

Empowering Communities: Guillain–Barré Syndrome (GBS) Awareness and Education in Qassim, Saudi Arabia

Mona Alromaihi¹

¹Department of Pediatrics, College of medicine, Qassim university, Buraydah 51452, Saudi Arabia

Correspondence: Mona.Alromaihi@qu.edu.sa, ORCID ID: <https://orcid.org/0000-0002-0735-9628>

ABSTRACT

Background: Guillain–Barré syndrome (GBS) is the most common acute autoimmune disease of peripheral nervous system. GBS has received little attention in Saudi Arabia. GBS causes an acute flaccid paralysis that may lead to respiratory failure. So, it requires early diagnosis and management. GBS is a clinical diagnosis which has no international criteria and needs a high index of suspicion for diagnosis. It is characterized by a heterogeneous group of clinical presentations that may delay the diagnosis. **Objective:** this study aimed to conduct an analytical, cross-sectional study based on the data obtained from the online self-administrated questionnaire about the level of awareness of GBS presentation in Qassim region. **Materials and methods:** This study follows an analytical, cross-sectional design, focusing on data collected through an online self-administered questionnaire to assess awareness of GBS presentation in Qassim region. The study comprised a randomly selected sample of at least 926 participants.

Results: The study revealed among 926 participants, 112 were familiar with GBS. Younger participants showed greater awareness. Notably, 62.5% without medical backgrounds knew about GBS. About 75% had personal contact with GBS patients, possibly influencing their awareness. Misconceptions persisted, with only 19.6% recognizing GBS's typical onset duration. Urgency was recognized by 61.6%, but only 29.5% identified the ER as the right care setting.

Conclusion: The results unveiled a mix of awareness and misconceptions about GBS. Strengthening education is crucial for better understanding and management.

Keywords: GBS, Immune-mediated disease, Flaccid paralysis, Respiratory failures, Immunomodulation therapy.

INTRODUCTION

Guillain–Barré syndrome (GBS) is a group of clinical syndromes that appear as an acute inflammatory polyradiculoneuropathy with paralysis and decreased reflexes¹. It is brought on by the autoimmune destruction of peripheral nervous system nerves, which causes symptoms including numbness, tingling, and weakness that can develop into paralysis². GBS is a cause of acute ascending flaccid paralysis in adults and pediatrics. The incidence rates showed an exponential increase, ranging from 0.62 to 2.66 cases per 100,000 persons across different age groups worldwide. Variations in GBS prevalence are highly sensitive to case detection, case definitions, and sample size³. There are multiple recognized subtypes of GBS, each with unique clinical and pathological characteristics. Twenty to thirty percent of cases with GBS have the severe, widespread presentation with respiratory failure⁴.

Fewer studies have been conducted and published about GBS in Saudi Arabia and this may be attributed to regional differences in the availability of incidence data due to differences in healthcare systems and reporting practices and underdiagnosis as GBS diagnosis may be challenging in mild cases⁵⁻⁸. According to prior study, men are substantially more likely to develop GBS³. It can be manifested at any age, but it is more common in adults⁹. Children under the age of five have a higher incidence of the disease¹.

It is classified as a postinfectious disease because roughly two-thirds of patient's report had an upper respiratory tract infection or gastroenteritis before developing the condition. Immune response against peripheral nerve antigens may be triggered by these illnesses^{4,10}. The causes of GBS have been linked to numerous diseases, immunizations, and other factors,

although a complete list of these factors is not yet accessible¹¹. Patients with GBS have been found to be infected with a wide variety of micro-organisms in the past, but only a select number had a relationship demonstrated in case-control studies. 25-50% of adult GBS patients, with a higher prevalence in Asia, tested positive for *Campylobacter jejuni*⁸, Cytomegalovirus (CMV), Epstein-Barr virus (EBV), influenza A virus (IAV), *Mycoplasma pneumoniae* (*M. pneumoniae*), and *Haemophilus influenzae* (*H. influenzae*)^{11,12}.

