# Family Caregivers' Experience during Caregiving Persons with Post-Stroke Cognitive Deficits: A Qualitative Study



By

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# **Statement of Authorship**

Except where it is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis presented by me for any other degree or seminar. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any other degree in any other tertiary institution. The ethical issue of the study has been strictly considered and protected. In case of dissemination of the findings of this project for future publication, the research supervisor will be highly concerned, and it will be duly acknowledged as an undergraduate thesis.

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# List of Abbreviations

AARP	American Association of Retired Person		
BAMSE	Bangla Adaptation of Mini-Mental State Examination		
CIND	Cognitive Impairment No Dementia		
COREQ	Consolidated Criteria for Reporting Qualitative Research		
СР	Care Partner		
MMSE	Mini-Mental State Examination		
PSCI	Post Stroke Cognitive Impairment		
SMMSE	Standardized Mini-Mental State Examination		
SS	Stroke Survivor		

# Abstract

**Background:** Stroke survivors frequently experience cognitive problems. Stroke survivors and their family caregivers are both impacted by cognitive issues and implement practical solutions to them. There is very little research about the caregivers' experience of stroke survivors with cognitive deficits, especially in the South Asian context. This study aims to explore caregivers' experiences while caring for individuals with post-stroke cognitive deficits.

**Methods:** This study was designed using a qualitative, phenomenological approach. Participants were recruited through the Patient Details Management System of a rehabilitation centre. The study employed a qualitative research design to gather data from six family caregivers of individuals with post-stroke cognitive deficits. The data collection method involved conducting in-depth face-to-face interviews using semistructured interview guidelines and field notes. The determination of the sample size was based on achieving data saturation. The study employed audio-recording techniques to capture first-person narratives in Bangla, which were transcribed and translated into English. The interview transcripts were returned to the participants for verification of the accuracy of their statements as reflected in the transcripts. The present study integrated thematic analysis, utilizing Braun and Clark's six-step approach.

**Results:** Six people between 18 and 65 were questioned; three were men, and the other three were women. The aforementioned qualitative investigation explores significant perspectives regarding the encounters of familial caregivers tasked with

providing care for individuals who have suffered from strokes and are experiencing cognitive impairments. Five overreaching themes were found: (i) Day-to-day Experience, (ii) Physical Impact, (iii) Emotional Health, (iv) Overcoming Obstacles and Adopting New Approaches, and (v) Lessons Learned through Providing care.

**Conclusions:** This research emphasizes the necessity for heightened focus and assistance for familial caregivers in the realm of cognitive impairments following a stroke, particularly within the South Asian context, where there exists a shortage of investigation in this area. By gaining a greater understanding of caregivers' experiences, healthcare practitioners can develop more empathetic and efficacious interventions to foster the well-being of stroke survivors and their caregivers. This study could enhance the quality of care and support services offered to people with post-stroke cognitive impairments and their families.

**Keywords:** Post-stroke Cognitive Deficits, Emotional Solace, Family Caregiver, Day to day experience, Providing care

# **CHAPTER I: INTRODUCTION**

### 1.1. Background

According to Pindus et al. (2018), stroke is the second-most significant cause of mortality worldwide and leaves its survivors with persistent impairment. Long-term difficulties brought on by stroke can also result in cognitive deficits (Tang et al., 2018). Post-stroke cognitive deficits have received less attention than other mental and cognitive impairments for years, but recently, they have become a concern for health professionals (Mahadevan et al., 2021). According to Mahadevan et al.'s systematic review and meta-analysis published in 2021, post-stroke cognitive impairment is more prevalent in the western and southern regions of Asia and Africa than in other globally developed nations. But post-stroke cognitive impairment occurs at an alarming rate, as Nayan et al., (2016) estimated that about 40% of stroke survivors have some sort of cognitive impairment in Bangladesh. Among them, 31% have mild cognitive impairment, and 9% have severe cognitive impairment. This study also showed a substantial correlation between cognitive impairment and increased dependency on daily life tasks (Nayan et al., 2016). This is an essential topic of health and rehabilitation science since fostering independence and well-being is a primary focus of rehabilitation.

There are various components of cognition, for instance: the degree of arousal, orientation, memory, recognition, attention span, problem-solving, learning, the start and end of an activity, concept formulation, sequencing, generalisation, etc. According to Jokinen et al. (2015), post-stroke cognitive impairment encompasses a

variety of deficits across different areas rather than just one component. The APA Dictionary of Psychology defines a "cognitive impairment" or "cognitive deficits" as any impairment in the capacity to perceive, grasp, and interpret reality, think abstractly, reason, comprehend, or use language. In older persons with neurodegenerative disease and survivors of clinical strokes, cognitive impairment and dementia are common manifestations of post-stroke cognitive impairment. (Rost et al., 2022). The cognitive outcomes of stroke survivors are also impacted by other minor cerebral artery illnesses such as "covert brain infracts," "white matter lesions," and "micro-bleeds" (Rost et al., 2022).

Effective performance in daily life activities depends heavily on cognitive ability (Stigen et al., 2022). Although physical recovery from a stroke may be apparent, unresolved, hidden deficits, such as cognitive impairment, persist (Tang et al., 2018). Therefore, these patients need special care once they return to the community (Jokinen et al., 2015). According to McCquay (2023), a caregiver is someone who attends to the wants or worries of a person with temporary or permanent limits due to illness, accident, or disability.

Family caregivers are essential in the healthcare system since they are the first contact person to provide care and have substantial knowledge about the patient (Irfan et al., 2017). Notably, individuals with cognitive deficits, statements cannot be used as reliable data for any clinical or research purpose (Ashrafizadeh et al., 2021). Health care can be compared to a three-legged stool, with the care recipient acting as the third leg. The professional caregivers and health professionals are serving as the first and second legs, respectively (McQuay, 2023).

The burden of providing care is enormous, especially for "family caregivers". Family caregivers must balance their responsibilities for providing care with their personal, professional, and social obligations (Blanton et al., 2020). The effects of caregiving on many facets of caregivers' lives were examined by Irfan et al. in 2017. According to their findings, most caregivers emphasise the adverse effects of various factors. Numerous studies demonstrate that providing care has positive effects on the caregivers as well as negative ones. 90% of caregivers report that they are more appreciative of their lives when giving care. Numerous aspects of a caregiver's life are impacted by providing care, including their relationships, social interactions, and physical and mental health. Recently, researchers have begun to pay attention to both caregiving's positive and negative effects. The care recipient's health and quality of life might be affected by the impact on the caregivers. These effects may result from both excellent and adverse consequences (Haley et al., 2009).

Therefore, it is evident that family caregiver involvement is essential for integrating stroke survivors into their community. Caregivers work as communicators and assist the care recipients in maintaining good health. It can be challenging to care for a patient who has physical limitations.

Caregiving is significantly more difficult for a person with mild to moderate poststroke cognitive deficits (Tang et al., 2020). Even though they may be physically able to conduct everyday duties, those with cognitive deficits constantly require extra care because they cannot do so. Long-term caregiving can also be advantageous and taxing (Tang et al., 2020). This study aims to explore caregivers' experiences while providing care for individuals with post-stroke cognitive deficits.

## **1.2. Justification of the Study**

## For Caregivers and Care-Recipients

Understanding the experiences that family members go through when caring for individuals with post-stroke cognitive deficiencies makes it possible to identify the source of burden and stress.

In addition, exploring the experience can help identify coping strategies that have been successful in managing the challenges of caregiving. These explored findings can assist other caregivers in learning and adopting effective coping strategies. Moreover, the findings of the study can be used to improve interpersonal communication among patients and other family members with the main caregiver. Recognising these individuals' unique experiences can help break down social stigmas and promote greater awareness and support.

### **For Health Professionals**

Healthcare providers can improve communication with caregivers and provide more targeted support if they have a better grasp of the experiences of family members and how those experiences impacted them.

Health professionals can provide evidence-based care while integrating caregiver assessment, providing caregiver education, promoting caregiver support groups, and promoting environmental modifications by exploring contextualized lived experiences, particularly by helping the professionals develop educational materials. Exploring their thoughts, understanding, and beliefs will provide rich information that will be used to design interventions for improving care quality.

#### **For Policymakers**

Firstly, it's essential to recognise that caregivers play a crucial role in supporting the well-being of patients and reducing the burden on the healthcare system. Caregivers provide support services such as managing medications, coordinating appointments, managing therapeutic interventions, and assisting with daily living activities.

It is also essential to recognise the diverse experiences of caregivers. Caregivers may come from different backgrounds and communities with varying needs and preferences. Policies and programs should be designed to be inclusive and culturally sensitive to meet the needs of all caregivers.

#### For Bangladesh

Research in Bangladesh focused on exploring the experience of caregivers is essential for developing effective policies and interventions to improve the quality of care, develop new interventions despite having low resources for paid caregiving, raise awareness, and contribute to the global knowledge base on caregiving.

In conclusion, studying family members of people with post-stroke cognitive deficits can reduce caregiver burden, identify effective coping strategies, improve communication between caregivers and healthcare providers, improve patient care, and advocate for better caregiver support.

# **1.3. Operational Definition**

**Family caregiver:** The definition of family (informal) caregiver used in national surveys is not standardized (Kent et al., 2016). Any relative, friend, or partner with whom a significant personal relationship exists who provides assistance for a person with a chronic disabling condition is known as a "family caregiver". Certain personality attributes, such as emotions, talents, knowledge, time, and a strong emotional bond with the care recipient, help caregiving (Hermanns & Mastel-Smith, 2015).

**Cognitive deficits:** The APA Dictionary of Psychology defines a "cognitive impairment" or "cognitive deficits" as any impairment in the capacity to perceive, grasp, and interpret reality, think abstractly, reason, comprehend, or use language. Any impairment in the individual's mental process that leads to deficits in performing any task using cognitive components. Cognitive deficits are not restricted to any illness or condition but can indicate one of the symptoms of an individual's underlying ailment (Aayush & Bradford, 2023).

**Experience:** Authors of various fields, such as anthropology, neuroscience, education, psychology, and religious studies, have shown that experience is a complex interaction between the body, sensory input, and neurological processing a relationship with the world as people encounter, interpret, and shape messages. Experience is a complicated phenomenon that people understand on the basis of cultural, cognitive, subconscious, and personal levels.

# 1.4. Study Question, Aim and Objectives

# **1.4.1. Overarching Research Question**

What are the experiences of family caregivers while caregiving individuals with poststroke cognitive deficits?

# 1.4.2. Aim

This study aims to explore caregivers' experiences while providing care for individuals with post-stroke cognitive deficits.

# 1.4.3. Objectives

- Explore the caregivers' daily life experiences.
- Identify the impact on the caregivers' emotional state.
- Determine the specific challenges that caregivers face while caregiving individuals with post-stroke cognitive deficits.
- Explore the lessons of caregivers learn from caregiving.

# **CHAPTER II: LITERATURE REVIEW**

The literature review helps to gain an understanding of the existing research and debates related to the area of interest, or particular topic, or area of study, which can be presented in the form of a written report. The guide for literature reviews from Western Sydney University shows that this is the main purpose of a literature review and also helps to build knowledge in a particular field.

This literature review is an overview of a few articles related to this research topic. Related works of literature were searched with these keywords; "Stroke", "Cognitive deficits", "caregivers" "caregiver's experience" "caregiver's stress" and "caregiver's burden".

This review chapter narrates the statements of different researchers in their studies about 'cognitive deficits after stroke', 'prevalence of cognitive deficits', 'impacts of cognitive deficits', 'caregivers' and 'impacts on caregivers'.

## 2.1. Cognitive Deficits after Stroke

"Cognitive Deficit" is an umbrella word used to represent the impairment of several aspects of cognition, according to Aayush & Bradford (2023). Cognitive deficits can result from various diseases and conditions, but they can also be an outward sign of a deeper problem. "Cognitive deficit" or "cognitive impairment" might be a temporary disorder, a progressive condition, or a lifelong ailment.

Stroke is one of the most frequent causes of acquired cognitive deficits. As a result, survivors are more likely to require institutionalisation, experience disability, and

have a lower quality of life, according to a study by Rajan et al. in 2014. The second most frequent reason for higher mortality is stroke.

