

Integrated Neurological Services community rehabilitation contributes to post-acute activities of daily living functional recovery

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Summary

This study aims to evaluate 1) INS' effectiveness at self-measurement so improvements can be made
2) INS' therapeutic efficacy compared to available benchmarks derived from the few RCTs in this area

Introduction

- Integrated Neurological Services (INS) voluntary organisation offers diagnosis-to-grave multidisciplinary rehabilitation to clients with Multiple Sclerosis (MS), Parkinson's Disease (PD), and Acquired Brain Injury (ABI - including stroke & head injury)
- INS needs to demonstrate efficacy of treatment for funding applications and post-acute period (avg. 3 months post-onset) rehabilitation referrals. Difficult to measure as patients have individual disease course plus/minus exacerbating factors
- INS uses the Functional Independence Measure (FIM) to assess client progress in activities of daily living (ADLs). The FIM is validated for this purpose⁽¹⁾. However very few RCTs exist using FIM or other measures⁽²⁾ as issues with ethics of control group where benefit accepted, so post-acute rehab proof of efficacy has small evidence base

Methodology

- Audit of 72 INS client records including progress in FIM and similar assessments. 156 variables for each client evaluated in SPSS^(3,4). 33 clients had acceptable FIM data to include in analysis. No other scales were used with enough consistency
- To yield benchmarks, review of available RCTs through search of COCHRANE⁽⁵⁾ MS Group^(6,7,8), Stroke Group & Acquired Brain Injury Group^(9,10,11,12,13,14), and Parkinson's Disease search^(15,16). NICE guidelines, MEDLINE and PUBMED searches
- Review of Neurological Rehabilitation literature^(2,16,17,18,19) to understand context and assist with self-measurement recommendations for INS

Discussion

- NICE⁽²⁰⁾ recognises that specialist multidisciplinary rehabilitation "has been demonstrated beyond all reasonable doubt" in stroke but we need more studies for post-acute care for other conditions
- Reporting progression including FIM results is challenging as expected progression varies markedly between individuals and also between conditions. Return to previous function is not appropriate for MS and PD patients. Supporting this, an ANOVA on INS data revealed there was a significant effect of neurological condition ($F_{(2,24)} = 3.755, p < .05$) on the difference in FIM results
- After 9 months' treatment, INS reports raised FIM scores in approx 3/4 of ABI, half of PD, and 1/3 of MS patients (see Figure 1) – consistent with expectations of progress for stroke but disproving the myth that no post-acute progress expected in PD or MS
- INS' performance exceeds the benchmark in ABI clients after 6-9 months' rehab, is lower but not far off in MS clients, however is lower in PD clients (see Figure 2). However the RCTs have small sample sizes and the PD benchmark may reflect this
- All results had wide confidence intervals, many spanning unity, reflecting the small sample size (ABI n=19; PD n=9; MS n=5), but no RCTs combined conditions for amalgamated results

Conclusions

- INS data was patchy meaning many individuals excluded from analysis, identifying need for systematic repetition of FIM as ADL measure supplemented with validated QoL and condition-specific instruments. Procedural changes already underway
- This study supports NICE's conclusion that anecdotal evidence suggests positive results at improving function or keeping degeneration at bay but larger sample sizes or more meta-analyses on comparable patients are needed

What INS clients say:

"Regained lost confidence in independence: completing 120 Christmas cards, making sandwiches independently, able to walk short distances independently"

"Benefit from companionship and opportunity to talk"

"Great help in movement, sociable group, daily functions generally easier to do"

