Quality of Life of Persons with Guillain-Barre Syndrome in Community of Bangladesh

By

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Statement of Authorship

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Dedication

"Surely my prayer, sacrifice, hard work and life all for Almighty Allah, the lord of the world.

Also, to my supportive and beloved parents, lovely siblings, honorable teachers and close friends..."

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List of Abbreviation

ADLs	Activities of Daily Living
BHPI	Bangladesh Heath Professions Institute
CRP	Centre for the Rehabilitation of the Paralysed
GBS	Guillain-Barre Syndrome
GDS	GBS Disability Scale
IRB	Institutional Review Board
OT	Occupational Therapy
PwGBS	Person with Guillain-Barre Syndrome
QOL	Quality of Life
SPSS	Statistical Package for Social Science
SD	Standard Deviation
WHOQOL	The World Health Organization Quality of Life
WHO	World Health Organization

ABSTRACT

Background: Guillain-Barre Syndrome is a long-standing disease that needs ongoing systemic attention. For many residual issues, it affects a person's quality of life. However, there is a paucity of evidence in Bangladesh and Asia countries.

Aim: The study aimed to evaluate the quality of life of persons with Guillain-Barre Syndrome in the community of Bangladesh.

Methods: The study followed a cross-sectional quantitative design by conducting a telephone survey among 101 participants who were selected purposively for this study. Data were collected using the World Health Organization Quality of Life (WHOQOL-BREF) and a questionnaire with sociodemographic variables and GBS disability score (GDS) to know the functional status. The study was conducted using quantitative descriptive analysis through Statistical Package for the Social Science (SPSS) software 25.0 version and Chi-square analysis using a Fisher's exact test to determine statistically significant association.

Results: The majority were male (82.2%) participants and female (18.8%) with mean current age of 36.69, SD (±1.2) years. About (9.9%) of participants were in a healthy state, (25.7%) of participants were within minor symptoms and capable of running, (41.6%) of participants were able to walk 10m or more without assistance but unable to run, (20.8%) participants were able to walk 10m across an open space with help, (2%) participants were bedridden or chair bound according to GBS disability score. Most reported their overall quality of life (3.09±1.011) and satisfaction about health (3.26±.844) was medium level. Their overall satisfaction level of health was better than their overall quality of life. There was a significant association between overall quality of life and occupation (*P*>.002) and their monthly income (*P*>.039). Furthermore, there was a strong significant (*p*-value 0.00) association between GBS disability score and overall quality of life. Among WHOQOL-BREF domains, Physical domain (12.91±2.728) and psychological domain (13.45±2.648) were the most affected domains than other domains.

Conclusions: The current rehabilitation practices should be developed, essential for developing new treatment strategies. So that they can properly benefit in their post-rehabilitation lives, they need to implement community advocates for patients in both aspects of physical and mental impairment.

Keywords: Quality of life, Guillain-Barre Syndrome, Person with disability,community.

CHAPTER I: INTRODUCTION

1.1Background

Guillain–Barre syndrome (GBS) is the leading cause of acute paralysis that can potentially affect the entire human population (Malek & Salameh, 2019). 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 different pathogenesis (Malek & Salameh, 2019). Guillain-Barre Syndrome (GBS) also known as acute inflammatory demyelinating polyneuropathy and Landry's Ascending Paralysis, is often preceded by an infection believed to evoke an immune response (van Doorn et al., 2008).

According to a worldwide epidemiological systematically reviewed, the overall incidence of GBS in adults is approximately 1.1 to 1.8 per 100,000 people per year, the incidence of GBS is influenced by gender, age and it increases with age after 50 years, from 1.7 per 100,000 per year to 3.3 per 100,000 per year (McGrogan et al., 2008). In addition, men have a significantly higher risk of developing the disease. (Malek & Salameh, 2019; Sulli et al., 2021) It can occur at any age but is most frequent between the ages of 30 and 50, with a male predominance. It can also affect children and adolescents. (Khan et al., 2010; Akanuwe et al., 2020)

The incidence of GBS in children below 15 years is remarkably high in Bangladesh, possibly due to more frequent exposure of the population to infections (Islam et al., 2011; Islam et al., 2016).

The disease has several variants: acute inflammatory demyelinating polyradiculoneuropathy (AIDP), the most common variant in North America and Europe (Hughes et al., 2005; Pithadia et al., 2010); acute motor axonal neuropathy (AMAN) more prevalent in Asia and South America (Hadden et al., 1998), acute motor sensory axonal neuropathy (AMSAN) and the less common atypical Miller Fisher syndrome**.** (Bondi et al., 2021; Malek & Salameh, 2019; Sulli et al., 2021)

The frequency of the pure motor forms, the Miller Fisher variant and axonal subtypes of GBS are higher in Asian countries than in Western countries (Islam et al., 2016).

In Bangladesh, GBS is associated with high mortality and poor outcome, which may be related to the predominance of the axonal subtype, lack of specific treatments and poor healthcare facilities (Islam et al., 2016; Ishaque et al., 2017). 12% of GBS patients in Bangladesh were dead from GBS within six months of disease onset (Ishaque et al., 2017).

Despite medical treatment, GBS often remains a severe disease; 3–10% of patients die, and 20% cannot walk after six months. In addition, many patients have pain and fatigue that can persist for months or years (van Doorn et al., 2008).

Those who experienced GBS may have long-term residual physical health problems such as fatigue, memory difficulties, pain, muscle weakness, mobility, sleep disturbance, paresthesia, and facial palsy that may limit them in their everyday activities even two years after the onset of their illness.(Rudolph et al., 2008, Forsberg et al., 2012,Demi˙r & KöseoĞlu.,2008 ;Djordjevic et al., 2019) As a result, they felt they had lost their identity as an independent person (Laparidou et al., 2021)

They also faced mental health problems such as frustration, guilt, feeling lost, elation, anger, gratitude, anxiety, depression, felt helplessness through loss of independence. (Forsberg et al., 2014, Laparidou et al., 2021) Emotional problems, anxiety, depression and stress are more common in patients after GBS than in the normal population. Both anxiety and depression may affect the patient’s well-being, even in complete recovery from GBS (Djordjevic et al., 2019).

Living with GBS made it harder for them to participate in society and restricted their social lives (Laparidou et al., 2021). Another area affected by a participant’s condition was their work since physical restrictions and residual GBS symptoms affected function or prevented them from returning to work. They were worried about their family’s well-being (Laparidou et al., 2021). After returning to the community, they faced many difficulties, such as social stigma, financial burden, barriers to marriage, and neative impact on marital or other relationships which ia impact their quality of life (Djordjevic et al., 2019).

Women faced double discrimination in many aspects, such as education facilities, employment facilities, low priority in society, exclusion from community activities and leading more restricted lives associated with low life satisfaction (Demi̇r & KöseoĞlu, 2008).

Workplace adaptations and positive attitudes were the main factors facilitating participants’ return to work (Akanuwe et al., 2020). Overall, it was evident that living with GBS had been a life-changing experience (Laparidou et al., 2021).

The great majority of patients with Guillain-Barre syndrome were dependent in ADL two weeks after onset, but this dependency resolves in most of them during the first six months, regarding the long-term impact of Guillain-Barre´ syndrome on ADL as well as the quality of life (Forsberg et al., 2005).In many patients with GBS psychological functioning is still seriously affected even when they have physically recovered or show only mild residual signs (Bernsen et al., 1997).

These unusual conditions attracted the student researcher's curiosity to look into the quality of life of people with GBS in the Bangladeshi community.

It is documented that studies regarding GBS were conducted in a limited geographical area. Most of the research was conducted in European countries such as Austria, Italy, the Netherlands, Serbia, Sweden, and the United Kingdom, so the findings cannot be generalised for all GBS populations worldwide.

Furthermore, as far as the student researcher is aware, Bangladesh has not yet had a study done on the QOL of community members who have GBS. This research explored the existing QOL of persons with GBS in Bangladesh to determine how it affects the physical, psychological, social, and environmental health domains and how their quality of life changes after rehabilitation. It is important for rehabilitation to investigate the long-term effectiveness of rehabilitation on patients' quality of life. This research will provide new insights into the field of GBS in Bangladesh and throughout Asia.

1.2Justification of Study

People with GBS experience many difficulties maintaining their daily life. GBS patients go through a variety of physical, emotional, and mental changes that affect their QOL.

This study provides a realistic and current overview of their health and lives, helping us to better understand the impact of this condition on their physical, psychological, and social well-being, which is vital for measuring rehabilitation outcomes in the community.

This study has the potential to provide useful insights into the experiences of individuals with GBS, including their views on the condition, treatment, and care. This knowledge can be applied to create more patient-centred treatment strategies and enhance patient-healthcare provider communication.

This study can provide evidence-based recommendations for improving care and support for pwGBS, such as improving access to healthcare services, rehabilitation programs, psychological counselling and developing social support programs. For Bangladesh, evidence is needed to support and justify rehabilitation treatment for pwGBS. Because not much research has been done in this area. Also, it will help to spread the importance of long-term rehabilitation.

This study can provide valuable information about the economic burden, which can help policymakers, patient advocacy groups and healthcare providers identify ways to minimize GBS's financial impact and support affected families.

Moreover, this study will be an important resource for all relevant professions, including physicians, psychologists, counsellors, occupational therapists, and physiotherapists, who need to know about the QOL of people with GBS. Knowing the current QOL of pwGBS can help rehabilitation experts develop more scientific treatment and rehabilitation plans.

As a result, future patients will benefit since their healthcare provider will be aware of the most recent information concerning their health and quality of life in the community.

This study is also significant for the researcher since it will provide updated information and current knowledge regarding the QOL of pwGBS. So, if any researcher can conduct additional research on this topic, this research generates new information.

Overall, this result will enhance the sustainable Quality of Life for persons with GBS and foster better understanding and care within healthcare and society.

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, 2019)

1.3.2 Quality of Life

The WHO defines QOL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (WHO, 2017).

1.3.3 Community

When a group of people interact with another is known as a community. This interaction occurs within a geographical boundary territory. They also share interests and values (Zachary & Neal,2012).

1.4 Aim of the Study

The aim of this study to evaluate the quality of life of persons with Guillain-Barre Syndrome in the community of Bangladesh.

CHAPTER II: LITERATURE REVIEW

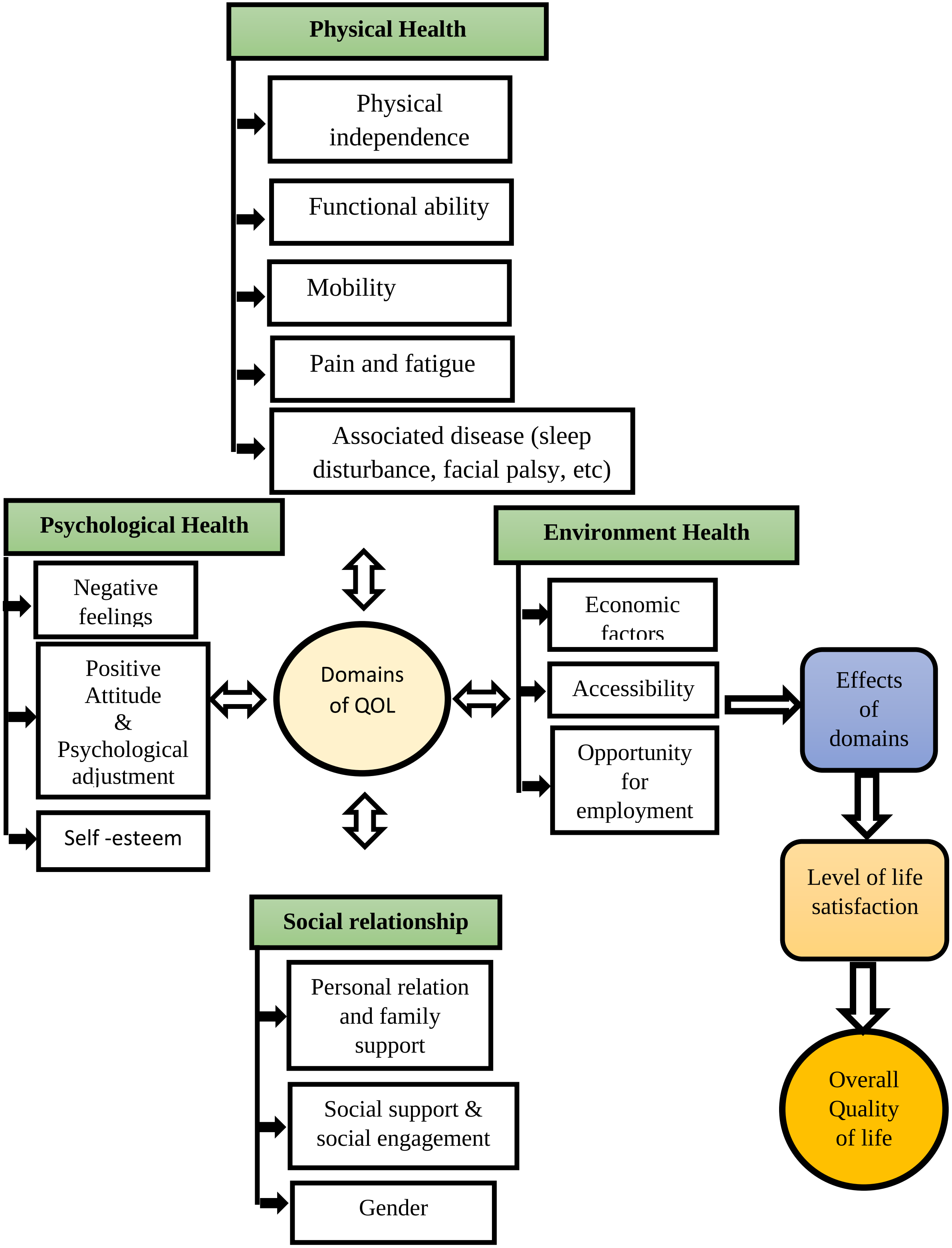

Figure 1: Overview of literature review findings.

2.1 GBS Physical health and QOL

The person with GBS has physical health problems, fatigue, muscle weakness, mobility, sleep disturbance, paresthesia, and facial palsy.