According to the study by Kalaria et al., (2016), stroke ranks third among causes and is the main factor in long-term disability and cognitive impairment. Healthcare systems must allocate a lot of resources to this. The risk of cognitive impairment rises after a stroke. Dementia that develops within three months of the beginning of the stroke is the most common definition of cognitive deficits or dementia after stroke. Unavoidably, many stroke survivors experience delayed dementia after three months or only after subsequent strokes. There were some estimates about dementia and stroke in this meta-analysis; for instance, one in ten patients had dementia before having their first stroke. Similarly, one in ten patients experienced a new case of dementia shortly after their first stroke, and more than one in three patients did not have dementia until they had their second stroke. The incidence of dementia and the development of cognitive impairment are prevalent in stroke survivors.

Stroke is linked to dementia and aging cognitive impairment. Most research on the connection between a stroke and cognitive function has concentrated on post-stroke cognitive impairment, particularly vascular dementia caused by a stroke. The additional risk of increased cognitive impairment below the dementia threshold in these instances hasn't been thoroughly proven, nevertheless. The probability of future cognitive loss below diagnosis thresholds appears to be rising along with the number of post-stroke survivors (Rajan et al., 2014).

In 2016, Eugene YH Tang and his colleagues conducted a systemic review. The longitudinal development of cognitive function in stroke survivors was examined in

this systematic study. It has been determined from the review that stroke survivors may or may not exhibit any signs of cognitive deficits or dementia, recover after a period, or eventually develop dementia. Mixed results were seen in several trials. These contradictory results could be due to various factors, including variations in the cognitive tests utilised and test timing, prior stroke history, location, large and smallvessel illness, demographic sample, ethnicity, etc.

## 2.2. Prevalence of Cognitive Deficits after Stroke

In Bangladesh, post-stroke cognitive impairment affects about 40% of stroke victims. According to their BAMSE score, 30.67% had severe cognitive impairments, and 9.33% had mild ones. Nayan et al., (2016) cited this data in their article.

A thorough review and meta-analysis of the prevalence of cognitive impairment without dementia in the first year after stroke was conducted by Sexton et al. (2019). In the first year following a stroke, this meta-analysis discovered a combined prevalence of 'Cognitive Impairment, No Dementia' (CIND) of 38%. According to a 2017 London Stroke Association poll, nearly half of the 77% of stroke survivors who experience memory issues reported paying little attention to their deficits. Mahadevan et al.'s systemic review and meta-analysis were completed in 2021. Stroke survivors from the West, South Asia, and Africa participated in this study. This systemic review and meta-analysis estimated the prevalence of psychiatric and cognitive problems in stroke survivors which comprised studies from 11 nations, including Bangladesh. Between 22 and 47% of people are thought to have post-stroke cognitive impairments (PSCI) (Jacquin et al., 2014; Douiri et al., 2013). PSCI gets little attention in contemporary research, which is subtle yet obstinate and deliberate. There isn't much

normative data because most PSCI examinations were conducted using short and simple tests for cognitive impairment, including the MMSE. The current evaluation included four papers (n=878) from the Mahadevan et al. study, with a pooled estimate of 16.76% and a range of 22% to 47% for the global trend.

#### **2.3. Impacts of Cognitive Deficits for Stroke Survivors**

Cognitive deficits cannot be considered a disease in and of themselves because they are just symptoms of other underlying illnesses (Aayush & Bradford, 2023). Some common features of people with cognitive deficiencies include difficulty remembering things (often asking the same question or recounting the same story repeatedly), difficulty focusing, visual problems, and difficulty speaking, among others. They have trouble locating people and places as well. They may find it intimidating to be in strange locations or situations. Once again, individuals frequently experience dizziness or agitation, mood swings, and changes in their behaviours or words, and they have trouble executing even simple everyday duties.

Since cognitive impairment is frequently accompanied by noticeable structural and functional changes in stroke survivors' brains, it is an organic disorder rather than a functional one (Brodaty et al., 2013). Along with diminished functionality, post-stroke cognitive impairment directly impacts a person's quality of life and sense of purpose (Park et al., 2013). Major cognitive diseases, traditionally known as dementia, frequently result from post-stroke cognitive impairment (Kalaria et al., 2016).

## 2.4. Family Caregiver

The definition of family (informal) caregiver used in national surveys is not standardized (Kent et al., 2016). Any relative, friend, or partner with whom a significant personal relationship exists who provides assistance for a person with a chronic disabling condition is known as a "family caregiver". Caregiving is facilitated by certain personality traits such as emotions, abilities, knowledge, time, and a connection to the care receiver on an emotional level (Hermanns & Mastel-Smith, 2015). There is strong evidence that more than half of caregivers are female. Male caregivers are more likely to provide financial help, but most female caregivers are typically involved in physically demanding duties like bathing, toileting, food preparation, feeding, and clothing (Sharma et al., 2016).

The ability to provide care is one of the most significant public health issues, and millions of people rely on it for their quality of life. Caregivers may provide emotional support or assistance in managing a chronic illness or disability; also they may also help with one or more daily activities such as bathing, dressing, paying bills, shopping, and providing transportation (Kemp, 2015).

The study of Talley and Crews (2007) says that caring has recently gained recognition as a crucial subject. As life expectancies rise, caregivers' capacity to provide care is impacted, making caregiving more complex. It is also evident that caregivers endure numerous potentially significant health issues and carry heavy obligations (Talley & Crews, 2007). In a different piece by Muhrodji et al. (2022), the authors discuss how caregivers maintain patients' physical well-being and serve as their primary means of communication. A lack of understanding of strokes and a lack of interest from family members were also mentioned as prevalent issues by Muhrodji et al. in 2022. As a result, it is strongly advised that caregivers take part in post-stroke patient rehabilitation programs to enhance the standard of patient care.

## 2.5. Impacts on Family Caregivers

Numerous challenges have been identified in published literature from developed nations that family caregivers face when providing care for individuals with poststroke cognitive impairments. Initially, caregivers may be obligated to assume supplementary duties, including but not limited to overseeing medication regimens, liaising with therapeutic service providers, coordinating transportation, and performing domestic chores (Kavga et al., 2021). Furthermore, providing care for a family member with post-stroke cognitive impairment can result in significant emotional fatigue. The caregiver may encounter various psychological challenges, such as depression, anxiety, and fatigue, along with emotions of guilt, resentment, and frustration (Pucciarelli et al., 2014). Conversely, providing care for individuals with post-stroke cognitive impairment can be financially burdensome due to the costs associated with medical treatment, in-home care, therapy services, and the loss of income due to work absenteeism (Keating et al., 2014). In addition, caregivers may feel isolated and unsupported, especially if other family members are unable or unwilling to help with caregiving responsibilities (Kavga et al., 2021). In addition, some may encounter challenges in effectively navigating the healthcare system to locate necessary resources and obtain support. The responsibility may decrease care quality and strain the caregiver's relationship with their loved one (Lutz & Young, 2010).

According to the study of Tang et al., (2020) their study, effects can occur in various contexts, including daily life, emotions, and compensatory measures taken in reaction to impacts. Additionally, they pointed out that once the stroke survivor moves into the community, having memory loss coupled with living with a stroke might have a severe impact on them and their family (Tang et al., 2020). All of the participants in this study were Caucasians, and it was limited to one region of England. Additionally, only people with memory deficits were recruited for this study; people with other cognitive deficits were left out. In particular, among informal family caregivers of different ethnicities, Tang et al. (2020) advised more research to see whether cultural factors may affect people besides those discovered in this study.

Haley et al., (2015) conducted a prospective epidemiological study on the drawbacks and advantages mentioned by stroke victims and their caregivers in 2015. The three most challenging issues for caregivers were physical care, memory care, and mood. More than 90% of caregivers claimed that providing care made them more appreciative of life. The fact that caregivers looked to be managing well and better than previously reported is a significant result of this study.

Between July and September 2015, Babar Irfan and his colleagues conducted a crosssectional study at a teaching hospital in Karachi, Pakistan, to examine the effects of caregiving on different facets of caregivers' lives. Sixty-four percent of the participants said they were actively providing care, and 48 percent said it had a negative effect overall. The findings of this study demonstrated how caring for others harms caregivers' physical, psychological, and professional lives. After stroke survivors were discharged from rehabilitation therapy, care partners began to experience symptoms of depression. According to Blanton et al., (2020), research, families with stroke survivors frequently experience family strife. This study's findings, behaviour and memory issues in stroke survivors are among the most significant risk factors for caregivers' depression symptoms. The information they gathered indicated that stroke survivors' (SS's) upper extremity function might be improved while care partners' (CP's) depressive symptoms could be decreased. Only the intervention program needs to be created to focus on CP skill improvement, encourage a home environment that supports autonomy, and combine these elements with intensive upper extremity rehabilitation (Blanton et al., 2020). Their findings demonstrated a connection between SS memory loss, behavioural modifications, and the severity of CP depression symptoms.

The advantages of caregiving are a growing area of research. Discovering how caregivers handle challenging caregiving conditions and how these situations benefit them is crucial. Providing care for others can improve their quality of life, strengthen their relationships, and bring them a lot of satisfaction. The load on caregivers may intensify as care recipients' and caregivers' ages and levels of disability increase. Caregiver challenges can also result from the cultural and financial effects of long-term chronic illness or disability (Hoffman & Zucker, 2016). Positive results were observed by Blanton et al. in 2020, who found that caregivers' appreciation of life had grown as a result of providing care. The advantages of caring for others could serve as their psychological assets.

# 2.6. Key Gap of the Evidence

Significant gaps exist in the literature regarding providing treatment for people with cognitive problems after a stroke. These gaps consist of the following:

- ➤ Limited research on this area in the South-Asian subcontinent: The prevalence of stroke survivors with cognitive deficits is increasing day by day, and family caregivers are continuously facing challenges caregiving them. More research on these caregivers' experiences and challenges in caregiving is needed for a better understanding.
- Lack of attention to caregivers: Much of the study on post-stroke cognitive impairment concentrates on patient understanding and effects.
- Limited research on interventions: More information on the best ways to help people with post-stroke cognitive problems needs to be provided. More study is required to identify the most efficient solutions for lessening caregiver load and enhancing the quality of life for caregivers and their loved ones.
- Lack of diversity: Most studies use a small sample of individuals, usually drawn from a specific population. More studies with diverse populations, such as those from various ages, genders, and socioeconomic backgrounds, are required.
- ➤ The lack of longitudinal studies: Most studies on caring for people with cognitive abnormalities following a stroke are cross-sectional or undertaken at a single moment. To monitor changes in caregiver burden and coping mechanisms over time are required.
- Limited research on different components of cognitive deficits: Most of the research in this area mainly focused on 'memory deficits' in stroke survivors. For

more effective findings, studies focused on all the components of cognitive deficits should be conducted.

❑ Understanding gaps in the impact on caregivers' employment: For caregivers who work outside the home, caring for a loved one who has cognitive deficits following a stroke can significantly impact their careers. There need to be more studies on the impact of caregiving on employment results and how caregivers might be assisted in juggling their caregiving duties with their careers.

# **CHAPTER III: METHODS**

### 3.1. Study Design

#### 3.1.1. Study Method

Qualitative research describes complicated phenomena, finds rare or unexpected happenings, and describes actors' experiences and interpretations of events. This holistic approach incorporates exploration (Williams, 2011). Qualitative research lets researchers immerse themselves in real-life situations (Creswell, 2017). This research question required a qualitative examination.

### **3.1.2. Study Approach**

The investigator took a phenomenological approach to data collection in this research study. According to the findings of a research project, phenomenology is an effective way of describing and classifying experiences. Phenomenology can be explicitly applied to the first-person experience of disease to shed light on this experience and assist healthcare providers in improving their understanding of it (Carel, 2010). The phenomenological method can deepen our comprehension of the multifaceted phenomena associated with learning, behaviour, and communication. In addition, it helps determine the significance of a person's perceptions, knowledge, and experiences in their lives (Neubauer et al., 2019). Therefore, the phenomenological approach was the best methodology for this particular study.

#### **3.2. Study Setting and Period**

Data was collected from the community dwellers of the Dhaka division. Through this study, the investigator wanted to identify the "experiences" of caregivers of persons with post-stroke cognitive deficits in the community after completing a rehabilitation program. So, expected data could only be collected from the community.

The entire investigation was carried out between April 2022 and February 2023. The time frame for collecting the information ranged from November 2022 to December 2022.

### **3.3. Study Participants**

#### **3.3.1. Study Population**

The population targeted for this study consisted of all the family caregivers in Bangladesh who provide care to stroke survivors with cognitive deficits.

