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Full Length Research Paper

Rehabilitation for Guillain Barre syndrome: Analysis of the Australian rehabilitation outcomes dataset

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To examine the outcomes of inpatient rehabilitation for Guillain Barre Syndrome (GBS) survivors using the Australian Rehabilitation Outcomes Centre (AROC) database. De-identified data from the AROC database was analysed for all rehabilitation admissions during 2003 - 2008, using 4 classes for functional level. The outcomes included: Functional Independence Measure (FIM) scores and FIM efficiency, hospital length of stay (LOS) and discharge destination. Of 577 case episodes 58% were male, mean age 56.7 years, 91% were discharged to the community and 64.8% (n = 374) were in the lowest functional classes (217, 218 and 219). The majority of GBS survivors were treated in the public hospital system (434 versus 143), and had a slightly longer LOS compared with patients treated in private facilities (30 versus 24 days, p 0.004). The FIM for all classes (216 - 219) showed significant functional improvement during the admission (p < 0.000). As expected those in the most functionally impaired classes showed most change (FIM change: 10 in class 216, 37 in class 219). FIM efficiency was highest in classes 217 and 218. The year -to -year trend was towards reducing hospital LOS however this was not significant (p = 0.721). The AROC dataset is a valuable research tool for describing rehabilitation outcomes. However more specific information needs to be collected alongside the core AROC data to allow more meaningful evaluation of outcomes for GBS rehabilitation.

Key words: Australian rehabilitation outcomes centre dataset, rehabilitation, outcomes, measurement, function, hospital length of stay, Guillain Barre syndrome.

INTRODUCTION

Guillain Barre syndrome (GBS) is an acute demyelinating polyneuropathy due to immune based inflammation of peripheral nerves and nerve roots, and presents as an evolving sensorimotor ascending paralysis and often central dysautonomia (Zochodne, 1994; Ropper et al., 1991; Asbury and Cornblath, 1990). It affects 1 - 2 per 100,000 persons worldwide with no geographical clustering (Hahn, 1998; Hughes and Rees, 1997). GBS affects both sexes (more male prevalence), is common in ages between 30 and 50 years and is a significant cause of disability (Khan and Ng, 2009; Khan, 2004). Although GBS generally has a favourable outcome with 80% of survivors ambulatory (without assistive devices) within 6 months of symptom onset, up to 15% may have residual neurological deficits (Meythaler, 1997). Forsberg et al. (2005) report ongoing impact of GBS at 2 years after onset on the individual's activities of daily living, work and social activity and quality of life (QoL). The impact of GBS on the families, health services and resource utilization, and overall financial costs are unknown (Khan and Ng, 2009; Meythaler, 1997).

There is now a substantial body of evidence to support effectiveness of rehabilitation following neurological conditions such as stroke (Langhorne et al., 2001), acquired brain injury (Turner et al., 2005) and Multiple sclerosis (MS) (Khan et al., 2008; Khan et al., 2007), and the place for rehabilitation in these conditions is well established amongst service planners and providers. Rehabilitation has the potential to reduce the care burden

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both for family (and for society), and associated costs of care by improving independence and autonomy. Despite availability of health service frameworks (National Services Framework, 2005) that promote rehabilitation for persons with long term neurological conditions (LTNC) such as GBS; and clinical guidelines and standards for GBS (Hughes et al., 2005; Asbury and Cornblath, 1990), gaining access to appropriate rehabilitation services continues to be challenging (Khan and Ng, 2009; DeJong, 2005; Khan, 2004; Meythaler, 1997). One reason for this is the relatively poor understanding of the specific benefits that may derive from rehabilitation in the context of this neurological disease.

Although randomized controlled trials are methodologically 'gold standard' for effectiveness of rehabilitation, they cannot answer all the questions that need to be answered (Whyte, 2002). Therefore prospective data collected systematically in the course of routine clinical practice has the potential to provide additional information about GBS survivors that will assist in understanding the nature of services provided as well as the outcomes and service implications. Practice-based evidence (Horn et al., 2005) can be used to address critical questions such as which patients have the most to gain, and what models and intensity of rehabilitation input are likely to be most effective (DeJong et al., 2005).

