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Long-term needs after stroke: an information mapping review

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Background: In 2007, the Stroke Association commissioned a mapping review on the long-term needs of stroke survivors and their carers.

Method: Comprehensive search for research published in the UK between 1996 and 2008 identifying the possible range of needs, the prevalence of need, and extent of unmet need. Research designs were prioritized by relevance and study quality. We also searched for dataset sources of information including population-based national surveys and hospital stroke registers.

Results/findings: The mapping review prioritized 46 studies. Eight studies identified the range of needs. Twenty-nine population-based studies measured need prevalence in mobility and personal care, incontinence,

general health status, risk indicators for secondary prevention, levels of social participation or engagement, vision and swallowing problems, mood disorders, communication problems, cognition problems, levels of institutionalization, need for care or equipment, and carer strain. Nine population-based studies identified the extent of unmet need in mobility and personal care, medical follow-up, secondary prevention treatment, help with speaking difficulties, obtaining aids and adaptations, and for information.

Discussion: Gaps in the information available from UK research on the prevalence of long-term need include extended aspects of everyday living; social needs relating to relationships and sexuality, work, and transport; needs related to personality/behaviour change and coping/adaptation; and information/training needs.

Conclusion: There is a lack of clear focus on the measurement of social factors rather than health states in the literature, and statistical resources including stroke registers cannot currently provide the information required. A minimum dataset of the information to be collated on long-term need is required.

Predicting safety to drive in people with dementia

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Background: Lincoln *et al.*¹ developed a cognitive test battery for predicting safety to drive in people

2 *Proceedings of SRR*

with dementia. We aimed to check the accuracy of this battery and to assess whether it could be improved by shortening it, including additional tests, and including measures of previous driving.

Methods: Cognitive testing included measures of concentration, executive function, visuospatial perception, verbal recognition memory and speed of information processing. Patients were then assessed on the Nottingham Neurological Driving Assessment by an Approved Driving Instructor, blind to the cognitive test results.

Results: Seventy-five patients were recruited and completed the cognitive test battery. Of these, 65 were assessed on the road and ten refused. These 65 participants were aged 59–88 (mean 75.2, SD 6.7) and 50 were men. Most (51.5%) had Alzheimer's dementia, 21.2% vascular and 27.3% other. Thirteen participants were unsafe and 52 safe to drive. Using a cut-off of 5, the original predictive equations correctly classified 79.0% of participants (sensitivity 81.6%; specificity 69.2%; positive predicted value 90.9%; negative predicted value 50.0%). Discriminant function analysis on the current data revealed no improvement in accuracy by including additional tests.

Discussion: In the present study, a lower proportion of participants were found to be unsafe on the road than in previous studies. Despite this, the previously identified equations reliably predicted safety to drive.

Conclusions: We suggest that the cognitive test battery might be used in routine clinical practice for identifying those patients with dementia who would benefit from an on-road assessment.

Reference

- 1 **Lincoln NB, Radford KA, Lee E, Reay AC.** The assessment of fitness to drive in people with dementia. *Int J Geriatr Psychiatry* 2006; **21**: 1044–1051.

Oral health care following stroke – a review of assessments and protocols

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Background: Many stroke-related impairments (including physical, sensory and cognitive difficulties) impact on a patient's ability to conduct independent oral health care. Stroke nurses strive to ensure patients

receive good oral health care but receive little support in providing oral health care to this specialist group. Few have access to oral health care assessment or protocol tools.

Method: We systematically searched electronic databases (MEDLINE, CINAHL) and contacted specialist stroke care settings across Scotland for examples of oral health care assessments and protocols in current use. We then independently appraised the tools identified, extracting data on a number of elements including their relevance to stroke care settings, their evidence base, staff training procedures and piloting arrangements.

Results/findings: We identified 24 different assessment tools (plus six examples from clinical sites) and 20 protocols. The tools varied in their origins, evidence base, description of staff training requirements and relevance to stroke patients and specialist stroke care settings. The components addressed varied across tools but included consideration of the teeth, dentures, soft tissues, lips, saliva, tongue, gums, palates and pain. Few tools addressed all these components. Less than half reported a pilot phase and fewer still were piloted on patients who had suffered a stroke.

Discussion: We failed to identify an oral health assessment or protocol tool specifically designed for the delivery and support of oral health care in specialist stroke care settings.

Conclusion: There is an urgent need for a comprehensive, evidence-based, stroke-specific oral health care assessment and protocol to support nurses to care for stroke patients' oral health.

