Caregiver Burden of Patient with Guillain-Barré Syndrome: A Cross-Sectional Study

By

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

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Statement of Authorship

This is to certify that the thesis work entitled "Caregiver Burden of Patient with Guillain-Barré Syndrome: A Cross-Sectional Study" has been carried out by (Md. Nadim Shahariar) in the Department of B.Sc. in Occupational Therapy, Bangladesh Health Professions Institute, Savar Dhaka, Bangladesh. The above thesis work has not been submitted anywhere for the award of any degree. The ethical issue of this study has been strictly considered and protected. The research supervisor will be quite concerned if the findings of this project are disseminated for future publication, and it will be properly acknowledged as an undergraduate thesis.

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Dedication

I want to dedicate my work to Almighty Allah who keeps me well and on the right track and helps me to keep patience during the work period. I dedicated my thesis to my beloved parents: Jafar Uddin & Nasima Sultana for their endless love, support and encouragement throughout my pursuit of education. I hope this achievement will fulfill the dream they envisioned for me.

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List of Abbreviations

AMAN	Acute Motor Axonal Neuropathy
AMSAN	Acute Motor and Sensory Axonal Neuropathy
BHPI	Bangladesh Health Professions Institute
CRP	Centre for the Rehabilitation of the Paralysed
GBS	Guillain-Barré Syndrome
GHQ-28	General Health Questionnaire (28-item version)
ICU	Intensive Care Unit
IRB	Institutional Review Board
OT	Occupational Therapy
WHO	World Health Organization
ZBI	Zarit Burden Interview

Abstract

Background: Guillain–Barré Syndrome (GBS) is an acute autoimmune disorder affecting the peripheral nervous system and the leading cause of acute flaccid paralysis. The sudden onset and unpredictable recovery process place substantial physical, psychological, social, and financial strain on caregivers, leading to caregiver burden.

Aim: The aim of the study was investigating the level of Caregiver Burden of Patient with Guillain-Barré Syndrome

Methodology: A quantitative cross-sectional study design was used. The study was conducted in the neurology units and outpatient departments of the Centre for the Rehabilitation of the Paralysed (CRP) Savar (head office) and its branches.

Results: The study findings revealed that caregiver burden was highly prevalent among the respondents. Based on the Zarit Burden Interview (ZBI) scoring, 17.6% of caregivers experienced little or no burden, 35.2% had mild to moderate burden, 28.6% reported moderate to severe burden, and 18.6% experienced severe burden. Overall, 82.4% of caregivers experienced some degree of burden, with nearly 47.2% falling within the moderate to severe and severe categories combined. Female caregivers demonstrated higher burden levels compared to males. Additionally, caregivers from lower socio-economic backgrounds and those in the middle-aged group reported significantly higher burden scores. Statistical analysis showed a significant association between caregiver burden and selected socio-demographic variables ($P < 0.05$).

Conclusion: The findings highlight the need for caregiver-focused interventions, psychosocial support, and policy-level initiatives to reduce the burden and improve the overall well-being of caregivers.

Key words: *Caregiver burden, Guillain-Barre Syndrome, ZBI, Primary Caregiver*.

CHAPTER I: INTRODUCTION

1.1 Background

Guillain-Barre syndrome (GBS) is an uncommon, acute, and complicated autoimmune pathology that attacks the peripheral nervous system and causes rapid progressive symmetrical muscle weakness, sensory aberrations, and in severe cases, complete paralysis (Akanuwe et al., 2020; Atkinson et al., 2006; Forsberg et al., 2006). It has been recognized as the major etiology of acute flaccid paralysis in the world after the elimination of poliomyelitis (Buzby et al., 1995; Habib et al., 2017; Sejvar et al., 2011). The GBS manifests itself in Bangladesh in a unique way: axonal forms of the condition, acute motor axonal neuropathy (AMAN) and acute motor sensory axonal neuropathy (AMSAN), are more common in the country compared to Western environment and are often preceded by a prior infection with Campylobacter jejuni (Habib et al., 2017; Papri et al., 2021). The patients in the region have a history of significant disability and high mortality rates (14–17%) due to the lack of resources, including the intensive care unit (ICU) beds and the prohibitive price of effective immunomodulatory treatments, including intravenous immunoglobulin (IVIg) and plasma exchange (Papri et al., 2021).

Normally a spouse or a close relative, the primary informal caregiver is placed in a situation that requires a long-term and demanding dedication (Aoun et al., 2012; Shrinivasa et al., 2022). People who perform this role regularly face the fast development of the disease, as a result, they need to provide a wide range of physical, emotional, and financial assistance (Aoun et al., 2012; Jenn, 2024). Medical management and Emotional support (the consideration of patient anxiety, depression, and feelings of helplessness and a simultaneous control over the caregiver distress) (Aoun et al., 2013; Atkinson et al., 2006; Jenn, 2024; Shrinivasa et al., 2022).

The stressor is referred to as caregiver burden, which is a multidimensional strain that occurs when individuals are subjected to physical, emotional, and financial issues in connection with taking care of an impaired person (Guger et al., 2021). The prognostic uncertainty and the changing course of the recovery path, that can take a few weeks up to years, increases this burden in the context of GBS (Cooke & Orb, 2003; Poppe, 2018). It is empirically proven that the psychological morbidity of caregivers of patients with neurological conditions is often more tangible than that of the general population, such as anxiety and depression (Von Gaudecker et al., 2023). Factors like family cohesion, family satisfaction, and good communication are also linked to reduced caregiver burden, and lack of support in the family structure and disengagement can exacerbate strain levels (Parekh et al., 2017; Tramonti et al., 2019).

The lack of national clinical guidelines and limited access to a professional neuro-rehabilitation facility in resource-limited environments, like Bangladesh, only exacerbates both the objective and subjective burden on family units (Farhin Khan et al., 2015; Papri et al., 2021). Although the apparent caregiver strain is especially evident among relatives, it is sparsely covered in the literature that challenges the particular caregiver burden related to GBS; specifically, in the contexts of family relations and psychosocial adaptation (Cooke & Orb, 2003; Poppe, 2018; Shrinivasa et al., 2022). This gap is addressed in the current research such that the determinants of caregiver burden are evaluated hence informing specific interventions that can reduce the levels of caregiver distress and improve the overall quality of life of the patients and the families (Bernsen et al., 2006).

1.2 Justification of the study

GBS is the leading cause of acute flaccid paralysis worldwide, often leading to rapidly progressive weakness that can result in complete paralysis and life-threatening respiratory failure. Unlike chronic conditions that allow for gradual adaptation, GBS strikes suddenly thrusting family members into unremitting caregiving roles without prior preparation. This sudden transition is associated with high levels of shock, anxiety and trauma for the relative. A GBS patient is extremely difficult to take care of and can require 12-15 hours of close attention daily when the patient is at the worst stage. They should also be on the lookout of abrupt change in heart rate and difficulty in breathing, which occur in approximately 17% to 30% of GBS victims. The role of the caregiver changing to that of a nurse brings about a sense of a succession of losses, loss of intimacy and the long-term grief may be a problem with many caregivers. Research is particularly critical in Bangladesh, where GBS presents unique challenges that exacerbate the burden. The more severe axonal subtypes (AMAN and AMSAN) are more prevalent in Bangladesh than in Western countries, leading to higher rates of disability and mortality (14–17%). National guidelines do not exist and there are limited rehab services, meaning that families have to deal with the complicated care with minimal assistance. Research has been done in other brain disorders (Alzheimer and Multiple Sclerosis) but little information has been established on the impact of GBS on mental and social wellbeing of caregivers. The majority of GBS studies consider only medical outcomes and not the family of the person who is anxious, depressed, and other mental issues, which may persist even after the patient has died. In addition, the issue of family proximity and dialog has not been investigated effectively on the load of a caregiver on GBS. We ought to inform the policymakers that we require more money and better rehab services in order to ensure that home care is not failing.

1.3 Operational Definition

1.3.1 GBS

Guillain–Barre syndrome (GBS) is a term used to describe a group of autoimmune disorders (variants) that share a common presentation of acute or subacute progressive polyradiculoneuropathy, though they may have a different pathogenesis (Malek & Salameh, 2020).

1.3.2 Caregiver

According to Collins English Dictionary (2012) "a person who has accepted responsibility for looking after a vulnerable neighbor or relative is called carer". Caregiving is an occupation that can encompass 24 hours a day, 7 days a week, with no sick family, and caregiving responsibilities simultaneously. These challenges put caregivers at risk for experiencing caregiver burden (Naguwa, 2010). The terms family caregiver and informal caregiver refer to an unpaid family member, friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care (Reinhard et al., 2000). Caregivers are more likely to be women in many countries of the world. Asian studies such as Japan, Taiwan, Malaysia, Philippines, Indonesia and India found about 70% of family caregivers are females. Globally about 80% of the caregivers are women. They are mother, wife, or daughter of the patients. Usually, their socioeconomic condition is not better (Chan, 2011)

1.3.3 Caregiver responsibilities

Caregiving responsibilities can make a burden on caregiver's daily lives, physical health, and emotional well-being. High levels of caregiver burden can have considerable consequences for patients and wider society as a whole as well as for caregivers themselves. For instance, the impact on the caregiver becomes too great, and then there could be some consequences on the delivery of care to patients, an increase in unmet needs of overburdened caregivers and an increasing reliance on formal, paid assistance resulting in costs to healthcare systems and wider society. In addition, caregiving has a significant impact on informal caregivers‟ own physical and psychological health (Gater et al., 2014)

1.3.4 Caregiver burden

Caregiver burden has been widely researched and is defined as "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience". Many studies have found that caregiving is related to physical and psychosocial issues, such as depression, illness, and decreased quality of life (Naguwa, 2010). Caregivers look at several stressors including financial, family structure, and physical health demands among many others. Burden of care can be conceptualized into two distinct components are objective and subjective. Objective burden of care is meant to indicate its effects on the household such as taking care of daily tasks, whereas subjective burden indicates the extent to which the caregivers perceived the burden of caregiving. Subjective burden means the positive and negative feelings and perceptions of the caregiver associated with providing caregiving function. Caregiver burden includes financial strain, being confined to the home, change in the relationship, the demands of caregiving and having little time for oneself.

The relationship between coping styles and perceived burden of care is complex because caregivers subjectively report “burden.” The burden of caregivers is more dependent on their judgment of the situation of their patients rather than the actual illness (Talwar & Matheiken, 2010)

1.4 Aim of the study

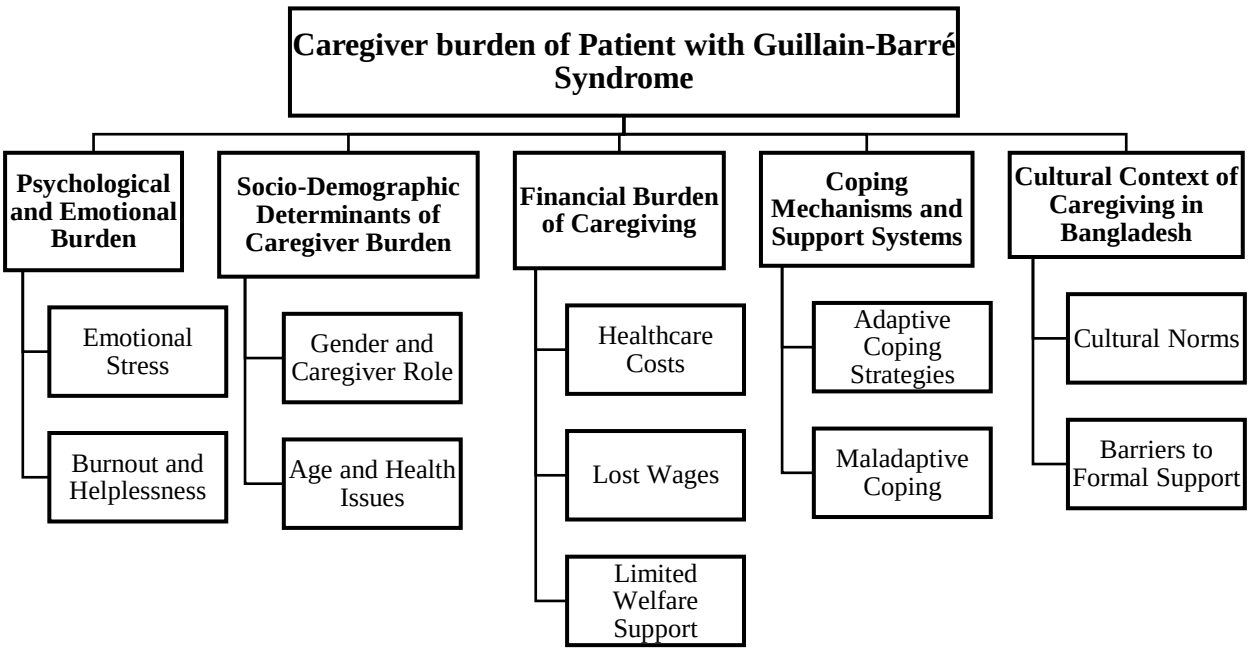
Aim: The aim of the study was investigating the level of Caregiver Burden of Patient with Guillain-Barré Syndrome

CHAPTER II: LITERATURE REVIEW

This literature review chapter focuses on studies related to the caregiver burden of patients with Guillain-Barré Syndrome. The chapter presents caregiver burden from different perspectives. Articles were identified through searches in Google Scholar, PubMed, Scopus, and Google. Figure 2.1 provides an overview of the main themes identified in the literature review.

Figure 2.1:

Overview of the Literature Finding



2.1 Psychological and Emotional Burden

2.1.1 Emotional Stress

According to (Adelman et al., 2015), long-term care for an ill or disabled family member creates significant difficulties (or burdens) for individuals providing this assistance. Caregivers suffer from physical, emotional, social and financial hardship. The caregiver burden due to GBS is increased by several factors: the rapid onset of the illness, risk of developing respiratory failure and an uncertain prognosis.

The acute onset, risk of respiratory failure, and uncertain prognosis of Guillain Barré Syndrome (GBS) tend to increase the burden on caregivers. Qualitative and mixed method studies have shown that patients and their families experience high levels of anxiety, fear, and shock when they are suddenly paralyzed, have been admitted to an intensive care unit (ICU) or are facing death (Laparidou et al., 2021). Caregiving for GBS patients also involves the additional burden of caring for a patient who quickly deteriorates. In a longitudinal study of the family's mental health during the first year following onset of GBS, the General Health Questionnaire 28 (GHQ-28) scores indicated significantly higher levels of mental distress (anxiety, depression and somatic complaints) in caregivers during the early months after disease onset than did normal populations (Bernsen et al., 2006). While distress associated with providing long-term care for GBS patients decreased from month 1 depending on several variables, a significant number of caregivers continued to have psychosocial problems when assessed at 12 months following patient onset (Bernsen et al., 2006).

Broader epidemiological literature further demonstrates that informal caregivers have a higher risk of depression, anxiety, and psychological distress compared with non-caregivers and that subjective burden is a key mediator between caregiving demands and mental health outcomes (Adelman et al., 2015).