A longitudinal study was conducted in Serbia and surrounding countries to assess the quality of life and analyse its association with patients' disabilities during a six-month follow-up period. The study comprised 74 adult patients diagnosed with GBS from seven tertiary healthcare centres. Health-related QOL was investigated using the SF-36 questionnaire and compared with functional disability assessed by the GBS Disability Scale (GDS). The study found that although patients were objectively improved according to GDS, their illness was still severe from the patient's perspective. Although GDS and SF-36 scores improved during a six-month follow-up in GBS patients, these changes were not parallel. After 28 days, GBS patients' functionality had improved, but their perception of their quality of life remained negative (Berisavac et al., 2020).

Another study location, setting, and participation were the same as above the study. It confirmed that the condition is still susceptible to alterations six months after it first manifests. Only 23% of GBS patients still had severe impairment at three months, and only 11% at six months, compared to 77% who had it in the acute period. However, the author pointed out a gap in the study GDS generally provides information on lower limb disability but not upper limb disability (Djordjevic et al., 2019).

Similarly, Walgaard et al. (2011) showed that 19% of patients at month 6 and 30% at month 3 had substantial disability. Moreover, Martic et al. (2018) found that even three years after an acute GBS event, 60% of patients still experience sensory symptoms, and 30% have functional limitations (Djordjevic et al., 2019). According to Drory et al. (2012), one-third of patients experience persistent pain 1-2 years after disease onset, and up to almost half of patients report significant fatigue after 1-20 years of follow-up. Despite a good neurological recovery, fatigue can persist and be severe in many people for many years following an acute GBS episode **(**Djordjevic et al., 2019)**.**

A qualitative study was conducted in the UK to explore people's experiences with GBS. Participants were purposefully recruited. The author showed that disease-related factors that mainly hindered recovery were identified by participants, including comorbidities, residual or late physical problems like peripheral neuropathy, chronic fatigue, and sequelae or complications of GBS that affected other body organs like the parathyroid, heart, and kidneys (Akanuwe et al., 2020).

A cross-sectional study was also conducted in the UK using a self-administered online questionnaire survey to explore symptoms, care experiences, and recovery in people who previously had GBS. They found that although many people with GBS are told they will recover, and some do so wholly, many are still affected in the longer term. The findings revealed that their limited physical conditions significantly impact GBS patients' quality of life (Siriwardena et al., 2021).

According to Hughes (2020), 8% could not walk, and 7% died in one year, with vast international variations in outcome. Previous studies have also shown long-term neurological deficits in most patients after a year or beyond. Furthermore, one-third had changed jobs or had their functional abilities affected, and half had changed their leisure activities (Bernsen et al., 2005; Siriwardena et al., 2021)**.**

A study conducted in Brazil systematically reviewed the literature on functional outcome domains in which GBS patients experience limitations in the short and long term and evaluated determinants of HRQL in GBS patients. Some studies showed similar findings that GBS patients experienced physical limitations, even years after the acute phase of the disease, while results were inconsistent for perceived pain levels, fatigue, and general mental well-being. And it generally showed considerable improvements in HRQL in the first year after GBS onset but not after that (Darweesh et al., 2014).

A study conducted in Sweden prospectively and longitudinally on disability and health-related quality of life uses the home as the primary site for evaluations. Patients were recruited from eight hospitals located in central Sweden. The study revealed an unusual view of Guillain-Barré syndrome. At two weeks, one year, and two years after the onset of Guillain-Barré syndrome, 76%, 14%, and 12% of patients were dependent on personal ADL, and 98%, 28%, and 26% were dependent on instrumental ADL, respectively. At two weeks, all patients working before onset could not work owing to Guillain-Barré syndrome; at two years, 17% were unable to work (Forsberg et al., 2005).

Furthermore, two years after beginning, residual motor and sensory deficits were still present in 55% of patients, and pain and fatigue were reported by approximately one-third of all patients. Because recovery during the second year was primarily in muscle strength, impairments may continue beyond this time (Forsberg et al., 2004; Forsberg et al., 2005).

Studies on Guillain-Barré syndrome have shown that the condition can have a negative impact on one's health, ability to work, and personal life up to three years after symptoms first appear (Bernsen et al., 1997; Bernsen et al., 2002; Forsberg et al., 2005).

In a Norwegian study, 50 healthy controls and 42 GBS patients were compared at a median of 6 years after the onset of the disease. Their objective was to examine the long-term effects of Guillain-Barré syndrome (GBS) on quality of life and the correlation between clinical factors at the time of the onset of the disease and symptoms at the time of follow-up for general health status. The study showed a negative long-term impact of GBS on patients' physical and functional health profiles, relatively independent from variables at the onset of the disease. Additionally, persistent impairment in quality of life was found (Rudolph et al., 2008)

According to Merkies et al., (1999), Interestingly, patients who reported lower functional health status and more pain tended to be more fatigued, indicating that fatigue is not a relatively independent but a physically dependent entity (Rudolph et al., 2008).

A previous study supports this theory because physical training has been shown to reduce fatigue and improve the quality of life in patients with GBS (Garssen et al., 2004; Rudolph et al., 2008).

Another prospective longitudinal research with 29 participants was undertaken in Sweden. The purpose of the study was to describe residual disability ten years following the onset of GBS. The study discovered that the facial paralysis reported in 5 people at two years was still present at ten years, 11 participants (38%) exhibited paresthesia, 6 (21%) had arm restrictions, and 15 (52%) had walking limitations. Lower extremities were more impacted than upper extremities. Physical impairment was associated with self-reported severe fatigue, higher subjective dysfunction in physical HRQL, and a more significant impact on walking ability ten years after GBS onset (Forsberg et al., 2012).

Along with physical limitations, some authors revealed a poor health-related quality of life (HRQL) and increased fatigue 3-8 years after GBS onset. Subjective HRQL and fatigue sensations appear to differ between people with residual symptoms and those fully recovered (Rudolph et al., 2008; Davidson et al., 2009; Forsberg et al., 2012).

In Turkey, a study compared the health-related quality of life (HRQOL) of control people and patients with severe Guillain-Barre syndrome (GBS) 6 months after rehabilitation. The study indicated that patients despite seeing improvements in impairments and disabilities, had little energy, were emotionally upset, and felt socially isolated. Impaired physical mobility, pain, and sleep disturbances impacted their life satisfaction (Demi˙r & KöseoĞlu, 2008).

2.2 Psychological health & QOL

A first qualitative study was conducted in the UK to explore people's experiences with GBS. The author identified several psychological factors that could support or limit recovery from GBS. In this case, a positive attitude is a helpful coping strategy that increases an individual's resolution or determination to recover. On the other hand, psychological problems, such as anxiety, depression, or sleep difficulties, were perceived to impede recovery, whether at the initial or later stages of the illness (Akanuwe et al., 2020). According to Khan et al. (2010), psychological disorders associated with GBS include anxiety, depression, post-traumatic stress disorder, insomnia and other sleep disturbances. Also, Rajabally et al. stated that psychological symptoms include experiences of sleep disturbance, anxiety or posttraumatic stress disorder, which can affect a person's daily life activities, work or social function over the years. (Siriwardena et al., 2021)

Several studies found similar findings that Psychological and social dysfunction often persist long-term, affecting health-related quality of life**. (**Bernsen et al.,1997; Darweesh et al., 2014; Siriwardena et al., 2021)

A prospective study was also conducted in Serbia and included 74 adult patients with GBS, which showed that maximal improvement in mental domains was achieved in the first three months, while physical domains continued to improve during the whole follow-up period. Bernsen et al, (2010) found that psychological distress was higher than normal three months after the onset of GBS, but it improved significantly after six months.

A prospective research of 76 GBS patients in Australia aimed to investigate factors influencing long-term health-related outcomes in GBS survivors (GBS). In comparison to the normative Australian population (13%), the study found moderate to extreme depression (18%), anxiety (22%), and stress (17%). This study also revealed that gender and age are factors associated with a higher impact and a lower degree of the current function. Moreover, women experienced higher levels of depression, anxiety, and stress, tended to stay at home more often, and had more restricted lives. The study emphasized clinical implications for GBS survivors' long-term monitoring, education, support, and counselling (and their families) (Khan et al., 2010).

A study conducted in Australia revealed certain critical social adjustment concerns during the transition period, such as the patient's perceptions of self-worth and self-image, as well as role changes within the family. Families frequently struggle to deal with the new demands of increased care needs, the inability to return to driving and work, financial restraints, marital stress, and general participation limitations (Khan & Ng, 2009). A cohort study conducted in the United Kingdom emphasized the fact that acquired neurological disability can impact certain aspects of communication, cognitive, and psychosocial function that may need to be actively addressed during the rehabilitation program, even in patients who do not have overt cognitive impairments (Alexandrescu et al., 2014).

2.3GBS Social relationship and QOL

According to Bernsen et al. (2006), more than 30% of GBS patients have had to make changes in their job, hobbies, or social activities five years after disease onset (Bernsen et al., 2002, Bernsen et al., 2005); Akanuwe et al., 2020, Darweesh et al., 2014)

A qualitative study found that social media, sharing one's GBS experience with others or peer support, support from family and friends, support from social care, and so on, facilitated recovery, with social support from family and friends also boosting coping, well-being, and quality of life. Additionally, spiritual practices or beliefs could serve as coping strategies for illness recovery. The study also revealed the stigma of using a wheelchair and the belief that having GBS has a negative effect on marital or other relationships (Akanuwe et al., 2020). Another cross-sectional study found that positive social interactions, such as family and peer support and changes at home were connected with recovery (Siriwardena et al., 2021).

A study found that there was a good functional recovery (median motor FIM score 90). However, 16% indicated a moderate to severe impact on their capacity to participate in the job, family, and social activities, while 22% significantly impacted their life satisfaction, mood, confidence, and ability to live independently (Khan et al., 2010).

The study also reveals that female GBS survivors had significantly lower life satisfaction, especially regarding social isolation, physical mobility, and energy level. Most of the female patients were housewives with lower educational backgrounds and led more limited lives (Demi˙r & KöseoĞlu, 2008)**.**

2.4GBS Environment health and QOL

A qualitative study revealed that, in the experience of GBS patients**,** supportive employers or work colleagues and in-work benefits promoted recovery. Supportive and understanding employers and work colleagues could help people return to work after their illness. Returning to a supportive working environment helped patients cope and reorder their goals, whereas early retirement due to the illness was perceived to further hinder recovery (Akanuwe et al., 2020).

Another study found that 62% of patients could return to their previous jobs after GBS, with the remainder requiring job changes to accommodate the physical demands of their roles.(Bernsen et al., 2002)Similarly, Forsberg et al. (2005) found that fewer than half (17%) of GBS patients returned to work within two years, with some only managing reduced hours or part-time employment due to muscle power loss, muscle pain, disrupted feeling, and fatigue. (Bernsen et al., 2002; (Akanuwe et al., 2020)

In a long-term study conducted in the Netherlands, 63% of GBS patients showed one or more lasting changes in psychosocial status as assessed 3–6 years after the onset by the following five elements: work, housing situation, functioning at home, lasting change for partner and leisure activities. Working stability appears to be an essential factor in the HRQOL in the GBS population (Demi˙r & KöseoĞlu, 2008).

2.5 Key Gaps of Studies

- Most of the studies have been conducted in developed countries and European countries such as Austria, Italy, Netherlands, Serbia, Sweden, and the United Kingdom, so the findings cannot be generalised worldwide.
- Majority of studies have been focused on specific populations, such as adults or those with severe GBS.
- Most studies have followed the same design and relied on clinician-reported outcomes rather than patient perspectives, which may not capture the individual's subjective experience with GBS.
- Some studies have focused on physical and psychosocial health, but other important aspects of environment and social functioning, such as economic factors, employment opportunities, and social support, were not focused appropriately.
- Many studies have focused on specific lower limb problems rather than upper limb disabilities.
- Most studies have focused on the natural history of the disease rather than interventions that can help individuals manage the symptoms of GBS or cope with the long-term impact of the disease.
- There was no detailed information about the rehabilitation of GBS in these studies.
- In Bangladesh, no study has been conducted regarding the QOL of persons with GBS in the community.

CHAPTER III: METHODOLOGY

3.1 Study Question, Aim, Objective

3.1.1 Study Question

How is the Quality of Life of persons with Guillain-Barre Syndrome (GBS) in the community of Bangladesh?

3.1.2 Aim

To evaluate the Quality of Life of persons with Guillain-Barre Syndrome (GBS) in the community of Bangladesh

3.1.3 Objective

1. To explore socio-demographic characteristics (age, gender, marital status, occupation, educational status, living area, monthly income, duration of taking rehabilitation) of persons with GBS.
2. To observe the GBS disability status.
3. To identify the overall quality of life and overall satisfaction of health level of persons with GBS.
4. To identify the association between social-demographic factors and the overall QOL of persons with GBS.
5. To identify t the association between the level of disability and overall QOL of persons with GBS.
6. To find out the most affected domain of QOL (physical, psychological, social-relation & environment) among persons with GBS.

3.2 Study Design

A cross-sectional approach of the quantitative method was used to conduct this study. This method aims to show causal explanations and relationships between variables (Bailey, 1997). Quantitative research is the process of collecting and analyzing numerical data. It can find patterns and averages, make predictions, test causal relationships, and generalize results to broader populations (Bhandari,2022).

The student researcher chose this method because this study was conducted on a selected population (GBS) at a specific period. student researcher found out the percentage of different variables and analysed numerical data of a predetermined population GBS at a specific period of a time which is similar to snap short. A cross-sectional involves collecting data from populations at a specific point in a time (Cherry,2019). It was found to be an appropriate design to determine the objectives. The study was conducted through a cross-sectional study design that represents the whole population of GBS who complete rehabilitation and return to the community. So the student researcher used this design to provide a “snapshot” of the QOL of persons with GBS who return to the community.

3.3 Study Setting and Period

3.3.1 Study Setting

Data was collected from the community of persons with GBS who received rehabilitation from CRP, Savar, Dhaka. The student researcher selected different districts in Bangladesh as study areas for collecting data.

3.3.2 Study Period

The whole study period was between April 2022 to March 2023. However, the student researcher got time for collecting data was one month, November 2022.

