

Submitted to SAGE 28/3/11 by Patricia Dziunka – Central Secretariat patricia.dziunka@srr.org.uk

The Society of Research in Rehabilitation (SRR) is the major multidisciplinary rehabilitation research society in the UK (<http://www.srr.org.uk>). Its aim is to advance education and research into all aspects of rehabilitation medicine and to disseminate the useful results of such research for the public benefit. The SRR runs two conferences a year, with topic-specific research symposia, free scientific presentations and 'research in progress' posters. The Society aims to be inspiring and educational, while providing excellent opportunities for networking for both junior and established researchers.

These are abstracts from the SRR Summer Meeting, hosted by the Sheffield University 7th and 8th July 2010.

Exercise for Multiple Sclerosis: a single blind randomised trial comparing continuous, intermittent and combined exercise

J Collett, H Dawes, A Meaney, Oxford Brookes University, C Sackley, University of Birmingham, K Barker, D Wade, Nuffield Orthopaedic Centre, J Duda, University of Birmingham, H Izadi, L Buckingham, Oxford Brookes University

Background: The most effective exercise dose has yet to be established for Multiple Sclerosis (MS). We compared 3 different intensities of cycle ergometer exercise.

Method: Design: Three group single blind randomised controlled trial, set in sport centres in the Thames valley. Participants: 55 adults (mean age 52 ± 9 years) with MS recruited through Consultant referral and MS society branches fulfilled inclusion and analysis criteria. Interventions: 20minute twice a week 12week cycle ergometer exercise of 3 different intensities. Continuous cycling at 45%peakpower, intermittent cycling (30sec on 30sec off) at 90%peakpower and combined (10minutes intermittent at 90%peakpower followed by 10minutes continuous at 45%peakpower. Assessments: Baseline, halfway (6weeks), end intervention (12weeks) and follow-up (24weeks). Primary outcome measure was 2minute walk distance. Timed up and go (TUG) and leg power and peakpower from an incremental cycle test were also assessed.

Results: 20, 18 and 17 participants received continuous, intermittent and combined interventions respectively and were included in the intention-to-treat analysis. No differences were found between groups. Considering all participants, after 6 weeks mean increase in 2minute walk was 6.96 ± 2.56 m (95%CI: 1.81-12.10, $p<0.01$), TUG ($p<0.05$) and leg power ($p<0.01$) also improved. At 12 weeks improvements in leg power continued ($p<0.01$) and there was a drop in attendance ($p<0.05$). At follow-up performance of TUG ($p<0.05$), leg power ($p<0.01$) and peakpower ($p<0.05$) had decreased.

Discussion: Whilst we found no difference between groups when considering all participants cycling exercise produced benefits. Most benefits were obtained in the first 6weeks when attendance was also greatest. Detraining was evident at follow-up (12 weeks post intervention)

Determinants of Physical Activity Participation following Traumatic Brain Injury

S Reavenall, University Hospital Birmingham NHS Foundation Trust; H Blake, University of Nottingham

Background: Interventions to promote physical activity in people with long-term conditions are on the increase, although we know little about barriers and determinants of participation. The objective of the study was to establish the environmental, social or personal determinants associated with physical activity participation in people with traumatic brain injury.

Method: A multi-centre cross-sectional questionnaire survey was undertaken using a convenience sample. Eight community day centres for brain injured populations were approached. The subjects were 63 individuals with traumatic brain injury (51 male, 12 female).

Results/Findings: Over half the participants were not active enough for health benefit. Univariate analysis showed that active participants were more independent in activities of daily living ($t=-2.21$, $p<.05$), had greater self-efficacy for exercise ($t=-3.02$, $p<.05$) and were more educated ($\chi^2=5.61$, $p<.05$) than inactive participants. Logistic regression showed self-efficacy for exercise to be the only significant predictor of physical activity participation ($\beta=.32$, OR 1.03, $p<.05$).

Discussion: Self-efficacy predicted physical activity participation. This supports previous work identifying self-efficacy as an important factor in physical activity participation in healthy populations.

Conclusion: Physical activity needs to be promoted in this population. Efforts to increase self-efficacy amongst brain injured participants may encourage activity participation and this warrants further investigation.

Working with back pain: a qualitative study of patients' concerns and their experiences of healthcare

C Coole, A Drummond, University of Nottingham, PJ Watson, University of Leicester, K Radford, University of Central Lancashire

Background: Little is known about the experiences of those who struggle to remain at work with back pain. A better understanding of these factors may help GPs and other clinicians in their approach to treatment.