2.1.2 Burnout and Helplessness

Caregiver burnout is often conceptualized as a state of emotional exhaustion, depersonalization, and reduced sense of personal accomplishment that arises from prolonged and unrelieved caregiving stress (Liu et al., 2020). Research indicates many caregivers of individuals with GBS suffer from feelings of powerlessness and helplessness, especially if their loved one is recovering slowly, or developing complications (Bernsen et al., 2006). Family caregivers report they are constantly watching for clinical signs of deterioration, fearing the possibility of a relapse or death, and feeling overwhelmed by making complex medical decisions (Laparidou et al., 2021). In addition, multiple studies have found that a prolonged mismatch between the resources (e.g., time, money, social support) available to provide care to an individual with GBS and the demands (e.g., hours of care many hours of care per week; complicated nursing tasks) placed on the caregiver leads to exhaustion and a sense of being trapped in their role as caregiver (Adelman et al., 2015). These findings suggest that caregivers of patients with GBS experience significant psychological and emotional burden, and therefore, should include burnout and powerlessness as fundamental dimensions of psychological and emotional burden among the caregivers of individuals with GBS.

2.2 Socio Demographic Determinants of Caregiver Burden

2.2.1 Gender and Caregiver Role

The burden of providing care is greatly influenced by socio demographic factors. Across systematic reviews and observational research, being a female, providing care to someone with whom you are cohabitating, and having low socio economic status have all been identified as important risk factors for an increase in care giving burden (Adelman et al., 2015; Liu et al., 2020).

An example of a population in which women are assumed to be the main caregivers for family members includes Bangladesh. Women provide much of the unpaid care work for elderly, people with disabilities, and people with chronic illnesses (Rahman, et al , 2025). Recent research from caregivers of those with dementia, Parkinson's disease, and Alzheimer's disease in Bangladesh found that approximately two-thirds of caregivers were female, and female caregivers reported significantly higher levels of care giving burden than male caregivers (M. R. Rahman et al., 2025). Caregivers of those individuals experiencing mood disorders or schizophrenia have also reported similar data: females are disproportionately represented among caregivers, and female caregivers report carrying a higher care giving burden than male caregivers (Ahmed et al., 2018). Further exploration of caregiving should continue to address the issue of women providing care to elderly persons in Dhaka because of the cultural expectation that women will provide care for family members, including providing intimate care (feeding, bathing, toileting, etc.) to older family members, often at the cost of their own employment and education (Henry Wasosa, 2025).

Because caring for others intersects with existing family responsibilities and frequently work commitments, female caregivers especially middle-aged women consistently experience higher levels of burden. Women's primary caregiving responsibilities are heavily reinforced by cultural norms in South Asian cultures, which exacerbates emotional and physical strain. Studies reveal that compared to their male counterparts, female caregivers have noticeably greater levels of worry, sadness, and physical health issues (Raggi et al., 2010).

2.2.2 Age and Health Issues

Another significant determinant of burden is the age and the state of health of the caregiver. Studies on caregivers of neurodegenerative and psychiatric disorders show that a significant proportion of caregivers are middle aged adults who must take responsibility in not only in generating income, taking care of children and elder care, and occasionally referred to as the sandwich generation (Henry Wasosa, 2025). Caregivers who are old and those with chronic illnesses have higher scores on physical strain and burden because heavy lifting, night time supervision and frequent hospital visits may be tiring (Adelman et al., 2015).

The literature on older age with respect to international caregivers perennially relates subjective and objective burden to older age, worse self-rated health, and more hours of daily care giving (Adelman et al., 2015; Liu et al., 2020). Caregivers themselves (who are elderly or physically constrained) might be especially vulnerable to musculoskeletal injury, fatigue, and emotional strain in the case of GBS, where patients remain largely dependent in terms of transfers, toileting, and mobility both at the acute and subacute stages.

2.3 Financial Burden of Caregiving

2.3.1 Healthcare Costs

The financial impact of GBS extends beyond the initial hospitalization cost and includes long-term rehabilitation, physical and occupational therapy, assistive technology, and ongoing medical care. These costs may be too expensive to the families in low- and middle-income countries, often involves the sale of property or the accrual of huge debts (López-Bastida et al., 2016).

The economic studies discussed at international health economics meetings have shown that the direct and indirect expenses of GBS hospitalization, rehabilitation, follow up care, and informal care giving are significant economic costs that are more than some of the leading infectious and gastrointestinal diseases (Rongcai et al., 2024). Out of pocket costs are also common within families (e.g., wheelchairs, hospital beds), home care, commuting to specialized neurology centers, and continuing physiotherapy (Finsterer, 2022). In low- and middle-income countries, where health insurance coverage is limited, these costs can be catastrophic and constitute a major component of caregiver burden.

2.3.2 Lost Wages

Caregivers of patients with Guillain-Barré Syndrome often experience a sudden and significant loss of wages as they are forced to shift from being full-time workers to full-time carers almost overnight (Aoun et al., 2012; Determeijer et al., 2024). This economic burden arises from the need to provide round-the-clock assistance, which results in missed workdays, job loss, or self-owned businesses suffering, directly reducing the household income (Determeijer et al., 2024; Von Gaudecker et al., 2023). The strain is particularly acute when the patient was the primary breadwinner or when the caregiver must reduce hours to manage long drives to care facilities (Poppe, 2018). Research indicates that within the first month of onset, nearly 23% of relatives are unable to perform their own work properly, and approximately 22% to 26% of families continue to report lasting financial hardship years after the initial illness (Aoun et al., 2013). In Bangladesh, time use and labor market studies have indicated that the pattern of employment of women is largely determined by the care responsibilities.

Women who have intense care giving responsibilities tend to be more inclined to work in home based, low waged or informal jobs or quite simply leave the workforce (RAHMAN, & et all, 2025). Programs reviews that consider unpaid family carers of people with disabilities in Savar indicate that most of the carers are women and that the majority of them have lost income or an education opportunity as a result of their caregiving duties (Anisuzzaman, 2024). To the caregivers of GBS victims, these limitations are directly translated into the loss of wages and the financial insecurity in the long-term.

2.3.3 Limited Welfare Support

Availability of welfare and social protection moderates the financial effects of care giving. In Bangladesh, social protection to persons with disabilities and chronic illness primarily disability allows and small cash transfers are only partially covered, and the value of the benefits is relatively low. According to a recent study of the data of the national surveys, it was revealed that only a small part of people with disabilities stated having received any social protection, and especially there is a low coverage among younger adults and those who do not belong to rural poverty targeted programs (M. Rahman et al., 2025).

UNICEF and other agencies also highlight how there are few families' friendly policies, including paid caregiving leave, subsidized respite care or publicly funded long-term care, that can directly decrease care giver burden. To the caregivers of patients with GBS, both of the financial and psychological aspects of burden are thus not easily addressed through formal financial support due to high costs of healthcare and lost income.

2.4 Coping Mechanisms and Support Systems

2.4.1 Adaptive Coping Strategies

Coping strategies refer to the cognitive and behavioral endeavors that are used to handle stress. Problem- oriented, emotion- oriented, and meaning- oriented are the most common adaptive coping approaches in care giving research (Gandy et al., 2024). Problem focused coping includes seeking information about GBS, learning safe transfer techniques, organizing medication schedules, and actively collaborating with health professionals to plan rehabilitation. Studies in caregivers of older adults and neurocritical patients show that such active, problem-solving approaches are associated with better perceived control and, in some contexts, lower subjective burden (Madathumkovilakath et al., 2018)

A variety of adaptive coping strategies are commonly used by caregivers who successfully manage the demands of GBS caregiving, such as active problem-solving, asking for emotional and practical support from friends and family, setting reasonable expectations for recovery, and taking time for self-care. According to research, caregivers who use benefit-finding strategies and take part in organized support programs have improved psychological adjustment and more lasting caring abilities (Cheng et al., 2014).

GBS specific resources from the GBS|CIDP Foundation International encourage caregivers to participate in support groups, utilise online communities, and access educational materials to reduce isolation and improve confidence (Rummelsburg, n.d.). A review of the emotional and psychological consequences of GBS similarly recommends structured support groups, caregiver training, and practical assistance including equipment and home modifications as core components of adaptive coping for families (Shrinivasa et al., 2021).

A case study conducted in Bangladesh has shown that psychosocial and training interventions can be structured to help caregivers greatly. In Dhaka, Bangladesh, community-based interventions providing children with chronic neurological conditions with caregiver education, psychological and material support have been shown to record elevated caregiver confidence and distress reduction (Chowdhury et al., 2021).

2.4.2 Maladaptive Coping

On the other hand, using drug abuse as a coping mechanism, avoidance-based coping mechanisms, or denial of the gravity of the issue likely to worsen caregiver distress and have a negative impact on caregiver health and care quality. Although social isolation and disengagement from support systems are natural reactions to the responsibilities of caring, they ultimately make people more at risk for depression and burnout (Gandy et al., 2024).

A meta-analysis of coping and caregiver burden in dementia found that avoidance based coping and some emotion focused strategies, such as wishful thinking, were positively related to subjective burden even after controlling for the severity of patients' behavioral symptoms (Huang et al., n.d.). For caregivers of patients with GBS, the combination of acute crisis, initially limited information, and unpredictable recovery trajectories may promote maladaptive patterns, including catastrophizing, withdrawal from social networks, or harmful substance use as means of managing anxiety. Case descriptions from GBS rehabilitation settings suggest that ongoing uncertainty, financial strain, and multiple role demands can lead to anger, hopelessness, or conflict within families if these issues are not adequately addressed (Shrinivasa et al., 2021).

2.5. Cultural Context of Caregiving in Bangladesh

2.5.1 Cultural Norms

In Bangladeshi society, Caregiving is part of within cultural frameworks of moral responsibility and family duty. Caregiving decisions are heavily influenced by the ideas of moral responsibility and family honor, with families frequently putting the needs of the patient before the welfare of the individual caregiver. The gender stereotypes still exist especially deeply, with women being the ones who should bear most of the care despite other obligations and health issues (Farhin Khan et al., 2015). Such a focus on family accountability and accountability can make the process of care-giving a significant source of meaning, social identity, and spiritual satisfaction.

Care responsibilities, however, are unequally distributed. Gender norms and labor market structures place the bulk of domestic and care work on women. National time use data and qualitative studies show that activities such as cooking, childcare, elder care, and care for sick family members are predominantly seen as women's responsibilities, while men are perceived mainly as financial providers (Chara Scroope, 2017). Consequently, when a family member develops a disabling condition such as GBS, wives, daughters, or daughters in law typically become the primary caregivers, often without formal training and sometimes without real choice.

These cultural norms have dual implications for caregiver burden. On one hand, they can foster a sense of duty and familial solidarity that supports meaning focused coping. On the other hand, they heighten women's vulnerability to role overload, financial dependency, and social isolation, reinforcing the gendered patterns of caregiver burden documented in studies of dementia, Parkinson's disease, and mental illness in Bangladesh (Rashidur, Noorjahan, n.d.).

2.5.2 Barriers to Formal Support

There are several factors that prevent the Bangladeshi families to access official care giving support, which include the stigma attached to mental illnesses, lack of information on available resources, financial constraints, and cultural orientation towards family-based care. Even under circumstances when the services of professional helping organizations are convenient and cost-effective, most families do not want to access them as they are afraid that by seeking outside help they are revealing that their family is in a challenging situation or incompetent (Farhin Khan et al., 2015).

CHAPTER III: METHODS & MATERIALS

3.1 Study Question, Aim, Objectives

3.1.1 Research question:

What is the level of caregiver burden experienced by individuals caring for patients with Guillain-Barré Syndrome in Bangladesh?

3.1.2 Research Aim:

The aim of the study is investigating the level of Caregiver Burden of Patient with Guillain-Barré Syndrome**.**

3.1.3 Research Objectives:

- To find out the socio-demographic information among the respondents
- To assess the level of caregiver burden
- To find out the association between caregiver's burden and socio-demographic information

3.2 Study Design

3.2.1 Study method: Quantitative Research Design

The purpose of this study is to quantify the level of caregiver burden experienced by individuals in Bangladesh who are providing care for patients with Guillain-Barré Syndrome (GBS). A quantitative research design is suitable as it facilitates the collection of measurable data that can be statistically analyzed to assess the intensity and influencing factors of caregiver burden (Creswell & Creswell, 2018). Using standardized tools such as the Zarit Burden Interview (ZBI) ensures objectivity and reliability in data collection (Polit & Beck, 2021).

3.2.2 Study Approach: Cross-Sectional Approach

To conduct this study the researcher used the cross-sectional survey method. Under the quantitative method the researcher used cross sectional methods that is one type of observational study, involves data collection from a population, or a representative

subset, at one specific point in time. According to (Levin, 2006) Cross-sectional study is an analysis of the present situation and is carried out at one specific time, or over a short period. Data can also be collected on individual characteristics, including exposure to risk factors, along with information about the outcome. In this way cross sectional studies provide a snapshot of the outcome and characteristics associated with it, at a specific point in time. Usually there is no hypothesis as such, but the aim is to describe a population or a subgroup within the population with respect to an outcome and set risk factors.

3.3 Study Setting and Period

3.3.1 Study Setting

The study was conducted in neurology units and Out-Patient unit of the Centre for the Rehabilitation of the Paralysed (CRP)- Savar (head office) and all branches of CRP (Mirpur, Manikganj, Mymensingh, Sylhet, Moulvibazar, Chattagram, Barisal, Rajshahi) which regularly manage patients with GBS. These centers provide a suitable environment to explore caregiver-patient dynamics in the context of GBS.

3.3.2 Study Period

The study was conducted from June 2025 to December 2025. Data was collected from 2 August 2025 to 15 September 2025.

3.4 Study Participants

3.4.1 Study Population

The target population includes primary caregivers of patients diagnosed with Guillain-Barré Syndrome in Bangladesh. These caregivers are typically close family members, such as spouses, parents, or children, and are responsible for the day-to-day care of the patients during the acute and recovery phases of the illness. Their experiences and stress levels are crucial to understanding caregiver burden in this context.

3.4.2 Study Sample

According to Cochran's formula, $n = \frac{Z^2.p,(1-p)}{d^2}$

Here, n= sample size

Z= the standard normal deviate usually set at 1.96

*P= estimated prevalence,18 % = 0.18, (Matiur, 2019)

d= margin of error is 5% =0.05

Confidence Interval (CI) = 95%

Sample size = $n = \frac{1.96^2.0.18(1-0.18)}{0.05^2}$

= 226.84

≈ 227

Non response 10% was added. So, the sample size was = 227 + (10% of 227) =253 The total sample size is 253.

If the student researcher used this standard measurement to find out the sample size, it would be 253. Though it is academic research, the data collection period was one month. Within one month, 253 participants' data collection was practically not possible. For this reason, the student researcher could collect 71 samples maintaining inclusion and exclusion criteria for this study.

3.4.3 Sampling Techniques

Non- Probability Purposive sampling was followed to conduct the study by following the inclusion and exclusion criteria. Purposive sampling is a sampling technique in which the researcher seeks out elements that meet specific criteria (Robinson, 2023). Therefore, purposive sampling is eligible for the study. Caregivers who meet the inclusion and exclusion criteria will be approached for participation.

