# Patients' experiences and perceptions of Guillain-Barré syndrome: A systematic review and meta-synthesis of qualitative research

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## Abstract

### Background

Guillain-Barré syndrome (GBS) is an immune-mediated polyradiculoneuropathy, with an incidence of 1-2/100,000 per year. Its severity is variable, ranging from very mild cases with brief weakness to severe paralysis, leading to inability to breathe independently, or even death. Currently there is limited evidence exploring the experiences of GBS patients. The aim of this study was to review patients' experiences and perceptions of GBS and its variants at diagnosis, discharge and during recovery, by conducting a systematic review and thematic meta-synthesis of qualitative studies of patients' experiences of GBS (and its variants).

### Methods

We searched twelve electronic databases, supplemented with internet searches and forward and backward citation tracking from the included studies and review articles. Data were synthesised thematically following the Thomas and Harden approach. The CASP Qualitative Checklist was used to assess the quality of the included studies of this review.

### Results

Our search strategy identified a total of 5,282 citations and after removing duplicates and excluding citations based on title and abstract, and full-text screening, five studies were included in the review and meta-synthesis; all included studies were considered of acceptable quality. Through constant discussions and an iterative approach, we developed six analytical themes following a patient's journey from suspecting that they had a health problem, through to being hospitalised, experiencing ongoing difficulties, slowly recovering from GBS, adjusting to their new circumstances, and re-evaluating their lives.

### Conclusions

Despite the variety of experiences, it was evident from all included studies that being diagnosed with and surviving GBS was a life-changing experience for all participants.

### Trial registration

Protocol was registered (CRD42019122199) on the International Prospective Register of Systematic Reviews (http://www.crd.york.ac.uk/PROSPERO).

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## Background

Guillain-Barré syndrome (GBS) is an immune-mediated polyradiculoneuropathy, with an incidence of 1-2/100,000 per year [1]. GBS can affect anyone and at any age, although it is more frequent in adults and older people [2]. It has a highly variable onset, clinical severity and course, and there are several variants of GBS (including chronic inflammatory demyelinating polyradiculoneuropathy and Miller-Fisher syndrome) [3]. In most cases, GBS has an acute (4 hours) to subacute (up to 1 week) onset with symmetrical weakness and numbness of the limbs progressing proximally, usually over 2–4 weeks, causing loss of reflexes [3]. Although most patients recover (70% eventually experience full recovery), for some recovery can be slow or incomplete; for example, about 30

percent of individuals diagnosed with GBS have residual weakness after 3 years and about 15 percent experience long-term weakness [2]. So even though GBS is not considered a chronic condition, it often has long-term effects and patients may have ongoing neurological deficits that affect their quality of life, their work and social lives [4, 5].

Currently there is limited evidence exploring the experiences of individuals who have had GBS. Previous research highlights the significant impact of GBS on individuals and their families. One study [6] exploring the presence of residual symptoms and the long-term effect of GBS on patients' daily lives, working activities, hobbies and social status, showed that, at follow-up, most patients had made a complete functional recovery; however, almost a third had to make substantial changes in their daily lives including jobs, hobbies or social activities. Similarly, Khan and colleagues [7], examining factors impacting long-term health-related outcomes in GBS survivors, found that it had moderate to extreme impact on ability to participate in work, family, and social activities for 16% of participants. GBS also had a substantial impact on mood, confidence and ability to live independently for 22% of their sample, while moderate to extreme depression, anxiety and stress were also reported. Another study [8] exploring utilization of and satisfaction with healthcare resources, informal help and the burden of care on family caregivers during the first 2 years after onset, found that although most participants were satisfied with their overall care, they were less satisfied with the information they received about GBS or with the cost of care. At 2 years after onset, almost a third of participants still depended on informal carers and their spouses, often expressing increased concern and responsibility for their household and family. Finally, a systematic review [9] of the literature on GBS patients' quality of life after onset of the disease concluded that many patients felt limited by their condition, even years after the onset, and that GBS had a lasting psychosocial impact, affecting patients' mental well-being, daily activities and work life.

#### Theoretical perspective

We used two theoretical models to facilitate data gathering, analysis and interpretation of the experiences of patients with GBS, the Illness Trajectory Framework (ITF) [10] and Taylor's [11] theory of cognitive adaptation to threatening events.

According to the ITF [10], chronic illnesses follow a course or *trajectory* which, although different for each individual, have eight common *trajectory phases*, which involve changes in health and the type of interventions or *trajectory scheme* needed: pre-trajectory, trajectory onset, crisis, acute, stable, unstable, downward, and dying. Overall, the ITF argues that chronic illness (and management) has an effect on different aspects of individual's identity, forcing patients to make identity adaptations to live (*come to terms*) with their chronic condition, its consequences and their own mortality.