3.4 Study Participant

3.4.1 Study Population

The target population of this study was persons with GBS who received rehabilitation services at CRP from 2018 to 2021 and lived in the community.

3.4.2 Sampling Technique

Purposive sampling technique was used to select the sample of this study by following the inclusion criteria and exclusion criteria. Purposive sampling also known as judgmental, selective, or subjective sampling, is a form of non-probability sampling in which researchers rely on their own judgement when choosing population members to participate in their surveys (Jordan, 2021). Purposive sampling helps the researcher reach the selected sample, which mainly fulfils the research requirement and is related to the study's objective (Crossman,2020). Purposive sampling is also the most time-effective and cost-effective technique (Etikanet al.,2016).

In this study, GBS patients from a particular population were chosen through purposeful sampling to identify an individual's level of QOL. Therefore, purposive sampling was the best approach for selecting participants for this study.

3.4.3 Inclusion Criteria

- Participants who have been receiving rehabilitation from CRP and returned to the community.
- Male and female whose ages range 18 years and older
- GBS disability scale (GDS) score<5

3.4.4 Exclusion Criteria

- Participants who have associated problems, e.g. cognitive or mental impairment.
- Participants who have hearing and speech impairment restricted meaningful conversation over the phone.

3.4.5 Sample Size

Sampling procedure for a cross-sectional study done by following equation (Hannan, 2016).

$$\boldsymbol{n = \frac{Z^2pq}{d^2}}$$

Here, n = required sample size. Z = confidence level. p = prevalence of person with GBS in Bangladesh. q= (1-p) and d= margin of error.

As there was no data has been found about the prevalence of persons with GBS in Bangladesh. The researcher used p= 50% prevalence (0.5) & if 95% confidence interval z= 1.96 (confidence level), q= (1-0.5) = 0.5 & d=0.05%.

According to this formula: $\boldsymbol{n = \frac{Z^2pq}{d^2}}$

= 384 participants

If the student researcher used this standard measurement to find out the sample size, it would be 384. Though it is academic research, the data collection period was one month. Within one month, 384 participants' data collection was practically not possible. For this reason, the student researcher could collect 101 samples maintataing inclusion and exclusion criteria for this study.

3.5 Ethical Considerations

3.5.1Consent Form IRB

At first ethical clearance has been taken from Institutional Ethical Review Board by presenting the purpose of the study through the Department of Occupational Therapy of Bangladesh Health Professions Institute (BHPI). After receiving the clearance (CRP/BHPI/IRB/09/22/628) from the board, the student researcher continued the process. The student researcher also took permission from the Occupational Therapy outpatient department of CRP before taking the participant's information. For using the Bangla Version of the WHOQOL-BREF questionnaire, the student researcher also took permission from the responsible author.

3.5.2 Informed Consent

Before conducting the data collection, the student researcher read out the information sheet where the title of the study, aim, objective and purpose are mentioned clearly. After understanding the purpose of the study, those who showed a willingness to participate only their data were collected. Verbal consent was taken from the participants as they were interviewed over the phone. And those who rejected their participation in the study, the student researcher thanked them for giving their time.

3.5.3 Unequal Relationship

The student researcher did not know those participants personally. So there was no unequal or power relationship between the student researcher and the participants.

3.5.4 Risk and Beneficence

The participants did not have any risk and did not get any beneficence from this study. The interview session was conducted over the phone, so participants did not need to come anywhere. They easily participated in this study by staying at their home.

3.5.5 Right of Refused to participant or withdraw

Participants had the right to leave or withdraw from the study whenever they wanted, and the student researcher was accountable to the participant to answer any study-related question.

3.5.6 Confidentiality

The information provided by the participants was confidential. It was used anonymously for education, discussion with the supervisor, or publication.

3.6 Data Collection

3.6.1 Participant Recruitment Process

At first student researcher collected a database of the GBS patients from the CRP out-patient unit of OT Department. Then listed all discharged GBS patients’ basic information, including their name, age, year of discharge, contact numbers.

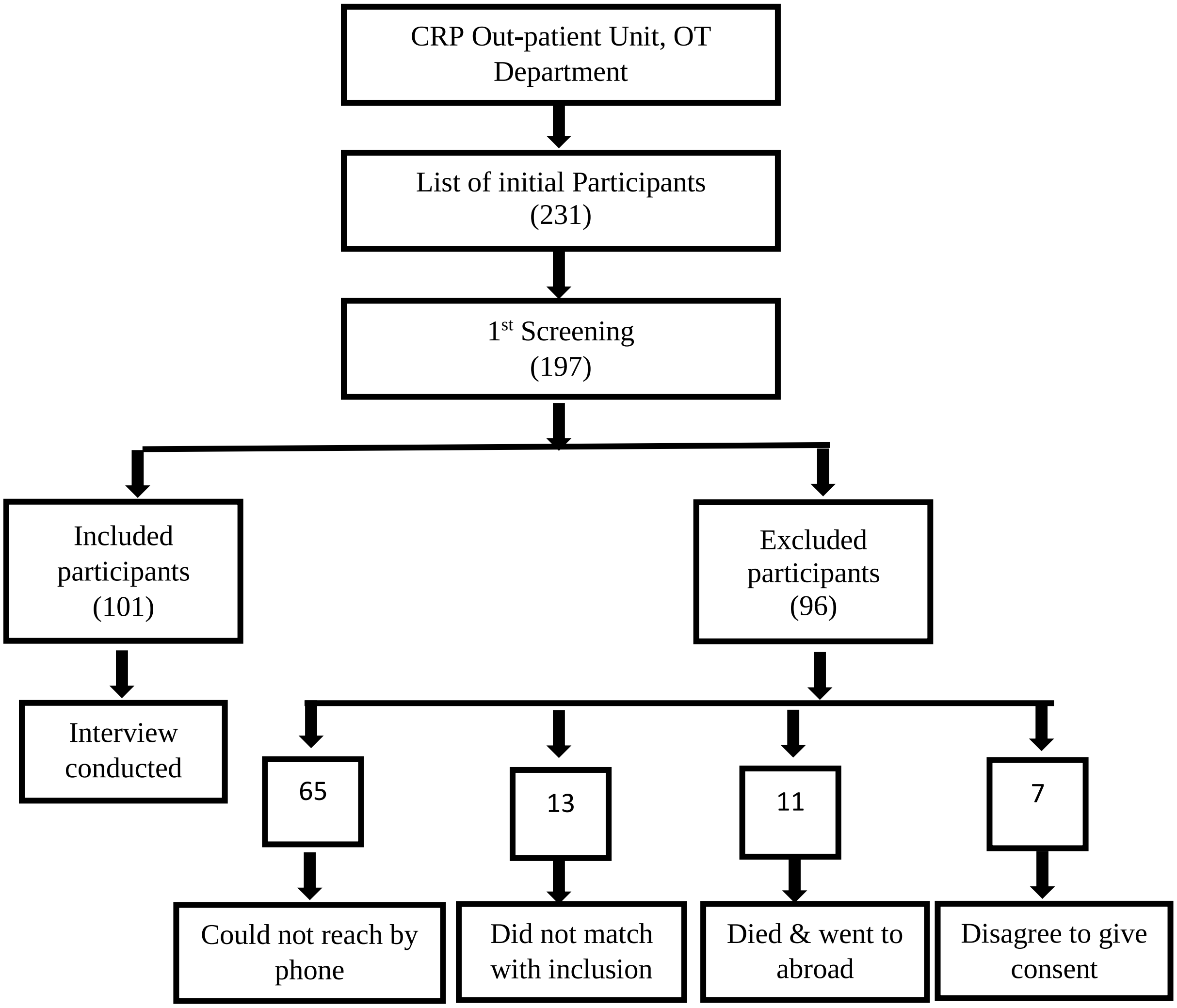

Figure 2: Overview of the participants' recruitment process.

The entire list of initial participants was 231 people who took services from CRP Savar in 2018 to 2021. Among them, 197 were selected through the initial screening, which was based on age level and missing phone numbers from the patients' documents. Then phone call was made. Sixty-five participants did not pick up the phone or their phone numbers were invalid. The decision was made after three attempts at the phone call. 13 were not matched with inclusion criteria,11 died or went abroad and 7 were not interested in participating in the study. Of those 197 GBS patients, 101 were selected as final participants for this study.

3.6.2 Data Collection Method

A telephone survey with a Close-ended questionnaire was used to collect the data from the participants. Participants were communicated over the phone because the face-to-face interview was not possible for student researcher as the time duration of data collection was short and participants were from different districts of Bangladesh. So, a telephone survey helped to collect data within a short time from different districts (Toole et al,2008).

Nowadays, phone-call interviews have become more interesting for collecting information. Because by this interview a large number of people can be conducted, information can be collected quickly, and mobile phone is available to all. For this, a telephone interview is fit for this study from the view of the student researcher.

At first, the researcher took permission from the Occupational therapy Department and Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI) and collected the patient’s details. For conducting a telephone interview, at first, the student researcher would verbally present the details of the study, such as the study's aim, objectives and purpose, then explain the rights, roles, benefits and importance of the written consent form descriptively to participants before collecting data. Then they could ask questions about the study and whether they were interested in participating. Verbal, recorded consent of the participant was taken as evidence. Once consent was received, the student researcher read the instructions of the questionnaires and collected data. The interview was conducted in Bengali, and the interview call was taped on a cell phone by call recording. The mean time of the interview was 18~25 minutes.

3.6.3 Data collection instrument

- Basic demographic information form
- Consent form.
- Standardized Bangla questionnaire of WHOQOL-BRFE
- GBS disability score (GDS).
- Mobile with recorder
- Airtel sim card
- Paper, pen and pencil.

3.6.3.1 WHOQOL-BREF

For identifying the quality of life among GBS the person in the community, a valid questionnaire called the World Health Organization Quality of Life (WHOQOL-BREF) short version of WHOQOL-100 was used by the student researcher. It comprises 26 questions that contain two items about the overall quality of life and general health, and the 24 items contain four domains: Physical health with 7 items, Psychological health with 6 items, Social relationship with three items, and Environmental health with 8 items. Each item of WHOQOL-BREF is scored from 1-5. The mean score of each item is needed to calculate the domain score. When we calculate all domain scores by simple algebraic sum, we can find the raw score. The raw score is essential because the raw score highlights the domain’s findings after getting the raw score, converting the raw score into the transformed score. The first transformation method converts scores to a range between 4-20, comparable with the WHOQOL-100, and the second transformation method converts domain scores to a 0-100 scale according to guidelines. Domain scores are scaled positively (i.e., a higher score denotes higher quality of life). (WHO, *Programme on Mental Health: WHOQOL user Manual* 1998)

3.6.3.2 GBS disability scale (GDS)

The Guillain-Barre syndrome disability score (GDS) is a widely accepted scoring system to assess the functional status of patients with GBS. It was mainly described by Hughes et al. (1978), and since then, various repeating has appeared in the literature. The Criteria requires that measure the patient's level of disability using a scale from 0 to 6. (Van Koningsveld et al., 2007).

3.7 Data Management and Analysis

After completing the initial data collection, every answer was cross checked to find out mistakes or unclear information. Then all data were analysed using Statistical Package for the Social Sciences (SPSS) statistics version 25.0. Microsoft Excel worksheet 19 was used to create most of the graph and charts. Then Descriptive analysis was used to analyses quantitative data. In the descriptive part, in the case of parametric data the central tendency and the measure of dispersion was presented through mean and standard deviation. The categorical data was presented as frequency and percentage of proportion through different visualization tool such as bar graph.

To show the association between overall QOL and demographic variables, GBS disability score (GDS), the Chi-square analysis using Fisher's exact test was selected as appropriate. While conducting chi-squire test more than 20% cells have expected count less than 5 therefore the fisher exact significant value was considered. Finally, the student researcher fulfilled the objectives and showed the result.

3.8 Quality Control and Quality Assurance

The WHOQOL-BREF is a reliable and valid questionnaire. It is good at finding out the quality of life in long-lasting diseases or disabilities that affect on person’s everyday life. On the other hand, the WHOQOL-BREF questionnaire was not translated manually; the authority has shared a ready-made translated Bangla version & previously, this Bangla version was used successfully.

The student researcher conducted the study in a rigorous manner and with trustworthiness. Experienced supervisor and teachers supervise all of the steps in the research process. During the interview, the student researcher did not try to influence the process by his biases but valued their perspectives. Data was collected carefully & the student researcher would accept the participants' answers whether they would deliver.

CHAPTER IV: RESULT

This chapter provides statistical analysis in a systematic way and interpretation of analyzed findings with the aim and objectives of the study. The chapter contains the study findings in tables and figures focusing on the socio-demographic information, GBS disability status, the overall of QOL and overall satisfaction of health of persons with GBS, the association between socio-demographic factors and overall QOL, GBS disability status. And the respondent's QOL domain score (physical, psychological health, social relationship and environment health).

4.1 Socio-demographic Characteristics of GBS

Table 1 socio-demographic characteristics

Variable	**Category**	**Frequency (n=101)**	**Percent (%)**
Gender			
	Male	82	81.2%
	Female	19	18.8%
Age			
	18-30	36	35.6%
	31-43	33	32.7%
	44-56	25	24.8%
	57-69	7	6.9%
Mean age	36.69 SD (±1.2)		
Marital status			
	Married	71	70.3%
	Unmarried	27	26.7%
	Separated	2	2.0%
	Divorced	1	1.0%
Occupation			
	Housewife	12	11.9%
	Student	21	20.8%
	Service holder	34	33.7%
	Business	19	18.8%

	Unemployed	13	12.9%
	Others	2	2.0%
Educational background	Illiterate	3	3.0%
	Primary	12	11.9%
	SSC	20	19.8%
	HSC	23	22.8%
	Bachelor	31	30.7%
	Masters or above	12	11.9%
Living area			
	Rural	34	33.7%
	Urban	39	38.6%
	Semi-urban	28	27.7%
Monthly income			
	No income	41	40.6%
	1000-10,000	14	13.9%
	11,000-20,000	18	17.8%
	21,000-50,000	19	18.8%
	More than 50,000	9	8.9%
Duration of taking rehabilitation	1-5months	43	42.6%
	6-11months	33	32.7%
	More than 1year	25	24.8%
Total		100	100.0%

Table 1 shows an overview of socio-demographic information of persons with GBS, including the participant's gender, age, marital status, occupation, educational background, living area, monthly income, and duration of taking rehabilitation. The total of participants in the study was 101; among them, the majority of participants, 81.2% (n=82) were male and 18.8% (n=19) were female. These data appoint a significant difference, indicating that males are significantly at higher risk than females. The participants were between 18 to 67 years old and the mean age in the group was 36.69 years. Among them, the majority of participants were from the 18 to 30 age group, about 35.6% (n=36) and then the second highest participants were from the 31 to 43 age group about 32.7% (n=33). The other participants were from these two ages groups; the 44 to 56 age group, about 24.8% (n=25) and the 57 to 69 age group about 6.9% (n=7).

