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HEALTH RELATED QUALITY OF LIFE OF THE PERSON WITH GUILLAIN-BARRE SYNDROME (GBS)

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Bachelor of Science in Physiotherapy (B.Sc. PT)

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We the undersigned certify that we have carefully read and recommended to the Faculty of Medicine, University of Dhaka, for the acceptance of this dissertation entitled

HEALTH RELATED QUALITY OF LIFE OF THE PERSON WITH GUILLIAN-BARRE SYNDROME (GBS)

Submitted by **MD. AL-AMIN**, for the partial fulfilment of the requirement for the degree of Bachelor of Science in Physiotherapy (B.Sc. PT).

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DECLARATION

I declare that the work presented here is my own. All sources used have been cited appropriately. Any mistakes or inaccuracies are my own. I also decline that same any publication, presentation or dissemination of information of the study. I would bind to take consent from the department of Physiotherapy of Bangladesh Health Profession Institute (BHPI).

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Contents

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Acronyms

ADL:	Activity of Daily Living
BHPI:	Bangladesh Health Profession's Institute
BMRC:	Bangladesh Medical Research Council
CIDP:	Chronic inflammatory demyelinating polyneuropathy
CRP:	Centre for the Rehabilitation of the Paralysed
GBS:	Guillain Barre-Syndrome
GDS:	GBS disability scale
HRQoL:	Health Related Quality of Life
ICU:	Intensive care unit
IRB:	Institutional Review Board
IVIg:	Intravenous immunoglobulins
OPD:	Outpatient department
PWD:	Person with Disability
QoL:	Quality of Life
SPSS:	Statistical Package for the Social Sciences
WHO:	World Health Organization

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Abstract

Purpose: To assess the health related quality of life of the person with GBS attending at specialized rehabilitation centre. ***Objectives:*** To evaluate the health related quality of life of GBS patients through the evaluation of physical functioning (PF), Role-emotional (RP), Bodily pain (BP), General health (GH), Vitality (VT), Social functioning (SF), Role-emotional (RE), Mental health (MH). ***Methodology:*** It was a cross-sectional study. Total 45 participants were selected conveniently for this study from Neurology Unit, Centre for the rehabilitation of the paralyzed (CRP), Savar, Dhaka. Data was collected by using a semi-structure questionnaire and health-related quality of life (HRQOL) was assessed by the Short Form-36v2 (SF-36v2) health survey questionnaire. The study was conducted by using quantitative descriptive analysis (Chi-squire test & Pearson correlation test) through using Statistical Package for the Social Science (SPSS) software 25.0 version. ***Results:*** Among 45 GBS patients evaluation, the majority are male 84.40% (n=38) participants and female are 15.60% (n=7). About 2.20% (n=1) participants were within healthy state, 6.70%(n=3) participants were within minor symptoms and capable running, 57.80% (n=26) participants were within Able to walk 10m or more without assistance but unable to run, 28.90% (n=13) participants were within Able to walk 10m across an open space with help, 4.40% (n=2) participants were within Bedridden or chair bound. Among SF36 domains Bodily pain (77.69±21.23) and Mental health (75.58±11.04) has shown good functional improvement rather than other domains. General health (61.67±11.18) & Vitality (68.76±9.30) has shown fair functional improvement and Physical functioning (47.84± 24.83), Role of physical (36.02±14.09) & Emotional (41.98±11.43) status, Social functioning (41.98±14.89) has shown poor functional improvement. The lowest mean score indicate the poor quality of life and highest mean score indicate the good quality of life. There is a significant association between gender of participants and GBS disability score ($P<0.05$). ***Conclusion:*** GBS is an auto-immune condition which causes individual's quality of life declining. The GBs affected persons reported low scores on all of the SF-36 dimensions that characterize poor quality of life (QOL) among all. The study demonstrated that GBS greatly affects quality of life and gives rise to more problems, especially in the areas of physical and mental health. It is necessary to take steps to improve the physical

and emotional status of persons with GBS, as this will eventually lead to improvement in their quality of life.

Key words: Health related quality of life (HRQoL), Person with Disability (PWD), Guillain-Barre Syndrome (GBS).

CHAPTER – I INTRODUCTION

1.1: Background

GBS is an acute, autoimmune condition, immune busting treatment which is first progressive in nature .Which significant disability with a physical course fast with high disability and normally episodic immune treatment; chronic inflammatory demyelinating polyneuropathy (CIDP) is a chronic, autoimmune, natural course, slow ongoing disability, generally maintenance immune treatment. In motor deficits, many number patients have cognitive, psychosocial problems resulting in complex disability, which may sometimes additional treatment require in a specialist rehabilitation service (Alexandrescu et al., 2014). It is an immune mediated polyneuropathy characterized by progressive weakness in all four limbs, absence of reflex, autonomic dysfunction and respiratory paralysis. It is considered to be the most significant cause of muscle paralysis in developing countries after poliomyelitis (Khan et al., 2011).

The worldwide annual incidence of GBS is 1–2 per 100,000 population (Hughes et al., 1997) with male to female ratio of 2:1, This disease has generally favorable outcome (majority of the patient starts ambulation with-in 6 months of the onset of the symptoms) with low mortality rate, however, 25% of the patients may require ventilator assistance, and 10-20% of the patient may have severe residual permanent disability (Darweesh et al., 2014). GBS is the main cause of prolong time disability in the patients which gets affected is relatively between 30 to 50 years youngers populations but at any age it can attack (Sriganes et al., 2013). Survival and early recovery timing in acute stage has achieved by advanced acute care for the patients with GBS. But for increasing the scope on disability improvement and social participation of patients, still plenty need to be done (Hughes et al., 2005).

A ten years study showed on that residual disability may last for prolong time in which 14% of the patient had moderate to severe disability and 50% had minor symptoms (Forsberg et al., 2012). One of the common consequence of GBS is fatigue. Which was reported on 60-80% of patient population and also associated with the activity limitation and poor quality of life (De Vries et al., 2010). There is no specific exercise for the GBS

patients with disability and activity limitations. Supportive care is considered as the main important care which is immunotherapy or IVIG in GBS patients (Hughes et al., 2008). Nehal & Manisha, 2015 reported that there is no specific guideline and exercise protocol available for GBS patients. Two-third patients with GBS achieve good physical recovery (Chio et al., 2003).

There are various treatments in different phases for the rehabilitation of a GBS patients. It mainly depends on the context of the patient's current condition. Treatment in the acute phase include respiratory care, passive movements, positioning, splinting. Even gentle progressive strengthening exercise; after acute phase, more intensive strengthening and functional activities may occur (Lennon et al., 1993). The muscle strength define as the ability or capacity of a muscle or muscle group to exert the height force against a resistance. Muscle weakness or imbalance in muscle groups can cause abnormal movement in others parts of the body and alter normal function of the muscle; it can also cause abnormalities to occur in organs. Patients with GBS have difficulty with doing activities of daily living such as walking, bathing and running independently, and due to lack of muscle strength and weakness problem in participation in physical activity decreases (Keyghobad et al., 2011).

Others research has shown that reinforcement exercises can magically increase the ability to produce power, and short-term exercises can improve walking, riding wheelchairs and other activities of motor function (Esmailiyan et al., 2014).

Health-related quality of life (HRQL) is a concept that follows an individual's perception of how an illness and its treatment affect the physical, mental, and social aspects of his or her life (Testa & Simonson, 1996)

Shah and Shrivastava stated that physiotherapy and rehabilitation process had an impact on the Quality of life of patients with GBS (Nehal & Manisha, 2015). The Quality of Life is focus to his position in relation to his goals, expectations, criteria and concerns in the participatet cultural event and the evaluate making system in which he lives. If quality of Life is properly evaluated, it will be considered as a sensitive and comprehensive criterion to measure the impact of disorders and therapeutic interventions as well as clinical

reasoning on determining therapeutic priorities. Examining and improving the Quality of Life in different groups of people and groups of people with disabilities is among the goals and policies of any society (Noori et al., 2015). Hence the current study was intended to explore the existing Quality of life in the person with GBS.

1.2 Rationale

Guillain-Barre syndrome (GBS) is an autoimmune disease of the peripheral nerves and their roots. The common feature of GBS are acute flaccid paralysis of limb, respiratory weakness and autonomic disturbance. Around 30% of GBS patients change their job, habits and social activities because of illness. Most of the GBS patients suffer fatigue. Patient`s quality of life (QoL) in GBS may be negatively affected due to all these factors.

Very few study's regarding health related quality of life of GBS patients have been conducted. But there is no study was found in Bangladesh. Therefore an attend has been taken by the investigator to find out the health related quality of life of GBS patient in specified hospital.

Health-related quality of life (HRQL) is a concept that consider an individual’s perception of how an illness and its treatment affect the physical, mental, and social aspects of his or her life. Knowing the existing Quality of life can guide the rehabilitation professional to device their treatment and rehabilitation strategies in more scientific ways.

1.3 Research question

What is the health related quality of life of person with Guillain-Barre syndrome?

1.4: Study objectives

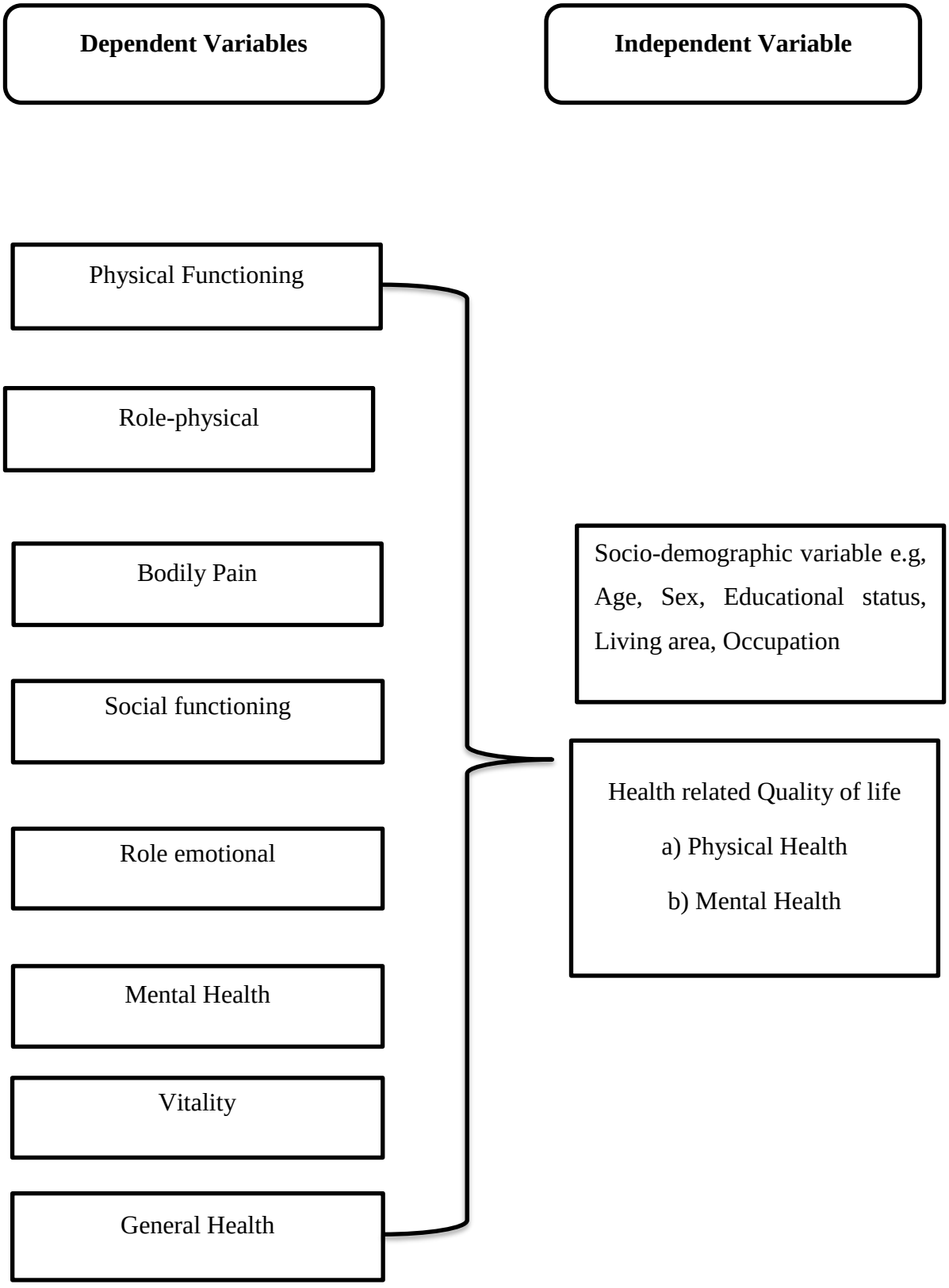
1.4.1: General objective

To evaluate the health related quality of Life of person with Guillain-Barre syndrome.

1.4.2 Specific objective

i. To explore socio-demographic (age, gender, marital status, family type, living area, educational status) characteristics of patients with GBS.
ii. To observe the level of physical functioning, role of physical, Bodily pain, Vitality, Social functioning, General health, Role of emotional, mental health of the participants.
iii. To find out the relationship between different sociographic, physiologic features and the individual domain of health related quality of life of person with GBS.

1.5 Conceptual Framework



1.6 Operational definition

Guillain-Barre syndrome

Guillain-Barre syndrome (GBS) is an acute inflammatory disease of the peripheral nerves. An autoimmune attack on the myelin results in demyelination. Loss of myelin can occur in sensory, motor or autonomic nerves.

Quality Of Life

Quality of life (QOL) is the general well-being of individuals and societies, outlining negative and positive features of life. It observes life satisfaction, including everything from physical health, family, education, employment, wealth, religious beliefs, finance and the environment.

Physical health

It is the soundness of the body, freedom from disease or abnormality. It includes pain present in the body, how much physical health interferes in ADL, limitation in bathing or dressing, energy, tiredness etc.

Mental health

Mental health refers to our cognitive, and/or emotional wellbeing. It includes depression, sadness, happiness, how much emotional problem interferes in ADL, satisfaction with relationship etc.

CHAPTER – II LITERATURE REVIEW

A comprehensive literature review was conducted through the use of the key words of the title and the associated area of Google, Google scholar, PubMed, PEDro, Hinari, BHPI library were the sources of the information. The literatures were taken from the different scholarly articles are as follows.

Guillain-Barre syndrome (GBS), an immune-based illness, presents as evolving acute polyneuritis, usually with motor deficits (symmetrical ascending paralysis), autonomic dysfunction and respiratory failure (Hughes and Cornblath, 2005).Acute inflammatory demyelinating polyradiculoneuropathy was more commonly referred to Guillain-Barre syndrome (GBS). GBS usually affects the peripheral nervous system and leading cause of acute flaccid paralysis (Novak et al., 2017). There are several diagnostic subtypes of GBS with acute inflammatory demyelinating polyradiculoneuropathy diagnosed most commonly (Khan et al., 2011). Patients who are medical diagnosis of GBS usually showing signs and symptoms including rapidly progressive bilateral and symmetrical ascending motor and sensory disturbances of the extremities resulting in hyporeflexia or areflexia (Van Doorn., 2008). More progressive forms of GBS affect respiratory muscles, muscles innervated by cranial nerves, and may cause autonomic dysfunction. Paresthesia and neuropathic pain are common due to inflammatory demyelination of peripheral nerves (Ruts et al., 2010)

Additionally, problem severe fatigue in patients with GBS has been observed both acutely and chronically with proposed mechanisms of peripheral fatigue due to a decrease in motor units, central fatigue due to neuroendocrine dysregulation, and experienced fatigue due to prolonged sympathetic response from stress (De Vries et al., 2010). Highest impairment typically occurs 2-4 weeks from the initial onset, however, chronic form of GBS known as chronic inflammatory demyelinating poly neuropathy (CIDP), symptoms may develop over eight weeks or longer (Fisher & Stevens., 2008). A large proportion of patient's reports pain that may even precede the onset of weakness and may subsequently persist for years after onset of the disease (Ruts et al., 2010).