The [11] theory of adaptation can be viewed as complementary to ITF, focusing particularly on the individual's cognitive response when faced with a threat. According to Taylor [11], when individuals are faced with a threatening event, such as a serious illness like GBS, they go through a readjustment process, during which they try to understand why the event happened, what caused it, and how it has affected their lives. Patients also try to regain mastery over their illness, while avoiding something similar happening again, as well as find ways to feel good about themselves again and enhance, or restore, their self-esteem. Often, making favourable social comparisons is the key to such enhancing attempts to regain control, whereby patients try to cope by feeling better off than others in the same situation, thus, making more positive self-evaluations and ultimately feeling better adjusted and able to cope with their illness.

The findings of this review will provide insights into the patient journey, which could be useful in informing patient care and support services.

#### Aim of the study

Given the severity of GBS and how variable its onset and course are, it is imperative to explore in depth the patients' experiences of GBS at the time of diagnosis, during their hospitalisation, in the period post-discharge from hospital and on their return to the community, in order to better understand this patient group's health and social care needs, as well as explore any potential facilitators and barriers to recovery and return to function. Furthermore, based on our preliminary searches, to date no systematic reviews of qualitative studies exploring patients' experiences of GBS have been published.

The aim of this study was to review patients' experiences and perceptions of GBS and its variants at diagnosis, discharge and during recovery, by conducting a systematic review and thematic meta-synthesis of qualitative studies of patients' experiences of GBS (and its variants).

## Methods

We followed ENTREQ guidelines for enhancing transparency in reporting the synthesis of qualitative research [12]. The review protocol was registered with the PROSPERO International prospective register of systematic reviews [13] and is available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42019122199.

Our review question was: What are patients' experiences and perceptions of GBS and chronic inflammatory demyelinating polyneuropathy (CIDP) and its care at diagnosis, discharge and during recovery?

#### Inclusion criteria

Studies were eligible for inclusion if they had a qualitative research design (e.g. interviews, focus groups, ethnography) and reported on patients' lived experience of GBS and CIDP. Healthcare services (including the treatment, care and support they provide) have changed considerably in the last 20 years and consequently so has patient experience of care. To ensure that the reviewed patient experiences are relevant to the present day and can inform improvements in current practice, only studies published between January 2000 and May 2020 were eligible for inclusion. In addition, only peer reviewed studies, written in English were considered for eligibility.

Qualitative studies published outside these dates or in other languages were excluded. Quantitative studies were also not eligible for inclusion, since we were interested in patients' lived experience of GBS and CIDP and we wanted to include in depth accounts of their experiences (preferably expressed in their own words, i.e. by using quotes).

#### Information sources and search strategy

Electronic database searches were performed in the Cochrane Library, Joanna Briggs Institute Evidence-Based Practice Database, PROSPERO, MEDLINE, Academic Search Complete, AMED, CINAHL, Humanities International Index, PsycARTICLES, PsycINFO, EMBASE, and PubMed. All databases searches were supplemented with internet searches (i.e. Google Scholar), and forward and backward citation tracking from the included studies and review articles.

The search strategy used in all the above databases included a combination of two sets of keywords and related terms: 1) Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), acute inflammatory demyelinating polyneuropathy (AIDP); combined with 2) qualitative research, interview, focus group, experiences, perceptions, attitudes, and views. The search terms were entered using Boolean operators and truncation, wherever deemed necessary. Medical Subject Headings (MeSH) were also employed in forming the search strategy. For the full search strategy used for the Medline database, see Table 1.

**Table 1. Search strategy for MEDLINE database.**
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#### Study selection and data extraction

All references were reviewed and screened by three reviewers (FC, DL, JA) independently. Titles and abstracts were initially screened for relevance and final eligibility was assessed through full-text screening against the inclusion criteria, using a pre-designed study selection form. Any disagreement between the reviewers over the eligibility of references was resolved through discussion between the reviewers, and in consultation with a fourth reviewer (ANS) when necessary.

A standardised, pre-piloted form was used to extract data from the included studies for assessment of quality and data synthesis. Extracted information included: study details (title, authors, date, country), methods (aims, objectives, research questions, study design, setting, data collection methods), participant characteristics (demographics, inclusion/exclusion criteria, method of recruitment, sample selection, sample size), and study findings (main and secondary outcomes, data analysis, conclusions). One reviewer extracted data and a second reviewer checked the data extractions for accuracy. Any discrepancies were resolved through discussion and missing data were requested from study authors.

