

Psychosocial Issues Associated with Guillain-Barré Syndrome and Their Management: Case Descriptions

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ABSTRACT

Guillain-Barré syndrome (GBS) is a neurological condition affecting the peripheral nerves of the body often leading to functional deficit with variable course of recovery. Uncertain prognosis, dependency of the affected person, multiplicity of roles of the caregivers, and the subsequent financial burden can cause emotional turmoil in persons with illness and their caregivers. These psychosocial sequelae warrant psychosocial assessment and management. We present descriptions of such assessment and intervention carried out in the neurorehabilitation ward of a tertiary care hospital. This study aims to highlight the need for nonpharmacological management during neurological rehabilitation.

Keywords: Guillain-Barré syndrome, Intervention, Psychosocial assessment.

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INTRODUCTION

Guillain-Barré syndrome (GBS) is a rare neurological condition affecting the peripheral nerves of the body. This is characterized by weakness, abnormal sensations, and even paralysis often leading to functional deficits with variable course of recovery. Acute onset and uncertainty concerning the outcome create fear, insecurity, and hopelessness among the patients.^{1,2} They tend to have difficulty in communicating, carrying out their activities of daily living (ADLs), and attending social and recreational activities. Forced dependency and shift in roles as a result of compromised functioning are reflected in their psychological aspects. Generally, caregivers are expected to take responsibility for the patients. This can disrupt their daily routine and the responsibility may be perceived as stressor by them.³ Additionally, uncertainty of the prognosis, future of the patient, and the financial concerns arising out of treatment expenditure often make their situation even worse.

Thus, both persons with GBS and their caregivers undergo a lot of emotional turmoil during the initial period of the illness. Although majority of the patients recover from most of the symptoms, life after GBS may be difficult for both parties.¹ As the psychosocial consequences of GBS may persist, psychosocial assessment and management is advised so that issues if any can be identified and addressed. However, there is a dearth of literature on this area, especially in the Indian context. Here, we make an attempt to describe the psychosocial assessment and interventions carried out with persons with GBS and their caregivers in the neurorehabilitation ward of a tertiary care hospital using case study methods with their consent.

CASE DESCRIPTIONS

Case 1

The first case was Mr M, a 47-year-old unmarried male, from low socioeconomic status, hailing from rural background. In his late 30s, he sought help from professionals for his depressive symptoms. His younger sister was sent back from family of procreation to the family of origin due to her severe mental illness and poor rate of recovery. To support his immediate family, he remained unmarried.

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At the acute onset of symptoms, he was taken to a local hospital initially. He was later referred to our center for further management. After acute management, he was referred to neurological rehabilitation to aid him in his functional recovery. After the detailed examination, he was referred to occupational therapy and physiotherapy for enhancing motor functioning and to make him independent on ADLs. Psychosocial assessment was carried out by the social worker, which revealed that the acute onset of illness left the family with no source of support both financially and emotionally. In the absence of parents at home, the patient's sister's medication was left unsupervised. The patient's mother was distressed about the prognosis of the illness and was also worried regarding managing household responsibilities by themselves.

Both parents were allowed to ventilate their emotions and their distress was acknowledged. They were educated about the condition, emphasizing the need for treatment adherence including the physical therapies. The prognosis of the patient was discussed with the family members after consulting the psychiatrists in the team. The family also attended support group meetings for caregivers of persons with neurological disabilities to avail support from people handling similar issues, to learn from the experience of others, and to understand the importance of self-care to support the patient in the long run. The patient was engaged in a peer

support group for people with a similar diagnosis with the objective of creating a sense of belongingness and hope. Meanwhile, the available social contacts were explored and relationships were established so that they could support the patient and his family in various ways possible. The Local District Mental Health Program team was contacted to ensure regular follow-up for the patient's sister and her daughter was asked to supervise her medications. Social welfare benefits were made available to her after facilitating disability certification. Prior to discharge, mobility aids were arranged through collateral contacts and predischARGE counseling was provided to plan the postdischarge care.

