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Review Article

Beyond Paralysis: A Sociology-Based Analysis of Underserved Youth with Guillain-Barré Syndrome in the United States and Pathways to Empowerment

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Abstract

Guillain-Barré syndrome (GBS) is a rare immune system disorder. It causes severe muscle weakness and difficulty breathing. Unfortunately, socioeconomically underserved children with GBS across the United States have an increased risk of death compared to the general public. This paper seeks to address this problem through creative approaches that are inspired by the field of sociology. These interventions include community-based efforts that encourage early diagnosis, proactive treatment, and recovery support. When these remedies are used on a nationwide scale, marginalized children have the potential to survive GBS.

Introduction

Priyadarshini et al. [1] explained that "Guillain-Barré Syndrome (GBS) is a rare but serious immune-mediated neuropathy characterized by acute-onset motor weakness and potential respiratory failure...Its pathogenesis often involves molecular mimicry triggered by antecedent infections, leading to autoimmune targeting of peripheral nerves." GBS leads to paralysis and breathing difficulties. Yet health outcomes are not determined by biology alone. Triki et al. [2] stated "Health disparities and inequities are an important and too long overlooked public health concern worldwide...These differences in health and health care can affect people with any disease, including neurological disorders."

Uwishema and Boon observed [3], "With over 3 billion individuals affected globally, disorders of the nervous system are now a major contributor to both economic burden and morbidity... Disparities in the management of neurological disorders exist, disproportionately affecting underprivileged groups." This is especially true throughout the United States (U.S.) – where it is not merely a public health problem. In fact, it is also a socioeconomic crisis that can jeopardize the lives of people in need.

Understanding GBS itself is crucial when aiming to empower affected youth nationwide. Bellanti and Rinaldi noted [4] "GBS is the most common cause of acute neuromuscular paralysis… it can be a severe, life-threatening condition, and early treatment is crucial for a better prognosis. Over 100 years after its first description, GBS is one of the best understood neuroinflammatory diseases, yet many aspects of its nature remain puzzling." In other words, GBS is a well-known paralysis-causing illness, but it still holds mysteries even a century after it was identified. Clinically, the syndrome can appear in different forms. Jin et al. [5,6] described "Typical GBS presents as rapidly progressive ascending bilateral symmetrical weakness with areflexia or hyporeflexia...GBS can also present atypically with asymmetrical or descending weakness, predominantly proximal or distal weakness, or simultaneous onset in all limbs." This means that while many patients experience a classic pattern of rising paralysis starting in the legs, others may have unusual patterns such as one-sided or top-down weakness.

Torricelli [7] provided a pediatric perspective, stating "Guillain-Barré syndrome in pediatrics is classically defined as an acute, areflexic, flaccid paralysis classified into four subgroups: acute inflammatory demyelinating polyneuropathy (AIDP), acute motor-sensory axonal neuropathy (AMSAN), acute motor axonal neuropathy (AMAN), and Miller-Fisher syndrome (MFS)...AIDP is associated with cranial nerve involvement in 30–50% of cases, which is not observed in AMAN. MFS is characterized by ataxia, ophthalmoplegia, and areflexia, and may also present cranial nerve dysfunction." This assertion describes the course of primary medical variations of GBS in children and the distinctiveness of symptoms and neuronal damage. Knowledge of these subtypes will enable physicians to detect and treat the disease with more precision. Bazaraa et al. [8] observed "Since poliomyelitis was eradicated, Guillain-Barré syndrome has been the leading cause of acute flaccid paralysis globally...Severe cases may require intensive care and mechanical ventilation support." GBS is now a leading global cause of paralysis. GBS occurs infrequently, but its impact is felt throughout the entire world.

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Bragazzi et al. [9] reported "GBS occurs worldwide with an overall incidence of 1–2 cases per 100,000 people per year...In 2019, there were approximately 150,095 cases of GBS worldwide, resulting in 44,407 years lived with disability...The absolute number of prevalent GBS cases was highest in children aged 5–9 years, highlighting the need for more health resource allocation and efforts to improve surveillance systems for children." GBS is a comparatively rare condition that produces a significant health burden to the U.S., especially in school-going children who need specialized treatment.