#### Data synthesis

Data were entered into NVivo 11 qualitative data analysis software to facilitate analysis. We used thematic synthesis to synthesise the data, following the Thomas and Harden [14] approach. Initially, three reviewers (DL, FC, JA) independently coded the 'results' sections (and 'discussion' sections, where new concepts were introduced) of the included papers line-by-line, according to meaning and content, using an inductive approach. Consequently, these free codes of findings were organised into 'descriptive' themes that encompassed the meaning of groups of the initial codes. Finally, based on the codes and 'descriptive' themes and through discussion with the wider review team, the final 'analytical' themes were developed.

We followed an inductive approach to analyse and synthesise the data, rather than imposing the illness trajectory framework (ITF) or Taylor's theory of cognitive adaptation onto our results. Instead, we used both these models to interpret the results and describe the patient journey from experiencing the first GBS symptoms to hospital discharge and recovery (see Discussion below).

#### Quality assessment of studies

The Critical Appraisal Skills Programme (CASP) Qualitative Checklist [15] was used to assess the quality of the included studies of this review. Low quality, however, was not a criterion for exclusion of a study, since we were interested in the synthesis and interpretation of all relevant and sufficiently rich data. The CASP qualitative checklist aims to assess various elements of qualitative research studies, including research aims, appropriate methodology, research design and strategy, methods of data collection and communication between researchers and participants, ethical considerations, rigor of data analysis, and the clarity and value of study findings.

Three reviewers (JA, FC, DL) independently assessed the quality of the included studies. Discrepancies were resolved by discussion and consensus, and in consultation with a fourth reviewer when needed (ANS).

#### Reflexive statement

Reflexivity enables authors to recognise the assumptions and preconceptions they bring into the research and may influence the research process, while allowing the reader to understand the dynamics between the researcher and the researched. This review was commissioned and developed in discussion with the chief executive and chair of the board of trustees of the charity 'Guillain-Barré and associated Inflammatory Neuropathies' (GAIN). GAIN was the main funder of the study and helped develop the review's main objectives: exploring GBS patients' experience of care, particularly focussing on the period following discharge from hospital and return to the community.

The reviewers (except for ANS and JA) had no prior knowledge of or experience with GBS. DL, a psychologist by background and a researcher in health services, has experience in quantitative systematic reviews and in the analysis of qualitative data. FC is a research fellow whose research predominantly focuses on non-pharmacological interventions for the prevention and management of chronic conditions. She has experience conducting systematic reviews of both quantitative and qualitative studies. JA has a background in clinical nursing and public health with expertise in qualitative and quantitative research methods, and systematic reviews. As a nurse, JA has general clinical knowledge of GBS. JJ is a community researcher with interest in the patient and service user experience, as well as extensive experience of qualitative and engaged research within the public sector, community and voluntary groups. TLH is a psychologist with interest in cognitive deficits in patients with neurodegenerative disorders, with experience of analysis of quantitative data and knowledge of the neurology of cognition and perception. ANS is a clinical academic general practitioner (GP) by background with expertise in social science methods, including systematic reviews, qualitative meta-syntheses and qualitative studies more generally. He has general clinical expertise and insight into GBS but is not an expert on the condition itself.

Familiarisation with the papers included in this review, together with being aware of the existence of GBS-dedicated charities, may have influenced the authors' suggestions regarding potential sources of support for patients in the future; such support may be available from multiple sources, and our view may have been influenced by the funding for this study.

## Results

The search strategy identified a total of 5,282 citations. After removing duplicates and excluding citations based on title and abstract, 63 articles remained for full-text screening. A further 58 articles were excluded based on inclusion/exclusion criteria (main reasons for exclusion: paper not written in English, and/or a quantitative design), leaving five studies to be included in the review and meta-synthesis. Fig 1 presents a flowchart illustrating the results of the selection process.

**Fig 1. Flow diagram of study selection.**
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### Characteristics of included studies

The five included studies (Table 2) were published between 2003 and 2015 and were from four countries: Australia [16], Sweden [17, 18], UK [19], and, USA [20]. One study [20] was a PhD thesis. All studies interviewed people living with GBS; none of the studies included participants diagnosed with other variants of GBS, such as CIDP or Miller-Fisher syndrome. All studies contained both men and women, but there were more male participants overall (55/94). Participants' ages ranged from 16 to 80 years. Studies were based on individual semi-structured interviews only; none included focus groups. Various methods of analysis were employed in the studies, including content analysis [17, 18, 20], interpretative phenomenological analysis [19], and the constant comparative method [16]. Most of the studies focused on the overall experiences of people during hospital care or recovering from GBS, whereas one study [19] focused specifically on their experiences returning to work following recovery from GBS.