Case 2

The next case was Mr S, a 57-year-old married male, hailing from a family of agricultural background. He was the sole breadwinner in the family. At the initial onset of symptoms, he was taken to religious/faith healers and subsequently to ayurvedic treatment in a nearby village. The family exhausted all their financial resources there and ultimately brought the patient to our center. The inability to pay off a preexisting loan, being dependent on family members for ADLs, worries about running the family, and looking after the expenses for daughters' education distressed him a lot.

The patient and his family members were provided a supportive environment to express their distress. Their concerns were acknowledged and empathized with. Medical model of the illness was discussed, along with detailed education about the diagnosis, focusing on the need for compliance and regular physiotherapy. The patient and his family members engaged in peer support groups for the patient and caregivers support groups, respectively. Since the family members were finding it difficult to afford a wheelchair, the same was facilitated by networking with nongovernmental organizations (NGOs) working in the field of disability.

DISCUSSION

The current work is an attempt to add to the sparse literature in the field of psychosocial assessment and interventions for various neurological conditions in general and GBS in particular. We aimed to depict common psychosocial issues of persons with GBS and their family members and the targeted interventions to address this issue.

Supportive psychotherapy was offered to the patients and their caregivers in order to (1) address the distress in the affected persons and (2) provide a source of comfort to carers burdened with caregiving. It was aimed at optimizing their functioning by strengthening their existing coping styles and helping them deal with challenges as adaptively as possible.⁴ Besides, it is also known to reduce the anxiety and depressive symptoms experienced by persons with GBS due to the social issues of the illness like the inability to fulfill social roles, loss of employment and income, and social dysfunction.⁵

One of the common issues in both the cases was that both persons with GBS and their caregivers had inadequate knowledge about the illness and its overall management. It was quite obvious that not having enough understanding led to the delay in seeking treatment from an appropriate facility in one of the cases.

In addition to that, lack of information related to the illness is also known to increase the emotional distress and worries related to the prognosis and various issues secondary to the illness like bowel and bladder issues, motor weakness, pain, etc.^{6,7} Being adequately informed by the healthcare professionals about the illness and its management helps patients and their families to adapt better

which may positively impact the disease management.⁸ It helps them improve their overall quality of life and aid in strengthening their relationship with clinicians.⁹

The diagnosis of GBS in any family member can have a significant impact on the lives of people around them. Family members who take caregiving may face different issues during the process. Relatives can have apprehension around the uncertainty related to the prognosis during the initial phase of the illness.¹ They may face difficulties in carrying out their own ADLs and maintaining their social life as they are forced to play multiple roles. Financial issues secondary to the treatment expenses and loss of income for the caregivers add to the already existing difficulties. These may cause psychological distress to the caregiver and result in mental health issues if they are not adequately supported.³

In line with the previous literature, the current study also reports various facets of burden on the caregivers. To address them, we linked the caregivers with available resources in their community and discussed with family members about the various ways to share the caregiving responsibilities so that it provides respite and avoids burnout among them. They were also asked to attend the support group meeting available for the family members. This provided them with a platform to express their concerns and emotions, to avail support from each other, and to understand the illness better, etc. Such support groups are known to help both patients and caregivers in a therapeutic way by reducing the emotional and psychological impact on them. Similar benefits were also reported from peer or professionally led support groups earlier.¹⁰

Along with the conservative medical management, add-on psychosocial management has helped both patient and family members to understand the illness, what to expect, and cope better with it. Through appropriate referrals and collateral contacts made, they got better access to the available resources. Being a part of peer or family support group gave them a sense of belongingness to the larger group with similar issues and made them feel less alone in the battle.

Though persons with illness and family members appreciated the psychosocial interventions provided to address their concerns, the effectiveness of the same was not assessed objectively. This limitation has to be addressed in future research.

CONCLUSION

The very nature of the illness being acute in onset and known to cause disability in persons with GBS, the management of illness warrants psychosocial assessment and interventions. This paper aims to underscore the need for routinely assessing persons with GBS and their relatives for psychosocial issues. Interventions to address the identified issues along with routine medical management will go a long way in their recovery.

Ethical Clearance

It is a part of the project which was ethically approved in NIMHANS, (NIMHANS/Do/104th IEC/2016) on May 16, 2016.

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