Method: A qualitative design with Thematic Analysis was used. Individual semi-structured interviews were conducted with twenty-five back pain patients prior to attending a rehabilitation programme. All were in employment and concerned about their ability to work due to back pain.

Results/Findings: Participants were concerned about their future ability to remain at work and the effect of back pain on their sickness record. They expressed a need to justify their condition at work. They had difficulty in managing flare ups and had concerns about using medication. Sickness certification was the main method that GPs had used to manage their work problems. The participants described having received little effective work-focused guidance and support from GPs and other clinicians, and communication between healthcare and the workplace was rare. Few participants had received assistance with temporary modifications and many had remained at work despite the advice they had received. There was little expectation as to what GPs and clinicians were able to offer regarding work.

Conclusion: The perceptions of employed patients with back pain suggest that GPs and other clinicians provide little to address patients' concerns about working with this condition. It may be that by focussing their interventions more directly on the effective management of back pain within the workplace, clinicians can improve their patients' ability and confidence to remain productively employed.

Using the ICF to systematically review outcomes used in the evaluation of robot assisted upper limb exercise in stroke

M Sivan, RJ O'Connor, Academic Dept. of Rehabilitation Medicine, University of Leeds, S Makower, Community Rehabilitation Services, Leeds Primary Care Trust, M Levesley, School of Mechanical Engineering, University of Leeds, B Bhakta, Academic Dept. of Rehabilitation Medicine, University of Leeds

Background: This review aimed to classify and evaluate outcomes used in evaluation of robot assistive upper limb rehabilitation to assist in the selection of outcomes for future clinical trials.

Method: Outcomes used in robot assisted arm exercise trials in people with stroke were identified from MEDLINE, EMBASE, CINAHL, PUBMED and PsychINFO databases. The scale items were categorised into the domains of International Classification of Function (ICF). The psychometric properties of the scales in people with stroke were analysed and rated using a standardised proforma.

Results/Findings: Thirty outcome measures were identified from 27 published robot assisted arm exercise studies. ICF body function based scales were Fugl Meyer(FM)(23 studies), Modified Ashworth Scale (12 studies), Medical Research Council strength grading (11 studies), Motor Status Score(MSS) (6 studies) and Kinematic measures (5 studies); ICF activity based scale was Functional Independence Measure(FIM) (9 studies); ICF participation, personal and environmental factors based scales were rarely used. Standardised rating identified FM, Action Research Arm Test(ARAT), Kinematic measures, FIM, Barthel Index(BI), ABILHAND and health status measure-EQ5D to have adequate measurement properties for use in robot assisted arm exercise trials. FM, FIM and BI are limited by their responsiveness. ARAT and BI are limited by floor and ceiling effects in stroke recovery.

Conclusion: The ICF provides (a) a method of classifying the content of outcomes used in robot assisted exercise studies and (b) a framework to select outcomes that will capture change in different domains in future studies. The current commonly used scales appeared to have reasonable measurement properties.

Patient outcome measures: a study of response shift

N Nasr,A Parry, Sheffield Hallam University

Background: The change assessed by Patient-reported outcome measures (PROMs) is the traditional notion of change and overlooks the effects of patients' experiences and their interpretations of the quality of life during the course of a disease. This study draws on a qualitative research design to examine the response shift phenomenon.

Method: Following the receipt of ethical approval, twenty nine Narrative interviews were conducted with patients from 1-2 years post-arthroplasty. Interviews were transcribed verbatim. The health condition was also measured by the SF-36, the PGI and the Oxford Hip Score.

Credibility was established by the method of member validation and the transcripts were sent back to the participants for their remarks on the accuracy of the narrative accounts, and transferability was achieved by providing the method of "thick description".

The narrative data were analysed using framework analysis. The participants used problem-focused, emotion-focused, spiritual, comparative and self-oriented coping strategies to accommodate to the new stressful situations and shifted their focus from the disease-related problems to other aspects of their lives, which were meaningful to them.

Results/Findings: The narrative data were analysed using framework analysis. The participants used problem-focused, emotion-focused, spiritual, comparative and self-oriented coping strategies to accommodate to the new stressful situations and shifted their focus from the disease-related problems to other aspects of their lives, which were meaningful to them

Conclusion: It is suggested that despite unchanged or even deteriorated health conditions, the participants alleviated the physical limitations associated with their conditions by changing their standards and values and placed greater emphasis on positive gains from the condition as the result of applying adaptation mechanisms. Hence the contemporary challenge for the measurement of outcomes from patients' perspectives is to address response shift in the form of the reprioritisation of goals or re-conceptualisation of values over the course of a disease.

