Master's thesis

NTNU
Norwegian University of Science and Technology
Faculty of Medicine and Health Sciences
Department of Public Health and Nursing

M Kamrul Ahsan

# A Qualitative Study in Bangladesh about The Everyday Life Experiences of Family Caregivers of Adult Individuals with a Physical Disability.

Master's thesis in Global Health
Supervisor: Gørill Haugan
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# Declaration

I, M Kamrul Ahsan, hereby declare that, I am the writer of this thesis based on my work where the literature used by other researchers is appropriately cited and that the work has not been submitted for any other degree or professional qualification.

Date: 30.11.2023

M Kamrul Ahsan

…………………………….

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Attested by

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……………………………..

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Professor, NTNU, Norway

# Acknowledgment

First of all, I want to express my gratitude to The Creator. Then I want to show my sincere gratitude and thankfulness to my supervisor, Professor Gørill Haugan, for providing valuable insights and showing me the pathway during this research project. I want to express my sincere gratitude to Associate Professor Jennifer J. Infanti and Advisor Ragnhild Lier for their valuable guidance and cooperation during my entire master's program.

I am thankful to Md. Shaikhul Hasan, Zahid Hasan, Zinat, The Ethical Review Committee of CRP (Centre for Rehabilitation of Paralyzed), Savar, Dhaka, and the entire team of CRP for their valuable support while conducting this study. I am forever grateful to the respected participants of this study, dedicated fighters who never lose hope. Then, I would like to show my appreciation to my beautiful wife Dr. Afsana Harun, my loving child Hamshad Muhammad Ahsan Kai, my parents, and my father and mother-in-laws for their unconditional love, sacrifices, and support during my entire academic pursuit. Finally, I want to dedicate my entire work to my mother and my younger brother, and to every mother in this world who is holding a lamp amid darkness, illuminating the path for her child where hurdles of life become less miserable, the motivation and true inspiration behind this study.

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# Abbreviations and Acronyms

ADL = Activities of Daily Living

BMRC = Bangladesh Medical Research Council

CRP = Centre for Rehabilitation of Paralyzed

ERC = Ethical Review Committee

HCPs = Health Care Professionals

IADL = Instrumental Activities of Daily Living

NGOs = Non-government Organizations

REK = Regional Committees for Medical and Health Research

RQ = Research Question

SDG = Sustainable Development Goals

Sikt = Norwegian Agency for Shared Services in Education and Research

UN = United Nation

# Summary

**Background:** Family caregivers in Bangladesh play an important role in providing care to physically disabled patients who can't do work or walk without any form of assistance. Although family caregivers' assistive part in making a disabled person's life easier and less miserable is known the obstacles they face in providing care and the coping techniques they implement are still understudied in Bangladesh. So, the purpose of this study is to explore the day-to-day life experience of family caregivers in Bangladesh taking care of physically disabled adult persons.

**Aim:** This study aims to identify common burdens of family caregivers, barriers to providing care, measures they are taking, social responses toward them, and how they are coping with them.

**Method:** A qualitative research method was adopted by conducting interviews of 11 participants (adult family caregivers including 7 females and 4 males) following a semi-structured interview guide at the Centre for Rehabilitation of Paralyzed, Savar, Dhaka, Bangladesh from January 28 to February 03, 2023. The interviews were transcribed verbatim into Bengali first and then translated to English before analysis. A thematic Analytical approach was taken to analyze and interpret the data. The data were read repeatedly to make sense as a whole, then meaning units were extracted and codes were produced by systematic categorization. These codes were then sorted according to similarities and differences to group them under sub-themes. Coherent subthemes were then divided into unique themes to produce the result.

**Results*:*** Five themes emerged: (1) *Unfolding a Family Caregiver's Journey,* (2) *Hurdles to Overcome: Sacrifices and Burdens,* (3) *Effective Caregiving: Obstacles, Measures, and Techniques,* (4) *Social Responses and Coping Strategies, and* (5) *Supports* and *Expectations: Making The Journey Easier*. Family caregivers develop their roles after certain sacrifices and considerations that involve physical and emotional burdens. The positive aspects of caregiving were personal satisfaction and development, being rewarded afterlife, and connection buildup with the care-receiver. Inaccessible roads and transports, a lack of necessary ramps, lifts, and assistive devices, and financial crises made it harder for them to ensure treatment and rehabilitation for their patient. Key management techniques were patience, training, support from family and friends, institutes, and believing in God. However, positive attitudes towards caregivers were rarely seen as society mostly showed negative attitudes; these were handled by silence, ignoring, self-understanding, and sometimes raising their voices and giving constructive messages to society.

**Conclusion:** Family caregivers' roles in Bangladesh are broader and more complex than they appear. Collaborative measures, policies, and continued further studies are requirements to ensure their well-being.

**Keywords:** Family Caregiver, Physically Disable, Disability, CRP, Centre for Rehabilitation of Paralyzed, Savar, Burden, Qualitative Analysis, Bangladesh, Caregiver Experience, Coping Techniques, Society Response, COVID-19, Pandemic, Pregnancy in Disability, Rehabilitation, SDG, UN, Policy, Caregiver Peer Support.

# 1. Introduction

## 1.1 Background

In many Asian countries, regardless of the availability of resources, family members give care while staying in the patient's room at hospitals and residences (1). People have always supported family members and they feel close emotionally, physically, and financially (2). Traditionally, emotional support and practical help are common in families (aging parents, grandparents, and other family members) when they are unable to care for themselves (3). Family caregivers are typically those who offer unpaid, continuous support with daily living tasks or essential daily living activities to those with chronic diseases, impairment, or disability (4, 5). The caregiving domains are multifaceted, varied, and extensive because carers frequently assist patients in their care not only with physical needs (such as basic and instrumental activities of daily living), but also with psychological, financial, and social needs (such as making medical bill payments, scheduling or accompanying appointments), and medical needs (such as nursing, medication administration, and titration) (6). Members of the family are essential in providing long-term care for patients and loved ones, but evidence shows that caring for patients with disabilities places a heavy load on family caregivers (7). The majority of the care load is now placed on family members due to several factors, including population aging, longer lifespans for older persons with serious chronic illnesses and disabilities, and a poorly financed and dispersed social and health support system (2). Because of these responsibilities, carers frequently experience extreme stress and run the danger of developing carer overload and deteriorating physical and mental health (8). The number of people who take on this role, the length and intensity of care given, and the complexity of the care delivered have changed over the past decades (2). A longitudinal study of the caregiver health effects found that many caregivers have both positive and negative experiences while caregiving (9). At present, disability affects approximately 1 billion people or around 16% of the world's population, and the figure is growing due to population aging and the prevalence of noncommunicable illnesses (10). In the context of Bangladesh, according to "Persons with Disabilities Rights and Protection Act 2013" of Bangladesh (11), 2.80% of people are disabled overall; this includes 3.28 percent of men and 2.32 percent of women, 2.89 percent of people living in rural regions and 2.45 percent of people living in urban areas (11). It is 2.24 percent for adults 18–49 years old, and 9.83 percent for the population 65 years and older (11). About 1.35 percent of the population is physically disabled including 1.66 percent of men and 1.03 percent are female (12). These figures are from 2013 and the worldwide disability burden is increasing day by day. Hence, the current situation might be different; most likely the situation in Bangladesh aligns with the rest of the world, because, a burgeoning economy, illiteracy, income redistribution, and an increase in the frequency of chronic illnesses all contribute to the burden of current impairment or disability (13). A recent study published in 2023 suggests that around 3% of Bangladesh's overall population is disabled and physical disability is the most common type of disability (14). Also, disability management and medical rehabilitation are not health priorities in Bangladesh, as they are in other developing nations, with the present emphasis on acute and basic primary healthcare services (13).

Different definitions of physical disability based on medical and social paradigms exist (15). Any physical or mental condition (impairment) that makes it harder for the person with the condition to do particular activities (activity limitation) or interact with the world around them (participation restrictions) is referred to as a disability (16). Whereas an abnormality of physical components or function is the definition of disability or impairment according to the medical or deficit model i.e., arthritis, limb loss, lung, or heart problems, however, the true effect of such problems on function determines physical impairment (17). Before a condition may be deemed a handicap, it must be severe enough to restrict physical activities (17) According to the Persons with Disabilities Rights and Protection Act 2013 (Bangladesh) a person with a physical impairment lacks one or both hands or legs or is partially or completely paralyzed in hand or leg function and/or cannot balance herself without assistance (12). On the other hand, the social definition of physical disability considers an impairment to be a social construct (18, 19). The definition of disability is determined by society and varies depending on the culture (17). According to the social model of disability, a person with a variety of features is rendered disabled by the way society responds to them (17).

In this study, the term" family caregivers" refers to those who provide unpaid support to someone who has physical, psychological, or cognitive limitations and they might be relatives, friends, spouses, or neighbors (2). A large and diversified group of people are caregivers, however, they are diverse in terms of their ages, closeness to the person for whom they offer care, nature, length, and intensity of help, as well as their connection and location with that person (2). A substantial body of existing research has used the definition of caregiver burden proposed by Zarit and colleagues in 1986, with all of them defining caregiver burden as carers' perceived deterioration of their emotional or physical health, social life, and financial status while caring for their family and relatives (20). The experiences of family caregivers in Bangladesh taking care of physically disabled persons are less explored but urgent to mobilize scholarly investigation and practical interventions.

## 1.2 Research Problem

Individuals with a chronic disease or disability may require continual support with activities of daily living (ADL), such as toileting, eating, bathing, walking, and dressing, as well as activities of daily living (IADL) such as shopping, food preparation, housecleaning, and financial management, etc. (21). In Bangladesh, it is trending that the length of stay for patients is as short as possible to reduce costs, thus resulting in an increased burden on the family of the disabled person (22). A burden is a subjective experience felt by caregivers, who sometimes develop psychiatric illnesses (22). In this context, service providers, health care professionals, social workers, etc. need access to knowledge and insight to understand the perspectives of individual experiences involving pressures and demands associated with caring for a person with a physical disability and coping strategies (22). Effective, acceptable, and suitable interventions are required as well as enhanced education of professionals working with family caregivers (22). To my knowledge, no study has fully explored the countrywide disability burden and its related correlates in Bangladesh (14). Many researchers have focused on the negative aspects of caring, highlighting characteristics such as burden, stress, clinical depression, cognitive impairment, physical health issues, and burnout that are widely reported among formal and informal carers (23-27). However, little effort is paid to investigating the beneficial aspects or sides of caregiving (28-31).

There is a dearth of research on developing countries like Bangladesh, but a huge amount of data from wealthy nations connects economic well-being with health (32). To the author’s knowledge, research exploring the experiences of family caregivers of Bangladesh providing care for physically disabled people, their most common burdens while caregiving, motivations, positive and negative aspects, obstacles in providing care, awareness about treatment, rehabilitation, and medical help-seeking tendencies among them, how society is impacting overall caregiving is scarce. Therefore, this master thesis will explore the experiences of the family caregivers of adult physically disabled persons in Bangladesh and provide suggestive advice for caregivers, relevant healthcare providers, and policymakers.

### 1.3 The Objective of The Study

The purpose of this study was to identify and understand the everyday experiences of family caregivers of physically disabled adults living in Bangladesh.

The following Research Questions (RQ 1-3) were addressed:

> RQ 1. What is the most challenging part of having a disabled person in a family and the common burdens of a caregiver's day-to-day life in Bangladesh?
>
> RQ 2. What are the barriers the caregivers are facing while getting medical help and rehabilitation for disabled persons and how the family caregivers are managing it?
>
> RQ 3. What are the family caregivers' perceptions about how society is treating them, and how the caregivers are coping with it?

This study aimed to develop knowledge about

- Challenges and common burdens the caregivers face regularly while giving care to the disabled person. Inspiration or aspects that might work behind developing coping techniques and strategies have been carried out by the caregivers.
- Identify the knowledge, awareness, affordability, access to rehabilitation therapy, and the medical help-seeking tendency among the caregivers for a physically disabled person.
- Understand what are the things that influence caregivers' everyday lives positively or negatively while giving care to disabled ones. How as a caregiver including his or her family with a disabled person deal with these influences?
- Provide experience-based suggestions to caregivers, relevant healthcare providers, and policymakers according to the findings.

## 2. Methodology

### 2.1 Preunderstanding

The master's student himself was raised in a family where he has seen his mother providing care for his younger brother who was physically disabled from the age of five. Since the master's student's younger age, he has observed and realized the true sacrifices, burdens, sleepless nights, and his mother's tireless efforts to make his sibling's life less miserable. Common burdens while taking care like bathing, feeding, toileting, hygiene maintenance, seeking medical treatment, and rehabilitation were not the only problems that his mother had fought but also heard blaming voices and negative words since day one, however, she didn’t stop caring for her son. The author realized that his mother is one of the hundreds and thousands of people who are continuously going through this same journey and are typically called “family caregivers”.

The author has finished his master’s in Pharmacy and has a professional background of working with renowned pharmaceutical companies like GlaxoSmithKline, Novartis, and Pfizer.  He closely worked with HCPs (Health Care Professionals), NGOs, hospitals, and institutes to generate awareness in the field of cancer, vaccination, and osteoporosis. While working he has observed patient sufferings and family burdens very closely and physical disability was one of them which was also a scenario inside his family.  Keeping that, in mind the master’s student got his inspiration to work with the family caregivers of physically disabled persons in Bangladesh, to know in depth about their experiences, burdens, motivations, and coping techniques, so that these can be documented, analyzed, and utilized for the betterment of not expected yet coming “family caregivers”.

## 2.2 Study Design and Setting

The experience of family caregivers while providing care for physically disabled adult patients was explored through individual in-depth interviewing by a semi-structured interview guide. The study was carried out using a qualitative approach of thematic analysis which is a technique for detecting, evaluating, and reporting data patterns or themes (33). The participants were family caregivers who were staying with their patients at a rehabilitation center called CRP (Centre for Rehabilitation of Paralyzed), Savar, Dhaka, Bangladesh. CRP started its journey in 1979, founded by a British-Bangladeshi physiotherapist Valerie Ann Taylor to satisfy the severe needs of disabled people and now expanded to 13 centres all over the country. The CRP provides treatment, therapy, and rehabilitation for disabled patients and it has residential facilities for temporary stay in the Savar District (Head Office) where family caregivers stay with their patients from one week to three months.

## 2.3 Inclusion Criteria

Adult family caregivers who have been taking care of a physically disabled person (adult) for more than a year were included in this study. Here, physically disabled means persons who can’t walk or work without any form of assistance. Family caregivers who were included here were parents, spouses, sons, and daughters of their respective physically disabled adult patients. Family members 18 years or older and residing at the CRP during the interview period were included in this study.

### 2.4 Participant Recruitment

Careful recruitment of participants is crucial for conducting a meaningful study. To make this study ethically sound the master's student did not recruit participants directly by himself. A participant recruiter, assigned by the master's student with the help of CRP, went to the caregivers' rooms to provide oral information about the study and ask if they were interested in giving an interview for the study. The participant recruiter was instructed about the study's purpose, duration, and participant recruitment criteria to help the master students recruit the appropriate participants for the study. The information page was shared with the participant recruiter beforehand so that she could go through the participant recruitment criteria and filter suitable participants from a list of probable participants. After contacting, interested participants were then given the information page of the study and allowed plenty of time to read through the paper. The information page and consent form consisted of six pages where the first two pages explained the research questions, aim and objective of the study, and the following pages explained their voluntary participation, privacy, and rights. The last page was the consent form where participant gave their consent by signing.  It was written in Bengali and English to ensure the participants' understanding. The phone number of the master's student, his supervisor, and the data protection officer was included in the information sheet so that the participants could contact any of them if required during or after the study. Then the participants were informed that the master's student would call to introduce himself and ask for final approval from them to make an appointment for the interview. It has previously been advised that a minimum sample size of 12 be used in qualitative analysis to achieve data saturation (Clarke & Braun, 2013; Fugard & Potts, 2014; Guest, Bunce, & Johnson, 2006) (34-37); accordingly, 15 participants consisting of 11 female and 4 male participants were shortlisted for interview. But later two of the female participants decided not to give the interview and another two interview was excluded from the study later for being too short and superficial data. So, finally, 11 participants including 7 females and 4 males were included in the study.

## Table 1. An overview of the participants

| No. | Name | Age | Gender | Length of Caregiving ( year) | Relation to the Care-receiver | Current Status of Profession | Length of Interview HH: MM |
|---|---|---|---|---|---|---|---|
| 1. | Participant 01 | 60 | Female | 14 | Mother | Left job | 00:42 |
| 2. | Participant 02 | 35 | Female | 1.5 | Wife | Not working due to caregiving | 01:15 |
| 3. | Participant 03 | 24 | Male | 2 | Son | Working | 00:33 |
| 4. | Participant 04 | 38 | Male | 5 | Husband | Working | 00:48 |
| 5. | Participant 05 | 47 | Male | 11 | Husband | Working | 00:19 |
| 6. | Participant 06 | 32 | Female | 10 | Wife | Couldn’t finish studies | 00:21 |
| 7. | Participant 07 | 45 | Female | 22 | Wife | Started working after being a caregiver | 00.35 |
| 8. | Participant 08 | 26 | Female | 1 | Daughter | Higher Study interrupted | 00:25 |
| 9. | Participant 09 | 39 | Male | 8 | Husband | Working | 00:37 |
| 10. | Participant 10 | 63 | Female | 2 | Wife | Started working after being a caregiver | 00:21 |
| 11. | Participant 11 | 43 | Female | 8 | Mother | Not working | 00:58 |

### 2.5 Data Collection

The qualitative interviews took place between January 28, 2023, to February 03, 2023. As it was prohibited to enter the patients’ rooms at the CRP, the interviews took place in the territory of CRP (indoor and outdoor places). Participants were asked about their experience of caregiving a physically disabled adult person. A semi-structured interview guide was used and interviews were audio recorded. Examples of follow-up questions were “*Can you elaborate*” or “*What did you mean by that?*”. These were used to explore in depth. To prevent interruptions during the interview a dedicated meeting room was allocated from CRP where 4 of the interviews took place, whereas 1 was conducted in the canteen, 2 in the corridor, and 4 outdoors in the CRP area. The places were different because of the participants’ availability, comfort, and flexibility. The interview duration was between 19 minutes to 1.15 hours depending on the openness and expressibility of the participants. During the entire interview period, the master’s student stayed at the CRP for one week paying for a single guest room. Staying inside the institution helped to offer the participants greater flexibility of timing as some of them were free in the morning, whereas, some others preferred the afternoon or evening. This also helped the author to better understand the participants' life world. In addition, it helped the interpretation of the data and the quality of the data collected.

### 2.6 Data Analysis

All of the participants were native Bengali speakers so the interviews were taken in Bengali language. The interviews were audio-recorded and then transcribed verbatim. Transcriptions were then translated into English but it was ensured that the meaning remained the same and held its originality. Thematic Analytical approach which was closely related to Braun and Clarkes'(2006) work (33) was adopted because the patterns emerging from data were more capturing and adaptive to thematic analysis. Some phases of theme analysis are comparable to phases of other qualitative research, therefore these stages are not completely exclusive to thematic analysis (33). The steps of analysis according to Braun and Clarke (2006) (33) were as follows-

**Step 01- Familiarizing with Data:** The data were examined several times and read actively- looking for patterns, meanings, and other things (33). Before starting coding, the complete data set was read at least once which helped to change thoughts, and the ability to see potential changes in the data (33).

**Step 02- Initial Code Generation:** After reading the data and becoming acquainted with it, a preliminary list of the items in the data and interesting points about them were made (33). That means, meaning units or data extracts were produced. Next, initial codes were generated using the data. Codes define a component of the data (semantic content or latent) that is noteworthy and can be related to the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon (38).

**Step 03- Searching for Themes:** Sorting the various codes into prospective themes and compiling all the pertinent coded data extracts within the themes that have been found were constituted in this step, which refocuses the study at the wider level of themes rather than codes (33). In short, codes were examined to find out how many codes may come together to create a larger theme. Tables were used as a visual representation to help sort different codes into themes. Some of the original codes developed into major themes and others into sub-themes that helped in illustrating the order of meaning within the data and in providing structure to particularly broad and complicated themes (33). Finally, at the end of this stage, a list of potential themes, subthemes, and all coded data extracts related to them were sorted and the relative importance of the individual themes was sensed.

