

USE OF HEALTHCARE, PATIENT SATISFACTION AND BURDEN OF CARE IN GUILLAIN-BARRÉ SYNDROME

Anette Forsberg, MSc^{1,2}, Jesús de Pedro-Cuesta, PhD^{3,4} and Lotta Widén Holmqvist, PhD^{2,3}

From the ¹Centre for Rehabilitation Research, Örebro, Sweden, ²Division of Physiotherapy, Neurotec Department, ³Division of Neurology, Department of Clinical Neuroscience, Karolinska Institutet, Karolinska University Hospital at Huddinge, Stockholm, Sweden and ⁴Department of Applied Epidemiology, National Centre for Epidemiology, Carlos III Institute of Health, Madrid, Spain

Objective: The aim of this study was to investigate, in an unselected sample of patients with Guillain-Barré syndrome in Sweden, the utilization of healthcare resources, satisfaction with these resources, informal help and the burden of care on family caregivers during the first 2 years after onset.

Subjects: Forty-four patients were enrolled from 8 hospitals, and 42 of them were followed for 2 years.

Methods: Data on the utilization of hospital inpatient and outpatient care, primary care and community-based services were collected via computerized registry information, medical records and a specific protocol. Patient satisfaction and the burden on family caregivers were studied using questionnaires.

Results: Forty-one patients required inpatient hospitalization for a mean of 82 days. Patients with persistent dependency during activities of daily living had significantly longer hospital stays and more days of outpatient rehabilitation. The majority of patients were satisfied with their care, but dissatisfaction was found regarding information and finances. At 2 years after onset, 26% of patients still depended on informal help. The spouses expressed increased concern and responsibility for household and family.

Conclusion: Patients with persistent disability due to Guillain-Barré syndrome were found to have long-term need for services from the healthcare system and informal help.

Key words: health services, patient satisfaction, caregivers, Guillain-Barré syndrome.

J Rehabil Med 2006; 38: 230–236

Correspondence address: Anette Forsberg, Centre for Rehabilitation Research, Box 1613, SE-701 16 Örebro, Sweden. E-mail: anette.forsberg@orebroll.se

Submitted September 22, 2005; accepted January 4, 2006

INTRODUCTION

Guillain-Barré syndrome (GBS) is an inflammatory, demyelinating polyradiculoneuropathy. The early clinical features include progressive muscle weakness and sensory changes (1). The acute onset phase is followed by a plateau phase of 2–4 weeks, before the start of recovery. GBS is characterized by defects in several physiological systems with a variety of clinical symptoms, each with a potential impact on many aspects of function and activity. The treatment strategies for GBS involve immunomodulatory treatment to shorten the acute phase (2)

although the effect on long-term outcome and disability is unclear. Plasma-exchange and intravenous immunoglobulin (IVIg) have been found to have equivalent efficacy in hastening recovery for patients with GBS who require assistance to walk (3). The outcome of GBS was traditionally considered as favourable; however, incomplete recovery with residual signs has been reported in proportion about 50% of patients at 1–2 years after onset (4–7). This partial recovery may be a significant cause of long-term disability. In a prospective study over 2 years, we found that 26% of patients were dependent in aspects of activities of daily living (ADL) and 24% reported a lower frequency of social activities (8). Other follow-up studies have reported disability in 10–30% of patients with GBS at one year after onset of disease (6, 7, 9) and in 16–20% at 2 years (10, 11).

During the course of GBS, hospital care is often required as acute care in the initial phase of the disease and as rehabilitation in the recovery phase. On retrospective data, poor walking ability after one month (6), increased age (12, 13), need of ventilator support (12, 14, 15), autonomic dysfunction (14) and cranial nerve dysfunction (14) were found to increase the duration of inpatient hospital stay. An individual-based approach in prospective studies accounting for disability enhances the possibility of catching the utilization of all health-related services. No study has been found investigating the utilization of healthcare resources, including rehabilitation and outpatient therapy.

Patient satisfaction, a multidimensional concept, includes the elements of subjectivity, expectation and perception (16). Patient satisfaction has been used to measure various outcome aspects of care, and is also of importance in the planning of rehabilitation services. This has not been studied before in patients with GBS.