Mapping Vocational Rehabilitation (VR) Services for people with Long Term Neurological Conditions (LTNC): A Questionnaire Survey

AM Gibson, KA Radford, University of Central Lancashire, ED Playford, University College London, C Burton, University of Bangor, J Sweetland, University College London, J Phillips, University of Nottingham, CL Watkins, University of Central Lancashire

Background: The NSF for LTNC highlights the need for VR services to enable people with LTNC to enter work or education, remain in/return to an existing job or withdraw from work at an appropriate time. Despite growing evidence about the benefits of VR, there is concern that they are in-accessible to people with LTNC or fail to meet their needs. The purpose of this study was to identify and describe VR services available to people with LTNC in England and explore fit with published recommendations.

Method: An expert panel comprising professionals and VR service users developed a questionnaire to explore current VR practice for LTNC. Consensus development techniques were used to ensure descriptors addressed the content of specialist VR for each of 4 disease trajectories. Questionnaires were sent in 3 tranches to professional networks with likely involvement in health-based VR services.

Results/Findings: Of 330 questionnaires sent, 138 responded. 87 VR services were identified. Few specialist VR services exist for people with LTNC (n=12). Most (n=75) were generic rehabilitation services with a vocational component. Few fit with published guidelines. Provision was patchy, geographically and across disease trajectories. There was little cross-partnership working. Service providers believed commissioners did not regard VR as a health issue.

Discussion: Resources are required to develop VR services to fit with published guidelines. Commissioning arrangements for sustainable, responsive VR services need further investigation.

Conclusion: There is a need for more specialist LTNC VR services and to determine the efficacy of general rehabilitation with a VR component in securing work outcomes.

Why don't Professionals Provide Speech Driven Environmental Controls?

Perceptions of current speech driven environmental controls

S Judge, Z Robertson, Barnsley Hospital NHS Foundation Trust, MS Hawley, University of Sheffield & Barnsley Hospital NHS Foundation Trust

Background: This study set out to collect data from assistive technology professionals about their provision of speech-driven environmental control systems. This study is part of a larger study looking at developing a new speech-driven environmental control system.

Method: A focus group for assistive technology professionals was conducted attended by 6 professionals (4 service managers and 2 Clinical Scientists). The topic guide for the focus group was developed through 2 exploratory interviews with 2 Clinical Scientist Service Managers.

The focus group was split into two parts, a morning session that explored the professionals' issues with existing speech-driven environmental control systems and an afternoon session that explored the professionals' aspirations for speech-driven environmental control systems. The focus group was facilitated by an experienced researcher with good knowledge of assistive technology but who was independent from the project. This focus group was recorded, transcribed and then analysed using a framework approach.

Results/Findings: The analysis suggested that professionals have a 'mental model' of a successful user of a speech-driven system and that in general they consider such systems either as a 'last resort' or to work in parallel with another system as a backup. Perceived poor reliability was highlighted as a major influence in the provision of speech-driven environmental control systems although there were also positive perceptions about the use of speech under controlled circumstances. Comparison with published data from end-users showed that professionals highlighted the majority of issues identified by end-users.

Discussion: Assistive technology professionals think that speech has potential as an access method but are cautious about using speech-driven environmental control systems predominantly due to concerns about reliability. Professionals seem able to empathise well with the challenges faced by end-users in use of these systems.

Conclusion: This work has provided evidence regarding the low provision of speech-driven environmental control systems in the UK. It has highlighted key reasons why professionals consider provision of such systems and suggests that they empathise with the challenges faced by end-users in the operation of these systems.

The main issues highlighted were around reliability of the systems and this corresponds with the results of the end-user study on the same topic. These results suggest that, if reliability could be improved, speech driven systems could become more widely used and the benefits, such as speed and compactness, could be appreciated by more end-users.

Employment rates and health costs one year after traumatic brain injury (TBI). A cohort comparison

J Phillips, University of Nottingham, KA Radford, University of Central Lancashire, A Drummond, University of Nottingham, T Sach, University of East Anglia, M Walker, University of Nottingham, A Tyerman, Cambourne Centre Aylesbury, N Haboubi, University Hospital Nottingham, T Jones, University of Nottingham

Background: Return to work (RTW) after TBI can be problematic. UK vocational rehabilitation (VR) after TBI is rare and service efficacy or costs seldom reported. The aim of this study was to determine the feasibility of measuring the effectiveness and cost effectiveness of a specialist intervention targeted at returning TBI participants to work/education.