The worldwide yearly incidence of GBS is 1–2 per 100,000 population (Hughes and Rees, 1997). Although the overall mortality rate is low patients with GBS, and the outcome (influenced by disease subtype) generally favorable (the majority of patients are ambulant within 6 months of symptom onset), 25% of patients may require artificial ventilation and 10–20% may have residual permanent severe disability (deficits in ambulation or require ventilator assistance 12 months later) (Meythaler, 1997).

GBS is known as a heterogeneous syndrome with several variant forms. Affect the most common type of GBS is acute inflammatory demyelinating polyradiculoneuropathy. Another axonal subtypes that include acute motor axonal neuropathy and acute motor and sensory axonal neuropathy. Variants of GBS include Miller Fisher syndrome (cranial nerve involvement, ataxia) and acute pandysautonomia (Hughes et al., 2005).

The ongoing impact of GBS on activities of daily living, work, social activities and health-related quality of life can be considerable (Forsberg et al., 2005). Although the incidence of GBS increases with age (more common in older persons), it can affect at a relatively young age (30–50 years), and be a significant cause of new long-term disability for many persons in the community. Historically, ascending paralytic illness has been recognized for centuries but it was the first reasonable clinical description. More adequately described the syndrome of a radiculoneuritis associated with elevated protein in the cerebrospinal fluid without a "cellular reaction"(Garssen et al., 2004).

The Guillain-Barre syndrome (GBS) is a monophasic polyneuropathy from which many patients ultimately recover optimally. However, artificial respiration is necessary in 10-20% of the patients in the acute phase of the disease, 10-22% finally remain disabled and there is a mortality of 3-5% (Kleyweg et al., 1989). For these reasons, an effective treatment has been sought and at present plasma exchange is generally accepted as such, early in the course of the GBS (Loffel et al., 1977). Despite major advances in acute care in GBS, the focus has been on improving survival and decreasing acute recovery time rather than on long-term benefits on disability and societal participation. A recent systematic review of the effectiveness of multidisciplinary care in GBS identified no randomized or clinical controlled studies in this population, and highlighted gaps in scientific evidence (Khan et al., 2011).

GBS is most commonly a post-infectious disorder usually occurs in otherwise healthy people, and is not typically associated with an autoimmune or other systemic disorder. In typical cases, among the first symptoms are pain, numbness, paresthesia, or weakness in the limbs. The main features of GBS are rapidly progressive bilateral and relatively symmetric weakness of the limbs with or without involvement of respiratory muscles or cranial nerve-innervated muscles (van der Meche et al., 2001).

Around 30% of GBS patients change their jobs, habits, or social activities after acute phase of the illness (Bersano et al., 2006). Patient's quality of life (QoL) in GBS may be negatively affected due to all these factors (Jacobs et al., 2017).

In a typical patient with GBS, the diagnosis was usually straightforward. However, in atypical patients, a clearly increased cerebro-spinal fluid cell count should raise the possibility of another illness, such as a leptomeningeal malignancy, Lyme disease, West Nile virus infection, HIV-related GBS, or poliomyelitis, particularly in developing countries (Ho et al., 1997).

In about most of the patients with GBS, serum antibodies to various gangliosides have be found in human peripheral nerves, including LM1, GM1, GM1b, GM2, GD1a, GalNAc-GD1a, GD1b, GD2, GD3, GT1a, and GQ1b. Another antibodies might bind with mixtures or complexes of different gangliosides instead of individual gangliosides. These gangliosides have a specific tissue distribution in peripheral nerves and are distribution in specialized functional micro domains called "lipid rafts", and play a part in the maintenance of the cell membrane structure. Most of the antibodies are specific to defined subtypes of GBS. Antibodies to GM1, GM1b, GD1a, and GalNAc-GD1a are associated with the pure motor or axonal types of GBS, whereas antibodies to GD3, GT1a, and GQ1b are present related to ophthalmoplegia and MFS type (Willison, 2002).

GBS patients are usually hypotonic or flaccid as well as immobilized. They develop complications of pressure ulcers, tendon shortening, joint contractures, and malalignment, as well as peroneal nerve palsies. Yet the treatment approach has been similar to that used for many patients who have an upper motor neuron lesion such as spinal cord injury or traumatic brain injury. How these medical complications and functional deficits affect the

final disability of these patients is unknown. The incidence of immobilization on the development of functional deficits is not well understood in GBS (Meythaler, 1986).

Immunotherapies are the available modes of treatment and have shown more beneficial effects. Therapeutic plasma exchange when applied during first few weeks of the onset of the symptoms and intravenous immunoglobulins (IVIg) in its recommended dosage has shown similar beneficial effects on the disease symptoms (Hughes et al., 2005).

In patients with Guillain–Barre syndrome (GBS) poor clinical outcome is most frequent among patients who were treated in an intensive care unit (ICU) and required mechanical ventilation (MV) during the acute phase with a reported long-term mortality rate of 20 % at 12 months or longer after hospital discharge (Fletcher et al., 2000). ICU-complications are most often associated with prolonged ventilation, concomitant medical conditions, or old age (Kohrmann et al., 2009). However, in comparison with other neurological ICU-patients (with, e.g., cerebral ischemia, intracerebral hemorrhage or subarachnoid hemorrhage) GBS patients are more likely to survive the acute phase (Kiphuth et al., 2010). Thus, they may suffer later from long-term consequences which are either GBS associated, such as chronic pain and fatigue (Garssen et al., 2004).

acute care of patients with GBS, survival and early acute recovery timing has been achieved but still a lot need to be done to increase the scope on improving the disability of patients and their social participation (Khan et al., 2011).The health related quality of life affect a lot in the patients with GBS showing moderate to severe impact in their ability to participate in work also long term psychological sequelae (Darweesh et al., 2014). It has been reported in a study on ten years follow-up that residual disability may last for longer years or life in which 14% of the patient population had moderate to severe disability whereas 50% had more minor symptoms.14 Fatigue is also reported on 60-80% of patient population as one of the common consequence and also associated with the poor quality of life and activity limitation (De et al., 2010). A systematic review on effectiveness of exercises on patients with polyneuropathy has evaluated poor quality studies and only one trial which failed to show favorable effects of strengthening and endurance training on functional ability of the patients with polyneuropathy however, also suggested the moderate effect of exercises on increasing the muscle strength of the patients. Further,

some observational and prospective studies also have reported the improvement in function, fatigue and muscle strength of the patient after supervised cycling or prescribed unsupervised exercises and aerobic activities (Graham et al., 2007).

The long term sequelae of GBS and their effect on everyday life are not yet fully understood. The impairment (weakness and sensory disturbance), disability and psychosocial and quality of life (QoL) effects (including work, leisure activities and social activities) can be prolonged. The studies was showed that psychosocial activity does not necessarily correlate with the severity of impairment in GBS, but may be describe by poor conditioning and fatigue (Forsberg et al., 2005). A recent study (N.=76) reported that despite good functional recovery up to 14 years post GBS (median 6 years, range 1-14), 16% continued to report moderate to extreme impact on work, family and social activities; and 22% reported ongoing substantial impact on mood, confidence and ability to live independently. With improvements in medical treatments and decreased mortality rates, the emphasis is on provision of integrated care to GBS survivors over a longer time period, as these individuals are often young. Long-term management of psychological sequelae impacting activity and participation is important. It is hypothesized that this may be best done through multidisciplinary rehabilitative care, which is defined as a problem solving educational process delivering coordinated care with clearly identified goals within a specified time period, utilizing at least two disciplines (medicine, physiotherapy, occupational therapy, other allied health professions); and targeted towards improvements at the level of activity (function) and /or participation (QoL, social reintegration, work) (Khan et al., 2011). In chronic neurologic conditions such as CIDP argued that more attention should be paid to the impact of illness and its treatment on functional, emotional, and social well-being of patients, thereby extending the goal of outcome evaluation from the traditional focus on disease symptoms, signs, and test results to quality-of-life measures (Vickrey et al., 2000).

In 1980 People have more concern about their overall physical and mental health. HRQOL refers to the health status of individuals affected by diseases, injuries, medical interventions, aging, and social environment. HRQOL also represents the subjective satisfaction linked to economic, cultural background, and an individual value HRQOL

describes the functional status of individuals in terms of physical, psychological, and social aspects. HRQOL covers physical health and MH and can clearly determine the health status indexes of individuals. As an important indicator of the quality of life of people in terms of physical health and mental health, HRQOL has also become an important means to evaluate and monitor the health status of people. HRQOL can reduce the boundaries between various disciplines and can be widely applied to social, psychological, and medical services. HRQOL also has a significant effect on health of the people (Liang et al., 2014).

Health-related quality of life (HRQL) is a concept that reflects an individual's perception of how an illness and its treatment affect the physical, mental, and social aspects of his or her life (Testa and Simonson, 1996). GBS encompasses multiple transient and permanent types of impairment, HRQL is recognized as an outcome variable that can provide well-standardized information on patient-perceived recovery after onset of the disease (Forsberg et al., 2004).

In general, quality of life (HRQoL or QOL) is the perceived quality of an individual's daily life that is an assessment of their well-being or lack thereof. Quality of life includes all emotional, social and physical aspects of the individual's life. Health-related quality of life (HRQoL) is an assessment procedure of how to assess the individual's well-being may be affected over time by a disease, disability or disorder. Quality of life is a model of integrated objective and subjective indicators assessment. It is a broad range of life domains, and individual values. It takes account of concerns that externally derived pattern should not be applied without reference to individual differences. Factors that play a role in quality of life vary according to personal preferences, but they often include financial security, job satisfaction, family life, health and safety (Masud et al., 2013).

As recovery from GBS is a lengthy and highly variable process, information on the frequency, nature, and predictors of patient-perceived disability after GBS could be of help for patients, neurologists, and other caregivers both in the acute and chronic phase of disease and many studies on QoL in GBS patients used similar questionnaires, such as SF36 (Darweesh et al., 2014). This questionnaire may capture some unnecessary issues

and miss out some important one which may instead be captured by disease- or symptom-specific QoL questionnaires (Vincentet al., 2007).

The SF-36 scale consists of eight scaled scores, which are the sum of the question in section. The eight sections are physical functioning, Role limitation due to physical health, Role limitation due to emotional problem, Bodily pain, General health, Vitality, Social functioning and mental health and four domains predominantly influence the physical component score: ‘‘role of physical,’’ ‘‘body pain,’’ ‘‘physical functioning,’’ and ‘‘general health,’’ The other four domains (‘‘vitality,’’ ‘‘role-emotional,’’ ‘‘social functioning,’’ and ‘‘mental health’’) mostly influence the mental component score (Ware and Sherbourne, 1992). Each scale is directly transformed into a 0-100 scale on the assumption that each question carries equal value. The difference between the categories may well be unequal, as the numbers allocated to the categories have no numerical value. (Stevens, 1946). In this study the scale 0-100 is subdivided into four section. Score 0-25 indicates poor status, Score 26-50 indicates poor status, Score 51-75 indicates fair status and Score 76-100 indicates good status of all domains.

The Guillain-Barre syndrome (GBS) disability score is a widely accepted scoring system to assess the functional disability status of patients with GBS. It was mainly described in Hughes et al. (1978) and since then, various repetition have appeared in the literature.

Assessment of functional disability is of main importance in GBS (Forsberg et al., 2005) GDS is the most commonly used disability outcome measure in this disease (Raphael et al., 2012).

Walgaard et al also used GDS > 2 for assessing poor outcome and found severe disability in 30% of patients at month 3 and in 19% patients at month 6. However, the percentage of patients with severe disability according to GDS did not contradict in the early stage of the disease (between day 14 and day 28), as well as in the later recovery period (between month 3 and month 6) (Walgaard et al., 2011).

CHAPTER – III METHODOLOGY

3.1. Study Design

A cross sectional study was chosen to conduct the study and as it was found to be an appropriate design to find out the objectives. Cross-sectional studies measure simultaneously the exposure and health outcome in a given population and in a given geographical area at a certain time.

This study included the maximum proportion of GBS participants who came for receiving treatment from December 2020 to August 2021 at the OPD of CRP. Moreover this design was cost and time effective for the researcher compare to an experimental study.

3.2 Study site

The data was collected from the Neurology OPD of CRP, Savar-Dhaka.

3.3 Study Population

The study populations were GBS patients who came to receive the treatment at CRP from treatment from December 2020 to 30 August 2021(the data collection was interrupted due to COVID-19 pandemic).

3.4 Sampling technique

Participants were selected from CRP because they were easily accessible for the researcher.

Convenient sampling method was used. The samples were collected on the basis of some inclusion and exclusion criteria. It is the one of the easiest, cheapest and quicker method of sample selection. Convenience sampling is a type of nonprobability sampling in which people are sampled simply because they are “convenient” sources of data for researches. Non probability sampling is does not involve known non-zero probabilities of selection.

It is a type of nonprobability or nonrandom sampling where members of the target population that meet certain practical criteria, such as easy accessibility, geographical

proximity, availability at a given time, or the willingness to participate are included for the purpose of the study (Etikan et al., 2016).

3.5 Sample size calculation

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

$$n = \frac{Z^2 Pq}{d^2}$$

Where

d is the desired level of precision (i.e. the margin of error).

p is the (estimated) proportion of population which has the attribute in question.

If p = 0.5 now let`s say we want 95% confidence, and at least 5% plus or minus precision.

A 95% confidence level gives us Z values of 1.96, per the normal tables, so we get,

Sample size:

$$n = \frac{Z^2 Pq}{d^2}$$

$$n = \frac{(1.96)^2 \times 0.5 \times 0.5}{(0.05)^2}$$

=384.16

=384

According to this equation sample size was 384. Due to the COVID-19 pandemic, the academic activities were closed and interrupted which influenced the data collection procedure therefore only 45 sample was taken.

3.5.1 Inclusion criteria

1. Patient with GBS who are treated by a physiotherapist in CRP Neurology unit.

2. Both male and female.

3. GBS disability scale (GDS) score < 5.

3.5.2 Exclusion criteria

1. Mentally ill and medically unstable participants.

2. Non co-operative /non interested participants.

3.5.3 Data collection tools

The tools that needed for the study were Bengali /English Consent form and questionnaire and other some necessary materials that were pen, pencil, eraser, clip board, white paper and note book.

3.5.4 Outcome Measurement tool

SF-36v2 questionnaire, GBS disability scale (GDS).

SF-36v2

SF-36 The Short Form-36 (SF-36) is a 36 item questionnaire which measures Quality of Life (QOL) across eight domains, which are both physically and emotionally based and it is a structured, self-report questionnaire (Jenkinson et al., 2014).The eight domains that the SF36v2 measures are as follows: physical functioning; role limitations due to physical health; role limitations due to emotional problems; energy/fatigue; emotional well-being; social functioning; pain; general health. It is the most widely used measures to predict health-related quality of life and it also help in showing the difference between subjects with variety of chronic conditions and between subjects with different level of severity of the same disease. The Test-retest reliability of sf-36 Bangla version has been tasted and the value of Test- retest reliability (.94-1.0) (Walton et al., 2012).

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 in Hughes et al. (1978) and since then, various repeating have appeared in the literature. The Criteria requires that measure the patient's level of disability using the scale from 0 to 6 as below (Van Koningsveld et al., 2007).

3.5.5 Procedure of data collection

Before data collection, researcher was first introduced himself to the participants & took verbal consent. Then provide written consent form to the participant, and after signed the consent form, data was collected through a questionnaire from the participants by face to face conversation. In that way questionnaire was present and data was completed. In the questionnaire, there was participant's demographic information including Demographic information included age, sex, educational level, marital status, previous occupation, along with questionnaire of SF-36 and GDS.