Among 101 participants, 70.3% (n=71) were married, 26.7% (n=27) were unmarried and 2% were separated and 1% were divorced. The findings showed that the majority of the participants, 33.7% (n=34), were service holders after rehabilitation, the second highest participants were students 20.8% (n=21) and continuing their studies, 18.8% (n=19) were running their business and 11.9% (n=12) were housewife, 12.9% (n=13) were unemployed, and 2% were from other occupations.

As for education, the majority 30.7% (n=31) were highly educated; they graduated or continued their degree, which is a positive finding. About 3% were illiterate, 11.9% (n=12) were up to primary completed, 22.8% (n=23) were up to secondary completed and about 11.9% were continued or completed their Masters. The maximum number of participants, 38.9% (n=39) lived in urban areas. The remaining participants, 33.7%, lived in rural areas, and 27.7% (n=28) lived in semi-urban areas.

Regarding income, most of the participants, about 40.6% (n=41) had no income, 13.9% (n=14) had little income, 17.8% (n=18) had income above 10,000 taka and 18.8% (n=19) have income above 20,000 takas; only 8.9% (n=9) has above 50,000taka. Many participants were not interested in talking about their income.

Approximately 42.6 % (n=43) took rehabilitation for almost 1-5 months, 32.7% (n=33) participants took 6-11months, and 24.8% (n=25) participants took rehabilitation services for more than 1 year.

4.2 The Rate of GBS Persons Disability Status According to GBS Disability Scale

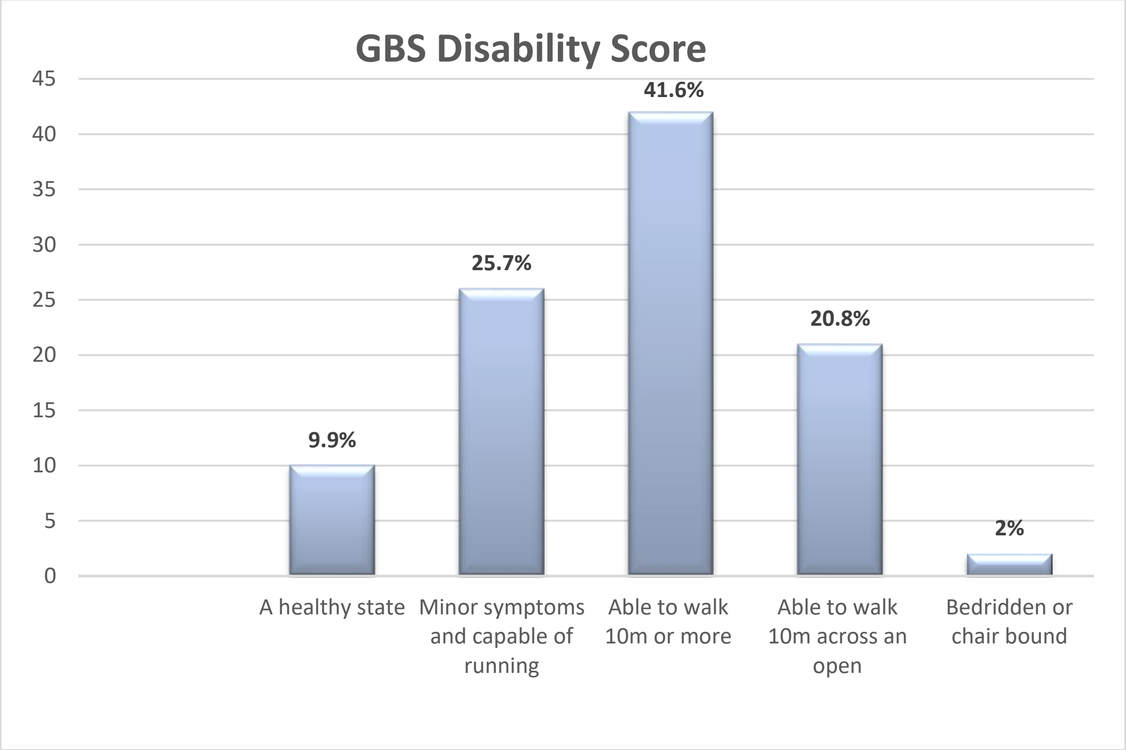

Figure 3: GBS disability Status.

Figure 3 shows GBS disability status of this study's participants according to GDS, about 9.9% (n=10) participants were in a healthy state, 25.7% (n=26) participants were within minor symptoms and capable running, 41.6% (n=42) participants were within able to walk 10m or more without assistance but unable to run, 20.8% (n=21) participants were within able to walk 10m across an open space with help, 2% (n=2) participants were within bedridden or chair bound. This condition needs long-term rehabilitation for physical wellbeing, which was indicated here.

4.3. Rate of Overall Quality of Life and Overall Health Status

Table 2 Overall Quality of life and health status of participants

Variable	Category	Frequency (n=101)	Percent (%)	Mean score
Overall QOL	Very poor	4	4.0 %	3.09
	Poor	25	24.8%	
	Neither poor nor good	40	39.6%	
	Good	22	21.8%	
	Very good	10	9.9%	
Overall health status	Very dissatisfied	2	2.0%	3.26
	Dissatisfied	15	14.9%	
	Neither satisfied nor dissatisfied	44	43.6%	
	Satisfied	35	34.7%	
	Very satisfied	5	5.0%	

Table 2 shows the findings of the overall quality of life and overall health status of the persons with GBS in Bangladesh. In the case of overall quality of life majority of the participants, 39.6% (n=40) had neither poor nor good QOL. 24.8% (n=25) had poor quality of life, 21.8% (n=22) had good quality of life, 9.9% (n=10) had very good quality of life and only 4% had very poor QOL. On the other hand, in the overall health status the maximum number of participants, 43.6% (n=44) were neither satisfied nor dissatisfied. Over 34% were satisfied with their current health condition.14.9% of participants were dissatisfied with their health. Only 2% were very dissatisfied and 5% were very satisfied.

So, the overall QOL was neither poor nor good; the mean score of the overall QOL was 3.09 indicating that as well as the overall health status of GBS person was also neither poor or nor good; the mean score of overall health status was 3.26. According to WHOQOL-BREF scale instruction, a higher score denotes a higher QOL. The findings showed that the overall satisfaction level of health was better than the overall QOL in this group of GBS population.

4.4 The Association of Overall QOL with Demographic Factors (Age, Gender, Education Level, Living Area, Marital Status, Occupation, Monthly Income and Duration of Taking Rehabilitation).

Table 3 Association between overall QOL and demographic factors:

Demographic Variables	**Overall QOL**					**Fisher Exact Sig. value**	**P-Value**
	Very poor	**Poor**	**Neither poor nor good**	**Good**	**Very good**		
	Percent(%)						
Age							
18-30	2.8%	16.7%	50%	19.4%	11.1%	15.520	.214
31-43	-	30.3%	30.3%	24.2%	15.2%		
44-56	8%	20%	40%	28%	4%		
57-69	14.3%	57.1%	28.6%	-	-		
Gender							
Male	3.7%	23.2%	40.2%	22%	11%	1.100	.894
Female	5.3%	31.6%	36.8%	21.1%	5.3%		
Marital status							
Married	2.8%	29.6%	32.4%	25.4%	9.9%	15.507	.170
Unmarried	3.7%	14.8%	55.6%	14.8%	11.1%		
Separated	50%	-	50%	-	-		
Divorced	-	-	100%	-	-		
Occupation							
Housewife	-	33.3%	41.7%	16.7%	8.3%	42.468	**.002**
Student	-	14.3%	61.9%	9.5%	14.3%		
Service holder	2.9%	17.6%	38.2%	32.4%	8.8%		
Business	-	21.1%	31.6%	36.8%	10.5%		
Unemployed	23.1%	61.5%	15.4%	-	-		
Others	-	-	50%	-	50%		
Educational background							

Illiterate	-	66.7%	33.3%	-	-	12.484	.926
Primary	8.3%	33.3%	41.7%	8.3%	8.3%		
SSC	-	20%	40%	30%	10%		
HSC	4.3%	21.7%	39.1%	21.7%	13%		
Bachelor	-	22.6%	41.9%	25.8%	9.7%		
Masters or above	16.7%	25%	33.3%	16.7%	8.3%		
Living area							
Rural	5.9%	23.5%	41.2%	20.6%	8.8%	9.836	.248
Urban	5.1%	12.8%	41%	25.6%	15.4%		
Semi-urban	-	42.9%	35.7%	17.9%	3.6%		
Monthly income							
No income	-	36.6%	41.5%	4.9%	7.3%	25.887	**.039**
1000-10,000	-	7.1%	50%	28.6%	14.3%		
11,000-20,000	-	27.8%	44.4%	27.8%	-		
21,000-50,000	-	15.8%	26.3%	42.1%	15.8%		
More than 50,000	-	11.1%	33.3%	33.3%	22.2%		
Duration of taking rehabilitation							
1-5months	2.3%	23.3%	39.5%	18.6%	16.3%	10.615	.224
6-11months	3%	15.2%	45.5%	27.3%	9.1%		
More than 1year	8%	40%	32%	20%	-		

*Level of significance ($p<0.05$), * fisher exact significant value*

The association between overall QOL and demographic factors is presented in table 4. There is a significant association between QOL and the occupation of the people with GBS and the *P*-value is .002. Additionally, most participants were engaged in different occupations. This is noticeable that participants who engaged in paid occupations (32.4% service holders, 36.8% business) have better QOL than unpaid only 16.7% housewives and 14.3% students. In monthly income, those with a high income lead a good QOL, and who have no income, 36.6% have poor and 41.5% lead neither poor nor good QOL. (P>.039) indicates that there is a significant association between overall QOL and income. This may be because these demographic factors have a greater impact on a person's QOL. On the other hand, there is no association between overall QOL and age (P<.214), yet there is a remarkable finding that adult age groups have good QOL than older age groups. In gender comparatively, males 22% lead very good QOL than females 21.1% and there has no association between gender and overall QOL (P<.894). This table also shows that the majority of participants are well educated, but surprisingly maximum of them lead medium QOL 40% SSC, 39.1% HSC, 41.9% bachelor, and 33.3% master's degree completed participants have neither poor nor good QOL. And 66.7% of illiterate participants lead poor QOL. (P<.926), indicates that educational background and overall QOL have no significant association. (P<.170) indicates that there is no significant association between marital status and overall QOL.in living area (P<.248) also has no significant association. Duration of taking rehabilitation 39.5 % have neither poor nor good QOL who take rehabilitation 1 to 5 months, 45% have neither poor nor good QOL who take rehabilitation 6 to 11 months, surprisingly 40% have poor QOL,32% have neither poor nor good QoL, only 20% has good QOL who took rehabilitation more than 1year. (P<.224) indicates that there is no association between overall QOL and duration of taking rehabilitation. This result shows that age, gender, marital status, educational background, and living area duration of rehabilitation have no relation with overall QOL of these participants.

4.5 The Association Between Overall Quality of Life and GBS Disability Score Category

Table 4 association between overall QOL and GDS

GBS disability Score	Overall QOL					Fisher Exact Sig. value	*P*-Value
	Very poor	Poor	Neither poor nor good	Good	Very good		
	Percent (%)						
0=A healthy state	-	-	20%	20%	60%	47.346	**0.00**
1 = minor symptoms and capable of running	3.8%	3.8%	69.2%	15.4%	7.7%		
2 = able to walk 10m or more without assistance but unable to run	2.4%	28.6%	31%	33.3%	4.8%		
3 = able to walk 10m across an open space with help	4.8%	52.4%	33.3%	9.5%	-		
4 = bedridden or chair bound	50%	50%	-	-	-		

**fisher exact significant value*

Table 4 result shows the association between overall QOL and GDS categories. This association shows a significant finding that among 101 participants, 10 participants had a healthy state; among them 20% had neither poor nor good, 20% had good, and 60% had very good QOL. 26 participants experienced minor symptoms and were able to run among them 3.8% had very poor and 3.8% had poor, a large proportion about 69.2% had neither poor nor good, 15.4% had good and 7.7% had very good QOL. The majority about 42 participants, were able to walk10m or more without assistance but unable to run. Among them 2.4% had very poor life, 28.6% had poor, 31% had neither poor nor good, 33.3% had good and 4.8% had very good QOL.21 participants were able to walk 10m across an open space with help among them 4.8% had very poor life, a large number 52.4% had poor QOL, 33.3% had neither poor nor good, 9.5% had good QOL and among the none had very good QOL. Only 2 participants lead bedridden or chair-bound life; 101 participants had very poor and poor QOL. These findings indicated that disability status greatly impacts these group's quality of Life of these group. The *p*-value (0.00) indicated a strong relation between QOL and GBS disability score category.

4.6 Most Affected Domain of QOL Domains (Physical, Psychological, Social Relationships, Environmental) among GBS Persons.

Table 5 Quality of life domains

Domain	Mean	± SD
Physical health	12.91	± 2.728
Psychological health	13.45	± 2.648
Social relationship	14.91	± 1.924
Environmental	13.48	± 1.753

SD=standard deviation, WHOQOL-BREF mean range 4-20

Table 5 shows the most affected domain among GBS persons. The WHOQOL-BREF domains displayed each domain mean score social relationships domain obtained the highest score, 14.91 ± 1.924. The physical health domain acquired the lowest score among all the domains, 12.91 ± 2.728. The Environmental domain score is 13.48 ± 1.753, and the psychological health obtains 13.45 ± 2.648. The study's overall findings about the quality of life of persons with GBS in Bangladesh estimated that patients who lived in the community were more satisfied with their social relationships than environmentally, psychologically and physically. So, the findings revealed that most GBS persons who participated in this study indicated that physical and psychological domains were the most affected domains.