Several illnesses have been reported to be associated with GBS. GBS has been linked to hepatitis E in patients hailing from the Netherlands and Bangladesh⁴. The initial suspicion of GBS is based upon the clinical presentation (**Table 1**).

Although there are many different clinical manifestations of the disease, the typical sensorimotor type of GBS typically manifests as symmetrical distal paraesthesias or sensory loss. This is followed by a gradual weakness that starts in the legs and moves up the body to the arms and eventually the cranial nerves^{4,9}. Reduced or absent reflexes are common at the time of diagnosis. Most people with GBS reach their maximal impairment within 2 weeks. Alternative diagnoses should be considered in patients who have reached the maximum disability within 24 hours of the disease's start or after 4 weeks, as the disease can progress quickly. About 20% of people with GBS require mechanical ventilation due to respiratory failure. The involvement of the autonomic nervous system can lead to cardiac arrhythmias and unstable blood pressure^{4,9}.

The weakness can vary from mild difficulty with walking to nearly complete paralysis of all extremity, facial, respiratory, and bulbar muscles, or sphincter control problems. Atypical manifestations of GBS may

also be possible. The symptoms of weakness and loss of sensation are always present on both sides of the body, but they might be asymmetrical or primarily proximal or distal and can originate in either the legs or the arms, or in both. In addition, the onset of weakness can be preceded by either severe and diffuse pain or localized cranial nerve dysfunction. Nonspecific or unusual clinical symptoms, such as poorly localized discomfort, refusal to bear weight, irritability, meningism, or an unsteady stride, may be evident in young children (6 years old or younger). The disease may be acute or sub-acute. Although GBS generally has a monophasic clinical history treatment-related fluctuations and relapses may occur^{9, 13}.

There are multiple subtypes of GBS with distinct clinical, electrophysiological, and histological changes. There are a number of clinically unique forms of GBS that have been described. Acute inflammatory demyelinating polyradiculoneuropathy (AIDP), acute motor axonal neuropathy (AMAN), acute motor and sensory axonal neuropathy (AMSAN) and Miller Fisher syn-drome are the most prevalent subtypes of GBS. Acute pan-dysautonomia, a paraparetic variation, ptosis without ophthalmoplegia, acute ophthalmoparesis and cervicobrachial-pharyngeal and facial diplegia or sixth nerve palsy with paranesthesia are all examples of extremely rare versions of this disorder. Different anti-ganglioside antibodies are linked to each subtype^{14, 15}.

Diagnosis of GBS is clinical but it can be supported by cerebrospinal fluid (CSF), spinal MRI images and electro-diagnostic studies, which can show typical abnormalities¹⁶. Other tests like complete blood count, glucose, electrolytes, kidney function and liver enzymes can be included. Ultrasound imaging of the peripheral nerves could be used as early pathological diagnostic strategies for GBS⁹. Some studies mention that early diagnosis and treatment is associated with better outcomes¹⁶. There are many reasons for delayed diagnosis and initiation of treatment of patients with GBS. Few studies point out the causes of delayed diagnosis including lack of evaluation by neurologists, distal sensory changes, pre-served reflexes, asymmetric pattern of weakness, and cranial nerves involvement^{8, 17}. The numerous subtypes of GBS are the primary reasons for its delayed diagnosis.

Table (1): Diagnostic criteria for Guillain-Barré syndrome

Major clinical features of GBS:

- Gradual loss of strength in both the legs and arms, occasionally starting in the legs first.
- Diminished or absent tendon reflexes observed in the weakened limbs⁴.
- Monophasic course and time between onset and nadir, 12 hours to 28 days¹⁸.

Other symptoms:

- The progressive stage typically spans from several days to up to four weeks, with a common duration of around two weeks.
- Relative symmetry.