Patients with long-term disability may require assistance with ADL and social activities from caregivers. In studies on multiple sclerosis, 30% of patients reported that help from a caregiver was needed (17), and in stroke 70% (18). In Sweden, formal caregivers are identified as a community-provided service, and informal caregivers are spouses, other family members or friends. In a study on stroke, informal caregivers were found to experience considerable strain (19). The level, amount of time as well as the psychosocial and physical burden on caregivers has not been studied for GBS. The aim of the present study was

to explore, in an unselected sample of patients with GBS in Sweden, the utilization of healthcare resources, the satisfaction with these healthcare resources, the amount of informal help and the burden of care on spouses during the first 2 years after onset of GBS.

METHODS

Subjects

Eight hospitals in central Sweden took part in this prospective study from April 1998 to December 1999. Patients, above 18 years of age and diagnosed with GBS according to the criteria of Asbury & Cornblath (20), were given written information about the study and asked about participation. Informed consent was obtained from each patient entering the study. Forty-nine patients were initially enrolled in the study. In 2 of these cases, the original diagnosis was revised to chronic inflammatory demyelinating polyradiculoneuropathy, 3 patients suffered from other diseases that prevented follow-up and 2 patients declined further contact during follow-up. Thus, a total of 42 patients (mean age 52 years, 12 patients were over 65 years of age) were followed for 2 years. At the evaluation at one year, a clinical neurologist confirmed the patients' diagnoses, on the basis of medical records. The majority of patients were enrolled at the Karolinska University Hospital at Huddinge (22 patients) and at Solna (5 patients). Fifteen patients were enrolled at 6 other hospitals: Sahlgrenska University Hospital (6 patients), Örebro University Hospital (4 patients), Uppsala University Hospital (2 patients), Borås Hospital (1 patient), Falun Hospital (1 patient), and Västerås Hospital (1 patient).

Measures

The patients were assessed and interviewed – depending on their individual situation – at home or at their local hospital/rehabilitation centre; at 2 weeks, 2 months, 6 months, 1 year and 2 years after GBS onset (4, 8). Evaluations were conducted by 2 trained physical therapists, independently of one another. Demographic characteristics, pre-existing illness, antecedent medical events, the use of immunomodulatory treatments and any use of mechanical ventilation were collected from medical records. Dependency in ADL was investigated via the Katz extended ADL (E-ADL) index (21, 22), retrospectively before GBS onset, and thereafter at all the evaluation time-points. Dependency was categorized as less than full score on the Katz E-ADL Index.

Data on the utilization of hospital inpatient and outpatient care and primary care was obtained for patients recruited at the Karolinska University Hospitals, Huddinge and Solna, via a computerized registry at the Stockholm County Council. For patients recruited at the other 6 hospitals, data was obtained through the perusal of medical records. Data was collected from the 6-month period before the onset of GBS until 2 years after onset.

A specific protocol was used to collect data on community-based services and other health-related resources for the same time-period: technical aids in the areas of mobility, personal care and household management; permits for transportation service for disabled persons; home-help service (personal care, indoor cleaning and washing); community-based day care (for therapeutic and social reasons to the elderly); visits to chiropodist. Data was collected retrospectively for the period prior to the latest evaluation. Supplementary information was obtained from spouses or caregivers. A similar protocol was utilized to collect data in the home environment in Swedish studies of multiple sclerosis and stroke (17, 23).

A patient satisfaction questionnaire used in earlier studies of patients with rheumatoid arthritis (24), stroke (23) and multiple sclerosis (17), was used in a modified version featuring 14 items constructed as statements. The questionnaire is based on the taxonomy by Ware et al. (25). The statements were each linked to different dimensions of care; art of care, technical quality of care, accessibility, finances, availability, continuity and efficacy of care. Answers were given on a Likert scale with 5 response options that were dichotomized in the analysis to 3 options, satisfied/uncertain/dissatisfied. The questionnaire was filled in during the evaluations at 6 months, 1 year and 2 years after GBS onset.