**Table 2. Study characteristics.**
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### Quality assessment of studies

Table 3 presents the results of the critical appraisal of the five studies, using the CASP criteria for qualitative research. All included studies were considered of acceptable quality. It should be noted here that three [16, 17, 20] of the five studies performed less well on the reflexivity question (CASP 06) and one study [17] performed less well on four CASP questions, since not enough relevant information was reported in the papers.

**Table 3. Quality assessment of studies.**
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### Data synthesis

After initial coding and development of descriptive themes, we developed six analytical themes (Table 4). We organised the themes chronologically into a model representing a patient's journey from their initial suspicion that they had a health problem, through to being hospitalised, experiencing ongoing difficulties, slowly recovering from GBS, and resuming their everyday lives.

**Table 4. Analytical and descriptive themes.**
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#### From uncertainty to hope.

Participants tried to ignore initial strange sensations due to GBS [17, 20]. As the condition deteriorated, they attempted to explain their symptoms as the result of normal everyday activities or occurrences (such as medication side effects or tiredness), or feared having better known conditions, such as cancer [17, 19, 20]. On occasions, healthcare professionals either misdiagnosed their symptoms (e.g. thinking the participant was having a stroke) or felt they were feigning illness [20].

Uncertainty for participants often became overwhelming, making them eager to find out what was happening to them [17, 20].This feeling of uncertainty was made worse by a general lack of information and knowledge of GBS, among patients and healthcare professionals [16, 17, 20]. Most participants had never heard of GBS and felt that healthcare professionals were lacking knowledge of and experience with GBS, which they did not find comforting, and left them needing more information about their illness [20]. Often patients' families and friends that had to find information about GBS themselves, mainly through searching on the internet [16, 20]. Many participants would have liked to have received more information about GBS to improve their understanding of their condition, but also because they found information about GBS, especially on prognosis and recovery, to be reassuring [16, 17, 20].

Although some participants were sad and disappointed about the long recovery ahead of them, many relied on the prospect of a positive prognosis and hoped for a full recovery [17]; indeed, participants' hope of recovery was their main motivation, giving them the courage to continue [16–18].

Feeling lost in a changing life.

Having GBS affected every aspect of participants' daily lives [16–20]. A variety of physical symptoms and problems were experienced at onset, starting with numbness or tingling in hands and feet, pain, leading to full paralysis requiring ventilation support [16–20]. Participants' experiences varied, but many had ongoing difficulties, such as fatigue and memory difficulties, that still limited them in their everyday activities even two years after the onset of their illness [16–20].

As a result, some participants felt they had lost their identity as an independent person [17, 19], while others felt helpless through loss of independence [16, 18]. These feelings were accompanied by shame or embarrassment, especially when help with hygiene was needed or appearance had altered as a result of GBS [17, 19, 20]. Participants described many emotions as a result of being diagnosed with and needing care for GBS, such as frustration, guilt, elation, anger, and gratitude [19, 20]. Other common psychological responses were: feeling lost; feeling abandoned; anxiety when in the intensive care unit or connected to a ventilator; sadness; depression; and fear [17–20].

Having GBS influenced participants' family lives. Participants were worried about their family's wellbeing, while they were hospitalised [20], or felt sad and frustrated about how limited mobility had forced them to accept changed family responsibilities [18]. Living with GBS made it harder for them to participate in society and restricted their social lives considerably, restricting visits to friends and travel [18]. Finally, another area affected by a participant's condition was their work, since physical restrictions and residual GBS symptoms affected function or prevented them from returning to work [18, 19].

Fractured care.

Participants were generally dissatisfied with healthcare service support which they considered a key barrier preventing recovery from GBS. Participants felt that there was lack of personalised and person-centred care, lack of continuity of care, lengthy waits for referrals, and staff shortages, which made it harder for participants to receive the care they needed [18, 20].

Participants also felt not listened to by healthcare staff and experienced poor communication from healthcare professionals [18, 20]. They sometimes felt doctors' attitudes were 'cavalier' or healthcare professionals lacked time to discuss their condition with them properly [20]. Specific needs, whether physical and psychological, were often not met [20].

Participants also identified a want of publicity about GBS as a main factor contributing to the lack of support they received, especially when returning to work, as the public did not have any insight into the long term effects of GBS or what to expect when interacting with the participants [19].

Positivity towards recovery.

In contrast, participants variously expressed an overall satisfaction with the care they received from community and hospital healthcare, commending kind staff attending to their physical care needs with efficient treatments [16, 18, 20]. More specifically, participants were often very satisfied with nursing care for their physical, psychological and social problems [16, 20].