3.4.4 Inclusion Criteria

- Primary caregiver of patient diagnosed with Guillain-Barré Syndrome
- Age between 18 and 65 years
- Providing care for at least one month

3.4.5 Exclusion Criteria

- Caregiver with severe physical or psychological illness
- Caregiver undergoing treatment for GBS or other severe conditions themselves
- Caregiver unwilling to participate

3.5 Ethical Consideration (According to Helsinki Act's guideline)

3.5.1 Ethical clearance

- Ethical clearance was sought from the Institutional Ethical Review Board of Bangladesh Health Professions Institute (BHPI) through the department of Occupational Therapy, BHPI. Ethical clearance No. Of this research, CRP-BHPI /IRB/07/2025/1127.
- The researcher informed the participants about the purpose and aim of the study.
- Permission was taken from the author to use the scale for this study (APPENDIX-A).
- Permission was taken from the Executive director of CRP.
- All the participants were informed that their information would be used in the research but their name and address would be confidential.

3.5.2 Informed Consent

Informed consent is an ethical and legal principle requiring medical interventions to be performed only after participants are fully informed about the purpose, nature, consequences, and risks (Guraya et al., 2014).

3.5.3 Participant Explanatory Statement

The Participant Information Sheet provides comprehensive information about the study, aids potential participants in deciding to participate, and offers contact details. (APPENDIX B)

3.5.4 Consent Form

Researchers emphasize that research participation should be voluntary, informed by sufficient information and understanding of the proposed research and its implications (NHMRC, 2023). (APPENDIX B).

3.5.5 Withdrawal Form

Throughout this study, individuals were free to choose, whether to participate or not. They were also allowed to withdraw participation from the study within 2 weeks from the time of interview. (APPENDIX B)

3.5.6 Unequal relationship

The researcher will prevent unequal relationships from affecting participant selection, ensuring fairness and unbiasedness. They will collaborate with the BHPI to employ a research assistant, addressing ethical considerations and confidentiality.

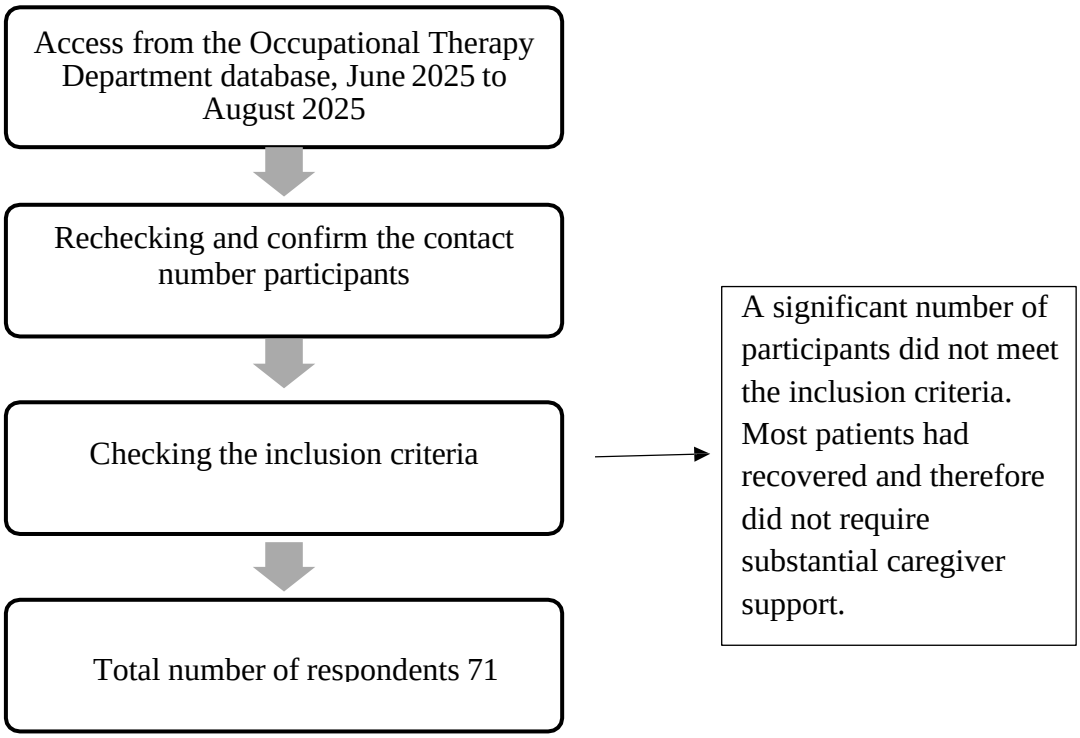
3.5.7 Risk and beneficence

According to the (NHMRC, 2023) guidelines the researcher must clearly explain the absence of physical, social, psychological, or environmental risks in the study, ensuring informed consent and upholding ethical conduct standards.

3.6 Data Collection Process

3.6.1 Participant Recruitment Process

Figure 3.1: Overview of Participants recruitment Process



3.6.2 Data collection instrument

The Researcher used three types of data collection instruments. These are:

- **Socio demographic profile sheet:** This questionnaire was developed by the researcher and included items related to the personal characteristics, such as age, sex, marital status, education, occupation, duration of illness and relationship with patient
- **ZBI (Zarit Burden Interview):** This was developed to assess caregiver's burden of patients with chronic mental illnesses. The burden interview used in many countries in translated version. The ZBI is composed of 22 items investigating in 5 domains (Rankin et al., 1994).

These domains are Burden in the relationship, Emotional wellbeing, Social and family life, Finances and finally Loss of control over one's life.

The instrument has a possible score of 0-88, depending on the caregiver's responses. Responses are rated from 0-4, based on the level of distress.

- Paper, pen, pencil, eraser, sharpener, writing board, information sheet and consent form.

3.7 Data collection method

The researcher conducted a telephone survey to gather data from participants because all the participants live in communities in different regions. So, it was not easy to reach the participants for face-to-face interviews.

3.8 Volunteer recruitment

The researcher recruited two volunteers for this study. The researcher first circulated the Information during the volunteer recruitment process, and then the two interested volunteers were found. After collecting data, the researcher did not provide a salary for this work. After the recruitment, the researcher provided training about the data collection process of the selected volunteers and take field tests. After completing the field test, the volunteer finally collected the data from the participants (APPENDIX D).

3.9 Data Management and Analysis

Data were analyzed through data entry, and analysis was performed using the Statistical Package for social science (SPSS), by using descriptive statistic method, version 27, and Microsoft excel spreadsheet. The presentation of data was organized in SPSS and in Microsoft Office Word. Data was analyzed through descriptive statistical analysis and it is presented by using tables, figures, bar and pie charts.

3.10 Data Analysis

The Kruskal Walis (H), Linear regression (The statistically significant difference was set at a 95 % confidence interval) test is used to discover if there is a relationship between two categorical variables. By (H) test, the researcher determines the association among age, sex, occupation, relation, duration of care giving with the level of burden. Total Caregiver Burden Scale questionnaire score ranges from 0-88. There were four different categories of total score in ZBI scale. Score (0-20) mentions little or no burden, mild to moderate burden (21-40), moderate to severe (41-60) and finally severe burden (61-88). ZBI discussed the level of caregiver burden in five domains and clusters .These are the questions no. 1, 8, 11, 14, 18, 20 indicate the Burden in the relationship, question no. 2, 4, 5, 9, 10, 21, 22, illustrate emotional well-being, question no. 3, 6, 12, 13 shows social and family life, question no.15 indicates finances and finally loss of control over one's life is indicated by question no.7, 16, 17, 19. In the case of these five domains, firstly Burden in the relationship minimum score is 0 and maximum is 24, secondly Emotional well-being ranges from 0-28, thirdly Social and family life strain range from 0-16, fourthly Economic strain range 0-4. Finally, Loss of control over one's life score ranges from 0-16.

3.11 Quality Control and Quality Assurance

To ensure data quality and safety, the stages of data life cycle management were followed properly. Data were collected through a telephonic survey. Before starting the survey, the study purpose and each question were explained clearly in Bangla so that participants could understand properly. Participation was voluntary, and consent was taken from every participant. With permission, all survey calls were recorded to maintain accuracy and transparency. The data collection and data entry process were non-biased. After the calls, the responses were checked carefully and then entered into

the system for analysis. The dataset was stored securely in the analysis software and also kept as a backup in a protected cloud storage system. Strong passwords and restricted access were used to ensure confidentiality. No unauthorized access occurred, and the data were used only for research purposes. No data modification or exploitation was done. All files are archived for future reference. The student researcher and the supervisor agreed that the research data will be kept for five years and then permanently destroyed for proper data safety and ethical compliance.

CHAPTER IV: RESULTS

This chapter presents the findings of the study. The study's findings are presented in tables and figures in this chapter, with an emphasis on the sociodemographic information, and caregiver burden of patient with GBS.

4.1 Sociodemographic characteristic

Table 4.1

Distribution of sociodemographic characteristics of the respondent

Variable	Category	Frequency (n=71)	Percentage %
Gender	Male	40	56.3
	Female	31	43.7
Age	18-33 Years	36	50.7
	34-49 Years	24	33.8
	50-65 Years	11	15.5
	Median=33.00 years, Median IQR (27-43), Minimum= 18 years, Maximum=65 years		
Division	Dhaka	27	38.0
	Chattogram	18	25.4
	Khulna	4	5.6
	Barisal	8	11.3
	Mymensingh	5	7.0
	Rajshahi	8	11.3
	Rangpur	0	0.0
	Sylhet	1	1.4
Marital Status	Unmarried	19	26.8
	Married	49	69.0
	Widowed	3	4.2
	Divorced/Separated	0	0.0
Occupation	Businessperson	12	16.9
	Homemaker	17	23.9
	Farmer	2	2.8
	Day Laborer	4	5.6
	Service Holder	24	33.8
	Unemployed	0	0.0

	Others (Retired)	1	1.4
	Student	11	15.5
Relationship with Patient	Spouse	21	29.6
	Parent	18	25.4
	Sibling	7	9.9
	Child	11	15.5
	Other (Nephew, Carer, Sister-in-law, Uncle, Aunty)	8	11.3
	Grand Father	6	8.5
Types of Family	Nuclear	45	63.4
	Joint	26	36.6
Types of Residence	Urban	27	38.0
	Semi-Urban	13	18.3
	Rural	31	43.7

Table 4.1 shows the socio-demographic characteristics of the caregivers of patients with Guillain-Barré Syndrome (n = 71). The majority of caregivers were male (56.3%, n = 40), while 43.7% (n = 31) were female. Most caregivers were young to middle-aged adults; half of them (50.7%, n = 36) were between 18–33 years of age, 33.8% (n = 24) were aged 34–49 years, and 15.5% (n = 11) were 50–65 years old. The median age of caregivers was 33.00 years, with ages ranging from 18 to 65 years. In terms of geographical distribution, the highest proportion of caregivers resided in Dhaka division (38.0%, n = 27), followed by Chattogram (25.4%, n = 18), Barisal and Rajshahi (each 11.3%, n = 8), Mymensingh (7.0%, n = 5), Khulna (5.6%, n = 4), and Sylhet (1.4%, n = 1), whereas no participant was from Rangpur division.

Most caregivers were married (69.0%, n = 49), while 26.8% (n = 19) were unmarried and 4.2% (n = 3) were widowed; none reported being divorced or separated. Regarding occupational status, 33.8% (n = 24) were service holders, 23.9% (n = 17) were homemakers, 16.9% (n = 12) were businesspersons, and 15.5% (n = 11) were students. Smaller proportions were day laborers (5.6%, n = 4), farmers (2.8%, n = 2), and retired (1.4%, n = 1), and no caregiver reported being unemployed.

In terms of relationship to the patient with Guillain-Barré Syndrome, spouses constituted the largest group of caregivers (29.6%, n = 21), followed by parents (25.4%, n = 18), children (15.5%, n = 11), and siblings (9.9%, n = 7). Additionally, 8.5% (n = 6) were grandfathers, and 11.3% (n = 8) were classified as "other" relatives, including nephew, carer, sister-in-law, uncle, and aunty. Most caregivers came from nuclear families (63.4%, n = 45), whereas 36.6% (n = 26) belonged to joint families. With respect to type of residence, 43.7% (n = 31) lived in rural areas, 38.0% (n = 27) in urban areas, and 18.3% (n = 13) in semi-urban areas, indicating that both urban and rural populations were substantially represented.

Figure: 4.1

Distribution of Respondents by Educational Qualification

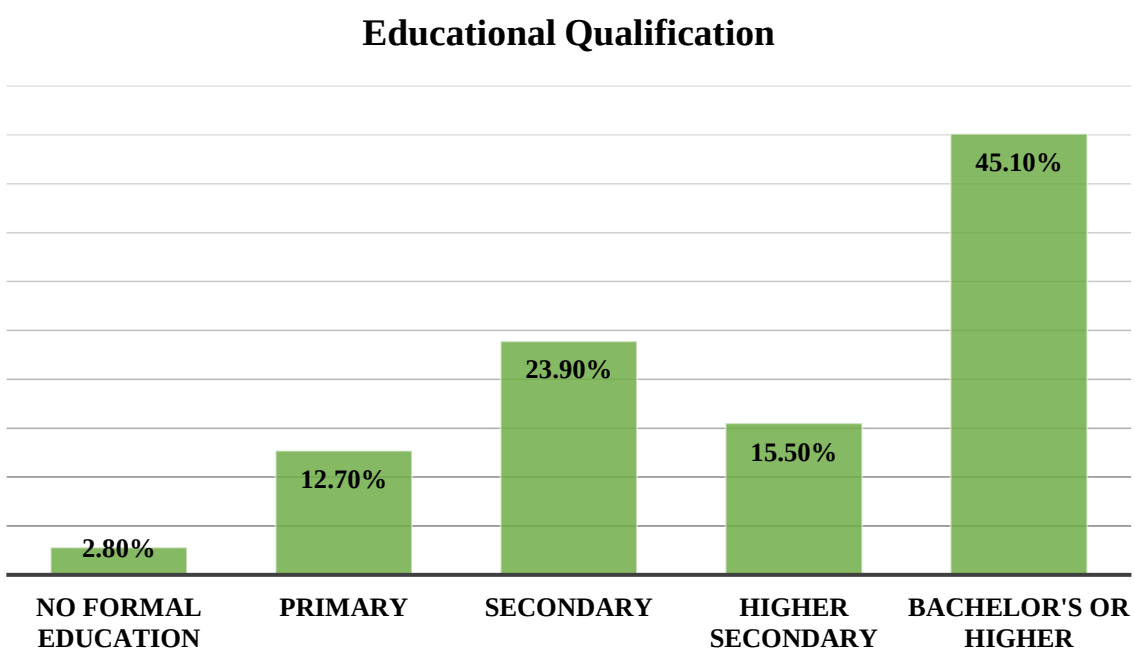


Figure 4.1 shows with respect to educational attainment, nearly half of the caregivers (45.1%, n = 32) had a Bachelor's degree or higher, 23.9% (n = 17) had completed secondary education, 15.5% (n = 11) had higher secondary education, and 12.7% (n = 9) had primary education; only 2.8% (n = 2) reported having no formal education.