## Table 2: Example of Data Analysis Procedure (From Data Extract to Theme)

| **Data Extract/ Meaning Unit** | **Codes** | **Sub-theme** | **Theme** |
|---|---|---|---|
| *"I became more sick, I became a prisoner of that house and for him."*<br>*"Thinking about money and everything, we have also seen that we cannot take the treatment ourselves, we cannot take care of ourselves."* | Captivity due to caregiving<br>Financial crisis | Sacrificing Caregiver's Interest and Financial Burden | Hurdles to Overcome: Sacrifices and Burdens |

**Step 04- Reviewing Themes:** In this stage, refinement of themes was done by assorting themes that were divergent or lacked supporting data, and overlapping (33). Patton's (1990) dual criteria for judging categories- internal homogeneity and external heterogeneity were taken into account (39). Meaning, that the data contained in each theme made sense when combined, and the themes themselves were easily distinguished from one another. In addition, if any extra information inside themes was overlooked in previous coding phases, recoding was done as it is a continuous, natural process and expected (33).

**Step 05- Defining and Naming Themes:** Naming and defining each theme were done in this step by figuring out the "essence" of each theme (individual and collective) and the specific piece of data that each theme highlighted (33). Finally, the themes' scope and content were refined and articulated in a way that they were well explained and concentrated (33).

**Step 06- Results Writing:** Finally, results were written by providing a succinct, rational, logical, non-repetitive, and engaging explanation of the tale the data convey, both within and between themes (33). The prevalence of the theme was supported by providing enough data extracts and vivid examples (33). Lastly, the analytical narrative was produced and arguments were made concerning the research questions.

### 2.7 Ethical Dimension, Data Protection, and Participant's Rights

The researcher was duly concerned about the ethical standpoint of the study. The Ethical Review Committee of the Centre for Rehabilitation of Paralyzed (ERC-CRP), Savar, Dhaka, Bangladesh permitted the study at their institute after the researcher addressed the concerns raised by the committee members. Bangladesh Medical Research Council (BMRC) like Regional Committees for Medical and Health Research (REK) in Norway provides approval for studies which is directly related to patients and process health-related data. This study is neither directly linked to any patients nor processes any medical or health-related data approval from only the Norwegian Agency for Shared Services in Education and Research (Sikt) was taken to conduct the study. To ensure compliance with the requirements of the General Data Protection Regulation and Personal Data Act, Sikt evaluated the research protocol. Adult participants aged 18 years and above, competent to give consent were provided with information pages and a consent form so that they could participate in the study by their own choice. Participants' understanding of the purpose and nature of the study, types of questions asked, reasons for asking them to participate, the risks and benefits of engaging in the study, their rights as a participant, their written consent to ensure that, they were informed and well aware of their rights and their participation is voluntary were ensured to make this study ethically sound. All of the participants' data were kept secure and confidential. Their names and contact information were replaced by a unique code that the researcher could only decode. The list of individual identities, contact information, and corresponding codes was separated from the remaining data and secured thoroughly by encryption and physical locking in a safe place. The consent forms were also placed in a separate file folder and locked physically in a secure place. No unauthorized person is allowed to use or get access to any of these confidential data. This study does not include any data that can personally identify a participant. Any sensitive information, name, or critical health information was removed from the data that was used in this study. Finally, the participants were well aware of their rights to update any data they provided and to partly or completely remove their data from the study.

## 3. Results

Five themes including fifteen subthemes emerged after a thematic analysis of the data. *"Unfolding a Family Caregiver's Journey", "Hurdles to Overcome: Sacrifices and Burdens", "Effective Caregiving: Obstacles, Measures and Techniques", "Social Responses and Coping Strategies"*, and *"Supports and Expectations: Making The Journey Easier"* were the five core theme. The first theme elaborates on the development of the caregiver role, how the journey starts, and the motivations and mindset behind caregiving. The second theme emerged as the sacrifices they offer and the common physical, mental, and financial burdens they suffer. The third theme describes obstacles the caregivers face while providing care, and the measures, and techniques they developed for effective caregiving, and the fourth theme describes how the neighboring society is treating them and how they process the attitudes of the society by coping techniques. Finally, the fifth one illustrates their expectation of getting help and support for caregiving. The results and discussions were written by answering the Research Questions by using parenthesis. (RQ1), (RQ2), and (RQ3). While providing quotation (…) term means there were some data in between which were irrelevant.

## Table 3: Overview of themes and subthemes with their relevant codes and meaning units.

| **Theme** | **Sub-theme** | **Codes** | **Data Extract/Meaning Unit** |
|---|---|---|---|
| Unfolding a Family Caregiver's Journey | Caregiver Role Development | Change in attitude | More courageous, still feel that I am not the same as I was before, and very soft-hearted. |
| | | Mutual Understanding | This is where we as caregivers have to be very conscious of not doing anything that will upset that disabled person. |
| | Mindset and Motivation Behind Caregiving | Change in Mindset | When Challenges come must be accepted. |
| | | Family bonding as a motivation | I can't think of my child as a burden. I feel burdened but I have to do it. |
| | | Motivation from result | Maybe it's too slow, but it's happening. |
| Hurdles to Overcome: Sacrifices and Burdens | Sacrificing Caregiver's Interest and Financial Burden | Captivity due to caregiving | I became more sick, I became a prisoner of that house and for him. |
| | | Financial Burden | Since the cost is high this month, I will buy in the month when the cost is low. |

| | | | |
|---|---|---|---|
| | Physical and Emotional Burden | Stress on the body and physical health | Such as my back pain, shoulder pain. It has been seen that my age is several times older than usual. |
| | | Mental breakdown during caregiving | It hurts me to see his friends, my son cannot lead a healthy life like them. |
| Effective Caregiving: Obstacles, Measures and Techniques | Obstacles to Providing Care and Welfare | Obstacles to getting medical aid and rehabilitation | In one place the doctor sits up there but there is no lift or no ramp. I had to hire one or two guys to lift my husband on their lap to climb the stairs. |
| | | | Patients like my son can't survive in villages, medicines are not available, and catheters are not available. |
| | Awareness About Medical Aid, Rehabilitation, and Training | Awareness about treatment facilities | They should see and know what work is done in any institution of the country, and how any health treatment is given. |
| | Physical and Mental Wellness | Equal importance to physical and mental health | It won't happen if you just work. Everything is needed, I think, when it comes to working in an organization. |
| | Patience | Patience as a tool for caregivers | The first thing for those who handle these patients is patience. |
| Social Responses and Coping Strategies | Mixed Response from the Social Environment | Negative social response toward caregiver and disability | There (at home), if you see a patient in a wheelchair all alone, people also stare. |
| | | The positive social response toward caregivers | Now those who say to us when, I, I walk with my husband, now they say hurrah!! |
| | | Fear about the social response | We live in such a society that whatever we do, we think about what society will say. How will society see it? |
| | Message to Society | Message to society | So if this can be done personally or socially, ten people will see and learn. |
| | Coping Strategies | Fight against society | If I heard, I would have said. I would answer each |
| | | Fight against negativity | People around me say a lot about me but I don't care what they say. |

| | | | |
|---|---|---|---|
| Supports and Expectations: Making The Journey Easier | Supports | Expectation to get family support | At that moment, if my family or at least my family or those around me, if they at least showed me a little sympathy, then I would feel very good. |
| | | Expectation to get physical help and support | Words cannot express how much support is needed. |
| | Caregiver Peer Support | Supporting another family caregiver | If the caregiver talks to another caregiver, the mind will be lightened or there will be some refreshment. Some experiences will be shared, experiences will be exchanged. |
| | Organizational Support | Support from therapists & rehabilitation centers | Making him understand what the problem is and bringing him back to normal, seems best to me. |
| | | Support from employer | The office needs to have some rules that, at least if it is special, there needs to be a separate rule in that case. |
| | Future expectation | Expectations for upcoming days | Maybe something better will come for me someday. |

## Theme 01: Unfolding a Family Caregiver's Journey

Every family caregiver from the very first day kept evolving their role as it wasn't created overnight. The establishment of the role, the mutual relationship between the family caregiver and disabled person, the motivation behind caregiving, and the preparation of mindset were the major components of a family caregiver's journey.

### *Caregiver Role Development*

Starting a journey as a family caregiver was a mixture of different attitudes and understanding. For some it was unexpected and devastating, meaning they were not prepared for this road of life.

*"I did not realize that he(her husband) would have such a critical condition and I didn't realize that it meant so much to me to go through such a journey." (Participant 02)*

*"Then I went blank. Nothing was working in my head. So, it seemed that maybe if I tried it(the condition of the patient) would be alright. At first, we had no idea what the effect(of disability) would be." (Participant 08)*

Interestingly, some of the participants started their caregiver journey by marrying a disabled male or female partner. Reasons for taking this pathway varied from childhood friendship, affection or love between caregiver and disabled person, liberal or progressive thinking, social responsibilities, etc.

"*We (Caregiver and Disabled Partner) have been friends since childhood. So, we were always together but we never thought of doing that (Marriage to a disabled person)." (Participant 04)*

*"I used to think a little leftist. I mean, I used to think a bit progressive. We used to dream of a beautiful society; we used to dream of a society without class discrimination… if we can at least play a small role in society means we can marry a disabled girl." (Participant 09)*

From a normal life to full-time family caregiving made some of the participants stronger and more confident about decision-making:

*"More courageous, still feel that now I am not the same as I was before, and very soft-hearted… I mean I wasn't very strong myself. Now I can make many decisions on my own. Maybe I couldn't think like that before." (Participant 08)*

Communication, understanding, and feelings were significant to building up companionship between the caregiver and the care receiver. Some of the caregivers showed care and a compromising attitude toward disabled patients, whereas some others expressed regrets about job sacrifices, imprisonment in their own house, and physical and mental stress of not getting enough time for their own due to excessive engagement in caregiving (RQ 1):

*"Sometimes I get angry with him that I quit my job for you, I have to drop everything for you, I can't go anywhere, I can't do anything." (Participant 01)*

But at the end of the day, mutual understanding was seen as developed over time, which fuels the further caregiving journey. To bring out a married partner from a disabled situation (RQ 1), participants stood by their (disabled person) side which is a reflection of deeper feelings and love for their disabled partner:

*"I always thought that situation If I didn't hold his hand, hold his up, he wouldn't be able to come out of this life." (Participant 02)*

Married caregivers also have needs and desires like sexual desire and the lifestyle of a healthy couple(RQ 1), though they didn't leave their disabled partner just because their (caregiver) needs or desires were not met.

*"In this case, I didn't leave her just because my needs were not met, or it's not like I don't have a relationship with her anymore." (Participant 04)*

According to caregivers, disabled persons became upset for becoming a burden to the caregiver and showed care, sympathy, and understanding for the overall situation of the caregiver. Mutual sympathy and understanding between them were shown. According to the caregivers, over time the disabled person tried to cope and be more independent and thus call or engage the caregivers less than before so that the caregiver can feel more relaxed and less stressed:

*"He (disabled person) is also upset, he is upset. Sometimes regrets that "You cost a lot for me. You sacrifice a lot." ... He used to be sicker, but now I understand, now he doesn't disturb me so much." (Participant 01)*

Caregiving to a physically disabled person also includes taking care of the disabled person's mental health (RQ 1). If the psychological state of the disabled person is not understood, proper caregiving can't be assured (RQ 1):

*"This is where we as caregivers have to be very conscious of not doing anything that will upset the disabled person… I have to understand the person I am caring for; I have to understand her mentality, I have to understand her perspective. So according to this, she has to get nursing." (Participant 09)*

A small harsh word, a simple act of negligence, not responding or late response to a disabled person when they are calling for help might upset a disabled person (RQ 1). This may result in a misunderstanding between the caregiver and the disabled person which will make it harder for both of them to maintain a healthy relationship (RQ 1).

### *Mindset and Motivation Behind Caregiving*

Whether the family caregivers were prepared for their journey to care for a physically disabled person or not, strong mindsets were seen as a fighting tool. Some were carrying out this mindset from the very beginning and some participants developed this over time. Some caregivers were stubborn in their decision to marry a disabled person. They held that mindset and fought against family and friends (RQ 1):

*"They know what I want, what I insist on, I do. So, they understood that since it was catching, I would not leave without doing this." (Participant 09)*

*"This supporting mindset must exist… To do this continuously, to do this patiently, to do this tolerably, is a great thing." (Participant 09)*

*"I will put my life partner through whatever comes in my life, I want to see the smile on his face again." (Participant 02)*

Also according to the caregivers, caregiving isn't an easy task so there should be a strong, patient, and tolerant mindset which is necessary to aim for the well-being of the disabled person. On the other hand, believing in self was dominant for some of the family caregivers, whereas, some showed positivity despite not getting the expected things in their lives.

*"This is the biggest fact I think, being you, without the people you are, it is not right to think that your world will not run without them." (Participant 08)*

*"Maybe I got less, and you got more. I am happy with this."* (Participant 07)

Participants emphasized believing in self meaning that to be self-dependent. Being dependent on others will only make someone weaker and less confident. Also, it is important not to complain about lacking in life but to be thankful for whatever someone already has because not everyone gets everything in their life, someone gets less, and someone gets more.

Motivation lies between family bonding or strong feelings for the disabled persons' recovery, and believing in miracles while some accept caregiving as a responsibility resulting from love. Though holding this motivation and continuing caregiving was found challenging (RQ 1) participants didn't feel their disabled offspring was a burden or load instead they showed their low probable anticipation and believed in the miracle that their son or daughter could walk or do things like normal people one day. A similar was seen with participants who were taking care of their husbands. The expectation to see the care receiver walking and working like normal people seemed as a resource of motivation:

"*I can't think of my child as a burden. I feel burdened but I have to do it… This is what I want if I could see him healthy before I die if he could walk." (Participant 01)*

*"I want to cure him as such. I am here to support him, to bring him back to his former life… Miracles happen in people's lives, indeed." (Participant 02)*

Sometimes participants cared for their disabled person from their responsibility. It was like giving back care to the parents who had taken care of the participants when they (caregivers) were children. Some participants compared this caregiving responsibility to their husband as they were giving care to their mother if she (mother) was alive and old and needed care:

*"I feel it is my responsibility. I don't want my mother to be dependent on anyone. This is actually where my motivation lies." (Participant 08)*

*'I lost my mother when I was young, and I take care of my husband like I cared for my mother." (Participant 12)*

## Theme 02: Hurdles to Overcome: Sacrifices and Burdens

This study aimed to identify family caregivers' day-to-day life experiences including their burdens and the sacrifices they are making. Prioritizing caregiving over a job, mental breakdown due to long-term caregiving, enormous physical burden, and financial crisis in the family were a few of the burdens they regularly face despite their condition (RQ 1).

### Sacrificing Caregiver's Interest and Financial Burden

Irrespective of family caregivers' role in Bangladesh being non-paid, it brings along a lot of sacrifices offered by the family caregivers (RQ 1). Like the financial crisis, sacrificing caregivers' self-interest, and job sacrifices to allocate more time to the disabled person were few of them (RQ 1). Being the only available resource to take care of the disabled person often made a few of the participants captive in their own houses (RQ 1):

*"I quit my job, he got sick, got bad. I was damaged on both sides… He also suffered from getting sick, and I also suffered by leaving the job. I became sicker, I became a prisoner of that house and for him." (Participant 01)*

*"And I couldn't even think of leaving the house with this patient, let alone my professional life… And now we don't even dare to say our likes and dislikes. This is our life; we have to accept it." (Participant 02)*

The caregivers don't get the chance to choose between options and preferences (RQ 1). Sacrificing daily needs, even treatment which was necessary for the physical health and wellness of a family caregiver (RQ 1), some of the participants expressed their struggles in handling expenses (RQ 1):

*"Thinking about money and everything, we have also seen that we cannot take the treatment ourselves, we cannot take care of ourselves." (Participant 02)*

*"Since the cost is high in this month, I will buy in the month when the cost is low. This is how I balance it." (Participant 07)*

As the disabled partner can't earn most of the time and the caregiver either solely earns for the family or does not earn at all, it is difficult for them to cover the daily expenses of family life (RQ 1). They even adjust it month to month meaning shifting a necessary purchase or expense to the next month to curtail cost (RQ 1).

### *Physical and Emotional Burden*

The most common and almost every participant mentioned the enormous physical load (RQ 1). They were taking care of physically disabled adults who usually have more body weight compared to a child or an elderly, it was quite challenging for the family caregiver to deal with regular chores like giving a bath, taking to the toilet, maintaining proper hygiene, etc. of their corresponding disabled person (RQ 1). They mentioned pain in the hands, and shoulders, backs and even explained that they felt like their ages had increased more than usual (RQ 1).

*"Such as my back pain, shoulder pain. It has been seen that my age is several times older than usual… I feel that because of this situation, I feel that my age has increased more." (Participant 02)*

*"I have a problem when I lift him in the chair when I put him in the bathroom, I have a problem with my hand… It costs, I can't, but I have to. No, there is no way." (Participant 01)*

The caregivers had no choice but to continue the care they were providing as there was no other way and this is making the pain worse (RQ 1). Working participants shared that being sleepless for a few hours is okay but being sleepless night after night will put tremendous tiring pressure on the professional work in the daytime (RQ 1).

*"A person can do it for four to five hours. Then I wouldn't be able to be normal at work, it will be a little hectic brother." (Participant 04)*

Disability-related family burden, mental breakdown from frustration and words from surrounding people, not getting expected improvement or recovery of the disabled person's physical condition from caregiving. Were common causes of an emotional burden for participants (RQ 1).

*"If one person in the family is sick, then the whole family becomes sick. Money lost, physically ill, humanly we are all sick, for one." (Participant 01)*

*"It hurts me to see his friends, my son can't lead a healthy life like them." (Participant 11)*

Having a disabled person in a family means the whole family is sick. The family will suffer in terms of money, physically tired, and mentally depressed (RQ 1). Sometimes seeing others having a healthy life makes the caregiver feel depressed (RQ 1). The sudden onset of a disability to a member of the family can cause devasted married life and uncertainty about the future, what will happen to the disabled person in the absence of the caregiver is also a concern for caregivers (RQ 1).

*"I saw in front of my eyes that my arranged life was shattered, messed up. I see before my eyes that the ground beneath my feet has shifted." (Participant 02)*

*"If I die, then sometimes I am concerned about what will happen to him" (Participant 07)*

Mental burdens were so concerning for one participant that suicidal tendencies were prominent:

*"Thoughts, consciousness, feelings are all empty. There were times when I thought I was suicidal." (Participant 02)*

## Theme 03: Effective Caregiving: Obstacles, Measures, and Techniques

Family caregivers in Bangladesh face different obstacles, however, considerations and defense mechanisms were adopted by the participants in this study. Lack of roads and transportation to carry their patients to potential places, lack of training, and obstacles to getting medical aid and rehabilitation for the person they are taking care of were the major barricades (RQ 2). Some of them were aware of the medical treatment facilities and physiotherapy before becoming family caregivers and suggested others keep an open eye, whereas some even got scammed by fraud (RQ 2). Awareness, balancing working life and personal life, taking necessary leaves from work, and training were proven effective for the caregivers according to their experiences (RQ 2).

### *Obstacles to Providing Care and Welfare*

Family caregivers take care of the disabled persons' daily needs like feeding, bathing, medicine intake, etc. Moreover, they look after medical aid necessities like doctor visits, rehabilitation arrangements, physiotherapies, and taking the disabled person to certain places for social interaction and welfare (RQ 2). Doing this, they faced notable difficulties due to a lack of accessible roads and transport, physical barriers like steps and curbs in a hospital or building, lack of lifts and ramps, lack of training, and so on (RQ 2):

*“In one place the doctor sits up there but there is no lift or no ramp. Then I had to hire one or two guys to lift my husband on their lap to climb the stairs.” (Participant 07)*

Sometimes, the family caregivers experienced difficulties going out for a walk with a wheelchair or to attend an invitation (RQ 2). No matter how much the family caregivers try to arrange something to refresh their minds, new challenges await with every step (RQ 2).

*“Because I am invited. Both of us would go there together but I could not take my wife due to lack of accessibility(lift, ramp) there.” (Participant 04)*

To maintain social responsibilities sometimes the family caregivers had no choice but to attend the program without the disabled person or skip attending it as they couldn’t leave the disabled person alone at home (RQ 1).

Caregivers faced difficulties getting maternity-related hospital care for disabled pregnant women due to COVID-19 and pandemic-related government restrictions that blocked getting support and necessary services (RQ 2). Roads were closed and transportation was not available (RQ 2). As a result, it was difficult to bring someone from the family or relative living remotely, to take care disabled pregnant wife (RQ 2). Hospitals were not taking patients during the pandemic hit (RQ 2).

