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Original Research Article

To Study the Health-Related Quality of Life (HRQOL) in Children Presenting with Guillain-Barré Syndrome (GBS) in a Tertiary Care Hospital

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Abstract: *Guillain-Barré Syndrome (GBS) is a rare and potentially life-threatening neurological disorder caused by an aberrant autoimmune response, leading to acute inflammation and damage to the peripheral nerves.* ***Objective:*** *The purpose of this study is to provide a comprehensive description of the impact of GBS on children, including functional disability and health-related quality of life, using the Hughes score.* ***Methodology:*** *This Cross-sectional observational study was conducted in the inpatient and outpatient departments of the Pakistan Institute of Medical Sciences Children's Hospital, Islamabad. Seventy-four children aged 1- 12 with GBS were recruited and followed for 1 year. Clinical characteristics of the disease, functional disability score, and HRQOL were reported at 3 and 6 months.* ***Results:*** *The Study showed a male predominance (78.4%) and the majority aged < 5 years (47.3%). Seasonal variation revealed the highest incidence during winter (62.2%), followed by summer (18.9%). Preceding symptoms included upper respiratory tract infections (35.1%) and diarrhea (18.9%); the rest of the children had no preceding risk factors. The clinical presentation of Guillain-Barré Syndrome (GBS) in the study cohort was dominated by limb weakness (100%) and areflexia (100%), with muscle pain also being prevalent (83.8%). Complications included cranial nerve palsies (41.9%) and autonomic instability (55.4%). At discharge, 50% required walking assistance, and 44.6% were bedridden or chair-bound. Over six months, significant functional improvements were observed, with 86.1% having normal function and only 8.3% still needing walking assistance. Health-related quality of life assessments showed marked physical, emotional, and social enhancements over three and six months. However, two patients (2.7%) experienced rapid disease progression leading to death, underscoring the severity of GBS despite overall positive outcomes.* ***Conclusion:*** *It is concluded that Guillain-Barré Syndrome (GBS) significantly impacts the health-related quality of life (HRQOL) in children, affecting their physical, emotional, and social well-being.*

Keywords: Guillain-Barré Syndrome, Pediatrics, Quality of Life, Disability Evaluation, Cross-Sectional Studies

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Introduction

Guillain-Barré Syndrome (GBS) is a rare and potentially life-threatening neurological disorder caused by an aberrant autoimmune response, leading to acute inflammation and damage to the peripheral nerves. This condition often presents as progressive muscle weakness, sensory disturbances, and, in severe cases, respiratory failure requiring intensive medical support. The disease can have profound implications in children due to their ongoing physical, cognitive, and emotional development. While much research has focused on the pathophysiology, clinical management, and long-term prognosis of GBS, the impact on pediatric patients' health-related quality of life (HRQOL) remains underexplored, particularly in low- and middle-income countries where healthcare access and support systems are limited. GBS is a rare but potentially disabling immune-mediated polyneuropathy, triggered by preceding infection, most frequently GIT or URTI. (1) Most common pathogens involved are Campylobacter Jejuni, CMV, EBV, Mycoplasma pneumoniae, AIDS, and Zika virus. (2) GBS is characterized by progressive, symmetrical motor weakness, areflexia, paresthesia, and cranial nerve involvement. (1) Of all the causes of acute flaccid paralysis, GBS remains the most important cause. Though GBS can occur at any age, it is more common in adults than in children. Overall incidence in the World is reported to be 4-5/100,000-person person-years. In children, incidence is 0.6/100,000 in children of the 0-9 age group and 0.75/100,000 person years in children between 10- 19 years of age. (3,4) GBS is classified into four subtypes based on clinical features, electrophysiological studies, and CSF findings. These include Acute Inflammatory Demyelinating Polyradiculoneuropathy (AIDP), Acute Motor-Sensory Axonal Neuropathy (AMSAN), Acute Motor Axonal Neuropathy (AMAN), and Miller Fisher Syndrome (MFS). AIDP is the most common type in Europe and North America; AMAN is the dominant subtype in China, Bangladesh, and Mexico. (5) In our region, results from a study conducted in Lahore on Childhood GBS showed the incidence of AIDP (67%), AMAN (16.5%), and AMSAN (8.4%) in Children. (2) The outcome of the disease depends on early diagnosis and treatment. The outcome in children is much better and shows more complete recovery than GBS in adults. (6) Despite a good prognosis, long-term disability remains a risk in children, especially walking disability and gait problems. Axonal type of GBS, the highest disability score, and need for mechanical ventilation showed poor outcome (7–9). As GBS encompasses a wide range of symptoms affecting many aspects of life, and its outcome is better in the Pediatric age group, disability and quality of life are assessed by the GBS disability score (Hughes Score), making this study beneficial in bringing a better approach in both management and supportive care and predicting the outcome.

