

Physiotherapy and Guillain–Barré syndrome: results of a national survey

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Abstract

Objective To discover the extent to which persons with Guillain–Barré syndrome receive treatment by a physiotherapist (as inpatients and outpatients), and to assess whether the amount of treatment received is related to outcome.

Design Survey method using self-administered questionnaires distributed through a national database.

Participants Members of the Guillain–Barré Syndrome Support Group ($n = 1535$).

Main outcome measures General patient data, general mobility, *F*-score, Hospital Anxiety and Depression Scale, Short Form-36 and Fatigue Severity Scale.

Results In total, 884/1535 (58%) complete responses were received. Nearly 10% of respondents had not received treatment by a physiotherapist in hospital despite their average functional level being the same as respondents who had received treatment in hospital. One-quarter of respondents said that they had not received treatment following hospital discharge despite the identification of relatively high levels of disability. Those who did not receive treatment by a physiotherapist following discharge were less severely disabled. This may indicate that physiotherapists tend to offer treatment to more severely disabled patients. The majority of patients reported disabling fatigue; whilst not statistically related to receipt of treatment by a physiotherapist, this highlights the importance of assessing fatigue in treatment plans to improve physical functioning.

Conclusion Improvements to policy and practice can be made by widening inpatient accessibility to treatment by a physiotherapist and increasing outpatient provision of treatment for patients with Guillain–Barré syndrome of all degrees of severity.

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Background

Guillain–Barré syndrome (GBS) remains the largest single cause of acute neuromuscular paralysis in most countries [1]. Incidence rates of 1.18–2 per 100,000 population have been reported [1–5], and these are relatively constant worldwide [2,4]. Men are affected twice as often as women [2,6,7], and there appears to be a bimodal distribution for age with two peaks: one in children and another in the elderly [1,8].

Mortality in GBS is estimated to be as high as 15% [9], and 20% are left with persistent and significant disability [9]. Two-thirds of GBS patients achieve good physical recovery [2,4,10–12], and approximately 40% of patients are referred for rehabilitation [6,13]. Interventions in the acute phase

include respiratory care, passive movements, positioning, splinting [14] and even gentle progressive strengthening exercises [6]; in the postacute phase, more intensive strengthening and functional activities may occur [14].

Studies investigating the effect of rehabilitation interventions have been few in number and have had small sample sizes [12,15–19]. No comprehensive and systematic studies have been conducted to assess the efficacy of treatment by a physiotherapist in GBS [6], but small-scale studies considering the effect of physiotherapeutic interventions have indicated positive outcomes in terms of strength [12], endurance [12,17], gait quality and function [15,16], and fatigue [12]. However, no studies have shown a definitive positive effect; consequently, efficacy remains unclear [6].

Treatment by a physiotherapist in GBS is not evidence based and appears to be applied with experience gained from

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other diseases [7]. Modalities employed reflect individual experience and institutional practice [9,19]. Despite this, it is suggested that physiotherapy referrals should be made in the early stages of GBS [19], implying that although physiotherapy interventions remain unproven [14], their application appears to be logical and appropriate.

This study sought to discover the extent to which a nationwide population of postacute GBS patients had access to treatment by a physiotherapist, and to assess relationships between those who received formal physical treatment and those who did not in terms of current and past disability.

Method

Data collection

Questionnaires were distributed to 1535 members of the GBS Support Group in January 2007. The five sections of the questionnaire were: general information, physical condition, anxiety and depression, general health and fatigue. General information was related to personal statistics (e.g. age, time since diagnosis and details of hospital admission). Physical condition was concerned with physical state at the time of completing the questionnaire and during the period of illness, such as mobility on discharge from hospital, whether or not the patient had received treatment by a physiotherapist, and information about the patient's occupation before and after their illness. Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale [20], general health was assessed using Short Form-36 (SF-36) [21], and fatigue was assessed using the Fatigue Severity Scale (FSS) [22,23].

Although questionnaires were sent to all members of the GBS Support Group, the target group was members who had had GBS and its variants but not those who had chronic inflammatory demyelinating polyradiculoneuropathy (CIDP). A covering letter asked those with CIDP not to answer the questionnaire as there was no way of screening out CIDP sufferers from the database. Ethical approval for the study was obtained from the local university ethics committee.

Good outcome in GBS

Good recovery in GBS is commonly defined as an *F*-score [24] of 0 (healthy) or 1 (minor symptoms or signs, able to run) [10]. The *F*-score is a 7-point ordinal scale describing functional level (Table 1). Moderate recovery is classed as an *F*-score of 2 (able to walk more than 5 metres without assistance but unable to run), and a higher score reflects severe neurological damage [10].