#### **3.3.2.** Sampling Techniques

Participants were chosen through a process known as purposive sampling. According to Black (2010), obtaining a representative sample through sound judgment can save time and money. The investigator used her expertise and knowledge to choose samples from the population intended to participate in the study and established the criteria for inclusion and exclusion, and the sample selection was based on those criteria. Participants who met the inclusion requirements were invited to participate, while those who met the exclusion criteria were excluded.

#### 3.3.3. Inclusion Criteria

The study included caregivers of stroke survivors with cognitive deficits. Only those people were included who successfully finished the first phase of a rehabilitation program and were reintegrated into their society before April 2022. The study only included individual caregivers between the ages of 18 and 65. The caregiver must also take care of the patient with post-stroke cognitive deficits for at least three months in order to meet the inclusion requirements.

### 3.3.4. Exclusion Criteria

The SMMSE score of 26 to 30 was used to eliminate caregivers of stroke survivors. As well, those who get payment from family members for caring for stroke patients were excluded from the study.

#### 3.3.5. Sample Size

This study was conducted with a limited sample size of six participants for qualitative research. As per the suggestion put forth by Braun & Clarke, (2019), small-scale projects can incorporate 6 to 10 interviews. The primary emphasis of this proposal pertained to the available resources (Fugard & Potts, 2015).

#### **3.3.6.** Participant Overview

The present investigation involved a cohort of individuals caring for stroke survivors experiencing cognitive impairments.

	rticipant pseudo name	Age	Occupation	Relation with stroke survivor	Duration of caregiving	SMMSE Score
01	Keya	29y	Teacher	Daughter	11-months	22
02	Khaleda	58 y	Housewife	Wife	18-months	23
03	Usman	30y	Service holder	Son	12-months	15
04	Rakib	33 y	Service holder	Son	45-months	13
05	Ena	25 y	Housewife	Daughter-in- law	23-months	15
06	Hafiz	63 y	Retired	Husband	15-months	16

Table 1: Participant's overview

## **3.4. Ethical Consideration**

The study adhered to the ethical principles outlined in the WMA Declaration of Helsinki for ethical considerations. The Institutional Ethical Review Board of BHPI was requested to grant ethical clearance by the Department of Occupational Therapy at Bangladesh Health Professions Institute (BHPI). IRB no. CRP/BHPI/09/22/641. The research protocol has provided a clear and justified description of the study's design and performance.

Before participating in the study, all individuals were given written informed consent. The data was gathered anonymously. The participants were provided with an information sheet that elucidated the study's objectives and the nature of their expected involvement. The participants were allowed to deliberate with their respective family members before participating. A withdrawal form was provided to the participants to facilitate retracting their previously provided data, should they choose to do so. Throughout the study, all participants were referred to by their pseudonyms to safeguard the confidentiality of their data. The study poses no potential harm to the participant, and no financial incentives were offered. There was no asymmetrical power dynamic between the student researcher and the participants. The investigator contacted all participants solely to conduct research without prior communication.

## **3.5. Data Collection Process**

#### 3.5.1. Participant Recruitment Process

The recruitment process involved the following steps to enlist all participants:

The initial step involved collecting the contact information of stroke survivors who had cognitive deficits from the Occupational Therapy Out-Patient Unit at CRP, with appropriate permission. The investigator analysed assessment records from January 2021 to April 2022 to identify patients who scored below 25 on the SMMSE. Contact information for these patients was subsequently collected.

In the second step, the investigator contacted the participants by utilising the collected phone numbers and arranged a meeting for in-person interaction.

The final step was a personal encounter, where the investigator initially evaluated stroke survivors using the SMMSE. The study recruited individuals whose SMMSE scores were below 25. The author of SMMSE granted permission to use this scale for screening purposes in the present study. The research participants were selected exclusively from those who consented to provide data. Appendix C and Appendix D

contain the Information Sheet, Consent Form, and Withdrawal Form in English and Bangla, respectively.

No novel codes or themes were identified during the fourth interview. However, the investigator conducted two additional interviews to ascertain whether new codes or themes would arise. Therefore, during the sixth interview, the investigator determined that the data collection process had reached saturation point.

### **3.5.2. Data Collection Method**

The investigator conducted face-to-face, semi-structured interviews to collect data for the study. In qualitative research, semi-structured interviews are the most effective method. Primarily when the researcher wants open-ended data, explores participants' beliefs, feelings, and thoughts, and sometimes goes through personal and sensitive issues (DeJonckheere & Vaughn, 2019). The investigator followed a few steps for designing and conducting semi-structured interviews.

Firstly, after determining the study aim, objectives, and study population, the investigator considered the ethical issues.

Secondly, the investigator developed the interview guide. Interview questions were set according to the study objectives.

In the third step, the investigator planned logistical aspects like how to ask the individual for an appointment, how to manage transport to go to the appointed place, and how to present the research purpose and participation process to the caregiver. All information about the research was provided to the caregivers through an information sheet. During the first personal encounter with participants, trust and rapport were

established. For this, the investigator set up a prior appointment to give them an information sheet and spend some time with them for rapport building.

The fourth step was conducting the interview. Interviews were conducted on the previous set date, time, and location. The investigator actively listened to the interviewees throughout the interview session. The investigator also audio-recorded the whole interview with her smartphone. Wrote down field notes after every interview.

All of these steps were followed by the investigator. Every interview took nearly 18 to 20 minutes. All interviews were audio recorded with a smartphone, device a named 'Oppo A95' after getting permission from the participant for further use in data analysis in the study. No interviews were repeated.

*Non-Participant.* During the fourth interview, a non-participant was present for two to three minutes. Father-son was the relationship with the participant. During the interview, it was observed that the nonverbal gesture was quite normal. However, the query was repeated to the participant to avoid a biased response in the presence of a non-participant. For the rest of the interviews, no non-participants were present.

*Member Checking.* The investigator gave the interview transcripts back to the subjects so that they could verify their integrity and determine whether or not the content resonated with their own experiences.

#### **3.5.3. Data Collection Instrument**

*Self-developed Interview Guide*. The interview guide had been developed based on the study objectives. The interview protocol comprised 28 questions categorised into

five distinct components, as presented in Appendices E. Following the field test, several investigations were incorporated. They introduced a new element labelled 'Social life'. The newly adapted interview guide comprised 31 questions that were listed under six components, namely "life experience", "basic self-care", "specific challenges", "social life", "emotional state", and "learnings from caregiving". The revised interview guide has been appended to Appendices F. The interview was administered in individual sessions lasting between 18 and 25 minutes.

*Field Notes.* The investigator took field notes in which they recorded every occurrence while gathering data and any variables that inspired the occurrence or behaviour, providing as much specific information as possible.

#### **3.6.** Data Analysis

The study involved a thematic analysis of all the gathered data. According to Braun & Clarke (2019), thematic analysis is a research methodology that involves identifying and analysing information to report themes within the data. Braun and Clarke (2019) identified six phases of thematic analysis in their research. The abovementioned procedures were executed, and the gathered information was subsequently analysed.

*Exploring the data.* The audio recording of all participant interviews was in Bangla. The investigator transcribed and translated all audio recordings from Bangla to English. This translation was necessary as both the participants and the investigator spoke Bangla as their first language, while English was the academic language of the investigator. Subsequently, the data was read multiple times, and initial ideas were

identified through underlining and highlighting. The initial ideas that were underlined and highlighted underwent a review process by a supervisor.

*Initial Code Development.* Three tiers of preliminary notes were kept. Descriptive notes were taken to record the experiences and thoughts of the participants in the form of descriptive statements. The second level pertained to the linguistic aspect, whereby the expressions of the participants were documented. Conversely, the third level centred on the conceptual dimension, encompassing a broader comprehension. The researcher systematically analysed the transcriptions and field note entries, identifying noteworthy features in the data and coding them consistently throughout the entire dataset. All underlined ideas were assigned initial codes and reviewed by a supervisor.

*Investigating for themes.* The initial codes underwent multiple reviews, and comparable codes were documented across various notebook pages. Several equivalent codes were subsequently identified and labelled according to their respective sub-themes. The analysis was limited to themes pertinent to the study's aims and objectives.

**Re-considering themes.** The themes underwent examination, renaming, and reorganisation to assess their coherence with each coded excerpt and the entirety of the dataset. The themes underwent scrutiny by the supervisor, and a consensus was reached to make slight modifications. A cartographic representation was created to conduct a thematic analysis.

*Identification and categorization of themes.* Each theme was meticulously defined and appropriately labelled with the supervisor's consent. The investigator employed

the inductive approach in this way. The study's aim and objectives were also considered.

*Developing the report.* The final analysis of selected extracts involves carefully creating vivid and compelling examples. The report incorporated the comprehension and encounters of the participants. The analysis reports were pertinent to the research inquiry and literature, generating an erudite analysis report.

The researcher personally coded the data and included a detailed explanation of the coding framework in the Results section. The result section contained verbatim participant quotations, accompanied by their corresponding facial expressions, to illustrate each theme. The text comprehensively presented and described both major and minor themes. Please review the result chapter.

## 3.7. Trustworthiness

As with validity and reliability, trustworthiness can also be evaluated in qualitative research (Shenton, 2004). There are several methods that can be employed to establish credibility. Fossey et al., (2002) have identified several crucial matters that need to be addressed to strengthen the credibility of the research in two sections: methodological rigour and interpretive rigour.

### **3.7.1 Methodological Rigour**

When evaluating methodological rigour, it is essential to consider five key factors: congruence, responsiveness to social context, appropriateness, adequacy, and transparency.

The present study employs a Qualitative Phenomenological approach, strictly adhering to the prescribed methods within this methodology. This study followed the phenomenological approach and was presented descriptively in the "Study Design" section. The interview was conducted at the participants' residences, considering their authentic life circumstances and social context during the analysis.

The present investigation employed a purposive sampling approach. The study utilized specific inclusion and exclusion criteria to determine suitable participants. The employed sampling methodology was highly appropriate for establishing communication with the prospective participants of this research. The "Study Participant" section outlines the sampling strategy and the inclusion and exclusion criteria employed.

The study's information sources were sampled until data saturation was achieved, and subsequently, the interview transcripts and field notes were analysed to generate a comprehensive depiction of the study. The description provided details regarding recruiting participants and their demographic information. The process of gathering and analysing data is elaborately described in the sections "Data Collection Process" and "Data Analysis". The level of detail provided in the "Methods" chapter is sufficient to facilitate comprehension of the study's context.

The data gathering and analysis process strictly followed the methods of the selected methodology (Phenomenological approach). All the collected data were verbatim transcripts. The supervisors were involved in every aspect of data analysis, so there was no chance of data manipulation.

#### **3.7.2 Interpretive Rigour**

When assessing the interpretive rigour of a study, it is crucial to consider five essential elements: authenticity, coherence, reciprocity, typicality, and the permeability of the researcher's intentions, engagement and interpretations.

The perspectives of all participants were conveyed in their own words, and exact quotations accompanied each sub-theme in the Results section. The sub-themes were reported based on the views and opinions of multiple participants. Following the interview, participants engaged in a two-step process whereby they were provided with their interview transcripts for review and commentary. Following the analysis, the study results were disseminated to all participants for member checking.

The results of the present investigation were organised into distinct themes and subthemes. The various sub-themes were subjected to coding and subsequently identified from the data gathered for the current analysis. The collaborative effort between the supervisors and students led to the emergence of these findings. The correlation between the data appears to be credible. The study solely considered information about its aim and objectives.

The transcripts of individual interviews were provided to the respective participants. The individuals reviewed their transcripts and provided feedback on them. The concluding remarks made by the participants were taken into account during the process of data analysis. The study results will be disseminated to all study participants. The investigator maintained a transparent role throughout the interpretive process, devoid of personal involvement. The present study investigated the phenomenon and experience of caregivers of stroke survivors who exhibit cognitive impairments.

# **CHAPTER IV: RESULTS**

This chapter is where the descriptive findings of the analysed data are presented. The primary purpose of the result section is to use the collected data to answer the posed research question. The result of qualitative methods gives a perception of people's social realities, consequences, and how they act in the social world. After analysing the collected data, the results show that caregiving a person with post-stroke cognitive deficits can provide a variety of experiences. Five broad themes, categorized into sub-themes, emerged. They are: (i) Day-to-day experience, (ii) Physical impact, (iii) Emotional health, (iv) Overcoming obstacles and adopting new approaches, and (v) lessons learned through providing care.