In the questionnaire, the patients also had the opportunity to write comments of their own.

At the evaluations at 6 months, 1 year and 2 years after GBS onset, the patients were asked to nominate their principal informal caregiver and to provide an estimate of the time the informal caregiver spent in helping them with physical tasks of ADL (hours/week).

A study-specific questionnaire on the burden of care was presented to the spouses at the evaluations at 1 year and 2 years. The questionnaire was developed specifically for the present study and the statements were partly adopted from the Sickness Impact Profile (26). It comprised 12 statements regarding responsibility, social and leisure activities and anxiety about the partner's health. The headline in the questionnaire was: "Your spouse has fallen ill with Guillain-Barré syndrome. How has this affected you?". Answers were on a Likert scale with 3 response options: "agree", "partly agree" or "disagree" with the statement. In the analysis the options "agree" and "partly agree" were summarized to "agree". The questionnaire was completed at the time of the evaluation or returned by post.

Statistical analysis

The data was analysed using descriptive statistics. Changes over time regarding the questionnaires were tested with the Wilcoxon signed rank test. Probability values less than 0.05 were considered statistically significant. In part of the analysis, subgroups were formed on the basis of any pre-existing illness or dependency with ADL. Differences between subgroups were tested with the Mann-Whitney test. Approval for the study was obtained through the Regional Ethics Committee of Karolinska Institutet in Stockholm.

RESULTS

The characteristics of the patients at disease onset are presented in Table I. Fatality rate was nil. The choice of immunomodulatory treatment was determined at the participating hospitals. Treatment was administered to 36 patients, starting a median of 6 days (inter-quartile range (IQR) 3–12) from clinical onset. Mechanical ventilation was required in 9 patients, for a median of 20 days (IQR 7–59). Before GBS onset, one patient was dependent with 1 item of personal ADL and another patient was dependent with 1 item of instrumental ADL on the Katz E-ADL Index (21, 22). At 2 years after onset, 11 patients were

Table I. Characteristics of patients with Guillain-Barré syndrome at disease onset ($n=42$)

Variable	Number or value (%)
Age, median (range) (years)	54 (20–80)
Sex, men/women (n)	24/18
Living with spouse (n (%))	28 (67)
Swedish/other nationality (n)	35/7
Basic/higher education (n)	12/30
Working or studying/unemployed (n)	24/3
Retired due to age/due to illness (or on sick leave) (n)	11/4
Dependent with activities of daily living (n (%))	2 (5)
Pre-existing illness, total (n (%))	16 (38)
Cardiovascular disorder (n)	10
Diabetes (n)	5
Musculoskeletal disorder (n)	5
Respiratory disorder (n)	2
Antecedent medical events the 4 weeks before onset (n (%))	30 (71)
Immunomodulatory treatment (n (%))	36 (86)
Mechanical ventilation (n (%))	9 (21)

dependent with ADL; 5 were dependent with items of both personal and instrumental ADL, and 6 only with items of instrumental ADL. All but one of the dependent patients at 2 years had a pre-existing illness. The patients with a persistent dependency with ADL were significantly older ($p=0.03$) than the independent patients, mean age 62 years vs 48 years. Marital status did not change during the study period. One patient had to move due to the residual deficits of GBS.

Utilization of healthcare resources

Data on the use of hospital inpatient and outpatient care and primary care for the patients with GBS are presented in Table II. The mean hospital inpatient stay was 82 days (standard deviation (SD) 99). Rehabilitation accounted for a major part of the healthcare use after GBS; days at rehabilitation department accounted for two-thirds of hospital inpatient days, while visits to a physical therapist accounted for 80% of total number of primary care visits.

