# Work Related Experience of Adults after Recovering from Guillen Barre Syndrome



# By **Chitra Biswas**

February 2023, held in February 2024

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

Bachelor of Science in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Faculty of Medicine
University of Dhaka

# Thesis completed by:

Thesis completed by:	
Chitra Biswas 4 <sup>th</sup> year, B.Sc. in Occupational Therapy Bangladesh Health Professions Institute(BHPI) Centre for the Rehabilitation of the Paralysed (CRP) Chapain, Savar, Dhaka: 1343	Signature
Supervisor's Name, Designation, and Signa	ture
Nayan Kumer Chanda Assistant Professor Department of Occupational Therapy Bangladesh Health Professions Institute(BHPI) Centre for the Rehabilitation of the Paralysed(CRP) Chapain, Savar, Dhaka: 1343	Signature
Head of the Department's Name, Designation	on, and Signature
Sk. Moniruzzaman Associate Professor & Head Department of Occupational Therapy Bangladesh Health Professions Institute(BHPI) Centre for the Rehabilitation of the Paralysed(CRP) Chapain, Savar, Dhaka: 1343	Signature

Statement of Authorship

Except where it is made in the text of the thesis, this thesis contains no material

published elsewhere or extracted in whole or in part from a thesis presented by me for

any other degree or seminar. No other person's work has been used without due

acknowledgement in the main text of the thesis. This thesis has not been submitted for

the award of any other degree in any other tertiary institution. The ethical issue of the

study has been strictly considered and protected. In case of dissemination of the findings

of this project for future publication, the research supervisor will be highly concerned,

and it will be duly acknowledged as an undergraduate thesis.

**Chitra Biswas** 

4<sup>th</sup> year, B.Sc. in Occupational Therapy

Bangladesh Health Professions Institute (BHPI)

Centre for the Rehabilitation of the Peralysed (CRP)

Chapain, Savar, Dhaka: 1343

Signature

ii

# Acknowledgement

First and foremost, praises and my gratitude to the God, the almighty for giving me a passion to go with the research project successfully in time. I am much grateful to my parents and family members for their constant support to continue this study.

I would like to express my deep and sincere gratitude to my research supervisor, Nayan Kumer Chanda, Assistant Professor ,Department of Occupational Therapy. Thank you for giving me the opportunity to do research and providing invaluable guidance throughout this research. His dynamism, vision, sincerity and motivation have deeply inspired me. He has taught me the methodology to carry out the research and to present the research works as clearly as possible. It was a great privilege and honor to work and study under his guidance.

I am very grateful to my parents for their love, prayers, caring and sacrifices for educating and preparing me for my future. My sincere thanks also goes to the all teachers of Occupational Therapy Department, BHPI for their continuous academic support throughout my study period. I am very grateful to Sk.Moniruzzaman, Associate Professor & Head of the Department, for his support and guidance. Thanks to my all friends for giving their support and inspiration. Moreover, I am also thankful to my beloved sister, Shanta Biswas who helped me throughout this research.

Deep-felt thanks to my junior Purnima Saha who helped me to transcript the data . I would like to thank all of the participants of the study for their cooperation.

# Dedication

Dedicated to my beloved parents.

# **Table of Contents**

Board of Examinersii
Statement of Authorshipii
Acknowledgementiii
Dedicationiv
Table of Contentsv
List of Tablesviii
List of Figuresix
List of Abbreviationsx
Abstractxi
CHAPTER I: INTRODUCTION1
1.1Background1
1.2Justification of the study4
1.3 Operational Definition
1.4Aim of the Study6
CHAPTER II:LITERATURE REVIEW7
CHAPTER III: METHODS15
3.1 Study Question
Aim15
Objectives15
3.2 Study Design
3.2.1 Method
3.2.2 Approach
3.3 Study Setting and Period16
3.3.1 Study Setting
3.3.2 Study period
3.4 Study Participant17
3.4.1 Study population
3.4.2 Sampling Techniques17
3.4.3 Inclusion Criteria17
3.4.4 Exclusion Criteria17
Participants Number18
3.4.5 Participants Overview
3.5 Ethical Consideration
3.5.1 Ethical Clearance
3.5.2 Informed Consent

3.5.3 Unequal Relationship	19
3.5.4 Risk and Beneficence	19
3.5.5 Power Relationship	19
3.5.6 Confidentiality	19
3.6 Data Collection Process	19
3.6.1 Participant Recruitment Process	19
3.6.2 Data Collection Method	20
3.6.3 Data Collection Instrument	21
3.6.4 Field Test	21
3.6.5 Non-Participant	21
3.7 Data Management and Analysis	22
3.8 Trustworthiness and Rigor	23
3.8.1 Methodological Rigor	23
3.8.2 Interpretive rigor	24
CHAPTER IV: RESULTS	25
Theme One: Engage in productive roles & responsibilities	27
Subtheme One: Return to work	27
Subtheme Two: Engage with productive work	27
Theme Two: Form uncertainty to hope of recovering from GBS	28
Subtheme one: Dependency on others	28
Subtheme Two: Lack of health professionals knowledge	28
Subtheme Three: Experiences of recovery varied	29
Theme Three: Motivation behind return to work	29
Subtheme One: Isolation from Society	29
Subtheme two: Financial dependency	30
Subtheme: Job helps to overcome negative feeling	30
Theme four: Adjustment in new situation	30
Subtheme One: Acceptance of their situation	31
Subtheme Two: Maintaining a positive attitude	31
Subtheme Three: Symptoms management	31
Subtheme Four: Adaption of work	31
Theme Five: Organizational facility	32
Subtheme One: Reduced working hours	32
Subtheme Two: Reduced caseload	32
Theme Six: Relationship with Colleagues	32
Subtheme one: Collaboration and acceptance	32
Subtheme two: Dilemmas to received support	33

Theme seven: Perceived the value of work	33
Subtheme one: Returning to work seen as going back to Normal	33
CHAPTER V: DISCUSSION	34
CHAPTER VI: CONCLUSION	37
6.1 Strength and Limitation	37
6.1.1 Strength	37
6.1.2 Limitation	37
6.2 Practice Implication	38
6.2.1 Recommendation for Future Practice	38
6.2.2 Recommendation for further Research	39
6.3 Conclusion	39
LIST OF REFERENCE	41
APPENDICES	48
Appendix A-Approval letter	48
Appendix B: Information Sheet & Consent Form	51
Information sheet	51
Consent Form	54
Withdrawal Form	55
Appendix C: Questionnaire	61
Sociodemographic Questionnaire	64
Appendix D :Supervision Record Sheet	65

# **List of Tables**

<b>Serial number of the Table</b>	Name of the Table	page no	
Table 1.	Participants Overview	18	
Table 2.	Overview of result	26	

# **List of Figures**

Serial nu	mber of the Figure	Name of the figure	Page no
Figure	1. Ove	erview of Literature review findings	s 7
Figure 2	Overvi	iew of participants recruitment prod	cess 20

# **List of Abbreviations**

AIDP- Acute Inflammatory Demyelinating Polyneuropathy

AMAN- Acute Motor Axonal Neuropathy

AMSAN-Acute Motor and Sensory Axonal Neuropathy

CRP- Centre for the Rehabilitation of the Paralysed

GBS- Guillen Barre Syndrome

HRQL- Health-Related Quality of Life

IGOS- The International GBS Outcome Study

IRB- The Institutional Review Board

RTW-Return to Work

UK- The United Kingdom

WHO-World Health Organisation

# Abstract

**Background:** Guillain-Barre' syndrome is a transient inflammatory disorder affecting peripheral nerves, characterised by weakness and numbness in limbs, upper body and face, with an incidence of 1-2/100,000 per year. Residual problems affect a large minority, and complicate return to work. This study explored the experiences of people who returned to work following their diagnosis of GBS and recovery, to gain insight into factors that facilitated or inhibited this process.

**Aim:** The aim of the study was to explore the work related experience of adults after recovering from GBS.

**Methods:** The study was explored through Qualitative study design with phenomenological analysis. Eight participant participated in this study and it selected through purposive sampling technique. Face to face in depth semi structure interviews were conducted through self develop interview guide to know individual and common experiences. The study was analysed thematically which was followed Braun and Clark`s six steps.

**Result**: The study are presented seven recurring themes: the perceived value of work; losing and recovering a familiar identity at work; Adjusted in a new situation; and motivation, long term GBS impact, Facility, Barrier, Responsibility Certain individual issues also emerged. Participants tended to measure their recovery in terms of returning to work yet continued to experience certain physical and psychosocial difficulties at work related to GBS, which required active coping strategies.

**Conclusion**: This study provides a rich account of the experiences that people encounter; when returning to work following GBS. Rehabilitation specialists and social worker may offer more effective preparation for this process.

**Keyword:** Guillen Barre Syndrome, work, experience, recovery, residual symptoms.

# **CHAPTER I: INTRODUCTION**

### 1.1Background

This study described the experiences of people returning to work following an acute or sub-acute onset of Guillain-Barre' syndrome (GBS), with the aim of uncovering the meanings of employment in their lives, and their experiences of managing their return to work. Guillain-Barré syndrome (GBS) is a rare neurological disorder in which the body's immune system mistakenly attacks part of its peripheral nervous system following an acute infection or other immunological challenge. GBS is a monophasic post-infectious condition, affecting peripheral nerves with variable presentation and severity, following which most people with the condition experience full neurological recovery and resolution (Akanuwe et al., 2020).

GBS is the most common cause of acute flaccid paralysis. Its annual incidence is 1–2 per 100 000 population, with almost twice as many males as females being affected and incidence rising with advancing age (Royal et al., 2009). Unusually for an autoimmune disease, higher incidence rates have been reported in males than females (McGrogan et al., 2009).

The incidence of GBS ranges from 0.16 to 4 cases per 100 000 person-years, with most studies reporting rates ranging from 1.1 to 1.8 cases per 100 000 person-years. The frequency in Europe and the United States is believed to be fewer than 2 cases per 100 000 person-years (McGrogan et al., 2008; Sejvar et al., 2011). According to recent French research (Delannoy et al., 2017), The study, which employed diagnostic codes collected upon discharge, reveals an incidence of 2.42 cases per 100

000 person-years, albeit the authors cannot rule out the over-coding of GBS. Certain Asian regions have the highest reported incidence rates (Radhakrishnan et al., 1987; Arami et al., 2006) and the Caribbean (Curacao, van Koningsveld et al., 2001). The latter had the most significant incidence rate, with 3.93 instances per 100,000 people yearly. The published prevalence estimates in Spain range from 0.85 to 1.56 incidences per 100 000 person-years (Matias-Guiu et al., 1993, Cuadrado et al., 2001).

The most common subtype of these four is acute inflammatory demyelinating polyradiculoneuropathy (AIDP) that constitutes 85%–90% of GBS cases, followed by the axonal subtypes (30%–47%) and Miller Fisher syndrome (5%). There are variants of the condition, for example affecting the eye muscles (Miller-Fisher syndrome), leading to motor but not sensory loss (acute motor axonal neuropathy [AMAN]), or causing distal weakness and sensory symptoms (acute motor and sensory axonal neuropathy [AMSAN]] (Akanuwe et al., 2020).

This disorder produces symmetrical weakness and numbness of the limbs, progressing proximally usually over 2–4 weeks, with symptom onset to nadir within 6 weeks (Siriwardena et al., 2022). Greater prevalence of the Miller Fisher variation, axonal subtypes, and pure motor forms of GBS is found in Asian nations than in Western countries (Asbury, 2000; McKhann et al., 1993).