Theme		Sub-Theme
1. Day-to-day exper	ience	1.1.Basic self-care
		1.2.Sleep disturbance
		1.3.Productive life
		$\Rightarrow$ Academic
		$\Rightarrow$ Work
		1.4.Social life
		1.5.Leisure
2. Physical impact		
3. Emotional health	l	3.1.Emotional disturbance
		3.2.Emotional solace
4. Overcoming obst	acles and	4.1. Embracing challenges
adopting new app	proaches	4.2. Coping strategies
5. Lessons learned t	hrough	5.1.Perception of Health
providing care.		5.2.Perception of the Environment

 Table 2: List of Themes and Sub-Themes

#### **4.1. Day-to-Day Experience**

During the interview, every participant discussed their experiences in everyday life. This central topic has been broken down into five distinct subthemes for more indepth comprehension.

#### 4.1.1. Basic Self-Care

Basic self-care encompasses essential activities of daily living such as self-feeding, drinking water, dressing, bathing, and other related tasks. An overall perspective among the respondents was that they could not adhere to the defined timetables for executing these tasks. The individuals were deeply immersed in their caregiving duties to the extent that they could not maintain their daily activities. The first interviewee (Keya) exhibited a high commitment towards providing care, as evidenced by her statement; there is no distinction between her daytime and nighttime activities. "I devote all of my time to my mother, ignoring the difference between day and night. The commencement of my day mirrors that of my mother's."

When asked about the preservation of basic self-care requirements, another respondent (Usman) responded,

"It is never possible with a patient. (With a smile)... When a family member is ill, other members take care of her, even if they do not take care; mental tension works, although they do not want to, right? And if you are responsible, there is nothing to say; it comes automatically". In addition to discussing the impact of daily self-care activities, half of the interviewees reported taking on responsibility for household chores previously managed by their mother (care recipient). This domestic obligation occupies a significant portion of one's time every day. The household tasks included grocery shopping, cooking, and cleaning the house. Participant 4 Rakib (son), conveyed a sentiment of sadness as they stated that they often have to prepare meals by themselves and must navigate specific tasks without the assistance of their mother. "We have to do things without our mother, thus I have to cook most of the time." This care recipient was cared by her son. Before experiencing a stroke, his mother was responsible for overseeing all domestic tasks and making decisions related to household management.

All other interviewees also felt that maintaining essential self-care could be challenging, but they could do it under different circumstances.

#### **4.1.2. Sleep Disturbance**

The theme, as mentioned earlier, exhibited a repetitive pattern within the entirety of the dataset. All participants in the interview indicated experiencing some degree of sleep disruption; however, these interruptions did not significantly impact their overall quality of at-night sleep. The physical and mental exertion during the daytime causes fatigue. This fatigue facilitates the rapid onset of sleep upon retiring to bed. Regarding this topic, Participant 2 Khaleda, stated that they do not have any sleeping difficulties. On this theme, Khaleda said, "No, [I] do not have any problem sleeping. He calls me and asks for bottles for peeing. Once he is done, we fall asleep again. Normally, trouble in sleeping does not happen. In this, he is okay."

### **4.1.3. Productive Life**

A productive life pertains to an individual's engagement in societal activities, whether compensated or voluntary. Out of the individuals who were interviewed, four respondents were employed in full-time paid positions, while two respondents were retired. However, two sub-themes were identified by highlighting the experiences of other interviewees. The authors presented a detailed account of the influence of caregiving on their jobs and academic endeavours, drawing from their personal experiences.

## 4.1.3.a. Academic

An expressed concern within academic circles pertains to the challenge of initiating or concluding advanced educational pursuits. Concerning the statement, Keya said,

"Once more, I realize that for a year, everything in my life has been stuck at one spot. I was meant to start a new marriage or move overseas for higher education. Then it feels a little sad."

This perspective was further reinforced by a separate participant in the interview who was unable to finish their post-graduate studies due to newly arising familial obligations. As Usman put it,

"I wanted to [complete post-graduation], but it is impossible. I completed graduation and wanted to complete my Masters but could not due to my family situation. My mother was the manager of our family, even in my father's presence, because she was literate, so she took care of the family ... Now I have to take care of 50% of her responsibilities."

Work life was another issue. All interviewees said they had to change jobs or take a break. Keya was disengaged. She may only resume her prior employment if she makes her mother's therapy or other treatment comfortable without her.

"Yes. Despite getting a call from the school, perhaps I will enrol in January. If I get a comfortable environment in January, I can continue Mom's treatment procedure so that she is not facing any difficulties while receiving therapies. If I can process that way, I will join, Inshallah."

## 4.1.4. Social Life

Upon being questioned regarding their familial connections, most interviewees expressed that their other family members were supportive. Two of the individuals who were interviewed expressed dissenting views on this matter. Keya expressed dissatisfaction with the level of cooperation received from their family members in the caregiving of their mother. Talking about this issue, another interviewee, Ena said, "There is no one in the family but me. My husband works all day at the store. My father-in-law only takes her to the doctor."

In all interviews, participants reported that their friends and neighbours were helpful and cooperative. Rakib, the only son of the care recipient, commented,"Yes. Suppose I cannot go [to the office] for some reason, calling my friend and saying, Pal, I cannot come today, and my father is not at home; I totally cannot come today. He completes my tasks." There are only three people in their family, caregiver, with his mother (the care recipient), and his father.

### 4.1.5. Leisure

The inclusion of leisure activities is a crucial aspect of human existence. Most interviewees indicated that they do not allocate any designated leisure time. An overall perspective among the interviewees was that utilizing the mobile phone briefly in between various tasks was regarded as a form of leisure. One of the interviewees expressed that they had not previously considered the concept of leisure in such a manner. For example, Keya said, "I actually never thought about this [leisure] like that. Cause we have a mobile phone in our hands, so whenever I find time, use my mobile phone." Conversely, the elderly participants responded to their leisure pursuits during the interview. One participant Hafiz, expressed that Namaj, which is a prayer to Allah, holds the utmost significance for them, and Khaleda commented, "As I am living in a rural area, normally I take care of the trees around our house."

## **4.2. Physical Impact**

The caregivers' physical health was questioned. Half the participants reported back pain, knee pain, and fatigue issues from long-term care. Two interviewees stated this. As Rakib said, "She is so heavily weighted, handling her causes us back pain. Father and I both suffer from back pain." And Hafiz commented that "I angrily told her (care recipient) I am, I am becoming a patient along with you. You go [to the hospital] however you can."

## **4.3. Emotional Health**

Multiple viewpoints were identified from the conversations conducted with the study participants. Several interviewees exhibited ambivalent emotions, while others conveyed their emotional turmoil. Providing care for a stroke patient can entail significant responsibilities and may sometimes pose a burden to caregivers. However, caring for a patient with cognitive deficits can compound the caregiving demands. This phenomenon also has an impact on the emotional well-being of caregivers.

#### **4.3.1. Emotional Disturbance**

Several interviewees disclosed experiencing emotional disturbances during the study. Consequently, they were questioned regarding the causative factors and mechanisms underpinning these disturbances. In response to this inquiry, Hafiz provided a solemn countenance,

"Nowadays, suppose that even if it is your son or your daughter, when anyone is sick for a long time, a negative feeling surely comes to everyone. Everyone is like this. Her sons tell her, "Oh, you are sick. You are sick; we will not take you [look after you]." Sometimes I also become so angry because there are always hundreds of patients when you see a doctor. You want to go to the lift, wait in line, see a doctor, and wait in line for hours. I even left her alone in the hospital two times. After returning home, called to get her again."

When the same question was asked, Usman said,

"Now always a mental tension works. I left a patient at home. We have to give her a lot of time, and fear always works for this kind [with the cognitive problem] of stroke patient because you cannot say when what will happen."

### **4.3.2. Emotional Solace**

Despite experiencing emotional instability, all participants persisted in their caregiving responsibilities due to their ability to find solace or overcome their emotional crisis. Several recommendations were made regarding the strategies employed by the interviewees to cope with emotional stress. Most participants agreed: "What Allah does is for our good. What else can I do?" The study's participants collectively exhibited a reliance on their Creator and a commitment to fulfilling their duties. The interviewees agreed on a different approach to stress management. They firmly believe that it is their responsibility to care for their sick family member (be it their mother, husband, or wife) and that they are obligated to fulfil this duty. Adopting a responsible mind-set facilitated the individual's ability to overcome emotional distress. Other responses to this question, Keya included,

"When someone puts their hand on my head and says, "You received a very fortunate opportunity, and you are doing very well" these words inspire me a lot. I mean, during these critical times or moments, these simple sentences like "You are working so hard", "You are doing good", or "You will have a bright future" change your moment. This! It is right."

The interviewee conveyed a strong sentiment regarding the positive impact of small gestures of appreciation on her motivation to continue caring for her sick mother. Keya referred to experiencing conflicting emotions.

"When I see my life is stuck at one point for almost a year... Then it is not that I never felt depressed, but when I see mom is learning a new... mom is developing, then I do not remember any of this... Then I feel that my mom can learn a new because I am staying with her. This! It (these feelings) is another achievement."

However, as per the testimony of only Ena, providing care for an individual with poststroke cognitive impairments did not impact her. She expressed happiness with a facial expression, saying "Now, what should be my problem? I cannot insist on her and say, do this, do that."

## 4.4. Overcoming Obstacles and Adopting New Approaches

Caregivers frequently encounter challenges when addressing the cognitive impairments and other physical disabilities of stroke survivors and have developed strategies to adapt and integrate them into the community effectively. This results in the emergence of two subordinate themes:

#### **4.4.1. Embracing Challenges**

Most interviewees agreed that a common challenge they face is the need to operate within time constraints. The act of providing care necessitates the completion of numerous tasks within a limited timeframe, which can often result in fatigue.

According to Usman, the care recipient, the interviewee's mother, required round-theclock attention due to cognitive impairments. It was believed that in cases where an individual is solely responsible, they may have to make sacrifices in their personal or professional lives to fulfil their obligations. He stated, "If a sick person becomes one person's responsibility, the responsible person also becomes sick. And nowadays, human life is dynamic, and if a person does not go with the pace, it becomes hard for that person."

Rakib also stated that the constant presence of his mother (care recipient) was challenging for him and his father (the only other family member) due to their employment obligations. The mother remains alone in her room throughout the day while they attend to their respective duties. The situation at hand correlated to his mother's inability to communicate with them via telephone, either through a landline or a cellular device. He stated, "Mother cannot call us screaming or even receive a phone call."

During the interview, Hafiz was questioned about the obstacles they encountered. They shared their experiences: "Suppose I gave her something to keep safe, and she forgets after putting it in one place. Again, she misplaces things and forgets about them."

#### 4.4.2. Coping Strategies

The family allocated their caregiving responsibilities based on individual convenience to confront the time-related challenge. This approach ensured that no individual had to make a complete sacrifice. Usman made a statement, "Caregiving-time distribution helped us a lot. ..... Although it is hard, if we allow other members to do their work, everyone can lead a good life."

Rakib proposed the concept of a "calling bell" device, which would enable their mother to request assistance with a simple button press. A calling bell switch is

conveniently located beside the mother to allow her to request assistance or communicate her needs. "If she were to press that button, we would promptly proceed towards her." Furthermore, the interviewee attempted to amuse his mother by acquiring bird companions. The installation of a fish aquarium adjacent to her sleeping quarters and the planting of different colours of trees in pots on the veranda of her room as his mother cannot watch a TV for a long time or operate a TV remote. Hafiz employed patience as a coping mechanism in response to his spouse's memory loss, noting that his wife could recall information after some time.

## 4.5. Lessons Learned through Providing Care

One notable finding from the data is that respondents reported both positive and negative effects of their caregiving experiences, which is surprising. Based on their experiences, individuals engaged in caregiving have made sacrifices and gained valuable insights that have significantly impacted their lives. 'Lessons learned through providing care' theme is categorized into sub-themes by carefully examining their insights.

## 4.5.1. Perception of Health

Keya reported, "I have become much more health conscious than before... Now I inspire everyone to have a properly balanced diet. Yes, this was my positive learning."

Again Usman hinted at the concept of prioritising one's health. He emphasised promoting overall knowledge regarding stroke and the resulting impairments. He proposed that there should be a wider dissemination of information regarding the primary indicators of stroke and appropriate first-aid assistance to the general public. He put it as,

"Many of us do not know about the disease, why these happen, or the stroke symptoms. The doctor said that if we could take my mother to the hospital within six hours, she would not have been damaged this much."

The general agreement among both interviewees was that familial support and patient effort are significant factors in facilitating recovery.