Duration of inpatient hospital stay was less than 3 months for 31 patients (74%), 3–6 months for 7 patients (17%) and more than 6 months for 3 patients (7%). These 3 patients were still dependent with personal ADL at 2 years after onset. If days at outpatient rehabilitation centres are combined with visits to physical therapists and occupational therapists, 33 patients (79%) received outpatient rehabilitation/therapy during these 2 years, a mean of 68 days/visits (SD 52). Five further patients received only inpatient rehabilitation. Patients with persistent dependency with ADL had longer inpatient hospital stays ($p=0.001$) and more days of outpatient rehabilitation ($p=0.04$) than the independent patients. In all, a total of 29 patients visited a physician the 6-month-period prior to onset; a mean of 4 visits (SD 5), and during the following 2 years, all patients had visits with a mean of 13 (SD 13). Those patients with a pre-existing illness accounted for more of the visits to physicians, both before onset of GBS and during the following 2-year period, compared with those without a pre-existing illness ($p=0.002$). The levels of healthcare, and the settings in which the patients received their care and rehabilitation, were partly determined by geography; in smaller cities, for example, primary care centres were the main providers of care and rehabilitation.

Other health-related services used during the study mainly consisted of technical aids and permits for health-related transportation (Table III). Before onset of GBS, 4 patients needed technical aids, 2 of them due to recent orthopaedic surgery. At 2 years after onset, 13 patients used technical aids to increase independence in ADL and mobility, 8 of them were above 65 years. The number of technical aids varied both between and within patients over time, and one patient had as many as 13 technical aids at 2 years. Ten patients used community-based service in their home for some period during the study period, which continued for 3 patients (7%) at 2 years after onset. The majority of patients who received treatment

from a chiroprapist during the study period had a pre-existing illness.

Patient satisfaction

Table IV presents data on the number of patients who manifested a need for care, and their satisfaction with the different dimensions of quality of care. One patient declined to answer the questionnaire. Reported patient satisfaction with the different dimensions of care varied at 6 months at between 66% and 98% of patients satisfied with care, and both at 1 year and 2 years between 61% and 100%. Least satisfaction was expressed with the dimensions "Good information" and "Finances" at all points in time. At between 6 months and 2 years, the number of satisfied patients decreased in 8 dimensions, although not significantly. Fifteen (36%) patients stated decreased satisfaction between 6 months and 2 years, while 9 (21%) stated increased satisfaction. Dissatisfaction or uncertainty in one or more dimensions persisted throughout the study period in 22 (52%) patients, 5 of them being in the dependent sub-group. Eleven patients wrote comments in the questionnaire regarding aspects on which they were dissatisfied. Seven patients commented that not enough physical therapy/rehabilitation was provided. Others commented that information of treatment and rehabilitation was poor. Several patients commented that follow-up visits to professionals only came as a result of their own initiatives, and would have preferred this to be scheduled by professionals.

Informal help

At 6 months after GBS onset, 16 patients (38%), all dependent with ADL, required help from an informal caregiver with ADL – personal care, cleaning, gardening, washing or household finances – for a mean of 19 hours/week (SD 41). Seven of them also used community home-help services. All but one of the informal caregivers was a member of the patient's family, and 9 were spouses. At one year, 11 patients (26%) received help for a mean of 25 hours/week (SD 33). Similarly, all but one of the informal caregivers was a member of the patient's family, and 6 were spouses. Four of these patients also used community home-help service. At 2 years, the same 11 patients received help from an informal caregiver, for a mean of 18 hours/week (SD 21). Three of them also used community home-help service.

Burden of care

Twenty-eight patients lived with a spouse, and 19 spouses (68%) answered the study-specific questionnaire (Table V). Answers on the questionnaire did not change significantly between the points in time. Approximately two-thirds of the spouses expressed concern over the patient's health and indicated increased responsibility for household and family. An increased burden of care was evident in the case of the spouses to patients with ADL-dependency as this impact was expressed on all but 2 statements.