- Mild sensory indicators may be present (in contrast to acute motor axonal neuropathy).
- Notable involvement of cranial nerves, particularly bilateral facial muscle weakness, along with autonomic dysfunction.
- Pain is a frequently reported symptom⁴.

Features that increase index of suspicion of GBS diagnosis:

- CSF white blood cells <50 cells/ μ L with albuminocytologic dissociation (<1% of GBS cases >50/ μ L)^{18, 19}.
- Severe impairment of lung function with minimal or no initial limb weakness.
- Pronounced sensory symptoms with minimal or no accompanying weakness.
- Onset marked by bladder or bowel dysfunction.
- Initial presentation includes fever.
- Distinct sensory level in the spinal cord characterized by sharp sensations.
- Striking and persistent asymmetry in the degree of weakness.
- Continued impairment of bladder or bowel function.
- Weakness progresses gradually without affecting respiration (consider subacute inflammatory demyelinating polyneuropathy or acute onset chronic inflammatory demyelinating polyneuropathy)⁴.

Nerve conduction studies:

- While they can provide valuable insights in clinical practice, they are generally not mandatory for diagnosing Guillain-Barré syndrome.
- Meeting all the Brighton criteria is necessary to establish a Guillain-Barré syndrome diagnosis.
- These criteria are indispensable for distinguishing between acute inflammatory demyelinating polyneuropathy and acute motor axonal neuropathy within the Guillain-Barré syndrome classification.
- In acute inflammatory demyelinating polyneuropathy, one can expect to observe features of demyelination such as reduced motor nerve conduction velocity, prolonged distal motor latency, increased F-wave latency, conduction blocks, and temporal dispersion.
- On the other hand, acute motor axonal neuropathy typically lacks demyelination features, with the exception of a single demyelinating feature in one nerve if the distal compound muscle action potential (CMAP) amplitude is less than 10% of the lower limit of normal (LLN), and distal CMAP amplitude less than 80% of LLN in at least two nerves. Occasionally, transient motor nerve conduction block may be present⁴.

CSF=cerebrospinal fluid. **CMAP**=compound muscle action

Common ED presentation problems like limb pain and paresthesia can initially be mistaken for other reasons, and GBS's low incidence further reduces its examination. Several studies have found misdiagnosis, particularly during the first ED visit, and a considerable proportion of patients have early symptoms that match GBS but were not recognized as such during previous ED visits. Consideration of additional diagnosis, such as orthopedic or vascular disorders, can result in delayed therapy along with the lack of well-established treatment initiation protocols, highlighting the complexities of diagnosis timing. Some GBS patients may have intact reflexes, and non-classic forms of weakness such as ataxia and ophthalmoplegia, hinder early diagnosis. Pain, particularly back pain and lower limb discomfort can be a presenting symptom and can hide the weakness associated with GBS. Ancillary testing may not always reveal abnormalities early in the disease, and the threshold for GBS diagnosis may take some time to reach as other disorders are evaluated and ruled out^{17, 20}.

GBS poses a potential threat to life. It is a potentially fatal condition. General medical care as well as immune-based therapies are crucial to avoid or manage complications. A strong emphasis on supportive measures is required. These methods include regular vital capacity tests and quick transfer of patients to the ICU as necessary. The Erasmus GBS Respiratory Insufficiency Score (EGRIS) can help with this decision-making process during hospitalization by estimating the possibility of a patient requiring artificial ventilation.

In addition, monitoring cardiac and hemodynamic functions (to address autonomic dysfunction), preventative measures for deep vein thrombosis, management of potential bladder and bowel issues, early initiation of physiotherapy and rehabilitation, and provision of psychosocial support are all important⁹. GBS has received little attention in Saudi Arabia leaving the doctors and researchers in the dark. Therefore, this study aimed to conduct an analytical, cross-sectional study based on the data obtained from the online self-administrated questionnaire about the level of awareness of GBS presentation in Qassim region.