“*At that time many private hospitals were also closing and they would not accept patients. There was a fear that if we had this disease, we would spread it… I could not get the support because of the government restrictions.” (Participant 04)*

### Awareness About Medical Aid, Rehabilitation, and Training

Awareness about medical aid and rehabilitation was found necessary to provide proper care to disabled people. The necessity of rehabilitation was well understood though some faced fraud while seeking it (RQ 2). Few of the caregivers even expressed their interest in getting devices like motorized wheelchairs (RQ 2), which can reduce their physical burden:

*“There was one beside me, she was coming here(rehabilitation center) with her mother. She also said, “You go to CRP.”... Plus I’ve been talking to a few people about wheelchairs that can be self-propelled.” (Participant 01)*

*“If he could use a device(motorized wheelchair) to move himself, that would be a little more support for me. I would have been a bit freer and had a little more time.” (Participant 07)*

*"Two times for the treatment of the patient, the money has been lost in the clutches of the hypocritical dervish(fraud)." (Participant 10)*

Frauds and charlatans often take the chance to cheat on caregivers lacking in education, knowledge, and awareness about medical treatment (RQ 2). They falsely claim that they can cure the patient and cheat to take money from unaware caregivers.

It was seen that training from institutes or motivated self-training from the Internet was quite helpful for most of the participants. It fine-tuned caregiving skills which helped reduce loads of family caregivers (RQ 2).

*"After he(physician) taught me, it seemed that they were a little easier for me. Before, I didn't think that I needed this kind of training. When I face it, I understand(necessity of training)." (Participant 02)*

Even caregivers mentioned how training and occupational therapies for the physically disabled person can help reduce extra work for the caregiver (RQ 2) as the disabled persons were able to do very basic chores by themselves.

*"After coming here to CRP, the occupational therapist she has here taught her everything she needs to go about her life on her own. So, I don't need to help her with basic things" (Participant 04)*

***Physical and Mental Wellness***

Balancing work life and caregiving was not easy for the participants (RQ 1) and emphasized taking leaves from work and giving personal time for mental and physical wellness as well as effective caregiving (RQ 2) to their disabled person.

"*I think that people with physical challenges or people who have them at home or who work with them, need to take some time off from the office." (Participant 04)*

*"When my husband needs to be taken care of, I schedule that time accordingly. I do it at that time." (Participant 07)*

Time management and scheduling work accordingly were found important to provide effective caregiving (RQ 2). It is important to take care of the disabled person's health and diet, but it is equally important for the family caregivers to take care of themselves mentioned by one participant.

*“We should be very conscious about our diet and also very conscious about our life.” (Participant 08)*

***Patience***

Patience was a key tool; almost all of the participants suggested having patience while giving care to a physically disabled person (RQ 2). They defined that it is like a routine and quite difficult to keep patience and energy, but it will be fruitful for a caregiver as well as a care receiver in the long run, and the results usually come very slowly (RQ 2). Without having patience caregiving can be provided for several months to one year but it will be harder to continue longer.

*“It’s(caregiving) not a one-day job, it becomes routine. You have to have the mindset, your energy, your patience to do it(caregiving) year after year.” (Participant 09)*

Chances of recovery or showing results are largely dependent on the patience of the caregiver, explained one caregiver (RQ 2). Meaning if the caregiver and patient leave the rehabilitation center impatiently and discontinue getting therapy then the patients might be stuck rest of their lives in a wheelchair or become bedridden (RQ 2).

*“I think those who come, those who leave (rehabilitation center) impatiently, those patients are not confined to that chair, but confined to that bed.” (Participant 02)*

## Theme 04: Social Responses and Coping Strategies

Family caregivers illustrated their thoughts about living in an environment where they were showered with different social responses and interactions (RQ 3). Meaningless blaming from surroundings, lack of positive attitudes towards a caregiver, embarrassing questions from curious neighborhoods, fear about what other people are thinking, and obligatory social interaction were common scenarios (RQ 3). It was amazing to see that some of the participants got positive approaches and supporting words from friends and family members, while some others tried to deliver constructive messages to society (RQ 3). Coping techniques were believing in god, self-understanding, not being reactive to social comments, and ignoring but sometimes responding by rejoinder (RQ 3).

### *Mixed Responses from the Social Environment*

*"We live in such a society that whatever we do, we think what the society will say. How will society see it?" (Participant 09)*

The above statement from Participant 09 describes well, that the presence of fear about responses and blaming from society makes it difficult for participants to take their patients outside of the house (RQ 3). People insensitively stare if they see a disabled person in a wheelchair as if they are seeing a curious thing like a cartoon which is quite embarrassing and inferior to the caregiver as well as the disabled person (RQ 3).

"*There (at home), if you see a patient in a wheelchair all alone, people also stare… for what it means it(disabled person) becomes like a cartoon, there, in that environment!"(Crying) (Participant 01)*

Seeing a disabled person in a wheelchair and a caregiver who is suffering, people assume that, the caregiver might sinned and therefore observing punishment (RQ 3).

"*At that time, I was a big criminal. It seems that I am a great sinner, I have committed many sins. If not, why am I facing this kind of situation?" (Crying) (Participant 02)*

Four of the participants who married a disabled person faced questions about whether getting financially benefited from marrying a disabled person. People believe that it is uncommon to marry a disabled person and if the caregiver is doing it, means he or she might benefit from this to get economic solvency (RQ 3)

*"Our society thinks about marriage if I get married here, there are benefits. Still, see that the wife's father has a lot? Are there resources(that can be taken)? This means seeking economic security." (Participant 09)*

Some even went to a larger extent and suggested the participants not marry a disabled person, instead, providing some financial help to that disabled person.

*"Then you support her by giving her money, why get married?... I may be marrying for the greed of my father-in-law's wealth. Many people are even wondering how many stacks of cash I have taken, even asking on my face." (Participant 05)*

Social responses from family members and friends were sometimes positive (RQ 3). Despite not being well accepted by family members like in-laws (RQ 3), these attitudes toward participants were sometimes submissive just because there was no one else in the family who could take care of that specific disabled person.

*“Because it turns out they(in-laws) need me a lot… Even though they are upset about some things, it is seen that at the end of the day, they are compromising with me for a yes.” (Participant 02)*

Even the participant might not have thought about marrying a disabled person in the first place, but friends came forward, showed a positive attitude (RQ 3), and insisted on marrying a disabled person which can be a responsibility taking on a small part of society.

*“I first ever thought about this when one of my friends suggested to me if we can take responsibility in this place.” (Participant 09)*

### ***Message to Society***

One of the participants expressed his experience in a unique way which was a message to society according to the participant. He married a disabled person to give a message to society that it can be done as a part of social responsibilities. So, society will see and learn from his act that, it is quite normal to marry a disabled person and it can serve the purpose of taking a single step of social responsibility and make a change in society (RQ 3).

*“If this(marriage to a disabled person) can be done personally or socially, ten people will see and learn.” (Participant 09)*

It is quite uncommon and embarrassing for a caregiver to take a disabled person to market and shopping centers (RQ 3) but if it can be done quite often society and people living in it will get used to it and will stop commenting and criticizing (RQ 3). The participant explained that society will not act weird in the future (RQ 3).

*“But if I go(to market and outside) again and again if they get used to it, they might say that there is no point in criticizing here.” (Participant 09)*

### ***Coping Strategies***

One of the few coping techniques that family caregivers showed during their interview was believing in God (RQ 3) and almost every participant showed submission to God for their respective patients’ recovery. Two of them also highlighted that the arrangement of marriage to a disabled person was not decided by them but instead a gift from the Creator. Expectations of getting benefits in the afterlife in return for caregiving were seen among participants, irrespective of the negative social response they got for marrying a disabled person (RQ 3).

*"The Creator makes miracles happen, meaning that what people say is not true… When people are in danger, all the doors are closed, but the doors of God, the creator, are open."(Participant 02)*

*"Allah arranged this marriage to me with His own hands and the marriage took place." (Participant 04)*

*"Since we are Muslims, I might benefit a bit in the hereafter(benefit at the afterlife)." (Participant 05)*

Participants responded in two different ways when fighting against negativity and society. Some prefer to be bold and responsive against any negative comments they get while others prefer to be silent and relinquish it, sometimes ignoring it (RQ 3).

"*If I heard, I would have said. I would answer each." (Participant 07)*

*"I have done many things and fought many words, and many faces. I have faced those situations in silence." (Participant 02)*

*"Even though I wanted to protest I didn't. Now there is nothing for him in the mind and nothing to say to him." (Participant 05)*

*"People around me say a lot about me but I don't care what they say." (Participant 09)*

Some stress-relieving activities (RQ 3) were practiced by a few of the participants where they talked to friends, spent time with families of children, and even went for a walk with their respective disabled person to feel better.

"*During those times, I found that if things got too bad, I would talk to a good friend." (Participant 02)*

*"When I feel bad, I talk to my mother, son, or relatives and try to make myself feel better." (Participant 10)*

## Theme 05: Supports and Expectations: Making The Journey Easier

Inconsistent journeys like the life of a family caregiver can become easier if they get the expected help and support from their surroundings. Participants elaborated on their anticipation from family members, friends, neighborhood, institutes like hospitals and rehabilitation centers, therapists, and even employer organizations.

***Supports***

While interviewing participants it was identified that they got positive support from family members like sisters, and friends though they sometimes get it negatively. Members of a family providing some quality time to a family caregiver and a disabled person were defined as a form of support by one of the participants. She added if family members come to visit a disabled person they shouldn't be busy with their phone or just give a formal visit.

"*If they(family members) had given that time, it would have been quality time for Mom. That means not being busy with their phone. It should not be that they came just because they had to come." (Participant 08)*

The expectation of the participants to get support includes physical support for burden reduction, emotional support, general help, and support like financial support for operation or mobilization. If someone comes forward and takes care of the disabled person for a few hours to 2-3 days the caregiver can get some free time to do necessary work or visit a place in case of emergency:

"*But then I feel like I get some relief, if I can take a little rest I can live. Whoever cooperates, I feel like I can breathe now. Yes, if someone comes forward and helps him, keep it(care-receiver) with him and I go somewhere for a while or I can go somewhere for a day or two, that seems like a great help to me." (Participant 01)*

*"Any cooperation (general help), concerning operations or, concerning finances or concerning wheelchairs (for the disabled person), in any way(financial help)." (Participant 01)*

One of the participants detailed how helpless she was in the initial state of caregiving as she was expecting physical support to lift his patient from the bed and another participant expected to get physical support from a female during his disabled wife's delivery period (RQ 2).

"*There has been such a time that the bed is filling up(with urine), I have to call someone to pick up my sheets (bed sheets). Brother, please come, help me a little(to change the bed sheet), a little, a little."(Participant 02)*

*"Every pregnant woman who is in a wheelchair user needs a lot of support. At least someone should be with her, a female." (Participant 04)*

Participant 02 illustrated that the family usually takes care of the financial side to pay medical bills and other expenses but they lack emotional support for the caregiver (RQ 1).

*"Family provides financial support, but emotional support is lacking." (Participant 02)*

***Caregiver Peer Support***

An interesting finding while interviewing participants is that a family caregiver finds it soothing or at least thinks that talking and experiencing sharing with other family caregivers is a great source of stress relief and refreshment (RQ 1, 2). They find it more homely and close to their heart when they see others going through a similar journey, more or less, seeing others doing the same thing, the same pathway makes them believe that- if others can do it, we can. Not only that, it increased their confidence and some of them even tried to guide and help others (RQ 2).

"*I now inspire many people to go to CRP(rehabilitation center)… Talking to many(patients), seeing and mixing (with other caregivers and patients), many patients here(rehabilitation center)." (Participant 01)*

*"This(caregiver journey) is the hard part. Going through this journey. So I like to see them(other caregivers), that as they are going, as I am going, many are going through it(same caregiving journey)." (Participant 08)*

"*I try to help caregivers of new patients by showing them ways from my experiences. If necessary, they come to my house and talk(experience sharing)." (Participant 11)*

From interviewing participants it was clear that female participants were more into experience-sharing than male ones. For example, one of the male participants knew it was necessary or beneficial but was one of them who didn't prefer to share emotions with others.

"*I have no idea about this(caregiver experience sharing). Because I've never shared so much with another caregiver… If the caregiver talks to another caregiver, the mind will be lightened or there will be some refreshment. Some experiences will be shared, experiences will be exchanged." (Participant 09)*

***Organizational Support***

Organizational support played a greater role for the participants in distinct ways. Some of the working participants mentioned expected support and policies from the employer organizations. They argued that employers should arrange special facilities like leaves for working caregivers who have a disabled person at home (RQ 1);

"*The office needs to have some rules that, at least if it is special(for working caregiver), there needs to be a separate rule(special arrangement of leave) in that case(caregiving)." (Participant 04)*

*“If the organization comes forward in such cases(arrange special facilities for working caregiver), then it will be good for the organization, it will be good for the employee,… if he continues the job next, he will give the maximum effort. It will also benefit the organization.” (Participant 09)*

This way both employer and employee will benefit mutually as the employee will be thankful to the organization and will work for the employer from heart. A female participant mentioned how her working organization was supportive of her as a family caregiver by providing her with the necessary support and cooperation.

*“This collaboration(from the office) does(exist), but my institute does this thing. I don’t know if it will do in other institutions.” (Participant 07)*

The environment of a rehabilitation center, therapists, counselors, and training were found supportive to the participants. When they leave behind their monotonous homestays behind and come to visit or stay at a rehabilitation center for a few days they forget their past for a moment and enjoy being at the rehabilitation center (RQ 3).

“*Humanly, and physically, I also improved myself when I came to CRP(rehabilitation center). I get much better when I come to CRP. They(therapists) have a lot of support. And they(therapist) speak humanly, they(therapist) behave very well.” (Participant 01)*

Another participant illustrated how a disabled counselor can be more efficient in making her (family caregiver) patient get back to normal life:

*“The counseling being done there(hospital) is also a physically challenged therapist, his two hands are not good. Making him(her husband)) understand what the problem is and bringing him back to normal, seems best to me.” (Participant 07)*

The third participant thinks that training from these types of rehabilitation centers can be useful (RQ 2) for family caregivers which focuses on familiarizing themselves with the disease, its limitations, and how the family caregivers can cope with their monotonous psychological situation (RQ 1) for extended caregiving

*“If something can be done like institutional education(caregiver training), it is better to know about the disease(of the disabled person), its limitations(disease), what he(caregiver) can do, and what he(caregiver) cannot do everything… at some point, he(caregiver) might get bored(due to caregiving). What else(coping technique) to cut it?”(Participant 09)*

***Future Expectation***

The future expectations of the participants were mostly related to the disabled person they were taking care of. Few of them expected their disabled persons' good health and recovery from God. Others expected good days to come and wanted to get back to their normal life, study, and career (RQ 1) which will make the caregiver more courageous in the future.

*"I hope Allah heals him(disabled person) and makes him well. Let him do it(something good) for me, and the country, let him do it for everyone." (Participant 01)*

*"I hope for a good day that such a good day will come in my life." (Participant 02)*

*"Maybe something better will come for me someday. When mom recovers a bit, I might be able to focus on my career. Then I will become more courageous." (Participant 08)*

This hope and expectation for better days were seen keeping them fueled further their caregiving journey.

## 4. Discussion

In this qualitative study, 11 participants were interviewed to explore their experiences while providing care to their respective physically disabled adult persons. The relationship of the caregivers with the physically disabled people varied from parents, spouses, sons, and daughters. The duration of the caregiving was from one year to 15 years. Analyzing the data, five main themes emerged. The first theme describes how these caregivers' journey develops, their mindsets, the sacrifices they offer, and the motivations behind caregiving. The starting journey of a caregiver was two-directional, meaning some jumped into this role suddenly due to acute incidents like accidents or diseases (RQ 1) while some of them have taken this journey as a choice by marrying a physically challenged person. It was quite clear from interviewing the participants that, those who chose this caregiving journey as a choice by marrying a disabled partner held better psychological satisfaction and well-being than those who started their journey involuntarily, which aligns with a study in Canada, in 2020 Lun Li and Yeonjung Lee found that family carers for spouses and children had considerably lower psychological well-being, although having the option of being a carer is connected with higher psychological well-being (40). This means those who took this caregiving role by choice are psychologically more stable than those who didn't. Irrespective of the degree of care delivered, relationship type, primary health condition of the care recipient, and demographic variables, another study suggests the same thing that a lack of choice for becoming a caregiver is connected with greater levels of emotional stress, physical strain, and poor health outcomes (41). Participants of this study who were married showed love and appreciation for their disabled partner meaning they were taking care of the partner despite facing challenges in everyday life. In this study interrupted sexual relationships were seen between married caregivers with their disabled spouses due to physical disability(RQ 1) but it was surprising to see that none of them left or even thought of leaving their partners. Instead, they keep forward looking after the disabled partner. This shows a greater extent of sacrifices and emotional bonding to a married partner. A similar finding was seen in a study by V. L. Solomi and R. E. Casiday where they found that the marriage relationship was extremely important, and many carers went to great lengths to maintain and strengthen their marital relationships (42). Caregivers keep themselves responsible and motivated to continue their caregiver role for purposes like deeper relationship buildup between caregiver and care-receiver, self-development and self-satisfaction, believing in getting rewards afterlife and future expectation of getting better days. Closely related findings were seen in systemic research in 2013 where the caregivers reported a variety of good elements of caring, including an improved relationship with the care receiver, a sense of being rewarded, a sense of personal progress, and a sense of personal fulfillment (29).

The second theme of the study answers about the common burdens caregivers face while providing care for their patients. Psychological problems were seen that have developed already or are being developed due to caregiving (RQ 1). Caregivers mentioned psychological problems due to stress, extensive engagement in caregiving, lack of personal time, financial loss, job sacrifice, lack of support from family members, and social abandonment (RQ 1). A study in America in 2016 on family caregivers of aging adults found that there is strong evidence to support the claim that many carers suffer from psychological problems (3). Numerous psychological problems and obligations that come with providing care might negatively affect the carer (43) were found in a study in Fiji that was similar to our study. There was no direct effect of psychological health on the physical health of the caregivers found in this present study but a study in Taiwan by Chang, H.Y., and colleagues found in their result that there is a significant impact of psychological health on the physical health of caregivers (8). Caregiving can cause physical problems like back and shoulder pain, lack of sleep, and weight loss, which was further fueled by skipping their treatment for cost reduction (RQ 1). Caregivers are so busy and involved with their patients that, they don’t have the courage, time, and financial freedom to ask for medical treatment for themselves (RQ 1).

Similarities were seen in a study carried out at the Outpatient Clinic of Neuro-psychiatry in Ain Shams University Hospitals, Cairo, Egypt found by mentioning carers as unnoticed patients who, due to their engagement in caring tasks, may be unable or unable to seek care for their own health needs (44). Female participants were more into cost reduction by not reporting health conditions, skipping necessary treatment and medications(RQ 1) for themselves to ensure cost reduction for the family, and arranging resources for their disabled patients. Similar findings were seen in a study in Southwest England in 2017 where the female spouse or women were less likely to report their physical condition and health because of being a family caregiver (42). Sometimes this attitude becomes more severe, and they feel emotionally distressed because of not bearing physically sound health conditions (RQ 1). Susan C. Reinhard and colleagues in their book "Patient Safety and Quality: An Evidence-Based Handbook for Nurses" stated that caregivers' stress and strain have been linked to greater rates of health-risk behaviors (such as smoking) and drug use (45), but there was no relevant incident were found in our studies. Instead, it was seen in only one participant who was susceptible to suicide at one point of caregiving due to strong psychological and physical stress (RQ 1). The financial crisis, job sacrifice, halt in higher education, and change in the profession were common risk factors for developing psychological instability among caregivers. Ronald D. Adelman and colleagues in their clinical review on caregiver burden found similarities that, poor educational attainment, living with the care recipient, increased amount of hours spent caring, depression, social isolation, financial stress, and lack of choice in becoming a carer are all risk factors for caregiver burden (46). Most disabled people can't work like normal people and the caregivers have fewer options to work due to extensive engagement with caregiving (RQ 1). This affected their overall lifestyle and treatment-taking willingness and capabilities (RQ 1).

The third theme was representing the obstacles in providing care and well-being for physically challenged persons (RQ 2). In addition, measures the caregivers take and techniques they apply for effective caregiving have emerged (RQ 2). Several obstacles to providing medical treatment, rehabilitation, and well-being to their patients were seen that caregivers have to handle every day. Physical barriers like steps and curbs not only made their care receivers ' lives miserable but also opposed their recreational outdoor activities (RQ 2). It was also observed that hospitals and other health-related service-providing organizations in Bangladesh lack the necessary lifts and ramps (RQ 2). To cope with this caregivers used manual help from other people to lift their patients upstairs (RQ 2). Some of them were aware of the necessity of medical treatment, rehabilitation, and other essential terms related to care and well-being while some of the caregivers faced fraud and charlatans (RQ 2).