Although criticised [6,11], the *F*-score is reliable, easy to use and widely applied in studies of GBS [25], the majority of which concentrate on pharmaceutical interventions such as intravenous immunoglobulins, plasma exchange and steroids [24,26,27].

Table 1

Physical functioning of patients with Guillain–Barré syndrome (*F*-score) [24].

0 – Healthy
1 – Minor symptoms or signs, able to run
2 – Able to walk more than 5 metres without assistance but unable to run
3 – Able to walk more than 5 metres with assistance
4 – Bed or chair bound
5 – Requiring assisted ventilation for at least part of the day
6 – Dead

Data analysis

The distribution of interval and ratio data were assessed using the Kolmogorov–Smirnov test and found to be non-normal. As such, all continuous and ordinal data were assessed using the Mann–Whitney *U*-test, and categorical data were assessed using Pearson's Chi-square test (χ^2). Central tendency was assessed using the median, and spread was assessed using the interquartile range (IQR).

Results

A response rate of 58% yielded 884 replies. No reminders were sent but a notice was posted on the GBS Support Group website inviting members to respond. The final questionnaire was returned in January 2008. In total, 742 eligible questionnaires were completed and analysed.

Forty-nine percent (366/742) of the cohort were male, and the median age of the total cohort was 66 years (IQR 56–74). The median time since diagnosis was 7 years (IQR 3–12.5), and the average reported length of stay in hospital was 63 days (IQR 28–119). Three hundred and forty respondents (46%) spent time in intensive care; for this group, the average reported length of stay in the intensive care unit was 21 days (IQR 8.5–43.5). Of 714 respondents admitted to hospital, 270 (37%) required assisted ventilation. The total cohort reported a median *F*-score of 5 (IQR 5–6) at worst and a current *F*-score of 3 (IQR 1–3). The median value of the difference between the *F*-score at worst and at best was 3 points.

Mobility

Five hundred and one respondents (68%) said that they had not regained their previous level of mobility. Fig. 1 shows the changes in mobilisation methods between the point of leaving hospital and the time of completing the questionnaire.

After discharge, patients used a variety of mobilisation methods; at the time of completing the questionnaire, the method of mobility was more likely to involve walking independently or with a stick. This demonstrates the general restorative nature of the condition, and that considerable improvement continues after discharge.

Physiotherapy

Seven hundred and twenty-seven respondents answered the question: 'During your stay in hospital, did you receive

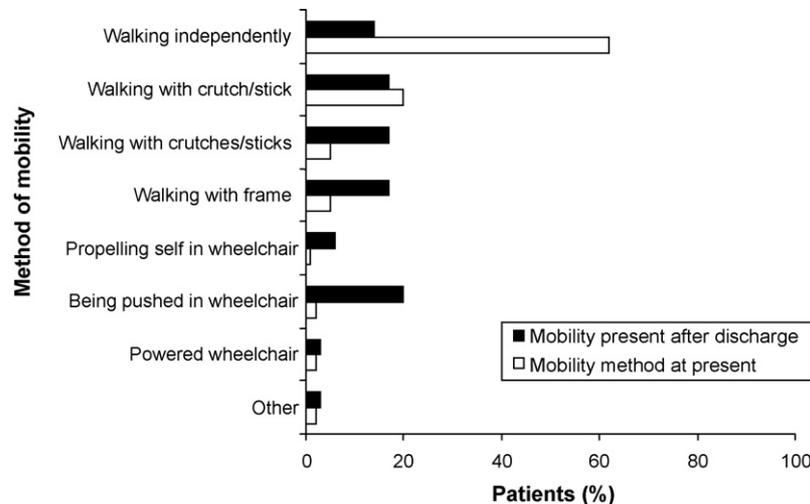


Fig. 1. Changes in method of mobility since hospital discharge.

physiotherapy?' Sixty-eight of these 727 respondents (9%) indicated that they did not receive treatment by a physiotherapist, two respondents could not remember, and 657 respondents (90%) indicated that they did receive treatment. The number receiving treatment after leaving hospital dropped to 75% (556/742); 387 (52%) received their treatment as an outpatient, and 88 (12%) had their treatment at home. The rest were a combination of outpatient and domiciliary patients, with only a few having other, less conventional locations for treatment.

Forty-one (6%) respondents said that they did not receive treatment by a physiotherapist as an inpatient or outpatient. Their median physical condition at worst was 5 (IQR 5–6) and at the time of completing the questionnaire was 2 (IQR 1–3). The median value of the difference between the *F*-score at worst and at best was 2; 1 point less than that for the total cohort.