MATERIALS AND METHODS

Study design: This analytical, cross-sectional study on the data obtained from the online self-administrated questionnaire about the level of awareness of GBS

presentation in Qassim region was conducted from mid-December 2022 to March 2023. The study sample was a group of Saudi males and females who were 18 years old and older. This group of people were randomly selected with a size of 926 people or more.

Data collection methods: Data were collected and obtained by the online questionnaire that was created in Google form and then published in different social media platforms (Twitter & WhatsApp). The participants filled an Arabic version of the online questionnaire, which was easy for understanding for non-English speakers. The questionnaire was divided into 2 sections to cover the aim of the study; section one was for demographic characteristics, while section 2 was for the awareness of GBS presentation and outcomes.

Ethical consideration:

Written informed consents were obtained from all the subjects involved in the study. Qassim University Ethical Research Committee, Committee of Health Research Ethics, Deanship of Scientific Research, Qassim University gave approval on January-12-2023, number. 23-20-12.

- **Independent variables:** The study included age, gender, residence and educational level as independent variables.
- **Dependent variables:** Awareness of GBS and its diagnosis among Saudi population.
- **Data analysis**
- Data were recorded in SPSS version 22. Appropriate statistic tools were used after the collection of data. GraphPad prism version 9.5.0 (USA) was used to create data visualization.

RESULTS

The socio-demographic findings:

The socio-demographic findings of study revealed that the majority of respondents aged 18-30 (38.12%) (Figure 1.a). Male participants constituted 55.6% of the sample, while females comprised the rest (Figure 1.b). The study focused on Qassim region, with 75.5% of participants from the largest city, Buraydah, and 11.7% from other smaller states (Figure 1.c). High educational levels were prevalent, with 67.6% holding a bachelor's degree, followed by 16% as high school graduates (Figure 1 d).