Table II. Utilization of inpatient and outpatient hospital services and primary care from the 6 months before onset of Guillain-Barré syndrome (GBS) to 2 years after onset (n=42)

	Total used days/visits											
	0-6 months before GBS			7-24 months			Total 0-24 months			0-24 months		
	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	number of visits	%		
Emergency department (visits)	4	1 (0)	40	1 (1)	5	2 (1)	41	2 (1)	70			
Hospital inpatient care, total (days)	7	8 (6)	41	65 (45)	6	111 (157)	41	82 (99)	3355	100		
Intensive care unit	0		10	25 (17)	0		10	25 (17)	249	7		
Neurology department	0		38	17 (14)	1	4	38	17 (14)	659	20		
Rehabilitation department/centre	0		35	46 (35)	3	217 (169)	35	64 (90)	2255	67		
Other department	7	8 (6)	19	10 (16)	2	6 (4)	20	10 (16)	192	6		
Outpatient rehabilitation (days)	0		7	27 (9)	7	87 (65)	11	72 (57)	787			
Hospital outpatient care, total (visits)	12	5 (7)	32	4 (4)	37	7 (10)	40	10 (13)	387	100		
Physician, neurology	3	2 (1)	27	2 (1)	30	3 (2)	36	4 (3)	132	34		
Physician, rehabilitation	0		6	2 (1)	3	2 (0)	7	2 (2)	15	4		
Physician, other	10	5 (8)	20	4 (5)	20	8 (12)	29	8 (14)	217	56		
Speech therapist	0		1	11	2	6 (6)	2	12 (13)	23	6		
Primary care, total (visits)	24	5 (8)	31	20 (17)	33	34 (33)	36	48 (43)	1720	100		
Physician	22	2 (3)	24	2 (2)	28	4 (4)	32	5 (4)	171	10		
Nurse	8	1 (0)	11	3 (4)	15	4 (5)	19	5 (5)	91	5		
Physical therapist	4	12 (18)	23	20 (12)	23	40 (34)	29	47 (42)	1376	80		
Occupational therapist	1	4	8	6 (11)	4	8 (4)	9	9 (14)	82	5		

DISCUSSION

In this prospective study, we provide a view on GBS in the caring environment. For a majority of the patients, we found a considerable need for healthcare, some elements of dissatisfaction with care and a relevant role of informal care. Patients with GBS require a profound amount of hospital care, rehabilitation and other health-related services.

A limitation to the reliability of the study is that the data rely on different sources of information. The methodology for collecting data – a combination of patient interviews and computerized registries – used in the present study has also been found to be feasible in other Swedish studies (17, 23). We also found that the patients were accurate and precise in the information they provided when we verified their information against available medical records. On that basis, this twin-track method of collecting data was considered reliable. A second limitation is the selection of patients. The selection bias in the material has been discussed elsewhere and considered to be modest (4). The percentages of antecedent events, respiratory failures and fatality rates in the present study were similar to those of other recent prospective studies (6, 9, 11) and our case series was considered representative of patients with GBS seen at hospitals in Sweden.

The Swedish pattern of GBS care is characterized by the use of emergency and inpatient services – 95% of patients – as well as the predominant use of health resources for rehabilitation. Our figures were consistent with a larger population-based Swedish register-study by Jiang et al. (13), which reported a mean inpatient hospital stay of 86 days (SD 210). However, Jiang et al. included long-term care, which in the case of some elderly individuals amounted to more than 400 days. In our study, no patient needed long-term care in a nursing home. Comparing utilization of healthcare resources between countries is difficult, in view of different healthcare and economic reimbursement systems. Generally speaking, there is a lack of population-based data, in that the majority of earlier studies have focused on selected patient material. Zelig et al. (27) reported 24 patients with severe GBS, where 46% required hospitalization for more than 3 months, compared with our unselected material, where 26% had inpatient hospitalization for more than 3 months. Shorter hospital inpatient length of stays has been shown in retrospective studies – 39 days (SD 46) by Sheth et al. (12) and 61 days (SD 56) in a selected material by Meythaler et al. (14). In recent trials examining the efficacy of plasma exchange and IVIg, one study (3) reported similar figures on median time in hospitalization compared with our study (median 55 days, IQR 36–94), while the other study reported slightly lower figures (28).

