

The clinical outcomes and quality of life in patients with Guillain-Barré syndrome: a literature review

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ABSTRACT

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Guillain-Barre syndrome (GBS) is an immune-mediated condition that targets the roots of the spinal cord and peripheral nerves. While most patients with GBS can achieve complete recovery with appropriate management, some may experience long-term sequelae that adversely impact their quality of life (QoL). Clinical outcomes are measured variables in research to evaluate the effects of interventions or exposures on a particular population's health. Patients with GBS may experience suboptimal clinical outcomes due to post-GBS disabilities, which may result from complications or residual symptoms of the syndrome. These disabilities can impede daily functioning and significantly lower QoL, often requiring patients to alter their lifestyles, work, and social interactions. Quality of life is a subjective assessment of how individuals perceive their circumstances in relation to their goals, influenced by their cultural and value systems. Various tools are available to assess the quality of life for GBS patients. The clinical outcomes and QoL for post-GBS patients are diverse and shaped by various factors. Through the early identification of these factors, clinicians can enhance management strategies to improve both clinical outcomes and the overall QoL for individuals recovering from GBS.

ABSTRAK

Sindrom Guillain-Barre (SGB) merupakan penyakit yang dimediasi sistem imun yang menyerang radiks nervus spinalis dan saraf perifer. Mayoritas pasien SGB akan mengalami pemulihan sempurna dengan pemberian tata laksana yang optimal. Namun, sebagian di antaranya akan memiliki gejala sisa yang dapat memengaruhi kualitas hidupnya. Luaran klinis adalah variabel yang dimonitor selama penelitian untuk mendokumentasikan efek dari intervensi atau eksposur yang diberikan terhadap kesehatan dari populasi tertentu. Luaran klinis pasien buruk dapat dialami pasien SGB akibat disabilitas pasca SGB. Disabilitas itu dapat muncul karena komplikasi maupun gejala residual dari SGB. Disabilitas tersebut akan mengganggu fungsi sehari-hari dan kualitas hidup pasien, sehingga banyak dari pasien yang harus mengubah gaya hidup, pekerjaan, dan aktivitas sosial, sehingga pada akhirnya menurunkan tingkat kualitas hidup. Kualitas hidup sebagai evaluasi subjektif dari persepsi seseorang tentang realitas mereka relatif terhadap tujuan mereka, yang diamati melalui lensa budaya dan sistem nilai mereka. Kualitas hidup pasien SGB dapat dinilai dengan menggunakan berbagai instrumen. Luaran klinis dan tingkat kualitas hidup pasien pasca SGB bervariasi dan dipengaruhi oleh berbagai faktor. Dengan melakukan identifikasi dini faktor-faktor tersebut, klinisi dapat mengoptimalkan tata laksana yang diberikan untuk meningkatkan luaran klinis dan kualitas hidup pasien pasca SGB. g

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INTRODUCTION

Guillain-Barré syndrome (GBS) is an immune-mediated disorder that impacts the roots of the spinal cord and peripheral nerves.¹ This syndrome is recognized as one of the possible causes of acute or subacute weakness and paralysis.² Antibodies play a crucial role in the pathophysiology of GBS. Additionally, molecular mimicry contributes to the condition, as lipooligosaccharides from certain bacteria and viruses, such as *Campylobacter jejuni* and Epstein-Barr virus, resemble the gangliosides found in the membranes of peripheral nerves.¹

Health-related quality of life (HRQL) is a multidimensional concept that encompasses how diseases and treatments impact overall patient functioning and well-being. It reflects an individual's perception of their illness and the therapies received, which can influence physical, mental, and social aspects of life.^{3,4} While HRQL and quality of life (QoL) are closely related, they are not identical. The World Health Organization (WHO) defines QoL as a subjective assessment of a person's perception of their reality in relation to their goals, expectations, standards, and concerns. Additionally, QoL is shaped by factors such as physical health, mental health, social health, and functional health.⁵ The various management approaches for patients with GBS significantly influence both their QoL and clinical outcomes. Implementing a comprehensive and appropriate management strategy is essential for enhancing QoL and achieving improved clinical results for these patients.