A randomized controlled trial to evaluate the clinical effect and cost effectiveness of treating upper limb spasticity due to stroke with botulinum toxin: one month results

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Background: Between 55% and 75% of stroke patients experience long-term upper limb problems. Upper limb

spasticity may cause pain, deformity and reduced function, affecting mood and independence. Botulinum toxin is used increasingly to treat focal spasticity, but impact on upper limb function after stroke is unclear.

Method: *Design:* A multicentre randomized controlled trial and economic evaluation. *Participants:* Adults with upper limb spasticity at the shoulder, elbow, wrist or hand and reduced upper limb function due to stroke more than one month previously. *Intervention:* Botulinum toxin plus upper limb therapy programme (intervention group), upper limb therapy programme alone (control group). *Primary objective:* To compare the upper limb function of intervention and control groups one month after study entry. *Primary outcome:* upper limb function measured by the Action Research Arm Test. *Secondary objectives:* To compare upper limb impairment, function, disability and quality of life at 1, 3 and 12 months. The Modified Ashworth Scale, Motricity Index, Grip Strength, Nine Hole Peg Test, Barthel ADL Index and Stroke Impact Scale were used. *Randomization:* Web-based randomization service. Participants stratified according to baseline upper limb function. *Blinding:* Outcome assessments by an assessor blinded to the randomization group.

Results/findings: Pre-defined success on the Action Research Arm Test was achieved by 42 (25.1%) of the intervention group and 30 (19.5%) of the control group ($P=0.232$). Muscle tone (Modified Ashworth Scale) decreased by 1 point in the intervention group and 0 points in the control group ($P<0.001$).

Discussion: Botulinum toxin decreases muscle tone but does not improve upper limb function at one month. Further analysis of the study is on-going.

Caloric vestibular stimulation effects are selective for asymmetrical motor activities in patients with spatial neglect

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Background: Spatial neglect, a relatively common attentional disorder following stroke, has a strong competitive element, best characterized through the related problem of extinction. Extinction refers to a relative failure to perceive a contralesional stimulus when presented with a simultaneous ipsilesional stimulus, and is known to also affect movement (motor extinction).

Caloric vestibular stimulation can improve visuo-spatial and motor functioning in affected patients. This study aimed to investigate the effects of caloric vestibular stimulation on functional movements that require symmetrical versus asymmetrical bilateral activity.

Method: Eighteen patients with either left brain damage ($n=6$), right brain damage without neglect ($n=6$), right brain damage with neglect ($n=6$) underwent caloric vestibular stimulation into the ear contralateral to their lesion side. Postural/balance performance was assessed via the Postural Assessment Scale for Stroke before, immediately after and 1 hour after stimulation. Data were explored using a 3×3 (group \times time) analysis of variance (ANOVA).

Results/findings: Post-stimulation scores demonstrated improved motor scores for participants with spatial neglect ($P<0.05$). Further analysis of Postural Assessment Scale for Stroke scores for this group showed motor improvements were selective for asymmetrical activities ($P<0.05$) with symmetrical activities unchanged ($P=0.6$).

Discussion: The findings confirm the positive effects of caloric vestibular stimulation on neglect-related movement difficulties, perhaps best explained by the induced activation of the right hemisphere. The selective improvement for asymmetrical tasks demonstrates the relative difficulty in modulating activities which demand synchronous activation of the limbs, with important implications for rehabilitation in this group of patients.

Conclusion: Caloric vestibular stimulation is a promising though relatively under-investigated intervention.

Advanced multiple sclerosis and the psychosocial impact on families

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Background: Research literature has paid little attention to the impact of advanced multiple sclerosis on families. Quality requirement 10 of the National Service Framework for Long-Term Conditions implores health care services to support families and carers; this is often overlooked. This study explores the family processes that are involved in adapting to a relative's advanced-stage multiple sclerosis.

4 *Proceedings of SRR*

Method: To gain in-depth personal accounts, a multisite qualitative study using semi-structured interviews of relatives of people with advanced multiple sclerosis in care, or accessing respite, was conducted. A purposive sample of 25 relatives was selected and interviewed at the Royal Hospital for Neuro-disability or participants' homes, by the research psychologist. Interviews were recorded, transcribed and analysed using grounded theory, constant comparison methodology and Atlas.ti.5.2 software. Data quality enhancement and validation checks included: self-report questionnaires, triangulation (memos, reflective diaries, team analysis) and member-checking.