COVID-19 and pandemic-related restrictions and lockdowns made it harder for the caregiver and their patients to get medical support which produced an additional burden (RQ 2). Indistinguishable findings were seen in another study that, people with disabilities may be especially exposed to the negative consequences of pandemic lockdown and other public health measures, particularly if these policies are not disability-inclusive and are not designed to prevent or alleviate any disproportionate effects (49). Lockdowns, enforced quarantines, and other public health and policy measures to limit the epidemic are frequently required, however, if not adequately managed, these policies can have detrimental educational, vocational, and socioeconomic repercussions, particularly for the most socially disadvantaged (49-52). Lack of transport made it harder to take a disabled person to hospitals when necessary (RQ 2). Lockdowns and government restrictions blocked their way to bringing someone as a helping hand in situations like pregnancy from close relatives living remotely (RQ 2).

Family caregivers not only provide care for their critically ill patients but also take care of the maintenance of hygiene. Either in the hospital or at paid home service the cleaning staff as well as nurses don’t want to engage themselves in cleaning patients’ urine or feces (RQ 2). The nursing staff find it lowering their position and usually skip the task of cleaning patients. A similar was found in two different studies where nurses avoid cleaning tasks because they believe it lowers their social position (47, 48). Lack of training making it harder for a caregiver to effectively take care of was seen in the primary stage of caregiving (RQ 2). Eventually, participants trained themselves by knowledge gathering from the internet, demonstrative training, counseling from therapists, and institutional training for better patient handling (RQ 2). A similar was found in an article, where the author illustrates that interventions like psychoeducation, skills training, and therapeutic counseling have been demonstrated to have minor to moderate success in improving carer quality of life and reducing carer load for carers of patients (49).

Family caregivers who are working besides caregiving find it difficult yet maintain both duties (RQ 1). Time management, scheduling work beforehand, and taking necessary leaves from employer organization were requirements for balancing a working-caregiving life and well-being.

One of the best but not always keepable coping techniques was patience (RQ 2). Most of the participants mentioned having patience which helped them do their duties in the long run as caregiving isn’t a one-day job or only a few weeks of engagement (RQ 2). Bookwala J. found in her study, that longer-term carers were considerably less pleased in their marriages than those who had just acquired the caregiving position, in a sample of adult caring daughters and sons, indicating that negative effects take time to appear (50).

In general, the similarity in the negative effect of taking time to appear was seen in this study where participants who caregiving for several years were a bit more frustrated compared to participants who had been caregiving for one year (RQ 1). To give the parents back the care they showed for their children, responsibility for the parents’ welfare and getting them back to normal life was the key to giving care to family caregivers who were sons and daughters. The Opposite was found in a study where offspring prefer to escape the burden of caring for their elderly parents since it requires ongoing physical and mental work, as well as substantial financial expenditures (51). However, participants who were caregiving their son or daughter didn’t think this caregiving was a burden. Love and affection for the offspring fueled their role to continue further.

In this study, participants found it difficult to socialize and interact with other people due to the lack of accessible transportation, roads, and lifts, and negative responses from the surrounding people (RQ 3) were discussed in the fourth theme. From marrying a disabled person to taking out a disabled patient outside on occasions like markets, parks, and social gatherings people from society always reacted by blaming, staring inappropriately, and asking awkward questions (RQ 3). People in Bangladesh often see disabled people as ominous due to superstitions (RQ 3) and participants faced a two-way problem while socializing. They can’t take the disabled person with them on occasion, nor they can leave the disabled person alone in the home (RQ 1,3). Recent research shows, that many carers face social isolation and disengagement from social activities and relationships as a result of care obligations and a lack of alternative assistance (2). However, in our study, one of the coping strategies developed was to go out with the patient and socialize more despite having difficulties (RQ 3). It helped to break down the social proscription about disabled people and familiarize society with the fact, that disabled people are also a part of society and they have every right to socialize with everyone it was found necessary to bring the disabled person to certain social occasions (RQ 3). A similar observation was highlighted in a systematic review:  communication and social support improved coping techniques or mechanisms for caregivers (52). On the other hand, some caregivers coped with negative attitudes towards them by self-understanding, being silent, and ignoring, and very few of them replied directly to the people's faces if something inappropriate and negative comments were heard (RQ 3).

The final theme emerged with the expectation and support family caregivers want or realize necessary for better engagement in caregiving. The family was found to provide financial support to caregivers but often lacked emotional or direct caregiving-related support (RQ 1). The mentality of providing support to the caregiver from family members was related to family backgrounds, social education, and cultural beliefs. Another finding suggested that the family as a unit makes significant efforts to adjust to stressful situations in the context of caring and demonstrates family resilience, which is intimately tied to the family's cultural background and community status (53). Caregivers mentioned several times about the requirement of physical, mental, or emotional support for effective caregiving. Something similar to respite care was seen offered by the other members of the family meaning when someone came forward to look after the disabled person for a few hours or longer then family caregivers could have some relaxed time to spend on their own. Though a lack of emotional support from family and surroundings was seen sometimes friends were found providing positive support for inspiration and decision making which was a relief to caregivers. Kazemi, A., and colleagues mentioned in their findings that, for informal carers to fulfill their duty for as long as feasible without endangering their physical or emotional well-being, they require support (4), which was found relevant to our study.

Organizational support like leave facilities and special arrangements for working caregivers who have disabled patients in their homes were found beneficial and well appreciated. Support from rehabilitation centers and institutes was also found effective and necessary if provided tailored way (RQ 2). A smile from therapists, psychological counseling, and other support services from a rehabilitation center made it easier for both the caregiver and the physically diseased person to implement the best coping techniques but not yet available everywhere in the country. Societies will need to come up with creative methods to scale up rehabilitation services by better integrating them into each nation's healthcare system to fulfill the rising demand for rehabilitation services internationally (54).

Another interesting finding of our study was, that most of the caregivers found it relaxing to be in an environment where they see other caregivers (RQ 3). When they go to rehabilitation centers and see a lot of similar patients and caregivers, experience sharing is done, patient to patient, caregiver to caregiver. It was found relaxing for them and they felt like they were in a place where no one would criticize or stare oddly (RQ 3). Finally, the future expectation was mostly similar and was related to their respective physically disabled person's health and welfare. Some of them wanted to back to their normal life, to study or job as soon as possible.

## 5. Summary of Knowledge Developed from This Study

From our current study, it was identified that the most challenging parts of caregiving in Bangladesh were physical and mental burdens, financial crises, job sacrifices, interruption in studies, social abandonment, and mobilization (RQ 1). For physical burden, seeking support from other family members, friends, and paid services can be helpful whereas for psychological burden reduction talking with a friend, sister, or mother, spending time with family members, and increasing outdoor activities can be a solution. Cost management and engagement in financial activities were found beneficial in financial burden reduction. Financial engagement can upgrade a lifestyle where excessive cost reduction causes psychological and physical problems (RQ 1). Lack of ramps and lifts, transport, accessible roads, training, and awareness about medical treatment and rehabilitation were common barriers to providing care to disabled persons (RQ 2). In addition, pandemic-related lockdowns and restrictions, financial limitations to get services like physiotherapy and buy devices like motorized wheelchairs, and unavailability of medicines, and equipment like catheters were noticed (RQ 2). Management techniques include hiring people to lift patients upstairs, seeking training for effective caregiving from institutes like CRP, physiotherapists as well as from the Internet, and believing in God and caregiver-to-caregiver peer support (RQ 2). Finally, lack of supportive attitudes, unnecessary blaming, abandoning and neglecting caregivers and care-receivers, insensitive staring, embarrassing questions, and opposing the marriage of a disabled person were common forms of social treatment perceived by caregivers (RQ3). Self-deception, being silent rather than showing a reaction, and actively ignoring, were common attitudes of caregivers against society (RQ 3). Uncommon attitudes were responding to any comments that were heard and trying to give a constructive message to society about how to react were also seen as coping strategies (RQ 3).

# 6. Strength & Limitations

This qualitative study was designed to explore the day-to-day experience of family caregivers in Bangladesh who are taking care of physically disabled adult people. The first and foremost strength of this study is the qualitative approach that helped explore the experiences of the family caregivers of physically disabled persons in Bangladesh in depth. The preunderstanding of the researcher involving experiences of having a physically disabled younger brother helped to create rapport with the participants, creating data with depth on the topic, as well as to better understand and interpret the present data. The researcher himself transcribed the data, from Bengali and thereafter translated the data into English. Through this procedure, the master's student got to know the data very well. The method for interpreting data was thematic analysis which was flexible, easy to use, and helped in-depth understanding and pattern identification. However, this study also has some limitations. Thematic analysis can be sometimes reliant on the author's perspective-producing biases. Also, it was time-consuming, and output largely depended on the skills of the author and understanding of the data. Coping techniques for Research Question (RQ 1) were not included in the primary objective of the study(limitation) but during interviewing and data interpretation they came forward which was necessary and highlighted accordingly in this study(strength). This study only asked about caregivers' common burdens and challenges but The present findings are limited to the experiences of 11 participants. However, some general insight is provided by this study. Furthermore, only caregivers of physically disabled people were included. However, several caregivers are taking care of other disabilities including disabled children, psychological disabilities, and disabled older adults. This study doesn’t include such participants. For this study, the participants were provided with a convenient time and place that was chosen by themselves and the environment so that they feel comfortable while giving the interview so that real-life experiences could be explored. Then, CRP is an institution mostly designed for patients having medium to lower income class. Very few of the high-income groups come there to take services like physiotherapy and rehabilitation. So, the experience explored there reflects, as a family caregiver, how it feels like to give care to a physically disabled person, having a financial crisis. On the other side, it also demonstrates their coping techniques with the situation, and how they handled and ensured caring in a low-resource setting which is a strength of this study. Next, the author himself grew up in a family seeing his mother as a caregiver for his disabled brother. Emotions and weaknesses might affect the researcher which can be reflected in the writing. On the other hand, it can be a strong tool and motivation for better understanding the positive and negative experiences of family caregiving. Also, what the physically disabled people think about the care they get from their respective caregiving family members might carry meaningful understanding. Finally, it was unknown about those caregivers who still hadn’t come to visit a rehabilitation center yet or those who were going to other rehabilitation centers. Family caregivers' experiences of taking rehabilitation from CRP were mostly positive but it is still unknown what is the experience of taking rehabilitation other than CRP. So, differences between the experience of family caregivers who visited a rehabilitation center like CRP with their disabled patient and those who didn’t might exist which urges further study on this topic.

# 7. Conclusion

Caregiving is a crucial part of the recovery, welfare, and quality of life of a disabled person, and family caregivers in Bangladesh don’t get any payments or financial benefits for providing their effort, care, and valuable time to their disabled family members. Formulation and implementation of policies that fulfill caregivers’ needs including healthcare services, financial aid, and respite services, concerned and comprehensive efforts are necessary within limited resources. In addition, training programs tailored to their needs for skill development and knowledge sharpening are crucial to ensure their well-being and the enhancement of the quality care they provide. The SDGs(Sustainable Development Goals 2030) adopted by the UN (United Nations) included disability, mentioned in several places, in sections that deal with inequality, growth and employment, education, human settlement accessibility, and data collecting and monitoring (55). Goal 10 is closely related and aims to empower and promote the social, economic, and political inclusion of all people, including those with disabilities, to minimize inequality both within and between nations (55), however, not achievable if family caregivers are not included. Integrating disability and family caregivers in the national policy and agenda to secure their rights is of vital importance to be aligned with the SDG 2030 goal. A health strategy should be developed to assist informal carers in receiving more professional assistance, moreover, training options for family carers should be made available to lessen the influence of caregiving on the delivery of appropriate care (56). Also, prioritizing SDG 2030 goals that are closely related to health, inclusive society, and reduction of inequalities will create a support network that will offer benefits to physically disabled persons and their caregivers. Counseling and psychological supports that are tailored to the specific needs of the caregiver, caregiver peer platforms to share caregiving experiences, accessible transport facilities, and adequate ramps and lifts to ensure physical access to public places and hospitals to ensure mobility and independent social integration of the disabled person are needed to be established. More investment in research and data collection to measure the real scenario of disability and related challenges is required to take targeted interventions. Finally, collaborative approaches, expertise, advocacy and resources from all levels of the country including government and non-government organizations, charitable organizations, health care providers and community will strengthen an impartial and supportive environment both for disabled persons and caregivers.

# References

1. Park JY, Pardosi JF, Islam MS, Respati T, Chowdhury K, Seale H. What does family involvement in care provision look like across hospital settings in Bangladesh, Indonesia, and South Korea? BMC Health Serv Res. 2022;22(1):922.

2. Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family Caregiving for Older Adults. Annu Rev Psychol. 2020;71:635-59.

3. Schulz R EJ. Families Caring for an Aging America. Washinton DC: The National Academies Press; 2016 November 8.

4. Kazemi A, Azimian J, Mafi M, Allen KA, Motalebi SA. Caregiver burden and coping strategies in caregivers of older patients with stroke. BMC Psychol. 2021;9(1):51.

5. Plöthner M, Schmidt K, de Jong L, Zeidler J, Damm K. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC Geriatr. 2019;19(1):82.

6. Loo YX, Yan S, Low LL. Caregiver burden and its prevalence, measurement scales, predictive factors and impact: a review with an Asian perspective. Singapore Med J. 2022;63(10):593-603.

7. Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis. Int J Nurs Sci. 2020;7(4):438-45.

8. Chang HY, Chiou CJ, Chen NS. Impact of mental health and caregiver burden on family caregivers' physical health. Arch Gerontol Geriatr. 2010;50(3):267-71.

9. Beach SR, Schulz R, Yee JL, Jackson S. Negative and positive health effects of caring for a disabled spouse: longitudinal findings from the caregiver health effects study. Psychol Aging. 2000;15(2):259-71.

10. WHO. Disability: World Health Organization; 2022 [Available from: https://www.who.int/health-topics/disability#tab=tab_1.

11. Bangladesh Bureau of Statistics (BBS) SaIDS. Report on National Survey on Persons with Disabilities (NSPD) 2021. 2022 December 2022.

12. Women with Disabilities Development Foundation (WDDF). Persons with Disabilities Rights And Protection Act 2013. 2013.

13. Uddin T, Islam MT, Rathore FA, O'Connell C. Disability and Rehabilitation Medicine in Bangladesh: Current Scenario and Future Perspectives. Journal of the International Society of Physical and Rehabilitation Medicine. 2019;2(4):168-77.

14. Rahman M, Rana MS, Khandaker G, Rahman MM, Khan MN. National Burden of Disability in Bangladesh and its Socio-Demographic Correlates. medRxiv. 2023:2023.09.13.23295500.

15. Mackelprang RW, Salsgiver RO. Disability : a diversity model approach in human service practice. Pacific Grove, CA: Brooks/Cole Pub. Co. Pacific Grove, CA; 1999. Available from: http://books.google.com/books?id=hHJHAAAAMAAJ.

16. CDC. Disability and Health Overview: Centre For Disease Control and Prevention; 2020 [Available from: https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html.

17. Clute MA. Disability: Physical Disabilities. NASW Press and Oxford University Press; 2013.

18. Overall C. Old Age and Ageism, Impairment and Ableism: Exploring the Conceptual and Material Connections. NWSA Journal. 2006;18:126-37.

19. Tremain S. On the Government of Disability. Social Theory and Practice. 2001;27(4):617-36.

20. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. Gerontologist. 1986;26(3):260-6.

21. Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: a reappraisal from population-based studies. Gerontologist. 2015;55(2):309-19.

22. Ahmed HU KA, Qusar MMAS, Uddin AFMH, Sulatana MM, Hossain T, Alam MF, Mullick MSI, Nahar JS, RabbaniMG. Caregivers' burden of the patients with mental illness: An update. Bangladesh Journal Psychiatry. 2012;26(2).

23. Beach SR, Schulz R, Williamson GM, Miller LS, Weiner MF, Lance CE. Risk factors for potentially harmful informal caregiver behavior. J Am Geriatr Soc. 2005;53(2):255-61.

24. Ampalam P, Gunturu S, Padma V. A comparative study of caregiver burden in psychiatric illness and chronic medical illness. Indian J Psychiatry. 2012;54(3):239-43.

25. Delalibera M, Presa J, Barbosa A, Leal I. [Burden of caregiving and its repercussions on caregivers of end-of-life patients: a systematic review of the literature]. Cien Saude Colet. 2015;20(9):2731-47.

26. Dunkin JJ, Anderson-Hanley C. Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention. Neurology. 1998;51(1 Suppl 1):S53-60; discussion S5-7.

27. Thakur V, Nagarajan P, Rajkumar RP. Coping and burden among caregivers of patients with major mental illness. Indian Journal of Social Psychiatry. 2022;38(1):63-8.

28. Sánchez-Izquierdo M, Prieto-Ursúa M, Caperos JM. Positive aspects of family caregiving of dependent elderly. Educational Gerontology. 2015;41(11):745-56.

29. Li Q, Loke AY. The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. Psychooncology. 2013;22(11):2399-407.

30. López J, López-Arrieta J, Crespo M. Factors associated with the positive impact of caring for elderly and dependent relatives. Arch Gerontol Geriatr. 2005;41(1):81-94.

31. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. Int J Geriatr Psychiatry. 2002;17(2):184-8.

32. Tareque MI, Begum S, Saito Y. Inequality in disability in Bangladesh. PLoS One. 2014;9(7):e103681.

33. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3:77-101.

34. Guest G, Bunce, A., & Johnson, L. (2006). How Many Interviews Are Enough? Field Methods. . 2006.

35. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. BMC Medical Research Methodology. 2018;18(1):148.

36. Fugard AJB, Potts HWW. Supporting thinking on sample sizes for thematic analyses: a quantitative tool. International Journal of Social Research Methodology. 2015;18(6):669-84.

37. Braun V, Clarke V. (Mis)conceptualising themes, thematic analysis, and other problems with Fugard and Potts' (2015) sample-size tool for thematic analysis. International Journal of Social Research Methodology. 2016;19(6):739-43.

38. Boyatzis RE. Transforming qualitative information: Thematic analysis and code development: sage; 1998.

39. Patton MQ. Qualitative evaluation and research methods: SAGE Publications, inc; 1990.

40. Li L, Lee Y. Caregiving Choice and Caregiver-Receiver Relation: Effects on Psychological Well-being of Family Caregivers in Canada. Can J Aging. 2020;39(4):634-46.

41. Schulz R, Beach SR, Cook TB, Martire LM, Tomlinson JM, Monin JK. Predictors and consequences of perceived lack of choice in becoming an informal caregiver. Aging Ment Health. 2012;16(6):712-21.

42. Solomi VL, Casiday RE. In sickness and in health: The strains and gains of caring for a chronically ill or disabled spouse. Chronic Illness. 2017;13(2):75-87.

43. Gajraj-Singh P. Psychological impact and the burden of caregiving for persons with spinal cord injury (SCI) living in the community in Fiji. Spinal Cord. 2011;49(8):928-34.

44. Mourad GM, Zaki RA, Ali RA. Improving coping abilities among caregivers of patients with cerebrovascular stroke. J Educ Pract. 2014;5(36):8-20.

45. Reinhard SC, Given B, Petlick NH, Bemis A. Advances in Patient Safety

Supporting Family Caregivers in Providing Care. In: Hughes RG, editor. Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008.

46. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. Jama. 2014;311(10):1052-60.

47. Hadley MB, Roques A. Nursing in Bangladesh: rhetoric and reality. Soc Sci Med. 2007;64(6):1153-65.

48. Hadley MB, Blum LS, Mujaddid S, Parveen S, Nuremowla S, Haque ME, et al. Why Bangladeshi nurses avoid 'nursing': social and structural factors on hospital wards in Bangladesh. Soc Sci Med. 2007;64(6):1166-77.

49. Collins LG, Swartz K. Caregiver care. Am Fam Physician. 2011;83(11):1309-17.

50. Bookwala J. The impact of parent care on marital quality and well-being in adult daughters and sons. J Gerontol B Psychol Sci Soc Sci. 2009;64(3):339-47.

51. Dhar RL. Caregiving for elderly parents: A study from the Indian perspective. Home Health Care Management & Practice. 2012;24(5):242-54.

52. Palacio GC, Krikorian A, Gómez-Romero MJ, Limonero JT. Resilience in Caregivers: A Systematic Review. Am J Hosp Palliat Care. 2020;37(8):648-58.