Management strategies for GBS patients can be classified into two categories: pharmacological and non-pharmacological. Pharmacological approaches include the administration of intravenous immunoglobulin (IVIg), steroids, and symptomatic therapy. Non-pharmacological strategies encompass

medical rehabilitation and plasma exchange.⁶ The chosen management approach can significantly influence the condition and clinical outcomes of patients recovering from GBS. One particular aspect that has been frequently studied for its impact on clinical outcomes in post-GBS patients is physiotherapy. As a component of medical rehabilitation, physiotherapy has been shown to enhance patients' mobility and strengthen their muscle function.⁷

Understanding the factors that influence clinical outcomes enables clinicians to better predict the QoL for patients undergoing GBS and to provide targeted care for those at higher risk.⁸ A thorough management approach has the potential to enhance clinical outcomes and QoL; conversely, clinical outcomes and QoL may influence subsequent management decisions.⁶ Thus, it is essential for neurologists, patients, and their families to engage in discussions regarding the clinical outcomes and QoL associated with GBS, along with the factors that impact them.⁴

Research on the QoL in post-GBS patients has been extensively conducted in various countries. However, studies focusing on GBS, particularly regarding the QoL of affected individuals, remain quite limited in Indonesia. There is one case report from Indonesia regarding a patient with GBS who was treated in the intensive care unit. This report indicates that the patient experienced psychological disturbances, specifically anxiety, as well as challenges in social interaction, communication, and work.⁹

This gap in research underscores the importance of further exploration and discussion on this significant topic within the Indonesian. This review aims to synthesize existing literature on the clinical outcomes and QoL in GBS patients, with a focus on identifying factors that influence these outcomes.

MATERIAL AND METHODS

This manuscript presents a literature review focused on clinical outcomes and QoL in post GBS. A comprehensive search of literature sources was conducted using a combination of keywords, including “Guillain-Barre syndrome,” “post Guillain-Barre syndrome,” “quality of life,” “clinical outcomes,” and “health-related quality of life.” The databases utilized for this search include PubMed, PMC, Semantic Scholar, Research Gate, and other journal website (such as Europe PMC, Wiley Online Library, BMJ Neurology Open, etc.). Considering the limitations of research in this field, the journals addressed in this literature review are those published within the past 20 yr. This review will incorporate research journals that utilize a variety of research methods, including systematic reviews and meta-analyses. Research with case report and case series methodologies will be excluded from consideration. Journals published in languages other than English will not be included in this review. To ensure

a systematic selection of journals, the author used the PRISMA guidelines.

RESULTS

The search results yielded a total of 305 manuscripts relevant to the specified keywords. Upon careful screening, 19 manuscripts were identified as meeting the inclusion criteria (FIGURE 1). A total of eight manuscripts examine clinical outcomes, while eleven manuscripts focus on QoL. Additionally, four of these studies are conducted within pediatric populations.

TABLE 1 and 2 provides a summary of the key findings from the selected journals. Clinical output research evaluates a variety of aspects that may manifest in patients following GBS. The primary physical outcome assessed is muscle strength, whereas the psychological aspect most frequently measured is the presence of depression (TABLE 1). GBS disability scale (GDS), formerly known as the Hughes disability score (HDS), is the most widely utilized instrument in numerous studies.

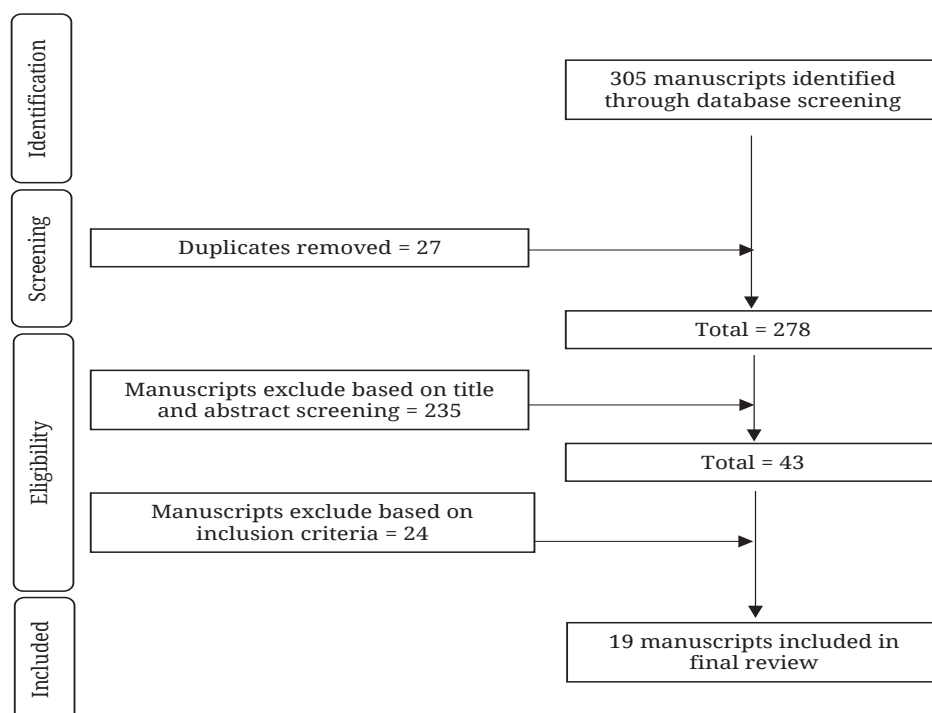


FIGURE 1. A PRISMA flow diagram

TABLE 1. Overview of clinical outcome research findings in patients following Guillain-Barre syndrome

