

Health-related quality of life in Guillain-Barré syndrome patients: a literature review

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Abstract

Guillain-Barré syndrome (GBS) is the leading cause of flaccid paralysis and significantly affects functionality and health-related quality of life (HRQoL). While disability and muscle strength scales remain standard for assessing recovery, HRQoL offers a broader perspective by integrating physical, emotional, and social aspects often overlooked in clinical practice. The objective of this review is to synthesize current evidence on the tools used to assess HRQoL in patients with GBS and to analyze demographic, clinical, and paraclinical factors associated with outcomes. Longitudinal studies indicate that HRQoL is most impaired during hospitalization and early recovery, with gradual improvement over time. Worse HRQoL is associated with advanced age, prolonged mechanical ventilation, dysautonomia, sensory deficits, high disability scores, axonal variants, urinary dysfunction, depression, and post-traumatic stress disorder. Overall, the evidence highlights the need for a disease-specific HRQoL instrument and longitudinal studies to enable accurate evaluation and guide targeted interventions that improve long-term outcomes in GBS patients.

Keywords: Guillain-Barré syndrome. Quality of life. Patient health questionnaire. Fatigue. Disability. Health-related quality of life.

Calidad de vida en pacientes con Síndrome de Guillain-Barré: una revisión sistemática

Resumen

El síndrome de Guillain-Barré (SGB) es la principal causa de parálisis flácida y afecta significativamente la funcionalidad y la calidad de vida relacionada con la salud (CVRS). Si bien las escalas de discapacidad y fuerza muscular siguen siendo el estándar para evaluar la recuperación, la CVRS ofrece una perspectiva más amplia al integrar aspectos físicos, emocionales y sociales que a menudo se pasan por alto en la práctica clínica. El objetivo de esta revisión es sintetizar la evidencia actual sobre las herramientas utilizadas para evaluar la CVRS en pacientes con SGB y analizar los factores demográficos, clínicos y paraclínicos asociados con los resultados. Estudios longitudinales indican que la CVRS se ve más afectada durante la hospitalización y recuperación temprana, con una mejora gradual con el tiempo. Una peor CVRS se asocia con edad avanzada, ventilación mecánica prolongada, disautonomía, déficits sensoriales, puntuaciones altas de discapacidad, variantes axónicas, disfunción urinaria, depresión y trastorno de estrés postraumático. En general, la evidencia destaca la necesidad de un instrumento de CVRS específico de la enfermedad y de estudios longitudinales que permitan una evaluación precisa y orienten intervenciones específicas que mejoren los resultados a largo plazo en pacientes con SGB.

Palabras clave: Síndrome de Guillain-Barré. Calidad de vida. Cuestionario de salud del paciente. Fatiga. Discapacidad. Calidad de vida relacionada con la salud.

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Introduction

Guillain-Barré syndrome (GBS) is the leading cause of acute flaccid polyradiculoneuropathy worldwide, with a global incidence of 1-2 cases/100,000 people. It shows a predilection for the male sex, occurring more frequently in men than in women (0.86 vs. 0.57 cases/100,000 people per year, respectively)¹. GBS is characterized by progressive, ascending, and symmetrical limb weakness, accompanied by reduced or absent deep tendon reflexes, mild sensory disturbances, and electrophysiological changes that allow classification and prognosis². Despite timely diagnosis and treatment, 30-40% of patients experience an unfavorable functional prognosis in both the short and long term, leading to impaired quality of life (QoL) even when they achieve acceptable functionality^{1,2}.

GBS functionality can be assessed through the following three main measures: recovery of independent walking (using a disability scale), overall muscle strength (measured by the Medical Research Council [MRC] scale), and the modified Erasmus GBS outcome score, which predicts walking ability at 6 months. These parameters should be evaluated at hospital discharge and during follow-up visits³. The combination of the GBS disability scale (GDS) and the MRC scale with QoL assessments across various daily activities provides a more comprehensive view of functional recovery⁴⁻⁶.

This review focuses on literature regarding key tools used to assess the QoL of GBS patients and analyzes demographic, clinical, and laboratory factors linked to both improved and reduced QoL.

