

Rehabilitation Training (ReTrain) for Long-Term Stroke Survivors

A before and after case series as part of the development phase for a future clinical trial

Sarah Dean, Vicki Goodwin, Leon Poltawski

With acknowledgement of the invaluable assistance of the ReTrain Study Advisory Group

Contact details: sarah.dean@pcmd.ac.uk

Background and Aims

Exercise programmes for long-term stroke survivors help maintain or enhance functional independence and encourage physical activity levels but evidence of effectiveness is based on a small number of low quality studies¹. However these programmes are increasingly being provided in the UK.

One example is ARNI (Action for Rehabilitation after Neurological Injury: www.arni.uk.com), a functional exercise programme which is currently offered in several centres in the UK but has not been subject to trial evaluation.

Our aim was to undertake development phase² work in preparation for a clinical trial.

We conducted a before-and-after case series study (n=6) of a 1:1 training programme based on ARNI to explore: feasibility and acceptability; potential risks and benefits; programme delivery and choice of outcome measures.

Methods

Participants were recruited via local clinicians and stroke support groups. They were: at least 6-months post-stroke but with residual disability (modified Rankin Scale score 2-4); not currently receiving physical rehabilitation but had no contraindications to exercise.

Participants received 1:1 ARNI-based programme that we have called ReTrain, led by a REPs* Level 3 Exercise Professional with additional ARNI training and accreditation.

Sessions lasted 1 hour and were provided twice-weekly over 12-14 weeks. Total supervised training time was 24 hours, but participants were also expected to do at least 2 hours/week physical exercise independently.

Training was personalised to the individual, but focussed on strengthening, mobility and functional tasks, conducted at a demanding level, with encouragement to attempt tasks and activities at the edge of personal ability.

Assessments were conducted at baseline (T1), post-12 week programme (T2) and 3-months follow-up (T3). Outcome measures were:

- **Nottingham Extended Activities of Daily Living**
- **Stroke Self-Efficacy Scale**
- **Fatigue Assessment Scale**
- **Reintegration into Normal Living Index**
- **EQ-5D and SF-36 Quality of Life Scales**
- **Timed Up and Go test**
- **Performance-Oriented Mobility Assessment.**

Semi-structured qualitative interviews were also conducted at the same time points.