## 4.5.2. Perception of the Environment

The following comment exemplifies Rakib's acquisition of knowledge regarding the necessity of environmental modifications in caregiving.

"Only if there were a proper set-up, mother [the care recipient] could have been supposed to get to the ground floor by a remote-controlled wheelchair, get up on the car, and go wherever she wants. But now, after some time, we have to lift her hands to get to the car. How much pressure will it apply? On both her and us."

The interviewee expressed his distress regarding the inadequate space that his mother, who uses a wheelchair, cannot access to the toilet. Expensive apartments hold no utility for them.

## 4.6. Summary of the Result

The act of providing care can have an impact on a caregiver's day-to-day life and pose a risk to their physical health. It is also possible to generate an emotional imbalance; nevertheless, caregivers can manage their emotional condition by adopting a variety of thoughts or obtaining various types of assistance. Caregivers of patients with cognitive deficits following a stroke confront the same obstacles or multiple challenges. To overcome these, they employ natural and convenient solutions. Individuals are exposed to various insights and learning opportunities when they care for others, which is not the least significant aspect of different kinds of realisations.

# **CHAPTER V: DISCUSSION**

#### **5.1. Discussion**

This investigation examines caregivers' encounters while caring for individuals with post-stroke cognitive impairments. Stroke is a prominent contributor to mortality, morbidity, and numerous other ailments. Stroke has the potential to result in enduring cognitive impairments among individuals who have experienced a stroke. As indicated in the literature review, post-stroke cognitive impairments are prevalent, affecting approximately 40% of individuals who have experienced a stroke (Nayan et al., 2016). According to Al-Qazzaz et al. (2014), stroke has the potential to impact various cognitive domains, such as attention, memory, language, and orientation. Providing care for a stroke patient can present both difficulties and benefits. The responsibilities and challenges associated with caregiving are amplified when cognitive deficits arise due to a stroke. The additional obligations imposed on caregivers often increase burdens and harm their overall quality of life. Following a thorough analysis of data collected from interviews with family caregivers providing long-term care for stroke survivors with cognitive deficits, several significant aspects and unique caregiving strategies were identified. The complete analysis of the data was presented through five overarching themes, further classified into sub-themes. The five critical areas of focus in caregiving include (i) Day-to-day experience, (ii) Physical impact, (iii) Emotional health, (iv) Overcoming obstacles and adopting new approaches, and (v) lessons learned through providing care.

According to Hermanns & Mastel-Smith (2015), any relative, friend, or partner with a significant personal relationship who provides assistance for a person with a chronic disabling condition is known as a family caregiver. A caregiver is responsible for performing these tasks and their routine daily activities. Providing care for a long-term disability patient, such as a stroke survivor, can be compounded by the added challenge of sustaining these efforts over an extended period. Consequently, this has an impact on the daily routine of family caregivers and their physical as well as emotional well-being. While caregiving may entail hardships, it offers valuable insights and enduring lessons.

The primary observation from the analysis pertains to the influence of caregiving on the individuals providing care. According to Irfan et al. (2017), individuals who provide care experience favourable and unfavourable effects associated with their caregiving responsibilities. Numerous investigations have been carried out thus far on individuals who care for individuals, have suffered from strokes. Several studies have been conducted on individuals with strokes experiencing cognitive or behavioural impairments and their respective caregivers. The results mentioned above align with my previous observation that the cognitive and behavioural difficulties experienced by stroke survivors are among the most significant contributing factors to depressive symptoms in their caregivers, as reported by Blanton et al. (2020).

The initial objective was to ascertain the daily life encounters of individuals providing care. Research has indicated that caregivers often encounter challenges in maintaining their fundamental self-care practices, such as obtaining adequate sleep while providing care. This phenomenon impacts both the individual's social and occupational functioning, as well as their recreational pursuits. The research of other studies in this field widely corroborates this discovery. According to Sidek et al. (2022), caregivers must balance their caregiving responsibilities with other family responsibilities. The additional responsibilities have an impact on the caregivers' daily routine. According to Byun et al. (2016), specific studies suggest that approximately 50-70% of family caregivers encounter sleep disruption while caring for a family member with dementia. According to the statistics provided by the National Alliance for Caregiving and AARP in 2015, a significant proportion of caregivers, precisely 70%, experience challenges in their work-related activities due to their additional responsibilities as caregivers.

The present study has identified that caregiving is associated with adverse effects on physical health. The study's participants reported experiencing various physical challenges, such as discomfort in the back, pain in the joints of the arms and legs, fatigue, and other related symptoms. Multiple reports further corroborate these findings. The physical well-being of caregivers of stroke survivors is impacted by factors such as inadequate rest and sleep and, in some cases, the neglect of their medical concerns to prioritise the care recipient and their family, as noted by Sidek et al. (2022). Numerous studies have demonstrated that the physical health of stroke survivors who receive caregiving is significantly impacted (Lutz et al., 2011; Qiu et al., 2018; Chow & Tiwari, 2014).

Numerous studies have also reported a high prevalence of depression and stress among care individuals (Irfan et al., 2017). Maintaining mental and emotional wellbeing is crucial to achieving a high quality of life. The research conducted by Sidek et al. (2022) suggests that family caregivers frequently encounter neglect despite their significant role in the rehabilitation of stroke survivors. In line with the findings mentioned earlier, the present study determined that providing care impacts the emotional well-being of caregivers. The effect is twice as pronounced when caring for a patient with cognitive impairments. Many participants indicated that they experienced various emotional obstacles while providing care. Additionally, they presented intriguing concepts regarding their methods for finding solace during emotional breakdowns and moving forward.

The fourth theme, titled "Overcoming obstacles and adopting new approaches" presents the most significant outcome of the study. Several participants disclosed difficulties arising from their caregiving responsibilities, primarily attributed to the cognitive impairments of their care recipients. The caregivers were able to devise a strategy independently to surmount these challenges. Providing care to stroke survivors, whether they have cognitive deficits or not, can affect their physical and emotional health and daily lives. However, the extent of these impacts can differ significantly depending on the challenges faced and the strategies employed to cope with them, as noted by Lutz et al. (2011). While there may be some overlap in the difficulties experienced by caregivers, the compensatory strategies employed by each individual may differ. Individuals' compensatory strategies vary due to their adaptation in the most optimal manner. The diversity observed in this discovery renders it intriguing and pertinent to the research's aims. In accordance with the research done by Tang et al.in 2020, it was observed that caregivers frequently display adaptability and devise innovative strategies to maintain their regular functioning within the community.

The present study affirms that caregiving facilitates the acquisition of novel insights, as posited in the research conducted by William E. Haley et al. in 2015. According to

a survey conducted by William E. Haley et al., the majority of caregivers, exceeding 90%, experienced an increase in appreciation for life after commencing their caregiving duties, providing them with a valuable life lesson. According to Mei et al. (2020), specific caregivers exhibited heightened levels of concern regarding their own and their family members' health and negative habits. This increased respect was positively associated with providing significant support in the recovery of stroke survivors, as Sundin et al. (2017) noted. The study results indicate that caregivers' educational outcomes from providing care may pertain to "health" or "environment".

The study is centred on the experiences of caregivers. Previous research has highlighted the significance of caregivers in the rehabilitation regimen for patients across various domains. Duncan et al. (2005) emphasised the importance of caregivers in enhancing the functional status of stroke survivors, as stated in a clinical practice guideline. Several studies have suggested that involving caregivers in the rehabilitation programs of post-stroke patients can enhance the quality of patient management (Talley & Crews, 2007; Hoffman, 2016). The findings of this research can potentially improve the level of caregiver engagement in the therapeutic intervention. Moreover, by being equipped with the latest information on natural compensatory strategies, healthcare practitioners can recommend more effective approaches for individuals and their caretakers to enhance their overall quality of life. Hence, it is recommended that further research be conducted on the present subject matter.

The affirmative and adverse results offer partial corroboration for a novel conceptual hypothesis that scholars currently emphasise the advantages of providing care. Talley and Crews (2007) suggest that compiling the favourable and unfavourable

consequences of providing care can aid experts in devising strategies for public health interventions. This intervention can potentially support individual and communal well-being while promoting the health of those providing and receiving care. Perceived benefits derived from caregiving can serve as a crucial source of motivation for caregivers.

# **CHAPTER VI: CONCLUSION**

### 6.1. Strength and Limitation

This study exhibits several notable strengths as well as limitations. The explicit reporting of the study design in accordance with Consolidated Criteria for Reporting Qualitative Research (COREQ) is its primary methodological strength. Again, this study was conducted according to the "Phenomenological approach". A phenomenological study can reveal the experiences of those who care for stroke survivors with cognitive deficits. By examining the subjective perspectives of caregivers and patients, researchers can better understand the impact of post-stroke cognitive deficits. This research can provide rich, detailed descriptions of caregivers' emotional responses, coping techniques, relationship alterations, and perspectives of caregivers of individuals with post-stroke cognitive deficits. Phenomenological research can also reveal caregivers' common themes and patterns, providing insight into potential areas of support and interventions.

The phenomenological are also subject to various constraints. Several constraints exist in this context, including: Phenomenological research is limited in its generalizability due to its emphasis on comprehending the subjective experiences of a specific cohort of individuals; thereby, the findings cannot be generalised to the broader population. Phenomenological research typically involves small sample sizes, which can limit the extent to which the findings reflect the experiences of a diverse group of caregivers. Phenomenological research typically aims to explore one aspect of caregivers' experiences, which may not necessarily indicate their overall experiences. Thus, the findings may need to capture the holistic experiences of caregivers.

Despite these limitations, phenomenological research remains a valuable approach to understanding the experiences of family caregivers for post-stroke cognitive deficiency. It provides an in-depth understanding of the subjective experiences of caregivers, which can inform the development of effective interventions and support programs.

The present study examines the experiences of caregivers from various ethnic backgrounds. However, the study's focus is solely on the experiences of caregivers. The study included an equal distribution of male and female caregivers, incorporating both genders' perspectives. Although the research participants were chosen through purposive sampling. Achieving demographic diversity among participants was deemed unattainable. Also, this study incorporated all cognitive deficit components: attention, memory, language, and orientation.

According to Mahadevan et al. (2021), the current body of literature regarding poststroke cognitive impairment in Western, Southern Asian, and African regions is limited. This study aims to enhance the statistical data about Western and Southern Asia and Africa's literary fields. Before enlisting the participants, a cognitive evaluation was conducted on their care recipients. The research utilised the SMMSE, and the investigator administered the assessment. The use of conventional neuropsychological evaluation instruments may offer normative data. It is important to note that the aforementioned data had no influence on the study's findings. One potential limitation of the study is the possibility of bias, as the researcher's subjective interpretation of the participants' experiences may influence the findings. The researcher's background and beliefs can influence the interpretation and reporting of experiences. "Member checking" and "peer debriefing" were used by the investigator to lessen this limitation. The supervisor was engaged in every step of data analysis and report drafting. The subject teacher additionally reviewed and suggested some modifications to the study results.

## **6.2. Practice Implication**

The following are some possible practice implications of research on caregivers' experiences while caregiving stroke survivors with post-stroke deficits:

*Creating specialised interventions.* Using the knowledge gathered from the study, healthcare professionals can create specialised and targeted interventions for caregivers, such as counselling, support groups, or services for respite care, that cater to their particular needs and concerns.

*Providing education and training:* Managing the care of a loved one presents many problems for caregivers. The research can aid in creating instructional materials or training courses for caregivers, giving them the knowledge and abilities they need to manage caregiving properly.

*Creating policy and practice recommendations:* The study's findings can help create policy and practice guidelines that encourage the appreciation and support of caregivers within healthcare systems and society.

*Increasing awareness and advocacy:* The research can aid in increasing awareness of the difficulties experienced by caregivers and campaigning for laws that assist them in their caregiving responsibilities.

Overall, research on caregivers' real-world experiences can help create support systems that are responsive and efficient, enhance caregivers' well-being, and guarantee that those getting care from their loved ones receive high-quality care.

## **6.3. Recommendation for Future Research**

Family caregivers of stroke survivors with cognitive impairment must be studied to understand their challenges and develop effective therapies. Future research should consider these:

- Conduct longitudinal studies to evaluate family caregiver needs and experiences throughout time.
- Conduct comparative studies to compare family caregivers of stroke survivors with cognitive impairment to those without cognitive impairment or caregivers of people with other cognitive impairments (e.g., dementia). This comparison technique can identify stroke-related cognitive impairment-specific issues and suggest targeted therapies.
- Examine caregiver burden, stress, depression, anxiety, and quality of life. Understanding these psychological elements might assist in identifying support and intervention needs.