3.6 Data analysis

After complete the initial data collection, every answer was cross checked to find out mistakes or unclear information. Then data was analyzed through Statistical package of social science (SPSS) Version 25. Microsoft Excel worksheet 16 was used to create the most of the graphs and charts. Then data was analyzed through descriptive and interferential statistics. In descriptive part, in 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 pie chart, bar graph. To find out the relationship between sociodemographic, physical parameters and health related QOL and GBS disability scale (GDS), Chi-square test for independence and Pearson correlation test was applied. In case of two categorical variable chi-square/ fisher exact test, and two continuous variable Pearson correlation test was applied.

3.7 Ethical consideration

The whole process of this research project was done by following the Bangladesh Medical Research Council (BMRC) guidelines, Institution Review Board (IRB) and World Health Organization (WHO) Research guidelines. The proposal of the dissertation including methodology was approved by Institutional Review Board and obtained permission from the concerned authority of ethical committee of Bangladesh Health Professions Institute (BHPI). Informed consent was used to take permission from all participants. Participants' rights and privileges were ensured. All the participants were aware about the aim and objectives of the study. Findings of the study were disseminated with the approval of regarding authority. The researcher strictly maintained the confidentiality regarding participant's condition and treatment.

CHAPTER–IV RESULTS

A descriptive and inferential statistical analysis have been conducted to find out the result. In the descriptive section the categorical variables were measured in percentage and have been showed in different bar diagrams, pie charts and tables. The continuous variable's central tendency and measure of dispersion was calculated through mean and standard deviation. In the inferential section, chi-square test for independence/ fisher exact test and Pearson's co-relation test were conducted to find out the association between different dependent and independent variables.

Sociodemographic Features

4.1 Age of participants

The study was conducted on 45 participants of having GBS. In the study the minimum age of participants was 12 and maximum age of participants was 58 their mean age was 34.58 and standard deviation was ±11.75. Among the 45 participants where 8.90% (n=4) participants of age between 10 to 20 years, 31.10% (n=14) participants of age between 21 to 30 years, 28.90% (n=13) participants of age between 31 to 40 years, 17.80% (n=8) participants of age between 41 to 50 years, 13.30% (n=6) participants of age between 51 to 60 years. Mean age 34.58 years.

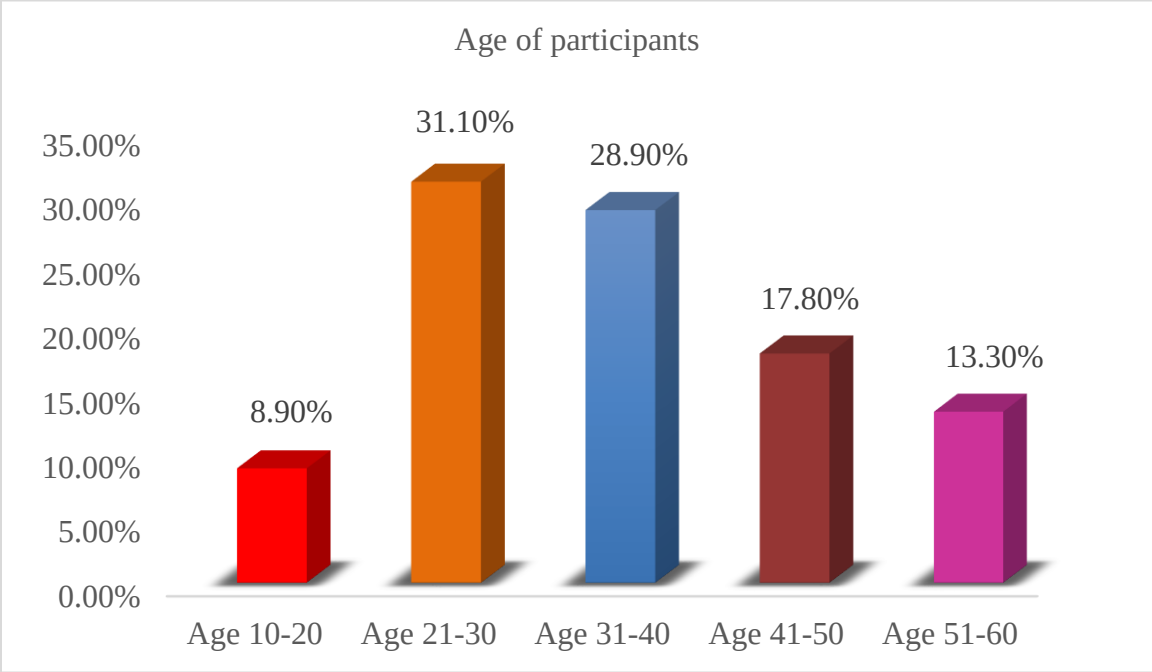


Figure-01: Age of participants

4.2 Gender

Out of 45 participants, the majority are male 84.40% (n=38) participants and female are 15.60% (n=7).

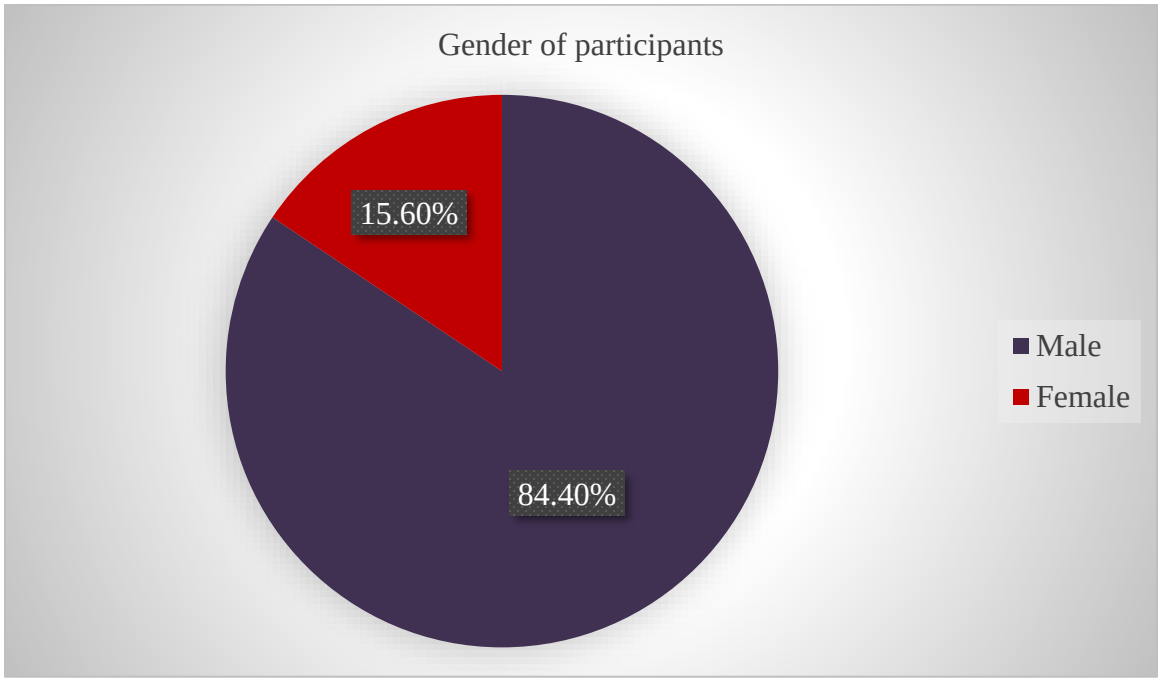


Figure-02: Age of participants.

4.3 Location of Initial symptoms

Among the 45 participants, where 51.10% (n=23) had location of initial symptoms like pain, heaviness in upper limb and 48.90% (n=22) had location of initial symptoms like pain, heaviness in lower limb.

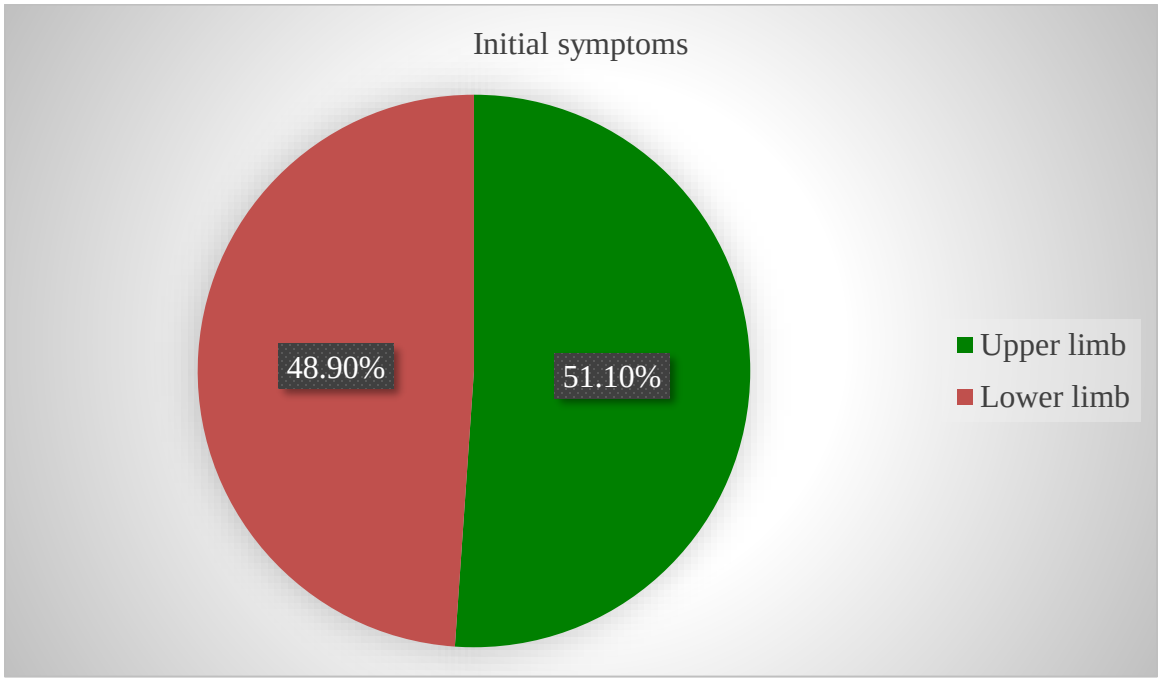


Figure-03: Initial symptoms.

4.4 Educational status

Among the 45 participants, where 2.20% (n=1) were illiterate, 22.20% (n=10) were completed primary, 17.8 (n=8) were completed SSC, 20% (n=9) were completed HSC, 33.30% (n=15) were completed Bachelor and 4.40% (n=2) were completed Masters-degree in educational status.

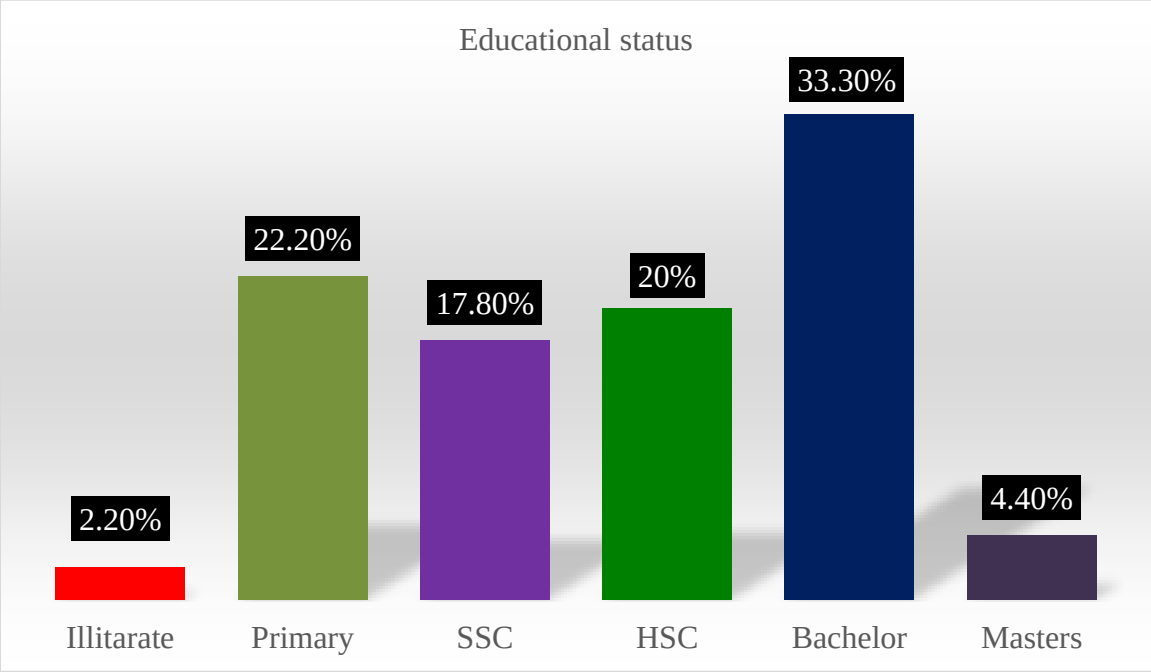


Figure-04: Educational status.

4.5 Living area

Out of 45 participants, where 51.10% (n=23) participants were rural area, 28.90% (n=13) participants are urban area, 20.00% (n=9) participants were semi-urban of living area.

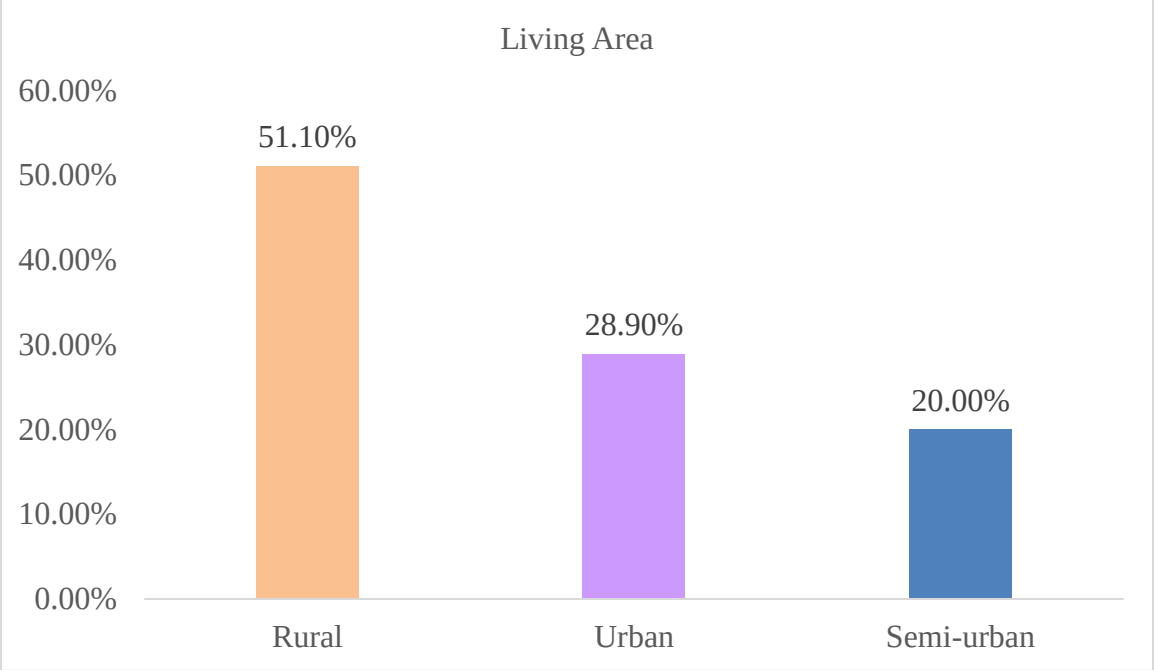


Figure-05: Living area.

4.6 Occupation

Out of 45 participants, 20% (n=9) participants were service holder, 22.20% (n=10) participants were businessman, 13.30% (n=6) participants were housewife, 22.20% (n=10) participants student, 6.70 (n=3) participants were teacher, 6.70 (n=3) participants are labor, 2.20% (n=1) participants were farmer, 6.70% (n=3) participants had other occupation.