Results/findings: Emerging themes and categories include: roles and carer identity; family relationship changes; multiple sclerosis impact and coping; responsibility and generational shifts; multiple sclerosis diagnosis, information and knowledge; professional and personal support; life outlook and reflection; and clinical implications.

Discussion: The psychosocial impact of multiple sclerosis on family life is pervasive and all-embracing. Provision of support appears to be 'hit and miss', and reactive rather than proactive. Relatives reported that had psychological family support been available, and they were able to accept it, it would have been beneficial.

Conclusion: Relational approaches to long-term care provision are advocated for people with multiple sclerosis and their families. There needs to be a shift from the traditional health care professional 'patient-centred' mindset towards more family-centred approaches.

Explicit information disrupts motor learning after stroke: an attentional hypothesis?

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Background: During stroke rehabilitation, clinicians often provide the patient with verbal (explicit) information (EI) as a means of enhancing their learning. The finding that such information, while helpful for the normal population, may disrupt learning following stroke,¹ is therefore both surprising and provocative. Converging evidence from other fields suggests attention may play a key role in explaining the finding. This study explored the relationship between attention, information and learning.

Method: Thirty-six adults with no known neurological damage performed a version of the serial response time (SRT) task, a classical paradigm used to measure motor learning. Participants were randomly assigned to one of four groups. Attention to task was manipulated using a secondary task (ST) and EI was either provided or not. Accordingly, groups were 'EI/ST', 'EI/No ST', 'No EI/ST' and 'No EI/No ST'. Data were explored via a 2×2 analysis of variance (ANOVA).

Results/findings: Explicit information resulted in enhanced learning ($P < 0.05$) and having a secondary task to perform resulted in reduced learning ($P < 0.05$). Exploring the simple effects of the ANOVA revealed that performing a secondary task in the absence of explicit information had no reliable effect on learning. However, performing a secondary task when explicit information was provided led to a significant reduction in learning ($P < 0.05$).

Discussion: The results suggest that attentional resources are critical in order to benefit from explicit information when learning a task, with potentially important implications for stroke rehabilitation.

Conclusion: Studies exploring learning in stroke populations with and without attentional deficits would be welcomed.

Reference

- 1 Boyd and Winstein, 2003.

Supervised 'interval' exercise training in fibromyalgia patients: a pilot study

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Background: Fibromyalgia is a chronic painful condition characterized by widespread pain, fatigue, muscle stiffness, sleep and mood disturbances, paraesthesia and other less common features. Exercise rehabilitation is a treatment strategy that has recently gained acceptance as a component of the symptom management for this condition. Pain associated with fibromyalgia limits an individual's ability to engage in continuous bouts of physical activity. The aim of this pilot study was to examine the feasibility of an 'interval training' exercise intervention in fibromyalgia patients.

Method: Thirteen female fibromyalgia patients (mean age 46.1 years) were recruited from the Rheumatology Department at the Royal Hallamshire Hospital, Sheffield. Patients attended supervised, short, intermittent aerobic and muscular conditioning exercise sessions for eight weeks.

Results/findings: The exercise training programme evoked significant improvements in overall fibromyalgia-related symptoms as measured by the Fibromyalgia Impact Questionnaire ($n=11$, pre-intervention mean 62.78, SD 16.7 vs. post-intervention mean 43.44, SD 15.5) ($P=0.05$) and cardio-pulmonary function ($n=11$), measured by treadmill walking distance (370.5 m vs. 572.1 m) ($P<0.05$). Focus group analysis revealed further important benefits 'I learnt that I could do exercise without causing harm'; 'I used to seize up, I don't seize up at all now'.

Discussion: Despite having higher than average Fibromyalgia Impact Questionnaire scores at baseline, after a short period of exercise training patients recorded Fibromyalgia Impact Questionnaire scores below average. Further research is needed to understand how to sustain the achieved benefits.

Conclusion: This pilot study demonstrates that a patient-centred, supervised 'interval-type' exercise programme is a feasible and effective way of improving exercise capacity and reducing patient-perceived fibromyalgia symptoms.

Do outpatient physiotherapists involve patients sufficiently in their initial consultation: an observational study

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Background: Little research has been conducted to explore physiotherapists' ability to involve patients in their care. This paper forms part of a larger programme of research examining physiotherapists' attitudes, knowledge and skill at involving patients in physiotherapeutic consultations.

Method: Twenty physiotherapists from three clinical areas (cardiorespiratory, musculoskeletal and neurology) were recorded in their initial consultation with 76 outpatients; approximately four consultations per physiotherapist. The recordings were then assessed using a 36-item Patient Involvement Evaluation rating tool.