Rehabilitation, either as inpatient or outpatient care, accounted for the major part of care. This information is not surprising, but stresses the importance of rehabilitation for this patient group. In an earlier study (4), we found about 50% of patients had residual impairment at 2 years. In the present

Table III. Use of other health-related services from the 6 months before onset of Guillain-Barré syndrome (GBS) to 2 years after onset (n=42)

	Before GBS		0–6 months		7–24 months	
	n	Median (range)	n	Median (range)	n	Median (range)
Technical aids (aids per person)	4	3 (1–4)	33	4 (1–14)	20	4 (1–17)
Permit for health-related transportation	1		27		16	
Home-help service	0		9		4	
Help from salaried personal assistants	0		0		1	
Community day care (visits)	0		1	16	2	17 (17–18)
Chiroprapist (visits)	3	1 (1–2)	9	1 (1–3)	7	2 (1–6)

study, a subgroup of patients with long-term ADL-dependency needed prolonged hospital stays and rehabilitation periods. This rather high figure indicates a need for continuous physical therapy to maintain level of function and reduce disability, a need also expressed by several patients. Surprisingly, only 5% of primary care visits were for occupational therapy. Since 26% of the patients were ADL-dependent at 2 years, more task-specific training aimed at ADL-activities might be helpful. Our findings suggest that there is probably a larger need for rehabilitation than what is provided by the healthcare society in Sweden.

The majority of patients in this study were satisfied with their care. The level of patient satisfaction on this study was comparable with a Swedish study on stroke (23). Lower patient satisfaction was reported in a study on MS (17), perhaps because of the unpredictable and progressive course of that disease. Dissatisfaction mainly concerned information and finances, and there were similar findings in the stroke study on costs of care, and the MS study on information and accessibility to care. Satisfaction with care, however, may depend on the patient's expectations (16). In GBS, the patients may have expectations of a favourable outcome, even though it can be difficult to predict the long-term outcome for an individual patient. Twenty-eight patients were dissatisfied in

one or more dimension at 2 years after onset, and of whom 64% had a residual disability due to GBS. Dissatisfaction with the amount of exercise therapy, seen here, constitutes a frequent finding in other studies on neurological diseases (17, 23, 29). Dissatisfaction with the disease-specific information, might correspond with a lack of provision of verbal and written information during hospital stay and follow-up visits.

The subgroup of patients with older age and/or pre-existing illness and persistent ADL-dependency had a larger utilization of all healthcare. A plausible explanation is that the combination of pre-morbid factors and the impact of GBS cause dependency and increased need for healthcare. The dependent subgroup had an increased utilization of health-related services, including chiropody. Residual sensory and motor impairment often affects overall function, this combined with diabetes and cardio-vascular disorder, may explain the use of chiropody and duration of hospital stay. In follow-up studies on stroke, 30–50% of patients visited a chiroprapist (18, 30).

The proportion of patients, 26%, still receiving help from an informal caregiver 1–2 years after onset, was surprisingly high. Compared with the studies using the same methodology, in MS about 20% of sufferers had informal help from others (17) and in stroke 56%, but both studies presented less hours per week.

Table IV. Satisfaction in patients with Guillain-Barré syndrome (n=41*)

Dimensions and related matters	6 months		1 year		2 years	
	Manifested need	Satisfied/uncertain/dissatisfied	Manifested need	Satisfied/uncertain/dissatisfied	Manifested need	Satisfied/uncertain/dissatisfied
Art of care						
Sympathy from staff		37/4/0		39/2/0		37/3/1
Kind treatment		38/3/0		39/2/0		39/2/0
Technical quality of care						
Good information		29/5/7		30/6/5		25/6/10
Training tailored to condition		35/4/2		36/1/4		35/1/5
Technical aids	23	22/1/0	18	18/0/0	16	16/0/0
Workplace adaptation	1	0/1/0	0		0	
Home adaptation	16	14/2/0	12	11/0/1	11	10/0/1
Health-related transport	27	25/0/2	17	15/1/1	16	13/1/2
Accessibility, easy to get in contact		34/4/3		35/4/2		32/5/4
Finances, cost of care		27/7/7		25/10/6		25/9/7
Availability						
Contact with expertise		35/4/2		36/3/2		32/6/3
Adequate amount of training		38/1/2		38/0/3		36/3/2
Continuity, meeting same staff		40/1/0		39/0/2		39/1/1
Efficacy, satisfied with received care		39/1/1		39/1/1		36/3/2

*One patient declined to answer.