Figure: 4.2

Distribution of Respondents by Monthly income

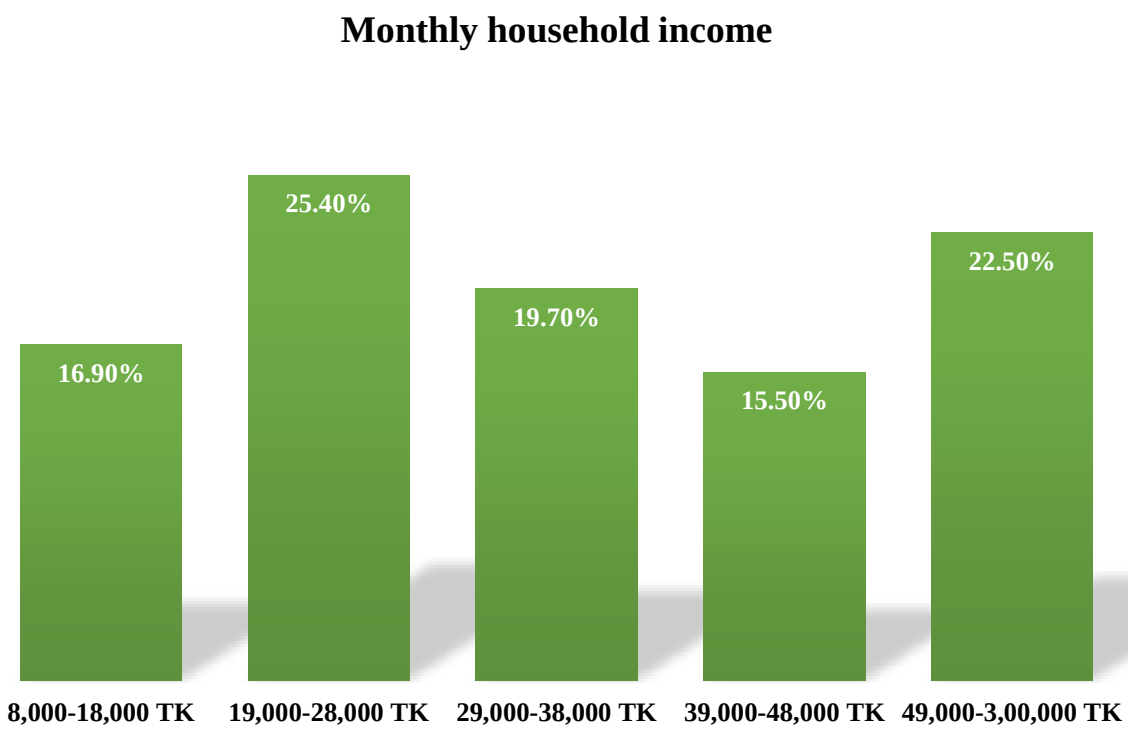


Figure 4.2 shows the monthly household income varied widely: 25.4% (n = 18) reported earning 19,000–28,000 BDT, 22.5% (n = 16) earned 49,000–300,000 BDT, 19.7% (n = 14) earned 29,000–38,000 BDT, 16.9% (n = 12) earned 8,000–18,000 BDT, and 15.5% (n = 11) earned 39,000–48,000 BDT. The median monthly income was 30000.00 BDT ranging from 8,000 to 300,000 BDT.

Figure: 4.3

Distribution of Respondents by Duration of Caregiving

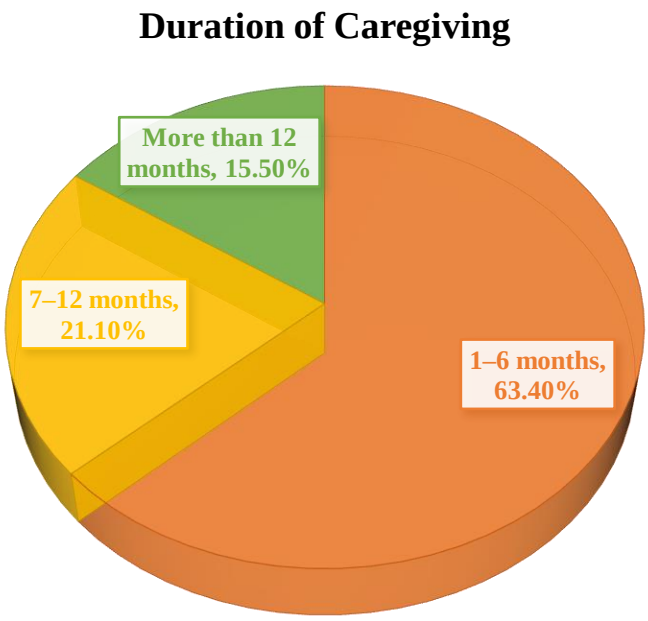


Figure 4.3 shows the Regarding caregiving duration, nearly two-thirds of caregivers (63.4%, n = 45) had been providing care for 1–6 months, 21.1% (n = 15) for 7–12 months, and 15.5% (n = 11) for more than 12 months. The mean duration of caregiving was 05 months, with a range from 1 to 60 months. This distribution suggests that while many caregivers were relatively early in their caregiving role, a considerable proportion had been engaged in prolonged caregiving for patients with Guillain-Barré Syndrome.

4.2. Overall Caregiver Burden

The study surveyed the caregiver burden of Guillain-Barré Syndrome by using ZBI which consist 22- questions. This scale analyzed the total caregiving burden as well as its five domains- Burden in the relationship, Emotional wellbeing, Social and family life, Finances and Loss of control over one's life. Analyzing Caregiver Burden scale, the researcher found out the overall burden.

Figure: 4.4

Severity of caregiver burden (according to ZBI score)

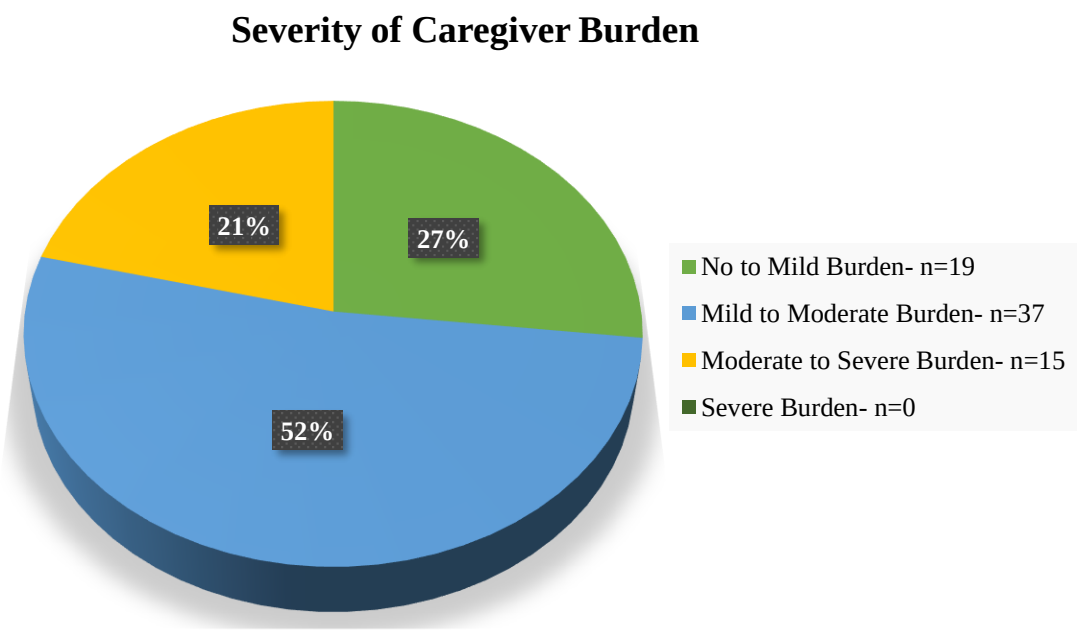


Figure 2 shows that caregiver burden scores that the majority of caregivers (52.1%, n=37) experienced a Mild to Moderate level of burden. Additionally, 21.1% (n=15) of the respondents reported a Moderate to Severe burden. In contrast, 26.8% (n=19) of caregivers experienced No to Mild burden. It is noteworthy that none of the participants (0%, n=0) fell within the Severe burden category. These results suggest that while a substantial proportion of caregivers endure moderate levels of burden, extreme burden is not prevalent within the study population.

4.3. Caregiver burden according to ZBI domains

The ZBI is composed of 22 items investigating in 5 domains (Rankin et al., 1994). These domains are Burden in the relationship, Emotional wellbeing, Social and family life, Finances and finally Loss of control over one's life.

Figure 4.5

Domain 1 (Caregiver Burden in the relationship)

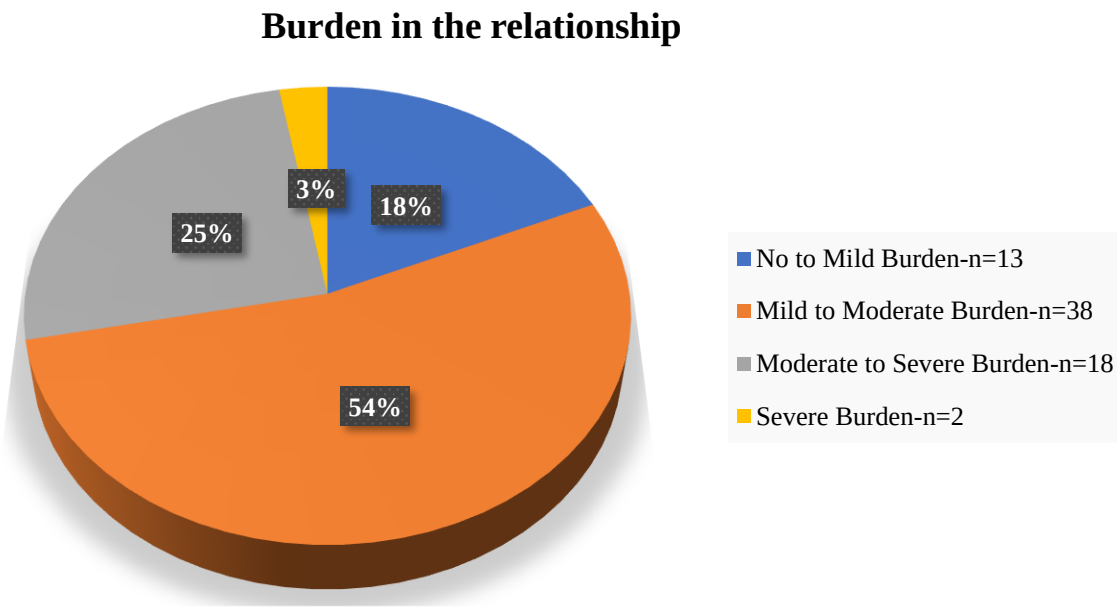


Figure 4.5 shows that, total of 71 participants were assessed for the level of caregiver burden in the relationship. Among them, 18.3% experienced no to mild burden, while the majority (53.5%) reported mild to moderate burden. Additionally, 25.4% of respondents experienced moderate to severe burden, and 2.8% reported severe burden. This distribution indicates that more than half of the caregivers were experiencing at least a mild to moderate level of burden, with a considerable proportion reporting higher levels of strain.

Figure 4.6

Domain 2 (Caregiver burden in Emotional wellbeing)

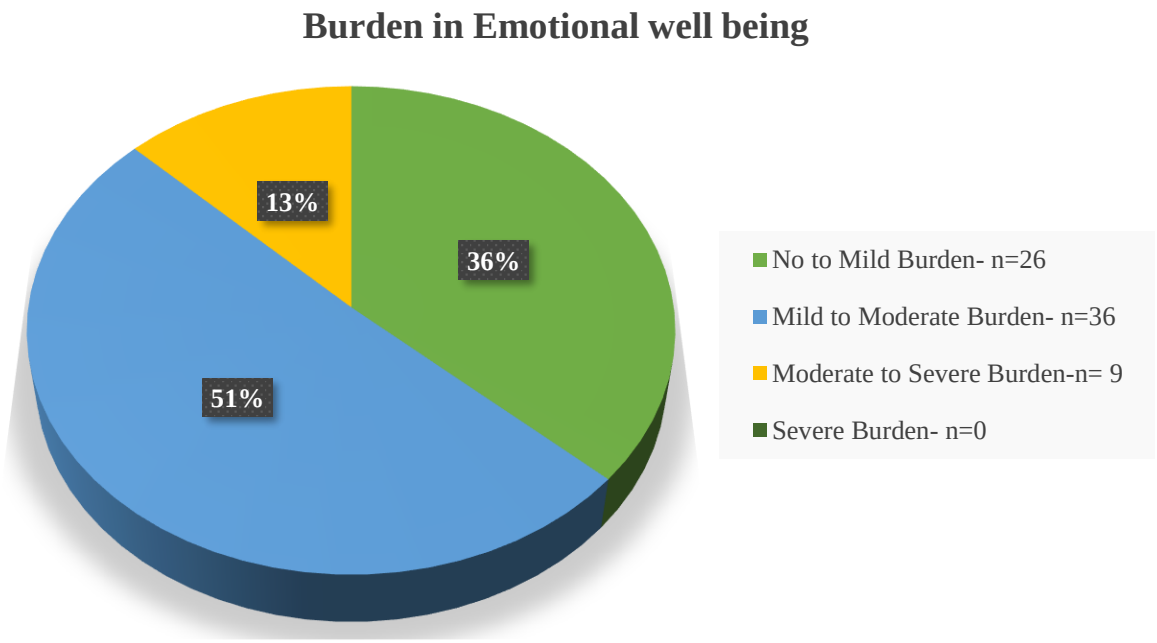


Figure 4.6 shows that, according to an analysis of the emotional well-being domain, 50.7% of individuals indicated mild to moderate burden, while 36.6% reported no to mild difficulty. Furthermore, none of the respondents indicated severe load, and 12.7% reported moderate to severe burden. These results show that while most caretakers experience some emotional strain, this group did not exhibit an exceptionally high emotional load.