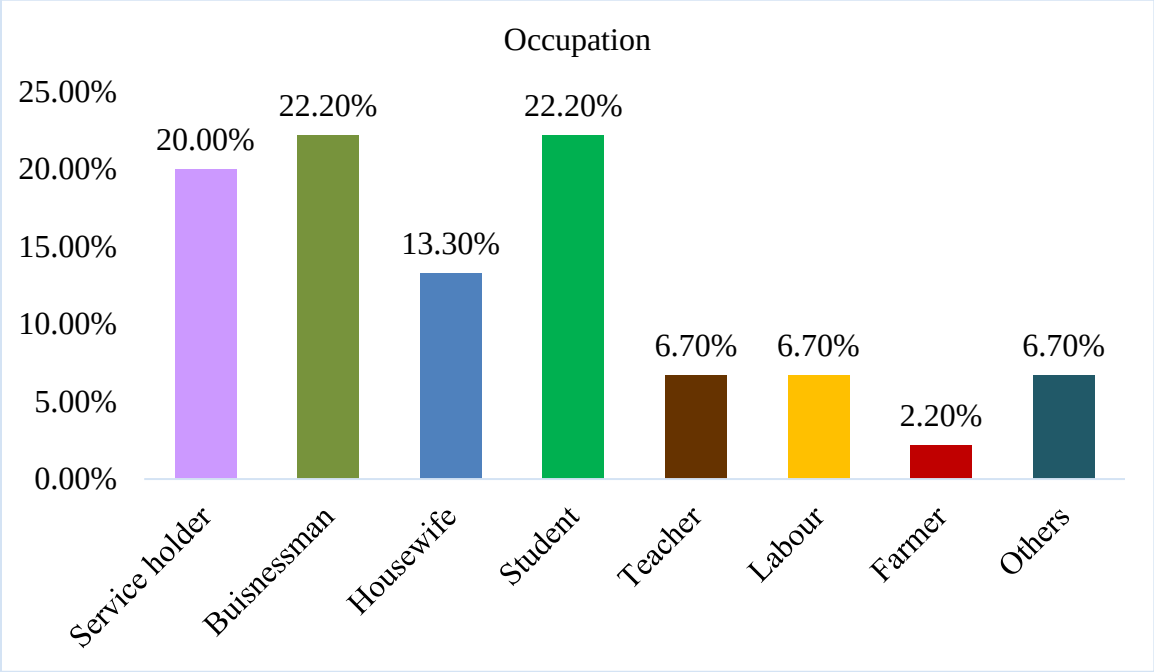


Figure-06: Occupation

4.7 Chronic disease

Among the 45 participants, 15.60% (n=7) have chronic disease such as high blood pressure, diabetics mellitus, heart disease and others chronic disease, 84.40% (n=38) have no chronic disease.

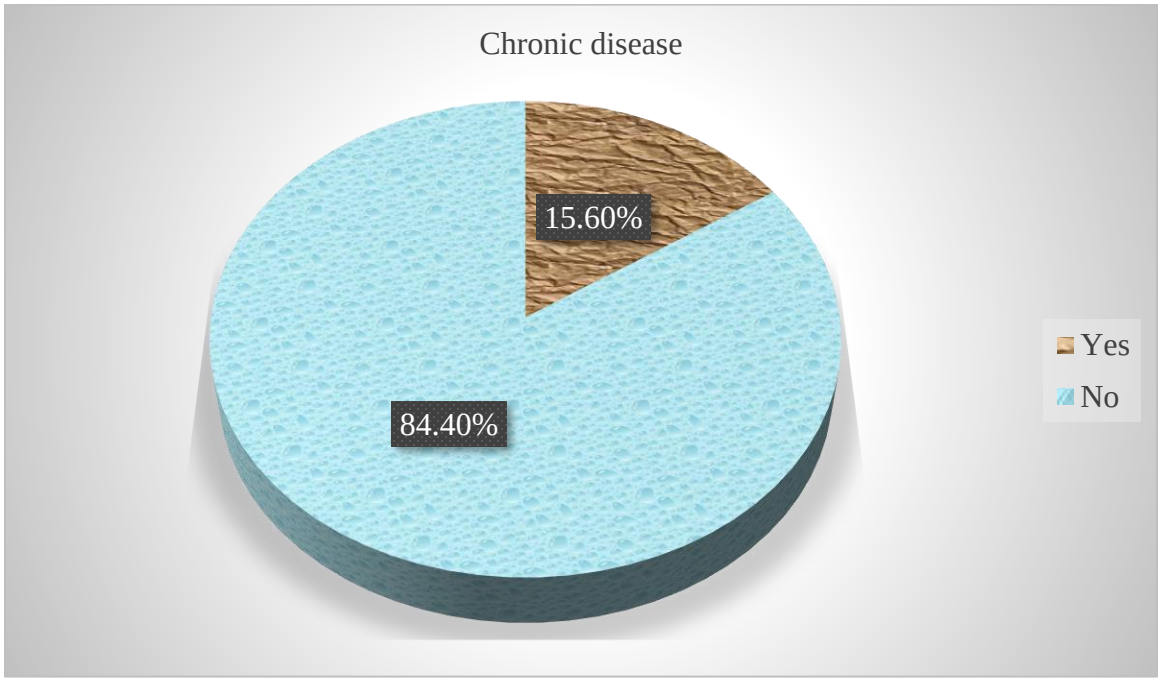


Figure-07: Chronic disease.

4.8 GBS disability status

Among 45 participants, where 2.20% (n=1) participants were within healthy state, 6.70%(n=3) participants were within minor symptoms and capable running, 57.80% (n=26) participants were within Able to walk 10m or more without assistance but unable to run, 28.90% (n=13) participants were within Able to walk 10m across an open space with help, 4.40% (n=2) participants were within Bedridden or chair bound.

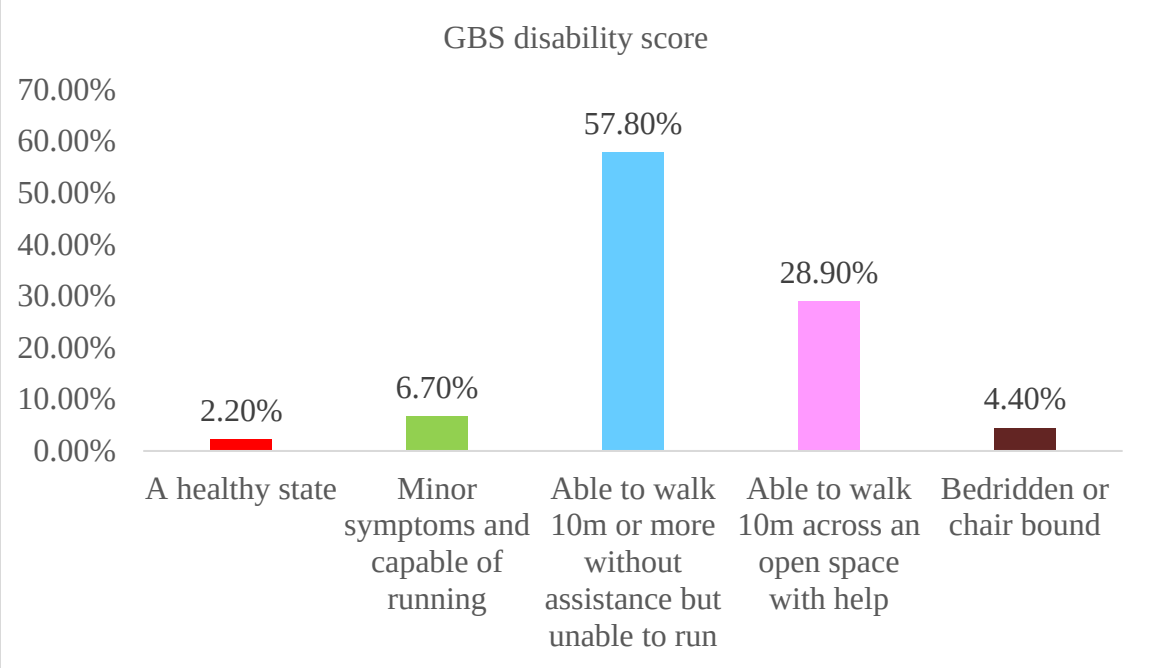


Figure-08: GBS disability status.

Descriptive analysis of SF-36 Scale

4.9 Physical functioning

In this study, 45 participants, where 22.20% (n=10) scored <25 at an average out of 100 which denotes very Poor physical functioning, 33.30% (n=15) scored 26-50 at an average out of 100 which denotes Poor physical functioning, 31.10% (n=14) scored 51-75 at an average out of 100 which denotes fair physical functioning, 13.30% (n=6) scored more than 75 at an average out of 100 which denotes good physical functioning through the short form-36 scoring system.

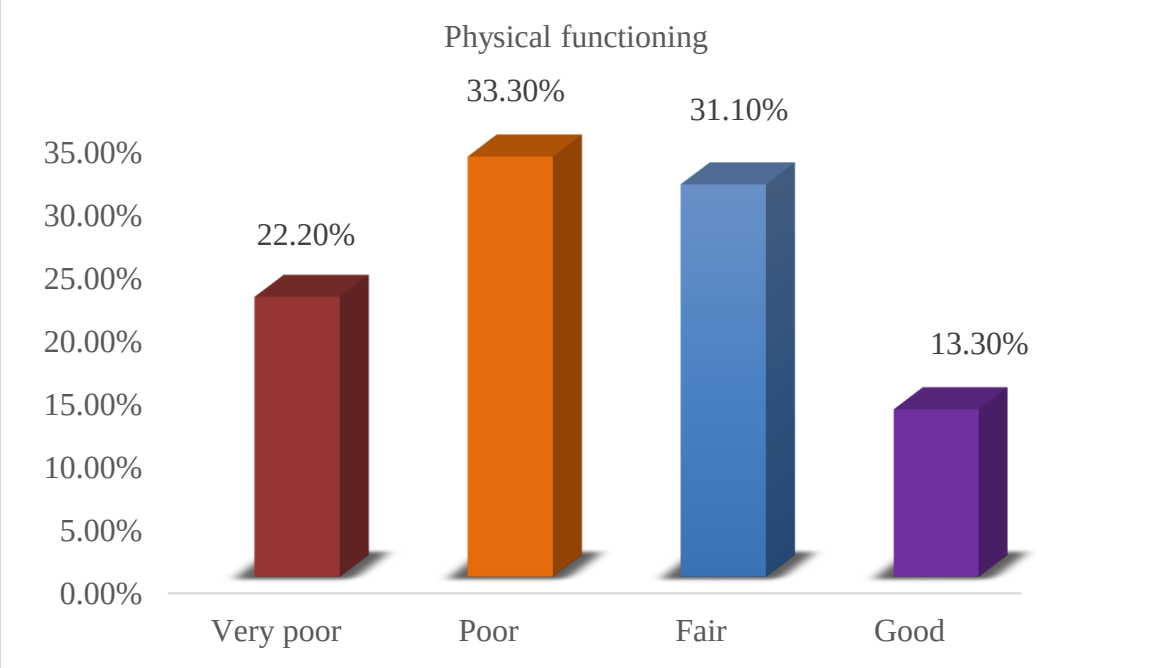


Figure-09: Physical functioning.

4.10 Role of physical

Among the 45 participants, where 24.40% (n=11) who scored less than 25 at an average out of 100 which denotes very Poor role of physical, 66.70% (n=30) who scored 26-50 at an average out of 100 which denotes Poor, 6.70% (n=3) who scored 51-75 at an average out of 100 which denotes fair, 2.20% (n=1) who scored more than 75 at an average out of 100 which denotes good.

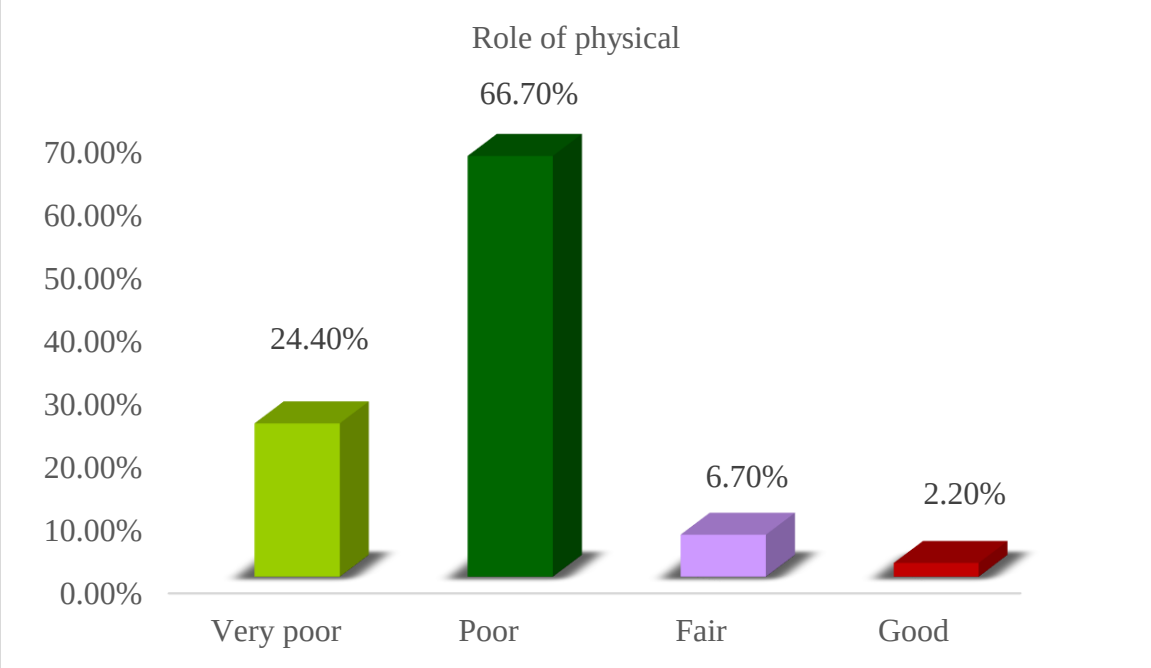


Figure-10: Role of physical.

4.11 Bodily pain

Among the 45 participants, 4.40% (n=2) scored <25 at an average out of 100 which denotes very poor physical status due to pain, 13.30% (n=6) scored 26-50 at an average out of 100 which denotes poor physical status due to pain , 31.10% (n=14) scored 51-75 at an average out of 100 which claims fair physical status and 51.10% (n=23) scored more than 75 at an average out of 100 which claims good physical status through the SF-36 scoring system.

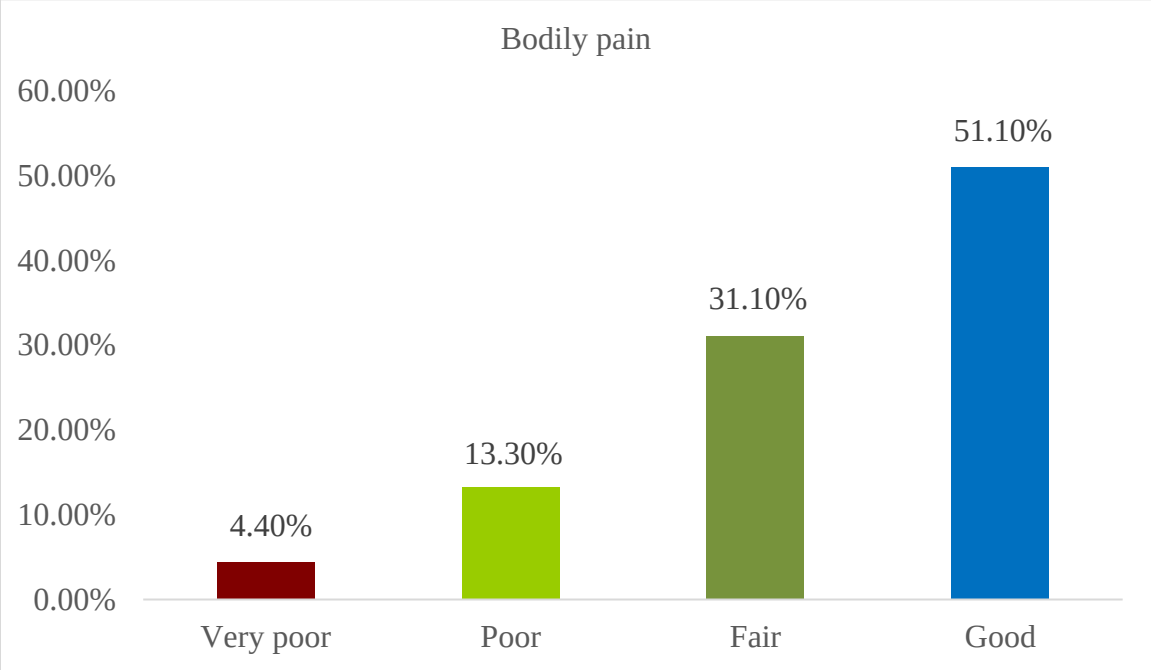


Figure-11: Bodily pain.