The purpose of this study is to provide a comprehensive description of the impact of GBS in children in terms of functional disability and health-related quality of life using the Hughes score.

Methodology

This Cross-sectional observational study was conducted in inpatient and outpatient follow-up clinics of the Children Hospital, Pakistan Institute of Medical Sciences, Islamabad, for 1 year from 01/12/23 till 30/11/24. Patients were recruited in the initial 6 months and then followed up for the next 6 months of the study duration. Data were collected through a Non-Probability consecutive sampling technique. The sample size was calculated using the WHO calculator, 74. With confidence level of 95%

and study population proportion 25.8% and absolute precision is 10% Children from 1yr to 12yr of age admitted at Children Hospital PIMS including ICU and pediatric ward Confirmed cases of GBS (based on clinical findings, Nerve conduction studies and CSF findings) Participants not willing to share their Information Age greater than12yr and less than 1yr Unconfirmed cases of GBS Ethical approval for the study was obtained from the Ethical Review Committee (ERC) of Shaheed Zulfiqar Ali Bhutto Medical University/PIMS, Islamabad, before initiating data collection. Parents or guardians of eligible participants were informed about the purpose and scope of the study, and written consent was obtained. Data was collected using a structured questionnaire to gather detailed information about each participant. This included demographic data (age, gender, weight), clinical details (preceding factors, initial presentation, disease progression, findings from EMG and NCS, CSF analysis, duration of hospital stay, and need for mechanical ventilation), and treatment-related information. Additionally, an overall assessment of functional ability and quality of life was conducted over three months and then six months using the Hughes Score. Adherence to the inclusion and exclusion criteria was strictly maintained to control for potential confounding factors and reduce bias in the study results.

Data were analyzed using the Statistical Program for Social Sciences (SPSS) version 27. For quantitative variables, mean values and standard deviations were calculated. In contrast, qualitative variables like age group, gender, preceding symptoms, initial clinical presentation, type of GBS, and functional disability (Hughes score) were summarized as frequencies and percentages. (10) Health-related quality of life was calculated using the Pediatric Quality of Life Inventory as mean score and percentage improvement. (11).

Results

Data were collected from 74 patients, with a male predominance (78.4%), and the majority aged < 5 years (47.3%). Seasonal variation revealed the highest incidence during winter (62.2%), followed by summer (28.9%). Common preceding symptoms included upper respiratory tract infections (35.1%) and diarrhea (18.9%). (Table1)

The clinical presentation of Guillain-Barré Syndrome (GBS) in the study cohort was dominated by limb weakness (100%) and areflexia (100%), with muscle pain also being prevalent (83.8%). Complications included cranial nerve palsies (41.9%) and autonomic instability (55.4%). Most patients (58.1%) had a hospital stay of 10-20 days, while 13.5% required over 20 days. Nerve conduction studies identified AMAN (43.2%), followed by Acute Inflammatory Demyelinating Polyneuropathy (AIDP) as the most common subtype (37.8%)

Treatment modalities in the study showed that 91.9% of the participants received Intravenous Immunoglobulin (IVIG). In comparison, 8.1% did not receive IVIG due to the patient's non-affordability or because the patient was in the recovery phase; hence, they were only given supportive care. Mechanical ventilation was required in 33.8% of the cases, indicating the severity of respiratory complications in some children. Hospital stay needed for the majority (58.1%) was between 10 and 20 days, reflecting the intensive care needs and prolonged recovery associated with Guillain-Barré Syndrome (GBS).

At discharge, most participants (50%) were walking with assistance and bedridden/chair-bound (44.6%). Unfortunately, two patients (2.7%) had rapidly progressive disease, which resulted in death. After three months, 28 participants (38.9%) achieved independent walking (Hughes Grade 2), and 29% regained normal function (Hughes Grade 1). The proportion of bedridden/chair-bound patients reduced to 2.8%, including those requiring mechanical ventilation at admission, reflecting substantial recovery with appropriate care and rehabilitation. After 6 months, 86.1% of patients had normal functioning and only 8.3% required assistance with walking, showing substantial improvement in symptoms with time.