Figure 4.7

Domain 3 (Caregiver burden in Social and family life)

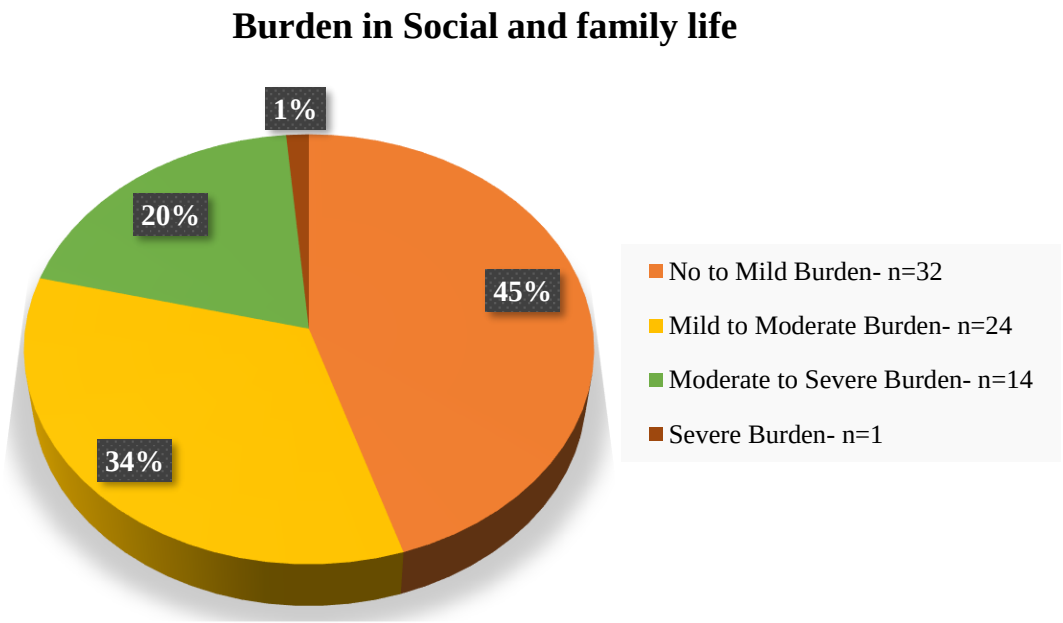


Figure 4.7 shows that 33.8% of respondents indicated mild to moderate load, while 45.1% expressed nil to light hardship in relation to the influence on social and family life. 1.4% expressed severe burden, and an additional 19.7% reported moderate to severe burden. This implies that even though many caregivers are able to keep up their social and familial functioning, a sizable percentage nevertheless encounter serious disruptions in these domains.

Figure 4.8

Domain 4 (Caregiver Burden in Financial Status)

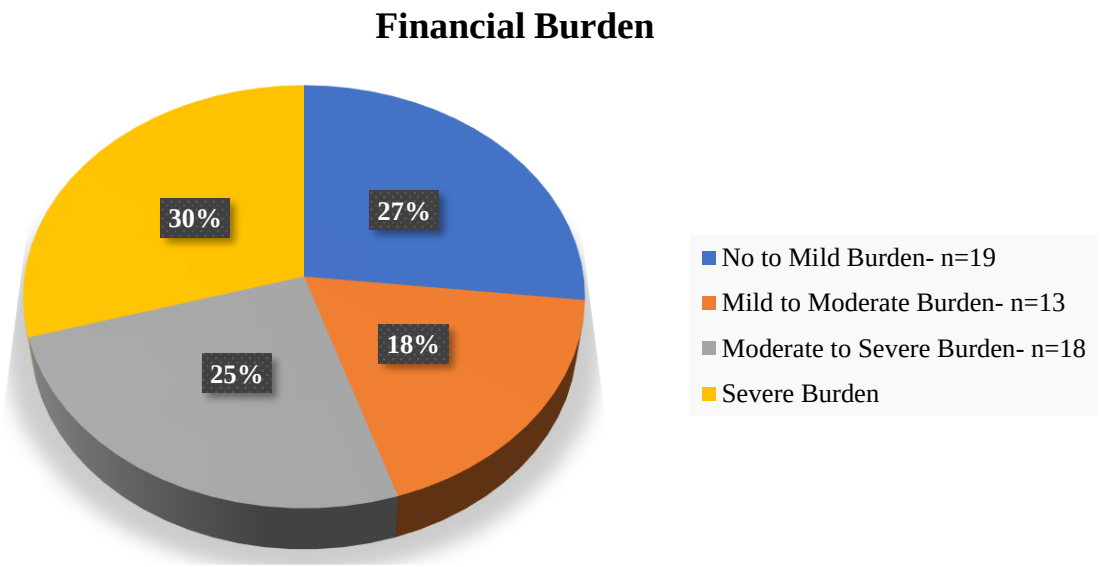


Figure 4.8 shows that, financial findings demonstrated great diversity in caregiver burden. A total of 26.8% indicated no to mild burden, while 18.3% reported mild to moderate burden. Meanwhile, 25.4% reported a moderate to severe financial hardship, while 29.6% stated a severe financial burden. These findings indicate that financial strain is a significant factor to overall caregiver stress, with the majority of respondents falling into the severe burden category.

Figure 4.9

Domain 5 (Loss of control over one's life)

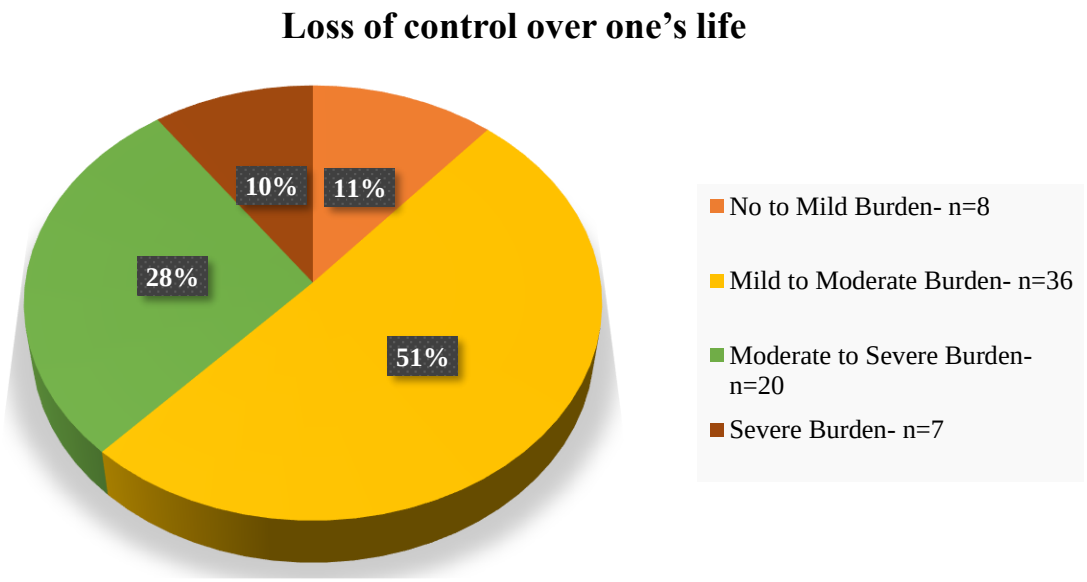


Figure 4.9 shows that, In the domain assessing perceived loss of control over one's life, 11.3% experienced no to mild burden, and 50.7% reported mild to moderate burden. Additionally, 28.2% experienced moderate to severe burden, while 9.9% reported severe burden. This distribution indicates that more than half of the caregivers felt some degree of loss of personal autonomy, with a meaningful proportion reporting high levels of impact in this domain.

4.4 Frequency and percentage of participants regarding their burden in each aspect's statements of Zarit Burden Interview Scale

Table 4.2

Frequency and percentage of participants regarding their Burden according to ZBI scale:

	Never n (%)	Rarely n (%)	Sometimes n (%)	Quite Frequently n (%)	Nearly Always n (%)
Do you feel that your relative asks for more help than he/she needs?	16 22.5	25 35.2	18 25.4	4 5.6	8 11.3
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	28 39.4	11 15.5	22 31.0	5 7.0	5 7.0
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	13 18.3	13 18.3	19 26.8	9 12.7	17 23.9
Do you feel embarrassed over your relative's behavior?	42 59.2	16 22.5	13 18.3	0 0.0	0 0.0
Do you feel angry when you are around your relative?	37 52.1	12 16.9	20 28.2	1 1.4	1 1.4
Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	40 56.3	11 15.5	18 25.4	1 1.4	1 1.4
Are you afraid what the future holds for your relative?	2 2.8	5 7.0	21 29.6	9 12.7	34 47.9
Do you feel your relative is dependent upon you?	9 12.7	22 31.0	12 16.9	11 15.5	17 23.9
Do you feel strained when you are around your relative?	35 49.3	16 22.5	12 16.9	6 8.5	2 2.8
Do you feel your health has suffered because of your involvement with your relative?	34 47.9	21 29.6	9 12.7	4 5.6	3 4.2
Do you feel that you don't have as much privacy as you would like, because of your relative?	31 43.7	13 18.3	16 22.5	8 11.3	3 4.2
Do you feel that your social life has	43	9	13	4	2

suffered because you are caring for your relative?	60.6	12.7	18.3	5.6	2.8
Do you feel uncomfortable about having friends over, because of your relative?	44 62.0	9 12.7	13 18.3	4 5.6	1 1.4
Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one, he/she could depend on?	12 16.9	18 25.4	15 21.1	9 12.7	17 23.9
Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?	8 11.3	11 15.5	13 18.3	18 25.4	21 29.6
Do you feel that you will be unable to take care of your relative much longer?	32 45.1	21 29.6	10 14.1	4 5.6	4 5.6
Do you feel you have lost control of your life since your relative's illness?	35 49.3	16 22.5	14 19.7	2 2.8	4 5.6
Do you wish you could just leave the care of your relative to someone else?	39 54.9	16 22.5	14 19.7	2 2.8	0 0.0
Do you feel uncertain about what to do about your relative?	9 12.7	17 23.9	24 33.8	9 12.7	12 16.9
Do you feel you should be doing more for your relative?	11 15.5	14 19.7	20 28.2	6 8.5	20 28.2
Do you feel you could do a better job in caring for your relative?	14 19.7	12 16.9	16 22.5	9 12.7	20 28.2
Overall, how burdened do you feel in caring for your relative?	15 21.1	11 15.5	28 39.4	5 7.0	12 16.9

The data in the table 4.2 shows how often participants experienced different types of caregiving burdens. Each question had five response options: Never, Rarely, Sometimes, Quite Frequently, and Nearly Always. Overall, most participants reported that they did not face many social or emotional difficulties because of caregiving. For example, 62.0% said they never felt uncomfortable having friends over, and 60.6% said their social life never suffered. Similarly, 59.2% said they never felt embarrassed by their relative's behavior. However, some areas showed higher levels of burden.

A large group of participants (47.9%) said they were nearly always afraid of what the future holds for their relative. Financial stress also appeared as a concern, with 29.6% reporting they nearly always struggled with money due to caregiving. In addition, 28.2% felt they nearly always should be doing more for their relative.

4.5 Association between caregiver's socio-demographic factors and level of caregiver burden among caregivers of Patient with GBS

Table: 4.3

Group differences analysis with ZBI scores (Kruskal Walis H Test)

Variable	Category	n (Frequency) =71	Caregiver Burden			
			Mean Rank	df	H	*P* value
Age	18-33 Years	34	36	2	.244	.885
	34-49 Years	42	24			
	50-65 Years	29	11			
Marital Status	Unmarried	19	32.63	2	1.978	.815
	Married	49	36.43			
	Widowed	3	50.33			
Division	Dhaka	27	29.83	6	10.110	.120
	Chattogram	18	39.42			
	Khulna	4	30.13			
	Barisal	8	46.94			
	Mymensingh	5	53.50			
	Rajshahi	8	29.19			
	Sylhet	1	44.00			
Educational Qualification	No Formal Education	2	14.00	4	11.235	**.024**
	Primary	9	47.61			
	Secondary	17	45.32			
	Higher Secondary	11	30.50			
	Bachelor's Or Higher	32	31.05			
Occupation	Businessperson	12	35.75	6	5.533	.478
	Homemaker	17	41.62			
	Farmer	2	25.75			
	Day Laborer	4	47.75			
	Service Holder	24	30.67			
	Others (Retired)	1	55.00			
	Student	11	35.09			

Monthly Household Income	8,000-18,000 TK	12	42.58	4	12.583	**.014**
	19,000-28,000 TK	18	46.00			
	29,000-38,000 TK	14	26.82			
	39,000-48,000 TK	11	39.27			
	49,000-3,00,000 TK	16	25.59			
Types of Residence	Urban	27	35.85	2	1.340	.512
	Semi-Urban	13	30.54			
	Rural	31	38.42			
Relationship with Patient	Spouse	21	34.43	5	4.450	.487
	Parent	18	38.61			
	Sibling	7	28.07			
	Child	11	30.50			
	Other (Nephew, Carer, Sister-in-law, Uncle, Aunty)	8	40.00			
	Grand Father	6	47.67			
Duration of Caregiving	1–6 months	45	36.03	2	6.668	**.036**
	7–12 months	15	27.00			
	More than 12 months	11	48.14			

Table 4.3 represents the Kruskal–Wallis H test results, where caregiver burden is the dependent variable and different socio-demographic and caregiving factors are the independent variables. The test showed that caregiver burden did not differ significantly by age (H= 0.244, *P* = .885), marital status (H= 1.978, *P* = .815), administrative division (H= 10.110, *P* = .120), occupation (H= 5.533, *P* = .478), type of residence (H= 1.340, *P* = .512), or relationship with the patient (H= 4.450, *P* = .487). This means caregivers in these groups had almost similar levels of burden.

However, caregiver burden differed significantly by education level (H= 11.235, *P* = .024), monthly family income (H= 12.583, *P* = .014), and duration of caregiving (H= 6.668, *P* = .036). Caregivers with primary and secondary education, those from lower- and middle-income families, and those who had been caregiving for more than 12 months had higher caregiver burden compared to more educated, higher income caregivers and those providing care for a shorter time.

Table 4.4

Linear regression assessing the association between Educational Qualification and Caregiver Burden

Predictor	Caregiver Burden			
Educational Qualification	**B Unstandardized Coefficient**	**SE**	**Beta Standardized Coefficient**	***P* value**
No Formal Education	Reference			
Primary	9.389 (.809 - 17.968)	4.297	.537	**.032**
Secondary	5.647 (.178 - 11.117)	2.739	.621	**.043**
Higher Secondary	2.227 (-1.991 - 6.445)	2.113	.277	.296
Bachelor's Or Higher	1.675 (-1.525 - 4.875)	1.603	.358	.300

Table 4.4 Association Between Educational Qualification and Caregiver Burden The caregiver burden for individuals with primary education is 9.389 times higher compared to those with no formal education, and this is statistically significant with a range of 0.809 to 17.968. For individuals with secondary education, the caregiver burden is 5.647 times higher than those with no formal education, which is also statistically significant, with a range of 0.178 to 11.117. In contrast, for individuals with higher secondary education, the caregiver burden is 2.227 times higher, but this result is not statistically significant with a range of -1.991 to 6.445. Similarly, for individuals with a bachelor’s or higher education, the caregiver burden is 1.675 times higher, but this result is also not statistically significant, with a range of -1.525 to 4.875.

Table 4.5

Linear regression assessing the association between Monthly Household Income and Caregiver Burden

Predictor	Caregiver Burden			*P* value
Monthly Household Income	**B Unstandardized Coefficient**	**SE**	**Beta Standardized Coefficient**	
8,000-18,000 TK	Reference			
19,000-28,000 TK	.708 (-3.385 - 4.801)	2.050	.053	.731
29,000-38,000 TK	-2.742 (-5.622 - .138)	1.443	-.281	.062
39,000-48,000 TK	-.669 (-2.961 - 1.624)	1.148	-.083	.562
49,000-3,00,000 TK	-2.054 (-3.732 - -.377)	.840	-.369	**.017**

Table 4.5 Association Between Monthly Household Income and Caregiver Burden For individuals with an income of 19,000-28,000 TK, the caregiver burden is 0.708 times higher compared to those in the 8,000-18,000 TK bracket, but this is not statistically significant, with a range of -3.385 to 4.801. The caregiver burden for those in the 29,000-38,000 TK bracket is 2.742 times lower, though this result is not statistically significant, with a range of -5.622 to 0.138. In the 39,000-48,000 TK bracket, the caregiver burden is 0.669 times lower, but this is also not statistically significant, with a range of -2.961 to 1.624. However, for individuals earning 49,000-300,000 TK, the caregiver burden is 2.054 times lower, and this result is statistically significant, with a range of -3.732 to -0.377.