4.12 General Health

Among the 45 participants, 17.80% (n=8) scored 26-50 at an average out of 100 which denotes poor general health, 75.60% (n=34) scored 51-75 at an average out of 100 which claims fair general health and 6.70% (n=3) scored more than 75 average out of 100 which claims good general health through the short form-36 scoring system.

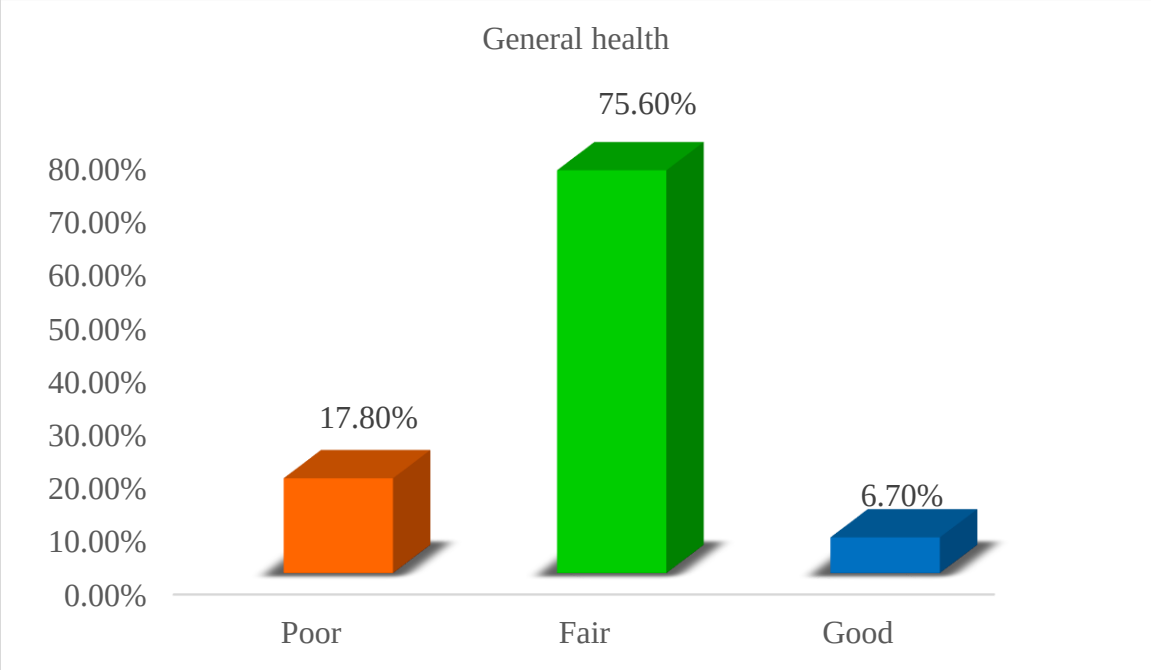


Figure-12: General health.

4.13 Vitality

Among the 45 participants, 4.40% (n=2) scored 26-50 at an average out of 100 which denotes poor vitality, 84.40% (n=38) scored 51-75 at an average out of 100 which denotes fair vitality and 11.10% (n=5) scored more than 75 at an average out of 100 which denotes good vitality through the SF-36 scoring system.

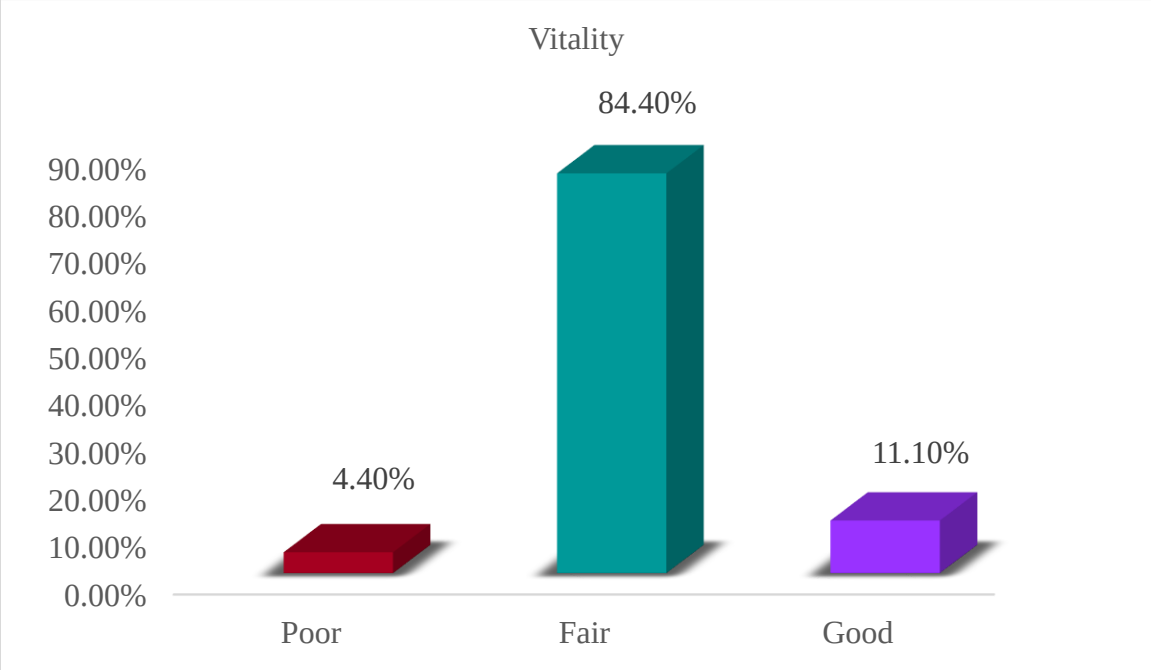


Figure-13: Vitality.

4.14 Social functioning

Out of 45 participants, 8.90% (n=4) scored <25 at an average out of 100 which denotes very poor social functioning, 75.60% (n=34) scored 26-50 at an average out of 100 which denotes poor social functioning, 13.30% (n=6) scored 51-75 at an average out of 100 which denotes fair social functioning 2.20% (n=1) scored more than 75 at an average out of 100 which denotes god social functioning through the short form-36 scoring system.

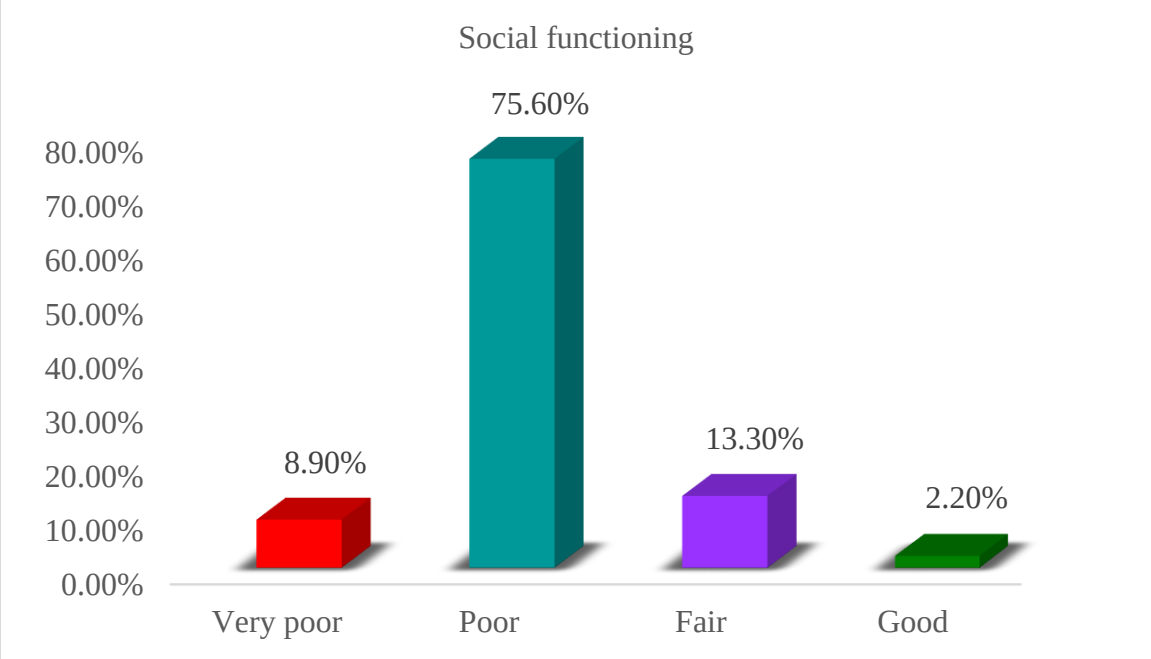


Figure-14: Social functioning.

4.15 Role of emotional

Among the 45 participants, 6.70% (n=3) scored <25 at an average out of 100 which denotes very poor role of emotion, 84.40% (n=38) scored 26-50 at an average out of 100 which denotes poor role of emotion, 6.70% (n=3) scored 50-75 at an average out of 100 which claims fair role of emotion and 2.20% (n=1) scored more than 75 at an average out of 100 which claims good of emotion through the short form-36 scoring system.

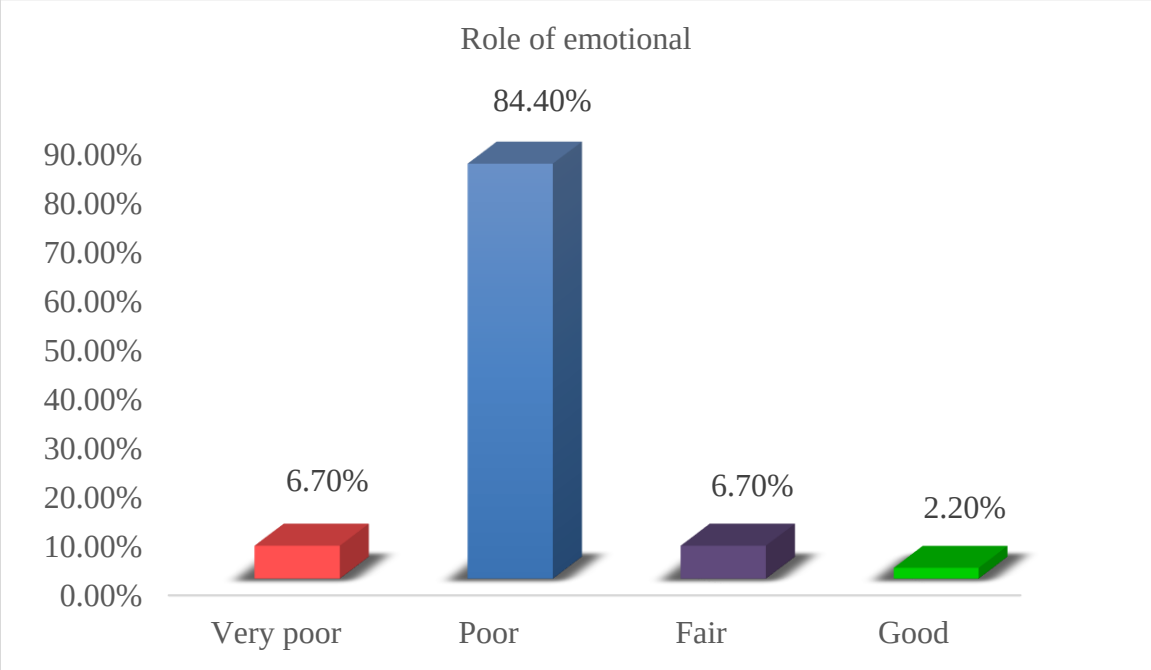


Figure-15: Role of emotional.

4.16 Mental health

Among the 45 participants, 57.80% (n=26) scored 51-75 at an average out of 100 which denotes fair mental health, 42.20% (n=19) scored more than 75 at an average out of 100 which claims good mental health through the short form-36 scoring system.

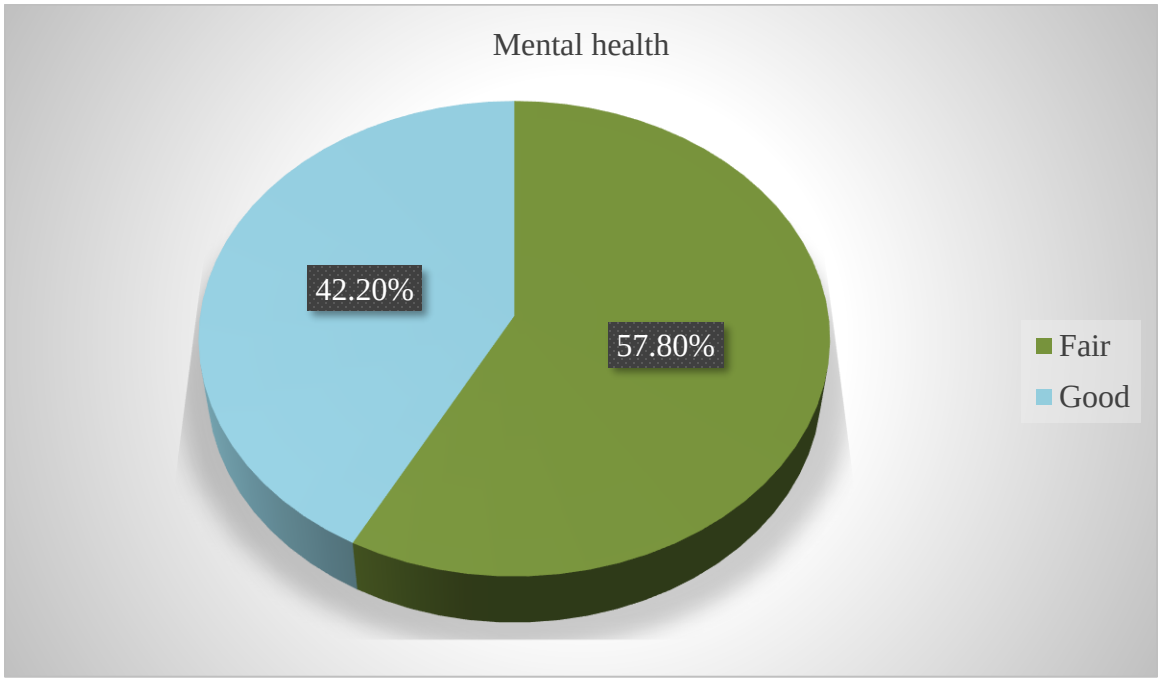


Figure-16: Mental health.