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Results

INS clients' 9-month change in FIM score

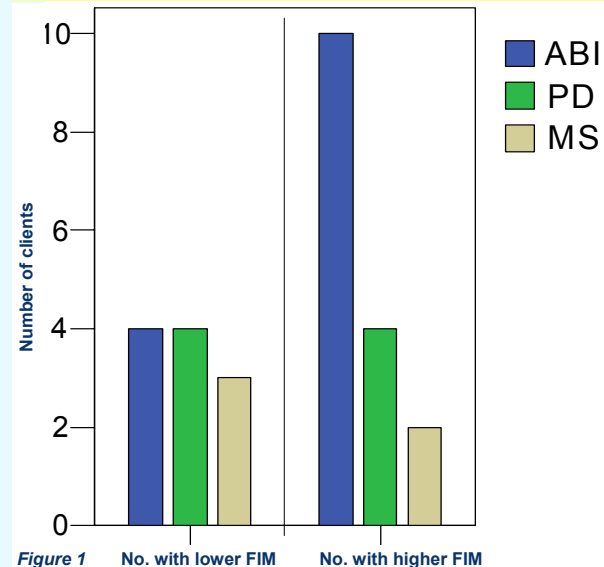


Figure 1 No. with lower FIM No. with higher FIM

INS vs. benchmark mean change in FIM scores

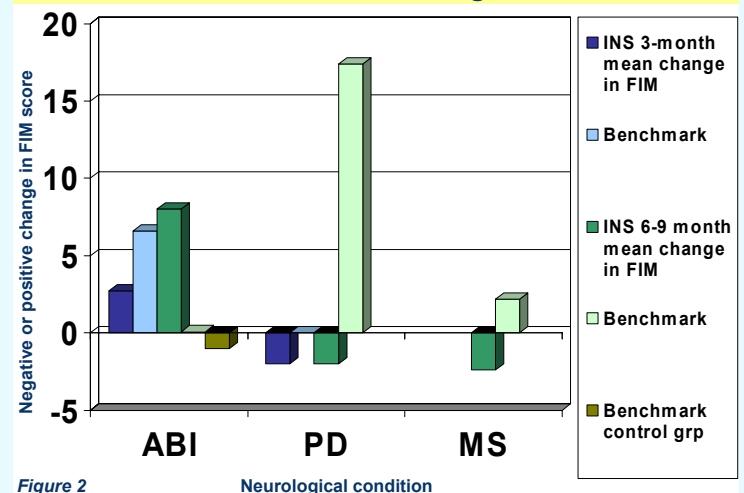


Figure 2 Neurological condition

References

- Greenwood R, Barnes M, McMillan T, Ward CD, editors. Handbook of Neurological Rehabilitation. 2nd ed. East Sussex: Psychology Press; 2003.
- Guillef R, editor. Clinical Trials in Neurology. London: Springer-Verlag; 2001.
- Brace N, Kemp R, Snelgar R. SPSS for Psychologists: A Guide to Data Analysis using SPSS for Windows. London: Palgrave; 2000.
- Field, A. Discovering Statistics using SPSS for Windows. London: Sage; 2002.
- The Cochrane Database of Systematic Reviews. 2001-2005. Available from: <http://www.mnh.int/ericsearch/wiley.com/cochrane/cdsr/articles.htm>
- Freeman J, Langdon D, Hobart J, Thompson A. The impact of inpatient rehabilitation of progressive multiple sclerosis. Ann Neurol. 1997;42:236-44.
- Freeman J, Langdon D, Hobart J, Thompson A. Health-related quality of life in people with multiple sclerosis undergoing inpatient rehabilitation. J Neurol Rehabil. 1996;10:185-94.
- Scian A, Filippini G, Gasco P et al. Physical rehabilitation has a positive effect on disability in multiple sclerosis patients. Neurology. 1999;52:63-70.
- Nielsen L, Carlsson J, Danielsson A, Fugli-Meyer A, Hellstrom K, Kristensen L, et al. Walking training of patients with hemiparesis at an early stage after stroke. Clin Rehabil. 2001;16:515-527.
- Jackson D, Thornton H, Turner-Stokes L. Can patients with complex disabilities regain the ability to walk more than three months after a stroke? Clin Rehabil. 1999;14:538-47.
- Koukolevski A, Yavuzer G, Elhan A, Sonel B, Tennant A. Adaptation of the Functional Independence Measure for use in Turkey. Clin Rehabil. 2001;15:311-319.
- Shel A, Swan JP, Henry D, Clark J, Wilson SA, Burnett MC, et al. The effects of intensive rehabilitation therapy after brain injury: results of a prospective controlled trial. Clin Rehabil. 2001;15(5):501-14.
- Powell J, Hestlin J, Greenwood R. Community based rehabilitation after severe traumatic brain injury: a randomised controlled trial. J Neurol Neurosurg Psychiatry. 2002;73(2):193-202.
- Werner RA, Kessler S. Effectiveness of an intensive outpatient rehabilitation program for poststroke stroke patients. Am J Phys Med Rehabil. 1996;75(2):114-20.
- Perovral R, Hobson P, editors. Parkinson's Disease: Studies in psychological and social care. Leicester: BPS Books; 1999:256-269.
- Palli F, Reggio A, Nicolletti F, Sellaroli T, Dentice G, Nicolletti Fr. Effects of rehabilitation therapy on parkinsonism's disability & functional independence. J Neurol Rehabil. 1996;10(4):223-231.
