

## Original Article

## Uncertainty about Chronicity: Relatives' Experiences of Guillain-Barré Syndrome: An Exploratory Qualitative Study of Online Forum Posts

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### Abstract

**Background:** Guillain-Barré syndrome (GBS) is a rare set of peripheral neuropathies leading to acute flaccid paralysis. While most patients recover completely in weeks to months, prognosis for individual cases is often difficult. Adding to the loss of functional independence, patients with GBS are under severe psychological distress. While some studies explored the experiences of patients with GBS, little is known about the experience of their relatives. Information about this experience is vital to improve nursing and other healthcare provision to patients with GBS and their families.

**Aims:** This qualitative study aims to explore the experience of GBS from from the perspective of the relatives.

**Methodology:** In a thematic analysis of 16 online forum posts of relatives, prevalent themes of the experience of GBS are analyzed.

**Results:** Four themes are prevalent in the forum posts of relatives: 1. Expression of a significant burden of care and impact on the family, 2. challenges and needs, especially relating to uncertain disease trajectories, 3. specific needs related to complications of GBS, and 4. coping and solutions of relatives.

**Conclusions:** The impact of GBS on the relatives is stressful in several regards. Prognostic uncertainty and informational needs have to be addressed by healthcare professionals attending to patients with GBS and their families. Special circumstances (e.g. pregnancy, coma) have to be taken into account. Psychosocial functioning might be improved by strengthening already available resources and coping mechanisms of relatives.

**Keywords:** Guillain-Barré Syndrome, GBS, relatives, family, experience, needs, caregiving

### Introduction

Guillain-Barré Syndrome (GBS) is an umbrella term for a range of severe, autoimmune-mediate neuropathies (Hughes & Cornblath 2005). After the eradication of poliomyelitis, GBS is the leading cause of acute flaccid paralysis in the Western world. Nonetheless, given the annual incidence 1-2 per 100000 (Govoni & Granieri 2001), it is a rare disease. From the extremities on, the most of the body of a person affected by GBS might become paralyzed, including the respiratory system (Willison, Jacobs, van Doorn 2016). The first period of deterioration is usually followed by a plateau phase. While most patients affected by GBS recover subsequently completely in weeks to months, some patients are impaired in their functional independence and daily activities for years after onset of first

symptoms (Willison, Jacobs, van Doorn 2016). Moreover, the disease course is highly variable (Hughes & Cornblath 2005), and even though some predictive factors and biomarkers are known (e.g., Hiraga et al. 2005, van den Berg et al. 2014) a certain prognosis of disease course for individual cases is often difficult to make.

While there is no cure for GBS, treatment options are available (immunoglobulin and plasmapheresis) and have been the evidence-based standard for the last 20 years (Hughes & Cornblath 2005). Further studies examine healthcare provision to this patient group (Khan et al. 2011). Apart of health-related quality of life (Darweesh et al. 2014), mental health of patients with GBS is also a major concern, ranging from reactive depression and anxiety to oneiroid

psychosis found in some patients with GBS (Heinz et al. 2002).

From the patient's side, few studies have examined their personal experience of GBS. One study associated the experience of GBS mainly with loss: using a Heideggerian hermeneutical approach they found that the sudden onset makes patients lose their identity and feel 'lost at sea' (Chetcuti, Sultana, & Depares 2016, p. 17) In a Swedish longitudinal study, Forsberg, Widén-Holmqvist, and Ahlström (2006) described the initial phase of GBS qualitatively. Their main findings were the experience of the deteriorating paralyzed body and the expectation of recovery, which was the case for most patients. The same study group (Forsberg, Widén-Holmqvist, & Ahlström 2014) found that patients with GBS still struggled in their everyday activities two years after onset of symptoms, but also described gains due to the disease. Some case reports and autobiographical reports have been published, for example of a pregnant woman developing GBS (Wada et al. 2010) or a nurse developing GBS (Blanco, 1983). While in these studies and reports the role of the family is almost always central, little is known about the experience of family and relatives of GBS. In one study with a longitudinal quantitative design, the impact of GBS on the family was assessed (Bernsen, de Jager, van der Meché, & Suurmeijer 2006). They found that GBS has an impact on the psychosocial functioning of relatives and recommend a family perspective for any supportive care interventions. So far, little is known about the descriptive needs of relatives. Meeting these needs might alleviate the burden of relatives and improve their psychosocial functioning.