4.21 SF-36v2 Score Tabulation (Physical functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, Mental Health)

Score tabulation of all component of SF-36v2 (n=45)

Scale	Minimum	Maximum	Mean	±SD
Physical functioning	0	90	47.84	± 24.83
Role physical	12	81	36.02	±14.09
Bodily pain	25	100	77.69	± 21.23
General health	35	95	61.67	± 11.18
Vitality	44	88	68.76	± 9.30
Social Functioning	13	100	44.49	± 14.89
Role emotional	25	83	41.98	± 11.43
Mental Health	55	95	75.58	± 11.04

Above table showing that in physical functioning domain minimum 0, maximum 100, mean and SD is 47.84±24.83. Role of physical domain minimum 12, maximum 81, mean and SD is 36.02±14.09. Bodily pain domain minimum 25, maximum 100, mean and SD is 77.69± 21.23. General health domain minimum 35, maximum 95, mean and SD is 61.67± 11.18. Vitality domain minimum 44, maximum 88, mean and SD is 68.76± 9.30. Social functioning domain minimum 13, maximum 100, mean and SD is 44.49± 14.89. Role of emotional domain minimum 25, maximum 83, mean and SD is 41.98± 11.43. Mental health domain minimum 55, maximum 95, mean and SD is 75.58± 11.04.In

Among SF36 domains Bodily pain and Mental health has shown good functional improvement rather than other domains; General health & Vitality has shown fair functional improvement and Physical functioning, Role of physical & Emotional status, Social functioning has shown poor functional improvement.

Inferential statistical analysis

4.17 Association between age group of the participants and Components of SF-36v2 category (Physical functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, Mental Health) :

H_0: There is no relationship between age group of participants and Components of SF-36v2 category (Physical functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, Mental Health).

Ha: There is relationship between age group of participants and Components of SF-36v2 category (Physical functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, Mental Health).

Test assumption:

1. Two categorical variables including two or more subcategories.

2. 0 cells (0.0%) have expected count less than 5.

Level of significance ($p<0.05$)

Age Groups of the participants	**Component of SF-36v2**	**Chi-square value ($\chi 2$)**	**P-value**	**Significance**
10-20 years (n=4) 21-30 years (n=14)	Physical functioning	13.501	0.334	Not significant
	Role physical	8.056	0.781	Not significant
	Bodily pain	13.292	0.348	Not significant

31-40 years (n=13) 41-50 years (n=8) 51-60 years (n=6)	General health	9.238	0.323	Not significant
	Vitality	8.505	0.386	Not significant
	Social Functioning	10.941	0.534	Not significant
	Role emotional	15.215	0.230	Not significant
	Mental Health	3.552	0.470	Not significant

(α= 0.05)

Above table-2 showed the association between age group of participants and 8 domain of SF-36v2 (Physical functioning, Bodily pain, General health, Vitality, Role emotional, Mental health). A chi-squire test was conducted where the assumption of the test were met. Alpha value was determined (α= 0.05).

All the P-values are >0.05 therefore the null hypothesis cannot be rejected. Hence no statistically significant association was found between age group and SF-36v2 domains.

4.18 Association between age group of the participants and presence chronic disease

H_0: There is no association between age group of the participants and presence or absence of chronic disease.

H_a: There is an association between age group of the participants and presence or absence of chronic disease.

Test assumption:

1. Two categorical variables including two or more subcategories.

2. More than 20% cells have expected count less than 5.

Level of significance ($p<0.05$)

Age Groups of the participants	Presence of Chronic Disease of Participants	Fishers Exact Sig. (2-sided)	P-value	Significance
<30 years (n=19) >30 years (n=26)	Yes No	0.633	0.681	Not significant

(α= 0.05)

While conducting chi-squire test more than 20% cells have expected count less than 5 therefore the fisher exact significant value was considered.

Above table showed the association between age group of the participants and chronic disease

The P-value is <0.05 therefore the null hypothesis cannot be rejected. Hence no statistically significant association was found between age group of participants and presence or absence of chronic disease of participants.

4.19 Association between gender of participants and GBS disability score category

H_0: There is no association between gender of the participants and GBS disability score.

H_a: There is association between gender of the participants and GBS disability score.

Test assumption:

1. Two categorical variables including two or more subcategories.

2. More than 20% cells have expected count less than 5.

Level of significance ($p<0.05$)

Gender of the participants	GBS disability score of Participants	Fishers Exact Sig. (2-sided)	P-value	Significance
Male (n=38) Female (n=7)	Minor symptoms activity without assistance Moderate symptoms activity with assistance	5.414	0.032	Significant

(α= 0.05)

While conducting chi-squire test more than 20% cells have expected count less than 5 therefore the fisher exact significant value was considered.

Above table showed the Association between gender of participants and GBS disability score.

The P-value was >0.05 therefore the null hypothesis can be rejected and alternative hypothesis can be accepted. Hence statistically significant moderate association (phi=0.347) was found between gender of participants and GBS disability score.

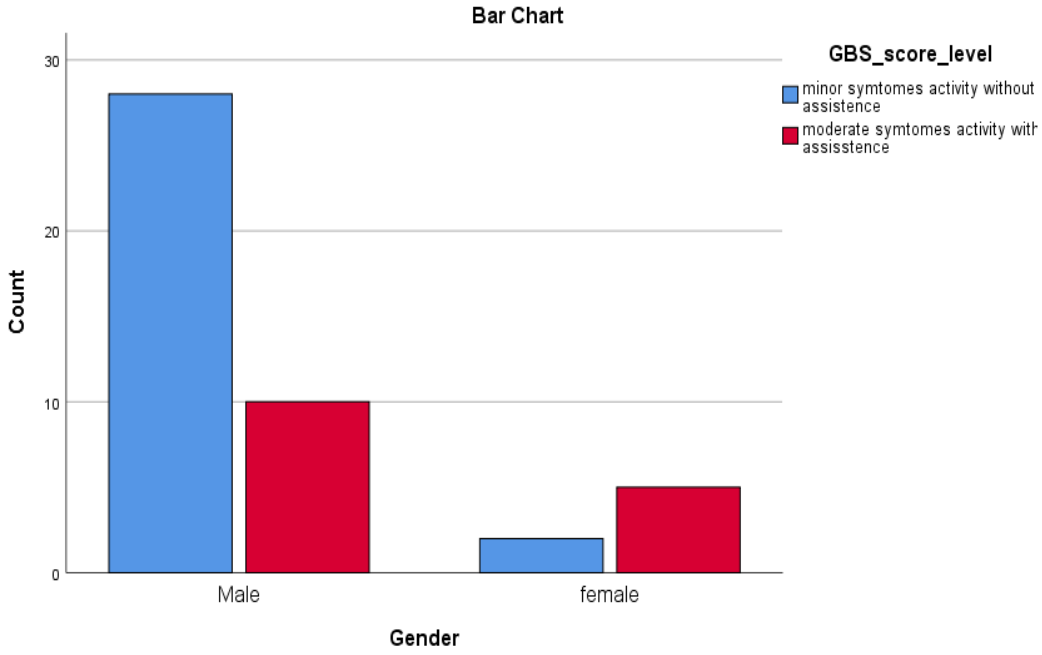


Figure-17: Association between gender of participants and GBS disability score.

In this Bar chart female participants are showing more vulnerable than male participants by identifying regarding activity with or without assistance.

4.20 Correlation between actual age count of participants and Components of SF-36v2 (Physical functioning, Role Physical, General Health, Vitality, Social Functioning, Mental Health) score and SF-36v2 subtotal score.

H_0: There is no association between actual age count of the participants and component of SF-36v2, SF-36v2 subtotal score.

H_a: There is association between actual age count of the participants and component of SF-36v2, SF-36v2 subtotal score.

Test assumption:

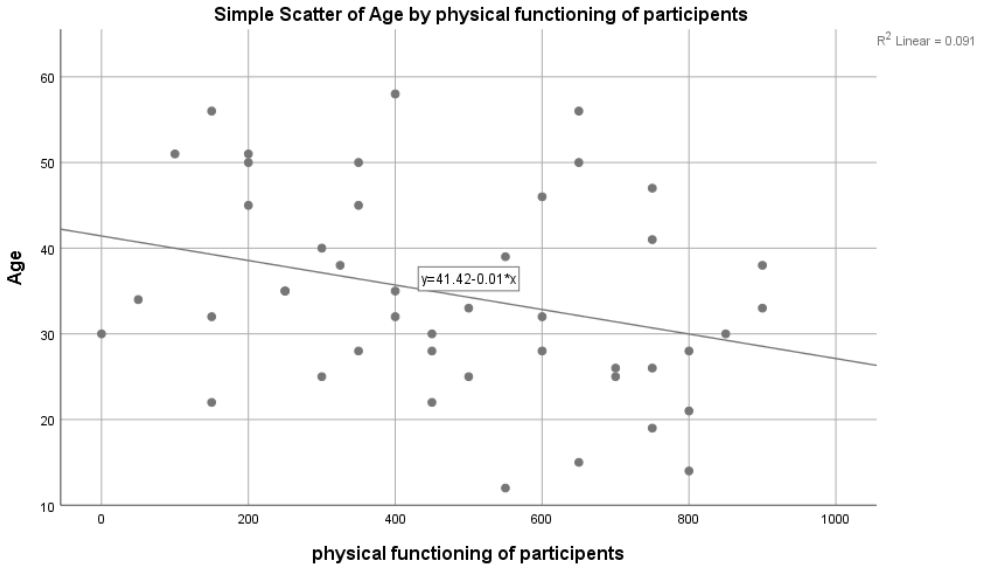
1. Two continuous variable
2. Normally distributed
3. Presence of linear association

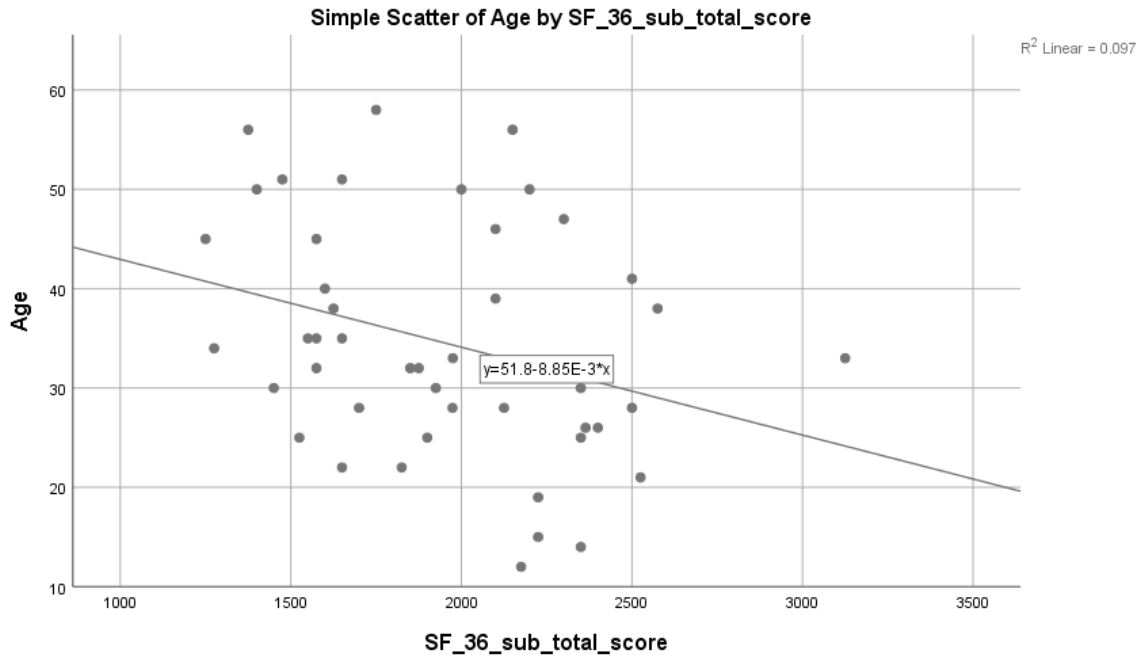
Level of significance (P value < .05).

Variable	Co-efficient value (r)	P-Value	Comment
Age & Physical functioning	-0.302	0.044	Significant negative moderate relationship
Age & Role of physical	-0.185	0.223	Not significant
Age & General health	-0.198	0.193	Not significant
Age & Vitality	-0.187	0.219	Not significant

Age & Social functioning	-0.130	0.393	Not significant
Age & Mental health	0.022	0.888	Not significant
Age & Subtotal score of SF-36	-0.311	0.038	Significant negative relationship

(α= 0.05)





Above table showed the Correlation between age of participants and Components of SF-36v2 (Physical functioning, Role Physical, General Health, Vitality, Social Functioning, Mental Health) individual scoring and SF-36v2 subtotal score.

Among 8 domains components only age and physical functioning (r=-0.302, P=0.044) and the subtotal score of SF-36(r=-0.311, P=0.038) denoted that there is medium strength negative correlation have been found.

Other 5 domains did not established significant relationship with age. 2 domains namely ‘bodily pain’ and ‘role of emotional’ didn’t meet the assumption therefore excluded from the test.

CHAPTER–V DISCUSSION

At present the quality of life has become a major topic of research in the area of health. The health related quality of life of patient with GBS was measured by the SF-36 and results showed a greater impact of the disease on the physical component than the mental component. A cross sectional study was used to assess the health related quality of life of individuals with Guillain Barre-Syndrome (GBS). As this was a cross-sectional study, this was considered as a preliminary study that can yield valuable information which clarify many important questions related to GBS and their quality of life. The obtained results may lead to the elaboration of strategies to reduce the impact caused by the disease in the life and health of the persons with GBS. This study showed that the 'severity of pain' and 'pain interferes in the work' did not hamper physical status. However the maximum number of participants felt 'physical health interferes in the normal work', 'limitations in bathing or dressing independently', 'accomplish less work than the participants want', as well as decline in energy and feeling tired most of the time. Hence, it was found that there was a reduced level of physical functioning in GBS clients.

Out of 45 participants where 8.90% (n=4) participants of age between 10 to 20 years, 31.10% (n=14) participants of age between 21 to 30 years, 28.90% (n=13) participants of age between 31 to 40 years, 17.80% (n=8) participants of age between 41 to 50 years, 13.30% (n=6) participants of age between 51 to 60 years. Mean age 34.58 years. Middle age participant are mostly affected.

Out of 45 participants, the majority are male 84.40% (n=38) participants and female are 15.60% (n=7).

Among the 45 participants, where 51.10% (n=23) had location of initial symptoms like pain, heaviness in upper limb and 48.90% (n=22) had location of initial symptoms like pain, heaviness in lower limb.

Among the 45 participants, where 2.20% (n=1) were illiterate, 22.20% (n=10) were completed primary, 17.8 (n=8) were completed SSC, 20% (n=9) were completed HSC, 33.30% (n=15) were completed Bachelor and 4.40% (n=2) were completed Masters degree in educational status.

Out of 45 participants, where 51.10% (n=23) participants were rural area, 28.90% (n=13) participants are urban area, 20.00% (n=9) participants were semi-urban of living area.

Out of 45 participants, 20% (n=9) participants were service holder, 22.20% (n=10) participants were businessman, 13.30% (n=6) participants were housewife, 22.20% (n=10) participants student, 6.70 (n=3) participants were teacher, 6.70 (n=3) participants are labour, 2.20% (n=1) participants were farmer, 6.70% (n=3) participants had other occupation.

Among the 45 participants, 15.60% (n=7) have chronic disease such as high blood pressure, diabetics mellitus, heart disease and others chronic disease, 84.40% (n=38) have no chronic disease.

Among 45 participants, where 2.20% (n=1) participants were within healthy state, 6.70%(n=3) participants were within minor symptoms and capable running, 57.80% (n=26) participants were within Able to walk 10m or more without assistance but unable to run, 28.90% (n=13) participants were within Able to walk 10m across an open space with help, 4.40% (n=2) participants were within Bedridden or chair bound. GBS outcome such as older age, female gender, greater disability at admission, short interval between symptom onset and admission (Walgaard et al., 2011). Witsch et al., (2013) found that out of 110 participants among the survivors, 53.8 % had a favorable outcome (defined as GBS disability score 0–1), 27.5 % had an intermediate (GBS disability score 2–3) and 18.7 % had an unfavorable outcome (GBS disability score 3). The latter group included the 15 death patients (GBS disability score 6).