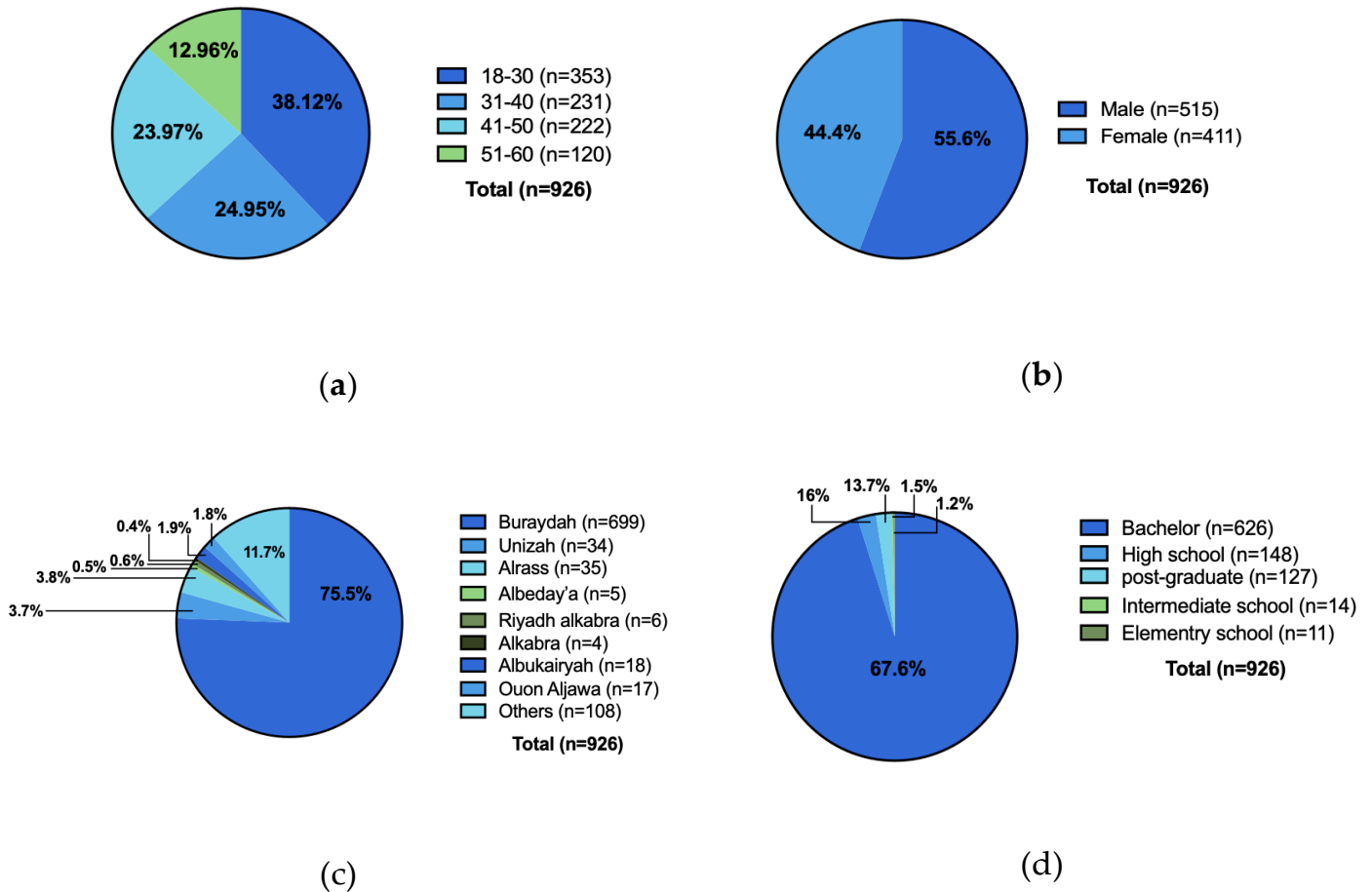


Figure (1): This figure showed the different socio-demographics characteristics of the participants. (a) The pie chart represented the age of the participants, (b) The pie chart represented the gender of the participants, (c) The pie chart represented the participants' residence and (d) The pie chart represented participants' level of education.

The knowledge distribution across various age groups and sex findings: Out of the 926 respondents, 112 were familiar with GBS. Figure (2.a) showed the knowledge distribution across various age groups, indicating that younger individuals tend to have better knowledge. Additionally, there was male predominance regarding the sex variable as shown in figure (2.b).