The neuropathy usually affects the motor, sensory, and autonomic nerves supplying the limbs and may involve the respiratory muscles facial, bulbar, and ocular motor nerves. (Hughes & Rees, n.d.). GBS is characterized by weakness and numbness or a tingling sensation in the legs and arms and possible loss of movement and feeling in the legs, arms, upper body, and face. It is frequently severe and usually presents as an ascending paralysis marked by weakness in the legs that spreads to the upper limbs and the face along with complete loss of deep tendon reflexes (Pithadia & Kakadia,

2010).

Patients with this disorder present with rapidly progressive tingling, numbness, weakness, pain and disturbances of autonomic functions. Weakness can be distal, proximal or both. Tendon reflexes are lost early. Patients can have facial and bulbar weakness and sometimes ophthalmoplegia. Speech and swallowing problems are common(J Pritchard 2004). Severe fatigue is a frequent phenomenon after GBS, and it may remain present independently of the level of initial weakness (Garssen et al., 2006). In addition, GBS is associated with impairment in several other aspects of physical and mental health (Ropper, 1992). A large proportion of patients reports pain that may even precede the onset of weakness (Ruts et al., 2010) and may subsequently persist for years after onset of the disease(Darweesh et al., 2014).

Large prospective studies such as the International GBS Outcome Study (IGOS) have shown wide variations in outcomes. Many patients, particularly those with mild forms of GBS, recover completely within 1–2 years, but others will have residual or long-lasting physical, psychological or social sequelae. Physical effects include pain, chronic fatigue and difficulty in walking. Reported psychological symptoms include experiences of sleep disturbance, anxiety or post traumatic stress disorder, including personality changes and mental disturbances (McFarland and Heller, 1966), hallucinatory experiences and oneiric states (De Morsier, 1973), dream-like scenic hallucinations (Schmidt-Degenhard, 1986), and psychotic symptoms (Weiss, 1991; Weiss et al., 2002; Cochen et al., 2005) , which can affect a person's daily life activities, work or social function over years(Laparidou et al., 2021).

Work has both practical and symbolic functions since those who work have the economic possibility of participating in society in a socially accepted manner and at the same time work is a symbol for a perfect citizenship. Participation or involvement

in work or occupations is important for all humans. World Health Organization(WHO) described that, participation has a positive impact on health and well-being Following injury and disease, an individual's capacity to return to work is commonly used to track the progress of rehabilitation (Amick et al. 2000).

Finally, a systematic review of the literature on GBS patients' quality of life after onset of the disease concluded that many patients felt limited by their condition, even years after the onset, and that GBS had a lasting psychosocial impact, affecting patients' mental well-being, daily activities and work life (Darweesh 2014). As a result, it is very important to identify work related experience after following recovery from GBS.

# 1.2Justification of the study

This study provided rich account of the experiences that people encounter returning to work after GBS. Guillain-Barré syndrome is a transient inflammatory disorder affecting peripheral nerves, characterised by weakness and numbness in limbs, upper body and face. Residual problems affect a large minority, and complicate return to work. This qualitative study explored the experiences of people who have returned to work following their diagnosis of GBS and recovery, to gain insight into factors that facilitated or inhibited this process.

Survivors of Guillain-Barré syndrome (GBS) may also have severe and long lasting disability. This study primarily focused on how they perceived the value of their work, work related experience in Bangladeshi community. Because the survivors have so many difficulties when they engage in their work. Although typically there is full neurological recovery, some people continue to experience residual physical, psychological or social problems longer term and have some environmental barrier.

Because of those problems, they are unable to perform activities such as returning to work. The survivors have so many limitation, when they return to their work, so it is crucial to understand the motivational factors, long term impact of GBS on their return to work and how they managed their return to work.

However, rehabilitation specialists have limited evidence about how these factors subjectively influence the process of returning to work, and how people manage this process successfully. The work related experiences of GBS patients help the health professionals to determine the area where they can support them with physically and psychosocially. From the findings Occupational Therapy practitioner can make an inclusive working area for them through work-related advocacy. And other organizations make the workplace accessible as the need of GBS patients. The findings have added insights for future literature about present situation about work related experience of adult after recovery from GBS.

# 1.3 Operational Definition

Guillain-Barre Syndrome: Guillain-Barré syndrome (GBS) is an acute inflammatory demyelinating polyneuropathy (AIDP), an autoimmune disease affecting the peripheral nervous system that is usually triggered by an acute infectious process. GBS is an inflammatory disorder of the peripheral nerves. The peripheral nerves convey sensory information (e.g., pain, temperature) from the body to the brain and motor (i.e., movement) signals from the brain to the body(Pithadia & Kakadia, 2010).

**Return to Work:** Return to work (RTW) is a key pillar in a set of workplace processes designed to facilitate the workplace reintegration of persons concerned, who experience a reduction in work capacity as a result of either occupational or non-occupational diseases or injuries (Vogel et al., 2011).

**Residual physical Disability**: A residual physical disability, also known as a partial disability, is typically defined as being unable to do one or more of the duties of occupation (Bernsen et al., 2002).

**Work:** Work is universally recognized to be an important aspect of life, providing social benefits as well as economic ones and, as a consequence, having positive impacts on individuals' health and wellbeing (ILO, 2015).

**Recovery**: A process of change through which individual improve their health and well being, live a self-directed life, and strive to reach their full potential (Hauck L 2008).

# 1.4Aim of the Study

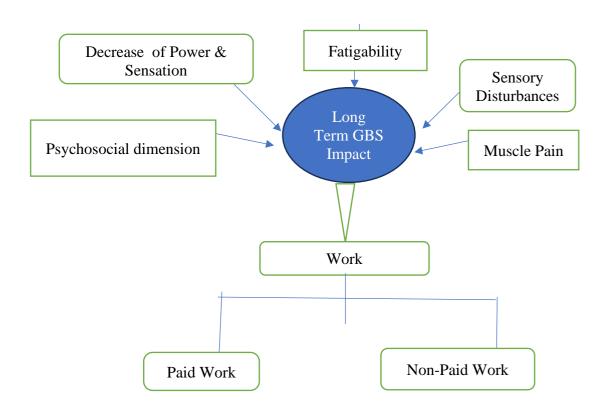
To explore the work related experience of adults after recovering from Guillan Barre Syndrome.

# CHAPTER II:LITERATURE REVIEW

This chapter covers the information regarding residual physical impairments following onset of GBS are responsible for changes to work patterns. Paid and Non-paid occupations or work such employment are also covered in this chapter.

Figure 2.1

Overview of Literature review findings



Most of the studies focused on the overall experiences of people during hospital care or recovering from GBS, whereas one study focused specifically on their experiences returning to work following recovery from GBS(Laparidou et al., 2021).

A detailed search using the terms 'Guillain-Barre 'syndrome', 'work', 'vocational rehabilitation', 'quality of life', 'follow-up', 'activities of daily living' and 'occupation' of the databases Medline, PsycInfo, AMED, CINAHL, British Nursing Index, Pubmed and Cochrane, revealed that previous research into the long-term effects of GBS on work was sparse and mostly used quantitative methods (Royal et al., 2009). GBS usually presents itself with a progressive paralysis that can involve the autonomic, bulbar, and respiratory systems. The most common subtype of these four is acute inflammatory demyelinating polyradiculoneuropathy (AIDP) that constitutes 85%–90% of GBS cases. The annual incidence of GBS as reported in one 10-year study was 0.42 cases per 100,000 persons. Higher incidence of GBS has been reported in younger adults and the elderly aged 50 years and older (Hauck L., 2008). A 6-year regional study revealed that the peak age of patients diagnosed with GBS was between 41 and 60 years with a median age of 47 years. In a study, (Matsui J,1993) reported that the prevalence of GBS was 49% and the male-to-female ratio was 1.45:1.

#### 2.1 Residual Impact of GBS

Many researchers suggest that residual physical impairments following onset of GBS are responsible for changes to work patterns, specifically loss of power(Bernsen et al., 2005), muscle pain(Bernsen et al., 1999), disturbed sensation and fatigability. But physical impairment may not be the sole explanation (Bernsen et al, 2002).

In a study,122 patients were asked to cooperate in a neurological examination and to complete a questionnaire three to six years after onset. On functional assessment 84 patients had no or only minor neurological symptoms or signs, 24 patients showed moderate recovery and 14 patients were left with severe residual signs. On neurological examination, residual sensory deficit was found in the arms of 38 % of the patients and in the legs of 66 % of the patients. Sensory disturbance was experienced as moderate to severe in the arms of 27 % of the patients and in the legs of 40 % of the patients. Muscle aches and cramps were still present in 48 %. There was a statistically significant relation between muscle aches and cramps and objective residual sensory deficit but not with residual weakness. Twenty-five percent of patients changed jobs after their illness, and 44% gave up some leisure activities (Bernsen et al., 2005).

A high percentage of patients experienced decrease in power and sensation at homecoming. Not only the presence but also the distribution of the decrease was significant. Up to 89% of the patients still experienced loss of power, not only in toes or feet but also, in most cases, even in the legs. Diminished power in a larger part of an extremity was present in more patients than sensory disturbance. Neuropathic pain was also found to affect over a third of people with previous and fatigue is another common symptom (Akanuwe et al., 2020).

A large proportion of patients 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). Furthermore, severe fatigue is a frequent phenomenon after GBS, and it may remain present independently of the level of initial weakness (Garssen et al., 2006). Previous long-term studies have found that residual problems adversely affected quality of life in adults recovering from GBS. For example, Bersano et al from interviews with 70 patients 3-5 years from onset of GBS found that most participants (64%) made a

complete functional recovery, while others (27%) were independent with only minor limitations in daily activities, and a few (9%) needed help during the day; importantly, over a quarter (27%) had substantial changes in their job, hobbies or social activities.

Studies, mostly based on quantitative methods, have reported residual physical problems in 20%-30% of patients, and long-term changes in leisure and social activities in 27%-37% of patients. These residual problems have reportedly led to reduced quality of life for patients several years after the onset of the condition(Akanuwe et al., 2020). GBS also had a substantial impact on mood, confidence and ability to live independently for 22% of their sample, while moderate to extreme depression, anxiety and stress were also reported (Laparidou et al., 2021).

At the time of the survey, most participants (252,86.6%) resided in the United Kingdom compared with non-UK residence (39, 13.4%). More participants were retired from work (89, 38%) compared with those in full-time employment (55, 23.5%) or part-time work (31, 13.2%) or those on disability and/or other benefits and not working (30, 12.8%) (Siriwardena et al., 2022).

#### 2.2 Losing and recovering a familiar identity at work

Work plays a major role in our health and social well being .There is now substantial evidence that employment is associated with both general health status(Wilkinson and Marmot., 2003) and facilitates social inclusion (Pantaziset al. 2006; Waddell and Burton., 2006). Following injury and disease, an individual's capacity to return to work is commonly used to track the progress of rehabilitation (Amick et al. 2000: Vogel et al., 2011). Complete and sustained return to work may indicate the effectiveness of treatment and subsequent, psychological and physical performance, capacity to function independently and to a wider extent the individual's contribution to their family, employer and society (MacDermid et al. 2009).

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). As 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.,2015). We aimed to gain insight into patient-perceived disability and changes in HRQL after GBS onset by systematically reviewing the literature on HRQL in GBS patients (Darweesh et al., 2014).

One criticism of the quantitative research concerns the limited sensitivity of many of the tools used to assess long-term problems in terms of impairment, disability, roles and occupations. For example, the Modified Rankin Scale has been criticized (Bernsen et al., 2005). Even though this scale provides a good measure of physical impairment, it may be inadequate for evaluating how residual impairments may hamper people's lives in relation to their occupational and social activities. For example, (Nicholas et al., 2000) noted that some people with GBS recorded relatively high modified Barthel Index scores of 20, yet were still be unable to perform activities such as returning to work. Clearly, there are complex factors underpinning return to roles and occupations in addition to measured physical disability (Royal et al., 2009).