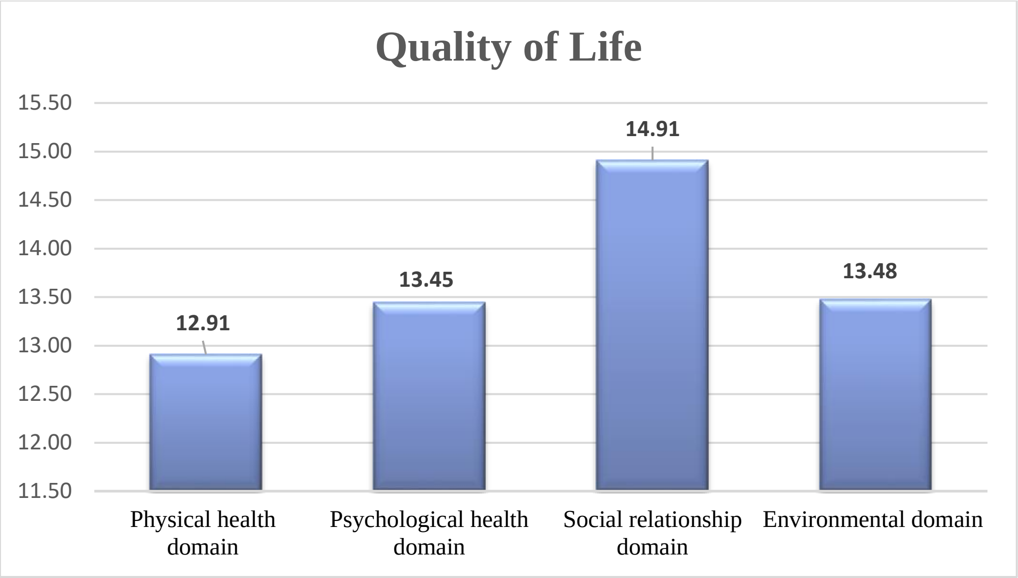

Figure 4: Most affected domain of QoL among GBS persons.

CHAPTER V: DISCUSSION

This study aimed to identify the Quality of Life of persons with GBS in the community of Bangladesh. It was conducted with 101 participants with a self-administered questionnaire. It was a telephone survey with a response rate of 51.3%.

This study shows that male participants were 81.2% and female participants were 18.8%. Males were more affected than females which was exactly similar to previous studies. They also claimed that men were significantly at higher risk than women. (Malek & Salameh, 2019; Sulli et al., 2021). In this study, the mean age at interview of the person with GBS was 36.69 years which was not matched with previous studies 52.5 years (Djordjevic et al., 2019) and 50 years (Forsberg et al., 2014). But nearly matched with previous studies where other authors found the most affected age range as 30 to 50 years (Khan et al., 2010; Akanuwe et al., 2020). It is difficult to explain the reason behind this inconsistency. However, it can result from age variation for different geographical locations of the world. The maximum number of participants were married about 70%, which is related to age because participants were adults, which also matches previous studies (Forsberg et al., 2004; Khan et al., 2010). Another important socio-demographic characteristic was the occupation of pwGBS in this study. Surprisingly more than 33.7% of participants were service holders and 18.8% and 20.8% were continuing their business and study, which is directly associated with QOL the reason was financial support and self-esteem. Other authors also found that occupational factors greatly impacted QOL (Akanuwe et al., 2020) and many participants have changed jobs due to GBS (Demi̇r & KöseoǦlu, 2008) which was consistent with this study.

Interestingly, in this study most of the participants were educated 30.7% were continuing their Bachelor and 11.9% were completed their master's degrees and this study shows a good number of participants' current occupation is "student". This finding is also consistent with other studies (Forsberg et al., 2005). A possible explanation for this could be a higher level of education associated with employment and quality of life (Akanuwe et al., 2020).it could be further research on the association between employment and education in Bangladesh. In this study, many participants about 41.6% had no personal income. This study found that 20.8% were students and 12.9% were unemployed. There was a possibility that they had no personal income and depend on family at the same time less social participation and low confidence to live independently, which could have negatively impacted their QoL. In a previous study,62% of patients could return to their former employment post-GBS with alteration of work role or managing reduced hours due to fatigue and loss of muscle power (Bernsen et al., 2002) which was consistent with this study's findings. Unemployment and retirement resulted in financial burdens. (Akanuwe et al., 2020)

Another socio-demographic characteristic shows that the duration of taking rehabilitation of participants about 44.6% took 1 to 5 months most of them not complete their rehabilitation due to high cost of treatment, 32.7% took 6 to 11 months and 24.8% took more than one year which is consistent with previous study findings as GBS patients had the most extended length of stay 80.0 days in the hospital and taking rehabilitation 12.3 months (Alexandrescu et al., 2014). These findings were according to the first objective characteristic of socio-demographic factors.

The study's second objective was to observe the GBS disability status pwGBS in the community. The study reveals an interesting finding about GBS persons only 9.9% a healthy state, and 25% had minor symptoms and were capable of running, the majority of participants about 41.6%, were able to walk 10m or more without assistance but were unable to run and 21% were able to walk 10m across an open space with help which is not matched with a previous study 77% of GBS patients had severe disability (GDS>2) in the acute phase and not after that only 19% patients at month 6 (Djordjevic et al., 2019) and 14% had moderately to severely residual disability at 10 years after onset, define as GDS>2 and 50% had minor symptoms such as paresthesia. Surprisingly the majority of GBS persons including those who stated themselves as healthy claimed that they had calf muscle shortening problems in winter the most and in summer at night and also had fatigue in this study. In one word, these patients were improved from the physician’s perspective which was not confirmed by patients’ own opinion (Djordjevic et al., 2019).

The third objective of the study was to identify the overall QOL and overall health status. This study shows that the mean score of the overall QOL was 3.09 and the mean score of overall health status was 3.26. So, the findings indicated that the overall satisfaction level of health was better than the overall QOL which was consistent with previous studies that found that even after physically recovering their perception of their quality of life remained negative (Berisavac et al., 2020; Siriwardena et al., 2021). In this study, the maximum participants about 40% of perceptions were neither poor nor good in overall QOL, 21% had good perceptions and 24.8% had poor perceptions on. On the other hand, 43.6% are neither satisfied nor dissatisfied about health status, 34.7% are satisfied and 14.9% are dissatisfied.

The fourth objective of this study was to identify the association between overall QOL and demographic factors .it was interesting that the quality of life was associated with occupation (P=.002) and monthly income (p=.039).

In this study, occupation shows the association with QOL about 38.2% were service holders, 61.9% were students and 41.7% were housewives, 31.6% were continuing their business and their QOL was neither poor nor poor. This finding was noticeable that among students most of their QOL were poor about 15% and only 9.5% had good QOL. The possible reason is that they had a gap in their student life and depend on family financially. On the other hand, the businessmen were comparatively happier with their QOL. Among homemakers a large number 33.3% lead a poor QOL which was consistent with previous studies as women were lead more restricted life than men (Akanuwe et al., 2020, Laparidou et al., 2021). On the other hand,12% were unemployment, and most of them 61.5% lead a poor QOL and 23.1% lead a very poor life which is also consistent with previous study findings (Akanuwe et al., 2020, Laparidou et al., 2021, Demi˙r & KöseoĞlu, 2008). This study shows that other socio-demographic factors age, sex, educational background, marital status and duration of rehabilitation were not associated with overall quality life, which was not consistent with previous studies mentioned association among them. The possible reason were maybe different geographical location or different coping strategies.

The fifth objective of my study was to identify the association between overall quality of life and GBS disability score which shows a strong significant association between overall QOL and GBS disability score. The QOL was influenced by the level of disability which was consistent with previous studies (Berisavac et al., 2020).

The last objective of this study is to identify the most affected domain of QOL domains among pwGBS. This study shows the findings that the physical health domain acquired the least score among all the domains which is 12.91 ± 2.728 which is partially consistent with previous studies because they found that GBS person physically recovered but they had residual problems and most participants (64%) made a complete functional recovery, while others (27%) were independent with only minor limitations in daily activities (Bersano et al 2005).The possible reason for this inconsistency is that developed counties have more facilities than lower or middle economic countries. The QOL was found poor in the psychological health domain which is consistent with previous study as they found anxiety, depression, stress, sleep disturbance was associated factors after years and affecting QOL (Bernsen et al., 1997; Darweesh et al., 2014; Siriwardena et al., 2021). The social relationship domain score was highest compared to other domains, which is inconsistent finding from previous studies because those research were conducted in different countries and their culture and social aspects are different (Laparidou et al., 2021). And in Bangladesh person with disabilities faces many difficulties for their environmental barriers and that was very common in our country. This study also found a poor finding in the environmental health domain.

Many factors were not included in this study and many were included but none of these factors are significantly correlated in our study as *p*-values showed that findings. Behind many reasons one might be for study design and data collection instruction as according to WHOQOL-BREF the participants answered all questions about their immediate last two weeks' feelings and experience. So, if these participants shared their whole experience, the result would be more clear and more effective.

CHAPTER VI: CONCLUSION

6.1 Strengths and limitations

6.1.1 Strengths

- This study was the first about the Quality of Life among GBS persons in the community of Bangladesh, so this study added the current knowledge about community persons with GBS.
- The bangle version of the WHOQOL-BREF tool was already validated, the author provided permission to use the tool.
- The student researcher could have a wide geographical variation of participants, as it was a telephone survey.
- The study was time effective.

6.1.2 Limitations

- This study was conducted with a small sample size (n=101), which was insufficient to generalise the findings.
- The student researcher got only 1 month for data collection which was very limited for the student researcher.
- The telephone response rate was low which was 51.3 %.
- Multiple invalid phone numbers in the database restricted reaching the overall population. (n=65)
- Some participants did not pick up the calls despite multiple attempts made.
- Building rapport with the participants was difficult as it was a telephone survey.

6.2Practice Implication

Rehabilitation Based

- Occupational therapists and other practitioners working with GBS patients should develop the current rehabilitation practices. Ensuring that individuals have the opportunity to access ongoing care, follow-up appointments and long term-rehabilitation.
- Healthcare providers should work with individuals to manage their symptoms effectively, in a multidisciplinary approach using a combination of medication, rehabilitation, and self-management strategies.

Community Based

- healthcare providers specially Occupational therapists should be community advocates for patients in both aspects of physical and mental impairments. Healthcare providers should advocate for policies and programmes that support the needs of individuals with GBS and their families.
- Providing employment support, such as job training, reasonable accommodations, and workplace modifications, can help individuals with GBS maintain employment and improve their quality of life.

6.2.1Recommendations

- For further research, the number of participants should be increased to represent the result as generalized.
- A telephone survey method was used to collect data from the community as a result, all the answers were subjective. So that might influence the findings of the research, for further research face-to-face survey method is appropriate.
- Qualitative study is recommended to explore the depth.
- It is necessary to give more attention to GBS patients' anxiety and depression and studies focusing on the psychological aspect are required.

6.3Conclusion

The purpose of the study was to evaluate the quality of Life of persons with Guillain-Barre Syndrome (GBS) in the community of Bangladesh. This is the first study on QOL among this population group in the community of Bangladesh. This study contributes to understanding this population's socio-demographic characteristics and current status. The study has found overall health status among this population is good, but overall QOL is poor. The research also found a strong association between physical disability level and overall QOL. Also, occupation and monthly income are also associated with overall QOL. Maintaining a good score in all four domains is essential for better QOL. So, the rehabilitation should focus more on community-based rehabilitation as it has many residual problems which seriously affect the QOL. Also, focus on mental health issues should be considered among this population.

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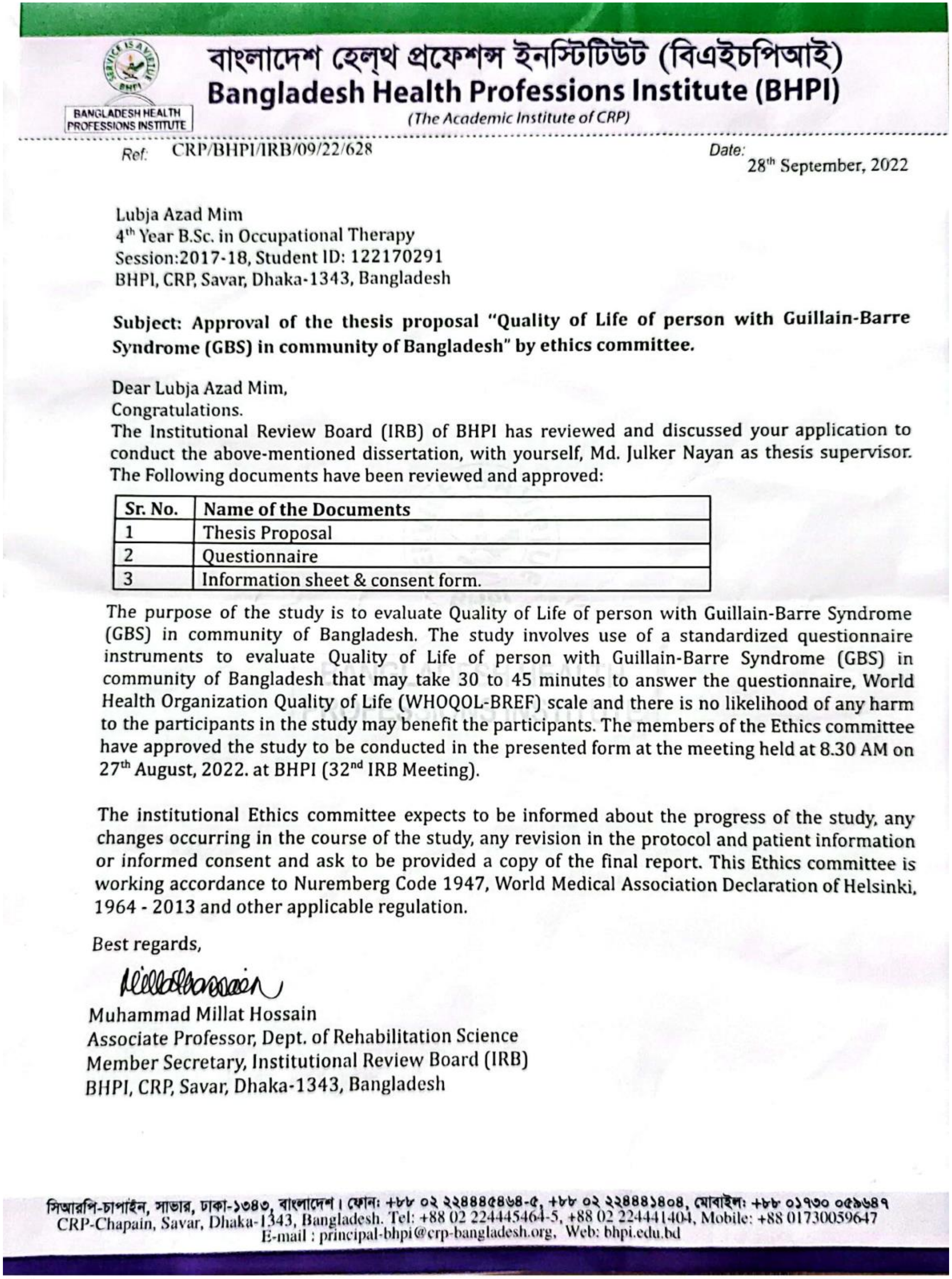
APPENDIX

Appendix 1



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

Ref: CRP/BHPI/IRB/09/22/628

Date: 28th September, 2022

Lubja Azad Mim
4th Year B.Sc. in Occupational Therapy
Session:2017-18, Student ID: 122170291
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "Quality of Life of person with Guillain-Barre Syndrome (GBS) in community of Bangladesh" by ethics committee.