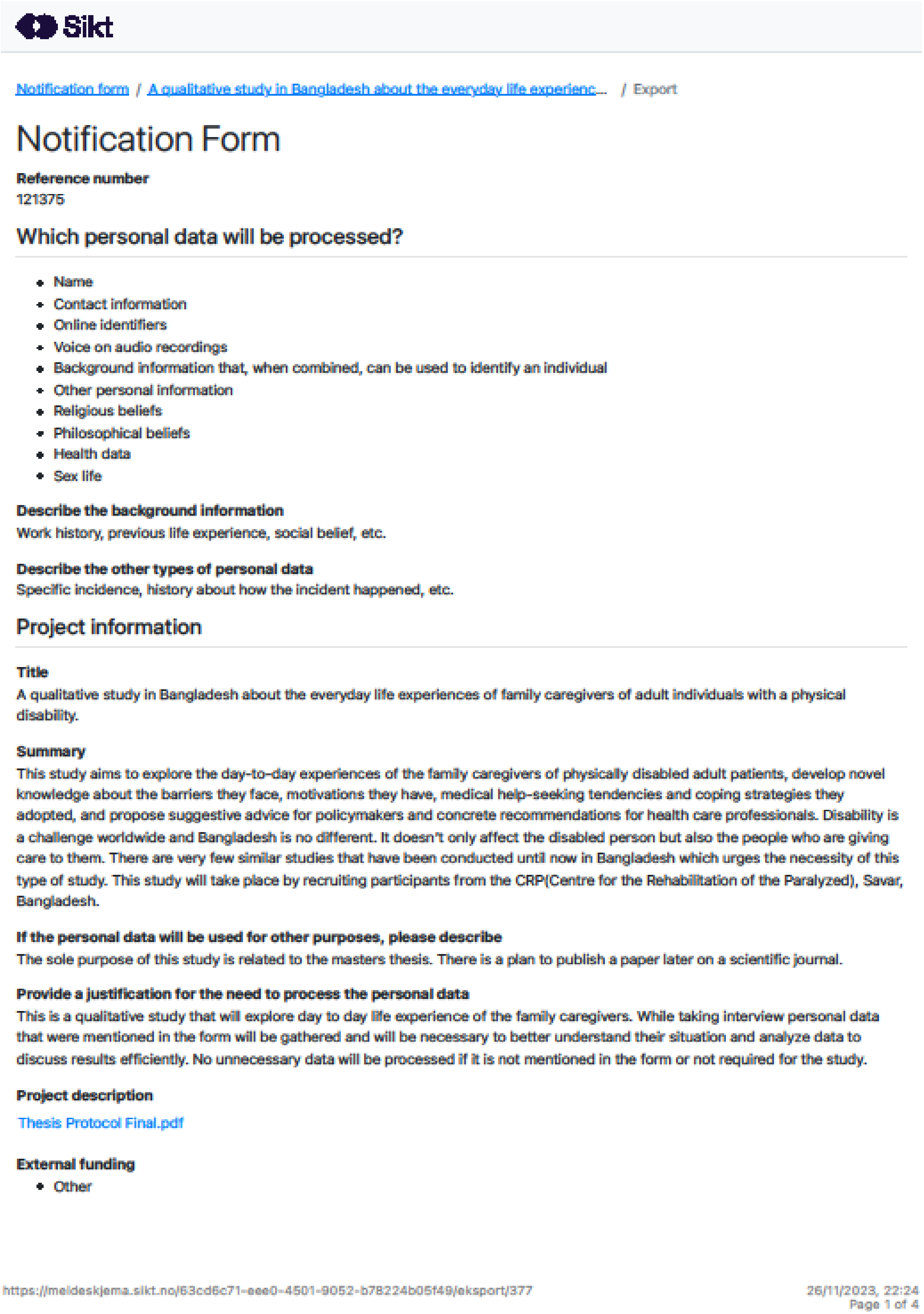
53. Abulaiti B, Zhang X, Guan T, Wang M, Jia S, Wang A. The dyadic care experiences of elderly individuals with disabilities and caregivers in the home setting from the perspective of family resilience: A qualitative study. Front Psychiatry. 2022;13:963101.

54. Jette AM. Global Prevalence of Disability and Need for Rehabilitation. Physical Therapy. 2021;101(2).

55. Nations U. The Sustainable Development Goals (SDGs) And Disability 2015 [updated 06 October 2015. Available from: https://social.desa.un.org/issues/disability/news/the-sustainable-development-goals-sdgs-and-disability#:~:text=Closely%20linked%20is%20Goal%2010,all%2C%20including%20persons%20with%20disabilities.

56. Chiao CY, Wu HS, Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: A systematic review. Int Nurs Rev. 2015;62(3):340-50.

# Appendix i. Notification Form (Sikt)



Sikt

Notification form / A qualitative study in Bangladesh about the everyday life experienc... / Export

## Notification Form

**Reference number**
121375

### Which personal data will be processed?

- Name
- Contact information
- Online identifiers
- Voice on audio recordings
- Background information that, when combined, can be used to identify an individual
- Other personal information
- Religious beliefs
- Philosophical beliefs
- Health data
- Sex life

**Describe the background information**
Work history, previous life experience, social belief, etc.

**Describe the other types of personal data**
Specific incidence, history about how the incident happened, etc.

### Project information

**Title**
A qualitative study in Bangladesh about the everyday life experiences of family caregivers of adult individuals with a physical disability.

**Summary**
This study aims to explore the day-to-day experiences of the family caregivers of physically disabled adult patients, develop novel knowledge about the barriers they face, motivations they have, medical help-seeking tendencies and coping strategies they adopted, and propose suggestive advice for policymakers and concrete recommendations for health care professionals. Disability is a challenge worldwide and Bangladesh is no different. It doesn't only affect the disabled person but also the people who are giving care to them. There are very few similar studies that have been conducted until now in Bangladesh which urges the necessity of this type of study. This study will take place by recruiting participants from the CRP(Centre for the Rehabilitation of the Paralyzed), Savar, Bangladesh.

**If the personal data will be used for other purposes, please describe**
The sole purpose of this study is related to the masters thesis. There is a plan to publish a paper later on a scientific journal.

**Provide a justification for the need to process the personal data**
This is a qualitative study that will explore day to day life experience of the family caregivers. While taking interview personal data that were mentioned in the form will be gathered and will be necessary to better understand their situation and analyze data to discuss results efficiently. No unnecessary data will be processed if it is not mentioned in the form or not required for the study.

**Project description**
Thesis Protocol Final.pdf

**External funding**
- Other

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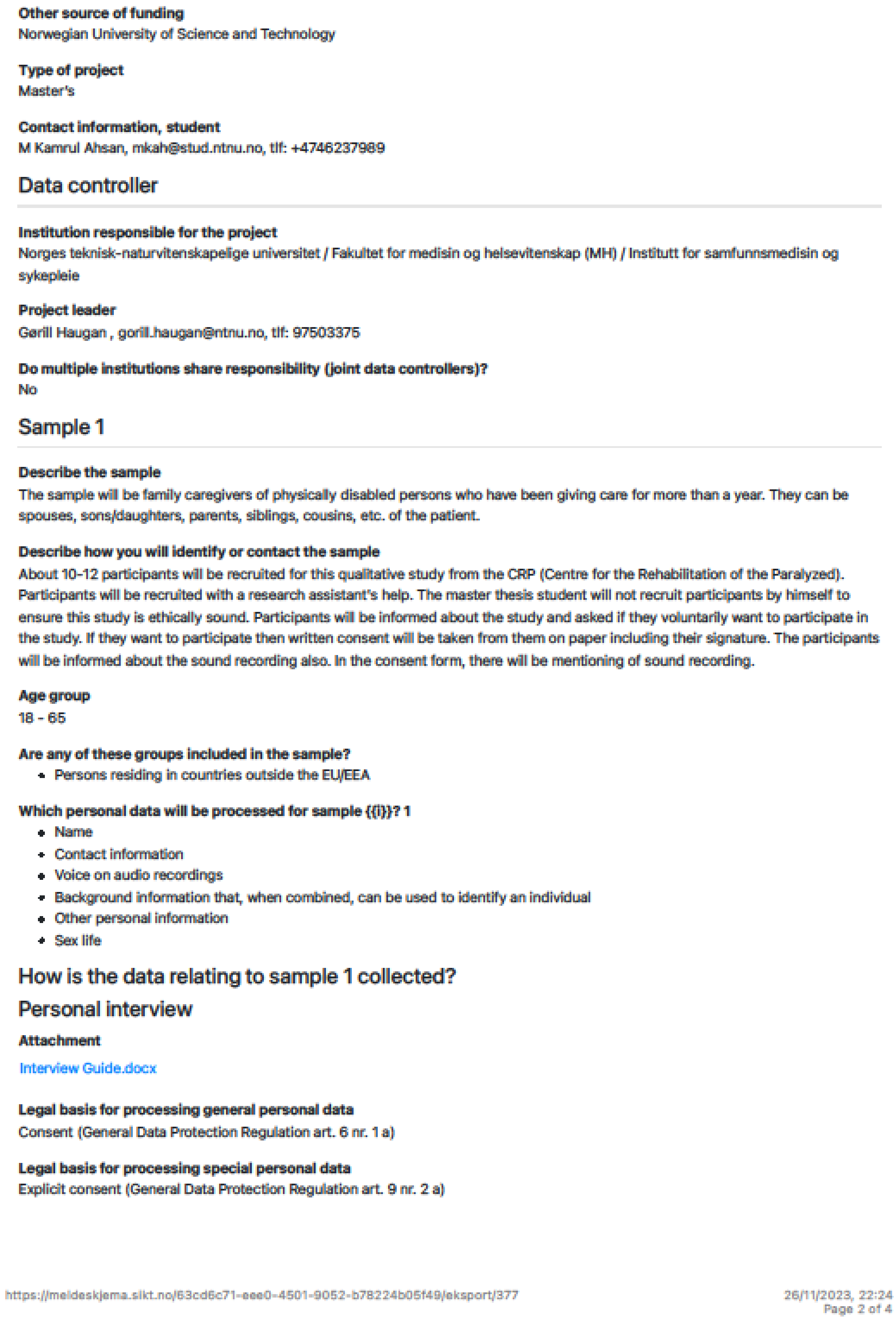


**Other source of funding**
Norwegian University of Science and Technology

**Type of project**
Master's

**Contact information, student**
M Kamrul Ahsan, mkah@stud.ntnu.no, tlf: +4746237989

## Data controller

**Institution responsible for the project**
Norges teknisk-naturvitenskapelige universitet / Fakultet for medisin og helsevitenskap (MH) / Institutt for samfunnsmedisin og sykepleie

**Project leader**
Gøril Haugan , goril.haugan@ntnu.no, tlf: 97503375

**Do multiple institutions share responsibility (joint data controllers)?**
No

## Sample 1

**Describe the sample**
The sample will be family caregivers of physically disabled persons who have been giving care for more than a year. They can be spouses, sons/daughters, parents, siblings, cousins, etc. of the patient.

**Describe how you will identify or contact the sample**
About 10-12 participants will be recruited for this qualitative study from the CRP (Centre for the Rehabilitation of the Paralyzed). Participants will be recruited with a research assistant's help. The master thesis student will not recruit participants by himself to ensure this study is ethically sound. Participants will be informed about the study and asked if they voluntarily want to participate in the study. If they want to participate then written consent will be taken from them on paper including their signature. The participants will be informed about the sound recording also. In the consent form, there will be mentioning of sound recording.

**Age group**
18 - 65

**Are any of these groups included in the sample?**
- Persons residing in countries outside the EU/EEA

**Which personal data will be processed for sample {{i}}? 1**
- Name
- Contact information
- Voice on audio recordings
- Background information that, when combined, can be used to identify an individual
- Other personal information
- Sex life

## How is the data relating to sample 1 collected?

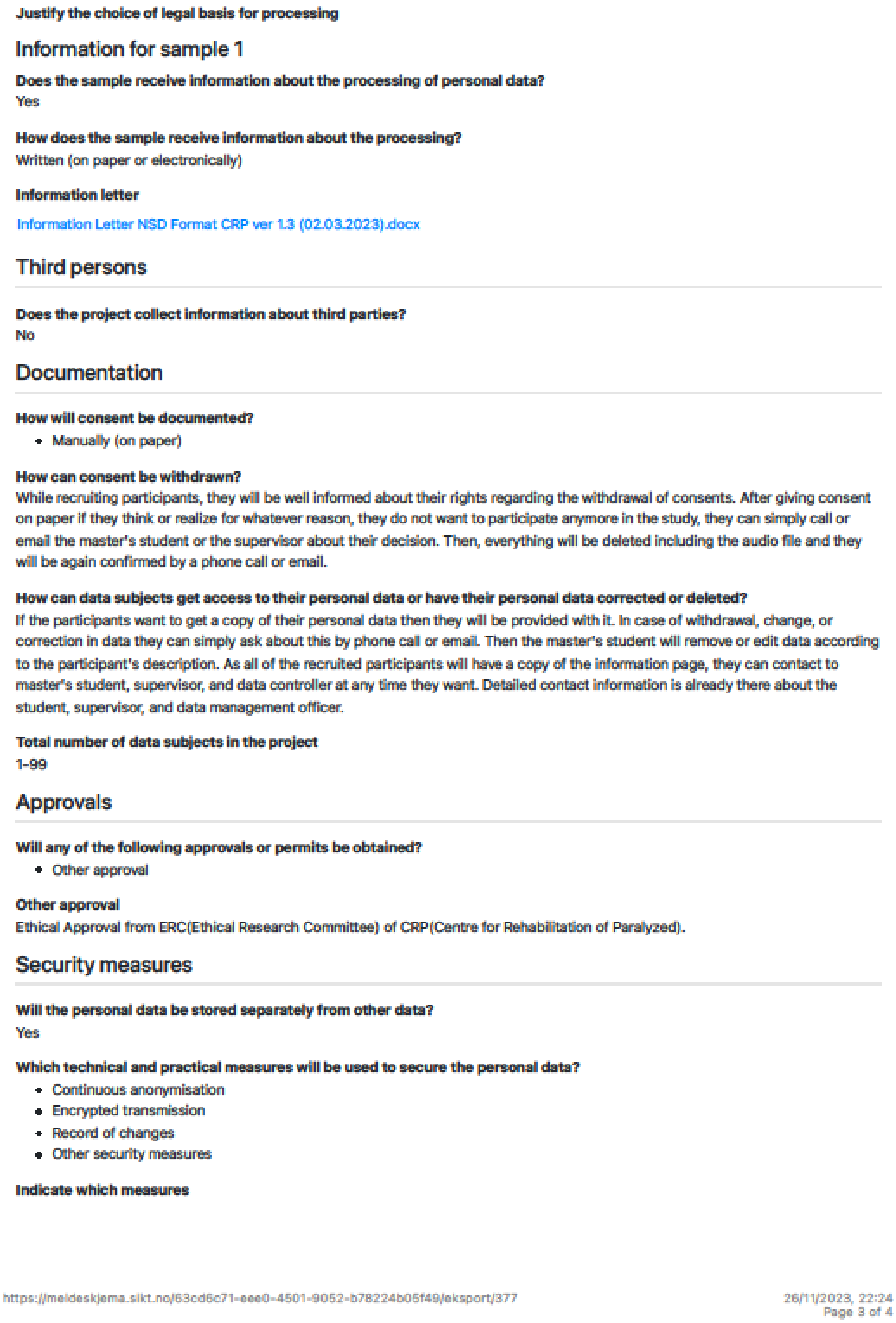
## Personal interview

**Attachment**

Interview Guide.docx

**Legal basis for processing general personal data**
Consent (General Data Protection Regulation art. 6 nr. 1 a)

**Legal basis for processing special personal data**
Explicit consent (General Data Protection Regulation art. 9 nr. 2 a)



**Justify the choice of legal basis for processing**

## Information for sample 1

**Does the sample receive information about the processing of personal data?**
Yes

**How does the sample receive information about the processing?**
Written (on paper or electronically)

**Information letter**

Information Letter NSD Format CRP ver 1.3 (02.03.2023).docx

## Third persons

**Does the project collect information about third parties?**
No

## Documentation

**How will consent be documented?**

- Manually (on paper)

**How can consent be withdrawn?**
While recruiting participants, they will be well informed about their rights regarding the withdrawal of consents. After giving consent on paper if they think or realize for whatever reason, they do not want to participate anymore in the study, they can simply call or email the master's student or the supervisor about their decision. Then, everything will be deleted including the audio file and they will be again confirmed by a phone call or email.

**How can data subjects get access to their personal data or have their personal data corrected or deleted?**
If the participants want to get a copy of their personal data then they will be provided with it. In case of withdrawal, change, or correction in data they can simply ask about this by phone call or email. Then the master's student will remove or edit data according to the participant's description. As all of the recruited participants will have a copy of the information page, they can contact to master's student, supervisor, and data controller at any time they want. Detailed contact information is already there about the student, supervisor, and data management officer.

**Total number of data subjects in the project**
1-99

## Approvals

**Will any of the following approvals or permits be obtained?**

- Other approval

**Other approval**
Ethical Approval from ERC(Ethical Research Committee) of CRP(Centre for Rehabilitation of Paralyzed).

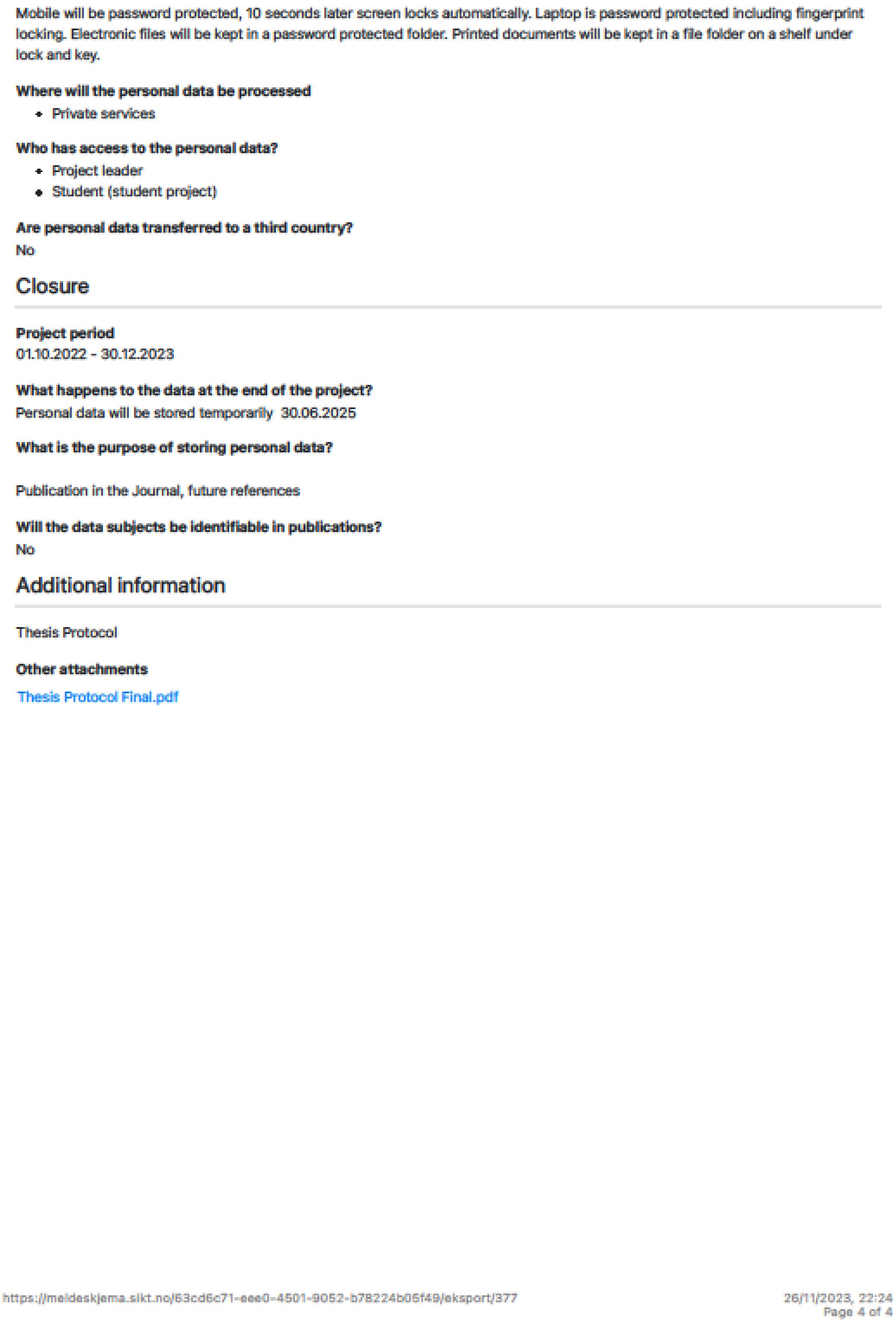
## Security measures

**Will the personal data be stored separately from other data?**
Yes

**Which technical and practical measures will be used to secure the personal data?**

- Continuous anonymisation
- Encrypted transmission
- Record of changes
- Other security measures

**Indicate which measures**



Mobile will be password protected, 10 seconds later screen locks automatically. Laptop is password protected including fingerprint locking. Electronic files will be kept in a password protected folder. Printed documents will be kept in a file folder on a shelf under lock and key.