Table V. Burden of care on spouses of patients with Guillain-Barré syndrome 1 year and 2 years after onset, respectively (n = 19)

Statements in the study-specific questionnaire	1 year Agree/disagree (n)	2 years Agree/disagree (n)
I have to help my spouse with transfers and body care	5/14	4/15
I pay more attention to the needs of my spouse	13/6	14/5
I express concern over the health of my spouse	15/4	13/6
I take more responsibility for household chores now	12/7	9/10
I take more responsibility for the family	13/6	12/7
I have cut down on the time spent visiting friends and relatives	9/10	8/11
I spend less time on social and community activities now	9/10	7/12
My choice of leisure activities has changed	7/12	10/9
I spend less time on hobbies and recreational activities now	8/11	8/11
I get sudden frights	7/12	9/10
I have difficulty with activities involving concentration and thinking	7/12	5/14
I lie down more often during the day in order to rest	4/15	4/15

In the acute phase of GBS, the uncertainty about the course of the disease may cause distress and anxiety to family and relatives. During the recovery phase, there may be apprehension regarding the outcome and level of disability. Answers on the spouses' questionnaire reflect this persistence of concern and sense of responsibility. This burden might be relieved by routinely provided information, psychosocial support and increased services from the community.

In conclusion, this study describes use of health resources by patients with GBS in Sweden, as well as dissatisfaction with the costs of care and lack of disease-specific information. Informal caregivers play an important role in enabling GBS patients to still maintain independent living 2 years after onset.

ACKNOWLEDGEMENTS

This study was supported by grants from the Swedish Association of Neurologically Disabled, the Board of Research for Health and Caring Sciences, Karolinska Institutet, the Research Committee of Örebro County Council and the Swedish Association of Registered Physiotherapists.