Table 4.6

Linear regression assessing the association between Duration of Caregiving Since Diagnosis and Caregiver Burden

Predictor	**Caregiver Burden**			***P* value**
Duration of Caregiving Since Diagnosis	**B Unstandardized Coefficient**	**SE**	**Beta Standardized Coefficient**	
1–6 months	Reference			
7–12 months	-2.356 (-5.702 - .991)	1.677	-.165	.165
More than 12 months	2.601 (.084 - 5.118)	1.261	.243	**.043**

Table 4.6 Association Between Duration of Caregiving Since Diagnosis and Caregiver Burden For individuals' caregiving for 7-12 months, the caregiver burden is 2.356 times lower compared to those caregiving for 1-6 months, but this result is not statistically significant, with a range of -5.702 to -0.991. In contrast, for individuals' caregiving for more than 12 months, the caregiver burden is 2.601 times higher, and this result is statistically significant, with a range of 0.084 to 5.118.

CHAPTER V: DISCUSSION

The overall aim of this study was to know the level of caregiver burden among caregivers of patients with Guillain-Barré syndrome (GBS) in Bangladesh. It was specifically examined in the intensity of burden in several domains, such as financial, social, and emotional, and how it is related to socioeconomic variables. Key findings revealed that while a significant portion of caregivers reported No to Mild Burden in social and family life (45%), a substantial nearly 30% struggled nearly always with money due to caregiving. Most importantly, the analysis also found that the duration of the caregiving as a factor was statistically significant in predicting burden (P =.036) but no significant correlations were observed between other demographics factors like age and occupation.

The findings of this study must be interpreted within the unique clinical and economic landscape of Bangladesh. GBS in this region is characterized by a higher prevalence of severe axonal subtypes (AMAN and AMSAN), which often result in greater disability and higher mortality rates compared to Western countries. The results align with global literature indicating that GBS imposes a significant psychosocial and physical strain on relatives (Bernsen et al., 2006). For instance, Bernsen et al. (2006) found that psychological morbidity among close relatives is significantly higher in the months following onset. This study's finding that duration of caregiving significantly impacts burden (P = .036) supports the idea that the "prolonged absence from home" and the long-term recovery trajectory of GBS create cumulative stress. While Western studies often highlight the psychological "shock" of the sudden onset, this study emphasizes the economic strain specific to the Bangladeshi context. The lack of resources, such as ICU beds and the prohibitive cost of IVIg and plasma exchange,

directly contributes to the financial burden reported by nearly a third of the participants. Interestingly, this study diverges from some neurological research (e.g., studies on ALS or dementia) where gender and age often significantly influence burden levels; in this GBS cohort, these factors were not statistically significant (Sandstedt et al., 2018).

A notable unexpected finding was that socio-demographic factors-such as age, gender, and marital status-did not significantly differ in their association with caregiver burden scores. One might expect older caregivers or female caregivers to report higher burden, as seen in other chronic conditions (Bergin & Mockford, 2016). This lack of significance may be attributed to the acute and crisis nature of GBS. Unlike progressive diseases, GBS strikes suddenly, thrusting all family members into intense caregiving roles regardless of their demographic background. The immediate need for 12–15 hours of daily attention during the worst stages may create a ceiling effect where the intensity of care required overwhelms all caregivers equally. Additionally, the small sample size (n=71) may have limited the statistical power to detect subtle differences between these subgroups.

This paper is unique as it focuses on the experience of caregivers in a low-resource setting where the presentation of GBS is significantly harsh. Although the majority of existing GBS literature is Scandinavian or North-American, this study highlights the difference between the costs of immunomodulatory treatment and the high number of axonal variants in Bangladesh, which increases the burden on the family. The current thesis provides vital evidence to local policymakers by creating empirically measured information on the financial and social disturbances experienced by the families of Bangladesh. It also emphasizes the necessity of the subsidized rehabilitation services and better access of the ICU to prevent the breakdown of home-based care systems in the area.

CHAPTER VI: CONCLUSION

6.1 Strength and Limitation

6.1.1 Strength

- The data collection from participants and the data entry process was non-biased.
- The researcher could have a wide geographical variation of participants, as it was a telephone survey.
- The study response rate as telephone response is reasonable, previously discussed in the literature (Toole et al., 2008), it was a great strength of this study.
- For data safety and validation, all the data used in this study will be destroyed.
- This study's findings assist rehabilitation health professionals in creating a comprehensive rehabilitation service plan for patients with GBS.

6.1.2 Limitation

The researcher acknowledges some limitations and barriers in this investigation.

These include:

- There are few published literatures available in Bangladesh regarding caregiver burden about Guillain-Barré Syndrome
- The sample was selected as convenient way rather than randomly.
- The overall samples were selected from CRP all branches because of time limitation.

6.2 Practice Implication (recommendation for future practice and research)

From this study it is clearly seen that the caregivers of Guillain-Barré Syndrome perceived Mild to Moderate Burden level of burden during caregiving. The researchers have drawn some recommendation based on the findings of the research. The researcher recommends that in future similar research might be conducted in the broader area with larger scale of sample size. Further research in this area might contribute to understand the characteristics of vulnerable caregivers and the factors or predictors that increasing caregiver burden. For ensuring effective treatment and rehabilitation of Guillain-Barré Syndrome Patients, it is necessary to ensure caregiver physical, mental and socio-economic wellbeing.

The current study also recommends that health professionals might contribute to minimize the caregivers‟ vulnerable situation by providing proper education, patient handling training, occupational training, counseling, information for maintaining own health, and promoting social participation of the target caregivers. Researcher recommends that more male caregivers need to be encouraged to participate in care giving activities rather than only female caregivers.

6.3 Conclusion

The primary objective of this study was to assess the level of caregiver burden and associated factors among caregivers of patients with Guillain-Barré Syndrome (GBS) in Bangladesh. The study found that many caregivers experienced mild to moderate burden, especially in relationship, emotional wellbeing, family and social life, finances, relationships, and loss of control over one's life.

The findings also showed that burden varied by caregivers' educational qualifications, monthly household income, and duration of caregiving, and spouse often reported higher burden than other family members. Although caregiving is commonly viewed as a family responsibility in Bangladeshi culture, caregivers still face significant stress and challenges. Therefore, health professionals should regularly assess caregiver burden and provide support services to improve both caregiver wellbeing and patient outcomes.

CHAPTER VII: LIST OF REFERENCE

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APPENDICES

Appendix A:

IRB Approval Letter

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

Ref: CRP-BHPI/IRB/07/2025/1127 Date: 21.07.2025

To
Md. Nadim Shahariar
4th Year B.Sc. in Occupational Therapy
Session: 2020-2021, Student ID: **122200458**
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal **Caregiver Burden of Patient with Guillain-Barre Syndrome: A Cross-Sectional Study** by ethics committee.

Dear Md. Nadim Shahariar,
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 **Nayan Kumer Chanda,** Assistant Professor, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP as thesis supervisor. The Following documents have been reviewed and approved:

Sl. No.	Name of the Documents
1	Research Proposal
2	Zarit Burden Interview (ZBI)
3	Information sheet & consent form.

The purpose of the study is to explore "investigate the level of Caregiver Burden of Patient with Guillain-Barré Syndrome". The study involves use of a Zarit Burden Interview (ZBI) to explore the level of Caregiver Burden of Patient with Guillain-Barré Syndrome that may take 20-30 minutes to answer the Interview Guide and there is no likelihood of any harm to the participants. There is no benefit 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 17 June, 2025 at BHPI (50th 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 regard,

Muhammad Millat Hossain
Associate Professor, Project and Course Coordinator, MRS
Member Secretary, Institutional Review Board (IRB)
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ। ফোন: +৮৮ ০২ ২২৪৪৪৫৪৬৪-৫, +৮৮ ০২ ২২৪৪৪১৪০৪, মোবাইল: +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

Permission Letter for Data Collection

বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)
CRP, Chapain, Savar, Dhaka-1343 Tel: 02-7745464-5, 7741404, Fax: 02-7745069

Date: 02/08/2025

To
Executive Director,
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka-1343, Bangladesh

Subject: Regarding permission for data collection for undergraduate research.

Sir,

With due respect I would like to draw your kind attention that I am a student of the 4th Year B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI), which is an academic institute of the Centre for the Rehabilitation of the Paralysed (CRP), affiliated to the Faculty of Medicine, University of Dhaka. According to my course curriculum, I have to conduct research, and my research title is **"Caregiver Burden of Patient with Guillain-Barré Syndrome: A Cross-Sectional Study"** with myself & Nayan Kumer Chanda as my thesis supervisor. The purpose of my study is to investigate the level of caregiver burden in patients with Guillain-Barré Syndrome. In order to fulfill the objectives of this study, I would like to collect data from the Occupational Therapy Department - CRP All Centers. Specifically, I require data on patients with Guillain-Barré Syndrome (GBS) from the Occupational Therapy department records of the past six (6) months. The data collection period is from 02/08/2025 to 15/09/2025. I assure you that the collected information will be used solely for academic purposes, and confidentiality will be maintained in accordance with ethical guidelines. Your permission and support would be invaluable to facilitate the successful completion of my research.

So, I therefore, pray and hope that you would be kind enough to grant me permission to collect data for my study and oblige thereby.

Sincerely yours,

Md. Nadim Shahariar
Md. Nadim Shahariar
4th Year, B.Sc. in Occupational Therapy
Session: 2020-21; Student ID: **122200458**
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

"Forwarded to ED Sir for his Approval."
19/8
Md. Shaikhul Hasan
Assistant Manager
Research Monitoring And Evaluation
CRP, Savar, Dhaka

Recommendation from the Head of the Department:

Prof. Sk. Moniruzzaman
Professor & Head
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Savar, Dhaka-1343
Attachments: Copy of IRB Approval Letter.

Permission Letter for using Zarit Burden Interview Scale from Author

Mapi Research Trust

SPECIAL TERMS No109098

These User Agreement Special Terms (Special Terms) are issued between Mapi Research Trust ("MRT") and Md. Nadim Shahariar (User).

These Special Terms include the terms and conditions of the User Agreement General Terms together, the Agreement, which are hereby incorporated by this reference as though the same was set forth in its entirety and shall be effective as of the Special Terms Effective Date set forth herein.

All capitalized terms which are not defined herein shall have the same meanings as set forth in the User Agreement General Terms.

These Special Terms, including all attachments and the User Agreement General Terms contain the entire understanding of the Parties with respect to the subject matter herein and supersedes all previous agreements and undertakings with respect thereto. If the terms and conditions of these Special Terms or any attachment conflict with the terms and conditions of the User Agreement General Terms, the terms and conditions of the User Agreement General Terms will control, unless these Special Terms specifically acknowledge the conflict and expressly states that the conflicting term or provision found in these Special Terms control for these Special Terms only. These Special Terms may be modified only by written agreement signed by the Parties.

1. User information

Category of User	Student
User contact details	Name: Md. Nadim Shahariar Email: nadimshahariar79@gmail.com Phone:

2. General information

Effective Date	Date of acceptance of these Special Terms by the User : 31 Jan 2025
Expiration Date (Term)	Upon completion of the Stated Purpose or full provision of translations, as applicable

3. Identification of the COA

Appendix B: Information Sheet & Consent Form

Participant Explanatory Statement

Research Title: "Caregiver Burden of Patient with Guillain-Barré Syndrome: A Cross-Sectional Study".

Researcher:

Md. Nadim Shahariar

4th year, B.Sc. in Occupational Therapy, Session: 2020-2021, Bangladesh Health Professions Institute (BHPI). CRP, Savar, Dhaka-1343

Contact: +8801635-507261

Email: nadimshahariar79@gmail.com

Supervisor:

Nayan Kumer Chanda

Assistant Professor,

Department of Occupational Therapy

Bangladesh Health Professions Institute (BHPI)

Savar, Dhaka-1343

Email: nayanchanda2020@gmail.com

Contact: +880 1735-296444

Research place: Bangladesh Health Professions Institute (BHPI) CRP, Savar, Dhaka-1343

This information sheet is for you to keep.

What is the purpose of this research?

The purpose of this study is to assess the level of caregiver burden experienced by individuals in Bangladesh who care for patients diagnosed with Guillain-Barré Syndrome (GBS). This study seeks to identify the psychological, emotional, and physical burdens that caregivers endure and to explore the factors influencing caregiver stress levels. By understanding these challenges, the study aims to provide insights into effective intervention strategies and support networks that can improve caregiver well-being and enhance patient care.

What does the research involve?

Participants in this study will complete a structured questionnaire that evaluates their experiences and perceived burden while providing care to individuals with Guillain-Barré Syndrome. The survey is expected to take approximately 20–30 minutes and can be administered either in person or online, depending on the participant's preference. The study will use standardized assessment tools, including the Zarit Burden Interview (ZBI), to quantify caregiver burden. For further inquiries, participants can contact the research team using the provided contact details.

Why were you chosen for this research?

You have been selected to participate in this study because you are a caregiver for someone diagnosed with Guillain-Barré Syndrome. Your insights are invaluable for understanding the difficulties caregivers face, which will contribute to the development of more effective support systems and interventions for individuals in similar caregiving situations.

Source of funding

This research is self-funded by the researchers and is conducted without external funding or sponsorship.

Consenting to participate in the project and withdrawing from the research

Your participation in this study requires your consent, which you can provide by signing the consent form before completing the survey. Participation is entirely voluntary, and there is no obligation to participate. If you decide to withdraw from the study at any point before the analysis phase, you may do so without any penalty or consequence. You may also choose to skip any questions you are uncomfortable with.

Possible benefits and risks to participants

While there may be no direct personal benefits from participating in this study, your contribution will help enhance understanding of caregiver burden in the context of Guillain-Barré Syndrome. The results of this research aim to inform healthcare providers and policymakers on how to better support caregivers.

The study is designed to be low-risk, but reflecting on caregiving experiences may cause psychological distress for some participants. If any distress arises, the research team will provide support and allow participants to take a break or withdraw if necessary. Additionally, participants may reschedule their participation if they feel uncomfortable continuing.

Confidentiality

All participant information will be kept confidential. No personal identifying details will be published in any reports. A unique code will be assigned to each participant to ensure anonymity during data analysis. Only the research team will have access to identifying information, and data will be securely stored on a password-protected system. All hard copies of the data will be stored in locked filing cabinets to ensure privacy and security.

Storage of data

The collected data will be kept in a secure cloud storage system and on a password-protected computer that only the researchers may access. Hard copies of the data will be safely kept at the CRP Savar, Dhaka, Bangladesh Health Professions Institute (BHPI). Data will be kept for five years after the study is over, after which it will be safely destroyed according to institutional policies.