The concentration of cases among young children indicates how healthcare systems need to focus more on pediatric neurological resources and improve monitoring techniques. A Polish review by Chrościńska-Krawczyk et al. [10] stated "GBS is the most common cause of acute neuromuscular paralysis in children...The incidence is about 0.34 per 100,000 in under-15-year-olds, and the condition has a higher prevalence in boys." This means that among diseases causing sudden paralysis in kids, GBS ranks first, though it remains quite rare (roughly one in 300,000 children annually) and tends to affect boys more often. Similar patterns are reported elsewhere – for instance, Ali, [11] found a comparable incidence range (approximately 0.34–1.34 per 100,000 children under 15) in his analysis, and Nasiri [12] documented that GBS, while it can occur at any age, is most frequent in boys 1–5 years old. Meanwhile, in the U.S., the annual incidence is on the order of 1 to 3 per 100,000 and rises with age [13]. Overall, these epidemiological trends emphasize that GBS, though uncommon, is a concern across populations.

Socioeconomic Gaps and Challenges

Health inequities are especially problematic for children with neurological disorders. Triki et al. [2] reported "Studies on the pediatric neurological population are limited...More efforts are needed to investigate existing inequities." Mayer et al. [14] showed just how important inclusion is throughout this process. "Inclusive representation in research is important for ensuring generalizability of results, equitable access to medical advances, and improved trust between patients and clinicians...This cohort study of 3154 children found disparities in approach and consent according to race and ethnicity, language, religion, and degree of social deprivation."

Mayer et al. [14] also reported detailed findings: "Of 3154 children included in the study (median age 6 years; 53.6% male), rates of approach and consent were lower for Black and Hispanic families, those of other races, speakers of Arabic and other languages, Muslim families, and those with worse social deprivation index...Mediation analysis revealed that 51.0% of the reduced odds of consent for Black individuals was mediated by lower probability of approach." This paper demonstrates that minority and poor families were less likely to be approached or consent to take part in the research. The observation implies that the disparity in outreach activities is one of the key factors in the lack of representation of the marginalized communities in pediatric research. Moreover, Barroso et al. [15] observed "The COVID-19 pandemic prompted investigation into its neurological sequelae in children...While children often have mild acute COVID-19, data on long-term complications or post-COVID syndrome are limited. Neurological manifestations like fatigue, headache, and muscle weakness are reported in pediatric post-COVID syndrome, but a systematic review of their relationship to GBS was needed." Furthermore, Barroso et al. [15] noted "Empirical studies (including case reports and series) involving children with GBS after SARS-CoV-2 infection were included." The analysis sought to learn through the review how COVID-19 could activate or exacerbate GBS in children. Through the analysis of reported cases, the researchers were trying to find patterns and enhance medical knowledge regarding this potential association. Jin et al. observed "Historically, most children with GBS were expected to have good outcomes.

Nevertheless, a subset of patients does not fully recover within six months, underscoring the need for early identification of those at risk for a poor prognosis..." This indicates that while many pediatric GBS cases resolve, some young patients experience long-term problems.

Asiri et al. [16] stressed that each case must be taken seriously, stating "Though GBS is a rare disease in children, when it does occur each case warrants thorough investigation. Better understanding of its epidemiology and risk factors in underserved populations will help tailor preventive strategies and optimize treatment protocols." In other words, improving outcomes for children – especially those in underserved groups – requires research and interventions targeted to their specific circumstances. Encouragingly, new studies are shedding light on these questions. Barroso et al. [15] concluded "Neurological symptoms related to COVID-19 were more common in adolescents...GBS was the most frequent neurological disease observed in the pediatric population following COVID-19." This finding suggests that among the various post-COVID neurological issues in youth, GBS has started to become a leading concern. Altogether, these insights underscore the urgency of focusing on children, particularly disadvantaged youth, in neurological research and care.

Taken to its worst extreme, underserved children who are diagnosed with GBS in the U.S. may face the horrendous outcomes of such children in less developed countries. Papri et al. [17] further noted "Poor hygiene and sanitation along with frequent exposure to pathogens render populations in low-income and middle-income countries prone to outbreaks of infectious diseases that can trigger GBS." This observation may apply to underserved areas of the U.S. as well. Khan et al. [18] similarly stated that "Already constrained health systems struggle to meet even baseline care needs." It is unfortunate that children who find themselves in these situations face severe obstacles to overcoming GBS. Shibeshi et al. [19] reported "There is a gap in the diagnosis and management of children with GBS...Neither IVIG nor plasma exchange are affordable for the majority of patients in resource poor settings... Mortality from GBS is higher in low-income as compared to high-income countries; for example, a mortality of 11.5%...was reported from India while no mortality was reported in a French and a Korean study."