Therefore, in this exploratory study, the experience and needs of relatives are described by analyzing online forum posts of relatives on a German GBS platform. While this procedure has its own ethical issues (Sixsmith & Murray 2001), it is also useful to access data to improve healthcare services which otherwise would have gone unnoticed, or, as it is in the case of rare diseases, rarely is subject to research funding.

## Methods

### *Data collection*

For this exploratory qualitative study, a search for forum posts of relatives on an online platform

for patients with GBS was executed with the following search terms (in German): 'brother', 'sister', 'mother', 'father', 'partner', 'husband', 'wife', and 'relative(s)'. This search revealed 16 initial forum posts ('threads') by relatives of patients with GBS. As most of these forum posts provided lengthy narratives, the number of forum posts was deemed sufficient for an exploratory analysis. The forum was searched from inception (i.e., September 2000 – July 2018) and includes a total of 1698 threads on various topics.

### **Data analysis**

These 16 blog posts were extracted as plain text (28 double-spaced pages in total) and were analyzed in an inductive analysis informed by thematic analysis (Braun & Clarke 2006). As a first step, different aspects of the relative's experience of GBS were coded line-by-line using MAXQDA (VERBI Software 2017). In a second step, the resulting codes were sorted and recoded into higher level codes. Subsequently, the resulting codes were grouped together and analyzed for common themes that explained their experiences as relatives of a person with GBS.

### *Ethical considerations*

The forum posts were accessible on the internet. As all relatives used a pseudonym, it was not possible to contact them and ask for consent. Data was anonymized in a two-step process: 1. all forum posts extracted and analyzed in German without any identifying information and 2. in the subsequent translation to English, peculiarities of language use were smoothed away without changing the content of the translated quotation. This leaves the remaining quotes to be untraceable and of fictitious status. Furthermore, all the included posts were of healthy individuals, therefore this study did not include any health data or vulnerable study subjects.

### **Findings**

Generally, relatives posted online to tell their story or to specifically ask for information and advice. Four themes were prevalent in the analyzed posts: 1. Psychological distress and burden of care, 2. challenges and needs, 3. specific needs related to complications of GBS, and 4. coping and solutions.

## Burden of care

Even if relatives are not directly involved in the care for a patient with GBS, e.g. if the patient is in an intensive care unit, a severe subjective burden of care is expressed. One daughter to a father with GBS reported that:

*“Our family is completely run down. My mother cannot go on. I can barely continue as I have a young child on my own” – post 2*

Generally, the psychological distress due to caring for a patient with GBS is reported by many relatives. The uncertainty of disease course is inducing anxiety in some relatives:

*“I’m totally anxious that she will be dependent on longtime care” – post 12*

or they put it simply as:

*“The fear is the worst.” – post 14*

Besides psychological stress, there are three major dimensions contributing to burden of care. Relatives of patients with GBS generally experience burden of care in their roles as caregivers, in their work, and their own health. One relative reflects about her role as a caregiving relative:

*“It shows time after time what balancing act relatives have to do. On the one hand, show strength and be hopeful for the patient, and on the other hand be confronted with one’s own limits. It’s a severe burden to live with my husband’s sudden chronic illness.” –post 1*

Relatives are not only burdened by the direct care for patient with GBS, but also by the impact of GBS in their own life. It impacts their work life as they are preoccupied with the disease or they have to reduce working hours for long drives to the care facilities (post 1 and 6). Burden of care proved to be also severe, if the partner with GBS was the breadwinner of the household (post 16). While some relatives wrote about neglecting self-care and their own health (post 1), others defend taking time for themselves:

*“No one should be ashamed, have to justify or have a bad conscience, or something similar. Health is the most important good and if that is taken from you as well, because you break down*

*from exhaustion, everything is not going to be easier.” –post 7*

## Challenges and needs

Most often, relatives reported the uncertain disease course to be the major challenge. While most patients recover completely, the chance that their relative might be permanently disabled is of major concerns. One relative notes:

*“I’m getting sick if I read that the disease can go on for months or years” – post 12*

The need for prognostic certainty is shared by many relatives and physicians rarely disclose prognosis to relatives or patients: “the physicians do not give any prognosis – except to wait. Are they unable?” (post 15).