Another facilitator to recovery from GBS was the invaluable support from their family and friends, including both practical (e.g. help with the home and transportation) and psychosocial support (e.g. gathering information about GBS or being emotionally supportive) [16, 18, 20]. However, in one study [18] participants expressed frustration over the lack of understanding from family and friends in relation to their physical limitations and the effect on the participants' capacity and everyday life in general.

Support from colleagues was also viewed very highly by participants and motivated them to go back to work, as they often considered their colleagues as friends as well [19]. Often, however, participants were ambivalent towards their co-workers, initially being grateful for their support, but finding them over-protective at the same time [19]. When this support soon decreased, participants found it difficult to perform their jobs, demonstrating how important such support had really been for participants [19].

Peer support was also viewed as really important by participants [16, 20], who valued being able to talk with and receive information from others who had also been ill with and survived GBS, as this communication filled them with hope about recovery and the future [20]. Equally, participants would have gladly done the same for others in their situation, as they considered peer support to be better received and more impactful [20].

Finally, participants' positive attitude was a major facilitator to their recovery from GBS and helped them realise that life wasn't over and that things would eventually improve [17, 20]. Hope and confidence in recovery were huge motivators, especially once their functions started to return, motivating them further [16, 17].

Adjustment.

There was wide variation in participants' experiences of recovery, coping with and adjusting to their new situation. For some recovery lasted months and was full, whereas others were still experiencing residual symptoms years later [18]. Those with continuing symptoms felt they had been forced to take over the responsibility for managing and treating their own symptoms and developed personal strategies to overcome physical difficulties, such as walking more slowly to save energy or using hydrotherapy to strengthen and relax their bodies [18]. During recovery, many participants described their need for increased control and independence [20], which they associated with improved physical capabilities [16]. Achieving independence was inspiring to participants and, together with their inner strength, were the key factors in gaining full recovery [16, 17, 20].

Setting and achieving 'milestones' was another major motivating factor, with different participants viewing different points in their patient journey as milestones [16, 17, 19, 20]. For some, it was being able to walk again [17] or becoming independent [20], while for others it was moving to the rehabilitation ward [16] or going back to work [19].

Adjusting to their new situation required participants to first accept their new circumstances [18–20] and this was a complicated process for many, with some neglecting the influence of the consequences of the disease on their life situation, and others reappraising their new situation and trying to find new ways to manage their residual difficulties [18]. For some participants that

meant remaining positive, often despite persisting symptoms [18, 20], or choosing to focus on the positive prognosis, and not thinking about a possible negative outcome (i.e. not recovering fully) [17].

Towards a new self.

A recurring theme was participants' attempts and eagerness to return to their 'normal' pre-GBS selves and everyday lives. Often, going back to an acceptably 'normal' identity and avoiding the potential stigma of GBS required rejection of overt disability, with participants trying to conceal their impairments or avoid discussing them [19], especially once they were back to work [19]. As a result, participants sometimes did not inform current or prospective employers about their residual difficulties [19].

Participants were sensitive to other's reactions at work, especially when colleagues' behaviour changed towards them [19]. In order to maintain their identity and cope with threats to their self-image, different coping strategies were used. One participant went as far as entering a 'supernormal' phase on his return to work, doing as much work as possible, and refusing extra help [19]. Others monitored colleagues' behaviour for possible negative responses, and sought to exert some control over these, for example by using humour [19]. And for one participant, it was having a senior position in the company and positive relationships with colleagues that were the contributory factors that helped him be open about his diagnosis and residual difficulties [19].

Despite these concerns, returning to work was seen positively, as going back to their 'normal' selves again, and offered a distraction from the participants' residual difficulties [19]. Reconnecting with colleagues was viewed as another benefit [19]. Other motivations for going back to work were financial, recovering physically, and having a purpose and structure to everyday life [19]. Some participants, however, reported feeling vulnerable returning to work, as they were worried that discussing their health difficulties would sound like complaining [19].

The main factor facilitating participants' return to work was workplace adaptations. For some, such accommodations included having the right workplace resources or limiting their responsibilities, especially if they considered stress as a factor in their illness, by being able to change or reduce working hours [19]. For those who were more senior in their workplace, modifying their role was even easier [19].

Some workplaces did not have any appropriate resources, such as a quiet place for resting, and when participants went back to work, they were offered only short term flexibility, being expected to soon fully return to their previous responsibilities [19]. Furthermore, not all participants considered work adaptations positively, making them feel vulnerable and threatening their re-established, pre-illness, 'normal' selves [19]. For others, accepting continued support went against their personal values or diminished their sense of achievement [19].

Overall, it was evident from all five studies that living with GBS had been a life-changing experience [16–20], often making participants re-evaluate or change their life accordingly [18].