### 2.3 Adaptation of work

In a study, reported that 62% of patients were able to return to their previous employment post-GBS, however the remainder needed alterations at work, to reduce its physical demands or their responsibilities. Less than half of patients returned to work within 2 years in the study by Forsberg et al., and some of these could only manage reduced hours (Forsberg et al., 2005). A need for part-time work for an extended period after GBS, or early retirement, has been noted in other studies (Bernsen et al, 2005). In

a study, Nineteen patients (48%) had residual neuropathy, which was independent of follow-up time (Dornonville De La Cour & Jakobsen, 2005).

A study shared that 21 out of a total of 70 participants identified that they were not able to perform their usual activities, such as outdoor walking, sport or housework 2 years post-onset (Bersano et al.2005). Similar findings were reported by Bernsen et al.(Royal et al., 2009). Overall, more than 30% of GBS patients have had to make changes in their job, hobbies, or social activities 5 years after disease onset (Bernsen et al., 2002; Darweesh et al., 2014).

Previous long-term studies have found that residual problems adversely affected quality of life in adults recovering from GBS. For example, Bersano et al from interviews with 70 patients 3-5 years from onset of GBS found that most participants (64%) made a complete functional recovery, while others (27%) were independent with only minor limitations in daily activities, and a few (9%) needed help during the day; importantly, over a quarter (27%) had substantial changes in their job, hobbies or social activities.

#### 2.4 Barrier in Workplace

Negative attitudes of the employer or a workplace superior may adversely interact with the challenges faced by the stroke survivor (Lock et al., 2005; Medin et al., 2006; Alaszewski et al., 2007), and result in harassment or discrimination as we do live in 'a disabling society with oppression of disabled people endemic in widely accepted institutional practices and expressed in some individuals' negative and patronizing words and actions' (Lock et al., 2005, ). The opportunity to return to a supportive working environment helped patients to cope and reorder their goals, whereas early retirement due to the illness was perceived to further hinder recovery (Akanuwe et al., 2020).

The stress of unfairness in the workplace can lead to not only higher rates of illness but also longer and less successful recovery' (Shain, 2001, p. 365). Research into TBI has identified that early intervention (O'Brien, 2007) and reasonable accommodations need to be made to ensure a positive return to work (Opperman, 2004; O'Brien, 2007; Gilworth et al., 2008), including the importance of natural supports within the workplace and employee mentoring (O'Brien, 2007). It has been acknowledged that the most significant barriers to employment arise from the environment, not the person (McMahon et al., 2005).

The evidence to date identifies that physical and psychological problems continue to affect a sizeable minority of patients, for several years post-onset of GBS. These problems are reported to have a considerable impact upon performance of everyday activities, including work and health-related quality of life. However, rehabilitation specialists have limited evidence about how these factors subjectively influence the process of returning to work, and how people manage this process successfully.

#### 2.5 Return to Work

Returning to work was especially seen as a really important step in going back to their 'normal' selves again, even though sometimes participants had to make accommodations before being able to return to their previous role. Such accommodations were necessary due to residual physical difficulties, but can also be seen as an attempt to control the situation by making changes in their lives that would allow them to adapt to their new situation success- fully. Being diagnosed with and surviving GBS was a life-changing experience for all participants that often made them search for meaning in their new situation, re-appraise their lives and re-order their priorities (Laparidou et al., 2021). The opportunity to return to a supportive working

environment helped patients to cope and reorder their goals, whereas early retirement due to the illness was perceived to further hinder recovery (Akanuwe et al., 2020).

The evidence to date identifies that physical and psychological problems continue to affect a sizeable minority of patients, for several years post-onset of GBS. These problems are reported to have a considerable impact upon performance of everyday activities, including work and health-related quality of life. However, rehabilitation specialists have limited evidence about how these factors subjectively influence the process of returning to work, and how people manage this process successfully.

# CHAPTER III: METHODS

#### 3.1 Study Question

What are the work related experience of adults after recovering from Guillain-Barré syndrome?

#### Aim

To explore the work related experience of adults after recovering from Guillain Barre Syndrome.

### **Objectives**

- To explore the patient's perspective about his return to work.
- To find out the motivation for returning to work and how they manage their return to work.
- To know the long term effect of GBS on their working activities.
- To explore relationship with colleagues and job responsibility of the workplace.

### 3.2 Study Design

#### **3.2.1 Method**

The student researcher used the Qualitative study design with phenomenological to conduct this study because the research can use participants universal structure to make sense of their experiences. The design of a qualitative study focused on interpretation includes shaping a problem for this type of study, selecting a sample, collecting and analyzing data, and writing up the findings. An understanding of this process was important for assessing the rigor and value of individual reports of research (Sundler et al., 2019). It has been suggested that when researching a subject, which has very limited pre-existing knowledge, or is complex, dilemmatic or novel, a qualitative approach may

be particularly useful.

#### 3.2.2 Approach

The researcher used a phenomenological approach because it is an approach to research that seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it. The goal of phenomenology was to describe the meaning of this experience both in terms of what was experienced and how it was (Neubauer et al., 2019).

This approach helped to understand individuals' personal perceptions or accounts whilst acknowledging that access to the participant's personal world is the result of interactions between the researcher and participant and that the process involves interpretative activity on the part of the researcher (Smith JA,2003).

# 3.3 Study Setting and Period

#### 3.3.1 Study Setting

This study was targeted all types of persons with Guillain-Barre syndrome at the Centre for the Rehabilitation of the Paralysed (CRP) in Savar and Mirpur,14 brunches those who had taken treatment from CRP. And data was collected from the community after taking information from the Centre for the Rehabilitation of the Paralysed (CRP). The data was taken from Dhaka district and name of those places were not disclosed here to maintain confidentiality. Five participants among eight participants participated in the study from their house and three participants participated in nearly office location.

#### 3.3.2 Study period

The whole study period was between May 2023 to February 2024.

The data collection period was 1 month, December 2023.

# 3.4 Study Participant

#### 3.4.1 Study population

Person with Guillain Barre Syndrome who were taken treatment from centre for the Rehabilitation of the Paralysed CRP of Savar and Mirpur and within Dhaka District.

#### 3.4.2 Sampling Techniques

The researcher used purposive sampling which represents a group of different non-probability sampling techniques. Also known as judgmental, selective or subjective sampling, purposive sampling relies on the judgement of the researcher when it comes to selecting the units that are to be studied. Usually, the sample being investigated is quite small, especially when compared with probability sampling techniques (Neetij & Bikash Thapa, nd.)

According to Adolph Jenson, "A purposive selection denotes the method of selecting a number of groups of units in such a way that selected groups together yield as nearly as possible the same average or proportion as the totality with respect of those characteristics which are already a matter of statistical knowledge." (Neetij & Bikash Thapa,.nd.)

#### 3.4.3 Inclusion Criteria

- Both male and female who engage in job or work.
- Age range:30-60 years old;
- Participants those who recovery from GBS;
- Participants those who discharged and returned to work within 2 years.

#### 3.4.4 Exclusion Criteria

- Patients those who are taking treatment from hospital now.
- Patients who are not stable condition.
- Patients who don't have any valid phone number or contact.

# **Participants Number**

The student researcher took 8 participants to collect data.

# 3.4.5 Participants Overview

Table:1

Psuedo Name	Age	Sex	Marital Status	Duration of work experience	Working sector	Designation
Shamima Akter	32 years	female	Married	1.5 years	Primary School	Teacher
Abdul Rahim	35 years	Male	Married	7 months	Own Organization	Teacher
Rubayet	37 years	Male	Unmarried	3months	Construction	Day labor
Sanowar Ail	38 years	Male	Married	1 year	Hospital	Lab Technologist
Mehadi	40 years	Male	Married	1.5 years	Madrasha college	Vice Principle
Azizul Houque	38 years	Male	Married	10 months	Govt.job	
Dipok Kumar	40 Years	Male	Married	1 years	Hospital	Pathologist
Md.Shaiful Ahamed	52 years	Male	Married	8 months	Shop	Businessman

### 3.5 Ethical Consideration

#### 3.5.1 Ethical Clearance

According to Helsinki, 2013

Ethical clearance has been taken from the Institutional Review Board (IRB) explaining the purpose of the research through the Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI). IRB form number CRP-BHPI/IRB/10/2023/772. The permission was also taken from the Savar and Mirpur1 CRP OT Neuro department before taking the participant's information for data collection.

3.5.2 Informed Consent

The student researcher explained the aim of the research to the participant who was

willingly interested in participating, and their data was collected. Verbal consent was

taken from the participant as they were interviewed

3.5.3 Unequal Relationship

The researcher didn't have an unequal relationship with the participants.

3.5.4 Risk and Beneficence

The participants did not have any risk and they did not get any kind of beneficence

from this research.

3.5.5 Power Relationship

The student researcher didn't have any kind of power relationship with any participants.

3.5.6 Confidentiality

Student researcher ensured and maintained confidentiality of the participants. Only the

student researcher and the supervisor had access to the interviews, and this was clearly

stated in the information sheet. Their name and identity, location were not disclosed to

anyone except for the supervisor. The participants were also informed that their identity

will remain confidential for future uses, such as report writing, publication, conference

or any other written materials and verbal discussion.

3.6 Data Collection Process

**3.6.1 Participant Recruitment Process** 

Figur:2

Overview of participant recruitment process:

19

Contacted with Savar & Mirpur CRP

Collected GBS Patients information from Outpatients Unit( record file)

Listed all participants

Selection of potential participants(Through phone call)

Fixed interview schedule

Conducted face to face Interview

Student Investigator went to the outpatient unit and got permission from the head of the department to collect information from the outpatient department database. After then collected the information from database (Name, Age, Sex, Date of injury, Year of leave and contact numbers) of the participants. Potential participants were identified based on the inclusion and exclusion criteria. After that contacted with them and fixed face to face interview.

### 3.6.2 Data Collection Method

The data were collected through a face-to-face in depth semi structured interview. At first the student researcher tried to developed rapport with the participants for taking in-depth information. Researcher had prepared some broad open-ended questions with the intention of eliciting in depth information. A quite place was selected for interview to avoid distraction and environment noise. So, the participant could feel comfort and gave adequate attention to interview. The researcher collected all the data herself through interview. Semi structured interview had been selected the place which was nearly place for them. Before start recording the formal interview researcher build rapport with the participants and made them comfortable for interview. As to make

them comfortable, researcher introduced with participant about self, explained about the cause of interview about the aim and objects of the study and its importance as stated in information sheet so that Participants could understand easily about interview most of the time, participants showed some interest to talk for interview. The interviews were recorded by mobile recorder. The student researcher made Bangla interview guide and conducted interview in Bangla because the entire participants were Bangladeshi. The average time for interview was 20-25 minutes.

#### 3.6.3 Data Collection Instrument

A semi-structured interview guide questionnaire was used to conduct interview for the working experience of GBS patients who have recovered. A semi-structured interview guide developed by student researcher which was both in Bangla and English. There were questions about one's job perceptions, responsibilities, motivations, facilities, co-worker relationships and barriers for working area. The interview guide was developed based on the literature review findings (Akanuwe et al., 2020; Bernsen et al., 2005; Laparidou et al., 2021; Royal et al., 2009) and in discussion with the supervisor.

#### 3.6.4 Field Test

Before starting the collection of data, the student researcher accomplished the field test with one participant. This test had been performed to find out the difficulties that are existing in the interview questionnaire to achieve the aim and objective of this study or not and there was change in questions after the field test in this study. The student researcher have added few questions and discussed that with the respected supervisor.