Physiotherapists' performance in each item was rated on a 5-point scale from very unsatisfactory to very good.

Results/findings: Physiotherapists were considered to have made a reasonable effort to involve their patients if they accrued satisfactory scores in half of the Patient Involvement Evaluation items. Six physiotherapists met this criterion, of which four specialized in neurology and two in musculoskeletal physiotherapy. The proportion of Patient Involvement Evaluation items that were performed to a satisfactory standard or above, per physiotherapist, varied between 21% and 60%. An ANOVA of total Patient Involvement Evaluation score per consultation suggested that no Hawthorne effect had occurred ($P=0.753$).

Discussion: Physiotherapists' strengths lay in eliciting patients' reasons for attending and in active listening. They were less effective at exploring patients' concerns and inviting patients to ask questions. The use of closed question pro forma appeared to limit patient involvement. Hence, physiotherapists may benefit from training in the use of open questioning techniques and strategies to explore patient concerns.

Conclusion: Physiotherapists could do more to encourage outpatients' involvement in their initial consultation.

A pilot randomized controlled trial of occupational therapy to optimize independence in Parkinson's disease

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Background: Parkinson's disease is a debilitating condition, with 50% of sufferers experiencing limitations in activity. However, access to occupational therapy in the UK can be poor and there is little evidence to support its provision. Therefore we conducted a phase II randomized controlled trial to ascertain feasibility of conducting a large definitive phase III trial.

Method: A feasibility randomized controlled trial was carried out in Birmingham, UK. Patients with idiopathic Parkinson's disease with ADL limitations were randomized to immediate therapy or control. The intervention consisted of six sessions of occupational therapy over two months in the home and was targeted at functional independence identified in partnership with the participant. Outcome measures were collected independently

6 *Proceedings of SRR*

at 0, 2 and 8 months. Including the Nottingham Extended Activity of Daily Living Scale and Parkinson's Disease Questionnaire-39.

Results/findings: Thirty-nine patients (25 male; mean age 73 years) were recruited from four centres over 16 months. The mean between group difference in NEADL at eight months was 3.5 (95% CI -3.2 to 10.2) favouring the no occupational therapy arm. The mean between group difference in Parkinson's Disease Questionnaire-39 summary score at eight months was 3.8 (95% CI -4.9 to 12.6) favouring therapy. There were strong correlations between the Parkinson's Disease Questionnaire-39 and other outcomes.

Discussion: The intervention was acceptable to patients, with a low withdrawal rate and good questionnaire completion.

Conclusion: Randomization to a trial of occupational therapy in Parkinson's disease is feasible. Nottingham Extended Activity of Daily Living Scale and Parkinson's Disease Questionnaire-39 are relevant outcome measures and provided data to inform sample size estimation for an adequately powered randomized trial for which there is a pressing need.

Needs after stroke rehabilitation: stroke service users' views

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Background: The Stroke Association commissioned a UK literature review and mapping survey on the unmet needs of community-dwelling stroke survivors. To inform the search, stroke service users were consulted three times to identify need, prioritize need and prioritize literature evidence gaps.

Method: Stroke service users in four nations were consulted at different stages to inform the review. In England and Northern Ireland to identify need;

in Northern Ireland, Scotland and Wales to prioritize need and all nations to prioritize evidence gaps. Four focus groups were held. Nominal group and card-sorting exercises facilitated need prioritization. Gaps prioritization questions were sent by post. Thirty-six stroke survivors, 12 carers and 15 service user representatives participated.

Results/findings: Service users identified needs for social and personal care, psychological and psychiatric support, carer support and training, community rehabilitation, equipment and financial help as most important. Priorities varied depending on local provision and geographical context. They also referred to third sector and private services roles' not found in the literature. Information on only some service user' identified needs was found in the literature, indicating evidence gaps in user priority areas. Mental well-being needs, secondary prevention, social, financial and care needs were prioritized as important literature 'evidence gaps' for research and service planning.

Discussion: Service users took a wider perspective of need (including access to services and environmental limitations) than the literature, which referred mostly to professional therapy input.

Conclusion: Future research should consider service users' priorities and adopt a societal perspective of need.

The Bangor Gambling Task: a useful clinical tool in the assessment of emo- tion-based decision-making in survivors of traumatic brain injury?