Authors	Year	Method	Subjects	Instrument for clinical outcome	Results
Bernsen, <i>et al.</i> ¹⁰	2010	Prospective study	85 adult GBS patients	GHQ SIP Center for Epidemiologic Studies Depression Scale	Psychological distress and depressive symptoms improved between 3 and 6 mo. At 12 mo, psychosocial health was still impaired, but depressive symptoms had no impact.
Walgaard, <i>et al.</i> ¹¹	2011	Prospective cohort study	397 adult GBS patients	MRC	Older age, preceding diarrhea, and low MRC sum score at admission and 1 week were linked to inability to walk at 4 wk, 3 mo, and 6 mo.
Inokuchi, <i>et al.</i> ¹²	2014	Retrospective observational cohort study	3835 adult GBS patients	Barthel index	Patients with GBS had a lower hospital mortality rate when they received rehabilitation therapy.
Sen, <i>et al.</i> ¹³	2021	Hospital record review	108 pediatric GBS patients	Hughes GBS disability scale	Patients with the axonal variety had higher Hughes disability scores at presentation, peak disease, discharge, and at 8 wk and 6 mo follow-up.
Bhatia, <i>et al.</i> ¹⁴	2022	Retrospective observational study	212 adult GBS patients	-	About 79% of patients showed improvement, while 21% did not. Lack of improvement was linked to hypertension, alcoholism, sepsis, and cardiac arrest. Notably, those treated with a combination of IVIgG or plasmapheresis with physiotherapy or occupational therapy were more likely to improve.

CN: cranial nerves; FSS: fatigue severity scale; GBS: Guillain-Barre syndrome; GDS: Guillain-Barre syndrome disability score; GHQ: general health questionnaire; IVIg: intravenous immunoglobulin; mEGOS : modified Erasmus GBS outcome score; MRC : medical research council; PLEX: plasma exchange; SIP: sickness impact profile; VAS: visual analogue scale

TABLE 1. Cont.

Authors	Year	Method	Subjects	Instrument for clinical outcome	Results
Patel, <i>et al.</i> ¹⁵	2022	Prospective observational study	50 adult GBS patients	Hughes GBS disability scale	Patients with CN involvement and axonal subtype had a Hughes score of ≥ 3 and showed less improvement at discharge. Respiratory involvement correlated with a higher Hughes Score on admission. In two treatment cohorts (PLEX vs IVIG), short-term functional outcomes were similar, with no difference in Hughes score improvement.
Roodbol, <i>et al.</i> ¹⁶	2023	Retrospective cohort study	421 pediatric GBS patients	GDS	Children who had a higher GDS at its lowest point and elevated CSF protein levels were less likely to walk independently at 1 mo. The GDS at nadir was the main predictor of outcomes at various time intervals.
Dang, <i>et al.</i> ¹⁷	2024	Retrospective study	109 adult and 111 pediatric GBS patients	GDS	Children displayed greater motor function impairment, with 90 (81.1%) having a GDS score of 3 to 6, compared to 66 (60.6%) adults. However, short-term outcomes for both groups were not significantly different.

CN: cranial nerves; FSS: fatigue severity scale; GBS: Guillain-Barre syndrome; GDS: Guillain-Barre syndrome disability score; GHQ: general health questionnaire; IVIg: intravenous immunoglobulin; mEGOS : modified Erasmus GBS outcome score; MRC: medical research council; PLEX: plasma exchange; SIP: sickness impact profile; VAS: visual analogue scale

The short form-36 (SF-36) is the most frequently instrument for assessing patient's QoL (TABLE 2). Most studies utilize prospective methodologies. In adult patients with GBS, assessments can be conducted directly with the patients, whereas in pediatric GBS cases, it is essential to verify findings through their parents. The results across these

studies are mixed; however, the majority indicate that the QoL of post-GBS patients tends to improve over time. Variations may arise from a range of influencing factors. A study conducted by Khedr *et al.*,¹⁸ and Devi *et al.*,¹⁹ evaluated both QoL levels and clinical outcomes in patients following GBS.