Dear Lubja Azad Mim,
Congratulations.
The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, Md. Julker Nayan as thesis supervisor. The Following documents have been reviewed and approved:

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

The purpose of the study is to evaluate Quality of Life of person with Guillain-Barre Syndrome (GBS) in community of Bangladesh. The study involves use of a standardized questionnaire instruments to evaluate Quality of Life of person with Guillain-Barre Syndrome (GBS) in community of Bangladesh that may take 30 to 45 minutes to answer the questionnaire, World Health Organization Quality of Life (WHOQOL-BREF) scale and there is no likelihood of any harm to the participants in the study may benefit 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 27th August, 2022. at BHPI (32nd IRB Meeting).

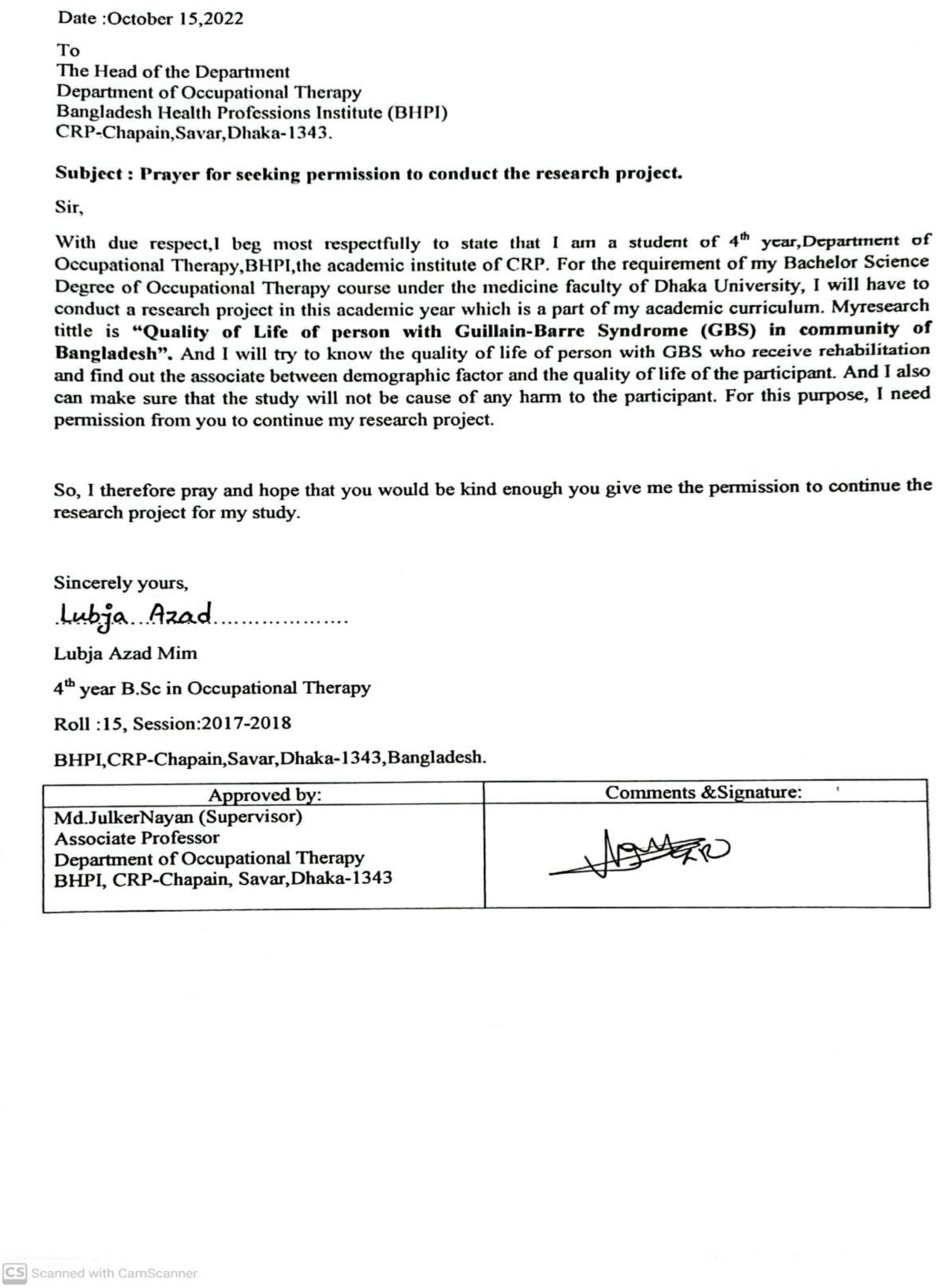
The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance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

Best regards,

Muhammad Millat Hossain
Associate Professor, Dept. of Rehabilitation Science
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

Appendix 2



Date :October 15,2022

To
The Head of the Department
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP-Chapain,Savar,Dhaka-1343.

Subject : Prayer for seeking permission to conduct the research project.

Sir,

With due respect,I beg most respectfully to state that I am a student of 4th year,Department of Occupational Therapy,BHPI,the academic institute of CRP. For the requirement of my Bachelor Science Degree of Occupational Therapy course under the medicine faculty of Dhaka University, I will have to conduct a research project in this academic year which is a part of my academic curriculum. Myresearch tittle is **"Quality of Life of person with Guillain-Barre Syndrome (GBS) in community of Bangladesh".** And I will try to know the quality of life of person with GBS who receive rehabilitation and find out the associate between demographic factor and the quality of life of the participant. And I also can make sure that the study will not be cause of any harm to the participant. For this purpose, I need permission from you to continue my research project.

So, I therefore pray and hope that you would be kind enough you give me the permission to continue the research project for my study.

Sincerely yours,

Lubja Azad

Lubja Azad Mim

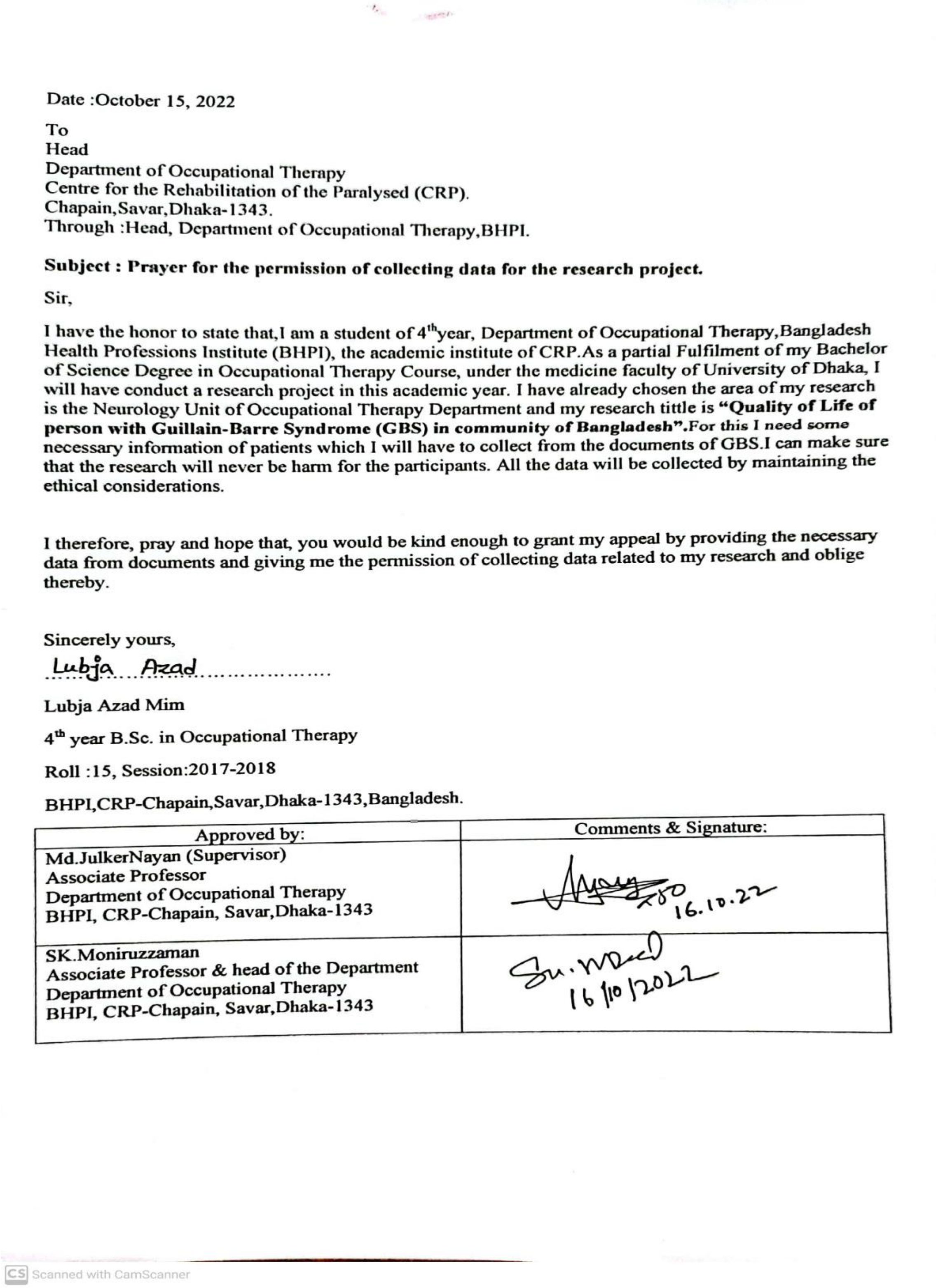
4th year B.Sc in Occupational Therapy

Roll :15, Session:2017-2018

BHPI,CRP-Chapain,Savar,Dhaka-1343,Bangladesh.

Approved by:	Comments &Signature:
Md.JulkerNayan (Supervisor) Associate Professor Department of Occupational Therapy BHPI, CRP-Chapain, Savar,Dhaka-1343	

Appendix 3



Date :October 15, 2022

To
Head
Department of Occupational Therapy
Centre for the Rehabilitation of the Paralysed (CRP).
Chapain,Savar,Dhaka-1343.
Through :Head, Department of Occupational Therapy,BHPI.

Subject : Prayer for the permission of collecting data for the research project.

Sir,

I have the honor to state that,I am a student of 4thyear, Department of Occupational Therapy,Bangladesh Health Professions Institute (BHPI), the academic institute of CRP.As a partial Fulfilment of my Bachelor of Science Degree in Occupational Therapy Course, under the medicine faculty of University of Dhaka, I will have conduct a research project in this academic year. I have already chosen the area of my research is the Neurology Unit of Occupational Therapy Department and my research tittle is **"Quality of Life of person with Guillain-Barre Syndrome (GBS) in community of Bangladesh".**For this I need some necessary information of patients which I will have to collect from the documents of GBS.I can make sure that the research will never be harm for the participants. All the data will be collected by maintaining the ethical considerations.

I therefore, pray and hope that, you would be kind enough to grant my appeal by providing the necessary data from documents and giving me the permission of collecting data related to my research and oblige thereby.

Sincerely yours,
Lubja Azad………………….
Lubja Azad Mim
4th year B.Sc. in Occupational Therapy
Roll :15, Session:2017-2018
BHPI,CRP-Chapain,Savar,Dhaka-1343,Bangladesh.

Approved by:	Comments & Signature:
Md.JulkerNayan (Supervisor) Associate Professor Department of Occupational Therapy BHPI, CRP-Chapain, Savar,Dhaka-1343	16.10.22
SK.Moniruzzaman Associate Professor & head of the Department Department of Occupational Therapy BHPI, CRP-Chapain, Savar,Dhaka-1343	16/10/2022

Appendix-4(A)

Information Sheet

Assalamu Alaikum,

I am Lubja Azad Mim, 4th year B.Sc. in Occupational Therapy student in Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). I am conducting this thesis as per the requirement of my study module. The Thesis titled "Quality of life of the person with Guillain-Barre Syndrome (GBS) in community of Bangladesh"

The study aim is to find out the Quality of life of the person with GBS in community of Bangladesh. To find out that I need to ask several questions to the participants. The entire session will take approximately 30-45 minutes.

Yours participation in this study is voluntary and you may withdraw yourself at any time during this study without any negative questions. You also have the right not to answer a particular question that you don't like or do not want to answer during interview.

The data which will be gathered from you will be recorded by the audio tape recorder. Confidentiality of all records will be highly maintained. The gathered information from you will not be disclosed anywhere except the researcher and supervisor. The study will never published the name of participant anywhere.

