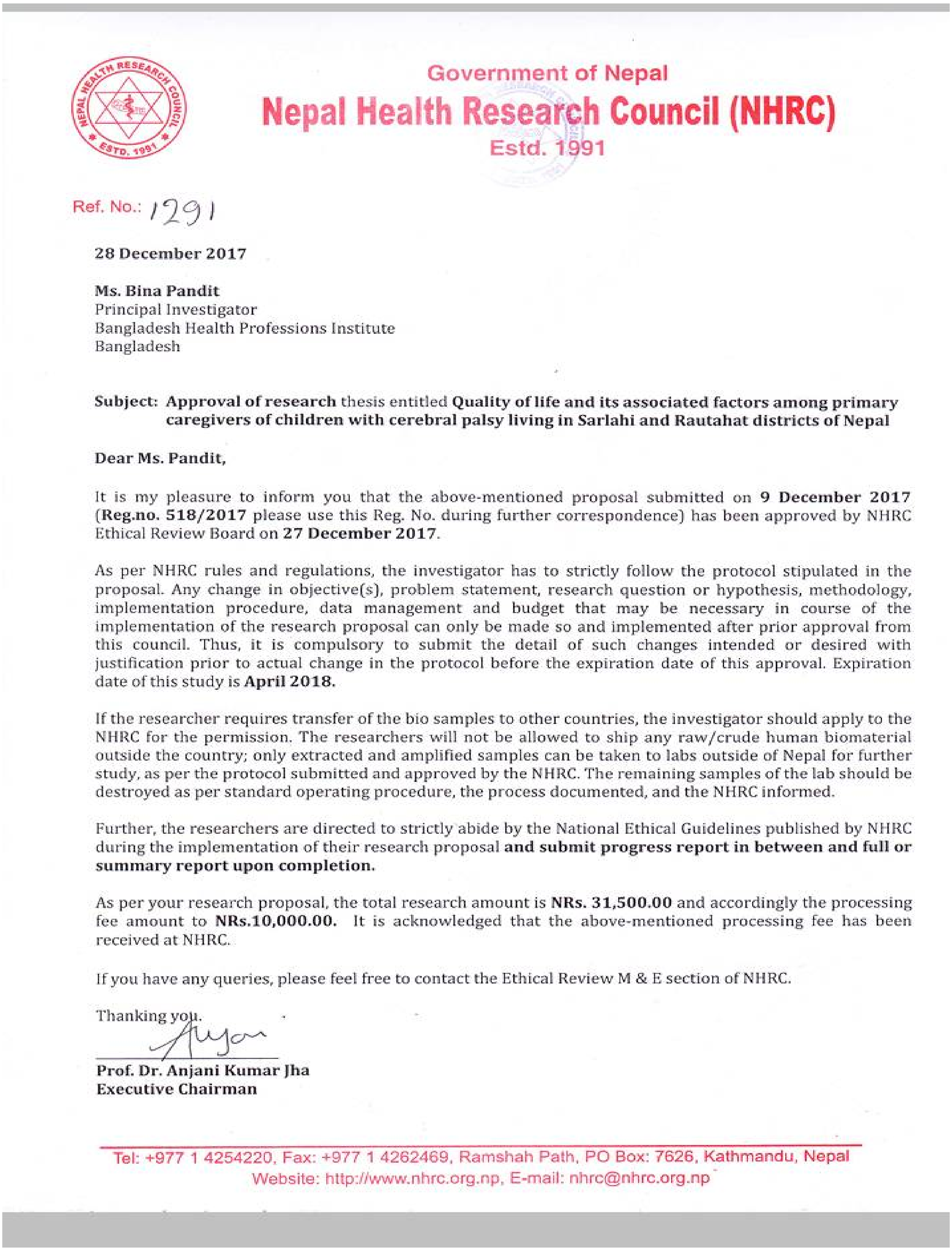
The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance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

Best regards,

Muhammad Millat Hossain
Assistant Professor, MRS
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-G: Approval letter from Nepal Health Research Council



Government of Nepal
Nepal Health Research Council (NHRC)
Estd. 1991

Ref. No.: 1291

28 December 2017

Ms. Bina Pandit
Principal Investigator
Bangladesh Health Professions Institute
Bangladesh

Subject: Approval of research thesis entitled **Quality of life and its associated factors among primary caregivers of children with cerebral palsy living in Sarlahi and Rautahat districts of Nepal**

Dear Ms. Pandit,

It is my pleasure to inform you that the above-mentioned proposal submitted on **9 December 2017** (**Reg.no. 518/2017** please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on **27 December 2017**.

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol before the expiration date of this approval. Expiration date of this study is **April 2018.**

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission. The researchers will not be allowed to ship any raw/crude human biomaterial outside the country; only extracted and amplified samples can be taken to labs outside of Nepal for further study, as per the protocol submitted and approved by the NHRC. The remaining samples of the lab should be destroyed as per standard operating procedure, the process documented, and the NHRC informed.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal **and submit progress report in between and full or summary report upon completion.**

As per your research proposal, the total research amount is **NRs. 31,500.00** and accordingly the processing fee amount to **NRs.10,000.00.** It is acknowledged that the above-mentioned processing fee has been received at NHRC.