Ten articles used the Medical Outcomes Study 36-item Short Form (SF-36), an instrument consisting of eight domain scores, which are the weighted sums of the questions in their section, and a mental and physical component score, which are both influenced by all eight items although the weight assigned to the domains differs for the two component scores (Ware and Sherbourne, 1992).

The SF-36 component summery scores mean of physical functioning (47.84), Role of physical (36.02), Bodily pain (77.69), General health (61.67) and the vitality (68.76), social

functioning (44.49), Role emotional (41.98) and mental health (75.58). The lowest score indicate the poor quality of life and highest score indicate the good quality of life.

The score was lowest for the role of physical domain and highest for the bodily pain domain. There are most affected domain were physical functioning (47.84), Role of physical (36.02), social functioning (44.49), Role emotional (41.98) and the highest score for the bodily pain domain. Lin et al., (2010) found their studies among the eight domain the score is lowest for the physical subscale and highest for the physical functioning domain. Reed et al. (2013) has said that one-third of the participants had poor overall quality of life at palliative care survivors with cancer. 66% has said that reported poor health satisfaction in quality of life at palliative center.

In this study, 45 participants, where 22.20% (n=10) scored <25 at an average out of 100 which denotes very Poor physical functioning, 33.30% (n=15) scored 26-50 at an average out of 100 which denotes Poor physical functioning, 31.10% (n=14) scored 51-75 at an average out of 100 which denotes fair physical functioning, 13.30% (n=6) scored more than 75 at an average out of 100 which denotes good physical functioning. Physical functioning domain minimum 0, maximum 100, mean and SD is 47.84±24.83.

Among the 45 participants, where 24.40% (n=11) who scored less than 25 at an average out of 100 which denotes very Poor role of physical, 66.70% (n=30) who scored 26-50 at an average out of 100 which denotes Poor, 6.70% (n=3) who scored 51-75 at an average out of 100 which denotes fair, 2.20% (n=1) who scored more than 75 at an average out of 100 which denotes good. . Role of physical domain minimum 12, maximum 81, mean and SD is 36.02±14.09. The ‘‘role-physical’’ domain, which was impaired in GBS patients in all but one study (Rudolph et al. 2008), assesses whether patients experience problems with work or other daily activities as a result of physical health.

Among the 45 participants, 4.40% (n=2) scored <25 at an average out of 100 which denotes very poor physical status due to pain, 13.30% (n=6) scored 26-50 at an average out of 100 which denotes poor physical status due to pain, 31.10% (n=14) scored 51-75 at an average out of 100 which claims fair physical status and 51.10% (n=23) scored more than 75 at an average out of 100 which claims good physical status. Bodily pain domain minimum 25,

maximum 100, mean and SD is 77.69± 21.23. Scores of GBS patients on the ‘‘body pain’’ domain were worse compared to healthy individuals in two studies (Rekand et al., 2009).

Among the 45 participants, 17.80% (n=8) scored 26-50 at an average out of 100 which denotes poor general health, 75.60% (n=34) scored 51-75 at an average out of 100 which claims fair general health and 6.70% (n=3) scored more than 75 average out of 100 which claims good general health. General health domain minimum 35, maximum 95, mean and SD is 61.67± 11.18.

Among the 45 participants, 4.40% (n=2) scored 26-50 at an average out of 100 which denotes poor vitality, 84.40% (n=38) scored 51-75 at an average out of 100 which denotes fair vitality and 11.10% (n=5) scored more than 75 at an average out of 100 which denotes good vitality. Vitality domain minimum 44, maximum 88, mean and SD is 68.76± 9.30. GBS patients were impaired on the ‘‘vitality’’ domain, indicating that the patient feels tired and worn out all the time (Darweesh et al., 2014).

Out of 45 participants, 8.90% (n=4) scored <25 at an average out of 100 which denotes very poor social functioning, 75.60% (n=34) scored 26-50 at an average out of 100 which denotes poor social functioning, 13.30% (n=6) scored 51-75 at an average out of 100 which denotes fair social functioning 2.20% (n=1) scored more than 75 at an average out of 100 which denotes good social functioning. Social functioning domain minimum 13, maximum 100, mean and SD is 44.49± 14.89. Kuitwaard et al. (2009) showed that the extent of interference with normal social activities due to physical and emotional problems is assessed in the ‘‘social functioning’’ domain. Djordjevic et al. (2020) found that after 3 months not significant improvement in social relations and emotions domains of SF-36.

Among the 45 participants, 6.70% (n=3) scored <25 at an average out of 100 which denotes very poor role of emotion, 84.40% (n=38) scored 26-50 at an average out of 100 which denotes poor role of emotion, 6.70% (n=3) scored 50-75 at an average out of 100 which claims fair role of emotion and 2.20% (n=1) scored more than 75 at an average out of 100 which claims good of emotion. Role of emotional domain minimum 25, maximum 83, mean and SD is 41.98±11.43**.** Rekand et al. (2009) showed that impairment of GBS patients in the ‘‘role-emotional’’ domain was observed in fair.

Among the 45 participants, 57.80% (n=26) scored 51-75 at an average out of 100 which denotes fair mental health, 42.20% (n=19) scored more than 75 at an average out of 100 which claims good mental health. Mental health domain minimum 55, maximum 95, mean and SD is 75.58±11.04.During follow-up, all HRQL scores showed a sharp increase, especially in the first 3 months. At 6 months, the mental component score and all principally mental domains of GBS patients were comparable to the reference group. (Darweesh et al., 2014).

In association it is found that there was no significant association between age group of the participants and Components of SF-36v2 category (Physical functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, Mental Health).

In association it is found there was no statistically significant association was found between age group of participants and presence or absence of chronic disease of participants.

There was a statistically significant association found between gender of participants and GBS disability score. Djordjevic et al. (2020b) showed that significant correlation between SF-36 domains and GDS score and physical domains showed the strongest correlation with GDS score and correlations between GDS score and mental and social functioning in SF-36 domains were weaker.

Among 8 domains components only age and physical functioning and the subtotal score of SF-36 denoted that there is medium strength negative correlation have been found. Other 5 domains did not established significant relationship with age. 2 domains namely ‘bodily pain’ and ‘role of emotional’ didn’t meet the assumption therefore excluded from the test.

5.1 Limitation of the Study:

There were a number of limitations and barriers in this research project which had affect the accuracy of the study. SF-36V2 questionnaire was used in this study based on Indian population and their culture although there are quite differences in culture and population. The samples were collected only from the CRP at Savar and the sample size was very small, so the result of the study could not be generalized to the whole population of GBS patients in Bangladesh. There was little evidence to support the result of this project in the context to Bangladesh. A convenience sampling was used that was not reflecting the wider population under study. The research project was done by an undergraduate student and it was first research project for him. So the researcher had limited experience with techniques and strategies in terms of the practical aspects of research. As it was the first survey of the researcher so might be there were some mistakes that overlooked by the supervisor and the honorable teacher.

CHAPTER – VI CONCLUSION & RECOMMENDATION

6.1 Conclusion

Among 45 GBS patients evaluation, the majority are male 84.40% (n=38) participants and female are 15.60% (n=7). Female participants are more vulnerable than male participants by identifying regarding activity with or without assistance. Among SF36 domains the lowest score indicate the poor quality of life and highest score indicate the good quality of life. Bodily pain and Mental health has shown good functional improvement rather than other domains; General health & Vitality has shown fair functional improvement and Physical functioning, Role of physical & Emotional status, Social functioning has shown poor functional improvement.

The score was lowest for the role of physical and highest for the bodily pain domain. Most affected domain were physical functioning, Role of physical, social functioning, role emotional and the highest score for the bodily pain. This study showed that the Quality of Life of Persons with GBS was remarkably lower. For patients with GBS, achieving a satisfactory HRQOL is a primary goal of treatment and rehabilitation. Along with greater awareness and proper counseling, necessary steps should be taken to improve the physical and mental health of persons with GBS, in order to improve their quality of life.

6.2 Recommendation

The aim of the study was to assess the health related quality of life of person with GBS. Though the study had some limitations but investigator identified some further step that might be taken for the better accomplishment of further research. The main recommendations would be as follow:

- Patients screening is suggested before collecting data for preventing drop-out of the participants.

- The duration of the study was relatively short, so in future wider time would be taken for conducting the study.

- This study was done in hospital setting. So, home based and community based quality of life study for GBS patients is encouraged with large sample size and patient follow-up.

- In this study, the investigator collected data from a selected hospital setting. So for further study investigator strongly recommended to include different hospital settings from all over the Bangladesh to ensure the generalized ability of this study.

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Appendix-I

সম্মতিপত্র বাংলা

আসসালামু আলাইকুম,
আমি মোঃ আল-আমিন, ৪র্থ বর্ষ বিএসসি ইন ফিজিওথেরাপির ছাত্র। এই গবেষণা প্রকল্পটি আমার কোর্স এর অধিভুক্ত। আমি "**গুলিয়ান বারি সিনড্রোম (জি বি এস) রোগীদের স্বাস্থ্য সম্পর্কীত জীবনযাত্রার মান**" এর উপর গবেষণা করছি ।
এই গবেষণার উদ্দেশ্য হলো **গুলিয়ান বারি সিনড্রোম (জি বি এস) রোগীদের স্বাস্থ্য সম্পর্কীত জীবনযাত্রার মান নির্ণয় করা।** আমি এক্ষেত্রে আপনাকে কিছু ব্যক্তিগত , রোগের বৈশিষ্ট্য এবং সংশ্লিষ্ট নিয়ামকের আনুসাঙ্গিক কিছু প্রশ্ন করতে চাচ্ছি। এতে আনুমানিক ২০-৩০ মিনিট সময় লাগবে। আমি আপনাকে অবগত করছি যে, এটা আমার অধ্যয়নের অংশ এবং যা অন্য কোনো উদ্দেশ্যে ব্যবহৃত হবে না । এই গবেষণায় আপনার অংশগ্রহণ বর্তমান ও ভবিষ্যৎ চিকিৎসায় কোনো প্রকার প্রভাব ফেলবে না। আপনি যেসব তথ্য প্রদান করবেন তার গোপনীয়তা বজায় থাকবে এবং আপনার প্রতিবেদনের ঘটনা প্রবাহে এটা নিশ্চিত করা হবে যে এই তথ্যের উৎস অপ্রকাশিত থাকবে। 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।
এই অধ্যয়নে অংশগ্রহণকারী হিসেবে যদি আপনার কোন প্রশ্ন থাকে তাহলে আপনি আমার সাথে অথবা / নিম্নবর্ণিত ব্যক্তির সাথে যোগাযোগ করতে পারেন।

মোঃ আল-আমিন
চতুর্থ বর্ষ
বি এস সি ইন ফিজিওথেরাপি
বি এইচ পি আই, সি আর পি.
(মোবাইল নংঃ ০১৭৬১-৩২৭৫২৫)

আমি কি আপনার অনুমতি নিয়ে সাক্ষাৎকার শুরু করতে পারি?

হ্যাঁ / না

অংশগ্রহণকারীর স্বাক্ষর ও তারিখ.....

উপাত্ত সংগ্রহ কারীর স্বাক্ষর ও তারিখ.....

ফিজিওথেরাপিস্টের স্বাক্ষর ও তারিখ.....

English Verbal Consent Form

Assalamu Alaikum,

I am MD.AL-AMIN, 4th year BSc in physiotherapy student. I am conducting this thesis as per the requirement of my study module. The Thesis titled **"Health related quality of life of the person with Guillain-Barre Syndrome (GBS)"**

The study aim is to find out the Quality of life of the person with GBS. To find out that I need to ask several questions to the participants. The entire session will take approximately 20-30 minutes.

I would like to also inform you that this is a purely academic study and will not be used for any other purpose. Your participation in the research will have no impact on your present or future treatment. All information provided by you will be kept confidential and in the event of any report or publication, it will be ensured that the source of information remains secret.

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.

Your participation will be voluntary therefore any type of remuneration will not be provided. No additional intervention will be provided.

If you have any queries about the study you may contact with me / can contact the person describe below.

MD. AL-AMIN

4th year

BSc in Physiotherapy

BHPI, CRP.

(Mobile no: 01761-327525).

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

Yes / No

Signature and date of the Participant …….

Signature and date of the Interviewer ……

Signature and date of the physiotherapist …….

Appendix-II

Questionnaire- বাংলা

পর্ব ১: ব্যক্তিগত বিবরণ

নামঃ

ঠিকানাঃ

যোগাযোগের নাম্বারঃ

রোগীর আইডিঃ

সাক্ষাতকারের তারিখঃ

পর্ব-২: জনসংখ্যাতাত্ত্বিক তথ্যাবলী

এই প্রশ্নপত্রটি গুলিয়ান বারি সিনড্রোম (জিবিএস) রোগীদের জীবনযাত্রার মান নির্ণয় করার জন্য তৈরি করা হয়েছে এবং এই পর্বটি ফিজিওথেরাপিস্ট বলপেন ব্যবহার করে পূরণ করবেন।

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

ক্রমিক নং	প্রশ্নসমূহ	অংশগ্রহণকারীর মতামত	কোড নং
১.১	বয়স (বছর):	……..বছর	
১.২	লিঙ্গ	পুরুষ মহিলা	০১ ০২
১.৩	রোগের সুত্রপাত	……..…….…	
১.৪	শিক্ষাগত যোগ্যতা	নিরক্ষর…….. প্রাইমারি……..….. এস এস সি……. এইস এস সি……. স্নাতক পাশ ……. স্নাতকোত্তর…….. অন্যান্য…….	০১ ০২ ০৩ ০৪ ০৫ ০৬ ০৭
১.৫	বসবাসের স্থান	গ্রাম শহর	০১ ০২

		উপ শহর পার্বত্য অঞ্চল	০৩ ০৪
১.৬	পেশা	চাকুরীজীবী ব্যবসায়ী গৃহিণী ছাত্র/ছাত্রী শিক্ষক শ্রমিক কৃষক অন্যান্য.....	০১ ০২ ০৩ ০৪ ০৫ ০৬ ০৭ ০৮
১.৭	পরিবারের ধরণ	ছোট পরিবার যৌথ পরিবার	০১ ০২
১.৮	প্রাথমিক লক্ষণ	জ্বর সর্দি ডাইরিয়া জি আই টি লক্ষণ অন্যান্য…….	০১ ০২ ০৩ ০৪
১.৯	আপনার কোন দীর্ঘস্থায়ী রোগ আছে কি না?	উচ্চরক্তচাপ…….. বহুমূত্র……. হৃদ রোগ…… রোগ প্রতিরোধ ক্ষমতা কমে যাওয়া পুষ্টি হিন্নতা অন্যান্য…….	০১ ০২ ০৩ ০৪ ০৫ ০৬
১.১০	আপনি কত মাস যাবত ফিজিওথেরাপি নিচ্ছেন?	..... মাস	

পর্ব ৩:গুলিয়ান-বারি সিনড্রোম ডিজাবিলিটি স্কেল

বর্তমানে আপনার শারিরীক অবস্থা কেমন?

বর্ণনা	কোড নং
সন্তোষ জনক সুস্থতা	০
সল্পলক্ষণ এবং দৌড়ানোর সক্ষমতা	১
সহায়তা ছাড়াই 10 মিটার বা তার বেশি হাঁটতে সক্ষম তবে দৌড়াতে অক্ষম	২
সহায়তা নিয়ে একটি খোলা জায়গা জুড়ে 10 মিটার হাঁটার সক্ষমতা	৩
শজ্জাসয়ী অথবা চেয়ারের উপর নির্ভরশীল	৪
দিনের অন্তত কিছু সময়ের জন্য শ্বাস-প্রশ্বাস সহায়ক যন্ত্রের প্রয়োজনীয়তা	৫
মৃত	৬

পর্ব ৪: জীবন যাত্রার মান (এস এফ-৩৬ স্বাস্থ্য সম্পর্কিত জরিপ)

এই প্রশ্নগুলোতে আপনার স্বাস্থ্য সম্পর্কে আপনার মতামত জানতে চাওয়া হয়েছে । এই তথ্যগুলি দ্বারা আপনি কি অনুভব করেন এবং কতটা ভালভাবে আপনার প্রাত্যাহিক কর্মসম্পাদনে সক্ষম সে ব্যাপারে নজর রাখতে সাহায্য করবে । এই সমীক্ষাটি সম্পূর্ণ করার জন্য আপনাকে ধন্যবাদ ।

নিম্নলিখিত প্রতিটি প্রশ্নের উত্তরগুলোর মাঝে যেটিকে আপনার সবচেয়ে সঠিক বলে মনে হয়, অনুগ্রহপুর্বক সেগুলোতে টিক চিহ্ন দিন ।

ক। সাধারনভাবে বলতে , আপনার মতে আপনার স্বাস্থ্য হলঃ

- চমৎকার
- খুব ভাল
- ভাল
- মোটামুটি
- খারাপ

খ। গত এক বছর এর সাথে তুলনা করলে আপনার স্বাস্থ্য কেমন ?