TABLE 2. Overview of QoL research findings in patients following Guillain-Barre syndrome

Authors	Year	Method	Subjects	Instrument for QoL	Results
Forsberg, <i>et al.</i> , ²⁰	2008	Prospective study	35 adult GBS patients	SIP	At 2 wk, SIP scores were elevated across all dimensions; at 2 yr, they remained high in physical health and in home management, work, and recreation categories.
Demir, <i>et al.</i> , ²¹	2008	Prospective study	31 adult GBS patients and 31 control	NHP`	The scores of all of the NHP dimensions of the GBS patients were significantly higher than in the control subjects.
Darweesh, <i>et al.</i> , ⁴	2014	Systematic review	-	SF-12 SF-36 SIP NHP WHOQOL-BREF	Many GBS patients faced physical limitations years after the acute phase. Three studies assessed HRQL at multiple time points, showing significant improvements within the first year, but not afterwards.
Djordjevic, <i>et al.</i> , ⁷	2019	Prospective study	74 adult GBS patients	INQoL	INQoL scores showed significant improvement over time ($p < 0.01$), but did not differentiate between day 14 and 28. Additionally, some scores also failed to distinguish between month 3 and 6
Berisavac, <i>et al.</i> , ²²	2020	Prospective study	74 adult GBS patients	SF-36	SF-36 scores improved over time ($p < 0.01$). SF-36 did not differ between day 14 and day 28.
Swami, <i>et al.</i> , ²³	2020	Prospective study	74 adult GBS patients	SF-36	Patients with GBS experiencing neuropathic pain demonstrated a significant association with sensory impairments, elevated CSF protein levels, and emotional QoL domains, while showing no association with disability.
Holtz <i>et al.</i> , ²⁴	2021	Cross sectional study	130 adult GBS patients	SF-36 ONLS	Former GBS patients scored lower in all 8 dimensions of the SF-36 compared to the control group, with the most limitations in physical role functioning, followed by physical functioning and general health perception.

CSF: cerebrospinal fluid; EGRIS: Erasmus GBS respiratory insufficiency score; GBS: Guillain-Barre syndrome; GDS: Guillain-Barre syndrome disability scale; GOS-E Peds: Glasgow Outcome scale-extended pediatric version; INQoL: individualized neuromuscular quality of life; MRS: medical research council; NHP: Nottingham health profile; ONLS: overall neuropathy limitations score; PCP: pediatric cerebral performance category; PedsQL: pediatric quality of life; POPC: pediatric overall performance category; QoL: quality of life; SF-36: short form 36; SIP: sickness impact profile; 5Q-5D-5L: Euroqol-5D-5L

TABLE 2. Cont.

Authors	Year	Method	Subjects	Instrument for QoL	Results
Idam, <i>et al.</i> ²⁵	2023	Restrospective study	23 adult GBS patients	SF-36	QoL improved after 6 mo, especially the physical, mental and emotional (anxiety, depression).
Khedr, <i>et al.</i> ¹⁸	2023	Prospective study	79 adult GBS patients	SF-36	QoL at 1 yr showed a significant correlation with baseline clinical variables, including age, the number of days between weakness and admission, the MRC sum score at onset and nadir, high GDS scores, and EGRIS scores.
Devi, <i>et al.</i> ¹⁹	2023	Cross sectional observational study	80 pediatric, aged one to 12 yr, with GBS admitted over 5 yr	PedsQL Hughes GBS disability scale PCP POPC GOS-E Peds	In the PedsQL score, the mean summary scores reported by parents and children were 79.8 (9.8) and 79.1 (10.1), respectively. A favorable outcome (score ≥ 70) was noted in 64 (80%) of the children on the parent summary and in 64 (85%) of the children on the child summary.
Papri, <i>et al.</i> ²⁶	2024	Prospective study	644 adult GBS patients	5Q-5D-5L	Pain presented as a serious symptom negatively affecting the QoL in GBS.

CSF: cerebrospinal fluid; EGRIS: Erasmus GBS respiratory insufficiency score; GBS: Guillain-Barre syndrome; GDS: Guillain-Barre syndrome disability scale; GOS-E Peds: Glasgow Outcome scale-extended pediatric version; INQoL: individualized neuromuscular quality of life; MRS: medical research council; NHP: Nottingham health profile; ONLS: overall neuropathy limitations score; PCP: pediatric cerebral performance category; PedsQL: pediatric quality of life; POPC: pediatric overall performance category; QoL: quality of life; SF-36: short form 36; SIP: sickness impact profile; 5Q-5D-5L: Euroqol-5D-5L