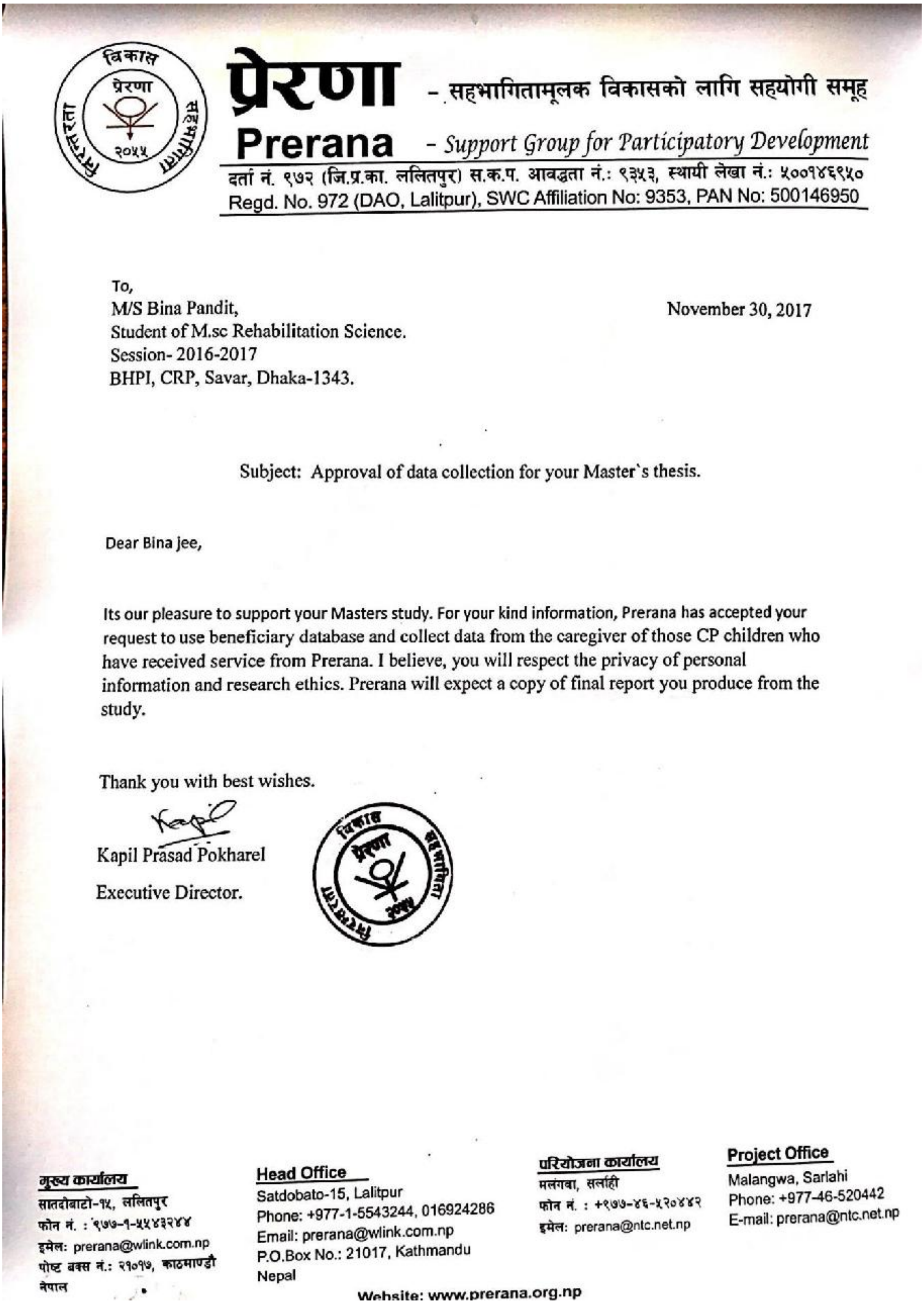
If you have any queries, please feel free to contact the Ethical Review M & E section of NHRC.

Thanking you.

Prof. Dr. Anjani Kumar Jha
Executive Chairman

Tel: +977 1 4254220, Fax: +977 1 4262469, Ramshah Path, PO Box: 7626, Kathmandu, Nepal
Website: http://www.nhrc.org.np, E-mail: nhrc@nhrc.org.np

Appendix-H: Permission letter for data collection from organization



प्रेरणा - सहभागितामूलक विकासको लागि सहयोगी समूह
Prerana - *Support Group for Participatory Development*
दर्ता नं. ९७२ (जि.प्र.का. ललितपुर) स.क.प. आवद्धता नं.: ९३५३, स्थायी लेखा नं.: ५००१४६९५०
Regd. No. 972 (DAO, Lalitpur), SWC Affiliation No: 9353, PAN No: 500146950

To,
M/S Bina Pandit,
Student of M.sc Rehabilitation Science.
Session- 2016-2017
BHPI, CRP, Savar, Dhaka-1343.

November 30, 2017

Subject: Approval of data collection for your Master`s thesis.

Dear Bina jee,

Its our pleasure to support your Masters study. For your kind information, Prerana has accepted your request to use beneficiary database and collect data from the caregiver of those CP children who have received service from Prerana. I believe, you will respect the privacy of personal information and research ethics. Prerana will expect a copy of final report you produce from the study.

Thank you with best wishes.

Kapil Prasad Pokharel

Executive Director.

मुख्य कार्यालय
सातदोबाटो-१५, ललितपुर
फोन नं. : ९७७-१-५५४३२४४
इमेल: prerana@wlink.com.np
पोष्ट बक्स नं.: २१०१७, काठमाण्डौ
नेपाल

Head Office
Satdobato-15, Lalitpur
Phone: +977-1-5543244, 016924286
Email: prerana@wlink.com.np
P.O.Box No.: 21017, Kathmandu
Nepal

परियोजना कार्यालय
मलंगवा, सर्लाही
फोन नं. : +९७७-४६-५२०४४२
इमेल: prerana@ntc.net.np

Project Office
Malangwa, Sarlahi
Phone: +977-46-520442
E-mail: prerana@ntc.net.np

Website: www.prerana.org.np