- Farrington C, editor. Neurological Physiotherapy: Basis of Evidence for Practice. London: Whurr Publishers Ltd; 2002.
- Scolding N, editor. Contemporary treatments in neurology. Oxford: Reed Elsevier; 2001.
- Umphred D. Neurological rehabilitation. 4th ed. St Louis: Mosby; 2001.
- Multiple Sclerosis: National clinical guideline for diagnosis and management in primary and secondary care. London: Royal College of Physicians; 2004. Available from: <http://www.rcophthor.ac.uk/underbooks/NMS/NMS.html>

Measuring the value of INS' services to carers

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Objectives

- To assist INS in measuring the benefits of its services to carers, and
- To aid future planning by identifying new services of value to carers

Summary

This project aims to evaluate the effectiveness of INS' current services to carers, establish the value and benefit of these services and identify new services that INS could offer to carers. A research study was developed with a questionnaire to measure the usefulness of INS' services and their benefit to carers and to gain carers' suggestions for new services.

Introduction

- INS is a charitable organisation providing a range of support services for people with neurological conditions and their carers
- It is important for all service organisations to evaluate their effectiveness
- INS has not previously evaluated their services to carers
- Carers' needs are acknowledged in The Carers and Disabled Children Act 2000, entitling all carers to an assessment of their needs (1)
- Studies have identified the importance of consultation with carers and involving them in the development of services (2)
- Previous research has underlined information, help and advice, advocacy and respite as priority areas where carers need support most (2, 3)

Methodology

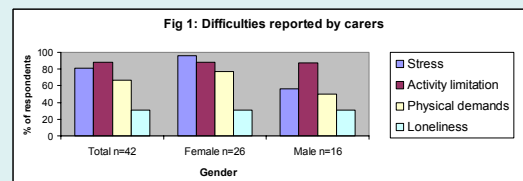
- A questionnaire of 19 questions for self-completion by carers was developed using guidance from Oppenheim (4), and Boynton and Greenhalgh (5)
- The study was refined with INS and was approved by Wandsworth LREC
- The questionnaire was piloted with 3 carers from the population to be studied to ensure that it was fit for purpose
- An information letter, providing details of the study, was produced
- The questionnaire and letter were posted to all 55 carers served by INS, together with an SAE for return
- The results of the study were collated using Excel, analysed and are presented below

Main results of the study

1. Response rate

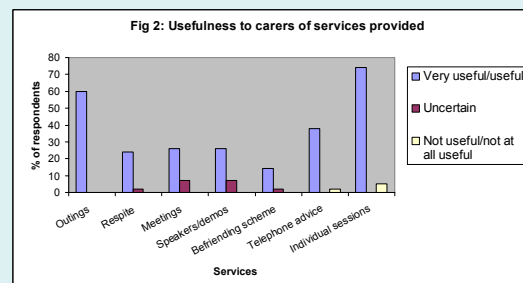
Number of questionnaires issued	Number of questionnaires completed	Overall response rate
55	42	76.36%