In Australia, the Australasian rehabilitation outcomes centre (AROC) holds a centralised database, which gathers a standard set of information on both process and outcomes for every person admitted for inpatient (IP) rehabilitation. It has data for over 160 accredited Australian hospitals (public and private) over the last 7 years. It provides a national benchmarking service, as well as providing information to improve understanding of factors that influence rehabilitation outcomes and costs. In a previous analysis (Khan et al., 2009), we described the broad outcomes from rehabilitation in persons with MS. The objective of this study was to examine the AROC database for first episode of IP GBS rehabilitation to understand the nature, outcomes and service implications for GBS survivors in Australia. The primary outcomes include improvement in patient functional status, hospital length of stay (LOS) and discharge destination. In addition the year on year trends in LOS and service efficiency were examined, as well as comparison of outcomes for service provision between the public and private sector. This analysis provides the types of information that can be obtained from such a dataset, and identifies additional information needed to answer the critical questions for rehabilitation in GBS survivors over the coming decade.

METHOD

AROC dataset and ANSNAP classes

AROC was established in 2002 as a joint initiative of the Australasian Rehabilitation sector (providers, payers, regulators and consumers), although development of the dataset started in 1999. The dataset comprises case episode data for admissions for rehabilitation from participating services across Australia (currently > 400,000 episodes of care from 165 rehabilitation units in Australia (90 public and 75 private facilities). The AROC dataset includes 42 items: socio-demographic, medical (impairment codes, co-morbidities, complications), episode items (admission dates), funding and employment details, and outcome data (patient level of function at admission and discharge) (Green and Gordon, 2007; Eager et al., 1997). The proportion of missing data in the AROC dataset items for 2003-08 is available from authors.

The Australian national subacute and non acute patient (ANSNAP) casemix classification system (Eager et al., 1997) was designed for sub and non-acute care, recognizing that such patients should be classified by treatment goals such as improvement in function, rather than by diagnosis and procedure. The case episode data is therefore subdivided based on both diagnosis and functional level, using the Functional Independence Measure (FIM™) (Granger et al., 1990). In 2007 the ANSNAP version II (Green and Gordon, 2007) was implemented to reflect the clinical and demographic profile of patients that receive IP rehabilitation, and included addition of more defined diagnostic classes for the neurological impairment groups (such as GBS) to ensure consistency in the allocation of patients. Similar to other neurological impairments groups the specific ANSNAP II classes for GBS are categorized based on functional level using motor score of the FIM™. These include:

- 2-216 (FIM motor (m) scores range 63 - 91)
- 2-217 (FIM m = 49 - 62)
- 2-218 (FIM m = 18 - 48), and
- 2-219 (FIM m = 14 - 17)

AROC holds a territory licence for use of the FIM™* in Australia and New Zealand and is the national certification and training centre for this tool for all accredited rehabilitation facilities (public and private). Clinical staffs are required to complete FIM training, and must sit a credentialing exam every 2 years. These procedures maximise the quality of data. All data received by AROC are screened for errors and missing data, and if necessary the submitting facility is requested to review and correct any inconsistencies

Data handling and statistical analysis

De-identified data for GBS survivors for first episode of IP rehabilitation during the 6 year period between 2003 and 2008 were extracted from the main AROC database, cleaned and transferred to SPSS version 15 for analysis. Missing and small sample data were excluded from the analysis as indicated in Box 1. Descriptive analysis included the mean and 95% confidence intervals (CI) for demographic, FIM, LOS and discharge destination collated by year, ANSNAP class and sector/provider type. Significant differences were tested by independent samples t-tests and between subjects ANOVA with post hoc pairwise comparisons using Bonferroni adjustments for significant ANOVA results. Given the large sample size, effect sizes (Cohen's d) were calculated for each t-test to provide an indication of the magnitude of each effect.

RESULTS

A total of 577 first episodes for GBS inpatient rehabilitation were submitted to AROC during the study

* FIM™ is a trademark of the Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc.

Table 1. Demographics split by ANSNAP class for GBS survivors for 2003-2008.