Generally, relatives see a lack of training on part of the healthcare professionals:

*„They [the healthcare professionals] naturally don’t have much experience with this disease because it is so rare” (post 16).*

In contrast, one relative noted that an excess of information, especially facts not relating to disease course or impact on daily living, was not helpful either (post 7).

Adding to these challenges, relatives experience severe impact on their own family life as well. Some relatives reported the difficulty of seeing their loved ones impaired by GBS:

*“I am not able to visit him (emotionally)” (post 2). In one case, the underage son of a patient with GBS did not want to visit his father. His mother writes:*

*„My husband is very sad because our son does not want to visit him. He is frightened to see his father because he is so alien to him. We parents have to try to understand and tolerate that.” –post 1*

Furthermore, old age of the affected person presents as a challenge to relatives as here rehabilitation is assumed to be complicated or not possible. In contact with healthcare providers, some relatives did not find advice to stay positive helpful. In the face of prognostic uncertainty, advice to stay positive sometimes is seen as

*“talk that is cheap” (post 15).*

### **Specific needs related to complicated disease courses of GBS**

There are several circumstances specific to GBS that have a special impact on the relatives. In the 16 forum posts, these are: medically induced coma, tracheostomy and weaning, locked-in state, treatment related fluctuation, and other complications.

#### ***Medically induced coma, tracheostomy and weaning***

Five relatives turned to the forum in search for information about a medically induced coma. The persons affected by GBS were either put on invasive ventilation and or were dependent on other respirator support whilst in coma. Relatives experience the time of coma as unclear:

*„When do they end the medically induced coma? In what kind of state is one then? How does one feel? Does one despair? What can I do as a relative?“ – forum post 6*

Most relatives either asked about the duration of the coma or about the weaning period after respirator support. One relative asked

*„What does 3 to 6 months mean for weaning – is it from disease onset, from transfer to early rehabilitation services, or from plateau stage on?“ – post 6*

Again, relatives are confronted with an unknown prognosis. Furthermore, even if the weaning period had begun, relatives experience this time as uncertain:

*“After 10 really critical days, there were first signs of hope: tracheostomy (because than they could start to wake him up). This again took a week. Suddenly, they transferred him to early rehabilitation services in the same hospital. We were not allowed to visit him because he was still in a critical state according to the physicians” –post 6*

#### ***Locked-in state***

If the person affected by GBS is in a locked-in state, i.e. the state of not being able to move all or most muscles, relatives have to rely on different communication strategies. Commonly, yes/no questions are answered by the person

affected by GBS by blinking once or twice. But even if some muscular activity remains, relatives might experience other difficulties:

*“She also wants to talk. And I see her despair and she becomes upset because I do not understand her. Is it possible that she hears herself talk in her head and does not understand why I do not listen and talk to her? I just want to help her. But sadly lip reading is not that easy” – post 15*

For relatives, the state of locked-in therefore is not simply the inability to communicate but also impacts their relationship to the person affected by GBS severely.

#### ***Treatment-related fluctuation***

Treatment-related fluctuation is a subtype of GBS (GBS-TRF) where there is a second exacerbation of symptoms after a short initial period of recovery. This subtype can indicate a more severe disease course. In comparison to the standard course of GBS with recovery of most patients, here relatives face long-term disability of the person affected by GBS:

*“Yesterday, my mother and I spoke to the treating physician. He did not want to give us any prognosis and referred to the severe and extreme disease course (due to the fact that it got better shortly, but then the curve went down). So it might be that he recovers completely but we have to think about that he might stay paralyzed forever, because now the central nervous system is involved.” – post 11*

#### ***Other complications of GBS***

There are other circumstances reported that affect the experience of relatives. For example, fatigue is a common symptom of patients with GBS. In one forum post (13), a relative reported that she felt that it is difficult to keep up conversation and motivate the person affected by GBS for treatment due to his fatigue. In another forum post (4), a mother reported that both her underage teenage daughter and her husband had been affected by a chronic subtype of GBS. In a third case, the woman affected by GBS was pregnant and her husband was severely worried about the health of the embryo.