Methodology

A structured review was conducted with the aim of identifying all studies that evaluated QoL in patients with GBS. The search used the keywords “Guillain-Barré syndrome” AND “quality of life” OR “health-related quality of life” in the PubMed, Scopus, and Embase databases, from January to May 03, 2025. Studies were included if they enrolled patients over 18 years of age with a diagnosis of GBS and employed at least one validated questionnaire to assess QoL. Case reports, case series with fewer than 10 patients, letters to the editor, and studies that did not report results on QoL assessment or associated factors of its deterioration were excluded. All articles published from 1950 to May 2025 were evaluated, where we found 153

total articles, 116 were eliminated, and the work was carried out with 37.

Health-related QoL (HRQoL) in GBS patients

HRQoL is a multifaceted concept that reflects how patients perceive their health, the impact of the disease, and the response to treatment. HRQoL assessment involves measuring both daily functioning and the degree of disability^{7,8}. Although numerous studies have explored the effects of GBS on QoL, they differ significantly in methodology, employing various assessment tools, domains, cutoff points, timelines, measurement frequencies, and variables⁹. Since 1994, the World Health Organization has defined QoL as an individual's perception of their position in life within the context of their culture and value system in relation to their goals, expectations, standards, and concerns rather than the absence of disease¹⁰.

The QoL domains of patients with GBS can be affected by demographic, clinical, and paraclinical factors, both at the time of hospitalization and during follow-up⁹. The tools used to assess QoL of GBS patients are either general questionnaires or those specific to neuromuscular diseases^{9,11}, such as the short form 36 (SF-36), the World Health Organization QoL Brief Version (WHOQoL-BREF), the SF-12, the sickness impact profile (SIP), the Nottingham health profile (NHP), the Centers for Disease Control and Prevention (CDC) healthy days and the individualized neuromuscular QoL questionnaire (INQoL), which is specific to peripheral neuropathy^{9,12,13}.

QOL of GBS patients from different perspectives (questionnaires)

During the follow-up of GBS patients, QoL has been studied at various intervals, ranging from 14 days to 10 years after acute episodes⁹. Studies have shown impairments across several areas, especially in physical function^{4,5,14}. Over time, patients typically show favorable and progressive improvement, which is in line with the transitory course. The most significant recovery occurs within the first few months after an acute episode¹⁵.

Longitudinal studies have reported that QoL measurements taken during the early stages of GBS, whether at symptom onset or during hospitalization, are directly influenced by clinical and paraclinical characteristics¹⁶⁻¹⁸. Long-term assessments have revealed

that GBS patients experience lower QoL than healthy individuals, mainly because of ongoing symptoms such as fatigue, pain, and lingering muscle weakness or sensory changes¹⁹⁻²². A patient's self-perceived ability to perform daily activities significantly impacts their QoL scores. This perception is closely tied to fatigue levels, which can be measured via the fatigue severity scale (FSS). Physical challenges and memory issues often persist for up to 2 years after the initial illness²³.

There is substantial evidence supporting the use of the SF-36 questionnaire to assess the QoL of patients with GBS. The SF-36 questionnaire consists of 36 items that evaluate the following eight domains: general health, physical role, physical function, bodily pain, vitality, mental health, emotional role, and social function. In addition, the SF-36 questionnaire provides two summary components: a physical component summary (PCS), which includes physical role, physical function, bodily pain, and general health; and a mental component summary (MCS), which includes social function, emotional role, mental health, and vitality^{9,16}. Short-term evaluations (at 14 and 28 days and 1, 3, and 6 months) have revealed impairment across all domains, with progressive improvement over time^{15,18}, and long-term measurements (at 1 and 3 years) have indicated significant QoL impairment compared with healthy controls²⁴⁻²⁷.

Long-term measurements have revealed persistent impairments in the QoL of patients with GBS. A case control study reported that 11 years after symptom onset, GBS patients exhibit deterioration across all SF-36 domains, with 80% lower scores compared to healthy controls²⁸. Another study revealed that patients have worse QoL scores at 12 years after symptom onset than healthy controls²⁹.