Table 2 presents *F*-score data at worst with the frequency of those who did and did not receive treatment by a physiotherapist as an inpatient. Many patients who did not receive treatment as an inpatient had considerable levels of disability. The median value was 5 (IQR 5–6) for both groups.

Table 3 shows that those who did not receive treatment by a physiotherapist had comparable ranges of disability as those who did receive treatment following discharge. Considering the top three methods of mobility, walking with crutches or two sticks was the main method for both groups. However, for those in receipt of treatment, less independent methods were reported [being pushed in a wheelchair (23%) and walking with a frame (21%)] compared with patients who did not receive treatment [walking with stick/single crutch (25%) and walking independently (32%)].

Using the Mann–Whitney *U*-test, an assessment was made of the difference between those who received treatment by a physiotherapist after discharge and those who did not in terms of their present *F*-score. The statistical analysis indicated that those who did not receive treatment after discharge from hospital had a lower *F*-score at the time of completing the questionnaire than those who did receive treatment [median values of 3 and 2 (IQR 2–3 and 1–3, respectively) for those who received treatment and those who did not receive treatment, respectively ($P = 0.023$, $z = -2.277$)]. In order to triangulate this finding statistically, an assessment was made between those who did and did not receive treatment on discharge from hospital against those who

Table 2
Comparison of patients who received/did not receive inpatient treatment by a physiotherapist against their physical functioning at worst ($n = 725$).

	Received treatment as an inpatient $n = 657$ (%)	Did not receive treatment as an inpatient $n = 68$ (%)
0 – Healthy	2	0
1 – Minor symptoms or signs, able to run	1	1 (2)
2 – Able to walk more than 5 metres without assistance but unable to run	6 (1)	7 (10)
3 – Able to walk more than 5 metres with assistance	22 (3)	10 (15)
4 – Bed or chair bound	375 (57)	35 (52)
5 – Requiring assisted ventilation for at least part of the day	183 (28)	6 (9)
Missing	68 (10)	9 (13)
Total	657	68

Table 3

Comparison of patients who received/did not receive treatment by a physiotherapist against their method of mobility after discharge ($n = 711$).

	Had treatment after discharge $n = 556$ (%)	Had no treatment after discharge $n = 155$ (%)
Walking independently without any walking aids	49 (9)	49 (32)
Walking with a stick (or single crutch)	87 (16)	39 (25)
Walking with crutches (or two sticks)	95 (17)	25 (16)
Walking with a frame	115 (21)	16 (10)
Propelling yourself in a wheelchair	41 (7)	4 (3)
Being pushed in a wheelchair	130 (23)	14 (9)
Powered wheelchair	23 (4)	1
Other	14 (3)	4 (3)
Missing	2	3 (2)
Total	556	155

Table 4

Comparison of patients who received treatment by a physiotherapist with those who did not receive treatment following hospital discharge.

Scale	Median scores (IQR): treatment received	Median scores (IQR): treatment not received	Mann–Whitney U (z value)
HADS (score range 0 to 21)			
Anxiety	6 (3 to 10)	7 (3 to 10)	0.99 (−0.016)
Depression	5 (2 to 8)	5 (2 to 8)	0.33 (−0.98)
SF-36 (0 to 100)			
SF-36: physical function	50 (20 to 80)	65 (30 to 90)	0.002 (−3.04) ^b
SF-36: role limitation (physical)	25 (0 to 100)	50 (0 to 100)	0.31 (−1.01)
SF-36: role limitation (mental)	100 (0 to 100)	100 (33 to 100)	0.42 (−0.81)
SF-36: social function	78 (44 to 89)	78 (56 to 89)	0.22 (−1.23)
SF-36: mental health	75 (56 to 88)	72 (56 to 92)	0.62 (−0.50)
SF-36: energy and vitality	45 (25 to 60)	50 (30 to 65)	0.2 (−1.3)
SF-36: pain	67 (44 to 89)	67 (44 to 100)	0.2 (−1.28)
SF-36: health perceptions	55 (32 to 72)	52 (35 to 77)	0.56 (−0.6)
SF-36: change in health	50 (50 to 50)	50 (50 to 50)	0.7 (−0.39)
FSS (0 to 7)			
FSS	5 (4 to 7)	5 (4 to 6)	0.039 (−2.07) ^a

IQR, interquartile range; HADS, Hospital Anxiety and Depression Scale; SF-35, Short Form-36; FSS, Fatigue Severity Scale.

said that they had not recovered their previous level of mobility. This was done using the χ^2 test and relative risk ratios.