**Where will the personal data be processed**

- Private services

**Who has access to the personal data?**

- Project leader
- Student (student project)

**Are personal data transferred to a third country?**

No

## Closure

**Project period**

01.10.2022 - 30.12.2023

**What happens to the data at the end of the project?**

Personal data will be stored temporarily 30.06.2025

**What is the purpose of storing personal data?**

Publication in the Journal, future references

**Will the data subjects be identifiable in publications?**

No

## Additional information

Thesis Protocol

**Other attachments**

Thesis Protocol Final.pdf

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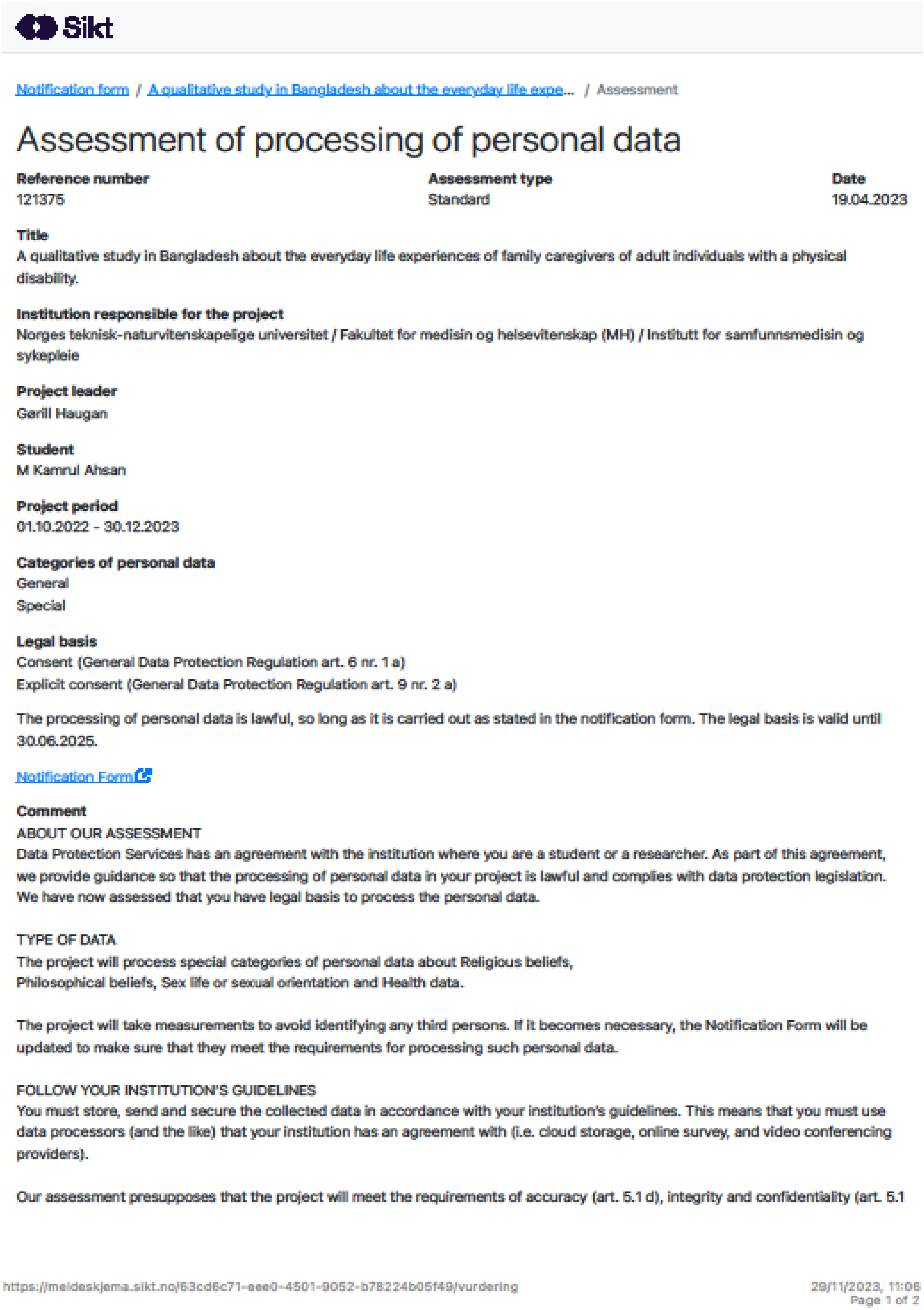
# Appendix ii. Assessment of Processing of Personal Data



Sikt

Notification form / A qualitative study in Bangladesh about the everyday life expe... / Assessment

## Assessment of processing of personal data

| Reference number | Assessment type | Date |
|---|---|---|
| 121375 | Standard | 19.04.2023 |

**Title**
A qualitative study in Bangladesh about the everyday life experiences of family caregivers of adult individuals with a physical disability.

**Institution responsible for the project**
Norges teknisk-naturvitenskapelige universitet / Fakultet for medisin og helsevitenskap (MH) / Institutt for samfunnsmedisin og sykepleie

**Project leader**
Gørill Haugan

**Student**
M Kamrul Ahsan

**Project period**
01.10.2022 - 30.12.2023

**Categories of personal data**
General
Special

**Legal basis**
Consent (General Data Protection Regulation art. 6 nr. 1 a)
Explicit consent (General Data Protection Regulation art. 9 nr. 2 a)

The processing of personal data is lawful, so long as it is carried out as stated in the notification form. The legal basis is valid until 30.06.2025.

Notification Form

**Comment**
ABOUT OUR ASSESSMENT
Data Protection Services has an agreement with the institution where you are a student or a researcher. As part of this agreement, we provide guidance so that the processing of personal data in your project is lawful and complies with data protection legislation. We have now assessed that you have legal basis to process the personal data.

TYPE OF DATA
The project will process special categories of personal data about Religious beliefs,
Philosophical beliefs, Sex life or sexual orientation and Health data.

The project will take measurements to avoid identifying any third persons. If it becomes necessary, the Notification Form will be updated to make sure that they meet the requirements for processing such personal data.

FOLLOW YOUR INSTITUTION'S GUIDELINES
You must store, send and secure the collected data in accordance with your institution's guidelines. This means that you must use data processors (and the like) that your institution has an agreement with (i.e. cloud storage, online survey, and video conferencing providers).

Our assessment presupposes that the project will meet the requirements of accuracy (art. 5.1 d), integrity and confidentiality (art. 5.1

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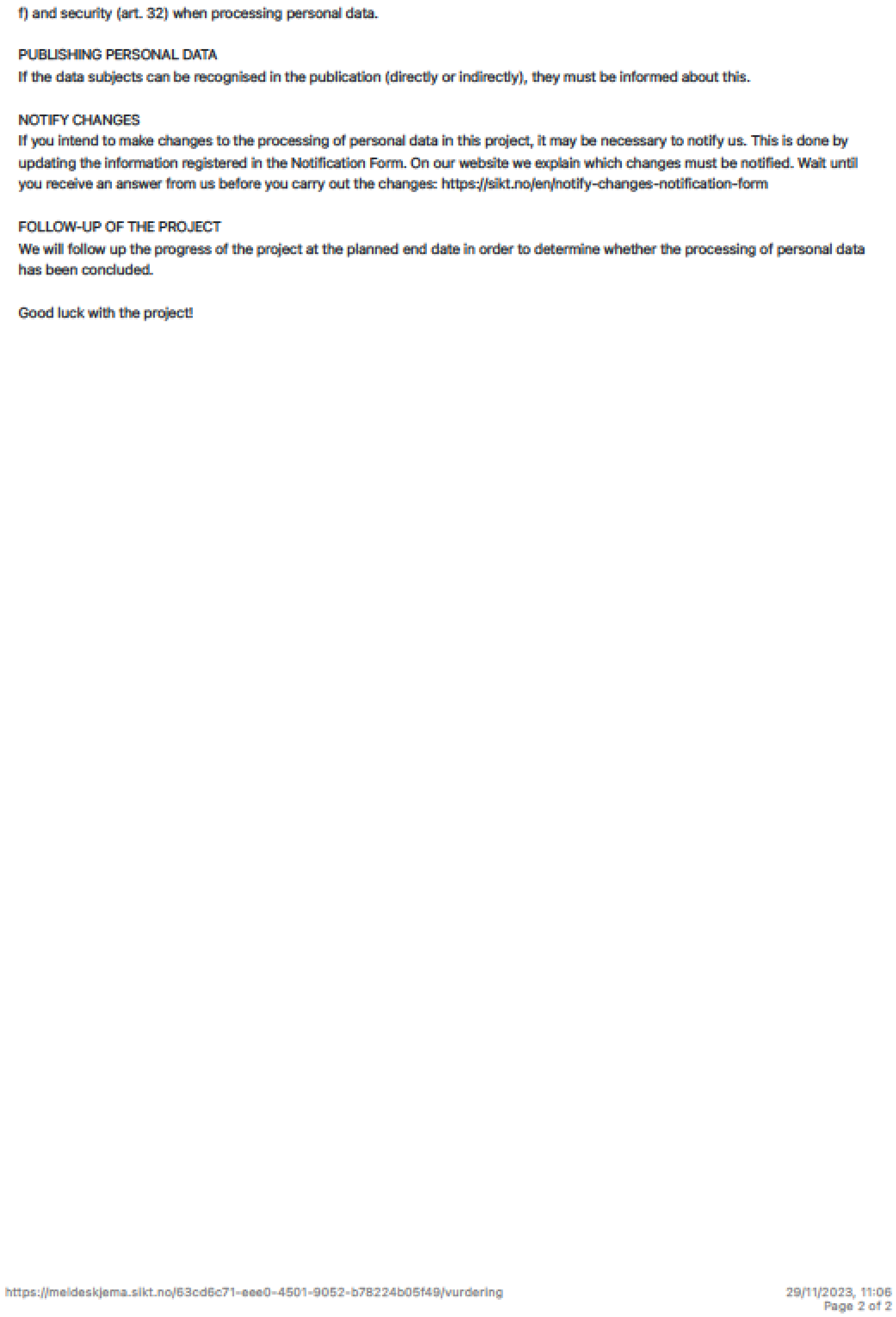


f) and security (art. 32) when processing personal data.

PUBLISHING PERSONAL DATA

If the data subjects can be recognised in the publication (directly or indirectly), they must be informed about this.

NOTIFY CHANGES

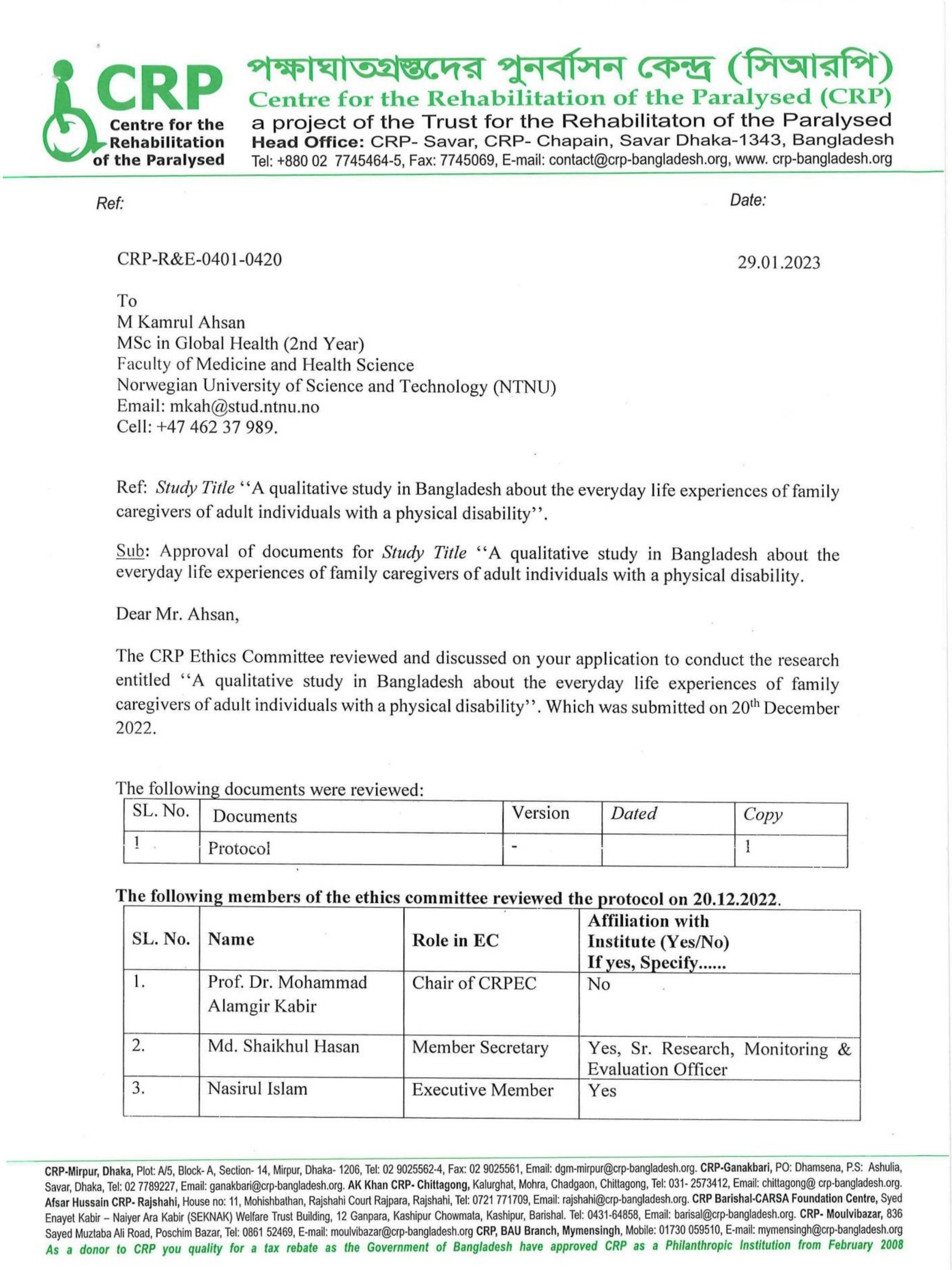
If you intend to make changes to the processing of personal data in this project, it may be necessary to notify us. This is done by updating the information registered in the Notification Form. On our website we explain which changes must be notified. Wait until you receive an answer from us before you carry out the changes: https://sikt.no/en/notify-changes-notification-form

FOLLOW-UP OF THE PROJECT

We will follow up the progress of the project at the planned end date in order to determine whether the processing of personal data has been concluded.

Good luck with the project!

# Appendix iii. Approval From CRP



CRP
Centre for the
Rehabilitation
of the Paralysed

পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্র (সিআরপি)
Centre for the Rehabilitation of the Paralysed (CRP)
a project of the Trust for the Rehabilitaton of the Paralysed
**Head Office:** CRP- Savar, CRP- Chapain, Savar Dhaka-1343, Bangladesh
Tel: +880 02 7745464-5, Fax: 7745069, E-mail: contact@crp-bangladesh.org, www. crp-bangladesh.org

*Ref:* CRP-R&E-0401-0420

*Date:* 29.01.2023

To
M Kamrul Ahsan
MSc in Global Health (2nd Year)
Faculty of Medicine and Health Science
Norwegian University of Science and Technology (NTNU)
Email: mkah@stud.ntnu.no
Cell: +47 462 37 989.

Ref: *Study Title* ''A qualitative study in Bangladesh about the everyday life experiences of family caregivers of adult individuals with a physical disability''.

Sub: Approval of documents for *Study Title* ''A qualitative study in Bangladesh about the everyday life experiences of family caregivers of adult individuals with a physical disability.

Dear Mr. Ahsan,

The CRP Ethics Committee reviewed and discussed on your application to conduct the research entitled ''A qualitative study in Bangladesh about the everyday life experiences of family caregivers of adult individuals with a physical disability''. Which was submitted on 20th December 2022.

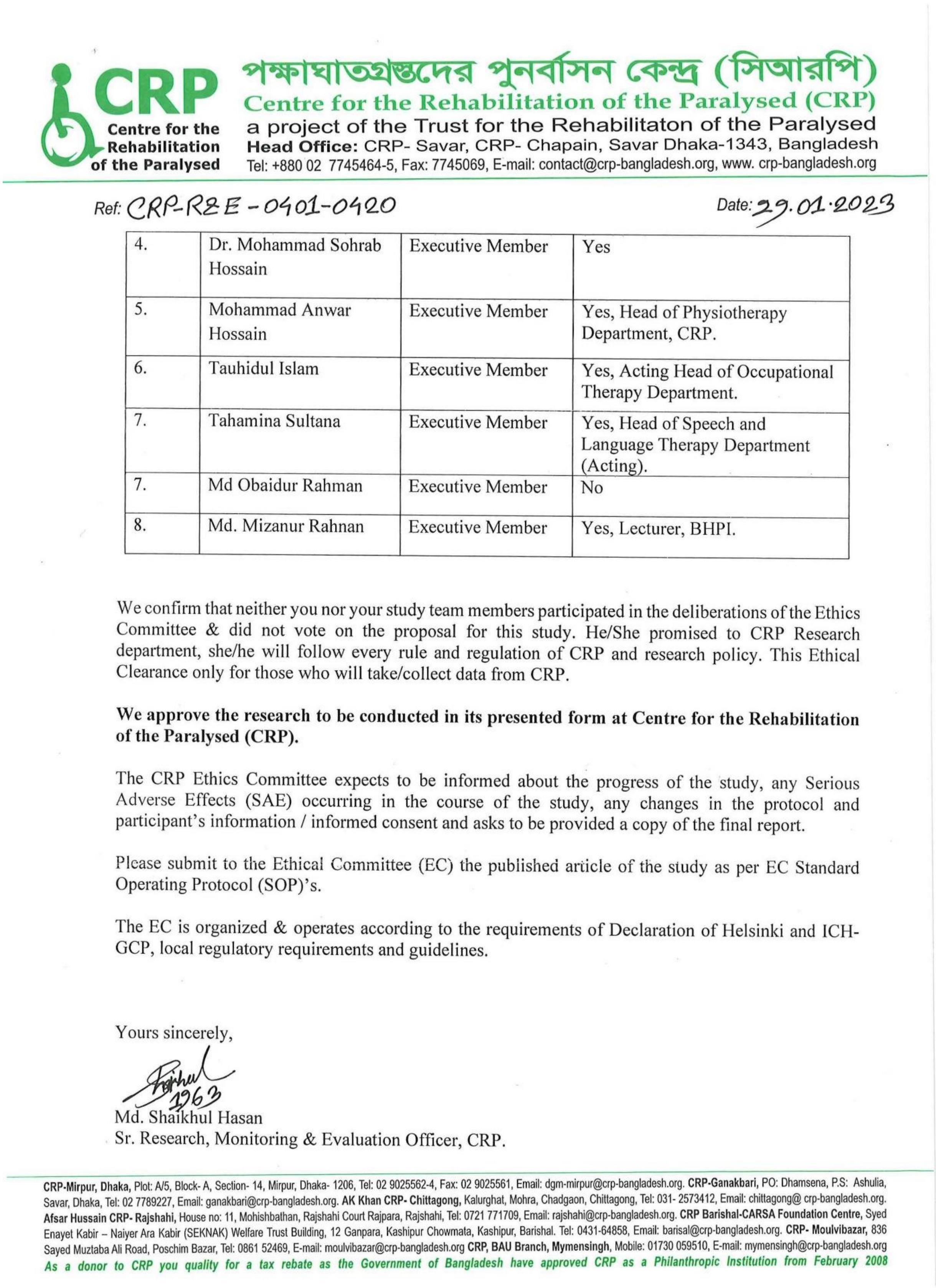
The following documents were reviewed:

| SL. No. | Documents | Version | *Dated* | *Copy* |
|---|---|---|---|---|
| 1 | Protocol | - |  | 1 |

**The following members of the ethics committee reviewed the protocol on 20.12.2022.**

| **SL. No.** | **Name** | **Role in EC** | **Affiliation with Institute (Yes/No) If yes, Specify......** |
|---|---|---|---|
| 1. | Prof. Dr. Mohammad Alamgir Kabir | Chair of CRPEC | No |
| 2. | Md. Shaikhul Hasan | Member Secretary | Yes, Sr. Research, Monitoring & Evaluation Officer |
| 3. | Nasirul Islam | Executive Member | Yes |

**CRP-Mirpur, Dhaka,** Plot: A/5, Block- A, Section- 14, Mirpur, Dhaka- 1206, Tel: 02 9025562-4, Fax: 02 9025561, Email: dgm-mirpur@crp-bangladesh.org. **CRP-Ganakbari,** PO: Dhamsena, P.S: Ashulia, Savar, Dhaka, Tel: 02 7789227, Email: ganakbari@crp-bangladesh.org. **AK Khan CRP- Chittagong,** Kalurghat, Mohra, Chadgaon, Chittagong, Tel: 031- 2573412, Email: chittagong@ crp-bangladesh.org. **Afsar Hussain CRP- Rajshahi,** House no: 11, Mohishbathan, Rajshahi Court Rajpara, Rajshahi, Tel: 0721 771709, Email: rajshahi@crp-bangladesh.org. **CRP Barishal-CARSA Foundation Centre,** Syed Enayet Kabir – Naiyer Ara Kabir (SEKNAK) Welfare Trust Building, 12 Ganpara, Kashipur Chowmata, Kashipur, Barishal. Tel: 0431-64858, Email: barisal@crp-bangladesh.org. **CRP- Moulvibazar,** 836 Sayed Muztaba Ali Road, Poschim Bazar, Tel: 0861 52469, E-mail: moulvibazar@crp-bangladesh.org **CRP, BAU Branch, Mymensingh,** Mobile: 01730 059510, E-mail: mymensingh@crp-bangladesh.org
***As a donor to CRP you quality for a tax rebate as the Government of Bangladesh have approved CRP as a Philanthropic Institution from February 2008***



**CRP**
Centre for the Rehabilitation of the Paralysed

পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্র (সিআরপি)
Centre for the Rehabilitation of the Paralysed (CRP)
a project of the Trust for the Rehabilitaton of the Paralysed
**Head Office:** CRP- Savar, CRP- Chapain, Savar Dhaka-1343, Bangladesh
Tel: +880 02 7745464-5, Fax: 7745069, E-mail: contact@crp-bangladesh.org, www. crp-bangladesh.org

Ref: CRP-R&E-0401-0420

Date: 29.01.2023

| | | | |
|---|---|---|---|
| 4. | Dr. Mohammad Sohrab Hossain | Executive Member | Yes |
| 5. | Mohammad Anwar Hossain | Executive Member | Yes, Head of Physiotherapy Department, CRP. |
| 6. | Tauhidul Islam | Executive Member | Yes, Acting Head of Occupational Therapy Department. |
| 7. | Tahamina Sultana | Executive Member | Yes, Head of Speech and Language Therapy Department (Acting). |
| 7. | Md Obaidur Rahman | Executive Member | No |
| 8. | Md. Mizanur Rahnan | Executive Member | Yes, Lecturer, BHPI. |

We confirm that neither you nor your study team members participated in the deliberations of the Ethics Committee & did not vote on the proposal for this study. He/She promised to CRP Research department, she/he will follow every rule and regulation of CRP and research policy. This Ethical Clearance only for those who will take/collect data from CRP.