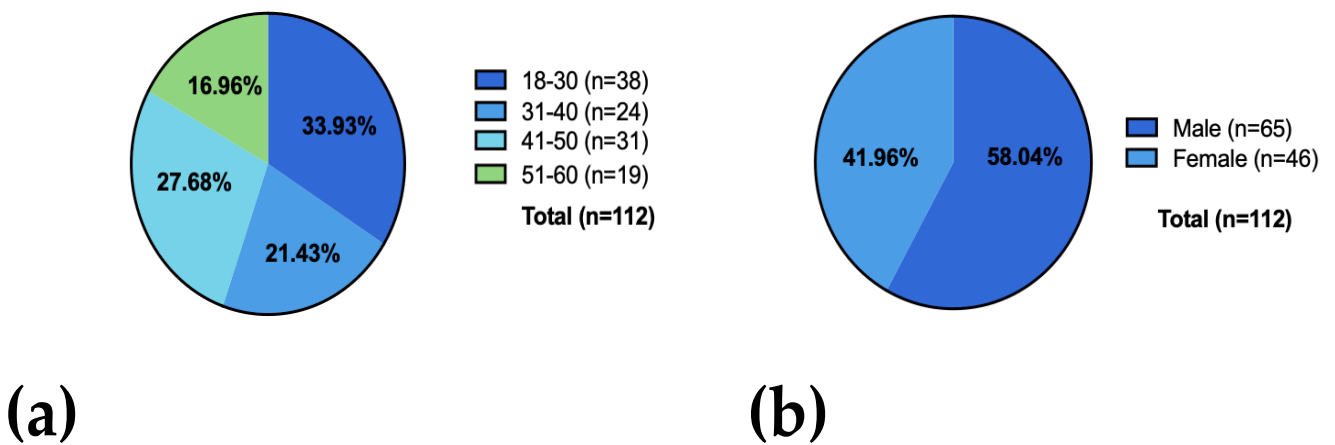


Figure (2): The participants' GBS knowledge. (a) The pie chart represented age in relation to GBS knowledge and (b) Sex in relation to GBS knowledge.

Awareness and knowledge of GBS:

Table (2) showed the general knowledge statement responses obtained about GBS. The results from the table on GBS awareness provided several key insights: Only 112 participants (12.1%) in the study were familiar with GBS out of 926 respondents. This indicated a relatively low level of awareness about the disease among the surveyed population. A notable proportion of participants were not in the medical field (62.5%) and were aware of GBS. Eighty-four of the participants (75%) had personal contact with a GBS patient, which could influence their awareness and understanding of GBS. Only a small percentage (19.6%) of participants correctly identified that GBS typically presents over a span of days. However, a substantial proportion of respondents chose other timeframes such as hours (8%), weeks (30.4%), or even months (42%).

This indicated a misconception about the rapid onset and progression of GBS. A majority of participants (78.6%) correctly chose all the parameters presented in a GBS patient, indicating an overall understanding of the variety of symptoms associated with the disease. However, there was a notable lack of awareness about sphincter disturbances, as no one selected this symptom. A significant proportion of respondents (75.9%) believed that GBS primarily affects adults, which aligns with the common perception that the disease is more prevalent in adults. However, a substantial number (57%) recognized that GBS can also affect children.

While, a majority of respondents (61.6%) acknowledged that GBS is an urgent condition. A lower percentage (29.5%) correctly identified that GBS cases should be taken to the Emergency Room (ER) for proper and immediate care. A notable portion (42.9%) of participants incorrectly believed that adults have a better prognosis in GBS cases, even though the disease's nature indicates that pediatrics generally have a better outcome. In summary, the results highlighted both areas of awareness and potential misconceptions about GBS among the surveyed participants.

The findings emphasized the need for increased education and awareness campaigns to improve the recognition, understanding, and appropriate management of GBS.

Table (2): Awareness and knowledge of GBS with details of awareness questionnaire

Description (n=926)	Percentage (%)
1. Do you know what GBS is?	
Yes	112 12.1
No	814 87.9
If yes, are you in the medical field?	
Yes	42 37.5
No	70 62.5
2. Have you had any contact with a GBS patient?	
Yes	84 75
No	28 25
3. How long does it take for Guillain-Barre to develop?	
Hours	9 8
Days	22 19.6
Weeks	34 30.4
Months	47 42
4. Clinical presentations of GBS	
Numbness and pain in feet (pins and needles)	9 8
Lower limbs weakness	4 3.6
Sphincter disturbance	0 0
Imbalance and gait difficulties	6 5.4
Problems in breathing, swallowing or chewing	5 4.4
All of the above	88 78.6
5. Can GBS affect adults?	
Yes	85 75.9
No	7 6.3
I do not Know	20 17.9
6. Can GBS affect children?	
Yes	64 57
No	8 7.1
I do not Know	40 35.7
7. Awareness that GBS treatment is:	
Urgent	69 61.6
Not urgent	15 13.4
No idea	28 25
8. Where a patient with GBS should be taken?	
Emergency department	33 29.5
Neurology outpatient clinics	74 66.1
Family physician	3 2.7
Internal medicine outpatient clinics	2 1.8
9. Who has better prognosis if has GBS?	
Adult	48 42.9
Children	22 19.6
No idea	42 37.5

DISCUSSION

To the best of our knowledge, this appears to be the first study addressing GBS awareness in the community, making it challenging to compare findings due to a lack of previous studies. The results underscore the need for healthcare professionals to enhance GBS awareness and understanding to improve patient outcomes. Early diagnosis and care of GBS patients is essential for better outcomes ¹⁶.