#### 3.6.5 Non-Participant

There was two non participant with two participants. One was his wife and other was Son of a participant. The participants allowed them as there was no space to give interview individually in the house. Participant provided information comfortably. But

the non-participant did not affect the interview.

### 3.7 Data Management and Analysis

Qualitative approaches are incredibly diverse, complex and nuanced (Holloway and Todres, 2003), and thematic analysis should be seen as a foundational method for qualitative analysis. The student researcher used thematic analysis according to Braun and Clarke's six steps of thematic analysis to analysis the data (Braun & Clarke, 2006). The six steps are given below:

- **1.Reading and familiarisation**: Initially, the student researcher transcribed data verbatim in Bengali as first language and translated them in English. She took help from volunteers in translating six interviews and refined the translation. She translated another two interviews by herself. After that the respected supervisor re-checked all the transcription and translation. Then the student researcher read those four times thoroughly to understand the meaning of data and noted down potential interest.
- **2. Generating initial codes**: In this step, the student researcher tried to generated interesting features of the data by highlighting important sentences and generated some initial code from the important sentences and named them. The potential codes were checked by the supervisor.
- 3. Searching for themes: The student researcher wrote down all the codes in paper and highlighted and under lined the similar codes through reading the translation and discussing with supervisor. Then the student researcher collated codes into potential theme and wrote them in loose paper notes and arranged them in together. Through this gathered all data relevant to each potential theme.
- **4. Reviewing themes**: Then, the student researcher re checked if the themes worked in relation to the coded extracts and the entire data set, generated a thematic 'map' of the analysis and discussed with supervisor.

- **5. Defining and naming themes**: In this step, the student researcher refined the specifics of each theme, and the overall story the analysis tells, generated clear definitions and named for each theme. The respected supervisor re checked all the theme.
- **6. Producing the report**: Finally, the student researcher identified themes and subordinate themes and produced a scholarly report in the dissertation by writing the results chapter with verbatim quotes from participants. Eight theme are produced from data analysis.

# 3.8 Trustworthiness and Rigor

The trustworthiness of qualitative research is crucial to the usefulness and integrity of the findings. It was maintained by methodological and interpretive rigor (Fossey et al., 2002).

#### 3.8.1 Methodological Rigor

**Congruence**: The study focused to explore the work related experience, and that was the phenomenological approach of qualitative research design which was fit for achieving the aim and objectives for the study. (see section 3.1&3.2: Study design).

**Responsiveness to social context**: The student researcher conducted the study face-to-face interviews that met the real-life situation in their community and communicated with participants which represent the familiarness with the context (see section 3.3 Study setting).

**Appropriateness and adequacy:** purposive sampling technique are followed to identify participants with inclusion and exclusion criteria. The data collection method was in-depth observational semi-structure and the interview was recorded by mobile phone which represents the originality of data (see sections 3.4 and 3.6 Sampling and recruitment) for details explanation.

**Transparency**: The student researcher collected and analysis data systematically with supervision under the supervisor. During the interview, the researcher did not try to influence the process with her biases, ideas and own perspectives. (see sections 3.6 and 3.7:Data collection and Data analysis).

### 3.8.2 Interpretive rigor

**Authenticity:** Data presentation and interpretation was maintained through providing verbatim quotation of participants .Those statement were checked by the supervision of supervisor. The student researcher used Bangla and English language because Bangla is the mother language and English is the academic language for the study.(see section 3.7 Data analysis).

**Coherence**: The findings were well matched for the research aim and objective and initial coding was checked with the supervisor (see section 3.7: Data analysis)

**Reciprocity**: Data was translated by keeping its original meaning unchanged .And data analysis was discussed only with supervisor. (see section 3.7: Data analysis).

**Typically**: The term "typicality" describes how well the results can be applied to different contexts (Fossey et al., 2002) Those findings of the study were related to other contexts, for more detail check (see section 3.7: Data analysis).

**Permeability:** By maintaining strictly rules of ethics and transparency, the student researcher completed data analysis and every step of data analysis was audited by the supervisor.

### **CHAPTER IV: RESULTS**

In this study, Eight participants who have recovered from GBS shared their working experience in different working sectors. Work related experience are included in this chapter. Seven themes were arisen from the data analysis and these are:(1) Productive roles Responsibilities. (2) Form uncertainty to hope of recovering GBS (3) Motivation behind return to work.(4) Adjustment in new situation.(5) Organizational facility (6) Relationship with Colleagues (7) Perceived the value of work.

### 4.1Table:Overview of result

Theme	Subtheme
Engage in productive roles & Responsibilities	Return to job
1	Engage with productive work
Form uncertainty to hope of recovering from GBS	Dependency on others
	Lack of health professionals knowledge
	Experiences of recovery varied
Motivation behind return to work	Isolation from society
	Financial independency
	Job helps to overcome negative feeling
Adjustment in a new situation	Acceptance of their situation
	Maintaining a positive attitude
	Symptoms management
	Adaption of work
Organizational facility	Reduced working hours
	Reduced caseload
Relationship with Colleagues	Collaboration and acceptance
	Dilemmas to received support
Perceived the value of work	Returning to work seen as going back to Normal

### Theme One: Engage in productive roles & responsibilities

After recovery from GBS, Participants have return to their work. Six participant didn't change their job and two participant changed their organization but didn't change their profession. The productive roles vary from one participant to another such as teacher, pathologist, day labor and so on. They shared their various responsibility according to their job position. The subthemes are-

### **Subtheme One: Return to work**

Participant have returned to their work according to their job position and the reason of return was vary from one participant to another. All participants placed extremely high value upon work and regarded the process of returning to work as a very significant step towards moving forwards with their lives. Rubayed said,

'I had been sort of moping around . . . . . . (disappointment) trying to pass the time to get better, about 3 months by then, and I got to a stage where nothing was happening, it probably was but I thought nothing was happening and my life, it wasn't my life . . . I felt that nothing was making anything change so I thought maybe it was something in my head, so if I go back to work, go back to a normal life at least it will be a step forward'.

### **Subtheme Two: Engage with productive work**

All the participants shared that they have returned to productive work and working sectors were Primary teacher, Govt.job, Hospital and Madrasha College and so on.

Mr Ali said, "I am lab technologist and I worked in a famous Hospital in my town. Because of GBS I had to leave my previous job but after recovering from GBS I have started work in different hospital"

### Theme Two: Form uncertainty to hope of recovering from GBS

The uncertainty became overwhelming, making them eager to find out what was happening to them. This feeling of uncertainty was made worse by a general lack of information and knowledge of GBS, among patients. That time they were dependent on family members, health professionals, co-workers and it was very helplessness situation for them. After being confronted with physical dependency and then encountering helplessness, the participants were hopeful that recovery was near.

### **Subtheme one: Dependency on others**

Participant reported that they were depended on their carer and had difficulty to perform any kind of activity without others assistance. Their bodily limitations disappointed them and made them feel helpless, as they were dependent on others. Three participate reported that they used wheelchair that time. As a result, some participants felt they had lost their identity as an independent person. A school teacher said,

"I never thought that I could ever walk with my legs again. I used wheelchair to go to my school and in wheelchair I continued my classes. I had to depend on my colleague to use toilet."

Mr.Mehedi said that, "My son helped me to reach Madrasha because I could not come alone.I had to depend on my son."

### Subtheme Two: Lack of health professionals knowledge

Most of the participant complained that health professionals are not well aware about GBS and they did not provide sufficient information about the condition. So patients had to find information about GBS themselves, mainly through searching on the internet. Many participants would have liked to have received more information about GBS to improve their understanding of their condition, but also because they found information about GBS, especially on prognosis and recovery, to be reassuring. Mr.

Azizul reported that,

"I had asked a nurse about GBS and she did not reply me properly and provided some wrong information".

### **Subtheme Three: Experiences of recovery varied**

There was a broad variation in the participants' experiences of the recovery process and adjusting to their new situation after falling ill with Guillain-Barre syndrome. Some said that they did not have any residual symptoms, and had regained full bodily strength and health by the time of the interview. Some said that they had residual symptoms which still affected their daily living activity including work.

Dipok kumar said that, "I still feel stiffness in my right hand and faced difficulty to hold things, after sometimes later it becomes normal".

Md Shaidul said, "I was in my home last two years. After two years, I was able to return to my work."

### Theme Three: Motivation behind return to work

Participants shared that they were motivated by various factors, as each individual's situation and priorities may differ. Here are some common motivations among participants are Isolation from society, Financial stability, social interaction and so on.

### **Subtheme One: Isolation from Society**

Three participants told that workplaces often serve as social environments where people interact with colleagues and build relationships. Returning to work can provide an opportunity for social engagement, reducing feelings of isolation that may occur during the recovery period.

Mrs Shamima reported that, "During recovery period I was becoming restless by staying at home .Aloneness was becoming my partner. I could not work or speak with anyone and also could not get along with anyone .These things were giving me

pain and also told me that if I talk with someone that will give me mental strength.

Then I thought I should return to my work"

### **Subtheme two: Financial dependency**

Most of the participant need to return to work to maintain financial stability. Medical treatments and recovery from GBS can incur significant expenses, and the individual may need their income to cover medical bills and everyday living costs. Five participant said that major reason was financial crises.

Mehedi told that, "I had responsibility for my family, my sons are still students....they can not manage their own study expense so I was so desperate that time to return to my organization so that I can support my family"

Rubayet shared that, "That time I had to borrow money for my treatment purpose.....long period of time I could not earn any money and my family could not bear the expense of my treatment, even I could not take regular therapy from CRP because of money".

### Subtheme: Job helps to overcome negative feeling

Participant shared that engaging in meaningful and purposeful activities can contribute to one's overall well-being and mental health. Two participant strongly told that return to work helps to overcome their negative feeling and reintegrate into a normal being.

Mr. Ali said that, "I need something to structure my life, to organise my life, it's not all about money, money is important obviously, but it is not all about money, it's about having a purpose in life. I thought my life was not worth of anything anymore."

### Theme four: Adjustment in new situation

There was wide variation in participants' experiences of recovery, coping with and adjusting to their new situation. For some recovery lasted months and was full, whereas others were still experiencing residual symptoms years later.

### **Subtheme One: Acceptance of their situation**

Adjusting to their new situation required participants to first accept their new circumstances and this was a complicated process for many, others reappraising their new situation and trying to find new ways to manage their residual difficulties . For some participants that meant remaining positive.

Mr.Ali said that, "some times I felt like my hand become numbness and I could not hold anything with this hand. But now I m able to do my work and for that I m grateful to Allah."

### **Subtheme Two: Maintaining a positive attitude**

Participants had positive attitude which was a major facilitator to their recovery from GBS and helped them to realize that life wasn't over and that things would eventually improve their recovery.

Mrs.Shamima told, "I had intension to return on my work from the very beginning. As I will lose my job if I do not return to my work .So I returned there with name of my Almighty and I keep my faith in Him".

### **Subtheme Three: Symptoms management**

Five participant Continued to follow the advice and Engage in physical therapy and rehabilitation exercises. And other three said they didn't feel much difficulties.

Mehedi said, "I used to exercise three times in a day but after joining office I was doing exercise twice in a day."

### **Subtheme Four: Adaption of work**

Some participant shared that initially days they did not get much work pressure from their work place and changed their working area.

Md Shaidul said, "I used to go market for shopping but after GBS I just sat in my shop and took care of account......(sad)."

### Theme Five: Organizational facility

All participant shared their organizational advantage and disadvantage. They told that how their organization accept them, understand their situation and ensure some consideration.

### **Subtheme One: Reduced working hours**

Two participant told that their organization reduced their working hours when they initially join in the organization. And two participant had own organization so they can easily take leave when they needed.

Mr. Azizul told that, "My office time was 9am to 5 pm but because of my disability my organization decided to offer my office time 2pm.....(smiling).