The SIP is a tool frequently used for measuring QoL, and it has 136 items covering the following 12 physical and psychosocial domains: body care; mobility; ambulation; social interaction; emotional and wakeful behavior; communication; household management; sleep; rest; recreation and hobbies; eating; and work⁹. A study that assessed patients at 2, 6, 12, and 24 months of follow-up revealed significant impairment in eating during the first 2 months; in addition, sleep, recreation, and household management remained affected for up to 12 months, and physical function was still compromised at 24 months, with patients reporting slowed gait^{30,31}. Another study conducted 10 years post-onset reported a significant decline in QoL compared with that of healthy controls, particularly in the physical domain³¹.

The NHP questionnaire, which includes 38 items across six dimensions, such as physical mobility, pain, sleep, emotional reactions, social isolation, and energy levels, has been used to assess the QoL of GBS patients. A 6-month follow-up study revealed that GBS patients had significantly lower QoL than healthy controls⁸.

The WHOQOL-BREF questionnaire has 26 items that assess four domains, namely, physical health, psychological health, social relationships, and the environment. The WHOQOL-BREF questionnaire has been used to assess GBS patients for 14 days, 28 days, 2 months, and 3 months after symptom onset, revealing progressive improvement across all the domains during follow-up. In addition, physical health and personal relationships were the most affected domains^{32,33}.

Evidence for the use of the INQoL to assess QoL of patients with GBS is limited. This 45-item questionnaire is divided into 10 sections as follows: four address the impact of motor neuropathy symptoms (weakness, myotonia, pain, and fatigue); five evaluate the impact of the disease on daily life (activities, independence, relationships, emotions, and body image); and one analyzes treatment, including its effects and expectations³⁴.

A study validated the usefulness of the INQoL in chronic neuromuscular diseases, including monoclonal gammopathy-associated polyneuropathy, multifocal motor neuropathy, and chronic inflammatory demyelinating polyneuropathy³⁵. Another study used the INQoL during patient follow-ups at 14 days, 28 days, 3 months, and 6 months, revealing statistically significant differences over time; however, there were no significant changes in subscores or total scores between 14 and 28 days or between 3 and 6 months in the pain, social relationships, and emotions sections¹².

Using the INQoL instead of general or non-specific QoL instruments can provide more accurate assessments by targeting domains particularly affected by these diseases, such as fatigue and weakness, which are related to their pathophysiological characteristics and functional impact³⁶. However, in the context of GBS, the acute or subacute nature of the INQoL presents a key limitation. Because the INQoL measure was designed for chronic diseases, its use could lead to an inaccurate evaluation of the impact of GBS on QoL.

The CDC healthy days questionnaire includes four core items and ten supplementary items that assess three categories, namely, physical health, mental health, and limitations in daily activities³⁷. QoL assessments of patients using this instrument over different periods within 30 days revealed poor physical health

(58.8%, 29.4% and 11.7% of patients on Day 1, between Days 1-10 and after 10 days, respectively), poor mental health (67.6%, 11.7% and 20.5% of patients on Day 1, between Days 1-10 and after 10 days, respectively) and limitations in daily activities (67.6%, 11.7% and 20.5% of patients on Day 1, between Days 1-10 and after 10 days, respectively)¹³.

Despite the use of different questionnaires, the previously mentioned studies agree that patients with GBS experience significant deterioration in their QoL at the time of hospital discharge. However, these patients show a gradual improvement in QoL scores and functional recovery over the following months. Nevertheless, some studies suggest that, even years later, patients fail to reach QoL levels comparable to those of healthy individuals.

Importantly, these questionnaires have limitations in accurately assessing patients with GBS, as these instruments are designed for chronic diseases and do not adequately address specific functional losses that characterize GBS. It is also important to consider the potential influence of modifiable and non-modifiable factors.

Factors related to impaired QOL

Studies have identified various factors associated with impaired QoL, each influencing the domains, components, and dimensions assessed by different questionnaires. Understanding these factors and their relationships with the aspects studied is essential for pinpointing specific areas that contribute the most to a decline in the QoL of these patients.