Dabilgou et al. [20] also found that "Outcomes in this low-resource setting were poor…Most patients received only steroids

(despite lack of proven efficacy), underscoring the need for better access to effective immunotherapies in such regions." These kinds of critical care deficiencies were widespread in the U.S. during the COVID-19 pandemic. Leonhard et al. [21] noted "The most important limitations were the availability of nerve conduction studies and ICU beds...Timely rehabilitation services were also insufficient in many regions."

Sociological Interventions

Community-Based Efforts for Early Diagnosis

Based on all of the data that has been analyzed so far, it is key for GBS to be diagnosed as early as possible. Groups that advocate for the public health of underserved communities should make people aware of this fact. Karalok et al. [22] noted "Diagnosis of pediatric GBS is often delayed due to variable presentations. Early hospital admission and prompt treatment can reduce the need for ventilatory support and improve recovery." In addition, Chrościńska-Krawczyk et al. [10] emphasized "Treatment of GBS in children involves immunotherapy (IVIG or plasma exchange) initiated as soon as the diagnosis is made...It is essential to diagnose early and begin therapy immediately to reduce mortality risk... Further clinical research is needed to discover new treatment options for pediatric GBS patients." This can prevent the disease from claiming even more lives than it already has throughout its history.

Bazaraa et al. [8] reported "Forty children with severe GBS were included.

Following initial treatment (33 patients received plasma exchange and 7 received IVIG), 16 patients (40%) showed improvement…Two patients died, and 22 patients (55%) did not respond to the initial treatment." It is very fortunate to acknowledge that children continue to recover from GBS if they are diagnosed quickly and also start receiving treatment immediately. Cavirani et al. [23] stated that "Timely treatment was provided to all: 10 patients (83%) received intravenous immunoglobulin (IVIG) within 2 weeks of weakness onset...Only one child required a second IVIG cycle due to relapse...At 6-month follow-up, 91.6% (11/12) of these children showed complete clinical and electrophysiological recovery. Only one case still had a mild residual paresis in one leg by 6 months."

Community-Based Efforts for Proactive Treatment

Researchers are now trying to use many different kinds of scoring systems and clinical indicators to predict which GBS-affected children are more likely to have a worse experience with the disease. Children from marginalized backgrounds who are shown to be more likely to be diagnosed with GBS must be proactively treated. Priyadarshini et al. reported that "Prognostic scoring (Erasmus GBS scores) at admission predicted outcomes well. Median modified EGOS (mEGOS) was 5 at admission and 4 at one week, and higher mEGOS correlated with greater disability at 4 weeks, 3 months, and 6 months. Similarly, a mean EGRIS (respiratory insufficiency score) of 5.67 was recorded, where higher EGRIS values predicted increased need for mechanical ventilation."

Validated scoring systems assist physicians in predicting which GBS patients are more vulnerable to severe complications that may require ventilator assistance. These evaluation instruments allow healthcare providers to spend resources allocated to intensive care appropriately and inform families about expected recovery patterns. At discharge, 22 cases (58%) had favorable outcomes (independent walking)." This means children whose paralysis comes on very fast, with very weak muscles and evidence of nerve axon damage, tend to respond less to initial treatments like IVIG or plasmapheresis – though over half of the cases still ended up walking independently by discharge.

Consistently, analyses from different regions reinforce the key role of disease subtype in outcomes. Nasehi et al. [24] reported that "Analysis showed that only axonal electrophysiologic involvement significantly predicted a poor prognosis in these children with GBS...Other clinical variables (age, sex, prodromal symptoms, autonomic dysfunction) did not have a significant impact on recovery...Overall, the axonal form of GBS emerged as a predictor of unfavorable prognosis in pediatric patients." In their Iranian cohort, factors such as the child's age or initial symptoms did not change recovery much – only the nerve conduction showing axonal damage reliably signaled a harder road to improvement. Together, these prognostic insights highlight that while most children overcome GBS, those with certain features (like axonal type or very rapid paralysis) may need closer monitoring and potentially augmented support during rehabilitation.