2. Difficulties reported by carers



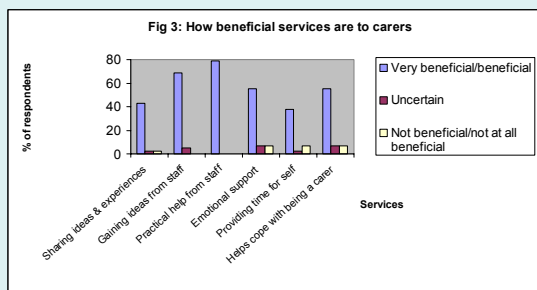
- This chart illustrates the main difficulties reported by carers, in particular stress, limitation of activities and physical demands
- Activity limitation was the difficulty reported by most male carers (87%), whereas large numbers of female carers reported all three
- 31% of respondents of both genders reported loneliness

3. Usefulness of services



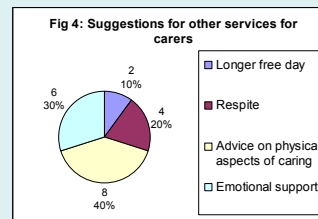
- This chart demonstrates that most carers who responded to this question find INS' current services very useful or useful
- Individual sessions with therapy staff (74%) and outings for clients and carers (60%) were scored most highly by most respondents

4. Benefit of services



- Fig 3 demonstrates that most respondents find INS' services very beneficial/beneficial, with services given by INS staff scoring most highly
- Practical help (79%) and gaining ideas to support their caring role (69%) are the most valued services
- Fewer (38%) respondents scored time for self as very beneficial/beneficial

5. Suggestions for other services for carers



- 18 respondents (43%) made suggestions for other services
- 40% would like emotional support and 30% advice on physical aspects of caring
- 20% and 10% respectively suggested respite and a longer free day for carers

Discussion

- Carers reported a range of psychological, physical and emotional difficulties, in common with studies by other carers' associations (2,3)
- INS is highly valued for its support services by most carers
- Professional services from staff tailored to carers' needs are most highly valued by the largest number of respondents and provide most benefits
- Respite services and the time they give to carers for themselves were seen as less useful and providing less benefit but were also among the suggestions for other services INS could provide

Conclusions & recommendations

- INS provides a valued service to its client base of carers. Its existing services are very useful and they provide significant benefits to carers
- Future services could include specific "themed" events on physical and emotional aspects of caring, perhaps involving outside experts, as well as introductory sessions for new carers and counselling sessions
- More communication of the respite services it offers would raise awareness of these services, and INS could consider expanding this area
- INS could also consider producing a small booklet explaining the services it offers, and information about other organisations supporting carers

References

1. The Carers and Disabled Children Act 2000. [Online] 2000 [cited 2005 July 31]. Available from: <http://www.opsi.gov.uk/acts/acts2000/20000016.htm>
2. Carers speak out project. Princess Royal Trust for Carers [Online] 2002 [cited 2005 July 28]. Available from: <http://www.carers.org/barclays/Findings.pdf>
3. Robinson J, Banks P. The Business of Caring. The Kings' Fund. 2005 [cited 2005 July 28]. Available from: http://www.kingsfund.org.uk/resources/publications/the_business_of_.html
4. Oppenheim AN. Questionnaire design, interviewing and attitude management. London: Pinter Publishers, 1992.
5. Boynton PM, Greenhalgh T. Selecting, designing, and developing your questionnaire. BMJ [Online] 2004 [cited 2005 July 31]; 328:1312-1315. Available from: <http://bmj.bmjournals.com/cgi/content/full/328/7451/1312>

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