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Background: The Bangor Gambling Task (BGT) was designed to be a 'bedside' test of emotion-based decision-making, thought to underpin the social and emotional difficulties associated with traumatic brain injury. However, evaluation of the performance of traumatic brain injury participants on the Bangor Gambling Task has not been carried out. The aims of this study were to: (1) characterize Bangor Gambling Task performance in survivors of traumatic brain injury; (2) investigate the relationship between performance on the Bangor Gambling Task and other cognitive measures; and (3) investigate whether Bangor Gambling Task performance is related to real-life social and emotional difficulties.

Method: Thirty survivors of traumatic brain injury and 41 age- and education-matched healthy controls completed the Bangor Gambling Task and measures of speed of processing, sustained attention, working memory and executive function. Carers also completed ratings of everyday social and emotional difficulties.

Results/findings: Survivors of traumatic brain injury were impaired relative to controls on the Bangor Gambling Task. Discriminant function analysis confirmed that performance on the Bangor Gambling Task effectively classified participants into their respective groups (traumatic brain injury, control), yielding a cut-off raw score (-5) that can be applied clinically. Performance on the Bangor Gambling Task in the traumatic brain injury group was only associated with speed of processing.

Discussion: Bangor Gambling Task performance is impaired in survivors of traumatic brain injury and this is unrelated to executive function and working memory. These data provide a platform for studies examining effects of location and aetiology of brain injury and psychophysiological changes predicted to be associated with Bangor Gambling Task performance.

Conclusion: The Bangor Gambling Task, with its practical advantages over other measures, is a useful clinical tool in the assessment of decision-making in survivors of traumatic brain injury.

Specialist services for people with long-term neurological conditions: service user and provider views

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Background: Over a million people sustain head injuries each year and several million have progressive neurological conditions requiring specialist neurological rehabilitation services. However, UK provision is patchy and little known about its efficacy, organization or delivery. The purpose of this study was to map specialist neuro-rehabilitation services in England.

Method: A mapping exercise was carried out in four strategic health authorities. Semi-structured interviews were used to ask key informants (neurological rehabilitation service users, providers and commissioners) about specialist neurological rehabilitation services in their area, in particular the organization and delivery of services received, delivered or commissioned and service gaps.

Results/findings: Two hundred and five local experts, service users (43), providers (139) or commissioners (23) were interviewed. Users spoke highly of acute services but felt longer term care was lacking, they wanted easier access, clinical expertise and personalized treatment. Users and providers felt lack of coordination produced poor continuity of care. Providers were concerned about psychotherapeutic and social care staff shortages, inadequate resources and community provision. Commissioners recognized difficulties in rural areas, observed conflict between specialist/local services and identified a lack of formal clinical pathways for accessing specialist services.

Discussion: Specialist neurological rehabilitation services are poorly described. They often focus on acute management in major cities. Deficiencies exist in rural areas, community and longer term care. In attempting to meet statutory provision shortfall, the charitable sector has become a major service provider. Evidence to guide commissioners in specialist neurological rehabilitation service provision is inadequate. Only stroke units have robust evidence to support them.

Conclusion: Investment into specialist neurological rehabilitation service evaluation is required.

A survey of urinary continence care practices in Scottish stroke care settings

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Background: Urinary incontinence occurs in 40-60% (approximately 60 000-90 000) of the UK's annual

8 *Proceedings of SRR*

stroke admissions. At discharge, a quarter will still have urinary incontinence and 15% will continue to experience problems a year after stroke. Depression is twice as prevalent in individuals with incontinence post stroke as those without. Furthermore, negative social consequences, such as isolation, can impact on both carer and stroke survivor. Stroke nurses have the responsibility of assessing, managing and supporting patients' continence needs. Although motivated, the availability of continence support, policy, guidelines and products is unclear.

Method: A postal questionnaire was designed to collect anonymized information on the urinary continence care practices in 69 stroke care settings across Scotland.

Results/findings: Our survey had an 88% response rate with 61 questionnaires completed and returned.

Continence care support was most commonly provided, on request, by continence advisors or urology doctors/consultants. Training levels were disappointing. In the past year 22 care settings failed to receive any form of training. The use of assessment tools varied. 31 (51%) care settings used micturition diaries or fluid balance charts. Ten of these settings added the Barthel Index. Eighteen care settings used either a local continence assessment tool ($n=14$) or a validated measure ($n=4$). Eleven care settings did not use any form of continence assessment tool.

Conclusion: An excellent response rate facilitates a comprehensive overview of the challenges nurses face in providing adequate continence care for patients across Scotland. Nurses' access to training, assessments, protocols and equipment varied considerably.