	216	217	218	219	Total	P- value
Number of episodes	203	125	226	23	577	
Proportion of episodes	35.2	21.7	39.2	4.0	100.0	
Sector (%)						
Private	27.6	35.2	18.6	4.3	24.8	0.001
Public	72.	64.8	81.4	95.7	75.2	
Gender (%)						
Female	47.3	42.4	37.3	39.1	42.0	0.340
Male	52.7	57.6	62.7	60.9	58.0	
Age years (mean+95%CI)	54.1 (51.7-56.6)	58.4 (55.2-61.6)	58.6 (56.2-60.9)	52.9 (47.0-58.8)	56.7 (55.3-58.2)	0.023
Admission FIM (mean+95%CI	108.2 (107.1-109.4)	88.7(87.7-89.7)	66.1 (64.7-67.6)	48.8 (46.3-51.2)	85.9 (84.1-87.6)	0.000
Discharge FIM (mean+95%CI	119.2 (118.3-120.1)	111.7 (109.4-114.0)	99.1 (95.8-102.3)	86.5 (71.6-101.5)	108.8 (107.1-110.4)	0.000
LOS (mean+95%CI)	16.2 (14.5-17.9)	26.2 (23.1-28.8)	37.9 (34.9-40.9)	60.5 (47.6-73.4)	28.1 (26.4-29.9)	0.000
Discharge destination (%)						
Discharged to community	97.0%	92.0	86.3	73.9	90.9	0.000
Remaining in hospital system	3.0%	8.0	13.7	26.1	9.1	
FIM improvement (mean+95%CI)	10.9 (9.9-12.0)	23.0 (21.0-25.1)	33.0 (30.1-35.8)	37.7 (22.6-52.8)	22.9 (21.3-24.5)	0.000
FIM efficiency (FIM gain/LOS)	0.68	0.89	0.87	0.62	0.81	

GBS, Guillain Barre syndrome; ANSNAP, Australian national subacute and non acute patient casemix classification system; CI, confidence interval; FIM, functional independence measure; LOS, length of stay; FIM, improvement significant at $p < 0.001$.

period (2003 - 2008) and included in the analysis below.

Differences between ANSNAP classes

Patient demographics split by ANSNAP class are provided in Table 1. Approximately 91% (n = 518) were discharged into the community, with only 9% (n = 52) remaining in the hospital system. The majority of admissions 554 (96%) were in the highest functioning three classes (ANSNAP 216,217 and 218), with only 23 (n = 4%) in the very disabled class (ANSNAP 219). However, some interesting patterns emerge:

- Gender: There were more male patients in all ANSNAP classes with more males (>60%) in the lowest functioning classes 218 and 219.
- Public versus private sector: Whilst in each ANSNAP class the majority of cases were treated in the public sector, this trend becomes more pronounced in the lowest functioning two classes (218 and 219).
- LOS increases progressively with loss of function across the 4 classes with a four fold difference between classes 216 (mean 16.2 days) and 219 (mean 60.5 days) (p 0.000).

The ANSNAP classes 216 - 19 all showed significant improvements in FIM scores from admission to discharge (Table 1). FIM improvement differed between the four ANSNAP classes, 219 had the most FIM change compared to class 216 (mean FIM change 37 versus 10) (p 0.000). This is expected as the lower the admission FIM scores the greater is the potential for possible improvement. Those with greater functional impairments were less able to return to their usual accommodation in the community. FIM efficiency was also higher in the middle classes 217 and 218 than in classes 216 and 219, likely due to the floor and ceiling effect of FIM.

The number of cases reported per year increased from 60 in 2003 and 123 in 2008. This is in line with the growth of facilities reporting to AROC over that period. The ratio of episodes per facility did not change substantially between 2003 and 2008. Table 2 shows there were no changes in the number of episodes per facility, ALOS,

Table 2. Year by year changes in case numbers, length of stay, discharge destination, and FIM change and efficiency.

	2003	2004	2005	2006	2007	2008	P value
# episodes	60	82	86	111	115	123	
# facilities	36	39	48	50	56	59	
Admission FIM (mean+95%CI)	82.4 (76.0-88.7)	82.0 (76.7-87.2)	83.3 (78.9-87.8)	88.3 (84.7-92.0)	85.5 (81.4-89.7)	89.9 (86.3-93.5)	0.050
Discharge FIM (Mean+95%CI)	106.3 (100.3-112.3)	103.5 (97.5-109.5)	105.9 (100.9-110.8)	110.4 (107.4-113.3)	112.5 (109.8-115.2)	110.6 (107.2-113.9)	0.018
LOS (mean+95%CI)	29.1 (22.8-35.4)	29.1 (23.7-34.4)	31.0 (26.3-35.8)	27.2 (23.2-31.1)	26.9 (23.2-30.6)	26.9 (23.4-30.4)	0.721
Discharge destination (%)							
Discharge to community	89.8	95.1	88.1	88.0	91.3	92.7	0.523
Remaining in hospital system	10.2	4.9	11.9	12.0	8.7	7.3	
FIM improvement (mean+95%CI)	24.0 (18.8-29.1)	21.5 (17.3-25.7)	22.5 (18.2-26.8)	22.0 (18.4-25.6)	27.0 (23.3-30.6)	20.7 (17.6-23.8)	0.175
FIM efficiency (FIM gain/LOS)	0.82	0.74	0.73	0.81	1.00	0.77	