Community-Based Efforts to Support Recovery

Public health organizations that fight for marginalized children should incorporate knowledge of GBS subtypes in their social outreach work. This is because such subtypes influence recovery rates for young people. Sen et al. [25] documented in a North Indian series that "52.8% had a demyelinating subtype and 33.3% an axonal subtype...At 6 months follow-up, 71.1% of the children achieved full recovery (Hughes grade 0–1), including ~68% of those with axonal GBS and ~79% of those with demyelinating GBS...This study concluded that, regardless of initial severity, children with the demyelinating form tend to have less long-term disability than those with axonal GBS." Children diagnosed with demyelinating GBS forms generally experience better long-term functional outcomes than those with axonal variants. Six-month follow-up data confirm that nerve sheath damage allows superior recovery compared to direct nerve fiber injury, regardless of initial symptom severity.

A Turkish study by Karalok et al. [22] found that "Children with axonal GBS had a higher incidence of sensory disturbances compared to those with demyelinating GBS...Despite such differences, all children in both the demyelinating and axonal groups achieved favorable outcomes." This indicates that while the axonal form in children might cause more numbness or sensory loss initially, it did not prevent the children from ultimately recovering the ability to walk and function well.

Interestingly, some clinical factors that predict poor outcomes in adult GBS do not appear to carry the same weight in pediatric cases. Parveen et al. [26] described a Pakistani pediatric cohort of

"23 GBS cases (mean age ~5.8 years), where AIDP was the most common subtype (39.1%), followed by AMSAN (26.1%) and AMAN (17.4%) prognostic factors in adults did not hold the same weight in these children – older age, need for ventilation, and axonal electrophysiology (factors linked to poor outcome in adult GBS) were not significant predictors of outcome in the pediatric group." This means that unlike in adult studies, a child being on a ventilator or having an axonal-type GBS did not necessarily mean they would have a bad outcome – many still recovered well. This demonstrates the improved capacity of younger people to begin to recover.

With appropriate therapy, even initially severe cases in children can turn around positively. Alanazy et al. [27] reported that "By 9 months post-discharge, roughly 50% of the patients could walk independently, and another one-third regained independent gait later on; only one patient (~0.6%) died...Overall, the clinical profile and outcomes of GBS in Saudi Arabia were similar to international observations – most patients eventually had a favorable prognosis with appropriate treatment." Such regional data emphasize why early treatment and supportive care are lifesaving – and they also alert public health officials that GBS is an important pediatric condition to watch. Globally, GBS encompasses a spectrum of subtypes, and their prevalence can differ by geography. Mujlli et al. [13] explained that "Based on clinical features and electrodiagnostic criteria, GBS can be classified into heterogeneous subgroups such as acute inflammatory demyelinating polyradiculoneuropathy (AIDP), acute motor axonal neuropathy (AMAN), acute motor-sensory axonal neuropathy (AMSAN), and Miller-Fisher syndrome (MFS). In Europe and the US, AIDP is the most prevalent form (85–90% of cases)."

Conclusion

Youth with GBS face a fast loss of strength. Many require urgent care in pediatric intensive care units (PICU). Care in that setting steers diagnosis and early treatment. Yet diagnosis and treatment – and even research in this field – are not equal across socioeconomic groups. Mayer stated, "In [a] cohort study of consent rates for PICU research participation, we found lower odds of enrollment according to race and ethnicity, language, religion, and degree of social deprivation...multiple sociodemographic variables were associated with disparate consent rates for PICU research, and strategies to increase approaches could contribute to equitable enrollment in PICU studies." PICU studies show how minority children are approached less often about treatment options and consent at lower rates.

In addition, the COVID-19 crisis clearly highlighted health inequities. This is because minority groups were more likely to have terrible symptoms over a longer period of time and even die. Triki et al. [2] explained, "In recent years, COVID-19 has shown the dangerous health circumstances of vulnerable and medically underserved populations around the world and continues to disproportionately affect racial/ethnic minority populations regarding infection and mortality rates...Improving population health means improving health for everyone; however, historically disadvantaged groups continue to trail dramatically behind, and actions are needed to reduce the inequities." To solve such disparities, community-based initiatives are very powerful. Sociologists continue to recommend that these initiatives promote proactive diagnosis, treatment, and recovery among vulnerable children across the nation. In turn, this has the potential to result in policy changes to ensure that researchers, public health organizations, social workers, and policymakers offer pathways to healing for these children.

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