DISCUSSION

Clinical outcomes in GBS

Clinical outcomes are key variables monitored during research to assess the impact of an intervention or exposure on the health of a specific population. These outcomes can manifest as total recovery, clinical deterioration, disability, or mortality. Ideally, clinical outcomes are patient-centered, focusing on aspects that hold significance for patients.²⁷ The majority of patients who undergo GBS experience favorable clinical outcomes, achieving a full recovery with proper management.²⁸ In managing GBS,

the primary objective is to enhance clinical outcomes by minimizing residual symptoms and preventing complications.⁶

The most prevalent complications include cardiovascular and respiratory issues, which may require ventilation support and close monitoring.^{14,29} Patients with severe cardiovascular dysfunction are particularly vulnerable, often experiencing rapid fluctuations in blood pressure and dysrhythmias. A prospective cohort study involving 156 patients revealed that 38% experienced tachycardia, 69% had hypertension, 45% had gastrointestinal dysfunction, and 19% presented with urinary

dysfunction.²⁹ Additionally, residual symptoms frequently reported among patients undergoing GBS include mild motor weakness, numbness in the extremities, fatigue, pain, and depression.^{2,4,6} It is estimated that approximately 10% of GBS patients will encounter these residual symptoms.²

Such disabilities can significantly disrupt daily functioning, leading many patients to alter their lifestyle, work commitments, and social interactions, ultimately diminishing their QoL.^{22,29} Research indicates that patients who are treated by a multidisciplinary team and engage in rehabilitative therapy tend to experience a decrease in disability, a shorter length of hospitalization, and an enhanced ability to reintegrate into community activities, thereby improving their overall QoL.^{22,28,30}

Regular medical rehabilitation programs can significantly reduce disability levels and enhance the overall QoL.²⁹ One common rehabilitation approach for patients with GBS is physiotherapy. This treatment not only alleviates residual symptoms, such as fatigue, but also strengthens muscles and enhances functionality. A case report by Gawande *et al.*,³¹ demonstrated that the QoL for GBS patients improved following a 30 d physiotherapy program. Medical rehabilitation not only helps prevent morbidity but also plays a crucial role in reducing mortality rates among post-GBS patients. Research conducted by Inokuchi *et al.*,¹² demonstrated that patients who received rehabilitation during their hospital stay experienced significantly lower mortality rates at 30 d (AOR=0.143; 95% CI=0.032-0.646; p=0.011) and 90 d (AOR=0.23; 95%CI=0.075-0.706; p=0.01) compared to those who did not undergo rehabilitation.

Residual complications and symptoms following a GBS not only lead to physical limitations but can also result in psychological disorders such as anxiety and depression. These issues significantly

impact the patient's capacity to engage in daily activities, maintain employment, and sustain social interactions.^{4,6} Research indicates that GBS patients are 4.8 times more likely to develop depression, with a notable prevalence rate of 67%. Furthermore, studies have demonstrated a correlation between depression and the severity of muscle weakness; the greater the disability experienced by GBS patients, the higher their risk of developing psychiatric disorders, subsequently diminishing their overall QoL.³² Addressing these psychological challenges through mental health support, coupled with the assistance of family and community, can enhance a patient's ability to manage their condition and facilitate recovery after GBS.³⁰

Bernsen *et al.*,¹⁰ conducted research focused on the psychological well-being of patients following GBS. Their findings indicate that post-GBS patients experience psychological distress and depressive symptoms; however, improvements are observed within 3-6 mo after the onset of GBS, with symptoms stabilizing around 12 mo post-diagnosis. This situation is influenced by lingering symptoms, including muscle pain and cramps.

Clinical outcomes in patients recovering from GBS can be assessed through a variety of evaluation tools. These include the Medical Research Council (MRC) sum score, the GBS disability scale (GDS), formerly known as the Hughes disability score, the Inflammatory Rasch-built overall disability scale (I-RODS), the inflammatory neuropathy cause and treatment (INCAT) disability scale, the modified Erasmus GBS outcome score (mEGOS), the international GBS outcome study (IGOS), and the overall neuropathy limitation scale (ONLS). These assessment instruments enable a comprehensive evaluation of clinical outcomes in patients recovering from

GBS from multiple perspectives.³³ Several previous studies have explored clinical outcomes utilizing the aforementioned instruments.