### **Subtheme Two: Reduced caseload**

Six participant shared that they did not feel any kind of work pressure during the initially period. Their organization reduced their job responsibility and did not give any pressure to complete their work.

Dipok kumar said, "I tried to complete my work but if I couldn't, my colleagues helped me to complete the task."

### Theme Six: Relationship with Colleagues

Most of the participant shared that their colleagues provided support or assistance during their recovery, express your gratitude. But two participants shared that they had Dilemmas to receive support.

### Subtheme one: Collaboration and acceptance

All participants shared that they had good relationships with their colleagues. Their colleagues helped them and accept their return

.Mrs Shamima shared that,"While I was in wheelchair, it was very difficult for me to

use washroom, my colleagues helped me to use washroom,......(smiling)without their help it was quite impossible for me to return to my job at that time".

### Subtheme two: Dilemmas to received support

Two participant shared that they had dilemmas to receive support from their colleagues.

Abdul said that, "initially my colleagues helped me and I was accepting because I couldn't perform well, but gradually it became very embarrassment for me."

Md. Shaiful said, 'Because people won't engage me in any work as they would have done previously in the work place.....(sad), so sometimes I have to sit down and it was very disappointing "

### Theme seven: Perceived the value of work.

All the participant shared returning to work was seen positively, as going back to their normal selves again, and offered a distraction from the participants' residual difficulties.

### Subtheme one: Returning to work seen as going back to Normal

All the participant shared that it was perceived to be a significant step to moving on with life and putting GBS firmly into the past.

Mrs Shamima, 'a desire to move on and get this thing behind me. One of the best ways of doing that is going back to work, definitely ......(smiling)',

### **CHAPTER V: DISCUSSION**

This study represented the work related experience of adults after recovering from GBS. Total seven participants had participated in this study who returned to their work in different working sectors such as Primary school, hospital, Govt.job, and so on. Every individual's recovery from GBS is unique, and returning to work will depend on the specific circumstances of their recovery and the nature of their job.

The findings of this study support current evidence concerning residual physical difficulties, quality of life post-GBS, and people's sense of vulnerability. Initially, they were depend on their family members. Gradually they were recovering from GBS and return to their work. All participants placed extremely high value upon work and regarded the process of returning to work as a very significant step towards moving forwards with their lives, and recovering health, social relationships and a 'normal' self-image. These findings resonate with the qualitative accounts given by people who have successfully returned to work following spinal cord injury, or stroke or TBI (Wolfenden & Grace, 2009).

This study found that form uncertainty, they get hope to recovery through the long term recovery process and various work offered opportunities for returning to a 'normal' or pre-illness self. Being diagnosed with and surviving GBS was a life-changing experience for all participants that often made them search for meaning in their new situation, re-appraise their lives and re-order their priorities (Laparidou et al., 2021).

This study reported that participant have returned to role and their job responsibility which vary from their job position. In a study reported that 62% of patients were able

to return to job after recovering from GBS (Bernsen et al., 2005). Return to work is seen as a significant indication of recovery by the stroke survivor (Medin et al., 2006;)Similarly, after recovering from GBS return to their job which is a significant indication for GBS survivor. Managing job responsibilities after recovery depends on several factors, including the their nature of the job, the extent of the recovery, and the support available from employers and family member.

This study found that participant had to adjust for their new situation. They have to manage their residual symptoms and remaining positive. In a study, about 30 percent of individuals diagnosed with GBS have residual weakness after 3 years and about 15 percent experience long-term weakness (Laparidou et al., 2021). They have accepted their new situation and had to adapt in their work. Our findings indicate that the motor and sensory residual post-GBS neuropathy is frequent and interferes with the daily life of previous GBS patients long after recovery from the acute attack (Dornonville De La Cour & Jakobsen, 2005). Because of some residual physical weakness ,they can not perform their work like before. For that reason, some organization reduced their working hours for them and also reduced their caseload. But it is temporary.

This study found that reducing their family burden, and removes their negative feeling they return to their work. Returning work helps them to forget their disability and the financial benefit of working inevitably motivated return to work. Literatures of United States and Nepal found that workplace as a source that bolsters their identity in a positive way and also the family encouragement was behind their job participation (Chowdhury et al., 2022; Rana et al., 2022) which means despite the country contexts, paid works play a positive role in life. In the early forties, Marie Jahoda found that work has other important meanings besides economic compensation, such as providing a structure for how to handle time, a social status and identity, daily social contacts with

others outside the family, and the possibility of taking part in working towards a common goal. Returning to work was viewed very positively by all participants. Primarily, it was perceived to be a significant step to moving on with life and putting GBS firmly into the past. The long-term impact of GBS on employment may vary among individuals. Some may fully return to their previous roles, while others may need to explore alternative career paths or make adjustments to accommodate their health status.

This study reported that, participants maintain good relationship with their colleagues and they help each other. Participants were actively receiving support from colleagues and managers, and making use of adaptations at work. They recognised their practical helpfulness yet also feared associated stigma. The key to navigating relationship with colleagues after recovering from GBS is communication, setting realistic expectations, and seeking support when needed.

### **CHAPTER VI: CONCLUSION**

### **6.1 Strength and Limitation**

In this study, there are some strengths and limitations which the student researcher has found out. These are-

### 6.1.1 Strength

- The data were collected from participants with various types of backgrounds such as; age, sex, area of residence, different occupation, different working area and different working environment experience, which added variation in experiences and provided rich, in-depth data from this study.
- This study was followed the qualitative methods to achieve the aim and objective which is best suited for the study.
- This study has new findings about health status, job perception, motivations behind the work, relationship with colleagues.
- This study provided in-depth and rich data regarding work-related experiences of GBS Patient in Bangladeshi community.
- This study will help in future research on this phenomenon.

### 6.1.2 Limitation

- This study followed a qualitative methodology for which limited number of
  participants, potential bias from participants while responding to the interview
  questions restricted the generalisability of this study.
- The student researcher collected data from only Dhaka district which is not more generalized.
- Identify the employment rate of women in GBS patients are limited.

• There would be any mistake for the student researcher as this was the first time to conduct a study which can be impacted on rich data quality.

### **6.2 Practice Implication**

This study will help the health professionals to identify work related difficulties after recovering from GBS. Participants saw positive value and meaning in returning to work after GBS. Occupational therapists, social workers and other many professionals who are working with people with disabilities can promote work-related advocacy to ensure the rights of people with disabilities in working sector. Within the rehabilitation program, consideration should be placed upon ways of educating and preparing patients in relation to issues such as managing residual physical symptoms, identity change, managing stigma, and possible dilemmas around receiving support and adaptations at work. Occupational therapy practitioners can advocate for an inclusive workplace for them. Different organisations and other NGOs must up-date information on new employment and self-employment opportunities in the formal and informal sectors. This research can be used by government to make important decisions about health, safety, and the environment of workplace for people with disabilities.

### **6.2.1 Recommendation for Future Practice**

- Health Professionals such as; Rehab doctors, nurses, physical therapists and occupational therapy practitioners may provide specialized teaching and training guidelines for them.
- Rehabilitation specialists play a vital role in providing an understanding of the limitations that result from GBS and how they affect employment capabilities.

- Physical adaptations at the workplace, a flexible work schedule, and support boost the individual's ability to return to work and maintain a sustainable employment position after a GBS.
- Promote work-related advocacy to ensure the rights of people with disabilities in working sector.

### **6.2.2** Recommendation for further Research

- The subject area would benefit from further qualitative studies involving larger sample sizes and both male and female participants from a wider range of social backgrounds and employment settings.
- Most urgently, this study focused on participants who were successful in returning to work. Further studies would also be useful to explore in more detail the psychosocial and contextual factors that prevent people from returning to work after GBS.
- Conducting further research to identify job satisfaction level of GBS patients.
- Identifying residual physical impairments impact on GBS patients daily living.

### **6.3 Conclusion**

This study has shown that return to work can be seen as a significant step towards recovering normal lives and identities after GBS. As well as financial support, work restored social relationships, provided impetus for activity, offered a focus and structure to life, and enabled people to back to their normal life. Nevertheless, participants faced certain dilemmas.

Successful return to work did not simply reflect physical recovery but was facilitated through individuals' positive attitudes as well as environmental factors. It will be important to extend or replicate this work and incorporate the findings into

rehabilitation strategies for people recovering from GBS.

### LIST OF REFERENCE

- Akanuwe, J. N. A., Laparidou, D., Curtis, F., Jackson, J., Hodgson, T. L., & Siriwardena, A. N. (2020a). Exploring the experiences of having Guillain-Barré Syndrome: A qualitative interview study. *Health Expectations*, 23(5), 1338–1349. https://doi.org/10.1111/hex.13116.
- Amick BCI, Lerner D, Rogers WH, Rooney T, Katz JN (2000) A review of health-related work outcome measures and their uses, and recommended measures. *Spine* 25(24):3152–3160.
- Arami MA, Yazdchi M, Khandaghi R: Epidemiology and characteristics of Guillain-Barre syndrome in the northwest of Iran. *Ann Saudi Med* 2006; 26: 22–27.
- Asbury AK, Cornblath DR. Assessment of current diagnostic criteria for Guillain-Barre´ syndrome. *Ann Neurol* 1990 ;27(suppl):S21–4.
- Alaszewski A, Alaszewski H, Potter J, Penhale B (2007). Working after stroke: survivors' experiences and perceptions of barriers to and facilitators of the return to paid employment. *Disabil Rehabil* 29:1858–1869.
- Bernsen, R. A. J. A. M., De Jager, A. E. J., Van Der Meché, F. G. A., & Suurmeijer, T. P.
  B. M. (2005). How Guillain-Barré patients experience their functioning after 1 year.
  Acta Neurologica Scandinavica, 112(1), 51–56. <a href="https://doi.org/10.1111/j.1600-0404.2005.00429.x">https://doi.org/10.1111/j.1600-0404.2005.00429.x</a>.
- Bernsen Robert AJAM, de Jager AEJ, Schmitz PIM, van der Meche´ FGA. Long-term impact on work and private life after Guillain-Barre´ syndrome. J Neurol Sci 2002;201:13–17.
- Bernsen Robert AJAM, de Jager AEJ, Schmitz PIM, van der Meche' FGA. Residual

- physical outcome and daily living 3 to 6 years after Guillain-Barre' syndrome. *Neurology* 1999;53:409–412.
- Cochen, V., Arnulf, I., Demeret, S., Neulat, M. L., Gourlet, V., Drouot, X., Moutereau, S., Derenne, J. P., Similowski, T., Willer, J. C., Pierrot-Deseiligny, C., & Bolgert, F. (2005). Vivid dreams, hallucinations, psychosis and REM sleep in Guillain-Barré syndrome. *Brain*, 128(11), 2535–2545. https://doi.org/10.1093/brain/awh585.
- Cuadrado JI, de Pedro-Cuesta J, Ara JR, Cemillán CA, Díaz M, Duarte J, Fernández MD, Fernández O, García-López F, GarcíaMerino A, García-Montero R, Martínez-Matos JA, Palomo F, Pardo J, Tobías A, Spanish GBS Epidemiological Study Group: Guillain-Barré syndrome in Spain, 1985–1997: epidemiological and public health views. *Eur Neurol* 2001;46:83–91.
- Chowdhury, D., Lund, E. M., Carey, C. D., & Li, Q. (2022). Intersection of discriminations: Experiences of women with disabilities with advanced degrees in professional sector in the United States. *Rehabilitation Psychology*, 67(1), 28. https://doi.org/https://psycnet.apa.org/doi/10.1037/rep0000419
- Darweesh, S. K. L., Polinder, S., Mulder, M. J. H. L., Baena, C. P., Van Leeuwen, N., Franco, O. H., Jacobs, B. C., & Van Doorn, P. A. (2014). Health-related quality of life in Guillain-BarréBarr Barré syndrome patients: a systematic review. In *Journal of the Peripheral Nervous System* (Vol. 19).
- Dornonville De La Cour, C., & Jakobsen, J. (2005). Residual neuropathy in long-term population-based follow-up of Guillain-Barré syndrome.
- Delannoy A, Rudant J, Chaignot C, Bolgert F, Mikaeloff Y, Weill A (2017). Guillain-Barré syndrome in France: a nationwide epidemiological analysis based on hospital discharge data (2008-2013). J Peripher Nerv Syst 22:51–58.
- De Morsier G. About 40 cases of polyradiculoneuritis. Landry-Guillain-Barre-Strohl's