CI, Confidence Interval; FIM, functional independence measure; LOS, length of stay.

discharge destination, FIM change and efficiency year by year.

Comparison of private and public services

Overall, the LOS was longer for patients treated in the public sector (29.6 days) than the private sector (23.7 days) (t (555) = -2.425, p .004, d = 0.28) (Table 3).

Within each ANSNAP class the LOS was longer for the public sector (Table 4), with the most functionally impaired classes having the greatest difference (4 days in class 218).

However, the FIM change achieved during that longer ALOS was higher (23.8 vs 20.2). The vast majority of patients were discharged to their usual residence in the community, but 10% remained within the public hospital system presumably due to greater complexity of patients treated in the public sector.

DISCUSSION

This is the first report of outcomes of IP rehabilitation (first episode only) for GBS survivors (n = 577) using a national dataset. The aim of this preliminary paper is to describe GBS rehabilitation outcomes including improvement in patient functional status, process measures (LOS, discharge destination) and comparison of these outcomes in public versus private facilities. Following rehabilitation the vast majority of persons with GBS returned to their usual accommodation in the community, however 9% stayed within the hospital setting unable to be discharged home due to greater disease severity. Most GBS survivors were in the higher functioning ANSNAP classes (216-18) with only 4% in the very disabled class (ANSNAP 219). As expected there were more male patients in all ANSNAP classes and more were in the lowest functioning classes. These patients stayed longer in hospital and were overwhelmingly treated within the public sector.

There was increase in the number of rehabilitation centres contributing to the AROC database over the years but there were no significant changes year to year in terms of LOS, discharge destination, FIM change or efficiency. The LOS in public hospitals was longer than private facilities.

Patients in all ANSNAP classes made functional gains, however as expected those in the more disabled classes (ANSNAP 219) improved most (p 0.000). Those in class 219 had a FIM score improvement of 37 compared with 10 for class 216. These gains in function translate into reduction of care needs of approximately 30 - 60 min per day to offset costs of treatment based on reports from a large US database (Granger et al., 1990). Similar to previous AROC reports for persons with MS (Khan et al., 2009), the GBS survivors showed a greater FIM change or improvement in the middle range of dependency (classes 217, 218). In GBS other difficulties include linking of the initial FIM scores to disease

Table 3. Comparison of outcomes for GBS survivors in public and private facilities.

	Public	Private	Mean difference +95%CO	P value	Effect size
# episodes	434	143			
Age (years; mean+95%CI)	55.8 (54.1-57.5)	59.6 (56.8-62.4)	3.8 (0.4-7.2)	0.027	-0.21
Admission FIM (mean+95%CI)	84.4 (82.3-86.5)	90.2 (87.1-93.3)	5.8 (1.8-9.9)	0.005	-0.27
Discharge FIM (mean+95%CI)	108.2 (106.2-110.2)	110.4 (107.5-113.4)	2.2 (-1.6-6.0)	0.257	-0.11
LOS (Mean+95%CI)	29.6 (27.5-31.7)	23.7 (20.7-26.6)	-6.0 (10.0-2.0)	0.004	0.28
Discharge destination (%)					
Discharged to community	89.9	93.7		0.175	
Remaining in hospital system	10.1	6.3			
FIM improvement (mean+95%CI)	23.8 (22.0-25.7)	20.2 (17.4-23.0)	-3.6 (-7.2-0.0)	0.048	
FIM efficiency (FIM gain/LOS)	0.80	0.85			

FIM, functional independence measure; LOS, length of stay.