Factors influencing clinical outcomes in GBS

Previous studies have identified various factors that can influence the clinical outcomes of patients with GBS, which subsequently impact their QoL. Gaining a deeper understanding of these factors can assist clinicians in delivering more targeted and effective management, ultimately enhancing the condition of patients at risk of unfavorable clinical outcomes.^{6,31} Notably, patients aged 40 years and older, those with a history of diarrhea (or *C. jejuni* infection within the last 4 weeks), and individuals experiencing severe disability at their nadir are correlated with poorer clinical outcomes.³⁴ Additionally, factors such as alcohol consumption (AOR=5.148; 95%CI=1.234–21.472; $p=0.025$), hypertension (AOR=4.512; 95%CI=1.309–15.556; $p=0.017$), presence of sepsis (AOR=9.139; 95% CI=1.102–75.760; $p=0.040$), and cardiac arrest (AOR=17.495; 95%CI=1.249–245.027; $p=0.034$) are associated with an increased risk of adverse outcomes in GBS.¹⁴ Patients who received IV Ig combined with physiotherapy or occupational therapy (AOR=0.062, 95%CI=0.016–0.242; $p=0.001$) and those who underwent plasmapheresis along with physiotherapy or occupational therapy (AOR=0.007; 95%CI=0.000–0.147; $p=0.001$) exhibited more favorable outcomes.¹⁴

The type of GBS significantly affects clinical presentations. Among these variations, Miller Fisher syndrome (MFS) demonstrated the most favorable clinical outcomes; however, multivariate analysis revealed no significant impact on overall outcomes. In contrast, axonal-type GBS is associated with a poorer prognosis and

overall outcomes.¹⁴ A study conducted in India involving 50 GBS patients found that patients with demyelinating lesions experienced shorter hospital stays compared to those with axonal lesions, a statistically significant finding ($p=0.03$). Additionally, patients with axonal lesions generally require a longer recovery period.¹⁵ This distinction is crucial, as the axonal type is characterized by a more profound impairment of nerve fibers, leading to more significant motor and sensory deficits. Understanding these differences not only emphasizes the need for specialized treatment strategies but also highlights the importance of early intervention to mitigate the long-lasting effects on the QoL for these young patients.¹³

Weakness remains one of the persistent symptoms observed in patients recovering from GBS. Several prior studies have investigated the factors that contribute to these residual symptoms. Walgaard *et al.*¹¹ noted that variables such as older age, a history of diarrhea preceding GBS, and low MRC scores at both admission and one week post-admission were correlated with patients' inability to walk after the fourth week, as well as at 3 and 6 mo after the onset of GBS ($p=0.05 - 0.001$).

The GDS or HDS is a commonly utilized clinical tool for external examinations. A patient is classified as having a severe level of disability when their GDS score is 3 or higher. Previous research indicates that those with cranial nerve involvement ($p = 0.0087$) and those experiencing respiratory disturbances during GBS ($p = 0.005$) often have GDS scores of 3 or above. This indicates worse clinical outcomes are found in these patients.¹⁵

QoL after GBS

When discussing the QoL among GBS patients, they often highlight the physical complaints they experience, as

these concerns are closely tied to their treatment options.³ A systematic meta-synthesis review conducted by Laparidou *et al.*,³⁵ examined five manuscripts that qualitatively explored the experiences of patients with GBS in relation to their QoL. The participants in the study ranged in age from 16 to 80 yr and were predominantly male. The findings revealed 6 perspectives influencing the QoL for GBS patients: a sense of uncertainty, feelings of loss, challenges in treatment, an optimistic outlook on recovery, necessary adjustments, and the concept of a “new self”.³⁵

The uncertainty experienced by patients with GBS arises from symptoms that are often perceived as unusual and can be mistaken for those of other conditions, such as a stroke. Since the incidence and prevalence of GBS is lower compared to other neurological diseases, many healthcare professionals may lack the necessary knowledge and experience to effectively address this condition. As a result, patients frequently find themselves questioning their diagnosis and seeking clarity from others who may have a deeper understanding of their disease. Additionally, GBS patients often report a deficit in ongoing care. They may feel that their concerns go unheard and that medical personnel do not provide satisfactory explanations, leaving them with a sense that their needs are not being fully met.^{35,36}

The sensation of loss is often felt by patients with GBS, as the symptoms can render them physically and mentally helpless. This dependency on others can lead to challenges in maintaining daily activities, social interactions, and employment. Consequently, patients may grapple with a diminishing sense of identity as independent individuals, leading to feelings of embarrassment, self-disappointment, and the potential development of psychological disorders. Emotions such as frustration, anger, and sadness are commonly experienced by

those with GBS.^{20,37,38}

The duration of treatment and recovery from GBS can vary significantly among patients. Some individuals maintain a positive outlook, buoyed by the support of family and friends. They find ways to accept and adapt to their physical changes, making efforts to continue their daily routines. Conversely, other patients may adopt a negative perspective, holding onto the desire to return to their previous lives and fearing social stigma associated with their condition.^{37,38}