- syndrome. Acta Neurol Belg 1973; 73: 220–8.
- Forsberg A, Press R, Einarsson U, de Pedro-Cuesta J,Holmqvist LW. Disability and health-related quality of life in Guillain-Barre' syndrome during the first two years after onset: a prospective study. *Clin Rehabil* 2005;19:900–909.
- Forsberg A, Widen-Holmqvist L, Ahlstrom G. Balancing everyday life two years after falling ill with Guillain-Barre syndrome: a qualitative study. *Clin Rehabil*. 2015; 29(6): 601–610. https://doi.org/10.1177/0269215514549564 PMID: 25200880.
- Fossey, E., Harvey, C., Mcdermott, F., & Davidson, L. (2002). Understanding and Evaluating Qualitative Research. *Australian & New Zealand Journal of Psychiatry*, 36(6), 717-732. <a href="https://doi.org/https://doi.org/10.1046/j.1440-1614.2002.01100.x">https://doi.org/https://doi.org/10.1046/j.1440-1614.2002.01100.x</a>.
- Gilworth G, Eyres S, Carey A, Tennant A (2008). Working with a brain injury:personal experiences of return to work following a mild or moderate brain injury. *J Rehabil Med* 40:334–339.
- Garssen MP, van Doorn PA, Visser GH (2006). Nerve conduction studies in relation to residual fatigue in Guillain-Barre syndrome. *J Neurol* 253:851–856.
- Hunt D, Smith JA. The personal experience of carers of stroke survivors: an interpretative phenomenological analysis. *Disabilty Rehabilitation* 2004;26:1000–1011
- Hughes, R. A. C., & Rees, J. H. (n.d.). Clinical and Epidemiologic Features of Guillain-Barré Syndrome.
  - https://academic.oup.com/jid/article/176/Supplement\_2/S92/841786
- Hauck LJ, White C, Feasby TE, Zochodne DW, Svenson LW, Hill MD: Incidence of Guillain-Barre syndrome in Alberta, Canada: an administrative data study. *J Neurol Neurosurg Psychiatry* 2008; 79: 318–320
- Holloway, I. and Todres, L. 2003: The status of method: flexibility, consistency and coherence. *Qualitative Research* 3, 345!/57.

- Lock S, Jordan L, Bryan K, Maxim J (2005). Work after stroke: focusing on barriers and enablers. *Disabil Soc* 20:3–47.
- ILO. (2015). Decent Work for Persons with Disabilities: Promoting Rights in the Global Development Agenda,. international Labour Office Geneva https://www.ilo.org/wcmsp5/groups/public/---ed\_emp/--- ifp\_skills/documents/publication/wcms\_430935.pdf
- Laparidou, D., Curtis, F., Akanuwe, J., Jackson, J., Hodgson, T. L., & Siriwardena, A. N. (2021a). Patients' experiences and perceptions of Guillain-Barré syndrome: A systematic review and meta-synthesis of qualitative research. *PLoS ONE*, *16*(2 February). <a href="https://doi.org/10.1371/journal.pone.0245826">https://doi.org/10.1371/journal.pone.0245826</a>
- Matias-Guiu J, Martín R, Blanquer J, González MJ, Falip R, Oltra A, Moltó JM: Incidence of Guillain-Barré syndrome and ganglioside intake in Alcoi, Spain. *Neuroepidemiology* 1993;12:58–60.
- McKhann GM, Cornblath DR, Ho TW, Li CY, Bai AY, Wu HS. Clinical and electrophysiological aspects of acute paralytic disease of children and young adults in northern China. *Lancet* 1991;338:593–7.
- McMahon B, West S, Shaw L, Waid-Ebbs K, Belongia L (2005). Workplace discrimination and traumatic brain injury: the national EEOC ADA research project. *Work J Prev Assoc Rehabil* 25:67–75.
- Medin J, Barajas J, Ekberg K (2006). Stroke patients' experiences of return to work. *Disabil Rehabil* 28:1051–1060.
- McFarland HR, Heller GL. Guillain-Barre´ disease complex. A statement of diagnostic criteria and analysis of 100 cases. *Arch Neurol* 1966; 14: 196–201.
- McGrogan, A., Madle, G. C., Seaman, H. E., & De Vries, C. S. (2009). The epidemiology of Guillain-Barré syndrome worldwide: A systematic literature review. In

- *Neuroepidemiology* (Vol. 32, Issue 2, pp. 150–163). https://doi.org/10.1159/000184748.
- MacDermid JC, R, MacIntyre NJ (2009) Using an evidence-based approach to measure outcomes in clinical practice. *Hand Clin* 25(1):97–111. doi:10.1016/j.hcl.2008.11.001
- Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education*, 8(2), 90–97. https://doi.org/10.1007/s40037-019-0509-2.
- Neetij, ◆, & Bikash Thapa, R. ♣. (n.d.). *A STUDY ON PURPOSIVE SAMPLING METHOD IN RESEARCH*. <a href="http://study.com/academy/lesson/what-is-sampling-in-research-definition-methods-importance.html">http://study.com/academy/lesson/what-is-sampling-in-research-definition-methods-importance.html</a>,
- Nicholas R, Playford ED, Thompson AJ. A retrospective analysis of outcome in severe Guillain-Barre' syndrome following combined neurological and rehabilitation management. *Disability Rehabilitation* 2000;22:451–455.
- National Institute of Neurological Disorders and Stroke. Guillain-Barre´

  SyndromeFactSheet.2018;Retrieved October 02, 2019, from 
  <a href="https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Guillain-Barr%C3%A9-Syndrome-Fact-Sheet">https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Guillain-Barr%C3%A9-Syndrome-Fact-Sheet</a>.
- Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help uslearn from the experiences of others. *Perspect Med Educ*, 8(2), 90-97. https://doi.org/10.1007/s40037-019-0509-2
- Opperman J (2004). Interpreting the meaning that individuals ascribe to returning to work after traumatic brain injury: a qualitative approach. *Brain Inj* 18:941–955.
- O'Brien L (2007). Achieving a successful and sustainable return to the workforce after ABI: a client-centred approach. *Brain Inj* 21:465–478.
- Pantazis C, Gordon D, Levitas R (eds) (2006) Poverty and social exclusion in Britain: the

- millennium survey. The Policy Press, Bristol.
- Pritchard J, Hughes RAC. Guillain-Barre' syndrome. Lancet 2004;363:2186–2188.
- Royal, E., Reynolds, F. A., & Houlden, H. (2009). What are the experiences of adults returning to work following recovery from Guillain-Barré syndrome? An interpretative phenomenological analysis. *Disability and Rehabilitation*, 31(22), 1817–1827. https://doi.org/10.1080/09638280902822294.
- Radhakrishnan K, el-Mangoush MA, Gerryo C. Descriptive epidemiology of selected neuromuscular disorders in Benghazi, Libya. *Acta Neurol Scand* 1987;75:95–100.
- Ruts L, Drenthen J, Jongen JL, Hop WC, Visser GH, Jacobs BC, van Doorn PA (2010). Pain in Guillain-Barre syndrome: a long-term follow-up study. *Neurology* 75:1439–1447.
- Rana, S., Murray, N., Sapkota, K. P., & Gurung, P. (2022). Lived Employment

  Experiences of Persons with Physical Disabilities in Nepal: A Phenomenological Study.

  Scandinavian Journal of Disability Research.

  https://doi.org/ http://doi.org/10.16993/sjdr.860
- Ropper AH (1992). The Guillain-Barre syndrome. N Engl J Med 326:1130–1136.
- Shain M (2001). Returning to work after illness or injury: The role of fairness. *Bull Sci Technol Soc* 21:361–368.
- Sundler, A. J., Lindberg, E., Nilsson, C., & Palmér, L. (2019). Qualitative thematic analysis based on descriptive phenomenology. *Nursing Open*, 6(3), 733–739. https://doi.org/10.1002/nop2.275
- Schmidt-Degenhard M. Oneiric perception in intensively treated panplegic polyradiculitis patients. *Nervenarzt* 1986; 57: 712–8.
- Siriwardena, A. N., Akanuwe, J. N. A., Botan, V., Laparidou, D., Curtis, F., Jackson, J., Asghar, Z. B., & Hodgson, T. L. (2022). Patient-reported symptoms and experience following Guillain-Barré syndrome and related conditions: Questionnaire development

- and validation. *Health Expectations*, 25(1), 223–231. https://doi.org/10.1111/hex.13367.
- Sejvar JJ, Baughman AL, Wise M, Morgan OW. Population incidence of Guillain-Barre syndrome: asystematic review and meta-analysis. *Neuroepidemiology*. 2011; 36(2): 123–133.https://doi.org/10.1159/000324710 PMID: 21422765.
- Testa MA, Simonson DC (1996). Assessment of quality-of-life outcomes. *N*Engl J Med 334:835–840.
- Vogel, A. P., Barker, S. J., Young, A. E., Ruseckaite, R., & Collie, A. (2011). What is return to work? An investigation into the quantification of return to work. *International Archives of Occupational and Environmental Health*, 84(6), 675–682. https://doi.org/10.1007/s00420-011-0644-5.
- Wolfenden, B., & Grace, M. (2009). Returning to work after stroke: A review. In *International Journal of Rehabilitation Research* (Vol. 32, Issue 2, pp. 93–97). <a href="https://doi.org/10.1097/MRR.0b013e328325a358.">https://doi.org/10.1097/MRR.0b013e328325a358.</a>
- Weiss H. Psychological changes in intensive care patients with acute Guillain-Barre´syndrome—psychoanalytic aspects of loss of communication and adjustment. Fortschr Neurol Psychiatr 1991; 59:134–40.
- Weiss H, Rastan V, Mu''llges W, Wagner R, Toyka K. Psychotic symptoms and emotional distress in patients with Guillain-Barre' syndrome. *Eur Neurol* 2002; 47: 74–8. https://doi.org/10.1159/000047956 PMID: 11844894.
- Waddell G, Burton AK (2006) Is work good for your health and well-being?. Department for Work and Pensions, The Stationary OYce, London.

### APPENDICES

### **Appendix A-Approval letter**

Approval letter of Institutional Review Board (IRB)



### বাংলাদেশ হেল্থ প্রফেশস ইনাস্টাটডট (বিএইচপিআই) Bangladesh Health Professions Institute (BHPI)

(The Academic Institute of CRP)

Ref: CRP-BHPI/JRB/10/2023/772

Date: 18 · 10 · 2023

Chitra Biswas

4th Year B.Sc. in Occupational Therapy Session: 2018-2019; Student ID: 122180301 Department of Occupational Therapy BHPL CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "Work related experience of adults after recovering from Guillan Barre Syndrome" by ethics committee.

Dear Chitra Biswas.