The risk ratio was calculated between the proportion of those who received treatment by a physiotherapist without regaining their previous level of mobility ($n = 396$, 72%) and those who did not receive treatment but who regained their previous level of mobility ($n = 85$, 55.6%). The risk ratio equalled 1.3, meaning that a patient who did not receive treatment was 1.3 times more likely to regain their previous level of mobility compared with a patient who did receive treatment.

Respondents who received treatment by a physiotherapist after discharge ($n = 556$) were asked how much treatment they received in the period after leaving hospital. The average amount of time was two 1-hour sessions per week for a period of 10 weeks. Total time received by respondents was calculated as the average of: treatment time per week \times (number of sessions \times number of weeks). The median time that each respondent received in treatment after discharge was 12 hours (IQR 5–36 hours). There was no significant difference in the amount of treatment time between the genders ($P = 0.83$, $z = -0.22$), and there was no association between age and

the amount of treatment received (Spearman's rho = 0.024, $P = 0.61$).

Table 4 indicates that similar levels of anxiety and depression were found between the two groups. However, in terms of general health, as measured by SF-36, a significant difference was found between the groups for the domain of physical function, with those who received treatment by a physiotherapist having lower levels of function compared with those who did not receive treatment. All other functions within SF-36 were found to be non-significant between the groups.

Fatigue

Severe fatigue was defined as a score of 5 or more on the FSS [12]. In the present study, 410/742 respondents (57%) reported severe fatigue, and 455/742 (61%) said that fatigue was among their three most disabling features. Women were just as fatigued as men ($P = 0.51$, $z = -0.67$), and there was no relationship between age and fatigue (Spearman's rho = 0.04, $P = 0.26$). There was also no relationship between time since diagnosis and FSS score (Spearman's rho = −0.06, $P = 0.13$).

Table 4 shows a significant difference in FSS score between the groups, although the median values are iden-

tical. Although the IQR is narrower for those who did not receive treatment by a physiotherapist, this does not wholly explain the significant difference. For a more sensitive assessment of the differences between the groups, an independent samples *t*-test was conducted; this showed a non-significant result ($P = 0.07$, 95% confidence interval 0.02–0.58) between those who received treatment (mean 5) and those who did not (mean 4.8). Consequently, it would be unsafe to conclude that there is a true significant difference between these two groups.

Discussion

Physical functioning

Changes in the reported *F*-scores reflect the restorative natural history of the condition, since the symptoms of GBS show recovery regardless of whether or not formal rehabilitation in the form of therapies is offered. This is reinforced by the observed improvement among those who did not receive treatment by a physiotherapist. However, it is debatable whether or not the restoration of neurological functioning is sufficient for the return to a level of physical functioning considered acceptable by those affected.

Inpatient treatment

Approximately 10% of respondents said that they did not receive treatment by a physiotherapist as an inpatient. This was a surprising finding, as the importance of physical interventions in the shape of formal therapy is widely accepted in the literature [6,12,14,15,17], to the extent that Hughes *et al.* [9] believe that the significance of the multidisciplinary team (MDT) is as important as immunotherapy. It is difficult to see that there could be a fully functioning MDT without physiotherapy. The absence of treatment by a physiotherapist for 68/742 respondents is noteworthy, particularly as the median *F*-scores at worst for those who received treatment as an inpatient and those who did not were identical at 5 (IQR 5–6, no scores for six patients). Consequently, the level of disability does not appear to be the reason why these patients did not receive treatment.

Postdischarge treatment

Even for those who did not receive treatment by a physiotherapist, considerable levels of disability were reported (Table 3), which may again indicate an unmet need for treatment. The risk ratio analysis and summary *F*-scores show that those who did receive treatment had severe disability and were 1.3 times more likely not to regain their previous level of mobility. Whilst not establishing a causative relationship, this suggests that more severely affected patients received treatment, and the more disabled patients within that group received more treatment time.

This is supported by the assertion made by Carroll *et al.* [13] that many patients are discharged without receiving rehabilitation. They also suggest that since rehabilitation makes a measurable difference, it should be available to all patients with GBS [13]. This notion of treatment by a physiotherapist making a difference could be supported by the findings of the present study, which has shown that whilst the *F*-score in the general cohort improved by 3 points, the *F*-score only improved by 2 points among those who did not receive treatment as either an inpatient or an outpatient. However, this may merely be an artefact of patients who are less severely disabled having less potential for improvement.

It is possible that the failure to offer treatment by a physiotherapist after hospital discharge is a function of resources, or merely a prevailing view that the majority of GBS patients make a good recovery [2,4,19,28], and that improvement will continue following discharge with or without treatment. This continued improvement is seen quite clearly in Fig. 1 which compares mobility at discharge with present mobility. It could be suggested that many discharges in GBS are premature and based on the presumption of an improving natural history and eventual good outcome; this may account for the sharp drop in provision of treatment by a physiotherapist following hospital discharge.