Previous research indicates a variety of findings regarding the impact of GBS on QoL. Some studies report an improvement in QoL following GBS, whereas others indicate a decline. Nevertheless, it is evident that QoL has changed in comparison to pre-GBS conditions. For instance, research by Holtz *et al.*²⁴ demonstrated that patients with GBS and CIDP had lower QoL scores than the comparison group. The challenges faced by these patients are typically reflected in limitations related to physical function.²⁴

Factors influencing QoL in GBS

In addition to the clinical outcomes previously mentioned, several other factors can influence the QoL for those with GBS. The various factors can be evaluated using QoL assessment instruments. These instruments can be categorized into two types: general QoL instruments, which are applicable across various diseases, and specific QoL instruments, designed for particular conditions. Common general QoL instruments include the WHOQOL-BREF, SF-36, SF-12, SF-8, 5Q-5D, Neuro-QoL, SIP, and NHP. In contrast, the specific QoL instrument for peripheral nerve disease is the INQoL.

The SF-36 is an instrument composed of eight domains, categorized into two components: the physical component

score (PCS) and the mental component score (MCS). The domains included in the PCS are physical role, body pain, physical functioning, and general health, while the MCS encompasses vitality, role-emotional, social functioning, and mental health. A study conducted by Berisavac *et al.*,²² employed the SF-36 to assess the QoL in patients with GBS. Evaluations were performed on the 14th, 28th day, 3rd, and 6th month following the onset of symptoms. The results indicated a statistically significant increase in SF-36 scores over time ($p < 0.01$), particularly notable during the first three months after GBS onset. The QoL assessments using the SF-36 in the acute phase can serve as a predictor for QoL at the 6th month post-onset. The pooled SF-36 scores, especially those relating to physical health, demonstrated a significant correlation with the pooled GDS scores. However, this correlation did not extend to the Bodily pain and role emotional scores, which showed distinct variations from the other measures.²²

A study conducted by Khedr *et al.*,¹⁸ utilized the SF-36 instrument to investigate factors influencing the QoL in patients with GBS over a one-year period. The findings revealed several predictors of poor QoL, including older age, longer intervals between the onset of weakness and hospitalization, neck muscle weakness, cranial nerve involvement, autonomic dysfunction, early use of mechanical ventilation, diarrhea, low MRC scores at onset and nadir, high scores on the GDS at onset, axonal-type GBS, and treatment with plasma exchange.¹⁸ A subsequent study conducted by Idam *et al.*,²⁵ reveals similar findings regarding QoL following GBS. This research indicates that a patient's overall well-being is closely linked not only to their physical capabilities but also to a range of demographic and medical factors. These variables encompass educational background, employment status, gender, necessity for mechanical

ventilation, and psychological well-being, all of which play a significant role in shaping the post-GBS QoL experience.²⁵ A study in Serbia involving 83 GBS patients revealed a correlation between age and QoL 6 mo after the onset of GBS.⁸ Furthermore, research conducted by Martic *et al.*,³⁹ found that being male was associated with poorer functional status at the 3 yr mark ($p < 0.05$).

An observational study involving 32 patients evaluated various factors including neuropathic pain, the MRC scale, the Fatigue severity scale, and the hospital anxiety and depression scale. The QoL was assessed using the SF-36 questionnaire. The findings revealed significant impairments in the emotional, social, and vitality components of the SF-36 among GBS patients experiencing neuropathic pain. Pain significantly impacts the QoL in individuals with GBS. Acute pain correlates notably with key QoL aspects, including 'self-care' ($p = 0.023$), 'usual activities' ($p = 0.049$), and the 'anxiety/depression' domain ($p = 0.048$), highlighting its disruptive effects. In contrast, chronic pain is chiefly associated with increased issues in the 'anxiety/depression' domain ($p = 0.005$), indicating its role in prolonged psychological distress. These findings by Papri *et al.*,²⁶ illuminate the intricate link between pain and QoL in GBS patients. Notably, there was a more pronounced increase in scores within the social and emotional components for those in the neuropathic pain group, indicating that neuropathic pain adversely affects social and emotional functioning. By managing pain through tailored therapy sessions and implementing psychosocial interventions, such as peer group support and recreational activities, patients with GBS may experience an improved QoL.²³

The SIP is a tool comprising 136 items categorized into 12 areas, including sleep and rest, eating, work, home management, recreation and entertainment, ambulation,

mobility, self-care, social interaction, alertness, emotional behavior, and communication.⁵ A prospective study conducted by Forsberg *et al.*,^{20,37} involving 35 GBS patients demonstrated that SIP scores improved across all dimensions within two weeks of onset and continued to rise over a two-year period.