Health-related quality of life (HRQOL) assessments demonstrated marked improvements over three and six months. Over the initial 3 months, physical functioning showed the most significant improvement, with a 50% increase from a baseline score of 40 to 60. Emotional well-being improved by 40%, rising from 35 to 49, reflecting better psychological recovery. Social functioning, while improved, showed slower progress with a 25% increase from 28 to 35. At 6 months follow-up, emotional well-being and social function showed marked improvement (100% and 96%) compared to physical functioning (80% improvement). (Table 5)

Table 1: Sociodemographic Characteristics

Characteristic	Options	Number of Participants (n)	Percentage (%)
Gender	Male	58	78.4
	Female	16	21.6
Age (years)	<5	35	47.3
	5–<10	15	20.3
	10–12	24	32.4
Seasonal Variation	Winter	46	62.2
	Spring	14	18.9
	Summer	14	18.9
Preceding Symptoms	Upper Respiratory Tract Infection (URTI)	26	35.1
	Diarrhea	14	18.9
History of Recent Polio Vaccination	Present	8	10.8
	Absent	66	89.2

Table 2: Clinical Presentation and Relevant Investigations

Characteristic	Options	Number of Participants (n)	Percentage (%)
Clinical Presentation	Limb Weakness	74	100.0
	Paraesthesia	26	35.1
	Muscle Pain	62	83.8
	Ataxia	10	13.5
	Slurred Speech	49	66.2
	Areflexia	74	100.0
Distribution of Complications	Cranial Nerve Palsies	31	41.9
	Respiratory Difficulty	39	52.7
	Dysphagia/Dysarthria	57	77.0
	Autonomic Instability	41	55.4

Type of GBS on NCS	Acute Inflammatory Demyelinating Polyneuropathy (AIDP)	28	37.8
	Acute Motor Axonal Neuropathy (AMAN)	32	43.2
	Acute Motor-Sensory Axonal Neuropathy (AMSAN)	12	16.2
	Miller Fisher Syndrome	2	2.7

Table 3: Treatment and Hospital Outcomes

Parameter		Number of Participants (n)	Percentage (%)
Intravenous Immunoglobulin (IVIG)		68	91.9
Mechanical Ventilation		25	33.8
Length of Hospital Stay (days)	<10	21	28.4
	10-20	43	58.1
	>20	10	13.5
Need for Ventilatory Support	Yes	25	33.8
	No	49	66.2

Table 4: Functional Ability (Hughes Grading)

Hughes Grade	At Discharge		After 3 Months		After 6 Months	
	Frequency (n=74)	Percentage (%)	Frequency (n=72)	Percentage (%)	Frequency (n)	Percentage (%)
Grade 1 (normal function)	0	0	21	29	62	86.1
Grade 2 (walk independently)	2	2.7	28	38.9	4	5.7
Grade 3 (walk with assistance)	37	50.0	21	29	6	8.3
Grade 4 (bedridden/chair-bound)	33	44.6	2	2.8	0	0
Grade 5 (assisted ventilation)	0	0	0	0	0	0
Grade 6 (death)	2	2.7	0	0	0	0

Table 5: Health-Related Quality of Life (HRQOL)

Domain	Baseline Score	3-Month		6-Month	
		Follow-Up Mean Score	Percentage Improvement	Follow-Up Mean Score	Percentage Improvement
Physical Functioning	40	60	50%	72	80%
Emotional Well-being	35	49	40%	70	100%
Social Functioning	28	35	25%	55	96%

Discussion

Guillain-Barré Syndrome (GBS) is a common cause of acute flaccid paralysis in children, and its impact on health-related quality of life (HRQOL) extends beyond physical symptoms. This study assessed the clinical characteristics, complications, and HRQOL of pediatric GBS patients treated at a tertiary care hospital. The results hold implications for understanding the existing burden of the disease and the factors affecting outcomes and, hence, offer directions for enhancing the quality of care and further research efforts. (12) The study revealed that GBS affects children across all age groups, with a male predominance (male-to-female ratio of 3:1). Similar gender distribution is reported by Ali et al. (2017, Shibeshi et al. (2023, and Levison et al. (2020. (2,13,14) The Majority of patients were aged less than 5 years, similar to Shibeshi et al., 2023, but in contrast to several other studies in the literature, which reported median ages of 5 or 8 years. (2,13-16)

Frequency was significantly higher during the winter season, which is in line with a periodicity of respiratory and gastrointestinal infections, which are known to be associated with GBS. Shibeshi et al. (2023) and Levison et al. (2020 noted a similar trend in seasonal variation. (13, 14) Prior infections were noted in 54% of patients, and this supports previous research findings linking prior episodes of infection to immune-mediated GBS pathophysiology. (13-15). Even though it has been proposed that the unsanitary and unhygienic settings that are common in developing nations raise the possibility of gastrointestinal infections, which could lead to a higher prevalence of GI infection-associated GBS. (17) Still, the most common type of infection prior to the onset of GBS reported in our study was upper respiratory tract infection, which was the same as evidenced in previous studies reported by Shibeshi et al. (2023) and Meshram et al. (2016. (13,15)

Pain and paresthesias may be among the earliest signs of GBS. Aching or cramping pains, which are frequently localized in the lower limbs but can also be widespread, are common in children with GBS. Often referred to as "deep" or "muscular," these pains can be intense. (13-16) In our study, 83.8% of the participants reported muscle pain, whereas paraesthesia was reported in 35.1%. Of all participants, 100% presented with limb weakness, and areflexia was also observed in 100% of cases, strengthening its diagnostic importance.