Table 4. Comparison of hospital length of stay and FIM change across ANSNAP classes for GBS survivors in public and private facilities

	ANSNAP class	Public	Private
FIM admission scores	S2-216	108.3 (107.0-109.6)	108.0 (105.7-110.2)
	S2-217	88.7 (87.4-89.9)	88.7 (87.1-90.3)
	S2-218	65.7 (64.1-67.3)	68.0 (64.7-71.3)
	S2-219	48.7 (46.1-51.3)	0.0 (0.0-0.0)
FIM discharge scores	S2-216	119.5 (118.5-120.5)	118.4 (116.4-120.5)
	S2-217	111.8 (108.8-114.8)	111.6 (108.0-115.2)
	S2-218	99.4 (95.8-103.0)	97.7 (89.7-105.7)
	S2-219	84.8 (69.4-100.2)	0.0 (0.0-0.0)
FIM change score	S2-216	16.8 (14.7-18.9)	14.6 (11.9-17.3)
	S2-217	27.5 (23.6-31.3)	23.3 (19.1-27.4)
	S2-218	38.4 (35.0-41.7)	35.8 (29.0-42.6)
	S2-219	60.4 (46.7-74.1)	0.0 (0.0-0.0)
LOS	S2-216	11.1 (9.9-12.3)	10.5 (8.4-12.5)
	S2-217	23.1 (20.3-25.9)	22.9 (19.8-26.0)
	S2-218	33.7 (30.6-36.9)	29.7 (22.2-37.1)
			0.0 (0.0-0.0)
	S2-219	65.1 (51.4-78.7)	1 episode=62days

ANSNAP Australian National subacute and Non acute patient casemix classification system; CI Confidence Interval; FIM Functional Independence Measure; LOS length of stay.

'nadir' which can peak over a 3 - 6 week period after contracting the illness, and may somewhat blur the ANSNAP class allocation in the initial stages. More detailed description of the FIM motor scores for all ANSNAP classes is beyond the scope of this study and will be presented in a separate report.

As reported previously (Khan et al., 2009), the originators of FIM (uniform data systems) use FIM efficiency as a marker for cost efficiency, benchmarking and outcomes of rehabilitation research. The floor and ceiling effects of the FIM scale, its ordinal nature, and separate motor and cognitive domains scores do not lend themselves to total summation scores nor manipulation such as division by LOS to derive measures for efficiency. Other studies (Turner et al., 2006) show that FIM efficiency does not indicate cost efficiency outside the middle range for more dependant patients. Further information is needed to see if differences reported here

are clinically meaningful for GBS survivors. Other factors impacting outcomes such as the cost implications of GBS care are beyond the scope of this study.

The usefulness of the AROC dataset depends on trained accredited staff and submission of accurate data, which is resource intensive. The year on year data shows reduction in missing data but other data fields have information that is hard to interpret clinically (such as time of onset, disease 'nadir'). Information about patient functional dependency is available, however other information not currently collected includes:

- Duration of ventilation, length of stay in intensive care setting.
- Type of treatment (plasmaphoresis, intravenous gammaglobulin and others).
- Range and severity of neurological impairments.
- Type of treatment provided that is 'black box' (disciplines involved, intensity of treatment, key intervention).
- Outcomes relating to participation and community reintegration (note - the AROC ambulatory dataset has commenced data collection in 2009).

All of the above indicate complexity of need for rehabilitation and expected outcomes. In addition to the AROC dataset, additional disease specific (GBS) datasets can be recorded alongside for a more informative comparison.

The World Health Organization's, International Classification of Functioning and Health (ICF) (WHO, 2001), provides a framework and common language to describe impact of GBS for limitation in activity and participation. Recently we listed patient reported disability following GBS and linked these with the ICF categories to highlight domains considered important by persons with GBS in multidisciplinary care settings (Khan et al., 2009, submitted for publication). In addition we have developed a preliminary Australian 'core' set of ICF categories for GBS survivors (Khan and Pallant, 2009, submitted for publication), using a delphi consensus exercise to facilitate communication and multidisciplinary assessments in subacute settings. In the future these may be used to supplement AROC information for defined rehabilitation outcomes in this population.

Compared with stroke and parkinson disease population (AROC, University of Woollongong NSW, Australia, personal communication), most GBS survivors are young and expected to make a good recovery (Bernson et al., 2002; Meythaler, 1997). However the longer term neurological sequale of GBS and outcomes are not clear. The AROC dataset is a unique resource and a valuable research tool for describing rehabilitation outcomes in 'real life settings'. However more specific GBS information needs to be collected alongside the core AROC data for more meaningful evaluation of outcomes for GBS rehabilitation.

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