In most studies on GBS treatment, the inclusion criteria targeted patients with severe disease, who cannot walk unaided. The guidelines from the current literature and expert's consensus recommend immunotherapy for GBS patients with walking abnormalities. The treatment approach for GBS involves initiating immunomodulatory therapy for patients unable to walk independently for 10 meters. If patients who can still walk independently show rapid weakness or severe symptoms, treatment should also be considered. Intravenous immunoglobulin (IVIg) is usually the preferred treatment, while corticosteroids have shown no significant benefit in GBS treatment based on trials ⁹. However, there's debate among neurologists ¹⁷. Some prefer early treatment initiation even for mild cases to prevent deterioration ²¹. Failing to consider GBS initially or not involving a neurologist in evaluation increases the likelihood of residual weakness or the need for intubation ¹⁷.

The study revealed that only around 12% of participants are familiar with GBS, with 61% recognizing its acute nature but lacking knowledge of proper patient management. Most respondents who knew about GBS had encountered a patient with the disease, despite a majority not being in the medical field. Awareness regarding GBS onset duration was lacking, as 42% believed it takes months to develop, rather than the more common presentation within a few days. While most participants selected various clinical presentations such as numbness and pain in the feet (pins and needles), weakness of lower limbs, sphincter disturbance, imbalance and gait difficulties as well as problems in breathing, swallowing or chewing etc. only 21% chose individual parameters. Notably, no respondents indicated awareness of sphincter control loss as a frequent symptom, despite it being significant.

A study by *Amatya et al.* ⁽²²⁾ showed that chronic urinary dysfunction caused long-term disability in more than half of the patients. Respondents often think GBS affects adults more than children, which aligns with its higher incidence in adults. Lastly, most participants are unaware that pediatric GBS patients tend to have better outcomes. While, the current study provided valuable insights, its limitations, including the small sample size and potential lack of representativeness underline the need for more extensive research efforts. In addition, the internal and external validity of a study are compromised by very small sample sizes.

CONCLUSIONS

The findings of this study revealed that a relatively small fraction of participants was aware of GBS (around 12%) and 70.5% of those lack the awareness about the critical nature of GBS and uncertainty about which department to seek for immediate intervention is concerning. Therefore, this study could be very beneficial in providing valuable information about GBS to the public. GBS is indeed a serious and potentially life-threatening condition that requires prompt medical attention. Educating the public about the urgency of GBS, its symptoms, and the appropriate steps to take can significantly improve patient outcomes. This aspect highlights the critical role that healthcare professionals play in educating the population about GBS.