## Discussion

This systematic review and thematic meta-synthesis explored patients' experiences and perceptions of GBS at diagnosis, discharge and during recovery. Participants' experiences of recovery varied significantly, many still experiencing residual (physical, psychological and social) difficulties even years after their discharge from hospital. These results are closely aligned with concepts suggested by both the Illness Trajectory Framework (ITF), proposed by Corbin & Strauss [10], and Taylor's [11] theory of cognitive adaptation to threatening events.

Our results showed that the *trajectory* of GBS was uncertain and varied significantly from patient to patient, depending on the severity of their condition, the care and support they received, and their own attitudes towards recovery [11]. During the first phase of *pre-trajectory* and the *trajectory onset*, delayed diagnosis and/or misdiagnosis were often reported, a finding that has been well documented previously. For example, Dubey and colleagues [21] reported that on initial emergency department visit, GBS was suspected in only 49.3% of the cases; this increased significantly when the patient was evaluated by a neurologist (67.5%) rather than the emergency department physician.

Although the *crisis and acute phases* left the participants fighting for their lives, once their condition had stabilised (*stable phase*), participants slowly started to recover. However, not all participants recovered fully and GBS continued affecting every aspect of their life, leaving them feeling lost in a changing, and often incomprehensible, life (*unstable phase*). These results echo those found in previous studies [6, 7, 9], which have also documented GBS' lasting effects.

There are many factors that affect how an illness progresses and how recovery can be affected positively or negatively. Our results, for example, showed that patients struggled with the lack of knowledge among healthcare professionals and the lack of information about GBS they received. Similar results were also found in past studies [8]. Our findings also showed that participants felt that their needs were not being met, mainly due to fractured care, lack of continuity and of personalised care. Uprichard and colleagues [22] also highlighted the importance of, and need for, an individualised approach to care for patients with GBS and how such care is essential for reducing the traumatic experience of recovery from such a severe illness.

Another facilitator to recovery was support from family and friends, also found in past studies [23]. Seeing how past GBS patients were able to get better and recover successfully (peer support) was also beneficial, by providing patients with models of good adjustment and giving them hope for their recovery and their future. One possible mechanism of having achieved this may have been by making upward social comparisons to others who were doing better than they were, thus, contributing to their self-enhancement and helping restore their self-esteem [11]. Past studies with patients in recovery from stroke have also documented the importance of support from stroke survivors in helping patients feel empowered, encouraged, motivated, validated, and less alone [24, 25].

More importantly, our meta-synthesis found novel factors that might positively affect recovery. Maintaining a positive attitude, for example, was the first step towards recovery from GBS and helped participants take control of their situation, try to manage their symptoms themselves and regain their independence; a finding in accordance with Taylor's theory [11], which argues that one of the main pathways to adjustment is by gaining a feeling of control over the threatening event.

Achieving major milestones also helped participants adjust to and *come to terms* with their new situation. Returning to work was especially seen as a really important step in going back to their 'normal' selves again, even though sometimes participants had to make accommodations before being able to return to their previous role. Such accommodations were necessary due to residual physical difficulties, but can also be seen as an attempt to control the situation by making changes in their lives that would allow

them to adapt to their new situation successfully [11]. Being diagnosed with and surviving GBS was a life-changing experience for all participants that often made them search for meaning in their new situation, re-appraise their lives and re-order their priorities [11].

For the majority of GBS cases there is no real *downward* or *dying phase*; mortality in GBS patients varies widely with rates between 1–18% [26]. However, the experience of illness will be present until death.

#### Strengths and limitations

This review has brought together papers discussing different aspects of people's experience (such as during an acute episode [20] or the initial phase of GBS [17], the recovery phase [16, 18], and their experiences returning to work [19]) and has synthesised them for the first time into a comprehensive overview of the illness and recovery journey of people diagnosed with GBS.

The study followed a rigorous pre-specified protocol (registered with PROSPERO), which ensured that the review process was transparent and replicable. We conducted a comprehensive search for published and unpublished work, through twelve electronic databases, internet searches and scanning of bibliographies. The five included studies were of acceptable quality and included rich data.

A potential limitation of this review was including exclusively English-language papers, as important evidence may have been excluded due to language restrictions. However, methods for translating concepts across languages, in addition to the initial challenge of translating them across studies, have not been sufficiently developed [27]. Finally, all five studies interviewed people living with GBS, but none included other variants of GBS, such as CIDP or Miller-Fisher syndrome. Future studies should also aim to include participants diagnosed with other variants of GBS, as these sub-groups of participants may have different experiences and needs.