**We approve the research to be conducted in its presented form at Centre for the Rehabilitation of the Paralysed (CRP).**

The CRP Ethics Committee expects to be informed about the progress of the study, any Serious Adverse Effects (SAE) occurring in the course of the study, any changes in the protocol and participant's information / informed consent and asks to be provided a copy of the final report.

Please submit to the Ethical Committee (EC) the published article of the study as per EC Standard Operating Protocol (SOP)'s.

The EC is organized & operates according to the requirements of Declaration of Helsinki and ICH-GCP, local regulatory requirements and guidelines.

Yours sincerely,

Md. Shaikhul Hasan
Sr. Research, Monitoring & Evaluation Officer, CRP.

**CRP-Mirpur, Dhaka,** Plot: A/5, Block- A, Section- 14, Mirpur, Dhaka- 1206, Tel: 02 9025562-4, Fax: 02 9025561, Email: dgm-mirpur@crp-bangladesh.org. **CRP-Ganakbari,** PO: Dhamsena, P.S: Ashulia, Savar, Dhaka, Tel: 02 7789227, Email: ganakbari@crp-bangladesh.org. **AK Khan CRP- Chittagong,** Kalurghat, Mohra, Chadgaon, Chittagong, Tel: 031- 2573412, Email: chittagong@ crp-bangladesh.org. **Afsar Hussain CRP- Rajshahi,** House no: 11, Mohishbathan, Rajshahi Court Rajpara, Rajshahi, Tel: 0721 771709, Email: rajshahi@crp-bangladesh.org. **CRP Barishal-CARSA Foundation Centre,** Syed Enayet Kabir – Naiyer Ara Kabir (SEKNAK) Welfare Trust Building, 12 Ganpara, Kashipur Chowmata, Kashipur, Barishal. Tel: 0431-64858, Email: barisal@crp-bangladesh.org. **CRP- Moulvibazar,** 836 Sayed Muztaba Ali Road, Poschim Bazar, Tel: 0861 52469, E-mail: moulvibazar@crp-bangladesh.org **CRP, BAU Branch, Mymensingh,** Mobile: 01730 059510, E-mail: mymensingh@crp-bangladesh.org

***As a donor to CRP you quality for a tax rebate as the Government of Bangladesh have approved CRP as a Philanthropic Institution from February 2008***

# Appendix iv. Questionnaire/ Interview Guide

Primarily, the following semi-structured interview guide is developed but later these guides will be tailored according to the need of the research. প্রাথমিকভাবে, নিম্নলিখিত আধা-কাঠামোগত ইন্টারভিউ গাইড তৈরি করা হয়েছে কিন্তু পরে এই গাইডগুলি গবেষণার প্রয়োজন অনুসারে পরিমার্জন করা হতে পারে।

| No. | Questionaries/ প্রশ্নাবলী |
|---|---|
| 1. | Relationship between the caregiver to the patient and how long they know the patient. রোগীর সাথে পরিচর্যাকারীর মধ্যে সম্পর্ক এবং তারা কতদিন যাবত রোগীকে চেনেন। |
| 2. | Can you please tell me when you first encountered the condition and what was the situation then? First thoughts and realization after hearing about the condition. আপনি কি আমাকে বলবেন যে, প্রথম কখন এই অবস্থার সম্মুখীন হয়েছিলেন এবং তখন আপনার পরিস্থিতি কী ছিল? অবস্থা সম্পর্কে শুনে আপনার প্রথম চিন্তা এবং উপলব্ধি কি ছিলো? |
| 3. | Do you experience your situation as stressful as a caregiver? a) Please tell me, what kind of stress do you experience? b) How does this affect you? Your family? Your profession? Your quality of life? Physical and mental health? একজন পারিবারিক পরিচর্যাকারী হিসেবে আপনার পরিস্থিতির মধ্যে কিরুপ চাপ অনুভব করেন? আমাকে এই বিষয়ে বলুন। ক) দয়া করে আমাকে বলুন, আপনি কি ধরনের মানসিক চাপ অনুভব করেন? খ) এটি আপনাকে কীভাবে প্রভাবিত করে? আপনার পরিবারের উপর ? আপনার পেশাগত জীবনের উপর? আপনার জীবনের সার্বিক মানের উপর? শারীরিক ও মানসিক স্বাস্থ্যের উপর? |
| 4. | Do you experience or feel any kind of burden? Please tell me some more about this. আপনি কি কোনো ধরনের বোঝা অনুভব করেন বা আপনার এই ব্যাপারে কোনরুপ অভিজ্ঞতা থাকলে আমাকে এই সম্পর্কে আরো কিছু বলুন। |
| 5. | How do you cope with the stress or burden? What could be supporting you? আপনি কিভাবে চাপ বা বোঝা মোকাবেলা করে থাকেন? কি ঙ্কি জিনিস পেয়ে থাকলে বা করা হয়ে থাকলে আপনি স্বস্তি অনুভব করতেন বা আপনার চাপ কম অনুভব হতে পারতো হতে বলে মনে করেন। |
| 6. | Caregiver’s knowledge about the process of taking medical help and rehabilitation from hospitals or centers for the person they are taking care of. পারিবারিক পরিচর্যাকারীরা যে ব্যক্তির যত্ন |

| | |
|---|---|
| | নিচ্ছেন তার জন্য হাসপাতাল বা চিকিৎসাকেন্দ্র থেকে চিকিৎসা সহায়তা এবং পুনর্বাসনের প্রক্রিয়া সম্পর্কে পরিচর্যাকারীরা কতটা যত্নশীল এবং তাদের এই সম্পর্কিত জ্ঞান সম্পর্কে ধারণা লাভ। |
| 7. | Practical experience or real-life experience while seeking medical help and rehabilitation for the patient by the caregiver. রোগীর জন্য চিকিৎসা সহায়তা এবং পুনর্বাসনের সময় পরিচর্যাকারীর ব্যবহারিক অভিজ্ঞতা বা বাস্তব জীবনের অভিজ্ঞতা। |
| 8. | Please, tell me about what you may experience as support in this situation as a caregiver. Do you have any wishes for support? What could be helpful for you, as you see it? অনুগ্রহ করে, একজন পরিচর্যাকারী হিসাবে এই পরিস্থিতিতে কি পেলে আপনি তাকে সহায়তা হিসাবে গন্য করতেন, সে সম্পর্কে আমাকে বলুন। সহায়তা পাওয়ার ব্যাপারে আপনার কোনরুপ আশা রয়েছে কি? কি কি জিনিস আপনার জন্য সহায়ক হতে পারবে? |
| 9. | What are the things that come to your mind while caring for your patient? Can you tell me more about your thoughts? আপনার রোগীর যত্ন নেওয়ার সময় আপনার মনে কী কাজ করে? আপনি কি আমাকে আপনার চিন্তা সম্পর্কে আরো বলতে পারেন? |
| 10. | From your point of view, what are the things that you think is important as a caregiver of a disabled family member in Bangladesh? Do you want to add something more? আপনার দৃষ্টিকোণ থেকে, বাংলাদেশে পরিবারের একজন প্রতিবন্ধী সদস্যের যত্ন নেওয়ার জন্য আপনি কী কী জিনিসকে গুরুত্বপূর্ণ বলে মনে করেন? আপনি আরো কিছু যোগ করতে চান? |

## Appendix v. Information Pages ( তথ্য পৃষ্ঠাবলী)

# Are you interested in taking part in the research project- “A qualitative study in Bangladesh about the everyday life experiences of family caregivers of adult individuals with a physical disability.”? (আপনি কি -"শারীরিকভাবে (চলাচলে বা কাজকর্মে) অসক্ষম প্রাপ্তবয়স্ক ব্যক্তিদের পারিবারিক পরিচর্যাকারীদের দৈনন্দিন জীবনের অভিজ্ঞতা সম্পর্কে বাংলাদেশে একটি গুণগত গবেষণা ।" শীর্ষক গবেষণা প্রকল্পে অংশ নিতে আগ্রহী?)

This is an inquiry about participation in a research project where the main purpose of this study is to identify and understand the everyday experiences of family caregivers of physically disabled adults living in Bangladesh. In this letter, we will give you information about the purpose of the study and what your participation will involve. (এটি একটি গবেষণা প্রকল্পে অংশগ্রহণের বিষয়ে একটি অনুসন্ধান যেখানে এই গবেষণার মূল উদ্দেশ্য হল বাংলাদেশে বসবাসকারী শারীরিকভাবে অসক্ষম প্রাপ্তবয়স্কদের পারিবারিক পরিচর্যাকারীদের দৈনন্দিন অভিজ্ঞতা সনাক্ত করা এবং এই ব্যাপারে ধারণা লাভ করা। এই চিঠিতে, আমরা আপনাকে এই গবেষণার মূল উদ্দেশ্য এবং আপনার অংশগ্রহণের সাথে কী কী বিষয় জড়িত সে সম্পর্কে তথ্য প্রদান করবো।)

### Purpose of the study (গবেষণার উদ্দেশ্য)

This research study is a part of a master’s thesis where family caregivers’ everyday life, challenges caregivers to face regularly, coping strategies, and motivations they have while giving care to their patients will be explored. The study area will be the experiences of family caregivers, the stress they feel, their day-to-day life barriers and coping strategies, medical help-seeking tendencies, knowledge about it, support, and expectations they have. This will help understand caregivers’ situations better so that suggestive advice can be provided to new caregivers and concrete recommendations can be given to healthcare professionals. (এই গবেষণা অধ্যয়নটি একটি মাস্টার্স থিসিসের অংশ যেখানে পরিবারের শারীরিরকভাবে চলাফেরা বা কাজকর্মে অসক্ষম প্রাপ্তবয়স্ক ব্যক্তির সেবাকারীদের দৈনন্দিন জীবন, নিয়মিত মুখোমুখি হওয়া বিভিন্ন চ্যালেঞ্জ, তা মোকাবিলা করার কৌশল এবং তাদের রোগীদের যত্ন নেওয়ার সময় তাদের যে অনুপ্রেরণাগুলি কাজ করে তা খুজে দেখার চেস্টা করা হবে। এই অধ্যয়নের গন্ডি হবে পারিবারিক পরিচর্যাকারীদের অভিজ্ঞতা, তারা যে মানসিক চাপ অনুভব করে, তাদের দৈনন্দিন জীবনের প্রতিবন্ধকতা এবং মোকাবেলার কৌশল, চিকিৎসা সহায়তা চাওয়ার প্রবণতা, এটি সম্পর্কে জ্ঞান, সমর্থন এবং তাদের প্রত্যাশা। এটি

পারিবারিক পরিচর্যাকারীদের পরিস্থিতি আরও ভালভাবে বুঝতে সাহায্য করবে যাতে করে নতুন পরিচর্যাকারীদের পরামর্শ প্রদান করা যেতে পারে এবং স্বাস্থ্যসেবা প্রদানকারী পেশার সাথে জড়িতদের সুনির্দিষ্ট সুপারিশ দেওয়া যেতে পারে।)

The following research questions will be addressed: (নিম্নলিখিত গবেষণামুলক প্রশ্নগুলোর উত্তর খোজা হবে)

1. What is the most challenging part of having a disabled person in a family and the common burdens of a caregiver's day-to-day life in Bangladesh? (একটি পরিবারে একজন প্রতিবন্ধী ব্যক্তি থাকায় সচেয়ে চ্যালেঞ্জিং অংশটি কি এবং বাংলাদেশে একজন পরিচর্যাকারীর দৈনন্দিন জীবনের সচরাচর বাধা-বিপত্তিগুলো কি কি?)
2. What are the barriers the caregivers are facing while getting medical help and rehabilitation for disabled persons and how the family caregivers are managing it? (প্রতিবন্ধী ব্যক্তিদের জন্য চিকিৎসা সহায়তা এবং পুনর্বাসন পাওয়ার সময় পরিচর্যাকারীরা কী কী প্রতিবন্ধকতার সম্মুখীন হচ্ছেন এবং পরিচর্যাকারীরা কীভাবে এটি ব্যবস্থাপনা করছেন?)
3. What are the family caregivers' perceptions about how society is treating them, and how the caregivers are coping with it? (সমাজ তাদের সাথে কীভাবে আচরণ করছে এবং তারা কীভাবে এটি মোকাবেলা করছে? সে সম্পর্কে পরিবারের পরিচর্যাকারীদের মনোভাব কী?)

This project will aim to develop knowledge about (এই গবেষণাটির মূল উদ্দেশ্য হলো নিম্নলিখিত বিষয়ে জ্ঞান অর্জন করা)

- Challenges and common burdens the caregivers face regularly while giving care to the disabled person. Inspiration or aspects that might work behind developing coping techniques and strategies that have been conducted by the caregivers. (প্রতিবন্ধী ব্যক্তির যত্ন নেওয়ার সময় পরিচর্যাকারীরা নিয়মিত যেসকল চ্যালেঞ্জ এবং সাধারণ প্রতিবন্ধকতার মুখোমুখি হন, উৎসাহ বা অনুপ্রেরণর দিক যা পরিচর্যাকারীদের দ্বারা আয়ত্তকৃত, মোকাবেলার কৌশল এবং কৌশলগুলি বিকাশের পিছনে যা যা কাজ করতে পারে।)
- Identify the knowledge, awareness, affordability, access to rehabilitation therapy, and the medical help-seeking tendency among the caregivers for a physically disabled person. (জ্ঞান, সচেতনতা, সামর্থ্য, পুনর্বাসন থেরাপির সহজপ্রাপ্যতা, এবং একজন শারীরিকভাবে অক্ষম ব্যক্তির জন্য পরিচর্যাকারীদের মধ্যে চিকিৎসা সহায়তা চাওয়ার প্রবণতা চিহ্নিতকরণ।)
- Understand what are the things that influence caregivers' everyday lives positively or negatively while giving care to disabled ones. How as a caregiver including his or her

family with a disabled person deals with these influences? (প্রতিবন্ধীদের যত্ন দেওয়ার সময় পরিচর্যাকারীদের দৈনন্দিন জীবনকে ইতিবাচক বা নেতিবাচকভাবে প্রভাবিত করে এমন জিনিসগুলি কী তা বোঝা। একজন প্রতিবন্ধী ব্যক্তির সাথে তার বা তার পরিবার সহ একজন তত্ত্বাবধায়ক হিসাবে কীভাবে এই প্রভাবগুলি মোকাবেলা করেন?)

- Provide experience-based suggestions to caregivers and concrete recommendations to healthcare providers according to the findings. (পরিচর্যাকারীদের অভিজ্ঞতা-ভিত্তিক পরামর্শ প্রদান করা এবং ফলাফল অনুযায়ী স্বাস্থ্যসেবা প্রদানকারীদেরকে সুনির্দিষ্ট সুপারিশ প্রদান করণ।)

The interview data will be used for the master’s thesis paper of the researcher only. No other institute or person will use them for any kind of research or educational purposes. (ইন্টারভিউতে প্রাপ্ত তথ্য শুধুমাত্র শিক্ষানবিশ গবেষকের মাস্টার্স থিসিস পেপারের জন্য ব্যবহার করা হবে। অন্য কোন ইনস্টিটিউট বা ব্যক্তি কোন ধরনের গবেষণা বা শিক্ষামূলক উদ্দেশ্যে তা ব্যবহার করবে না।)

### Who is responsible for the research study? (এই গবেষণার জন্য দায়ী কে?)

The master’s student M Kamrul Ahsan is responsible for the research project and is a student of Global Health currently doing his master’s at NTNU (Norwegian University of Science and Technology). (শিক্ষানবিশ গবেষক এম কামরুল আহসান এই গবেষণা কার্যক্রমের জন্য দায়ী। তিনি গ্লোবাল হেলথ বিষয়ে নরওয়েজিয়ান ইউনিভার্সিটি অফ সায়েন্স অ্যান্ড টেকনোলজির একজন মাস্টার্স পর্যায়ের শিক্ষার্থী। )

### Why are you being asked to participate? (কেন আপনাকে অংশগ্রহণ করতে বলা হচ্ছে?)

We are looking for family caregivers who have been giving care to his/her physically disabled family members for more than a year and can participate voluntarily in this study. Around 10-12, participants will be asked to be included in the study. The participant can be anyone related to the patient, for example, spouse, son/daughter, parents, siblings, cousin, etc.