- Assess family caregiver support interventions for stroke survivors with cognitive impairment. These interventions results can inform evidence-based support programs.
- Examine how family caregivers navigate the healthcare system and access resources and services.
- Recognize how culture and circumstance affect family caregivers. Explore how cultural beliefs, values, and social support networks affect caring and help-seeking.
- Explore the benefits and drawbacks of telemedicine, mobile apps, wearable devices, and other emerging technology for caregiver well-being and caregiving tasks.

## 6.4. Conclusion

Physical disabilities burden stroke survivors and their family caregivers. However, post-stroke cognitive deficits are more burdensome. Cognitive loss impacts people's functional capacities as much as physical deficiencies. 40% of Bangladeshi stroke survivors have post-stroke cognitive abnormalities, which is alarming and yet ignored. People don't grasp cognitive deficits since they're harder to perceive than other physical disabilities. This study investigated caregivers' experiences with post-stroke cognitive issues. This study indicated that caregivers of individuals with post-stroke cognitive impairments had some daily effects but also acquired crucial lessons. This study found that caregivers set challenges and compensate, also confirms that caregivers gain from caregiving. This study will help health professionals understand the family and community circumstances and arrange support for the patient and family after returning home. Caregiving advantages can be shared with other

caregivers. If caregivers' physical, emotional, or daily lives are disrupted, patients' quality of life will decreased. Rehabilitators must reduce caregiver loads before returning stroke patients to the community. This area needs more research. Post-stroke cognitive deficiency burdens caregivers and impairs their function. Thus, stroke survivors' effects should be studied, using well-established cognitive assessment instruments to collect normative data.

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# APPENDICES

## **Appendices A: Approval/ Permission Letter**



Mahfuja Akther 4<sup>th</sup> Year B.Sc. in Occupational Therapy Session: 2017-18, Student ID: 122170298 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

# Subject: Approval of the thesis proposal "Experience of Caregivers Caregiving Individuals with Post-Stroke Cognitive Deficits"

Dear Mahfuja Akther,

Congratulations.

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, as the principal investigator and Shamima Akter as thesis supervisor. The Following documents have been reviewed and approved:

Sr. No.	Name of the Documents					
1	Thesis Proposal					
2	Questionnaire					
3	Information sheet & consent form.					

The purpose of the study is to explore the experience of the caregivers, caregiving individuals with post-stroke cognitive deficits. The study involves use of a self-developed interview guide that may take to approximately 30 to 40 minutes to answer the and there is no likelihood of any harm to the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 8.30 AM on 27<sup>th</sup> August, 2022. at BHPI (32<sup>nd</sup> IRB Meeting).

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

Best regards,

Hellothassaen

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

সিআরপি-চাপাইন, সাডার, ঢাকা-১৩৪৩, বাংলাদেশ। ফোন: +৮৮ ০২ ২২8888৫৪৬৪-৫, +৮৮ ০২ ২২8888১৪০৪, মোবাইগ: +৮৮ ০১৭৩০ ০৫৯৬৪৭ CRP-Chapain, Savar, Dhaka-1343, Bangladesh. Tel: +88 02 224445464-5, +88 02 224441404, Mobile: +88 01730059647 E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd

# **Appendices B: Approval to use SMMSE for Pre-Screening**

**Mahfuza Akter Nafisa** <mahfuzaakternafisa@gmail.com>Mon, Feb 27, 2023 at 10:55 AM To: w.molloy@ucc.ie

Dear sir,

Myself Mahfuja Akther, Final year B.Sc. in Occupational Therapy student at Bangladesh Health Professions Institute (BHPI), Bangladesh. We have a mandatory research course "course code: OT-401" in our certification.

I am willing to research "Family Caregivers' Experience During Caregiving Post-Stroke Cognitive Deficits: A Qualitative Study". This study aims to explore the experience of caregivers' while caregiving individuals with post-stroke cognitive deficits. For this research, I have to pre-screen the participants using SMMSE. This pre-screening will only be done to identify if the sample full fills the inclusion criteria of this study and these test results will not be used in the result of this study result.

So, kindly permit me to use the scale in my study.

Sincerely **Mahfuja Akther** Final year B.Sc. in Occupational Therapy Bangladesh Health Professions Institute (BHPI), CRP Savar, Dhaka:1343 Call: +88 01644400279

Willie Molloy <u>W.Molloy@ucc.ie</u>

Mon, Feb 27, 2023 at 11:40 PM To: Mahfuza Akter Nafisa <mahfuzaakternafisa@gmail.com>

Dear Mahfuza

You are welcome to use the SMMSE in your research Copies of scoring sheet and instruction booklet attached... Best wishes wm

# Appendices C: Information Sheet, Consent Form, and Withdrawal Form [English Version]

# **Information Sheet**

Exploring experiences of caregivers', caregiving individual with post-stroke cognitive deficit.

#### Thesis ID: CRP/BHPI/IRB/09/22/641

**Thesis tittle:** Experience of Caregivers' Caregiving Individuals with Post-Stroke Cognitive Deficits.

You are being invited to take part in a research project. Before you decide it is important for you to understand why this research is being done and what participation will be involved. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **Principal investigator:**

Mahfuja Akther

Final year, Department of Occupational Therapy

**Bangladesh Health Professions Institute** 

CRP, Savar, Dhaka-1343

Mobile no: 01644400279

Email ID: mahfuzaakternafisa@gmail.com

#### Supervisor:

Shamima Akter

Assistant Professor, Department of Occupational Therapy

BHPI, CRP, Savar, Dhaka-1343, Bangladesh

IRB office address: BHPI, CRP, Savar, Dhaka-1343, Bangladesh

#### What does the research involve?

The aim of this study is to explore the experience of caregivers while caring for individuals with post-stroke cognitive impairment. Caregiver's experience will be explored in several areas, like daily life experience, social life experience, impact on emotional state, what challenges the caregiver's face and learnings of caregiver's while caregiving. You will be asked different questions under these domains.

Previous researches show that, post-stroke cognitive deficits are very common. Almost 40% of stroke survivors have cognitive impairment and caring for these individuals can be full of challenges. Cognitive impaired individuals may be physically fit to perform different daily tasks but their caregivers have to learn to manage and adapt with their deficits. These difficulties and strategically changes can easily impact upon the daily life performance of caregiver's life. Some research from other countries have shown that caregiving can also have some positive learnings for the caregivers. We aim in this study to figure out the challenges and learnings of caregivers on daily life aspect, social life aspect and their emotional aspect.

If you choose to participate in this study, you will be asked to participate in a face-to-face interview at the place of your choice. Researcher will ask few questions and let you answer them your way. The interview may take approximately from 40-60 minutes to complete. The whole interview will be digitally audio recorded. This recording will only be used in the analysis of this research. No other use will be made of them without your written permission and no one outside the project will be allowed access to the original recordings.

If you agree to participate in the study you have to give a written consent in the consent form. By giving consent you are indicating that you understood what this research is about and that you consent to the collection of data you have provided for the reasons outlined here.

#### How participants are being chosen?

Your contact information is collected from CRP, where the patient completed first phase of rehabilitation program. You will be selected if you meet the mentioned criteria's below:

- ✓ Caregivers of stroke survivors' who have cognitive problems
- ✓ Completed first phase of rehabilitation program and returned to their community before April, 2022
- ✓ Age group from 18 years to 60 years
- ✓ Caregiver who has cared the individual with post-stroke cognitive deficits at least for 3 months

If you meet these criteria, a cognitive assessment will be done on the stroke survivor you care for. You will not be able to participate if you meet the below mentioned criteria.

 $\times$  Stroke survivor who scores 26-30 in SMMSE

 $\times$  Caregivers who are being paid for caregiving from the family of the stroke survivor

\*\* It is totally up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time without giving a reason\*\*

#### Withdrawal of consent

You will be given a withdrawal form; with this you will be able to withdraw your consent to participate the study. You have to fill up the withdrawal form and send the hard copy to the given address. You can withdrawal any time. But once the data analysis is completed, we may not be able to withdraw your information from the study due to the analysis process.

#### **Risk and benefits**

The assessment of the stroke survivor will not impose any risk to the patient and no such question will be asked during the interview that is highly personal or may impose any risk to you or your family.

Although no economical beneficence will be provided but by providing your data you will be contributing to the improvement of the rehabilitation program for the stroke survivors with cognitive impairment. The accumulated result found from your provided data will be another evidence for the importance of caregiver involvement in rehabilitation program. This result may also emphasis on the necessities of caregiver education.

#### Confidentiality

All the collected identifying information will be kept confidential, no 3<sup>rd</sup> person will have access to these data.

#### Result

The result of the study will be documented in student thesis as part of the graduation program of B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI), CRP.

Thank you, Mahfuja Akther

# **Consent form**

Code no: .....

I have read and understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost. I understand that I will be given a copy of this consent form. I voluntarily agree to take part in this study.

Participant's signature	Date
Investigator's signature	Date
Witness's signature	Date

# Withdrawal form

Code no: .....

To the thesis principal investigator, Mahfuja Akther

**Thesis tittle:** Experience of Caregivers' Caregiving Individuals with Post-Stroke Cognitive Deficits.

I hereby request to withdraw from the study, although I have agreed to participate in the study above. Consent code no.....

Date of withdrawal.....

Signature: .....

[Conformation Field]

I confirmed that the participant above withdrew from the study.

Conformation date of withdrawal .....

Signature: .....

# Appendices D: Information Sheet, Consent Form, and Withdrawal Form

[Bangla Version]

#### তথ্য পত্র

কোড নংঃ.....

স্ট্রোক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তির শুশ্রাঝারারী ব্যক্তির অভিজ্ঞতা অম্বেষণ। গবেষণা পত্র নং : সি.আর.পি/বি.এইচ.পি.আই/আই.আর.বি/০৯/২২/৬৪১

গবেষণা শিরোনামঃ স্ট্রোক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তির শুশ্রূষাকারী ব্যক্তির অভিজ্ঞতা অম্বেষণ। আপনাকে একটি গবেষণা প্রকল্পে অংশ নিতে আমন্ত্রণ জানানো হচ্ছে। আপনি সিদ্ধান্ত নেওয়ার আগে এই গবেষণাটি কেন করা হচ্ছে এবং আপনার কেমন অংশগ্রহণ এখানে প্রয়োজন তা বোঝা আপনার জন্য গুরুত্বপূর্ণ। অনুগ্রহ করে নিচের তথ্যগুলো মনোযোগ সহকারে পড়ার জন্য সময় নিন এবং আপনি চাইলে অন্যদের সাথে আলোচনা করুন। যদি এমন কিছু থাকে যা স্পষ্ট নয় বা আপনি যদি আরও তথ্য চান তবে আমাদের জিজ্ঞাসা করুন। আপনি অংশ নিতে চান কি না তা সিদ্ধান্ত নিতে সময় নিন। পড়ার জন্য আপনাকে ধন্যবাদ।

গবেষণাকারীর নামঃ

মাহফুজা আক্তার

চতুর্থ বর্ষীয় শিক্ষার্থী, অকুপেশনাল থেরাপি ডিপার্টমেন্ট বাংলাদেশ হেলথ প্রফেশনস ইনসটিটিউট সি,আর,পি, সাভার, ঢাকা-১৩৪৩ মোবাইল নং: ০১৬৪৪৪০০২৭৯ ই-মেইলঃ mahfuzaakternafisa@gmail.com

#### সুপারভাইজারঃ

শামীমা আখতার সহকারী অধ্যাপক, অকুপেশনাল থেরাপি ডিপার্টমেন্ট মোবাইল নং: ০১৭১৬৮০৬৮৬৪ ই-মেইলঃ shamimaakterot@gmail.com বি,এইচ,পি,আই, সি,আর,পি, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ

আই, আর, বি, অফিসঃ বি,এইচ,পি,আই, সি,আর,পি, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ

এই গবেষণাতে কি কি রয়েছে?