Demographic factors

Demographic variables influence HRQoL outcomes in GBS. Female patients consistently report lower scores, particularly in domains such as pain, social isolation, and physical mobility⁸. Low educational attainment and unemployment are also associated with greater impairment in psychosocial dimensions, including emotional reactions, sleep, and social participation. Age emerges as a predictor of long-term deterioration in the physical component of HRQoL, with older patients showing slower or incomplete recovery²³.

Clinical factors

Evaluations with the SF-36 at different follow-up points (14 days to 6 months) consistently showed that

disability, measured by the GDS, strongly correlated with HRQoL, particularly in the physical domains¹⁷. Early impairment in SF-36 scores predicted poorer outcomes at 6 months. Similarly, studies using the NHP confirmed that physical mobility, energy, sleep, social isolation, and emotional reactions were more affected in GBS patients than in controls, with greater deterioration among those with depressive symptoms or functional dependency⁸.

The INQoL also demonstrated close associations between disability and multiple domains of QoL, including weakness, fatigue, independence, and social roles. Interestingly, treatment modality influenced outcomes, such as patients receiving intravenous immunoglobulin reported worse QoL at 6 months than those treated with plasmapheresis¹².

Other clinical features, such as urinary dysfunction, pain, and fatigue, further compromised HRQoL. Up to 60% of patients experienced bladder symptoms, which many reported as interfering with daily life³⁸. Pain, assessed with the McGill Pain Questionnaire, affected all subscales and was significantly correlated with both physical and mental components of HRQoL. Persistent neuropathic pain after rehabilitation was linked to worse vitality, emotional role, and social participation^{19,39}.

At 1 year of follow-up, SF-36 assessments revealed that age, early disability scores (GDS, MRC), and delays in hospitalization were consistent predictors of poorer HRQoL. Clinical complications such as antecedent infections, dysautonomia, cranial nerve involvement, neck muscle weakness, and the need for mechanical ventilation were also linked to worse outcomes, with treatment modality (plasmapheresis vs. immunoglobulin) showing an additional impact¹⁹. These findings reinforce that both baseline severity and acute complications determine long-term QoL.

In patients who required prolonged mechanical ventilation, follow-up with the SF-36 and NHP demonstrated persistent moderate disability. Notably, nearly one quarter developed post-traumatic stress disorder, which was associated with marked reductions in vitality, general health, mental health, and social function²⁹.

Long-term evaluations confirm that disability at onset strongly predicts persistent impairment in HRQoL. In studies with 6-10 years of follow-up, patients with higher GDS scores consistently showed greater deterioration in physical and psychosocial domains, and many remained functionally limited compared with healthy controls^{22-24,40}. Age was also identified as a predictor of worse physical function in extended follow-up^{40,41}.

Table 1. Factors associated with poor quality of life during follow-up, organized by statistical level

Variables	Follow-up duration			
	6 months	1 year	2-3 years	> 5 years
Univariate analysis	Female, basic education, unemployment, depressive symptoms, high FIM score, immunoglobulin treatment, urinary symptoms ⁹	Pain, diarrhea, neck muscle weakness, dysautonomia, involvement of cranial nerves, mechanical ventilation, axonal electrophysiological variants ¹⁸	Mechanical ventilation for ≥ 2 months ²⁸	
Bivariate analysis	High GDS score ¹³	Pain, advanced age, days between symptom onset and hospitalization, low MRC at symptom onset, low MRC at nadir, high GDS at symptom onset, high EGRIS at symptom onset, low MRC 1 year after symptom onset, high GDS 1 year after symptom onset, elevations of light neurofilament protein in CSF, high ODSS at symptom onset ¹⁸		High GDS score at 6 months, NSS, high GDS score at discharge ²²
Multivariate analysis	High GDS score, low global score on SF-36 at 14 days ¹⁶	Advanced age, diarrhea or respiratory infection, days between symptom onset and hospitalization, mechanical ventilation, dysautonomia, weakness of neck muscles, involvement of cranial nerves, low MRC score at symptom onset, low MRC score at nadir, high GDS score at symptom onset, plasmapheresis ¹⁸		Advanced age, sensory deficit in upper and lower extremities, and high GDS score at 6 months ^{22,41}

CSF: cerebrospinal fluid; FIM: functional independence measure; GDS: GBS disability scale; MRC: medical research council; NSS: neuropathy symptom score; ODSS: overall disability sum score.