If you have any queries about the study you may contact the person describe below.

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

So, may I have your consent to proceed with the interview?

Yes / No

Appendix -4(B)
Information Sheet (Bengali)

তথ্যপত্র

আসসালামু আলাইকুম,

আমি লুবজা আজাদ মিম, পক্ষাঘাত পূনর্বাসন কেন্দ্র (সি আর পি) এর অধিনস্থ বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউটের অকুপেশনালথেরাপি বিভাগ এর ৪র্থ বর্ষের ছাত্রী। এই গবেষণা প্রকল্পটি আমার কোর্স এর অধিভুক্ত। আমি **" বাংলাদেশের সমাজে গুলিয়ান বারি সিনড্রোমে (জি বি এস)আক্রান্ত বাক্তিদের জীবন যাত্রার মান"** এর উপর গবেষণা করছি।

এই গবেষণার উদ্দেশ্য হলো বাংলাদেশের সমাজে গুলিয়ান বারি সিনড্রোমে (জি বি এস) আক্রান্ত বাক্তিদের জীবন-যাত্রার মান নির্ণয় করা। আমি এক্ষেত্রে আপনাকে কিছু ব্যক্তিগত,রোগের বৈশিষ্ট্য এবং সংশ্লিষ্ট নিয়ামকের আনুসাঙ্গিক কিছু প্রশ্ন করতে চাচ্ছি। এতে আনুমানিক ৩০-৪৫ মিনিট সময় লাগবে।

এ অধ্যয়নে আপনার অংশগ্রহণ স্বেচ্ছা প্রণোদিত এবং আপনি যেকোনো সময় এই অধ্যয়ন থেকে কোনো নেতিবাচক ফলাফল ছাড়াই নিজেকে প্রত্যাহার করতে পারবেন। এছাড়াও কোন নির্দিষ্ট প্রশ্ন অপছন্দ হলে উত্তর না দেয়া এবং সাক্ষাৎকারের সময় কোন উত্তর না দিতে চাওয়ার অধিকার ও আপনার আছে।

আপনার কাছ থেকে প্রাপ্ত তথ্য টেপ রেকডার এর মাধ্যমে রেকড করা হবে।আপনার কাছ থেকে প্রাপ্ত তথ্যসমূহের সর্বোচ্চ গোপনীয়তা রক্ষা করা হবে । গবেষক এবং গবেষনার সমন্বয়কারী ব্যতিত এই তথ্যগুলো অন্য কোথাও প্রকাশিত হবে না এবং গবেষণার কোথাও অংশগ্রহনকারীর নাম প্রকাশ করা হবে না ।

এই অধ্যয়নে অংশগ্রহণকারী হিসেবে যদি আপনার কোন প্রশ্ন থাকে তাহলে আপনি নিম্নবর্ণিত ব্যক্তির সাথে যোগাযোগ করতে পারেন।

লুবজা আজাদ মিম
৪র্থ বর্ষ বি এস সি ইন অকুপেশনাল থেরাপি
অকুপেশনাল থেরাপি বিভাগ
বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট
পক্ষাঘাত পূনর্বাসন কেন্দ্র (সি আর পি)
চাপাইন ,সাভার,ঢাকা-১৩৪৩

আমি কি আপনার অনুমতি নিয়ে সাক্ষাৎকার শুরু করতে পারি?

হ্যাঁ / না

Appendix-5(A)

English Verbal Consent Form

This research is part of Occupational Therapy course and the name of the researcher is Lubja Azad Mim. She is a student of 4th year B.Sc. in Occupational Therapy in Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). The study was entitled as “Quality of life of the person with Guillain-Barre Syndrome (GBS) in community of Bangladesh”. The purpose of the study is to know the Quality of life of the person with GBS in community of Bangladesh.

In this study I am .... a participant and I have been clearly informed about the purpose and aim of the study. I will have the right

to refuse in taking part any time at any stage of the study. I will not be bound to answer toanybody. This study has no connection with me and there will be no impact on my treatment at present and in future.

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

Participant’s signature_______________________ Date_____________

Name (BLOCK LETTER) ____

Investigators ’s signature________________________ Date_____________

Name (BLOCK LETTER) ____

Appendix -5(B)
Consent Form (Bangali)

সম্মতিপত্র

এই গবেষণাটি অকুপেশনাল থেরাপির কোর্সের একটি অংশ এবং গবেষণাকারীর নাম লুবজা আজাদ মিম ।সে পক্ষাঘাত পূনর্বাসন কেন্দ্র (সি আর পি) এর অধিনস্থ্ বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউটের অকুপেশনালথেরাপি বিভাগ এর ৪র্থ বর্ষের ছাত্রী। এই গবেষনাটির শিরোনাম **“বাংলাদেশের সমাজে গুলিয়ান বারি সিনড্রোমে (জি বি এস)আক্রান্ত বাক্তিদের জীবন যাত্রার মান”** । এই গবেষণার উদ্দেশ্য হল, বাংলাদেশের সমাজে গুলিয়ান বারি সিনড্রোমে (জি বি এস)আক্রান্ত বাক্তিদের জীবন-যাত্রার মান সম্পর্কে জানা

এই গবেষনাতে আমি...একজন অংশগ্রহনকারী এবং পরিষ্কারভাবে এই গবেষনার উদ্দেশ্য সম্পর্কে অবগত। আমার যে কোন সময়ে এই গবেষনা থেকে নিজেকে প্রত্যাহার করার অধিকার আছে। এজন্য আমি প্রশ্নের উত্তর প্রদান করার জন্য করো কাছে দায়বদ্ধ না। এই গবেষণাটির সাথে আমার কোন সম্পৃক্ততা নেই । এই গবেষনাটি বর্তমানে এবং ভবিষ্যতে আমার চিকিৎসার ক্ষেত্রে কোন রকম প্রভাব ফেলবে না।

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

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

অংশগ্রহনকারীর স্বাক্ষর এবং

তারিখঃ...

গবেষণাকারীর স্বাক্ষর এবং

তারিখঃ...

Appendix 6(A)

Withdrawal Form

Can you withdraw from this study:

You can cancel any information collected for this research project at any time. After the cancellation, whether the data can be used or not should be mentioned in the participations withdrawal form.

Participants
Name:………………………………………………………………………………………

Reason of withdraw:

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………
………………………………………………………………………………

Whether the use of previous data will be allowed?

Yes / No

Participant signature: …………………………..

Data :……………………..

Appendix -6(B)

গবেষণা থেকে নিজেকে প্রত্যাহার করা যাবে কি ?

আপনি সম্মতি প্রদান করা সত্ত্বেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন। বাতিল করার পর তথ্যসমূহ কি ব্যবহার করা যাবে কি যাবেনা তার অনুমতি অংশগ্রহণকারীর প্রত্যাহার পত্রে উল্লেখ করা থাকবে।

অংশগ্রহনকারীর প্রত্যাহার পত্র

(শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারির জন্য প্রযোজ্য)

অংশগ্রহণকারীর নামঃ...

প্রত্যাহার করার কারনঃ

....
....
....
....
....
....
....

পূর্ববর্তী তথ্য ব্যবহারের অনুমতি থাকবে কিনা ?

হ্যাঁ / না

অংশগ্রহণকারীর নামঃ...........................

তারিখঃ.................

Appendix 7(A)

Questionnaire (English)

SECTION-1: Personal Details

Participant no:

Name:……………………………………………………………………………………

Address:…………………………………………………………………………………

Contact Number:………………………………………………………………….

Date of interview:…………………………………………………………………….

SECTION-2: Socio-Demographic Information

This questionnaire is developed to measure the quality of life of GBS patients and this section will be filled by an Occupational therapist or investigator using a pen.

Please give tick (√) mark at the left side box of the best correct answer.

Question Number	Questions/ Information on	Response of the participant
1.	**Age (in year):**	………..years
2.	**Gender:**	1) Male 2) Female
3.	**Marital status:**	1)Married 2)Unmarried 3)Separated 4)Divorced
4.	**Home town:**	1) Dhaka 2) Khulna 3) Rajshahi 4) Barisal 5) Chittagong 6) Rangpur 7) Sylhet 8) Comilla 9)Faridpur 10)Pabna 11)Mymensingh 12)Other specify………………
5.	**Living area**	1)Rural 2)Urban 3)Semi-urban 4)Hill tracks
6.	**Occupation:**	1) Housewife 2) Student

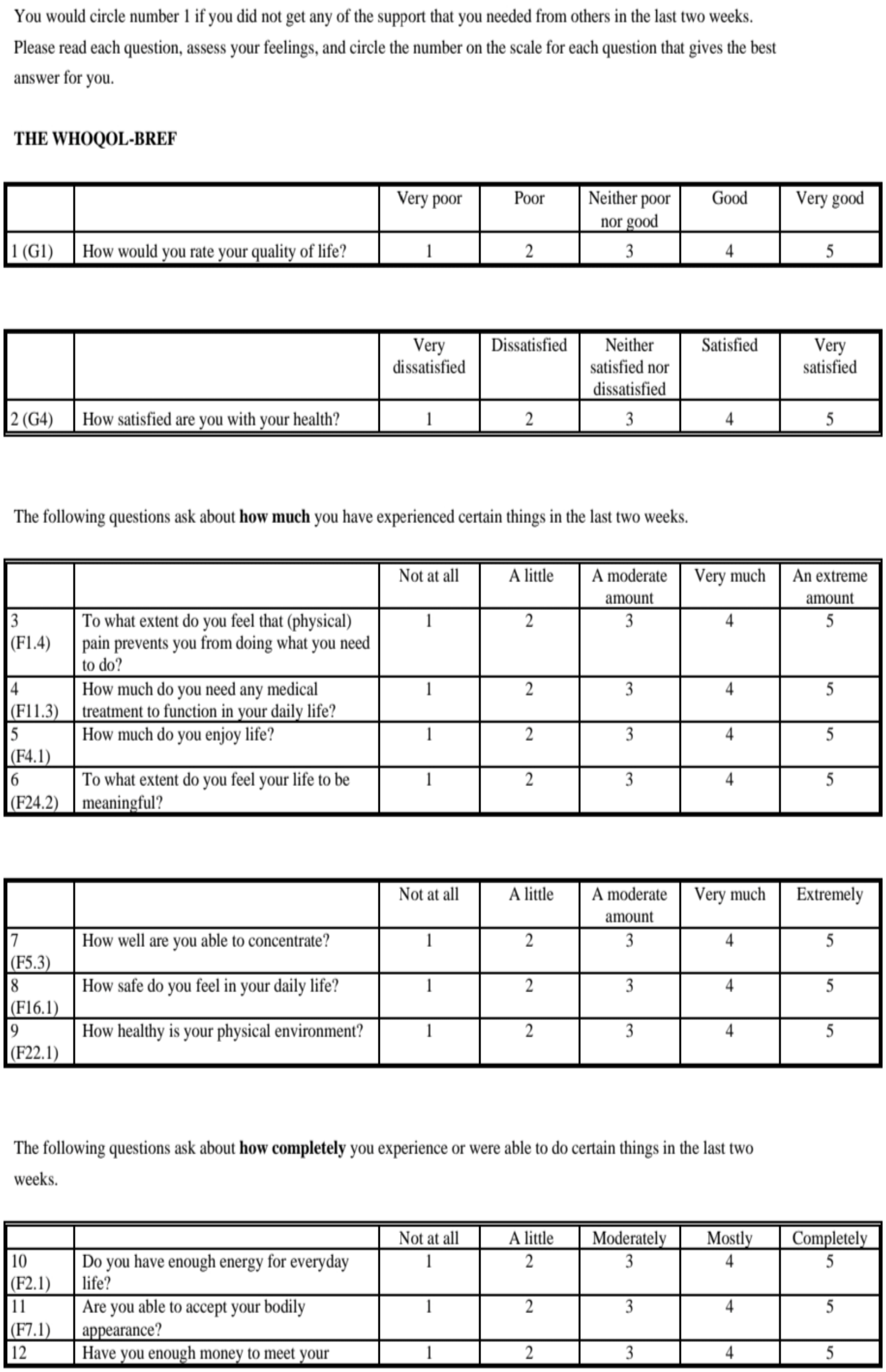
		3) Service holder 4) Business 5) Unemployed 6) Others……………..
7.	**Educational background:**	1) Illiterate 2)Primary 3)Secondary school certificate (SSC) 4)Higher secondary certificat(HSC) 5)Bachelor 6) Bachelor 7)Other (Specify)………………
8.	**Monthly income:**	1) No income 2)1000-10000 3)11000-20000 4)21000-50000 5) More than 50000. 6)Other……………
9.	**Disease onset/Symptoms at onset**	1)Fever 2)Cold 3)Diarrhea 4)GIT symptoms 5)Others………….
10.	**Do you have any chronic disease?**	1) HTN……………………. 2) DM………………. 3) Heart Diseases…………… 4) Immune deficiency disorder 5) Nutritional disorder 6) Others………
11.	**How long have you been taken therapy or rehabilitation service?**	

Section 3: Guillain-Barre syndrome disability scale

What is the condition of your physical state now?

Descriptions	**Score**
A healthy state	0
Minor symptoms and capable of running	1
Able to walk 10m or more without assistance but unable to run	2
Able to walk 10m across an open space with help	3
Bedridden or chair bound	4
Requiring assisted ventilation for at least part of the day	5
Dead	6

Section 4:WHOQOL-BREF English



You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks. Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

THE WHOQOL-BREF

		Very poor	Poor	Neither poor nor good	Good	Very good
1 (G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that (physical) pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5 (F4.1)	How much do you enjoy life?	1	2	3	4	5
6 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your	1	2	3	4	5

(F18.1)	needs?					
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18 (F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20 (F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24 (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?..

How long did it take to fill this form out?...

Do you have any comments about the assessment?

....
...

....
...

THANK YOU FOR YOUR HELP

Appendix 7(B)

Questionnaire - বাংলা

পর্ব -১ : ব্যক্তিগত বিবরণ

অংশগ্রহণকারীর সংখ্যাঃ

নামঃ...

ঠিকানাঃ...

যোগাযোগের নাম্বার..

সাখাতকারের তারিখঃ...