এই গবেষণার প্রধান লক্ষ্য হচ্ছে, স্ট্রোক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তির শুশ্রূষাকারী ব্যক্তির অভিজ্ঞতা অম্বেষণ করা। শুশ্রূষাকারী ব্যক্তির অভিজ্ঞতা বিভিন্ন ক্ষেত্রে অম্বেষণ করা হবে, যেমন, তাদের দৈনন্দিন জীবনের প্রতিকূলতার সম্মুখীন হতে হয় এবং শুশ্রূষাকালীন সময়ে তারা নতুন কি শিখতে পেরেছে। আপনাকে এইসব বিষয় সম্পর্কিত বিভিন্ন প্রশ্ন করা হবে।

পূর্ববর্তী গবেষণাগুলি দেখায় যে, স্ট্রোক-পরবর্তী জ্ঞানগত অক্ষমতা খুব সাধারণ। স্ট্রোক থেকে বেঁচে যাওয়া প্রায় ৪০% লোকের জ্ঞানগত প্রতিবন্ধকতা রয়েছে এবং এই ব্যক্তিদের যত্ন নেওয়া প্রতিকূলতাপূর্ণ হতে পারে। জ্ঞানগত প্রতিবন্ধী ব্যক্তিরা বিভিন্ন দৈনন্দিন কাজ সম্পাদন করার জন্য শারীরিকভাবে উপযুক্ত হলেও তাদের শুশ্রূষাকারী ব্যক্তিদের তাদের ঘাটতিগুলি পরিচালনা করতে এবং মানিয়ে নিতে শিখতে হয়। এই অসুবিধাগুলি এবং কৌশলগত পরিবর্তনগুলি শুশ্রূষাকারী ব্যক্তিদের দৈনন্দিন জীবনের কর্মক্ষমতাকে সহজেই প্রভাবিত করতে পারে। অন্যান্য দেশের কিছু গবেষণায় দেখা গেছে যে সেবা দেওয়ার ফলে শুশ্রুষাকারী ব্যক্তিদেরজন্য কিছু ইতিবাচক শিক্ষাও থাকতে পারে। আমরা এই গবেষণার মাধ্যমে শুশ্রুষাকারী ব্যক্তিরে দৈনন্দিন জীবনের দিক, সামাজিক জীবনের দিক এবং তাদের মানসিক দিক সম্পর্কে যেসব প্রতিকুলতা এবং শিক্ষা রয়েছে তা অনুসন্ধান করতে চাই।

আপনি যদি এই গবেষণায় অংশগ্রহণ করতে চান, তাহলে আপনাকে আপনার সুবিধামত জায়গায় সরাসরি সাক্ষাৎকারে অংশগ্রহণ করতে অনুগ্রহ করা হবে। গবেষক কয়েকটি প্রশ্ন জিজ্ঞাসা করবেন এবং আপনি আপনার মত করে উত্তর দিবেন। সাক্ষাৎকারটি সম্পূর্ণ হতে প্রায় ৪০-৬০ মিনিট সময় লাগতে পারে। পুরো সাক্ষাৎকারটি ডিজিটালি অডিও রেকর্ড করা হবে। এই রেকর্ডিং শুধুমাত্র এই গবেষণার কাজে ব্যবহার করা হবে. আপনার লিখিত অনুমতি ব্যতীত এগুলিকে অন্য কোথাও ব্যবহার করা হবে না এবং এই গবেষণার বাইরের কাউকে মূল রেকর্ডিংগুলো শোনার বা ব্যবহারের অনুমতি দেওয়া হবে না।

আপনি যদি এই গবেষণায় অংশগ্রহণ করতে রাজী থাকেন তবে আপনাকে দেওয়া সম্মতি পত্রে একটি স্বাক্ষর করতে হবে। আপনার সম্মতি এর মাধ্যমে আমরা বুঝতে পারবো যে আপনি এই গবেষণার বিষয়বস্তু বুঝতে পেরেছেন এবং আপনি উল্লেখিত কারনে প্রয়োজনীয় তথ্য প্রদানে সম্মত আছেন।

#### কিভাবে অংশগ্রহণকারীদের বাছাই করা হবে?

আপনার সাথে যোগাযোগের তথ্য আমরা সি,আর,পি থেকে সংগ্রহ করেছি, যেখানে আপনার রোগী পুনর্বাসনের প্রথম ধাপ সম্পূর্ণ করেছেন। নিম্নে উল্লখিত বিষয়গুলো যদি আপনার পূরন হয়ে থাকে তবে আপনাকে এই গবেষণায় অংশগ্রহণের জন্য আহ্বান করা হবেঃ

- স্ট্রাক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তির শুশ্রূষাকারী
- স্ট্রাক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তি যে এপ্রিল, ২০২২ইং এর আগে পুনর্বাসনের প্রথম ধাপ সম্পন্ন করে নিজের এলাকায় ফিরে গেছেন
- ৩শ্রুমাকারী যাদের বয়স ১৮ বছর থেকে ৬০ বছরের মধ্যে
- সন্ট্রাক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তির শুশ্রূষাকারী যে কমপক্ষে ৩ মাস ধরে রোগীর সেবা করে যাচ্ছে

আপনি যদি উল্লেখিত বিষয়গুলো পুরন করে থাকেন তবে আপনার স্ট্রোক রোগীর একটি জ্ঞানীয় এ্যাসেসমেন্ট করা হবে। উপরে উল্লেখিত বিষয়গুলো পুরন করা সত্ত্বেও আপনি যদি নিম্নে উল্লিখিত বিষয়গুলো পুরন করেন তবে আপনি এই গবেষণায় অংশগ্রহণ করতে পারবেন নাঃ

- 🗢 এস,এম,এম,এস,ই এ্যাসেসমেন্টে যদি স্ট্রোক রোগী ২৬-৩০ এর মধ্যে নাম্বার পায়
- 🗢 যেসব শুশ্রুষাকারীকে স্ট্রোক রোগীর পরিবার থেকে সেবাদানের জন্য অর্থ প্রদান করা হচ্ছে

\*\* আপনি এই গবেষণায় অংশগ্রহণ করবেন কি না তা সম্পূর্ণ আপনার উপর নির্ভর করে। আপনি যদি এই গবেষণায় অংশ নেওয়ার সিদ্ধান্ত নেন তবে আপনাকে এই তথ্য পত্রটি দিয়ে দেওয়া হবে এবং একটি সম্মতি ফর্মে স্বাক্ষর করতে বলা হবে। আপনি যেকোন সময় এই গবেষণায় অংশগ্রহণ প্রত্যাহার করতে পারেন। \*\*

### সম্মতি প্রত্যাহার

আপনাকে একটি প্রত্যাহার ফর্ম দেওয়া হবে; এর মাধ্যমে আপনি গবেষণায় অংশগ্রহণের সম্মতি প্রত্যাহার করতে পারবেন। আপনাকে প্রত্যাহার ফর্মটি পূরণ করে প্রদন্ত ঠিকানায় ফর্মটি পাঠাতে হবে। আপনি যে কোন সময় সম্মতি প্রত্যাহার করতে পারবেন। কিন্তু একবার ডেটা বিশ্লেষণ শেষ হয়ে গেলে, বিশ্লেষণ প্রক্রিয়ার কারণে আমরা আপনার তথ্য গবেষণা থেকে প্রত্যাহার করতে পারব না।

### ঝুকি এবং সুবিধাসমূহ

স্ট্রোক রোগীর এ্যাসেসমেন্ট, রোগীর কোন ক্ষতির কারন হবে না এবং সাক্ষাৎকারের সময় আপনাকে এমন কোনো প্রশ্ন করা হবে না যা অত্যন্ত ব্যক্তিগত বা আপনার অথবা আপনার পরিবারের জন্য কোন ঝুকির কারন হতে পারে। যদিও কোন প্রকার আর্থিক সাহায্য প্রদান করা হবে না তবে আপনার মুল্যবান তথ্য প্রদানের মাধ্যমে আপনি স্ট্রোক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তির পুনর্বাসন ব্যবস্থার উন্নয়নে গুরুত্বপূর্ণ ভূমিকা রাখতে পারবেন। আপনার প্রদানকৃত তথ্য থেকে আমরা গবেষণায় যে ফলাফল পাবো তা প্রমান দিবে যে স্ট্রোক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তির পুনর্বাসন ব্যবস্থার উন্নয়নে গুরুত্বপূর্ণ ভূমিকা রাখতে পারবেন। আপনার প্রদানকৃত তথ্য থেকে আমরা গবেষণায় যে ফলাফল পাবো তা প্রমান দিবে যে স্ট্রোক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তির পুনর্বাসন প্রোগ্রামে শুদ্রাবারীর অংশগ্রহণ কতটা গুরুত্বপূর্ণ। এই ফলাফল শুদ্রাবারারীর রোগীর রোগ ও পুনর্বাসন সম্পর্কিত শিক্ষার প্রয়োজনীয়তার উপরও জোর দিতে পারে।

#### গোপনীয়তা

সমস্ত সংগৃহীত শনাক্তকরণ তথ্য গোপন রাখা হবে, কোন তৃতীয় ব্যক্তির এই তথ্যগুলি দেখার বা ব্যবহারের অনুমতি থাকবে না।

#### ফলাফল

অকুপেশনাল থেরাপির স্নাতক প্রোগ্রামের অংশ হিসাবে গবেষণার ফলাফল বাংলাদেশ হেলথ প্রফেশনাল ইনস্টিটিউট (বিএইচপিআই), সিআরপি-এর ছাত্র গবেষণায় নথিভুক্ত করা হবে।

ধন্যবাদ মাহফুজা আক্তার

#### সম্মতি পত্র

কোড নং: .....

আমি প্রদত্ত তথ্য পড়েছি এবং বুঝেছি এবং প্রশ্ন করার সুযোগ পেয়েছি। আমি বুঝতে পেরেছি যে আমার অংশগ্রহণ সম্পূর্ণ স্বেচ্ছায় হবে এবং আমি কোনো কারণ ছাড়াই এবং কোনো খরচ ছাড়াই যে কোনো সময় সম্মতি প্রত্যাহার করতে পারব। আমাকে এই সম্মতি ফর্মের একটি কপি দেওয়া হবে। আমি স্বেচ্ছায় এই গবেষণায় অংশ নিতে সম্মত।

অংশগ্রহণকারীর স্বাক্ষর \_\_\_\_\_

তদন্তকারীর স্বাক্ষর \_\_\_\_\_ তারিখ \_\_\_\_\_

সাক্ষীর স্বাক্ষর \_\_\_\_\_ তারিখ \_\_\_\_\_

#### প্রত্যাহার পত্র

কোড নং: .....

গবেষণার প্রধান তদন্তকারী, মাহফুজা আক্তার বরাবর,

গবেষণার শিরোনাম: স্ট্রোক পরবর্তী জ্ঞানগত অক্ষমতা সম্পন্ন ব্যক্তির শুশ্রূষাকারী ব্যক্তির অভিজ্ঞতা অম্বেষণ।

আমি এতদ্বারা অধ্যয়ন থেকে প্রত্যাহার করার জন্য অনুরোধ করছি, যদিও আমি উপরে অধ্যয়নে অংশগ্রহণ করতে সম্মত হয়েছি। সম্মতি কোড নং.....

প্রত্যাহারের তারিখ .....

স্বাক্ষর: ....

[কনফরমেশন ফিল্ড]

আমি নিশ্চিত করেছি যে উপরের অংশগ্রহণকারী অধ্যয়ন থেকে সরে গেছে।

প্রত্যাহারের তারিখ .....

স্বাক্ষর: ....