Method: RTW/educational outcomes of participants receiving specialist TBI VR rehabilitation (intervention group) were compared to outcomes of participants in adjacent areas receiving routine care (non-intervention group).

94 participants (40 intervention) with TBI resulting in hospitalisation ≥ 48 hours, who were working/studying at injury were followed up by postal questionnaire at 3, 6 & 12 months post hospital discharge. Primary outcome was RTW/education. Secondary outcomes were functional ability (Brain Injury Community Rehabilitation Outcome), mood (Hospital Anxiety and Depression Scale) and quality of life (EQ5D). Health resource use was by self report. Ethics and R&D approvals obtained.

Results/Findings: Secondary outcomes showed no significant baseline differences between groups.

At 12 months, 15% more intervention participants were in work/education than non-intervention participants (27/36, 75% v 27/45, 60%). An even greater difference was observed in people with moderate/severe TBI (16/23, 70% v 9/21, 43%).

Mean health costs per person (consultant, GP, therapy, medication) were £75 greater in the intervention group at one year.

Discussion: More people in the intervention group returned to work/education and returned sooner. Those with moderate/severe TBI appeared to benefit most. This positive trend was achieved without a large increase in health costs.

Conclusion: This feasibility study justifies the need for and can inform a definitive RCT.

Managing fatigue in advanced cancer: a pilot randomised controlled trial of a customised rehabilitation intervention

G Eva, University of Oxford, M Black, Oxford Radcliffe Hospitals NHS Trust, D Cox, University of Cumbria, R Perera, University of Oxford, E Watson, Oxford Brookes University, B Wee, University of Oxford

Background: Cancer-related fatigue in advanced disease curtails social participation, adversely affecting quality of life. This study piloted a customised rehabilitation 'toolkit' intervention determining its effect in a small sample to define the parameters necessary for a substantive study in terms of feasibility, recruitment, acceptability of randomisation, and quality of outcomes data derived.

Methods: Patients were randomised to three groups: toolkit plus 3 sessions; toolkit plus 1 session; lay advice. Data were collected from: quantitative measures (Piper Fatigue Scale and Impact on Participation and Autonomy), in-depth interviews, patient diaries, and clinical notes.

Results: 32 patients agreed to participate – 13 women, 19 men; age range 42-92, median age 67.5. 21 completed the programme, lower than the intended target of 45. 22 completed or partially completed diaries were returned. 6 patients participated in qualitative interviews. Exploratory analysis of the distribution of data on the quantitative measures showed no difference across the three groups; however, supplementary data indicated that the intervention was feasible and acceptable, and that patients' ability to understand and manage their fatigue was enhanced.

Discussion: Interview and diary data distinguished between more and less helpful toolkit strategies, and also identified the specific aspects in which the toolkit format and the one-to-one intervention delivery was helpful. The intervention targets the behavioural determinants of fatigue, and a limitation is its ability to address the mental fatigue resulting from patients' anxiety about the future.

Conclusions: Patients value engagement in daily activities and social participation. Recruitment strategies developed will aid recruitment in future studies.

Head and neck cancer and dysphagia; caring for the carers

J Patterson, Macmillan SALT, Sunderland, P Carding, Freeman Hospital, Newcastle, J Wilson, Newcastle University, E McColl, Newcastle University

Background: Families can play a key role in caring for the patient with head and neck cancer (HNC). These patients experience changes to basic functions such as swallowing, which increase dependency on others and can affect family life. This is a preliminary study, using a longitudinal design to explore carer quality of life (QOL), pre- and post-treatment and its relationship to patient reported swallowing.

Methods: HNC patients referred for radiotherapy were asked to identify a carer. Carers and patients were asked to complete questionnaires (QOL tool and a swallowing specific questionnaire) pre-treatment, three and twelve months post-treatment. Data were supported by patient and carer interviews.

Results: A significant improvement in carer QOL was observed during the post-treatment period ($p=0.012$), whereas no change was seen in the swallowing questionnaire ($p>0.05$). The patient questionnaires accounted for 47% of the variance in carer QOL measurements ($R^2=0.47$, $F=51.4$ $p<0.001$). Themes from the interviews included; food provision, monitoring, motivation and changes to lifestyle.

Discussion: These findings suggest a relationship between carer QOL and patient well-being and post-treatment swallowing problems. Other research has shown the greater the patients' physical care, the poorer the carers' and patients' QOL. As well as managing the associated physical swallowing difficulties, living with someone with dysphagia is likely to impact on their social lives such as participation in shared meals, leading to permanent changes to family lifestyles. Careful counselling is required to prepare families for these changes.