Congratulations

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

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

The purpose of the study is to explore the work related experience of Guillan Barre Syndrome patients after recovery from GBS and their perception about their return to work. The study involves use of A selfdeveloped semi structured interview guide will be used in the study for conducting the research and face to face in depth interview method that may take about 30 to 35 minutes to fill in the questionnaire to know the experiences and their perception about their return to work and there is no likelihood of any harm to the participants and no economic benefits for the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 8.30 AM on 23rd September 2023 at BHPI 38th 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 in accordance to Nuremberg Code 1947, World Medical Association Declaration of Helsinki, 1964 - 2013 and other applicable regulations.

Best regards.

Hellathanaer

Member Secretary Institutional Review Board

BHPI, CRP, Savar, Dhaka-19

ন্তারপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ। কোন: +৮৮ ০২ ২২৪৪৪৫৪৬৪-৫, +৮৮ ০২ ২২৪৪৪১৪০৪, মোবাইল: +৮৮ ০১৭৩০ ০৫৯৬৪৭ CRP-Chapain, Savar, Dhaka-1343, Bangladesh. Tel: +88 02 224445464-5, +88 02 224441404, Mobile: +88 01730059647

### Permission letter for conducting study from Occupational Therapy Department

Date: 07.10.2023

To

The Head of the Occupational Therapy Department
Centre for the Rehabilitation of the Paralysed (CRP)

CRP-Savar, Dhaka-1343, Bangladesh

Subject: Application for permission to collect data for the research project.

Sir,

With due respect, I would like to draw your kind attention that I am a 4th year student of B.Sc. in Occupational Therapy at Bangladesh Health Professionals Institute (BHPI). I have to submit a research paper to the University of Dhaka in partial fulfilment of the degree of Bachelor of Science in Occupational Therapy. I would like to collect information about Guillen Barre Syndrome (GBS) patients from Outdoor unit from January 2021 to June 2023. The research title is "Work related experience of adults after recovering from Guillain Barre Syndrome." The Study design is Qualitative method with phenomenology approach. I would like to take face to face in depth interviews with male and female GBS patients. I assure you that anything of my project will not be harmful for the participants, and any data collected will be kept confidential.

So, I look forward to having your permission to start data collection to conduct a successful study as a part of my course.

Sincerely yours,

Chitro Chitra Biswas

4th Year B.Sc. in Occupational Therapy
Session: 2018-2019
Bangladesh Health Professions Institute (BHPI)
CRP-Savar, Dhaka-1343, Bangladesh

Signature and comments of the head of the department

Sk.Moniruzzaman

Associate Professor & Head of the Department Department of Occupational Therapy Bangladesh Health Professions Institute (BHPI) CRP-Savar, Dhaka-1343, Bangladesh

CS Scanned with GamScanner

### Permission letter from Occupational Therapy Clinical Unit

Date: 19.10.2023

To

The Head of the Occupational Therapy Department

Centre for the Rehabilitation of the Paralysed (CRP)

CRP-Savar, Dhaka-1343, Bangladesh

Subject: Application for permission to collect data for the research project.

With due respect, I would like to draw your kind attention that I am a 4th year student of B.Sc. in Occupational Therapy at Bangladesh Health Professionals Institute (BHPI). I have to submit a research paper to the University of Dhaka in partial fulfilment of the degree of Bachelor of Science in Occupational Therapy. I would like to collect information about Guillen Barre Syndrome (GBS) patients from Outdoor unit from January 2021 to June 2023. The research title is "Work related experience of adults after recovering from Gillian Barre Syndrome." The Study design is Qualitative method with phenomenology approach. I would like to take face to face in depth interviews with male and female GBS patients. I assure you that anything of my project will not be harmful for the participants, and any data collected will be kept confidential.

So, I look forward to having your permission to start data collection to conduct a successful study as a part of my course.

Sincerely yours,

Chitra\_ Chitra Biswas 4th Year B.Sc. in Occupational Therapy Session: 2018-2019 Bangladesh Health Professions Institute (BHPI) CRP-Savar, Dhaka-1343, Bangladesh

Signature and comments of the head of the department

well 1560

Tauhidul Islam 1910 (1973)
Head of the Occupational Therapy Department (Acting) Centre for the Rehabilitation of the Paralysed (CRP)

CRP-Savar, Dhaka-1343, Bangladesh

CS Sounned with CamScanne

### **Appendix B: Information Sheet & Consent Form**

## Information sheet, Consent form and Withdrawal from (English Version)



### বাংলাদেশ হেলথ্ প্রফেশনস ইন্সটিটিউট

Bangladesh Health Professions Institute (BHPI)

Department of Occupational Therapy

CRP-Chapain, Savar, Dhaka-1343, Telephone: 02-7745464-5. 7741404. Fax: 0774506

Code Number:

**Research title:** : "Work related experience of adults after recovery from Guillen Barre Syndrome."

**Researcher:** Chitra Biswas, B.Sc. in Occupational Therapy (4th Year), Session: 2018-2019, Bangladesh Health Profession Institute (BHPI), Savar, Dhaka-1343

**Supervisor:** Nayan Kumer Chanda, Assistant professor, Department of Occupational Therapy, Bangladesh Health Professions Institute.

Lecturer, Department of Occupational Therapy, Bangladesh Health Profession Institute.

**Research place:** The study will be conducted in community in Bangladesh.

Information sheet

### **Information Sheet Introduction:**

I'm Chitra Biswas, B.Sc in occupational therapy student of Bangladesh health professions institute BHPI), Have to conduct a thesis as a part of this bachelor course under thesis supervisor Nayan Kumer Chanda. You are going to have detailed information about the study purpose, data collection process, ethical issues.

You do not have to decide today whether you will participate in the research. Before

you decide, you can talk to anyone you feel comfortable with about the research. If this consent form contains some words that you do not understand please ask me, I will take time to explain.

### **Background and purpose:**

You are Bing invited to be a part of this research. The general purpose of the study is to explore work related experience after recovering from GBS.

### **Research related Information:**

The research related information will be discussed with you in detail before you sign the consent form. If you want to participate in this study, you must sign the consent form. Participants will then be asked to complete a structured questionnaire. This questionnaire will contain questions on socio-demographic factors.

The information will be maintained confidentiality, and your identity will not be disclosed, only a number will identify you and no one expect Nayan Kumer Chandra, supervisor of the study.

### **Right to Withdraw:**

If you think you shouldn't give consent, you may withdraw your participation without providing any explanation to the researcher until the time before the data is approved.

### **Risks and Benefits:**

During the research project, you may have to answer some personal and confidential questions due to which you may feel uncomfortable. If you don't want to answer any questions or take part in a discussion it also okay. On the other hand, you may not benefit directly from participating in this study, but your valuable participation will help to identify work related experiences and perception. It is expected that there is no additional risk, hazard, or discomfort in participating in the relevant research here.

### **Confidentiality**

By signing this consent letter, you have allowed the research staff studying in this research project to collect and use your personal information that will not be shared with anyone outside of the research team. The information about you will have been mentioned in a number. The information will not be shared with anyone except the supervisor Nayan Kumer Chanda of this research.

### **Sharing the results**

It is expected that nothing will be shared with anybody outside of the research team and attributed to you by name but the results or knowledge that we get from this research project will be published and presented in various forums. A summary of the results will be received by the participant. There will be small presentation, and these will be published. People who are interested will learn from the research, so we published the results according to the presentation.

### Who to contact?

If you have any questions about the research project, you can ask now or at any later time. If you wish to ask questions you may contact the following: Chitra Biswas, Bachelor of Science in Occupational Therapy, Department of Occupational Therapy, and cell phone 01754188873. This proposal has been reviewed and approved by Institutional Review Board (IBR), Bangladesh Health Professions Institute (BHPI), CRP-Savar, Dhaka-1343, Bangladesh.

### **Consent Form**

I am Chitra Biswas, 4<sup>th</sup> year, B.Sc. in Occupational Therapy student at Bangladesh Health Profession Institute (BHPI) under the Faculty of Medicine, University of Dhaka. As a part of B.Sc. in Occupational Therapy course curriculum, I am going to conduct a research under the supervisor of Nayan Kumer Chanda, Assistant Professor, Department of occupational Therapy, Bangladesh Health Professions Institute (BHPI). The research title is "Work related experience of adults after recovery from Guillen Barre Syndrome".

In this research I am \_\_\_\_\_\_ A participant and I have been clearly informed about the purpose and aim of the study. I am also informed that the information collected will only be used for study purposes and would be kept confidential. Name and address will not be published anywhere. Participation in this study is voluntary, I am willing to participate in the study.

Signature of the participant: \_\_\_\_\_\_ Date: \_\_\_\_\_\_

Signature of the researcher: \_\_\_\_\_ Date: \_\_\_\_

### Withdrawal Form

Research Title:. "Work related experience of adults after recovery from Guillen			
Barre Syndrome"			
Name of the Researcher: Chitra Biswas, 4 <sup>th</sup>	year, Occupational Therapy, Roll:24		
I confirm	m that I wish to withdraw all my data		
from the study before the data analysis has b	een completed and that none of my data		
will be included in the study.			
Signature of the participant:	Date:		
Name of the Researcher:	Date:		

### **Information sheet, Consent form and Withdrawal from (Bangla Version)**



বাংলাদেশ হেলথ্ প্রফেশনস ইন্সটিটিউট

(বিএইচপিআই)



Bangladesh Health Professions Institute (BHPI)

### অকুপেশনাল থেরাপি বিভাগ

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

কোড নাম্বার:

### গবেষণা তথ্য

গবেষণার শিরোনাম: "গুইলেন ব্যারে সিনড্রোম থেকে পুনরুদ্ধারের পরে প্রাপ্তবয়স্কদের কাজের অভিজ্ঞতা।"

গবেষক:, চিত্রা বিশ্বাস। ৪র্থ বর্ষ, বি.এসসি অকুপেশনাল থেরাপি বিভাগ, সেশন: ২০১৮-১৯, বাংলাদেশ হেলথ প্রফেশন ইনস্টিটিউট (বিএইচপিআই), সাভার, ঢাকা- ১৩৪৩

তত্ত্বাবধায়ক: নয়ন কুমার চন্দ,, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট। প্রভাষক, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেলথ প্রফেশন ইনস্টিটিউট (বিএইচপিআই)

গবেষণার স্থান: কমিউনিটি

### আমার স্নাতকের তথ্য পত্রের ভূমিকা

আমি চিত্রা বিশ্বাস। , বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট বিএইচপিআই-এর অকুপেশনালথেরাপি (বিএসসি) শিক্ষার্থী, থিসিস সুপারভাইজার নয়ন কুমার চন্দের অধীনে, এই ব্যাচেলর কোর্সের অংশ হিসাবে একটি থিসিস পরিচালনা করতে হবে। আপনার কাছে অধ্যয়নের উদ্দেশ্য,ডেটা সংগ্রহ প্রক্রিয়া, নৈতিক সমস্যা সম্পর্কে বিস্তারিত তথ্য থাকবে। আপনি গবেষণায় অংশগ্রহণ করবেন কিনা তা আজকে সিদ্ধান্ত নিতে হবে না। আপনি সিদ্ধান্ত

নেওয়ার আগে, গবেষণা সম্পর্কে আপনি যার সাথে স্বাচ্ছন্দ্য বোধ করেন তার সাথে কথা বলতে পারেন। যদি এই সম্মতি ফর্মে এমন কিছু শব্দ থাকে যা আপনি বুঝতে না পারেন দয়া করে আমাকে জিজ্ঞাসা করুন, আমি ব্যাখ্যা করব।

### পটভূমি এবং উদ্দেশ্য

আপনি এই গবেষণা একটি অংশ হতে আমন্ত্রিত. অধ্যয়নের সাধারণ উদ্দেশ্য হল গুইলেন ব্যারে সিনড্রোম থেকে পুনরুদ্ধারের পরে প্রাপ্তবয়স্কদের কাজের অভিজ্ঞতা।