Paraclinical factors

Paraclinical findings further illustrate differences in prognosis. Patients with axonal variants consistently show poorer HRQoL across all SF-36 domains compared with those with demyelinating forms¹⁹. At 12 years after symptom onset, higher disability scores at baseline measured with both the GDS and the overall disability sum score were associated with poorer HRQoL, particularly in the physical and general health domains, and emerging biomarkers such as neurofilament light chain levels in cerebrospinal fluid are associated with greater impairment in physical and social function³⁰.

Factors that enhance QOL

Patients with the acute inflammatory demyelinating polyneuropathy variant and those treated with intravenous immunoglobulin generally report better HRQoL than those with axonal variants or treated with plasmapheresis¹⁹.

Rehabilitation plays a central role in modifying these outcomes. Intensive programs are linked to reduced disability and improved functionality, although their benefit may be limited by the persistence of neuropathic pain^{42,43}. Studies show that patients with ongoing pain

after rehabilitation continue to report lower scores in vitality, emotional role, and social participation, highlighting the importance of addressing pain management alongside physical recovery^{12,44,45}. Trials of rehabilitation programs, whether standard, intensive, or prolonged, consistently show functional gains and partial improvements in QoL, even if differences between high and low intensity regimens are not always significant^{46,47}.

An evaluation of low- and high-intensity rehabilitation in patients with GBS used the WHOQoL-BREF to measure QoL and the functional independence measure (FIM) to assess functionality at 12 months. The rehabilitation group was compared with a control group, as were the high-intensity group and the low-intensity group. No significant differences were found in the QoL scores between the groups. However, a significant improvement in FIM motor subscale scores was observed in the rehabilitation group compared with the control group. Comparison of the high-intensity group with the low-intensity group revealed significant differences in the overall FIM motor subscale scores⁴⁷.

When patients completed a 12-week program of three weekly cycling sessions, consisting of 5 min of warm-up and 30 min of exercise, they showed a 20% reduction in fatigue and significant improvements in

PCS and MCS scores of the SF-36 relative to healthy controls⁴⁸.

Patients who received physical therapy after hospitalization were evaluated with the SF-36 and FSS instruments at 7 years of follow-up. QoL and fatigue scores were compared between those who received physical therapy during or after hospitalization (90%) and those who did not (10%). Significant differences were observed, with greater deterioration in the physical function domain among patients without physical therapy, although no difference was found in FSS scores⁴⁹.

Rehabilitation over 12 weeks, delivered as outpatient physical therapy sessions of 60 min 2-3 times per week, was compared with a control group that received only a home exercise program for GBS patients. QoL was measured with WHOQoL-BREF at 6 and 12 months. Greater benefits were observed in the environmental domain at 6 months, whereas improvements in physical health and psychological domains were also evident at both 6 and 12 months⁵⁰. A summary is presented of the factors related to QoL impairment across different follow-up periods, organized at the statistical level (Table 1). This allows the changes in each variable to be observed as other factors intervene, as well as the persistence of certain factors throughout the evaluation period.

Conclusion

Measuring QoL provides an integrated assessment of disease impact in both short- and long-term follow-up. It directly relates to disability, defined by independent walking ability, and to demographic (female), clinical (fatigue, pain, and dysautonomia), and paraclinical factors (neurofilament light chain levels in cerebrospinal fluid) at hospital admission, which clinicians often underestimate. These findings emphasize the need to evaluate HRQoL regardless of gait recovery or functional improvement, ensuring a more complete understanding of disease burden and supporting strategies to optimize patient outcomes.

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The authors declare that this work was carried out with the authors' own resources.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Ethical considerations

Protection of human subjects and animals. The authors declare that no experiments on humans or animals were performed for this research.

Confidentiality, informed consent, and ethical approval. This study does not involve personal patient data, medical records, or biological samples, and does not require ethical approval. SAGER guidelines do not apply.

Declaration on the use of artificial intelligence (AI). The authors declare that no generative artificial intelligence was used in the writing or creation of the content of this manuscript.

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