NHP is an instrument for assessing QoL, comprised of two parts. Part 1 includes 38 yes/no items across six dimensions: pain, physical mobility, emotional responses, energy levels, social isolation, and sleep. Part 2 consists of 7 common yes/no questions that address various everyday life issues, such as paid employment, household tasks, personal relationships, social interactions, sexual life, hobbies, and vacations. Both parts can be utilized independently.⁴⁰ A QoL study conducted by Demir *et al.* involving 31 GBS patients utilizing NHP and the functional independence measure revealed that the quality of life for GBS patients was significantly lower in comparison to the control group. Furthermore, various sociodemographic and medical variables, such as education, psychological factors, gender, mechanical ventilation, and occupation, can significantly influence the QoL in individuals with GBS.²¹

INQoL is an instrument comprising 45 items across 11 subscales, categorized into three dimensions: the symptom dimension, the 'life domain,' and the treatment effect. The QoL score is derived from the items within the 'life domain' dimension and reflects the patient's overall HRQL level.⁴¹ Djordjevic *et al.*,⁷ conducted a prospective study involving 74 GBS patients. The results indicated a significant improvement in patients' INQoL scores over time ($p < 0.01$), although no significant differences were observed between days 14 and 28. Additionally, certain scores in INQoL did not show significant changes from month 3 to 6, particularly in the subscales of pain, social relationships, emotions, and

the total INQoL score ($p > 0.05$). Pooled GDS scores demonstrated a correlation with pooled INQoL scores, particularly with the subscores for independence, activities, and weakness ($p < 0.01$). A multiple linear regression analysis revealed that the GDS score at day 14 ($p < 0.01$) and the fatigue score at day 14 ($p < 0.01$) were independent predictors of the worse GDS score at month 6 ($p < 0.01$ for the overall model).

QoL in pediatric population

It has been previously noted that patients with axonal lesions generally require a longer recovery period.¹⁵ Comparable patterns are also present in the pediatric population. Specifically, children diagnosed with the axonal subtype of GBS often face a higher incidence of long-term disabilities compared to those with the demyelinating variants of the disease. The degree of disability in GBS can be evaluated utilizing the GDS. A GDS score of less than 3 indicates a low level of disability in the patient. This finding is supported by research on GBS in pediatric populations. Notably, a lower GDS score at the nadir correlates with a higher likelihood of recovery and an increased chance of walking again one month after GBS (OR 0.43; 95% CI 0.25–0.74).¹⁶

Assessing QoL in the pediatric population presents more challenges compared to adults. It is essential that QoL evaluations in children also involve input from parents. Research conducted by Devi *et al.*,¹⁹ indicates that the average PedsQL score reported by parents is 79.8, while children report an average score of 79.1. The maximum possible score on the PedsQL is 100, with higher scores reflecting better QoL. Factors such as quadriplegia at admission, the need for mechanical ventilation and tracheostomy, poor ambulation at discharge, and extended stays in the

PICU and hospital are associated with poorer outcomes.¹⁹

A study aimed to differentiate clinical outcomes in adult patients with children. The research findings revealed that at their respective nadir points, children showed more pronounced motor function impairment, with 90 (81.1%) children exhibiting a GDS score between 3 and 6, compared to 66 (60.6%) adults ($p < 0.05$). The average duration of hospital stay was 13.3 ± 10.0 d for adults and 10.1 ± 5.7 d for children. However, the short-term outcomes between the two groups did not show significant differences.¹⁷

Limitation

This literature review primarily focuses on studies employing prospective and retrospective observational methods. The sample sizes are relatively small, and there is a lack of research conducted on a larger scale. Given the limited number of studies addressing this theme, the range of research years considered remains quite broad.

Conducting further research with a larger and more diverse sample size will significantly enhance our understanding of this topic. It is essential that this research is carried out prospectively to ensure the collection of high-quality, real-time data. Additionally, performing studies in multiple geographic regions will allow us to explore regional variations and factors that may influence the outcomes. This comprehensive approach will be invaluable in advancing research in this field and may lead to more generalized and applicable findings.

CONCLUSION

Clinical outcome and QoL assessment for patients following GBS can be effectively conducted by healthcare professionals utilizing various assessment tools. Among these, the GDS

for clinical outcome and 5D-5Q-5L for QoL are the most succinct instruments available. The clinical outcomes and QoL for individuals following GBS exhibit significant variability, influenced by a range of factors. Medical rehabilitation, especially through physiotherapy, plays a crucial role in enhancing the clinical outcomes and QoL for these patients. By promptly identifying other factors, healthcare professionals can enhance the management strategies employed, ultimately improving both clinical outcomes and the overall QoL for post-GBS patients.

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