#### Implications for policy and practice

Exploring this literature has enabled us to identify how patients may need extra support to cope better with their recovery and also identify ways that healthcare professionals and services can help facilitate further such a recovery.

One of the most important areas that needs to be addressed is the lack of knowledge about GBS among many healthcare professionals, including the lack of provision of information to patients about their condition and prognosis. Offering additional training on GBS for healthcare professionals might be an appropriate first step towards improving their knowledge, while providing educational resources and information for the public could be another helpful action. Informing patients of available support services (such as financial aid, health and social care services, as well as relevant charities) would further ensure that people receive appropriate and personalised care, facilitate their transition from hospitalisation to returning to their everyday lives and, potentially, aid recovery.

Patients' psychological needs were often not met by healthcare services, while maintaining a positive attitude was identified as essential for participants to be able to cope with and successfully recover from GBS. It would be useful, therefore, to add psychological therapies to patients' treatment regimens, if needed and wanted by patients.

We found that participants also viewed peer support as important in their road to recovery. Peer support could help address both areas discussed earlier, regarding lack of information and emotional support offered to patients with GBS. This could also be an area for future research, exploring how peer support should be provided and that it was clinically beneficial before planning for peer support to be widely available to patients with GBS, potentially through hospitals or GBS charities.

Finally, patients often reported requiring extra support to enable them going back to work. This, according to our results, would include increased awareness of GBS and its sequelae for employers, which in turn would increase understanding of the condition by employers and, therefore, making them more inclined to provide adaptations at work for patients wanting to return to their jobs (e.g. flexible working hours/days, areas for rest, etc.).

## Conclusions

This systematic meta-synthesis explored patients' experiences of GBS at diagnosis, discharge and during recovery. One factor that positively influenced management and eventually outcomes was having a positive attitude and thinking towards recovery. Other key factors influencing management were receiving adequate information about GBS, having support from valued others (such as family members, friends or peer support), and receiving satisfactory care from healthcare services (especially nursing care). Despite the variety of experiences, it was evident from all included studies that being diagnosed with and surviving GBS was a life-changing experience for all participants.

## Supporting information

**S1 File. ENTREQ checklist.**
https://doi.org/10.1371/journal.pone.0245826.s001
(DOCX)

**S2 File. PROSPERO protocol registration.**
https://doi.org/10.1371/journal.pone.0245826.s002
(PDF)

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## References

1. Sejvar JJ, Baughman AL, Wise M, Morgan OW. Population incidence of Guillain-Barre syndrome: a systematic review and meta-analysis. Neuroepidemiology. 2011; 36(2): 123–133. pmid:21422765
View Article • PubMed/NCBI • Google Scholar

2. National Institute of Neurological Disorders and Stroke. *Guillain-Barré Syndrome Fact Sheet*. 2018; Retrieved October 02, 2019, from https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Guillain-Barr%C3%A9-Syndrome-Fact-Sheet

3. Willison HJ, Jacobs BC, van Doorn PA. Guillain-Barré syndrome. Lancet. 2016; 388: 717–727. pmid:26948435
View Article • PubMed/NCBI • Google Scholar

4. Bernsen RAJAM, de Jager AEJ, van der Meche FGA, Suurmeijer TPBM). How Guillain–Barre patients experience their functioning after 1 year. Acta Neurol Scand. 2015; 112: 51–56. pmid:15932357
View Article • PubMed/NCBI • Google Scholar

5. Roodbol J, de Wit MCY, Aarsen FK, Catsman-Berrevoets CE, Jacobs BC. Long-term outcome of Guillain-Barré syndrome in children. J Peripher Nerv Syst. 2014; 19: 121–126. pmid:24863162
View Article • PubMed/NCBI • Google Scholar

6. Bersano A, Carpo M, Allaria S, Franciotta D, Citterio A, Nobile-Orazio E. Long term disability and social status change after Guillain-Barré syndrome. J Neurol. 2006; 253: 214–218. pmid:16096809
View Article • PubMed/NCBI • Google Scholar

7. Khan F, Pallant JF, Ng L, Bhasker A. Factors associated with long-term functional outcomes and psychological sequelae in Guillain–Barre syndrome. J Neurol. 2010; 257: 2024–2031. pmid:20625757
View Article • PubMed/NCBI • Google Scholar

8. Forsberg A, de Pedro-Cuesta J, Widen-Holmqvist L. Use of healthcare, patient satisfaction and burden of care in Guillain-Barré syndrome. J Rehabil Med. 2006; 38: 230–236. pmid:16801205
View Article • PubMed/NCBI • Google Scholar