Implications for practice

The definition of good recovery by Bernsen *et al.* [10] using the *F*-score appears to have an arbitrary basis, and can be viewed as a very crude estimate of whether or not the outcome is good. It has been noted by a number of authors [10,12,23] that problems persist even in patients with a good outcome, particularly in relation to fatigue [23,29]. However, substantial improvement can be achieved with physical activity [12] which, in remedial conditions, is usually conducted or directed under the auspices of physiotherapists. Whilst it is clear that physiotherapists, quite understandably, provide more treatment for the more disabled, the opportunity cost of this is to deny treatment to those who are less obviously disabled but who may benefit just as much, or even more, from physiotherapeutic interventions. This is *de facto* rationing. The concern is that many patients with a supposedly good outcome still have severe problems, such as fatigue, which could be assisted by timely intervention.

Fatigue

The majority of respondents reported severe fatigue (410/742, 57%) and stated that fatigue was among their three most disabling symptoms (455/742, 61%). This has been reported as even higher in other studies. For instance, Merckies *et al.* [23], in their study of 113 postacute GBS patients, demonstrated that severe fatigue (defined as FSS scores at

or above the 95th percentile of the control group – equivalent to a score of at least 5 on the FSS) was present in 80% of GBS patients compared with the control group, and was found to be a most disabling symptom, apparently unrelated to strength or sensation. In both studies, no relationship between fatigue and age or time since onset of symptoms was found. There is clearly a potential for physiotherapists to treat fatigue in GBS patients given its prevalence, disabling effect and the evidence of its utility.

For example, Garssen *et al.* [12] demonstrated a statistically significant improvement in FSS scores in a group of 20 GBS and CIDP patients following three-times weekly progressive resistance training on a cycle ergometer for 12 weeks. Improvements were also seen in levels of anxiety, depression and quality of life. Consequently, the failure to offer treatment by a physiotherapist in the postdischarge stage of recovery could either hinder the rate of recovery, or result in untreated fatigue and a poorer outcome regardless of the level of disability.

Limitations of the study

Since recruitment was from a single source, it is not possible to extrapolate the study's findings to the general population of people who have had GBS. Furthermore, whilst the gender split is comparable with previous studies [1,23,30], the average age in previous studies was between 48 and 54 years [2,23,30], compared with 66 years in the present study. Even taking into account the median time since diagnosis, this would still make the average age older than previous cohorts. Use of assisted ventilation in this cohort also suggests that they are a more severely disabled group of patients. It is generally expected that approximately 30% of GBS patients require assisted ventilation [9,11], but in this study, the figure was 37%; this could reflect those most likely to access the support of the GBS Support Group. Consequently, the findings of this study cannot be widely generalised. It can also be proposed that since physiotherapists tend to offer more treatment to more severely disabled patients, the results of the present study, based on a relatively severe group of patients, could be an overestimate of the total amount of physiotherapeutic interventions offered to GBS patients in general. As such, many more people may not have access to rehabilitation and physiotherapy services than reported in this paper. Alternatively, it cannot be assumed that the number of people who received treatment by a physiotherapist is the actual number of people who were offered treatment, as the offer may have been declined. The study is also reliant on patient recall of the number of treatment sessions received and number of days in hospital, and was not verified by other sources such as medical or practitioner records; therefore, respondents may not have recalled these details accurately and the results should be interpreted with caution. However, it could be argued that the suddenness and severity of this condition makes it more likely that memories are maintained in sharp focus.

Conclusion

This national study on GBS found that, overall, there was substantial improvement in physical functioning of patients since diagnosis. This is consistent with the natural history of the condition. However, improvements were far from a return to the pre-GBS level of functioning, and most patients still experienced disability. The majority of patients in this study also reported severe fatigue that has a disabling effect on their life. A good outcome for GBS patients must therefore address fatigue as an important element of physical functioning by assessing fatigue in patients as well as their ability to perform tasks. Surrounding evidence suggests that treatment by a physiotherapist is a beneficial and integral part of an MDT's delivery of rehabilitation. However, treatment is not universally offered during the inpatient stay, despite high levels of disability among patients.

It is suggested that changes in policy and practice should be introduced that recommend minimum provision of rehabilitation following hospital discharge, and that all GBS patients should have access to rehabilitation services as inpatients. Adequately funded trials of physiotherapeutic interventions are also needed in order to assess the efficacy of physical rehabilitation in this condition.

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