REFERENCES

- Ropper AH. The Guillain-Barré syndrome. *N Engl J Med* 1992; 326: 1130–1136.
- Hughes RA, Wijdicks EF, Barohn R, Benson E, Cornblath DR, Hahn AF, et al. Practice parameter: immunotherapy for Guillain-Barré syndrome: report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology* 2003; 61: 736–740.
- Plasma Exchange/Sandoglobulin Guillain-Barré Syndrome Trial Group. Randomised trial of plasma exchange, intravenous immunoglobulin, and combined treatments in Guillain-Barré syndrome. *Lancet* 1997; 349: 225–230.
- Forsberg A, Press R, Einarsson U, de Pedro-Cuesta J, Widen Holmqvist L. Impairment in Guillain-Barré syndrome during the first 2 years after onset: a prospective study. *J Neurol Sci* 2004; 227: 131–138.
- de la Cour CD, Jakobsen J. Residual neuropathy in long-term population-based follow-up of Guillain-Barré syndrome. *Neurology* 2005; 64: 246–253.
- Cheng Q, Jiang GX, Press R, Andersson M, Ekstedt B, Vrethem M, et al. Clinical epidemiology of Guillain-Barré syndrome in adults in Sweden 1996–97: a prospective study. *Eur J Neurol* 2000; 7: 685–692.
- French Cooperative Group on Plasma Exchange in Guillain-Barré Syndrome. Plasma exchange in Guillain-Barré syndrome: one-year follow-up. *Ann Neurol* 1992; 32: 94–97.
- Forsberg A, Press R, Einarsson U, de Pedro-Cuesta J, Widen Holmqvist L. Disability and health-related quality of life in Guillain-Barré syndrome during the first 2 years after onset: a prospective study. *Clin Rehabil* 2005; 19: 900–909.
- Rees JH, Thompson RD, Smeeton NC, Hughes RA. Epidemiological study of Guillain-Barré syndrome in south east England. *J Neurol Neurosurg Psychiatry* 1998; 64: 74–77.
- The Italian Guillain-Barré Study Group. The prognosis and main prognostic indicators of Guillain-Barré syndrome. A multicentre prospective study of 297 patients. *Brain* 1996; 119: 2053–2061.
- Chio A, Cocito D, Leone M, Giordana MT, Mora G, Mutani R. Guillain-Barré syndrome: a prospective, population-based incidence and outcome survey. *Neurology* 2003; 60: 1146–1150.
- Sheth RD, Riggs JE, Hobbs GR, Gutmann L. Age and Guillain-Barré syndrome severity. *Muscle Nerve* 1996; 19: 375–377.
- Jiang GX, Cheng Q, Ehrnst A, Link H, de Pedro-Cuesta J. Guillain-Barré syndrome in Stockholm County, 1973–1991. *Eur J Epidemiol* 1997; 13: 25–32.
- Meythaler JM, DeVivo MJ, Braswell WC. Rehabilitation outcomes of patients who have developed Guillain-Barre syndrome. *Am J Phys Med Rehabil* 1997; 76: 411–419.
- Jiang GX, de Pedro-Cuesta J, Fredrikson S, Solders G. Guillain-Barre syndrome in south-west Stockholm, 1973–1991, 2. Clinical epidemiology. *Ital J Neurol Sci* 1997; 18: 49–53.
- Mahon PY. An analysis of the concept "patient satisfaction" as it relates to contemporary nursing care. *J Adv Nurs* 1996; 24: 1241–1248.
- Gottberg K, Einarsson U, Fredrikson S, von Koch L, Holmqvist LW. Multiple sclerosis in Stockholm County. A pilot study of utilization of health-care resources, patient satisfaction with care and impact on family caregivers. *Acta Neurol Scand* 2002; 106: 241–247.
- von Koch L, de Pedro-Cuesta J, Kostulas V, Almazan J, Widen Holmqvist L. Randomized controlled trial of rehabilitation at home after stroke: one-year follow-up of patient outcome, resource use and cost. *Cerebrovasc Dis* 2001; 12: 131–138.
- Bugge C, Alexander H, Hagen S. Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. *Stroke* 1999; 30: 1517–1523.
- Asbury AK, Cornblath DR. Assessment of current diagnostic criteria for Guillain-Barré syndrome. *Ann Neurol* 1990; 27(suppl): S21–S24.
- Asberg KH, Sonn U. The cumulative structure of personal and instrumental ADL. A study of elderly people in a health service district. *Scand J Rehabil Med* 1989; 21: 171–177.
- Katz S, Ford A, Moskowitz R, Jackson B, Jaffe M. Studies of illness in the aged. The Index of ADL: a standardized measure of biological and psychosocial function. *J Am Med Ass* 1963; 185: 94–99.
- Widen Holmqvist L, von Koch L, de Pedro-Cuesta J. Use of healthcare, impact on family caregivers and patient satisfaction of rehabilitation at home after stroke in southwest Stockholm. *Scand J Rehabil Med* 2000; 32: 173–179.
- Bendtsen P, Bjurulf P. Perceived needs and patient satisfaction in relation to care provided in individuals with rheumatoid arthritis. *Qual Assur Health Care* 1993; 5: 243–253.

25. Ware JE, Jr, Snyder MK, Wright WR, Davies AR. Defining and measuring patient satisfaction with medical care. *Eval Program Plann* 1983; 6: 247–263.
26. Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. *Med Care* 1981; 19: 787–805.
27. Zelig G, Ohry A, Shemesh Y, Bar-On Z, Blumen M, Brooks ME. The rehabilitation of patients with severe Guillain-Barre syndrome. *Paraplegia* 1988; 26: 250–254.
28. The French Cooperative Group on Plasma Exchange in Guillain-Barré Syndrome. Appropriate number of plasma exchanges in Guillain-Barré syndrome. *Ann Neurol* 1997; 41: 298–306.
29. Hagell P, Nordling S, Reimer J, Grabowski M, Persson U. Resource use and costs in a Swedish cohort of patients with Parkinson's disease. *Mov Disord* 2002; 17: 1213–1220.
30. Wilkinson PR, Wolfe CD, Warburton FG, Rudd AG, Howard RS, Ross-Russell RW, et al. A long-term follow-up of stroke patients. *Stroke* 1997; 28: 507–512.