9. Darweesh SK, Polinder S, Mulder MJ, Baena CP, van Leeuwen N, Franco OH, et al. Health-related quality of life in Guillain-Barre syndrome patients: a systematic review. J Peripher Nerv Syst. 2014; 19(1): 24–35. pmid:24456426
View Article • PubMed/NCBI • Google Scholar

10. Corbin JM, Strauss A. A nursing model for chronic illness management based upon the Trajectory Framework. Sch Inq Nurs Pract. 1991; 5(3): 155–174. pmid:1763239
View Article • PubMed/NCBI • Google Scholar

11. Taylor SE. Adjustment to Threatening Events: A Theory of Cognitive Adaptation. Am Psychol. 1983; 38(11): 1161–1173. DOI: https://doi.org/http://dx.doi.org/10.1037/0003-066X.38.11.1161
View Article • Google Scholar

12. Tong A, Flemming K, McInnes E, Oliver SA, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Med Res Methodol. 2012; 12: 181. pmid:23185978
View Article • PubMed/NCBI • Google Scholar

13. Curtis F, Laparidou D, Akanuwe J, Ellis-Vowles V, Jackson J, Senevirathna M, et al. Patient experiences and perceptions of Guillain-Barre Syndrome and associated inflammatory neuropathies following discharge from hospital. 2019. PROSPERO 2019 CRD42019122199. Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42019122199
View Article • Google Scholar

14. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol. 2008; 8: 45. pmid:18616818
View Article • PubMed/NCBI • Google Scholar

15. Critical Appraisal Skills Programme. CASP Qualitative Checklist. 2019. [Online] Available at: https://casp-uk.net/casp-tools-checklists/ Accessed: 21/01/2019.

16. *Cooke JF, Orb A. The recovery phase in Guillain-Barre syndrome: moving from dependency to independence. Rehabil Nurs. 2003; 28(4): 105–108. pmid:12875142
View Article • PubMed/NCBI • Google Scholar

17. *Forsberg A, Ahlstrom G, Holmqvist LW. Falling ill with Guillain-Barre syndrome: patients' experiences during the initial phase. Scand J Caring Sci. 2008; 22(2): 220–226. pmid:18489692
View Article • PubMed/NCBI • Google Scholar

18. *Forsberg A, Widen-Holmqvist L, Ahlstrom G. Balancing everyday life two years after falling ill with Guillain-Barre syndrome: a qualitative study. Clin Rehabil. 2015; 29(6): 601–610. pmid:25200880
View Article • PubMed/NCBI • Google Scholar

19. *Royal E, Reynolds FA, Houlden H. What are the experiences of adults returning to work following recovery from Guillain-Barre syndrome? An interpretative phenomenological analysis. Disabil Rehabil. 2009; 31(22): 1817–1827. pmid:19479500
View Article • PubMed/NCBI • Google Scholar

20. *Hooks JD. Understanding the patient's recalled experience of an acute episode of Guillain-Barre syndrome: a qualitative descriptive study (Unpublished doctoral dissertation). 2015. University of Kansas, Kansas, USA.

21. Dubey D, Kapotic M, Freeman M, Sawhney A, Rojas JC, Warnack W, et al. Factors contributing to delay in diagnosis of Guillain-Barré syndrome and impact on clinical outcome. Muscle Nerve. 2015; 53: 384–387. pmid:26185107
View Article • PubMed/NCBI • Google Scholar

22. Uprichard E, Martin A, Evans S. Guillain-Barré syndrome- patients' and nurses' perspectives. Intensive Care Nursing. 1987; 2: 123–134. pmid:3643954
View Article • PubMed/NCBI • Google Scholar

23. Weiss H, Rastan V, Mullges W, Wagner RF, Toyka KV. Psychotic Symptoms and Emotional Distress in Patients with Guillain-Barré Syndrome. Eur Neurol. 2002; 47: 74–78. pmid:11844894
View Article • PubMed/NCBI • Google Scholar

24. Christensen ER, Golden SL, Gesell SB. Perceived Benefits of Peer Support Groups for Stroke Survivors and Caregivers in Rural North Carolina. N C Med J. 2019; 80(3): 143–148. pmid:31072940
View Article • PubMed/NCBI • Google Scholar

25. Kessler D, Egan M, Kubina LA. Peer support for stroke survivors: a case study. BMC Health Serv Res. 2014; 14:256. pmid:24935460
View Article • PubMed/NCBI • Google Scholar

26. Netto AB, Taly AB, Baburao Kulkarni G, Rao UGS, Rao S. Mortality in mechanically ventilated patients of Guillain-Barré Syndrome. Ann Indian Acad Neurol. 2011; 14(4): 262–266. pmid:22346014
View Article • PubMed/NCBI • Google Scholar

27. A Booth (personal communication, April 28, 2020).