Complications were relatively frequent; cranial nerve palsies, autonomic instability, and respiratory problems were seen in all age groups. (15,16) The study also underlined the critical need for invasive mechanical ventilation in 33.8% of patients due to impending respiratory failure. Similar to prior study findings, patients using ventilatory support had longer durations of hospitalization and worse functional status on discharge. Most patients were discharged between 10 and 20 days, proving the need for intensive care and rehabilitation interventions. (13) NCS confirmed that 43.2% of patients had AMAN, and 37.8% had the AIDP variant. This distribution is variable from global data, where AIDP is found often in children among all GBS variants. (15,18,19) However, the present study showed that axonal subtypes accounted for more than

50 percent of this disease, and, in particular, the AMAN and AMSAN variants have a worse prognosis than AIDP. (19)

The Hughes functional grading scale used to evaluate functional recovery improved significantly during the three months and then again at 6 months. At the time of discharge, 50% of participants had walking difficulty but could walk with some assistance, and 44.6% were either bedridden or chair-bound, with a 2.7% incidence of mortality in rapidly progressive cases. The mortality reported with GBS is 1-2 % previously, compared to our study findings. (20, 21). At the three-month follow-up, most of the patients had either normal function (29%) or could walk independently (38.9%), implying that with adequate medical and rehabilitative intervention, there can be a vast improvement, while 21% still needed assistance. Nevertheless, 2 percent of the patients maintained the grade 4 Hughes score, implying that there are special procedures that need to be instituted to look at the residual disability. Similar findings were presented in previous studies on functional scores in children with GBS at 3 months. (1) At 6-month follow-up, most patients had normal function (86.1%) and only 8.3% required assistance with walking. (22) Recent studies on children with Guillain-Barré syndrome (GBS) have revealed long-term favorable outcomes, showing 86–90.5% of children return to normal function by 6 months, and most attain independent walking within 3–6 months. (23,24)

HRQOL revealed a significant increase in physical health, mental health, and social functioning in the follow-up period. Social functioning and emotional well-being appeared to gradually improve in the initial 3 months, thereby increasing rapidly in the next 3 months. This highlights the need for psychological support and the provision of community reintegration services early in the disease process. In most children, even those with severe initial presentations, long-term follow-up studies have shown positive neurological, behavioral, functional, and quality of life results. (23-25)

Mechanical ventilation is associated with reduced HRQOL. However, it provides an insight into long-term consequences with potential for early intervention and a rounded care plan mitigation. In this work, child and multiple-symptom aspects of GBS are presented, and the need for the essential discussion of physical, social, and psychological rehabilitation is underlined. Despite marked functional recovery, patients may have residual deficits, a decline in HRQOL, or both, suggesting the importance of post-acute event follow-up and rehabilitation. Further studies should examine what factors may put patients at high risk for a less than desirable quality of life and determine whether any specific interventions are beneficial for enhancing HRQOL.

Conclusion

It is concluded that Guillain-Barré Syndrome (GBS) significantly impacts children's functional and health-related quality of life (HRQOL), affecting their physical, emotional, and social well-being. The results highlight how critical it is to promptly identify and manage pediatric GBS. Most patients showed significant improvement despite the severity of the early symptoms, which included respiratory compromise requiring mechanical ventilation in a third of cases. The timely administration of IVIG therapy and supportive care facilitated this recovery. However, the occurrence of mortality in two patients highlights the potential severity of GBS, emphasizing the need for vigilant monitoring and prompt therapeutic intervention. The study emphasizes the role of early intervention and rehabilitation in improving both functional outcomes and HRQOL for children affected by GBS. The significant improvements observed in the Hughes scores and HRQOL align with findings from other studies, which report that many GBS patients experience physical limitations even years after the acute phase of the disease. However, improvements are notable within the first year. These results highlight the importance of a multidisciplinary approach to care, addressing both physical rehabilitation and psychological support to optimize recovery.

Declarations

Data Availability statement

All data generated or analysed during the study are included in the manuscript.

Ethics approval and consent to participate

Approved by the department concerned. (IRBEC-MCH-02980-24)

Consent for publication

Approved

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Conflict of interest

The authors declared the absence of a conflict of interest.

Author Contribution

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All authors reviewed the results and approved the final version of the manuscript. They are also accountable for the integrity of the study.

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