### গবেষণা সম্পর্কিত তথ্য

আপনি সম্মতি ফর্মে স্বাক্ষর করার আগে গবেষণা সম্পর্কিত তথ্য আপনার সাথে বিশদভাবে আলোচনা করা হবে। আপনি যদি এই গবেষণায় অংশগ্রহণ করতে চান, তাহলে আপনাকে অবশ্যই সম্মতি ফর্মে স্বাক্ষর করতে হবে। অংশগ্রহণকারীদের তারপর একটি কাঠামোগত প্রশ্নাবলী সম্পূর্ণ করতে বলা হবে। এই প্রশ্নাবলীতে সামাজিক-জনসংখ্যা বিষয়ক প্রশ্ন থাকবে। তথ্য গোপনীয়তা বজায় রাখা হবে এবং আপনার পরিচয় নয়ন কুমার চন্দ্র, অধ্যয়নের তত্ত্বাবধায়ক ব্যতিত কারো কাছে প্রকাশ করা হবে না, শুধুমাত্র একটি সংখ্যা আপনাকে সনাক্ত

### প্রত্যাহারের অধিকার

আপনি যদি মনে করেন যে আপনার সম্মতি দেওয়া উচিত নয়, তাহলে ডেটা অনুমোদনের আগে পর্যন্ত আপনি গবেষককে কোনো ব্যাখ্যা না দিয়েই আপনার অংশগ্রহণ প্রত্যাহার করতে পারেন।

### ঝুঁকি এবং সুবিধা

গবেষণা প্রকল্পের সময়, আপনাকে কিছু ব্যক্তিগত এবং গোপনীয় প্রশ্নের উত্তর দিতে হতে পারে যার কারণে আপনি অস্বস্তি বোধ করতে পারেন। আপনি যদি কোনো প্রশ্নের উত্তর দিতে না চান বা আলোচনায় অংশ নিতে না চান তাহলেও ঠিক আছে। অন্যদিকে, আপনি এই গবেষণায় সরাসরি অংশগ্রহণ করে উপকৃত নাও হতে পারেন, কিন্তু আপনার GBS থেকে পুনরুদ্ধারের পরে কীভাবে কর্মজীবন পরিচালনা করে তা অন্বেষণ করা। এটি প্রত্যাশিত যে এখানে

প্রাসঙ্গিক গবেষণায় অংশগ্রহণ করার জন্য কোন অতিরিক্ত ঝুঁকি, বিপত্তি বা অস্বস্তি নেই। গোপনীয়তা

এই সম্মতি পত্রে স্বাক্ষর করার মাধ্যমে, আপনি এই গবেষণা প্রকল্পে অধ্যয়নরত গবেষণা কর্মীদের আপনার ব্যক্তিগত তথ্য সংগ্রহ এবং ব্যবহার করার অনুমতি দিয়েছেন যা গবেষণা দলের বাইরের কারো সাথে শেয়ার করা হবে না। এই গবেষণার তত্ত্বাবধায়ক নয়ন কুমার চন্দ ছাড়া অন্য কারো সাথে তথ্য শেয়ার করা হবে না। ফলাফল শেয়ার করা এটা আশা করা যায় যে গবেষণা দলের বাইরের কারো সাথে কিছুই প্রকাশ করা হবে না এবং নাম দ্বারা আপনাকে চিহ্নিত করা হবে তবে না ,আমরা এই গবেষণা প্রকল্প থেকে যে ফলাফল বা জ্ঞান পাই তা প্রকাশ করা হবে এবং বিভিন্ন ফোরামে উপস্থাপন করা হবে। ফলাফলের সারাংশ অংশগ্রহণকারীরা পাবেন। সেখানে হবে ছোট উপস্থাপনা হবে এবং এই প্রকাশ করা হবে. যারা আগ্রহী তারা গবেষণা থেকে শিখবেন যাতে আমরা উপস্থাপনা অনুযায়ী ফলাফল প্রকাশ করেছি।

### কার সাথে যোগাযোগ করবেন?

গবেষণা প্রকল্প সম্পর্কে আপনার কোন প্রশ্ন থাকলে, আপনি এখন বা পরে যেকোনো সময় জিজ্ঞাসা করতে পারেন। আপনি যদি প্রশ্ন করতে চান তবে আপনি নিম্নলিখিতগুলির সাথে যোগাযোগ করতে পারেন: চিত্রা বিশ্বাস। , অকুপেশনাল থেরাপিতে ব্যাচেলর অফ সায়েন্স, অকুপেশনাল থেরাপি বিভাগ, এবং সেল ফোন 01754188873। এই প্রস্তাবটি প্রাতিষ্ঠানিক পর্যালোচনা বোর্ড (আইআরবি), বাংলাদেশ দ্বারা পর্যালোচনা এবং অনুমোদিত হয়েছে বাংলাদেশ হেলথ প্রফেশন ইনস্টিটিউটে (বিএইচপিআই), সিআরপি-সাভার, ঢাকা-১৩৪৩, বাংলাদেশ।

### সম্মতি পত্ৰ

গবেষকের স্বাক্ষর:

তারিখ:

### প্রত্যাহার পত্র

শুেধুমাত্র স্বেচ্ছায় প্রত্যাহারের জন্য প্রযোজ্য)

গবেষনার শিরনামঃ "গুইলেন ব্যারে সিনড্রোম থেকে পুনরুদ্ধারের পরে প্রাপ্তবয়স্কদের

TO THE	
কাজের অভিজ্ঞতা"	
গবেষক: চিত্রা বিশ্বাস।, ৪র্থ বর্ষ, অকুপেশনাল থেরাপি	বিভাগ
আমি	(অংশগ্রহণকারী), আমার অংশগ্রহণ
থেকে উদ্ভূত ডেটা ব্যবহারের জন্য আমার সম্মতি প্র	ত্যাহার করতে চাই।
প্রত্যাহারের কারণ	
অংশগ্রহনকারীর স্বাক্ষর	তারিখ:
গবেষকের স্বাক্ষর	তারিখ:

### **Appendix C: Questionnaire**

### **Self Developed Interview Guide in English**

- 1. How are you?
- 2. Can you share your experience of returning to work after recovering from GBS?
- 3. Did you switch your past occupation because of your disability? If yes, Why?
- 4. What is your perspective about return to work?
- 5. How did you feel during this transition?
- 6. What type of job responsibility you have?
- 7. How do you feel to perform your job?
- 8. What is the motivational fact that influence to return to work?
- 9. Can you complete your work in time? If no, how do you manage your caseload?
- 10. What challenges did you face when returning to work after GBS?
- 11. How did you overcome them?
- 12. Did you use any assistive device to perform your job effectively post-GBS?
- 13. How did you manage your long term GBS impact while working?
- 14. What are the specific difficulties you faced in the workplace due to GBS-related physical limitations?
- 15. How did you overcome them?
- 16. How do you manage potential fatigue or physical limitations while working?
- 17. How did your colleagues support your return to work after GBS?Do they help you in your work?

### Self Developed Interview Guide in Bangla

### প্রশ্নাবলী

- 1.আপনি কেমন আছেন?
- 2. আপনি জিবিএস থেকে সুস্থ হওয়ার পরে কাজে ফিরে আসার অভিজ্ঞতা সম্পর্কে কিছু বলেন ?
- 3. আপনি কি আপনার অসুস্থতা কারণে আপনার অতীতের পেশা পরিবর্তন করেছেন? যদি হ্যাঁ, কেন?
- 4. কাজে ফেরার বিষয়ে আপনার দৃষ্টিভঙ্গি কী?
- 5.এই পরিবর্তনের আপনি কেমন অনুভব করেছিলেন?
- 6. আপনার কি ধরনের কাজের দায়িত্ব আছে?
- 7. কাজ গুলো করতে আপনার কেমন লাগে?
- 8. কোন বিষয়গুলো কাজে ফিরে যেতে অনুপ্রাণিত করে?
- 9. আপনি কি সময়মতো আপনার কাজ শেষ করতে পারবেন? যদি না হয়, তাহলে আপনি কীভাবে আপনার কাজ পরিচালনা করবেন?
- 10.জিবিএস-এর পরে কাজে ফিরে আসার সময় আপনি কোন চ্যালেঞ্জের মুখোমুখি হয়েছিলেন?
- 11. আপনি কীভাবে সেগুলি কাটিয়ে উঠলেন?
- 12. আপনি কি জিবিএস-এর পরে কার্যকরভাবে আপনার কাজ সম্পাদন করার জন্য কোন সহায়ক ডিভাইস ব্যবহার করেছেন?
- 13. আপনি কীভাবে আপনার দীর্ঘমেয়াদী জিবিএস প্রভাবগুলি সমাধান করেছেন?

- 14. জিবিএস-সম্পর্কিত শারীরিক সীমাবদ্ধতার কারণে কর্মক্ষেত্রে আপনি কোন নির্দিষ্ট সমস্যার সম্মুখীন হয়েছেন ?
- 15. আপনি কিভাবে তা কাটিয়ে উঠলেন?
- 16. কাজ করার সময় আপনি কীভাবে সম্ভাব্য ক্লান্তি বা শারীরিক সীমাবদ্ধতা পরিচালনা করবেন?
- 17. আপনার সহকর্মীরা কীভাবে জিবিএস-এর পরে আপনার কাজে ফিরে আসাকে সমর্থন করেছিল? তারা কি আপনার কাজে সাহায্য করে?

### Sociodemographic Questionnaire

1.Name:				
2.Gender:	Male	Female		
3.Age:				
4.Material state	us:			
Married	Unmarried			
5. Religion:				
6.Family numb	er:			
7.Living status:	:			
Rural	semi-urb	an	urban	
8.Occupation:				
9.Education :				
10.Date of incid	lence:			
11.Other inform	nation (if any):			

### Appendix D : Supervision Record Sheet

## Bangladesh Health Professions Institute Department of Occupational Therapy 4th Year B. Sc in Occupational Therapy OT 401 Research Project

# Thesis Supervisor- Student Contact; face to face or electronic and guidance record

Title of thesis: Worck related experience of adults recovering from Buillain - Barre Syndrome.

Name of student: Chi-hra Biswas

Name and designation of thesis supervisor: Nayan Kumer Chanda, Assistant professor, Department of Occupational Therapy, Bangladesh Health Professions Institute.

14.08.14 14.15		
BHPI building	c 2 2	Ubrany Library Library
16	Time Hane & Budget 50 minut	Study design & inclusion exculsion oritheria Data Collection method Data anaylsis Time frame & Budget Information, Onsent & willulia
westimmain questions	ent & wHudrowson	Study design & inclusion & excells in creteria a Data collection method Data concepts is Time frame & Budget formetion, Consent & withdrawton
	20	2 hows  45 minutes  1 how Lominutes  50 minutes
2 nowship mod to sel Questionnain	2 hours Need to do therefore	2 hours Need to do estudy  45 minutes Need to do date congless  1 hour soming Need to do date congless  50 minutes Need to do date congless  2 hours Need to do thuse to tome
and Chithra	Outra	
Zar T	3	

CS Sourced with ComScound

	_
ned with Camberman	mete les
9 9 10	27

16	05.10,23	BHPI building	· Data Monggement 26 Analysis	2 hours	- more do the data	chitra	Noup
17	20 - 10 - 23	υ	·Trustworthiness & Prigor; Pescults	2.5 hours	need to do the	ChiHra	May
18	07.11.23	U	· Discussion · Corclusion	2 hours	need to do the discussion, condusion	Chiltra	Nagr
19	09.12.23	ц	· Result	1 howrs	· Need to do result	alitra	Neys
20	27.12.23	u	· Methodology review	1 LOUTS	· Need to do methodology	chietra	North

### Note:

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