Results

The data collected from this study will be analyzed quantitatively, and the results will be compiled into a detailed report. Findings may be published in peer-reviewed academic journals or presented at academic conferences. A summary of the results will be available to participants upon request. Additionally, key findings will be shared with relevant organizations to contribute to the development of improved support systems for caregivers of patients with Guillain-Barré Syndrome.

Complaints

If you have any concerns or complaints about the research's conduct, you are welcome to contact the supervisor.

Nayan Kumer Chanda

Assistant Professor,

Department of Occupational Therapy

Bangladesh Health Professions Institute (BHPI)

Savar, Dhaka-1343

Contact: +880 1735-296444

Thank you,

Md. Nadim Shahariar

অংশগ্রহণকারীর জন্য ব্যাখ্যামূলক বিবৃতি

বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)

অকুপেশনাল থেরাপি বিভাগ

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩ টেলিফোন:০২-৭৭৪৫৪৬৪-৫,৭৭৪১৪০৪, ফ্যাক্স:০৭৭৪৫০৬

গবেষণার বিষয়: "গুলিয়ান-বারে সিনড্রোমে আক্রান্ত রোগীদের পরিচর্যাকারীদের উপর চাপ"

গবেষক: মোঃ নাদিম শাহারিয়ার

৪র্থ বর্ষ, বি.এসসি ইন অকুপেশনাল থেরাপি, সেশন: ২০২০–২০২১

বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), সিআরপি, সাভার, ঢাকা-১৩৪৩

মোবাইল: +৮৮০১৬৩৫৫০৭২৬১

ই-মেইল: nadimshahariar79@gmail.com

তত্ত্বাবধায়ক: নয়ন কুমার চন্দ, সহকারী অধ্যাপক, অকুপেশনাল থেরাপি বিভাগ,

বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), সাভার, ঢাকা-১৩৪৩

ই-মেইল: nayanchanda2020@gmail.com

মোবাইল: +৮৮০১৭৩৫-২৯৬৪৪৪

গবেষণার স্থান:

বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), সিআরপি, সাভার, ঢাকা-১৩৪৩

এই তথ্যপত্রটি আপনার কাছে রাখার জন্য, দয়া করে এটি সংরক্ষণ করুন।

এই গবেষণার উদ্দেশ্য কী?

এই গবেষণার উদ্দেশ্য হলো গুলিয়ান-বারে সিনড্রোমে (GBS) আক্রান্ত রোগীর যত্নদাতারা যে মানসিক, আবেগজনিত ও শারীরিক বোঝা অনুভব করেন তা মূল্যায়ন করা। গবেষণায় যত্নদাতার স্ট্রেসকে প্রভাবিতকারী উপাদানসমূহ চিহ্নিত করা হবে। এর মাধ্যমে কার্যকর সহায়তা ব্যবস্থা ও হস্তক্ষেপ কৌশল উন্নয়নের জন্য প্রয়োজনীয় তথ্য পাওয়া যাবে, যা যত্নদাতার কল্যাণ বৃদ্ধি ও রোগীর যত্নে সহায়ক হবে।

এই গবেষণায় কী অন্তর্ভুক্ত রয়েছে?

এই গবেষণায় অংশগ্রহণের সিদ্ধান্ত নেওয়ার আগে অনুগ্রহ করে সংযুক্ত তথ্যসমূহ মনোযোগ সহকারে পড়ুন। যদি গবেষণার কোনো অংশ সম্পর্কে আপনার কোনো প্রশ্ন থাকে বা আরও ব্যাখ্যার প্রয়োজন হয়, তাহলে উপরে দেওয়া ফোন নম্বর বা ইমেইল ঠিকানায় শিক্ষার্থী গবেষকের সঙ্গে যোগাযোগ করতে পারেন। আপনাকে একটি জরিপভিত্তিক গবেষণায় অংশগ্রহণের জন্য আমন্ত্রণ জানানো হয়েছে, যা বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), সিআরপি'র অকুপেশনাল থেরাপি বিভাগের একজন শিক্ষার্থী পরিচালনা করছেন।

অংশগ্রহণকারীদের একটি গঠনমূলক প্রশ্নপত্র পূরণ করতে হবে, যা গুলিয়ান-বারে সিনড্রোম আক্রান্ত ব্যক্তিকে যত্ন দেওয়ার সময়কার অভিজ্ঞতা ও অনুভূত বোঝা মূল্যায়ন করবে। সার্ভেটি সম্পন্ন করতে আনুমানিক ২০–৩০ মিনিট সময় লাগবে। এটি ফোন কল এর মাধ্যমে অংশগ্রহণকারীর সুবিধামতো সম্পন্ন করা যাবে। যত্নদাতার বোঝা পরিমাপের জন্য Zarit Burden Interview (ZBI) সহ মানসম্মত মূল্যায়ন টুল ব্যবহার করা হবে।

আপনাকে কেন এই গবেষণার জন্য নির্বাচন করা হয়েছে?

আপনাকে এই গবেষণায় অন্তর্ভুক্ত করা হয়েছে কারণ আপনি গুলিয়ান-বারে সিনড্রোমে আক্রান্ত একজন ব্যক্তির যত্নদাতা। আপনার অভিজ্ঞতা যত্নদাতাদের সমস্যা ও চাহিদা বোঝার জন্য অত্যন্ত মূল্যবান, যা ভবিষ্যতে উন্নত সহায়তা ব্যবস্থা ও হস্তক্ষেপ কৌশল তৈরিতে সহায়তা করবে।

অর্থায়ন:

এই গবেষণাটি গবেষকের নিজস্ব অর্থায়নে পরিচালিত হচ্ছে। কোনো বাহ্যিক অর্থায়ন বা পৃষ্ঠপোষকতা নেই।

অনুমতি ও অংশগ্রহণ প্রত্যাহার:

যদি আপনি এই গবেষণায় অংশগ্রহণে সম্মতি দেন, তাহলে আপনাকে একটি অনুমতি ফর্মে স্বাক্ষর করতে হবে এবং তা সাক্ষাৎকারের সময় গবেষকের কাছে জমা দিতে হবে। আপনার এই গবেষণায় অংশগ্রহণ সম্পূর্ণ স্বেচ্ছামূলক, এবং এটি করা আপনার জন্য বাধ্যতামূলক নয়। যদি আপনি অংশগ্রহণ করতে সম্মত না হন, তাহলে আপনি যেকোনো সময়, ফলাফল বিশ্লেষণের আগে, গবেষণা থেকে সরে আসতে পারবেন। আপনি যদি সরে যেতে চান বা কোনো প্রশ্নের উত্তর না দিতে চান, তাহলে এর জন্য আপনার কোনো নেতিবাচক প্রভাব পড়বে না।

সম্ভাব্য সুবিধা ও ঝুঁকি:

এই গবেষণায় অংশগ্রহণের মাধ্যমে আপনার কোনো সরাসরি ব্যক্তিগত সুবিধা নাও হতে পারে, তবে আপনার অবদান গুলিয়ান-বারে সিনড্রোম সম্পর্কিত যত্নদাতাদের বোঝা বোঝার ক্ষেত্রে গুরুত্বপূর্ণ ভূমিকা রাখবে। ফলাফল স্বাস্থ্যসেবা প্রদানকারী ও নীতিনির্ধারকদের জন্য সহায়ক হবে।

গবেষণাটি স্বল্প-ঝুঁকিপূর্ণভাবে নকশা করা হয়েছে। তবে যত্নদানের অভিজ্ঞতা স্মরণ করার সময় কিছু অংশগ্রহণকারীর মানসিক কষ্ট হতে পারে। এমন হলে গবেষণা দল সহায়তা প্রদান করবে এবং প্রয়োজনে আপনাকে বিরতি নেওয়া বা গবেষণা থেকে সরে আসার সুযোগ দেওয়া হবে।

গোপনীয়তা:

আপনার তথ্য গোপন রাখা হবে এবং কেবলমাত্র এই গবেষণার সঙ্গে যুক্ত শিক্ষার্থী গবেষক তা দেখতে পারবেন। কোনো প্রকাশিত লেখায় আপনার নাম উল্লেখ করা হবে না। প্রশ্নপত্র পূরণ শেষ হলে আপনার নামের পরিবর্তে একটি প্রতীক ব্যবহার করা হবে এবং যেকোনো তথ্য বিশ্লেষণে সেই কোড/প্রতীক ব্যবহার করা হবে।

তথ্য সংরক্ষণ:

সংগ্রহিত তথ্য একটি নিরাপদ ক্লাউড স্টোরেজ সিস্টেমে এবং পাসওয়ার্ড-সুরক্ষিত কম্পিউটারে সংরক্ষণ করা হবে, যা কেবল গবেষকেরা ব্যবহার করতে পারবেন। তথ্যের মুদ্রিত কপি (hard copy) সিআরপি সাভার, ঢাকা, বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)-এ নিরাপদে সংরক্ষণ করা হবে। গবেষণা শেষ হওয়ার পর এই তথ্য পাঁচ বছর পর্যন্ত সংরক্ষণ করা হবে, এরপর প্রতিষ্ঠানের নীতিমালার অনুযায়ী নিরাপদভাবে ধ্বংস করে ফেলা হবে।

ফলাফল

সংগৃহীত তথ্য পরিসংখ্যানিকভাবে বিশ্লেষণ করা হবে এবং একটি বিস্তারিত প্রতিবেদনে সংকলিত হবে। গবেষণার ফলাফল একাডেমিক জার্নালে প্রকাশিত হতে পারে বা সম্মেলনে উপস্থাপন করা হতে পারে। অংশগ্রহণকারীর অনুরোধে একটি সারসংক্ষেপ প্রদান করা হবে। এছাড়া, প্রাসঙ্গিক সংস্থাগুলোর সঙ্গে মূল তথ্য শেয়ার করা হবে, যাতে গুলিয়ান-বারে সিনড্রোম আক্রান্ত রোগীর যত্নদাতাদের জন্য উন্নত সহায়তা ব্যবস্থা গড়ে তোলা যায়।

অভিযোগ:

গবেষণা নিয়ে কোনো অভিযোগ থাকলে আপনি নিম্নোক্ত ব্যক্তিদের সঙ্গে যোগাযোগ করতে পারেন:

নয়ন কুমার চন্দ

সহকারী অধ্যাপক,

অকুপেশনাল থেরাপি বিভাগ

বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)

সাভার, ঢাকা-১৩৪৩

মোবাইল: +৮৮০১৭৩৫-২৯৬৪৪৪

ধন্যবাদান্তে,

মোঃ নাদিম শাহারিয়ার

Consent Form

Research title: “Caregiver Burden of Patient with Guillain-Barré Syndrome: A Cross-Sectional Study”.

Patient’s Consent (Written/Verbal):

I am _____

After a clear explanation from the responsible researcher, I give my full consent to participate in the research titled “Caregiver Burden of Patient with Guillain-Barré Syndrome: A Cross-Sectional Study.” I have read the above statement and understand the nature of my participation in the study. I understand that all interview data collected for the research will be kept confidential and secure. Only the researcher and the supervisor will have access to the data, and it will be published anonymously. I am also aware that I may withdraw my participation within one month of the study, without any obligation to provide a reason or face any consequences. I acknowledge that I am aware of all the above information and agree to be a participant in this study.

Name of participant: _____

Date:

সম্মতি পত্র

আমি **মো. নাদিম শাহারিয়ার**, ঢাকা বিশ্ববিদ্যালয়ের চিকিৎসা অনুষদের অন্তর্ভুক্ত পক্ষাঘাতগ্রস্তদের পুনর্বাসনকেন্দ্র (সিআরপি), সাভার, ঢাকা, এর একাডেমিক ইনস্টিটিউট বাংলাদেশ হেলথ প্রফেসনস ইনস্টিটিউট (বিএইচপিআই) এ অধ্যয়নরত ৪র্থ বর্ষের শিক্ষার্থী। বি.এস.সি ইন অকুপেশনাল থেরাপি কোর্স কারিকুলামের একটি অংশ হিসেবে আমি অকুপেশনাল থেরাপির একজন সহযোগী নয়ন কুমার চন্দ্র এর অধীনে একটি গবেষনা পরিচালনা করতে যাচ্ছি। গবেষনার উদ্দেশ্য হলো **"গুলিয়ান-বারে সিনড্রোমে আক্রান্ত রোগীদের পরিচর্যাকারীদের উপর চাপের মাত্রা"** সম্পর্কিত তথ্য বের করা।

আমি _____। দায়িত্বপ্রাপ্ত গবেষকের কাছ থেকে স্পষ্ট ব্যাখ্যা পাওয়ার পর, আমি ‘‘গুইলেন-বারে সিনড্রোমে আক্রান্ত রোগীর পরিচর্যাকারীর ওপর বোঝা: একটি ক্রস-সেকশনাল গবেষণা’’ শীর্ষক গবেষণায় অংশগ্রহণের জন্য আমার পূর্ণ সম্মতি প্রদান করছি।

আমি উপরের বিবৃতিটি পড়েছি এবং এই গবেষণায় আমার অংশগ্রহণের প্রকৃতি সম্পর্কে অবগত আছি। আমি বুঝতে পারছি যে, এই গবেষণার জন্য সংগৃহীত সকল সাক্ষাৎকারভিত্তিক তথ্য সম্পূর্ণভাবে গোপন ও নিরাপদ রাখা হবে। শুধুমাত্র গবেষক এবং তত্ত্বাবধায়ক এই তথ্যের প্রবেশাধিকার পাবেন এবং গবেষণার ফলাফল নাম-পরিচয় গোপন রেখে প্রকাশ করা হবে।

আমি আরও অবগত আছি যে, এই গবেষণায় অংশগ্রহণ করার পর এক মাসের মধ্যে যেকোনো সময় আমি চাইলে কোনো কারণ না দেখিয়েই এবং কোনো ধরনের নেতিবাচক প্রভাব ছাড়াই আমার অংশগ্রহণ প্রত্যাহার করতে পারব।

উপরোক্ত সকল তথ্য সম্পর্কে অবগত থেকে আমি এই গবেষণায় অংশগ্রহণ করতে সম্মতি প্রদান করছি।

অংশগ্রহণকারীর নামঃ

তারিখঃ

গবেষকের স্বাক্ষরঃ

WITHDRAWAL OF CONSENT FORM

Research title: "Caregiver Burden of Patient with Guillain-Barré Syndrome: A Cross-sectional study".

Student investigator: Md Nadim Shahariar

I, _____(the participant), wish to WITHDRAW my consent to the use of data arising from my participation. Data arising from my participation must NOT be used in this research project as described in the Information and Consent Form. I understand that data arising from my participation will be destroyed provided this request is received within four weeks of the completion of my participation in this project. I understand that this notification will be retained together with my consent form as evidence of the withdrawal of my consent to use the data I have provided specifically for this research project.