পর্ব- ২ : জনসংখ্যাতাত্ত্বিক তথ্যাবলী

এই প্রশ্নপত্রটি গুলিয়ান-বারি সিনড্রোম (জিবিএস) রোগীদের জীবনযাত্রার মান নির্ণয় করার জন্য তৈরি করা হয়েছে এবং এই পর্বটি অকুপেশনাল থেরাপিস্ট বা অনুসন্ধানকারী বলপেন ব্যবহার করে পূরন করবেন ।

অনুগ্রহপূর্বক নিচের প্রশ্নগুলির মধ্যে সঠিক উত্তরের বাম পাশে টিক (√) চিহ্ন দিন ।

ক্রমিক নং	**প্রশ্নসমূহ**	**অংশগ্রহণকারীর মতামত**
১.১	বয়স (বছর)	.........বছর
১.২	লিঙ্গ	১)পুরুষ ২) মহিলা
১.৩	বৈবাহিক অবস্থা	১)বিবাহিত ২)অবিবাহিত ৩) আলাদা ৪) বিবাহ বিচ্ছেদ
১.৪	স্থায়ী বাড়ি (বিভাগ)	১) ঢাকা ২) খুলনা ৩) রাজশাহী ৪)বরিশাল ৫)চট্রগ্রাম ৬)রংপুর ৭)সিলেট ৮) কুমিল্লা ৯) ফরিদপুর ১০)পাবনা ১১)ময়মানসিং ১২)অন্যান্য.......
১.৫	বসবাসের স্থান	১)গ্রাম ২)শহর ৩)উপশহর ৪)পার্বত্য অঞ্চল
১.৬	পেশা	১)গৃহিণী ২)শিক্ষার্থী ৩)চাকুরীজীবী

		৪)ব্যবসায়ী ৫)বেকার ৬)অন্যান্য.......
১.৭	শিক্ষাগত যোগ্যতা	১)নিরক্ষর ২)প্রাইমারি ৩)এস এস সি ৪)এইস এস সি ৫)স্নাতক পাস ৬)স্নাতকোত্তর ৭)অন্যান্য.......
১.৮	মাসিক আয়	১)কোন আয় নাই ২)১০০০-১০,০০০ ৩)১১,০০০-২০,০০০ ৪)২১,০০০-৫০,০০০ ৫)৫০,০০০ এর বেশি
১.৯	রোগের সূত্রপাত/প্রাথমিক লক্ষণ	১)জ্বর ২)সর্দি ৩)ডাইরিয়া ৪)জি আই টি লক্ষণ ৫)অন্যান্য.......
১.১০	আপনার কোন দীর্ঘস্থায়ী	১)উচ্চরক্তচাপ ২)বহুমূত্র ৩)হৃদরোগ ৪)রোগের প্রতিরোধ ক্ষমতা কমে যাওয়া ৫)পুষ্টিহীনতা ৬)অন্যান্য.......
১.১১	আপনি কতদিন থেরাপি বা পুনর্বাসন সেবা নিয়েছেন?	

পর্ব -৩ : গুলিয়ান-বারি সিনড্রোম (জিবিএস) ডিজাবিলিটি স্কেল

বর্তমানে আপনার শারীরিক অবস্থা কেমন ?

বর্ণনা	স্কোর
সন্তোষ জনক সুস্থতা	০
সল্পলক্ষণ এবং দৌড়ানোর সক্ষমতা	১
সহায়তা ছাড়াই ১০ মিটার বা তার বেশি হাঁটতে সক্ষম তবে দৌড়াতে অক্ষম	২
সহায়তা নিয়ে একটি খোলা জায়গা জুড়ে ১০ মিটার হাঁটতে সক্ষমতা	৩
শয্যাশায়ী অথবা চেয়ারের উপর নির্ভরশীল	৪
দিনের অন্তত কিছু সময়ের জন্য শ্বাসপ্রশ্বাস সহায়ক যন্ত্রের প্রয়োজনীয়তা	৫
মৃত	৬

পর্ব-৪ জীবন যাত্রার মান (WHOQOL-BREF)বাংলা

C. (WHOQOL-BREF) এ অংশের মূল্যায়ন, আপনি আপনার জীবন, স্বাস্থ্য ও জীবনের অন্যান্য দিক সম্পর্কে কি ভাবেন, সে সম্পর্কে দয়া করে সবগুলো প্রশ্নের উত্তর দিন। যদি কোন প্রশ্নের উত্তর কি হবে না বুঝেন তবে যেটিকে সবচেয়ে সঠিক মনে হবে সেই উত্তরটি দিন। এটা প্রায়ই প্রথম উত্তর হতে পারে।

আপনার মান, আশা, আনন্দ ও বিবেচ্য সমূহ স্মরন রাখুন। আমরা আপনার জীবনের গত দুসপ্তাহের কথা স্মরন করতে বলবো।

সবগুলো প্রশ্ন পড়ুন, আপনার অনুভুতি যাচাই করুন এবং পাশের ছকে যে উত্তরটি সবচেয়ে সঠিক মনে হবে সে নম্বরটিতে বৃত্ত তৈরী করুন।

		খুব খারাপ	খারাপ	ভালও নয় খারাপও নয়	ভাল	খুব ভাল
1. (G1)	আপনার জীবন যাত্রার মান কেমন?	1	2	3	4	5

		খুব অসন্তুষ্ট	অসন্তুষ্ট	সন্তুষ্টও নয় অসন্তুষ্টও নয়	সন্তুষ্ট	খুব সন্তুষ্ট
2. (G4)	আপনার স্বাস্থ্য নিয়ে কি আপনি সন্তুষ্ট?	1	2	3	4	5

নিচের প্রশ্নগুলো গত দুপ্তাহে নিম্নবর্নিত অভিজ্ঞতাগুলো কি পরিমানে হয়েছে সে সম্পর্কে ।

		একদম না	কম	মোটামুটি	বেশী	খুব বেশী
3. (F1.4)	শারীরিক ব্যথার জন্য আপনি কি পরিমান প্রয়োজনীয় কাজ থেকে বিরত ছিলেন?	1	2	3	4	5
4. (F11.3)	আপনার দৈনন্দিন কার্যক্রম ঠিক রাখতে চিকিৎসা কতটুকু প্রয়োজন?	1	2	3	4	5
5. (F4.1)	আপনি জীবনকে কতটুকু উপভোগ করেন?	1	2	3	4	5
6. (F24.2)	জীবনকে আপনার কতটুকু অর্থপূর্ন মনে হয়?	1	2	3	4	5

		একদম না	কম	মোটামুটি	বেশী	খুব বেশী
7. (F5.3)	আপনি কাজে কতটুকু মনসংযোগ করতে পারেন?	1	2	3	4	5
8. (F16.1)	আপনি দৈনন্দিন জীবনে কতটুকু নিরাপত্তা অনুভব করেন?	1	2	3	4	5
9. (F22.1)	আপনার ভৌত পরিবেশ কতটুকু স্বাস্থ্যকর?	1	2	3	4	5

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নিচের প্রশ্নগুলোতে জানতে চাওয়া হয়েছে - গত দুই সপ্তাহে আপনি কতটুকু সম্পূর্ণভাবে কোন কাজ করতে বা অভিজ্ঞতা লাভ করতে পেরেছেন।

		একদম না	কম	মোটামুটি	অধিকাংশ	পরিপূর্ণভাবে
10. (F2.1)	আপনার কি প্রতিদিন কাজ করার মত শক্তি আছে?	1	2	3	4	5
11. (F7.1)	আপনি কি আপনার শরীরের গড়ন নিয়ে সন্তুষ্ট?	1	2	3	4	5
12. (F18.1)	আপনার কি প্রয়োজন মেটাতে যথেষ্ট টাকা আছে?	1	2	3	4	5
13. (F20.1)	আপনি কি দৈনন্দিন জীবন-যাপনের জন্য প্রয়োজনীয় তথ্য পান?	1	2	3	4	5
14. (F21.1)	অবসর কাটানোর/বিনোদনের সুযোগ আপনার কতটুকু আছে?	1	2	3	4	5

		খুব খারাপ	খারাপ	ভালও না মন্দও না	ভাল	খুব ভাল
15. (F9.1)	আপনি কতটা ভালভাবে চলাফেরা করতে পারেন?	1	2	3	4	5

নিচের প্রশ্নতে জানতে চাওয়া হয়েছে - গত দুসপ্তাহে আপনার জীবনের বিভিন্ন দিক নিয়ে আপনি কতটুকু সন্তুষ্ট?

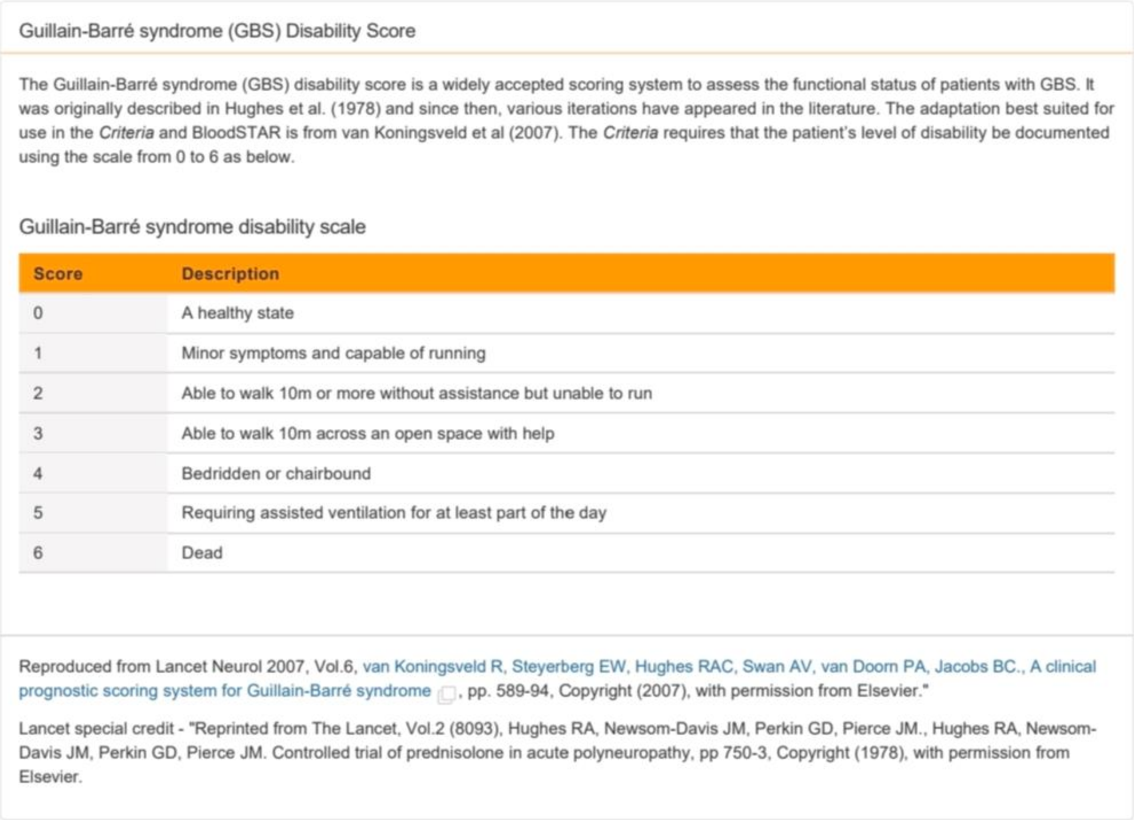
		খুব অসন্তুষ্ট	অসন্তুষ্ট	সন্তুষ্টও নয় অসন্তুষ্টও নয়	সন্তুষ্ট	খুব সন্তুষ্ট
16. (F3.3)	আপনার ঘুম নিয়ে আপনি কতখানি সন্তুষ্ট	1	2	3	4	5
17. (F10.3)	দৈনন্দিন কাজ করার ক্ষমতা নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
18. (F12.4)	আপনার কাজ করার ক্ষমতা/দক্ষতা (ক্যাপাসিটি) নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
19. (F6.3)	নিজেকে নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
20. (F13.3)	অন্যদের সাথে আপনার ব্যক্তিগত সম্পর্কসমূহ নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
21. (F15.3)	আপনার যৌন জীবন নিয়ে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
22. (F14.4)	বন্ধুদের কাছ থেকে পাওয়া সাহায্যে আপনি কতটুকু সন্তুষ্ট?	1	2	3	4	5
23. (F17.3)	আপনি আপনার বাসস্থানের অবস্থা নিয়ে কতটুকু সন্তুষ্ট?	1	2	3	4	5
24. (F19.3)	আপনি যে স্বাস্থ্যসেবা পান তাতে কি সন্তুষ্ট?	1	2	3	4	5
25. (F23.3)	আপনি যাতায়াত ব্যবস্থা নিয়ে কতটুকু সন্তুষ্ট?	1	2	3	4	5

নিচের প্রশ্নগুলোতে জানতে চাওয়া হয়েছে - গত দুসপ্তাহে ঐ নির্দিষ্ট বিষয়সমূহ আপনি কতবেশী/ঘনঘন অনুভব করেছেন?

		কখনো না	কখনো কখনো	মাঝে মাঝে	প্রায়শঃই	সব সময়
26. (F8.1)	আপনার হতাশা, উদ্বেগ, অবসন্নতা এই সব নেতিবাচক অনুভুতি কত ঘন ঘন হয়?	1	2	3	4	5

(নিশ্চিত হোন যে সব প্রশ্নের উত্তর দেয়া হয়েছে।)

Appendix-8



Guillain-Barré syndrome (GBS) Disability Score

The Guillain-Barré syndrome (GBS) disability score is a widely accepted scoring system to assess the functional status of patients with GBS. It was originally described in Hughes et al. (1978) and since then, various iterations have appeared in the literature. The adaptation best suited for use in the *Criteria* and BloodSTAR is from van Koningsveld et al (2007). The *Criteria* requires that the patient's level of disability be documented using the scale from 0 to 6 as below.

Guillain-Barré syndrome disability scale

Score	Description
0	A healthy state
1	Minor symptoms and capable of running
2	Able to walk 10m or more without assistance but unable to run
3	Able to walk 10m across an open space with help
4	Bedridden or chairbound
5	Requiring assisted ventilation for at least part of the day
6	Dead

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