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REFERENCES

1. **Dimachkie M, Barohn R (2013):** Guillain-Barré Syndrome and Variants. *Peripheral Neuropathies*, 31 (2): 491-510.
2. **Nguyen T, Taylor R (2023):** Guillain-Barre Syndrome. In: *StatPearls*. StatPearls Publishing, Treasure Island (FL), PMID: 30335287. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK532254/>
3. **Sejvar J, Baughman A, Wise M, Morgan O (2011):** Population incidence of Guillain-Barré syndrome: a systematic review and meta-analysis. *Neuroepidemiology*, 36 (2): 123-133.
4. **Willison H, Jacobs B, van Doorn P (2016):** Guillain-barre syndrome. *The Lancet*, 388 (10045): 717-727.
5. **Alanazy M, Bakry S, Alqahtani A, AlAkeel N et al. (2021):** Clinical features and outcome of Guillain-Barre syndrome in Saudi Arabia: a multicenter, retrospective study. *BMC Neurology*, 21 (1): 275.
6. **Asiri S, Altwaijri A, Ba-Armah D, Al Rumayyan A et al. (2019):** Prevalence and outcomes of Guillain-Barré syndrome among pediatrics in Saudi Arabia: a 10-year retrospective study. *Neuropsychiatric disease and treatment*, 15: 627-635. DOI: [10.2147/NDT.S187994](https://doi.org/10.2147/NDT.S187994)
7. **Ahmad A, Abdullah A, Muhannad A et al. (2017):** Guillain-Barre Syndrome: Tertiary Center Experience in Saudi Arabia. *Neurology*, 88: 112.
8. **AlKahtani A, Alkhudair A, Bensaeed Z et al. (2023):** Guillain-Barré Syndrome in Adults in a Decade: The Largest, Single-Center, Cross-Sectional Study From the Kingdom of Saudi Arabia. *Cureus*, 15(6): e40995. DOI: [10.7759/cureus.40995](https://doi.org/10.7759/cureus.40995)
9. **Leonhard E, Mandarakas R, Gondim A et al. (2019):** Diagnosis and management of Guillain-Barré syndrome in ten steps. *Nat Rev Neurol.*, 15 (11): 671-683.
10. **Jacobs C, Rothbarth H, van der Meché G et al. (1998):** The spectrum of antecedent infections in Guillain-Barré syndrome: a case-control study. *Neurology*, 51 (4): 1110-1115.

11. **Finsterer J (2022):** Triggers of Guillain–Barré Syndrome: *Campylobacter jejuni* Predominates. *International Journal of Molecular Sciences*, 23 (22): 14222.
12. **Tam C, O'Brien S, Rodrigues L (2006):** Influenza, *Campylobacter* and *Mycoplasma* infections, and hospital admissions for Guillain-Barre syndrome, England. *Emerging infectious diseases*, 12 (12): 1880.
13. **Ruts L, Drenthen J, Jacobs C, Doorn V (2010):** Distinguishing acute-onset CIDP from fluctuating Guillain-Barré syndrome. *Neurology*, 74 (21): 1680.
14. **Kannan M, Khadilkar S, Murthy J (2011):** Treatment guidelines for Guillain–Barré Syndrome. *Annals of Indian Academy of Neurology*, 14: S73-81.
15. **Naik S, Meena K, Reddy K et al. (2017):** Anti-ganglioside antibodies profile in Guillain-Barré syndrome: Correlation with clinical features, electrophysiological pattern, and outcome. *Neurology India*, 65 (5): 1001.
16. **Gordon P, Wilbourn A (2001):** Early Electrodiagnostic Findings in Guillain-Barré Syndrome. *Archives of Neurology*, 58 (6): 913-917.
17. **Kenan G, Regev T, Kushnir M et al. (2022):** Reasons for delayed treatment initiation in Guillain-Barre syndrome. *Journal of the Neurological Sciences*, 434: 120179.
18. **Ghazanfar H, Qazi R, Ghazanfar A, Iftexhar S (2020):** Significance of Brighton criteria in the early diagnosis and management of Guillain-Barré syndrome. *Cureus*, 12 (5): : e8318. DOI 10.7759/cureus.8318.
19. **James S (2023):** CSF in Guillain-Barré Syndrome. *Neurology*, 100 (23): 1081.
20. **Dubey D, Kapotic M, Freeman M et al. (2016):** Factors contributing to delay in diagnosis of Guillain-Barré syndrome and impact on clinical outcome. *Muscle & Nerve*, 53 (3): 384-387.
21. **French Cooperative Group on Plasma Exchange in Guillain-Barré S (1997):** Appropriate number of plasma exchanges in Guillain-Barré syndrome. *Annals of neurology*, 41 (3): 298-306.
22. **Amatya B, Khan F, Whishaw M, Pallant F (2013):** Guillain-Barré syndrome: prevalence and long-term factors impacting bladder function in an Australian community cohort. *Journal of Clinical Neurology*, 9 (3): 144-150.