Contact information about you was obtained from CRP (Centre for the Rehabilitation of the Paralyzed). Prior approval was taken from the institute’s ERC (Ethical Review Committee) to conduct the study. (আমরা পরিবারের এমন পরিচর্যাকারীদের খুঁজছি যারা তার শারীরিকভাবে অক্ষম পরিবারের সদস্যকে এক বছরেরও বেশি সময় ধরে যত্ন দিচ্ছেন এবং এই গবেষণায় স্বেচ্ছায় অংশগ্রহণ করতে পারেন। প্রায় ১০-১২ জন অংশগ্রহণকারীদের গবেষণায় অন্তর্ভুক্ত

হতে আমন্ত্রণ করা হবে। অংশগ্রহণকারী রোগীর সাথে সম্পর্কিত যে কেউ হতে পারে, উদাহরণস্বরূপ- পত্নী, পুত্র/কন্যা, পিতামাতা, ভাইবোন, চাচাতো-মামাতো ভাই ইত্যাদি।

আপনার সাথে যোগাযোগের তথ্য সিআরপি (সেন্টার ফর দ্য রিহ্যাবিলিটেশন অফ দ্য প্যারালাইজড) থেকে পাওয়া গেছে। অধ্যয়ন পরিচালনা করার জন্য ইনস্টিটিউটের ই আর সি (নৈতিক গবেষণা কমিটি) থেকে পূর্বে অনুমোদন নেওয়া হয়েছে।

## What does participation involve for you? (অংশগ্রহণে আপনার জন্য কি কি বিষয় জড়িত?)

If you chose to take part in the project, this will involve you giving a direct interview. It will take approx. 45 minutes. The interview includes questions about your day-to-day experience while taking care of the physically disabled person in your family. Answering question is also voluntary. You have the right not to answer any question that you don't want to answer. Your interview will be recorded electronically with an audio recorder. (আপনি যদি এই গবেষণায় অংশ নেওয়ার সিদ্ধান্ত নেন, তাহলে আপনাকে একটি সরাসরি সাক্ষাৎকারে অংশগ্রহণ করতে হবে। এটা প্রায় ৪৫ মিনিট স্থায়ী হতে পারে। সাক্ষাত্কারে আপনার পরিবারের শারীরিকভাবে অক্ষম ব্যক্তির যত্ন নেওয়ার সময় আপনার প্রতিদিনের অভিজ্ঞতা সম্পর্কে প্রশ্ন অন্তর্ভুক্ত রয়েছে। প্রশ্নের উত্তর দেওয়া আপনার ইচ্ছার উপর নির্ভর করে। আপনি যে প্রশ্নের উত্তর দিতে চান না তার উত্তর না দেওয়ার অধিকার আপনার আছে। আপনার সাক্ষাৎকার একটি অডিও রেকর্ডার দিয়ে ইলেকট্রনিকভাবে রেকর্ড করা হবে।)

## Participation is voluntary. (স্বেচ্ছায় অংশগ্রহণ)

Participation in the project is voluntary. If you chose to participate, you can withdraw your consent at any time without giving a reason. All information about all of the participants will be made anonymous. There will be no negative consequences for you if you chose not to participate or later decide to withdraw. Participation in this study neither harms nor benefits you in any way from CRP or the researcher himself. It will not affect your treatment at CRP, your relationship with your physiotherapist or occupational therapist, or any other place in this institute. ( এই প্রকল্পে অংশগ্রহণ স্বেচ্ছায় । আপনি যদি অংশগ্রহণ করার সিদ্ধান্ত নেন, আপনি কোনো কারণ না জানিয়ে যে কোনো সময় আপনার সম্মতি প্রত্যাহার করতে পারেন। আপনার সম্পর্কে সমস্ত তথ্য তারপর বেনামী করা হবে। আপনি অংশগ্রহণ না করা বা পরে প্রত্যাহার করার সিদ্ধান্ত নিলে আপনার জন্য কোন নেতিবাচক পরিণতি হবে না। এই গবেষণায় অংশগ্রহণের জন্য CRP বা শিক্ষানবিশ গবেষকের কাছ থেকে আপনার কোনো ক্ষতি বা বাড়তি সুবিধা আপনি পাবেন না। এটি CRP-তে আপনার চিকিৎসা, আপনার ফিজিওথেরাপিস্ট বা অকুপেশনাল থেরাপিস্টের সাথে আপনার সম্পর্ক বা এই ইনস্টিটিউটের অন্য কোনো জায়গায় প্রভাব ফেলবে না।

## Your personal privacy – how we will store and use your personal data (আপনার ব্যক্তিগত গোপনীয়তা আমরা কীভাবে আপনার ব্যক্তিগত ডেটা সংরক্ষণ এবং ব্যবহার করব)

We will only use your personal data for the purpose(s) specified in this information letter. We will process your personal data confidentially and in accordance with data protection legislation (the General Data Protection Regulation and Personal Data Act). আমরা শুধুমাত্র এই তথ্য চিঠিতে উল্লেখ করা উদ্দেশ্য(গুলি) জন্য আপনার ব্যক্তিগত ডেটা ব্যবহার করব। আমরা আপনার ব্যক্তিগত ডেটা গোপনীয়ভাবে এবং ডেটা সুরক্ষা আইন (সাধারণ ডেটা সুরক্ষা প্রবিধান এবং ব্যক্তিগত ডেটা আইন) অনুসারে প্রক্রিয়া করব।

- As a master’s student M Kamrul Ahsan (Global Health, NTNU) and his supervisor Professor Gørill Haugan will have access to the personal data of the participants for the research purpose only. (একজন মাস্টার্সের ছাত্র হিসেবে এম কামরুল আহসান (গ্লোবাল হেলথ, এনটিএনইউ) এবং তার তত্ত্বাবধায়ক প্রফেসর গরিল হাউগান শুধুমাত্র গবেষণার উদ্দেশ্যে অংশগ্রহণকারীদের ব্যক্তিগত ডেটাতে অ্যাক্সেস পাবেন।)
- Your name and contact details will be replaced with a code. The list of names, contact details, and respective codes will be stored separately from the rest of the collected interview data, the audio recording will be stored on a research cloud server, locked away/encrypted, etc. No unauthorized person will be allowed to use or gain access to the data. (আপনার নাম এবং যোগাযোগের বিবরণ একটি কোড দিয়ে প্রতিস্থাপিত হবে। নামের তালিকা, যোগাযোগের বিশদ বিবরণ এবং সংশ্লিষ্ট কোডগুলি সংগৃহীত সাক্ষাত্কারের বাকি ডেটা থেকে আলাদাভাবে সংরক্ষণ করা হবে, অডিও রেকর্ডিং একটি গবেষণা ক্লাউড সার্ভারে সংরক্ষণ করা হবে, লক করা/এনক্রিপ্ট করা থাকবে। কোনও অননুমোদিত ব্যক্তিকে ডেটা ব্যবহার বা অ্যাক্সেস লাভের অনুমতি দেওয়া হবে না।। )
- A research assistant will help to recruit participants. (একজন গবেষণা সহকারী অংশগ্রহণকারীদের নিয়োগ করতে সাহায্য করবে।)
- Interview will be taken by the master’s student(researcher) himself and the audio recording will also be done by him. (সাক্ষাৎকারটি মাস্টার্সের ছাত্র (গবেষক) নিজেই নেবেন এবং অডিও রেকর্ডিংও তিনিই করবেন।)
- Transcription of the interview will be kept under a file folder in a safe and secure place with a lock and key. No unauthorized person will have access to the files. ( সাক্ষাৎকারটির

ট্রান্সক্রিপশন একটি ফাইল ফোল্ডারের মধ্যে রেখে একটি তালা এবং চাবি সহ একটি নিরাপদ এবং সুরক্ষিত জায়গায় রাখা হবে। কোনো অননুমোদিত ব্যক্তির ফাইলে অ্যাক্সেস থাকবে না। )

The participants will not be recognizable as their names will not be disclosed. Age group, occupation, and whether they are living in a town or village may be published but in a way that, they will not be recognizable. (অংশগ্রহণকারীদের নাম প্রকাশ করা হবে না বলে তাদের চেনা যাবে না। বয়স শ্রেনী, পেশা, এবং তারা শহরে বা গ্রামে বসবাস করছে কিনা তা প্রকাশ করা যেতে পারে কিন্তু এমনভাবে যেন তাদের চেনা না যায়। )

**What will happen to your personal data at the end of the research project? (গবেষণা প্রকল্পের শেষে আপনার ব্যক্তিগত ডেটার কী হবে ?)**

The master’s thesis is scheduled to end in mid-2023. After the result publication and thesis defense, all of the personal data will be kept for two more years for reference (until 30.06.2025). After that audio recording will be deleted and the interview transcripts in paper will be discarded using a paper shredder. But if within this time the research will go further to publish a paper in a scientific journal, follow-up studies, or future research, then all the data will be stored for longer periods in a safe and secure place to use as a reference. The data will be processed solely by the master’s student himself and his supervisor for future research if necessary. Nobody else will get access to personal data. (মাস্টার্স থিসিস ২০২৩-এর মাঝামাঝি শেষ হওয়ার কথা। ফলাফল প্রকাশের পর এবং থিসিস ডিফেন্সের জন্য সমস্ত ব্যক্তিগত তথ্য রেফারেন্সের জন্য আরও দুই বছরের জন্য রাখা হবে (৩০.০৬.২০২৩ পর্যন্ত)। এর পরে অডিও রেকর্ডিং মুছে ফেলা হবে এবং কাগজে ইন্টারভিউ ট্রান্সক্রিপ্টগুলি একটি পেপার শ্রেডার ব্যবহার করে বাতিল করা হবে। কিন্তু এই সময়ের মধ্যে যদি গবেষণাটি একটি বৈজ্ঞানিক জার্নালে প্রকাশিত করা হয়, ফলো-আপ স্টাডিজ বা ভবিষ্যতের গবেষণায় প্রকাশের জন্য আরও এগিয়ে যায়, তবে সমস্ত ডেটা আরো বেশ কিছুদিন রেফারেন্স হিসাবে ব্যবহার করার জন্য একটি নিরাপদ এবং নিরাপত্তা সম্বলিত জায়গায় সংরক্ষণ করা হবে। ব্যক্তিগত তথ্য শুধুমাত্র মাস্টার্স শিক্ষানবিশ গবেষক এবং তার সুপারভাইসার প্রসেস করবেন ভবিষ্যৎ গবেষণার প্রয়োজনবোধে। অন্য কেওই এই ব্যক্তিগত তথ্য ব্যবহারের অনুমতি পাবেন না )

**Your rights (আপনার অধিকার )**

So long as you can be identified in the collected data, you have the right to: (যতক্ষণ না আপনি সংগৃহীত ডেটাতে চিহ্নিত হতে পারেন, আপনার অধিকার আছে)

- access the personal data that is being processed about you. (আপনার সম্পর্কে প্রক্রিয়া করা হচ্ছে এমন ব্যক্তিগত ডেটা অ্যাক্সেস করতে পারবেন।)

- request that your personal data be deleted. (আপনার ব্যক্তিগত তথ্য মুছে ফেলার অনুরোধ করতে পারবেন।)
- request that incorrect personal data about you be corrected/rectified. (অনুরোধ করতে পারবেন যে আপনার সম্পর্কে ভুল ব্যক্তিগত তথ্য সংশোধন বা পরিমার্জন করার। )
- receive a copy of your personal data (data portability), and (আপনার ব্যক্তিগত ডেটার একটি অনুলিপি গ্রহণ করতে পারবেন (ডেটা বহনযোগ্যতা), এবং)
- send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data. (আপনার ব্যক্তিগত ডেটা প্রক্রিয়াকরণের বিষয়ে ডেটা সুরক্ষা অফিসার বা নরওয়েজিয়ান ডেটা সুরক্ষা কর্তৃপক্ষের কাছে একটি অভিযোগ পাঠাতে পারবেন)

### What gives us the right to process your personal data? (কি আমাদেরকে আপনার ব্যক্তিগত তথ্য প্রক্রিয়া করার অধিকার দেয়?)

We will process your personal data based on your consent. (আমরা আপনার সম্মতির ভিত্তিতে আপনার ব্যক্তিগত ডেটা প্রক্রিয়া করব।)

Based on an agreement with NTNU(Norwegian University of Science and Technology), Data Protection Services has assessed that the processing of personal data in this project is in accordance with data protection legislation. (NTNU (নরওয়েজিয়ান ইউনিভার্সিটি অফ সায়েন্স অ্যান্ড টেকনোলজি) এর সাথে একটি চুক্তির ভিত্তিতে ডেটা সুরক্ষা পরিষেবাগুলি মূল্যায়ন করেছে যে এই প্রকল্পে ব্যক্তিগত ডেটা প্রক্রিয়াকরণ ডেটা সুরক্ষা আইন অনুসারে হয়।)

### Where can I find out more? (কোথায় আমি আরও জানতে পারি?)

If you have questions about the project or want to exercise your rights, contact: **আপনার যদি প্রকল্প সম্পর্কে প্রশ্ন থাকে বা আপনার অধিকার প্রয়োগ করতে চান, যোগাযোগ করুন:**

- NTNU (Norwegian University of Science and Technology) via M Kamrul Ahsan (MSc. In Global Health), email:mkah@stud.ntnu.no, Cell: +4746237989(Norway), +8801988300107(Bangladesh), Supervisor: Gørill Haugan Professor, Ph.D., RN Head of the Division of Nursing (Bachelor) and Vocational Health Studies NTNU-Department of Public Health and Nursing Address: Post-box 8905, 7491 Trondheim, Norway e-mail: gorill.haugan@ntnu.no Phone: +47 73 41 21 58 Cell: +47 975 03 375. (NTNU-**নরওয়েজিয়ান ইউনিভার্সিটি অফ সায়েন্স অ্যান্ড টেকনোলজি) এম কামরুল আহসান (এমএসসি ইন গ্লোবাল হেলথ)**, ইমেইল**:**

mkah@stud.ntnu.no, **সেল:** +৪৭৪৬২৩৭৯৮৯ **(নরওয়ে)**, +৮৮০১৯৮৮৩০০১০৭ **(বাংলাদেশ), সুপারভাইজার: গরিল হাউগান, প্রফেসর, পিএইচ.ডি., নার্সিং (স্নাতক) এবং ভোকেশনাল হেলথ স্টাডিজ এনটিএনইউ- ডিপার্টমেন্ট অফ পাবলিক হেলথ অ্যান্ড নার্সিং বিভাগের প্রধান, আরএন । ঠিকানা: পোস্ট-বক্স** ৮৯০৫, ৭৪৯১ - **ট্রন্ডহেম, নরওয়ে। ই-মেইল:** gorill.haugan@ntnu.no **ফোন:** +৪৭৭৩৪১২১৫৮ মোবাইল**:** +৪৭৯৭৫০৩৩৭৫।

- Our Data Protection Officer: Thomas Helgesen, Data protection officer, Director Organization and Infrastructure, email: thomas.helgesen@ntnu.no, cell:+4793079038, Address: Sluppenveien 12B/C, Møllenberg 4 etg, Trondheim (**আমাদের ডেটা প্রোটেকশন অফিসার: থমাস হেলগেসেন, ডেটা সুরক্ষা অফিসার, ডিরেক্টর অর্গানাইজেশন অ্যান্ড ইনফ্রাস্ট্রাকচার, ইমেল:** thomas.helgesen@ntnu.no, মোবাইল**:**+ ৪৭৯৩০৭৯০৩৮ **ঠিকানা:** স্লুপ্পেনভেইয়েন, ১২ বি/সি, মোলেনবার্গ ৪র্থ তলা, ট্রন্ডহেইম। )
- Data Protection Services, by email: (personverntjenester@sikt.no) or by telephone: +47 53 21 15 00. (**ডেটা সুরক্ষা পরিষেবা, ইমেলের মাধ্যমে: (**personverntjenester@sikt.no) **বা টেলিফোনের মাধ্যমে:** +৪৭৫৩২১১৫০০।

Yours sincerely,
আপনার অনুগত,

Project Leader / সুপারভাইসর

(Researcher/supervisor)

Student (if applicable)/ শিক্ষানবিশ সাক্ষাৎ গ্রহণকারীর সাক্ষর

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# Appendix vi. Consent form (সম্মতি ফর্ম)

I have received and understood information about the project "A qualitative study in Bangladesh about the everyday life experiences of family caregivers of adult individuals with a physical disability." and have been given the opportunity to ask questions. I give consent: (আমি "শারীরিকভাবে (চলাচলে বা কাজকর্মে) অসক্ষম প্রাপ্তবয়স্ক ব্যক্তিদের পারিবারিক পরিচর্যাকারীদের দৈনন্দিন জীবনের অভিজ্ঞতা সম্পর্কে বাংলাদেশে একটি গুণগত গবেষণা।" প্রকল্প সম্পর্কে তথ্য পেয়েছি এবং বুঝতে পেরেছি এবং প্রশ্ন করার সুযোগ দেওয়া হয়েছে। আমি সম্মতি দিচ্ছি)

- ☐ to participate in the interview. (ইন্টারভিউতে অংশগ্রহণ করতে।)
- ☐ for the audio recording of the interview. (সাক্ষাৎকারের অডিও রেকর্ডিংয়ের জন্য। )
- ☐ for my personal data to be processed outside Bangladesh. (আমার ব্যক্তিগত তথ্য বাংলাদেশের বাইরে প্রসেস করার জন্য।)
- ☐ for information about me/myself (age group, occupation, living area) to be published in a way that I can be recognized. (আমার/আমার সম্পর্কে তথ্যের জন্য (বয়স গ্রুপ, পেশা, বসবাসের এলাকা) একটি উপায়ে প্রকাশ করা হবে।)
- ☐ for my personal data to be stored after the end of the project for follow-up studies and future references. (ফলো-আপ অধ্যয়ন এবং ভবিষ্যতের রেফারেন্সের জন্য প্রকল্প শেষ হওয়ার পরে আমার ব্যক্তিগত ডেটা সংরক্ষণ করার জন্য।)
- ☐ that I will not be benefited financially from the institute (CRP) or the researcher himself. যে আমি ইনস্টিটিউট (CRP) বা গবেষক নিজে থেকে আর্থিকভাবে উপকৃত হব না।
- ☐ that I know who and where to contact if I have any queries about the study and my rights or want to discontinue my participation and opt-out of the study. (যে আমি জানি যে অধ্যয়ন এবং আমার অধিকার সম্পর্কে আমার কোন প্রশ্ন থাকলে বা আমার অংশগ্রহণ বন্ধ করতে এবং অধ্যয়ন থেকে অপ্ট-আউট করতে চাইলে কার এবং কোথায় যোগাযোগ করতে হবে। )

I give consent for my personal data to be processed until the end date of the project, approx. mid-2023. (আমি আমার ব্যক্তিগত ডেটা প্রকল্পের শেষ তারিখ পর্যন্ত প্রক্রিয়া করার জন্য সম্মতি দিচ্ছি, যেটা প্রায়, ২০২৩ সালের মাঝামাঝি। )

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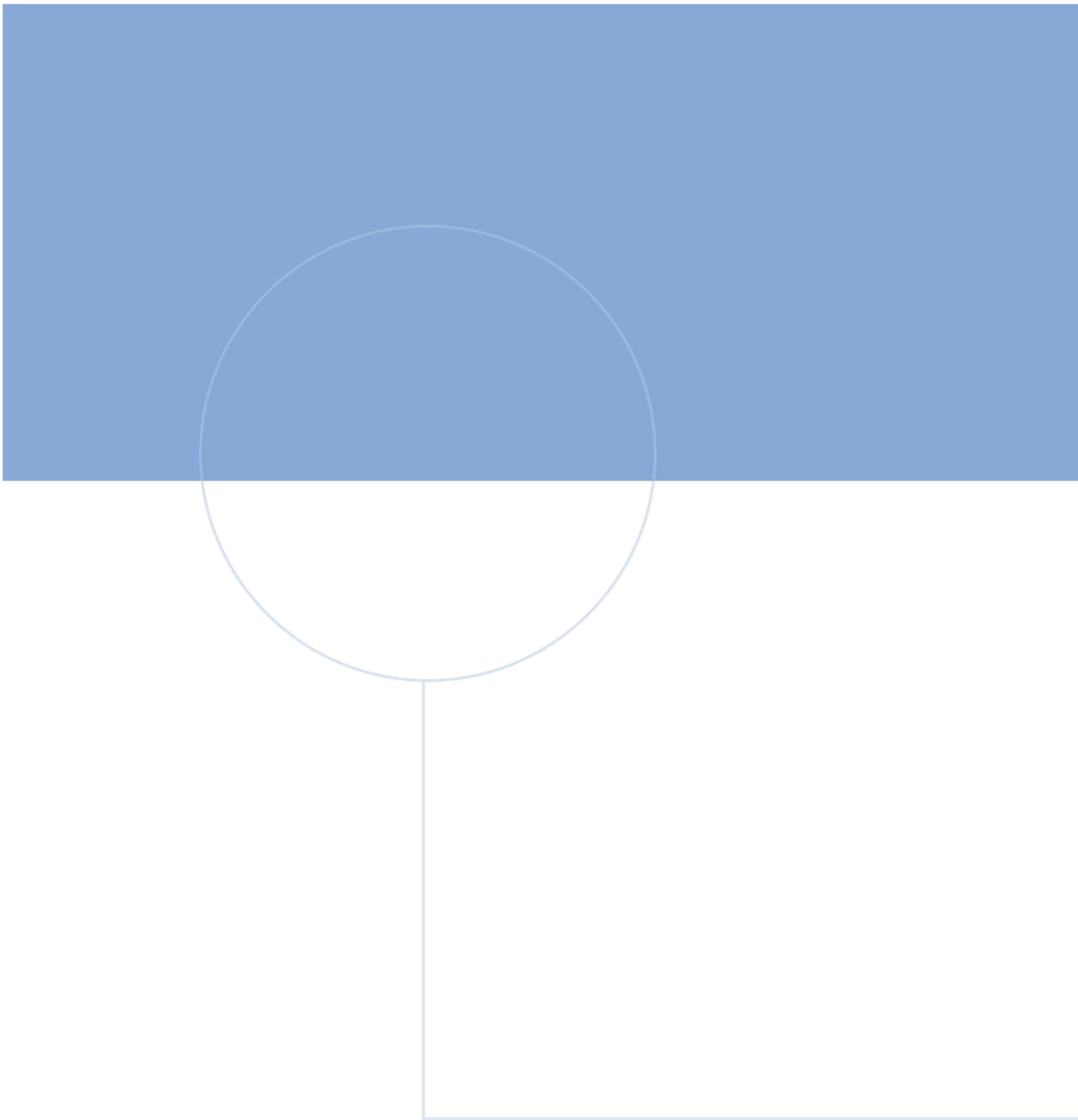
(Signed by participant, date)/ (অংশগ্রহণকারীর স্বাক্ষর ও তারিখ)



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