- গত এক বছরের তুলনায় এখন অনেক ভাল
- গত এক বছরের তুলনায় এখন খানিকটা ভাল
- প্রায় গত এক বছরের মতন

- গত এক বছরের তুলনায় এখন কিছুটা খারাপ
- গত একবছরের তুলনায় এখন অনেক খারাপ

গ। নিম্নলিখিত প্রশ্নগুলো আপনি একটি সাধারণ দিনে যেসব কাজকর্ম করে থাকেন সেই সম্পর্কিত। আপনার স্বাস্থ্য কি আপনার কাজকর্ম বাঁধা হয়ে দাড়িয়েছে? যদি হয়, তবে কতটুকু?

গ.১। খুব পরিশ্রমসাধ্য কাজগুলি, যেমন দৌড়ানো, ভারি জিনিস তোলা, শ্রমসাধ্য খেলাধুলা করা -

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

গ.২। অপেক্ষাকৃত কম পরিশ্রমসাধ্য কাজগুলি, যেমন টেবিল সরানো, ঘর ঝারু দেওয়া, বাগানে কাজ করা অথবা সাইকেল চালানো –

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

গ.৩। মুদিখানার পন্যদ্রব্য তোলা বহন করা –

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

গ.৪। কয়েক তলা সিঁড়ি বেয়ে উঠা-

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

গ.৫। একতলা সিঁড়ি বেয়ে উঠা-

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

গ.৬। ঝুকে কিছু করা, হাঁটু গেড়ে বসা, নিচু হয়ে কাজ করা-

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

গ.৭। এক মাইলের বেশি হাঁটা –

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

গ.৮। কয়েকশত মিটার হাঁটা-

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

গ.৯। একশো মিটার হাঁটা-

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

গ.১০। নিজে নিজে গোসল করা বা জামাকাপড় পড়া-

- হ্যাঁ, অনেকখানি বাঁধা হয়ে দাঁড়িয়েছে
- হ্যাঁ, খানিকটা বাঁধা হয়ে দাঁড়িয়েছে
- না, একেবারেই বাঁধা হয় নি

ঘ। বিগত চার সপ্তাহে, প্রাত্যহিক জীবনের কাজগুলো সম্পাদন করতে গিয়ে আপনার সাস্থ্যের জন্য আপনি কি পরিমা্ণ সমস্যার মুখে পড়েছেন ?

ঘ.১। আপনার কর্মস্থলে এবং অন্যান্য কাজগুলোতে আপনি কম সময় দিয়েছেন –

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়
- কখনই নয়

ঘ.২। আপনি যতটুকু চেয়েছিলেন তার চেয়ে কম কাজ করেছেন –

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়
- কখনই নয়

ঘ.৩। আপনার নিজের কাজ বা অন্যান্য কাজেই সীমাবদ্ধ ছিলেন –

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়
- কখনই নয়

ঘ.৫। আপনার নিজের কাজ বা অন্যান্য কাজ করতে গিয়ে অসুবিধা বোধ করেছিলেন –

- সবসময়
- বেশির ভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়
- কখনই নয়

ঙ। বিগত চার সপ্তাহে, প্রাত্যহিক জীবনের কাজগুলো সম্পাদন করতে গিয়ে আপনার মানসিক সমস্যার কারণে আপনি নিচের কোন সমস্যাগুলোর মুখে পড়েছেন ? (যেমন – মানসিক চাপ বা দুশ্চিতাগ্রস্থ হওয়া)।

ঙ.১। আপনার কর্মস্থলে এবং অন্যান্য কাজগুলোতে আপনি কম সময় দিয়েছেন –

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়
- কখনই নয়

ঙ.২। আপনি যতটুকু চেয়েছিলেন তার চেয়ে কম কাজ করেছেন –

- সবসময়
- বেশির ভাগ সময়

- মাঝেমধ্যে
- খুব কম সময়
- কখনই নয়

ঙ.৩। অন্যান্য সময়ের চেয়ে কাজে কম মনযোগ দিয়েছেন –

- সবসময়
- বেশির ভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়
- কখনই নয়

চ। বিগত চার সপ্তাহে আপনার শারীরিক বা মানসিক সমস্যাগুলি আপনার পরিবার , বন্ধুবান্ধব , প্রতিবেশী বা গোষ্ঠীর সাথে সামাজিক কাজকর্মে কতখানি বাঁধা সৃষ্টি করেছে?

- একেবারে না
- সামান্য রকম
- মাঝামাঝি রকম
- অনেখানি
- অত্যন্ত বেশিরকম

ছ। গত চার সপ্তাহে , আপনি কতখানি শারীরিক ব্যাথা অনুভব করেছেন?

- একেবারে না
- সামান্য রকম
- মাঝামাঝি রকম
- অনেখানি
- অত্যন্ত বেশিরকম

জ। গত চার সপ্তাহে , আপনি কতখানি শারীরিক ব্যাথা আপনার প্রাত্যাহিক কাজে কি পরিমাণ বাঁধা সৃষ্টি করেছে (ঘরে ও বাইরে) ।

- একেবারে না
- সামান্য রকম
- মাঝামাঝি রকম
- অনেখানি
- অত্যন্ত বেশিরকম

ঝ। বিগত চার সপ্তাহে, আপনার শারীরিক অবস্থা কেমন ছিল এবং আপনি কেমন অনুভব করেছিলেন নিচের প্রশ্নগুলো সেই সম্পর্কিত। প্রতিটি প্রশ্ন এর জন্য আপনি যেমন অনুভব করেছিলেন সে অনুযায়ী সবচেয়ে প্রযোজ্য উত্তরটি দিন।

গত চারসপ্তাহে কতবার –

ঝ.১। আপনি কি খুব স্বাচ্ছন্দবোধ করেছিলেন?

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ঝ.২। আপনি কি খুব বিচলিত ছিলেন?

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ঝ.৩।আপনি কি এমনই হতাশাগ্রস্থ হয়ে পড়েছিলেন যে কোনকিছুই আপনাকে উদ্দীপিত করতে পারছিলনা?

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ঝ.৪। আপনি কি খুব স্থির ও শান্ত ছিলেন ?

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ঝ.৫। আপনার কি প্রচুর প্রাণশক্তি ছিল ?

- সবসময়
- বেশিরভাগসময়
- মাঝেমধ্যে
- খুবকমসময়

ঝ.৬। আপনি কি মানসিকভাবে হতাশ ও মনমরা হয়ে পড়েছিলেন ?

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ঝ.৭। আপনি কি বিপর্যস্থবোধ করেছিলেন ?

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ঝ.৮। আপনি কি আনন্দে ছিলেন ?

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ঝ.৯। আপনি কি ক্লান্ত ছিলেন ?

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ঞ। বিগত চার সপ্তাহে, আপনার শারীরিক এবং মানসিক সমস্যাগুলো আপনাকে সামাজিক কার্যক্রমে কি পরিমাণ বাধার সৃষ্টি করেছে ? (যেমন – বন্ধু-বান্ধব এবং আত্মীয়-স্বজনদের সাথে দেখা করতে যাওয়া)।

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ট। নিম্নলিখিত বিবৃতিগুলো প্রত্যেকটি আপনার ক্ষেত্রে কতটুকু সত্য বা মিথ্যা ?

ট.১। আমার মনে হয় অন্যান্য মানুষের চেয়ে একটু বেশি অসুস্থ হয়ে পড়ি –

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ট.২। আমি আমার জানাশোনা মানুষ গুলোর মতই সুস্থ্য –

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ট.৩। আমি আমার স্বাস্থ্য খারাপ হবার আশংকা করি –

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

ট.৪। আমার স্বাস্থ্য অনেক ভাল –

- সবসময়
- বেশিরভাগ সময়
- মাঝেমধ্যে
- খুব কম সময়

[এই প্রশ্নগুলির উত্তর সম্পুর্ন করার জন্য আপনাকে ধন্যবাদ]

Questionnaire- English

SECTION-1: Personal Details

Name:

Address:

Contact Number:

Patient ID:

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 physiotherapist 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**	**Code No.**
1.1	Age (in year):	……..years	
1.2	Sex	o Male o Female	**01** **02**
1.3	Disease onset	……..……	
1.4	Educational status	o Illiterate…… ……. o Primary……...…..... o Secondary school certificate (SSC) … o Higher secondary certificate (HSC)…	**01** **02** **03** **04**

		○ Bachelor ……... ○ Masters or above……. ○ Other (Specify): _____	**05** **06** **07**
1.5	Living area	○ Rural ○ Urban ○ Semi-urban ○ Hill tracks	**01** **02** **03** **04**
1.6	Occupation	○ Service holder ○ Businessman ○ Housewife ○ Student ○ Teacher ○ Labor ○ Farmer ○ Other.....	**01** **02** **03** **04** **05** **06**
1.7	Family type	○ Nuclear family ○ Extended family	**01** **02**
1.8	Symptoms at onset	○ Fever ○ Cold ○ Diarrhoea ○ GIT symptoms ○ Others	**01** **02** **03** **04** **05**

1.9	Do you have any chronic disease?	o HTN…… o DM……. o Heart Diseases…… o Immune deficiency disorder o Nutritional disorder o Others…….	**01** **02** **03** **04** **05** **06**
1.10	How many times have you take physiotherapy		**01** **02**

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: Quality Of Life Scale (SF-36 V2 Health Survey)

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

A. In general, would you say about your health related quality of life?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

B. Compared to one year ago, how would you rate your health in general now?

1. Much better now than a year ago
2. Somewhat better now than a year
3. About the same as one year ago
4. Somewhat worse now than one year ago
5. Much worse now than one year ago

C. The following items are about activities you might to do during a typical day. Does your health now limit you in these activities? If so, how much?

C.1 Vigorous activities, such as running, lifting heavy object, participating in strenuous sports.

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

C.2 Moderate activates, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

C.3. Lifting or carrying groceries

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

C.4. Climbing several flights of stairs

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

C.5. Climbing one flight of stairs.

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

C.6 Forward bending, kneeling or stooping

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

C.7 Walking more than a mile

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

C.8 Walking several hundred yards

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

C.9 Walking one hundred yards

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

C.10 Bathing or dressing yourself

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

D. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of a physical health?

D.1 Cut down on the amount of time you spent on work or other activities

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

D.2 Accomplished less than you would like?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

D.3 Were limited in the kind of work or other activities?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

D.4 Had difficulty performing the work or other activities (for example, it took extra time)

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

E. Have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depression or anxious)?

E.1 Cut down the amount of time you spent on work or other activities?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

E.2 Accomplished less than you would like?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

E.3 Didn’t do work or other activities as carefully as usual

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

F. What extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups?

1. Not at all
2. Slightly
3. Moderately
4. Quite a bit
5. Extremely

G. How much bodily pain have you had during the past 4 week?

1. Not at all
2. Slightly
3. Moderately
4. Quite a bit
5. Extremely

H. How much pain interferes with your normal work (including both work outside the home and housework?

1. Not at all
2. Slightly
3. Moderately
4. Quite a bit
5. Extremely

I. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks.

I.1 Did you fell full of pep?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

I.2 Have you been a very nervous person?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

I.3 Have you felts so down in the dumps nothing could cheer you up?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

I.4 Have you felt calm and peaceful?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

I.5 Did you have a lot of energy?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

I.6 Have you felt downhearted and blue?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

I.7 Did you feel worn out?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

I.8 Have you been a happy person?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

I.9 Did you feel tired?

1. All of the time
2. Most of the time

3. Some of the time
4. A little of the time
5. None of the time

J. How much of the time physical or emotional problems interfere your social activities (like visiting friends, relative neighbors etc.)?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

K. How true or false is each of the following statements for you?

K.1 I seem to get sick a little easier than other people

1. Definitely true
2. Mostly true
3. Don’t known
4. Mostly false
5. Definitely false

K.2 I am as healthy as anybody I know

1. Definitely true
2. Mostly true
3. Don’t known
4. Mostly false
5. Definitely false

K.3 I expect my health to get worse

1. Definitely true
2. Mostly true
3. Don’t known

4. Mostly false
5. Definitely false

K.4 My health is excellent

1. Definitely true
2. Mostly true
3. Don’t known
4. Mostly false
5. Definitely false

Appendix-III: IRB Permission Letter

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

BANGLADESH HEALTH PROFESSIONS INSTITUTE

Ref: CRP/BHPI/IRB/12/2020/426

Date: 23/12/2020

Md. Al-Amin
B.Sc. in Physiotherapy
Session: 2015-16, Student ID: 112150320
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal **"Health related quality of life of the person with Guillain-Barre Syndrome (GBS)"** by ethics committee.

Dear Md. Al-Amin,

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

Sr. No.	Name of the Documents
1	Dissertation/thesis/research Proposal
2	Questionnaire (English & / or Bengali version)
3	Information sheet & consent form.

The purpose of the study is to find out the health related quality of life of the person with Guillain-Barre Syndrome (GBS). The study involves use of a questionnaire to explore that may take 20 to 30 minutes to answer the specimen and there is no likelihood of any harm to the participants. Data collectors will receive informed consents from all participants any data collected will be kept confidential. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 10:00 AM on 1st March, 2020 at BHPI 23rd 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
Assistant Professor, Dept. of Rehabilitation Science
Member Secretary, Institutional Review Board (IRB)
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404
E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd, www.crp-bangladesh.org

Appendix-III: Data collection Permission letter

Permission Latter

Date: December 23, 2020

Head

Department of Physiotherapy

Centre for the Rehabilitation of the Paralysed (CRP)

Chapain, Savar, Dhaka-1343

Through: Head, Department of Physiotherapy, BHPI.

Subject: Prayer for seeking permission to collect data for conducting research project.

Sir,

With due to respect and humble submission to state that I am MD. AL-AMIN, a student of 4th year B.Sc. in physiotherapy at Bangladesh Health Professions Institute (BHPI). The Ethical committee has approved my research project entitled: **"Health related quality of life person with Guillain-Barre Syndrome (GBS)"** under the supervision of Asma Islam, Assistant professor, Department of Physiotherapy, BHPI. I want to collect data for my research project from the Department of Physiotherapy at CRP. So, I need permission for data collection from the Neurology Unit of Physiotherapy Department at CRP-Savar, Dhaka-1343. I would like to assure that anything of the study will not be harmful for the participants and the Department itself.

I, therefore pray and hope that you would be kind enough to grant my application and give me permission for data collection and oblige thereby.

Yours faithfully,

MD. AL-AMIN
MD.AL-AMIN

4th Year

B.Sc. in Physiotherapy

Class Roll: 49; Session: 2015-16

Bangladesh Health Professions Institute (BHPI)

(An academic Institution of CRP)

CRP-Chapain, Savar, Dhaka-1343.

Approved
24/12/2020
MOHAMMAD ANWAR HOSSAIN
Senior Consultant &
Head of Physiotherapy Dept
Associate Professor, BHPI
CRP Savar, Dhaka-1343

Forwarded for your kind consideration.
23/12/2020

Considering heath safety, allow him to collect data.
24.12.2020