## Coping and support

In the forum posts, family members described different coping mechanisms and sources of support. In the adaption to the changing nature of GBS, three coping mechanisms were prevalent: acceptance, focus on the patient, and setting priorities. A relative stated that one had to accept GBS:

*“that is sadly the case – GBS takes time” (post 7).*

Additionally, some relatives found it helpful to realize that they are healthy and should not focus on themselves, but rather on the patient. This seemed very difficult to others:

*“Is it wrong that I – who is healthy – had to cry in front of her?” (post 15).*

All in all, relatives experience a change of priorities during the course of GBS. One family member sums it up:

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All in all, relatives experience a change of priorities during the course of GBS. One family member sums it up:

*“Firstly, I have a changed outlook on patience since the onset of GBS. I have learned to deal differently with time and to set priorities in my/our life” (post 1).*

Apart from personal coping mechanisms and adaption to the disease, relatives also describe sources of support. Foremost, family members support each other and provide consolation. One family member described it as helpful that her family lives close by. A wider social support is also experienced as helpful. One relative described the formation of friendships with other family members of persons affected by GBS or other severe illnesses, while another found the narratives of patients with GBS in the forum helpful. All in all, relatives experienced the online forum as supportive as it went beyond the information supplied by healthcare professionals.

## Discussion

These findings show that the experiences of relatives of patients with GBS form a wide spectrum. Foremost, the severe burden of care of relatives found in other studies (Bernsen, de Jager, van der Meché, & Suurmeijer 2006) is expressed by the relatives themselves as well.

This burden of care is directly linked to anxious feelings towards the uncertain future and may be a reason why psychosocial functioning in relatives is impaired. Providing relatives with information about prognostic factors and other patients' stories might help to meet the informational need experienced by many relatives, as these are reported to be helpful by relatives. This informational need is often not met by healthcare professionals and a reason for relatives to turn to online forums. As GBS is a rare disease, healthcare professionals generally might not have extensive experience with it. Therefore, training nurses and other healthcare practitioners on the relatives' needs might help relatives to deal with the challenges outlined in this study.

Given that Guillain-Barré syndrome is an umbrella term for a set of neuropathies with different prognostic outlooks, it is not surprising that specific needs arise when there are complicated trajectories of disease. In fact, this aspect of GBS is similar to other neurodegenerative diseases, which render a certain prognosis by the physician difficult. As there are known adverse indicators for prognosis in GBS (e.g., GBS-TRF, old age, or high disability at nadir; Willison, Jacobs, van Doorn 2016), these indicators have to be disclosed to the family. Medically induced coma and tracheostomy are sources of anxiety for relatives and healthcare professionals should inform about possible outcome and risks in a sensible way, if possible. For many relatives, the information that patients will most likely recover eventually might be helpful. Likewise, information about the duration of weaning should be thoroughly deployed. Further studies should explore coping and support strategies of relatives of patients with GBS, so that these strategies can be strengthened. This can also help to support family members who are severely psychologically impacted by the disease of their relative.

This exploratory qualitative study is limited. The secondary use of data from online forum posts has the disadvantage that important aspects of relatives' experience of GBS might not be covered in these posts, as would be, for example, in semi-structured interviews. Given the little research on the topic, this study might still be

helpful to direct further research. Nonetheless, online forum posts provide a valuable source for research on the topic of orphan diseases. In combining the perspectives of relatives and caregivers, this cannot only help to empower them, but also provide information for healthcare practitioners working with patients with GBS and their families.

### Conclusion

This exploratory study provided first insights in the experience of relatives of patients with GBS. Further research of improved data quality is needed to derive at interventions for healthcare service provision to this patient group and their families. This is urgently wanted given the severe distress relatives of patients with GBS experience.

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