# **Appendices E: Interview Guide 1**

# **Interview guide 1**

# A. Life experiences (জীবন অভিজ্ঞতা)

- 1. What problems the patient is still facing?
- স্ট্রোকের পর রোগীর এখনও কি কি সমস্যা রয়েছে?
- 2. How much do you think the patient (stroke survivor) recovered after completing the rehabilitation program?
- ২) পুনর্বাসনের প্রথম ধাপ শেষ করে বাসায় ফেরার পর কতটুকু উন্নতি হয়েছে রোগীর?
- 3. Do you think he/she is still recovering?
- ৩) রোগীর এখনও উন্নতি হচ্ছে বলে কি আপনার মনে হয়?
- 4. Would it be better if he/she recovered more?
- 8) আপনার কি মনে হয় রোগীর আরও কিছু কি উন্নতি হওয়া দরকার?
- 5. How does your day start?
- ৫) আপনার দিন কিভাবে শুরু হয়?
- 6. What are the main tasks that you must perform every day?
- ৬) কোন কোন কাজগুলো আপনার প্রতিদিন করতেই হয়?
- 7. Which tasks you didn't have to do before the patient's stroke?
- ৭) এর মধ্যে কোন কোন কাজগুলো রোগীর স্ট্রোকের আগে আপনাকে করতে হতো না?
- 8. How much help you get from the patient after his/her rehabilitation? Are you satisfied with his/her help?
- ৮) ট্রিটমেন্ট নিয়ে বাসায় আসার পর রোগী আপনাকে বিভিন্ন কাজে কতটুকু সাহায্য করতে পারে? রোগীর সাহায্য পেয়ে কি আপনি সন্তুষ্ট?
- 9. Did you had to change your job after the patient's stroke?
- ৯) রোগী স্ট্রোক করার পর আপনাকে কি আপনার চাকরি পরিবর্তন করতে হয়েছে?
- 10. Did you return to your old job after rehabilitation (if changed)?
- ১০) রোগীর চিকিৎসার পর কি আপনি আপনার আগের চাকরিতে ফিরে যেতে পরেছেন? (যদি চাকরি পরিবর্তন করে থাকে)

- 11. Are you involved in any new job? What is it? (If not returned)?
- ১১) আপনি নতুন কোনো চাকরি করছেন কি? কি চাকরি করছেন? (যদি আগের চাকরিতে ফিরে না যান)
- 12. How much effort you can provide at your job?
- ১২) আপনি চাকরিতে কতটুকু সময় ও শ্রম দিতে পারেন?
- 13. How much time of the day you can give to yourself? How do you utilize that time?
- ১৩) সারাদিনে কতটুকু সময় আপনি নিজের জন্য দিতে পারেন? সেই সময় আপনি কি করেন?
- 14. Are you satisfied with your current life? Your family, your job and over all?
- ১৪) আপনার বর্তমান জীবন, আপনার পরিবার, আপনার চাকরি ও অন্যান্য সবকিছু নিয়ে আপনি কি আপনি সন্তুষ্ট?
- 15. What do you think about the updates that can help for better lifestyle than now?
- ১৫) কি ধরনের বা কি কি পরিবর্তন আসলে আপনার মনে হয় যে জীবন নিয়ে আপনার সন্তুষ্টি বর্তমানের থেকে আরও বৃদ্ধি পাবে?
- 16. What are the barriers for these updates?
- ১৬) এইসব পরিবর্তন বা উন্নয়নের পথে কি কি বাধা রয়েছে?

# B. Specific challenges (নির্দিষ্ট প্রতিকুলতা)

- 1. What challenges do you face while caregiving? What do you think what are the reasons for these challenges?
- ১) রোগীর সেবা/ পরিচর্যা করার সময়় আপনাকে কি কি প্রতিকুলতার সম্মুখীন হতে হয়? এসব প্রতিকুলতার কারন কি বলে আপনার মনে হয়?
- 2. How do you manage these challenges?
- ২) এই প্রতিকুলতাগুলোর বিপক্ষে আপনি কি ব্যবস্থা গ্রহণ করেন?
- 3. As the patient have cognitive problem, do you have to follow any strategies for new challenges in any kind of activities?
- ৩) রোগীর জ্ঞানীয় প্রতিবন্ধকতার জন্য যেকোনো কাজে কি আপনার নতুন কোনো পন্থা অবলম্বন করতে হয়?
- 4. What are the strategies you are following for those challenges?
- 8) আপনি নতুন কি কি পন্থা অবলম্বন করছেন এই প্রতিকুলতাগুলোর সম্মুখীন হতে?
- 5. What is the source of your strategy ideas?
- ৫) নতুন পন্থা অবলম্বনের বুদ্ধি আপনি কোথা থেকে পেয়েছেন?

- 6) What is the success rate of these strategies in your view?
- ৬) আপনার কি মনে হয়, এই পন্থাগুলো কতটুকু উপযোগী?

# C. Social life (সামাজিক জীবন)

- 1. How much help do you get from your other family members?
- আপনার পরিবারের অন্যান্য সদস্যদের থেকে আপনি কতটুকু সাহায্য পান?
- 2. How much help do you get from your friends and neighbours?
- ২) আপনার বন্ধু ও প্রতিবেশীদের থেকে কতটুকু সাহায্য পান?

### D. Emotional state (মানসিক অবস্থা)

- 1. How do you feel about caring the patient?
- ১) রোগীর যত্ন নেওয়ার বিষয়ে আপনি কেমন অনুভব করেন?
- 2. Do you get to spend any personal time for yourself?
- ২) আপনি কি নিজের জন্য ব্যক্তিগত সময় ব্যয় করতে পারেন?
- 3. How do you manage any kind of emotional stress?
- ৩) কোন ধরনের মানসিক চাপের সম্মুখীন হলে আপনি তা কিভাবে মোকাবিলা করেন?

# E. Learnings from caregiving (নিজস্ব উপলব্ধি)

- 1. Do you have any realizations after caring the patient?
- ১) রোগীর যত্ন নেওয়ার পর আপনি কি উপলব্ধি করতে পারছেন? জীবন সম্পর্কে আপনার কোনো নতুন জ্ঞান বা ধারনা এসেছে কি?

# **Appendices F: Interview Guide 2**

# **Interview guide**

# A. Life Experiences (জীবন অভিজ্ঞতা)

- 1. What problems the patient is still facing?
- স্ট্রোকের পর রোগীর এখনও কি কি সমস্যা রয়েছে?
- 2. How much do you think the patient (stroke survivor) recovered after completing the rehabilitation program?
- ২) পুনর্বাসনের প্রথম ধাপ শেষ করে বাসায় ফেরার পর কতটুকু উন্নতি হয়েছে রোগীর?
- 3. Do you think he/she is still recovering?
- ৩) রোগীর এখনও উন্নতি হচ্ছে বলে কি আপনার মনে হয়?
- 4. Would it be better if he/she recovered more?
- 8) আপনার কি মনে হয় রোগীর আরও কিছু কি উন্নতি হওয়া দরকার?
- 5. How does your day start?
- ৫) আপনার দিন কিভাবে শুরু হয়?
- 6. What are the main tasks that you must perform every day?
- ৬) কোন কোন কাজগুলো আপনার প্রতিদিন করতেই হয়?
- 7. Which tasks you didn't have to do before the patient's stroke?
- ৭) এর মধ্যে কোন কোন কাজগুলো রোগীর স্ট্রোকের আগে আপনাকে করতে হতো না?
- 8. How much help you get from the patient after his/her rehabilitation? Are you satisfied with his/her help?
- ৮) ট্রিটমেন্ট নিয়ে বাসায় আসার পর রোগী আপনাকে বিভিন্ন কাজে কতটুকু সাহায্য করতে পারে? রোগীর সাহায্য পেয়ে কি আপনি সন্তুষ্ট?
- 9. Did you had to change your job after the patient's stroke?
- ৯) রোগী স্ট্রোক করার পর আপনাকে কি আপনার চাকরি পরিবর্তন করতে হয়েছে?
- 10. Did you return to your old job after rehabilitation (if changed)?
- ১০) রোগীর চিকিৎসার পর কি আপনি আপনার আগের চাকরিতে ফিরে যেতে পরেছেন? (যদি চাকরি পরিবর্তন করে থাকে)

- 11. Are you involved in any new job? What is it? (If not returned)?
- ১১) আপনি নতুন কোনো চাকরি করছেন কি? কি চাকরি করছেন? (যদি আগের চাকরিতে ফিরে না যান)
- 12. How much effort you can provide at your job?
- ১২) আপনি চাকরিতে কতটুকু সময় ও শ্রম দিতে পারেন?
- 13. Are you continuing your studies? what problems are you facing for this?
- ১৩) আপনি কি পড়াশোনা চালিয়ে যাচ্ছেন? এর জন্য আপনার কোন সমস্যার সম্মুখীন হতে হচ্ছে?
- 14. Are you satisfied with your current life? Your family, your job and over all?
- ১৪) আপনার বর্তমান জীবন, আপনার পরিবার, আপনার চাকরি ও অন্যান্য সবকিছু নিয়ে আপনি কি আপনি সন্তুষ্ট?
- 15. What do you think about the updates that can help for better lifestyle than now?
- ১৫) কি ধরনের বা কি কি পরিবর্তন আসলে আপনার মনে হয় য়ে জীবন নিয়ে আপনার সন্তুষ্টি বর্তমানের থেকে আরও বৃদ্ধি পাবে?
- 16. What are the barriers for these updates?
- ১৬) এইসব পরিবর্তন বা উন্নয়নের পথে কি কি বাধা রয়েছে?

# B. Basic Self-care (নিজস্ব পরিচর্যা)

- 1. Can you do eating, sleeping, bathing etc. daily on time?
- প্রতিদিনের খাওয়া, ঘুম, গোসল ইত্যাদি কাজ আপনি কি সময়মত করতে পারেন?
- 2. How many hours can you sleep every day? Do you have any disturbance in your night sleep?
- ২) আপনি প্রতিদিন কত ঘণ্টা ঘুমাতে পারেন? রাতের ঘুমে আপনার কোনো ব্যঘাত হয় কি?
- 3. How much time of the day you can give to yourself? How do you utilize that time?
- ৩) সারাদিনে কতটুকু সময় আপনি নিজের জন্য দিতে পারেন? সেই সময় আপনি কি করেন?

# C. Specific Challenges (নির্দিষ্ট প্রতিকুলতা)

- 1. What challenges do you face while caregiving? What do you think what are the reasons for these challenges?
- ১) রোগীর সেবা/ পরিচর্যা করার সময়় আপনাকে কি কি প্রতিকুলতার সম্মুখীন হতে হয়? এসব প্রতিকুলতার কারন কি বলে আপনার মনে হয়?

- 2. How do you manage these challenges?
- ২) এই প্রতিকুলতাগুলোর বিপক্ষে আপনি কি ব্যবস্থা গ্রহণ করেন?
- 3. As the patient have cognitive problem, do you have to follow any strategies for new challenges in any kind of activities?
- ৩) রোগীর জ্ঞানীয় প্রতিবন্ধকতার জন্য যেকোনো কাজে কি আপনার নতুন কোনো পন্থা অবলম্বন করতে হয়?
- 4. What are the strategies you are following for those challenges?
- 8) আপনি নতুন কি কি পন্থা অবলম্বন করছেন এই প্রতিকুলতাগুলোর সম্মুখীন হতে?
- 5. What is the source of your strategy ideas?
- ৫) নতুন পন্থা অবলম্বনের বুদ্ধি আপনি কোথা থেকে পেয়েছেন?
- 6. What is the success rate of these strategies in your view?
- ৬) আপনার কি মনে হয়, এই পন্থাগুলো কতটুকু উপযোগী?

### D. Social life (সামাজিক জীবন)

- 1. How much help do you get from your other family members?
- আপনার পরিবারের অন্যান্য সদস্যদের থেকে আপনি কতটুকু সাহায্য পান?
- 2. How much help do you get from your friends and neighbours?
- ২) আপনার বন্ধ ও প্রতিবেশীদের থেকে কতটুকু সাহায্য পান?

# E. Emotional State (আবেগীয় অবস্থা)

- 1. How do you feel about caring the patient?
- রোগীর যত্ন নেওয়ার বিষয়ে আপনি কেমন অনুভব করেন?
- 2. Do you get to spend any personal time for yourself?
- ২) আপনি কি নিজের জন্য ব্যক্তিগত সময় ব্যয় করতে পারেন?
- 3. How do you manage any kind of emotional stress?
- ৩) কোন ধরনের মানসিক চাপের সম্মুখীন হলে আপনি তা কিভাবে মোকাবিলা করেন?

# F. Leanings from caregiving (নিজস্ব উপলব্ধি)

- 1. Do you have any realizations after caring the patient?
- রোগীর যত্ন নেওয়ার পর আপনি কি উপলব্ধি করতে পারছেন? জীবন সম্পর্কে আপনার কোনো নতুন জ্ঞান বা ধারনা এসেছে কি?



Bangladesh Health Professions Institute Department of Occupational Therapy 4<sup>th</sup> Year B. Sc in Occupational Therapy OT 401 Research Project Thesis Supervisor-Student Contact; face to face or electronic and guidance record

Title of thesis: Experience of Caregivers Caregiving Individuals with Post-Stroke Cognitive.

Name of student: Mahfuja Akther

Name and designation of thesis supervisor: Shamima Akter

Assistant Professor, Department of Occupation Therapy, BHPI, CRP, Savar, Dhaka-1343

Thesis supervisor signature	D	De	A
Student's signature	Matric	Mahanjo	Mahaja
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# Appendices G: Thesis Supervisor-Student Contact

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Appointment number will cover at least a total of 40 hours; applicable only for face-to-face contact with the supervisors.
 Students will require submitting this completed record during submission your final thesis.