Name of participant: _____

Date:

প্রত্যাহার পত্র

শিরোনাম: "গুলিয়ান-বারে সিনড্রোমে আক্রান্ত রোগীদের পরিচর্যাকারীদের উপর চাপ"

ছাত্র গবেষক: মো. নাদিম শাহারিয়ার

(অংশগ্রহণকারী), আমার অংশগ্রহণ থেকে উপরুক্ত ডেটা ব্যবহারের জন্য আমার সম্মতি প্রত্যাহার করতে চাই। আমার অংশগ্রহণ থেকে উপরুক্ত ডেটা তথ্য এবং সম্মতি ফর্মে বর্ণিত এই গবেষণা প্রকল্পে ব্যবহার করা উচিত নয়। আমি বুঝি যে আমার অংশগ্রহণ থেকে উপরুক্ত ডেটা ধ্বংস করা হবে যদি এই অনুরোধটি এই প্রকল্পে আমার অংশগ্রহণ সম্পূর্ণ হওয়ার চার সপ্তাহের মধ্যে প্রাপ্ত হয়। আমি বুঝিতে পেরেছি যে এই বিজ্ঞপ্তিটি আমার সম্মতি ফর্মের সাথে একত্রে রাখা হবে এই গবেষণা প্রকল্পের জন্য আমি বিশেষভাবে দেওয়া ডেটা ব্যবহার করার জন্য আমার সম্মতি প্রত্যাহারের প্রমাণ হিসাবে।

অংশগ্রহণকারীর নাম----------

তারিখ:

Appendix C: Questionnaire

Sociodemographic Questionnaire

Date: / /2025 **Mobile Number:** _____

1. **Participant's Name:** _____ **Age:** _____ years
2. **Address:**
   Village: _____ **Sub-district (Upazila):** _____ **District:** _____
3. **Gender:**
   ☐ Male ☐ Female ☐ Other (please specify): _____
4. **Marital Status:**
   ☐ Unmarried ☐ Married ☐ Widowed ☐ Divorced/Separated
5. **Educational Qualification:**
   ☐ No formal education ☐ Primary (Grade 1–5) ☐ Secondary (Grade 6–10)
   ☐ Higher Secondary (Grade 11–12) ☐ Bachelor's or higher
6. **Occupation:**
   ☐ Businessperson ☐ Homemaker ☐ Farmer ☐ Day laborer
   ☐ Service holder ☐ Unemployed ☐ Other (please specify): _____
7. **Monthly Household Income (in BDT):**
8. **Relationship with the Patient:**
   ☐ Spouse ☐ Parent ☐ Sibling ☐ Child ☐ Other (please specify): _____
9. **Type of Family:**
   ☐ Nuclear ☐ Joint
10. **Type of Residence:**
    ☐ Urban ☐ Semi-urban ☐ Rural
11. **Duration of Caregiving Since Diagnosis:** _____ months

Zarit Caregiver Burden Assessment (Revised, 22-items)

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

4. Do you feel embarrassed over your relative's behavior?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

5. Do you feel angry when you are around your relative?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

7. Are you afraid what the future holds for your relative?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

8. Do you feel your relative is dependent upon you?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

9. Do you feel strained when you are around your relative?

   0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

10. Do you feel your health has suffered because of your involvement with your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

12. Do you feel that your social life has suffered because you are caring for your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

13. Do you feel uncomfortable about having friends over, because of your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

16. Do you feel that you will be unable to take care of your relative much longer?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

17. Do you feel you have lost control of your life since your relative's illness?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

18. Do you wish you could just leave the care of your relative to someone else?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

19. Do you feel uncertain about what to do about your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

20. Do you feel you should be doing more for your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

    0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

    0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

সামাজিক- জনসংখ্যাগত প্রশ্নমালা

গবেষণার নাম: "গুলিয়ান-বারে সিনড্রোমে আক্রান্ত রোগীদের পরিচর্যাকারীদের উপর চাপ"

তারিখঃ____/____/**২০২৫ ইং** **মোবাইল নম্বরঃ**_____

১। অংশগ্রহণকারীর নাম: _____**বয়স:** _____ **বছর**

২। ঠিকানাঃ গ্রামঃ_____**উপজেলাঃ**_____**জেলাঃ**_____

৩। লিঙ্গ: ☐ পুরুষ ☐ নারী ☐ অন্যান্য (উল্লেখ করুন): _____

৪। বৈবাহিক অবস্থা: ☐ অবিবাহিত ☐ বিবাহিত ☐ বিধবা/বিপত্নীক ☐ তালাকপ্রাপ্ত/আলাদা

৫। শিক্ষাগত যোগ্যতা: ☐ কোনো প্রাতিষ্ঠানিক শিক্ষা নেই ☐ প্রাথমিক ☐ মাধ্যমিক ☐ উচ্চ মাধ্যমিক ☐ স্নাতক বা তার বেশি

৬। পেশা: ☐ ব্যবসায়ী ☐ গৃহিণী ☐ কৃষক ☐ দিনমজুর ☐ চাকরিজীবী ☐ বেকার

☐ অন্যান্য (উল্লেখ করুন): _____

৭। মাসিক পারিবারিক আয় (টাকায়): _____

৮। রোগীর সাথে সম্পর্ক: ☐ জীবনসঙ্গী ☐ পিতা/মাতা ☐ ভাই/বোন ☐ সন্তান ☐ অন্যান্য (উল্লেখ করুন): _____

৯। পরিবারের ধরণ: ☐ একক পরিবার ☐ যৌথ পরিবার

১০। বাসস্থানের ধরন: ☐ শহর ☐ উপ-শহর ☐ গ্রাম

১১। রোগ নির্ণয়ের পর থেকে পরিচর্যার সময়কাল: _____ **মাস**

(Zarit burden interview Bangali version)

নির্দেশনাবলী: নীচে কিছু প্রশ্নের তালিকা দেয়া আছে যা থেকে কোন ব্যক্তি যখন অন্য কারো যত্ন নেয় তখন তার কেমন অনুভূত হয় সেটি বুঝা যায়। প্রতিটি প্রশ্নের পর বলুন যে আপনি কতটা প্রায়শই এরূপ বোধ করেন; যেমন- কখনোই না, খুব কম, মাঝেমাঝে, প্রায়ই, প্রায় সবসময়। প্রশ্নগুলোর কোন সঠিক বা ভুল উত্তর নেই।

1. **আপনার কি মনে করেন যে আপনার আত্মীয়টি প্রয়োজনের তুলনায় বেশি সাহায্য চায়?**

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

2. **আপনার কি মনে হয় যে আত্মীয়কে সময় দেয়ার কারণে আপনার জন্য পর্যাপ্ত সময় থাকেনা?**

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

3. **আপনার আত্মীয়ের যত্ন নেয়া এবং পাশাপাশি পরিবার, চাকুরি সবকিছু একসাথে সামলাতে গিয়ে কোন চাপ অনুভব করেন?**

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

4. **আপনি কি আপনার আত্মীয়ের আচরণে বিব্রত হন?**

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

5. **আপনার আত্মীয়ের আশেপাশে থাকলে আপনি কি রেগে যান?**

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

6. **আপনি কি মনে করেন যে আপনার আত্মীয়ের কারণে আপনার পরিবারের অন্যান্য সদস্য ও বন্ধুবান্ধবের সাথে আপনার সম্পর্ক খারাপ হচ্ছে?**

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

7. **আপনি কি আপনার আত্মীয়ের ভবিষ্যত নিয়ে চিন্তিত?**

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

8. **আপনার কি মনে হয় যে আপনার আত্মীয়টি আপনার উপর নির্ভরশীল?**

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

9. আপনার আত্মীয়ের পাশে থাকলে আপনি কি চাপ অনুভব করেন?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

10. আপনার কি মনে হয় যে আপনার আত্মীয়ের সাথে থাকার কারণে আপনার স্বাস্থ্যের ক্ষতি হচ্ছে?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

11. আপনার কি মনে হয় যে আপনার আত্মীয়ের কারণে আপনার নিজের জন্য একান্তভাবে যতটুকু সময় দরকার তা থাকে না?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

12. আপনি কি মনে করেন যে আপনার আত্মীয়ের যত্ন নেয়ার কারণে আপনি সামাজিকতা রক্ষা করে চলতে পারছেন না?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

13. আপনি কি আপনার আত্মীয়ের কারণে বন্ধুদের আমন্ত্রণ করতে অস্বস্তি বোধ করেন?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

14. আপনার আত্মীয় কি আপনার কাছে এমনভাবে সেবা চায় যাতে মনে হয় আপনিই একমাত্র ব্যক্তি যার উপর তিনি নির্ভর করতে পারেন?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

15. আপনার কি মনে হয় যে আপনার অন্যান্য খরচ মিটিয়ে আপনার আত্মীয়ের যত্ন নেয়ার মত যথেষ্ট টাকা আপনার হাতে নেই?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

16. আপনার কি মনে হয় যে আপনি আর বেশী দিন আপনার আত্মীয়ের যত্ন নিতে পারবেন না?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

17. আপনি কি মনে করেন যে আপনার আত্মীয়ের অসুস্থতার পর থেকে আপনি আপনার জীবনের নিয়ন্ত্রণ হারিয়ে ফেলেছেন?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

18. আপনার কি এরূপ ইচ্ছা জাগে যে আপনার আত্মীয়ের যত্নের ভার যদি অন্য কারো কাছে ছেড়ে দিতে পারতেন?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

19. আপনার আত্মীয়কে নিয়ে কি করা উচিত সে বিষয়ে আপনি কি অনিশ্চয়তায় ভোগেন?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

20. আপনি কি মনে করেন যে, আপনার আত্মীয়ের জন্য আরও কিছু করা উচিত ছিল আপনার?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

21. আপনি কি মনে করেন যে, আত্মীয়ের যত্ন আপনি আরও ভালো করতে পারতেন?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

22. সর্বোপরি, আত্মীয়ের যত্ন নিতে গিয়ে আপনি কতটা মানসিক বা শারীরিক চাপ অনুভব করেন?

0. কখনোই না 1. খুব কম 2. মাঝেমাঝে 3. প্রায়ই 4. প্রায় সবসময়

Appendix D:

Volunteer Recruitment Form

This research is part of the Occupational Therapy course. The researcher's name is Md. Nadim Shahariar, a student of B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI), the academic institute of the Centre for the Rehabilitation of Paralysed (CRP), which is affiliated with the University of Dhaka. The study was entitled "Caregiver Burden of Patient with Guillain-Barré Syndrome: A Cross-sectional study". For data collectors for conducting interviews: Please read the following statements and put tik (✓) on yes or no to say that you understand the research aim and objectives and your involvement and agree to participate as a non-paid data collector in the above-named study.

1. I confirm that I have understood the aim and objectives of the study or that it has been explained to me …….....Yes/ No

2. I understand that my role is voluntary….....Yes/ No

3. I have sufficient time to come to my decision about participation.....Yes/No

4. I agree to participate in the above study as a data collector…….....Yes/No

Data collector's name and signature:

Date:

Appendix E: Supervisor Contact Sheet

Bangladesh Health Professions Institute
Department of Occupational Therapy
4th 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: Caregiver Burden of Patient with Guillain-Barré Syndrome: A Cross-Sectional Study

Name of student: Md. Nadim Shahariar, 4th year, B.Sc. in Occupational Therapy.

Name and designation of thesis supervisor: Nayan Kumer Chanda, Assistant Professor, Department of Occupational Therapy, Bangladesh Health Professions Institute, BHPI, CRP, Savar

Appointment No	Date	Place	Topic of discussion	Duration	Comments of student	Student's signature	Supervisor signature
1	25/05/2025	BHPI Teachers room	Finalization of research title, aim and objectives	1 hr	Title and objectives clarified	Nadim	Nayan
2	27/05/2025	BHPI Teachers room	Review of literature outline and variable selection	1 hr 30 min	Guidance taken	Nadim	Nayan
3	31/05/2025	BHPI Teachers room	Study design and cross-sectional approach	1 hr	Design finalized	Nadim	Nayan
4	16/06/2025	BHPI Teachers room	Tool selection (Zarit Burden Interview)	1 hr 30 min	Measurement tool confirmed	Nadim	Nayan
5	18/06/2025	BHPI Teachers room	Operational definition and variables	1 hr	Definitions refined	Nadim	Nayan
6	22/06/2025	BHPI Teachers room	Sampling technique and inclusion and exclusion criteria	1 hr	Criteria finalized	Nadim	Nayan
7	23/06/2025	BHPI Teachers room	Ethical issues and consent procedure	1 hr 30 min	Ethical section prepared	Nadim	Nayan
8	25/06/2025	BHPI Teachers room	Questionnaire review and modification	1 hr	Questionnaire finalized	Nadim	Nayan
9	30/06/2025	BHPI Teachers room	IRB application guidance	1 hr	IRB process clarified	Nadim	Nayan
10	02/07/2025	BHPI Teachers room	Data collection plan and field preparation	1 hr 30 min	Field plan approved	Nadim	Nayan
11	07/07/2025	BHPI Teachers room	Pilot testing discussion	1 hr	Pilot test guidance	Nadim	Nayan

20	23/09/2025	BHPI Teachers room	Discussion chapter structure	1 hr	Discussion outline improved	Nadim	Naqy
21	12/11/2025	BHPI Teachers room	Linking results with literature	1 hr 30 min	Interpretation refined	Nadim	Naqy
22	18/11/2025	BHPI Teachers room	Limitation and strengths	1 hr	Section finalized	Nadim	Naqy
23	02/12/2025	BHPI Teachers room	Conclusion and recommendations	1 hr	Conclusion finalized	Nadim	Naqy
24	08/12/2025	BHPI Teachers room	Final thesis formatting	1 hr	Formatting corrected	Nadim	Naqy
25	09/12/2025	BHPI Teachers room	Final proofreading	1 hr	Minor errors corrected	Nadim	Naqy
26	03/01/2026	BHPI Teachers room	Supervisor final review	1 hr 30 min	Final feedback received	Nadim	Naqy
27	10/01/2026	BHPI Teachers room	Corrections after review	1 hr	Corrections done	Nadim	Naqy

12	10/07/2025	BHPI Teachers room	Data collection troubleshooting	1 hr	Issues discussed	Nadim	Naqy
13	12/07/2025	BHPI Teachers room	Data coding and SPSS preparation	1 hr 30 min	Coding method learned	Nadim	Naqy
14	15/07/2025	BHPI Teachers room	Data entry checking	1 hr	Accuracy ensured	Nadim	Naqy
15	23/07/2025	BHPI Teachers room	Descriptive statistics guidance	1 hr	Analysis approach clarified	Nadim	Naqy
16	30/07/2025	BHPI Teachers room	Association tests (*Kruskal Walis*)	1 hr 30 min	Statistical test selection	Nadim	Naqy
17	03/08/2025	BHPI Teachers room	Regression analysis discussion	1 hr	Logistic regression explained	Nadim	Naqy
18	06/08/2025	BHPI Teachers room	Results interpretation	1 hr	Findings clarified	Nadim	Naqy
19	12/09/2025	BHPI Teachers room	Chapter – IV (Results) review	1 hr 30 min	Corrections noted	Nadim	Naqy

28	14/01/2026	BHPI Teachers room	Pre-submission checking	1 hr	Ready for submission	Nadim	Naqy
29	03/02/2026	BHPI Teachers room	Submission guidance	1 hr	Submission confirmed	Nadim	Naqy
30	07/02/2026	BHPI Teachers room	Final supervision consultation	1 hr	Thesis approved	Nadim	Naqy

Note:

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