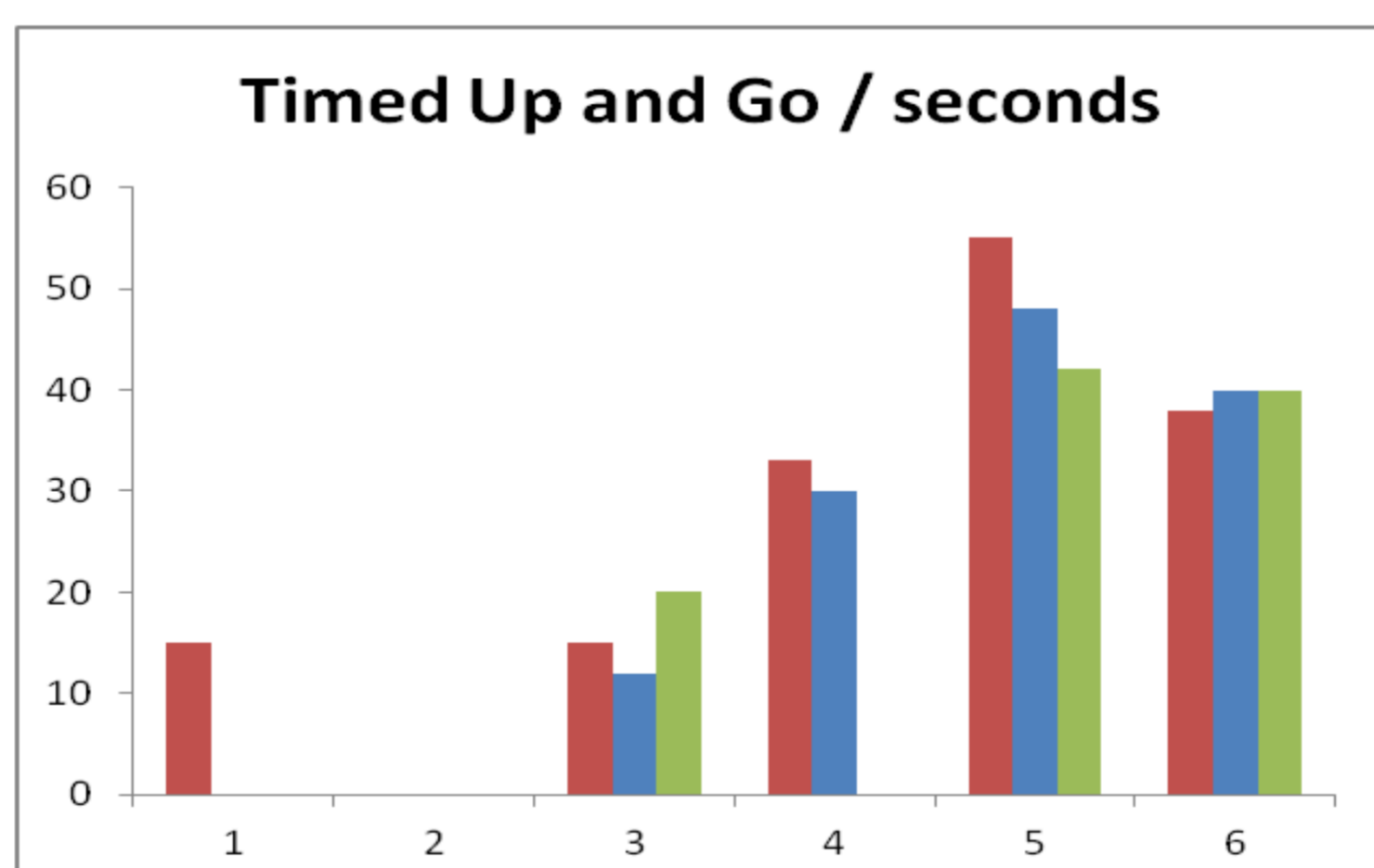
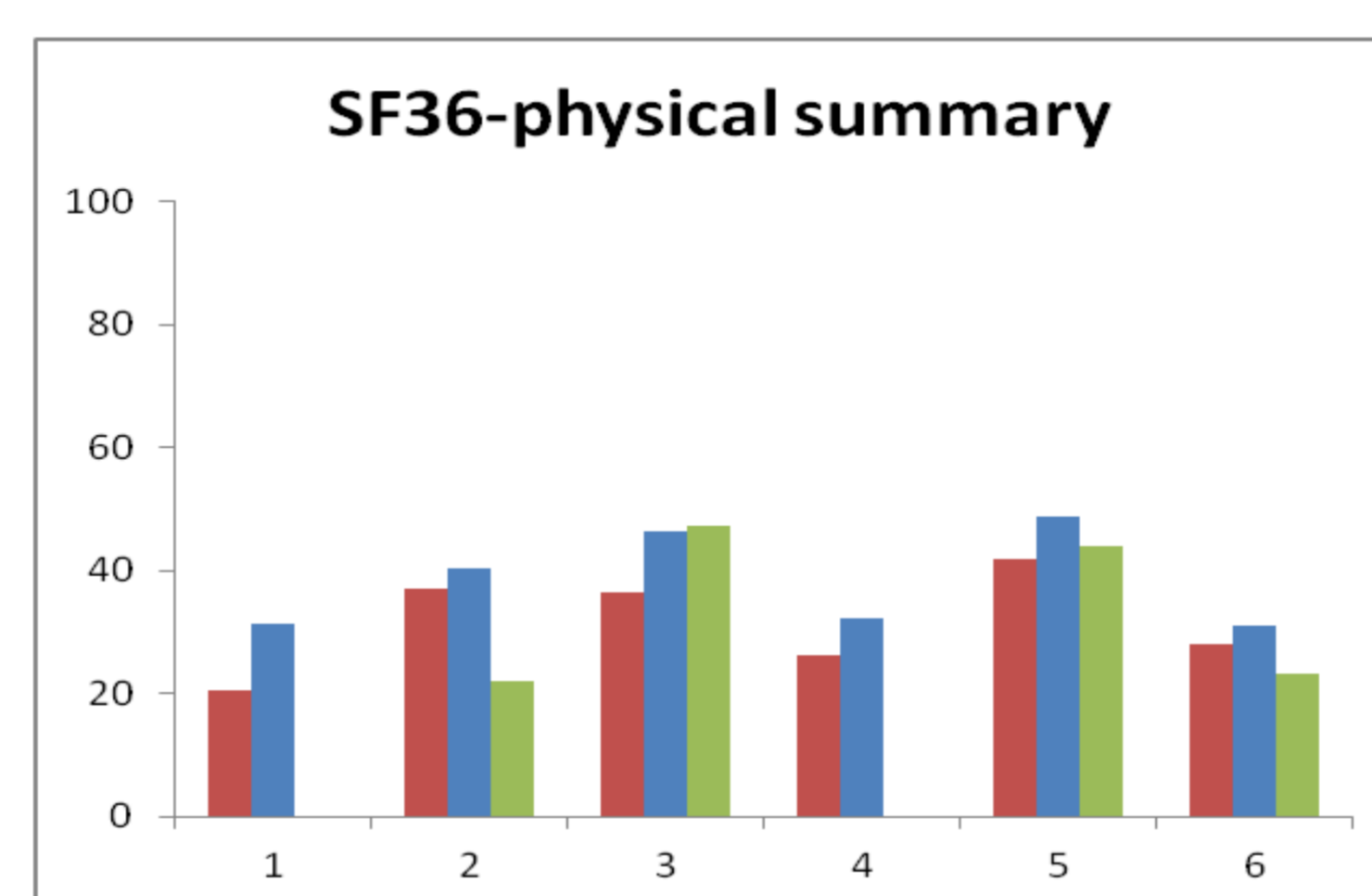
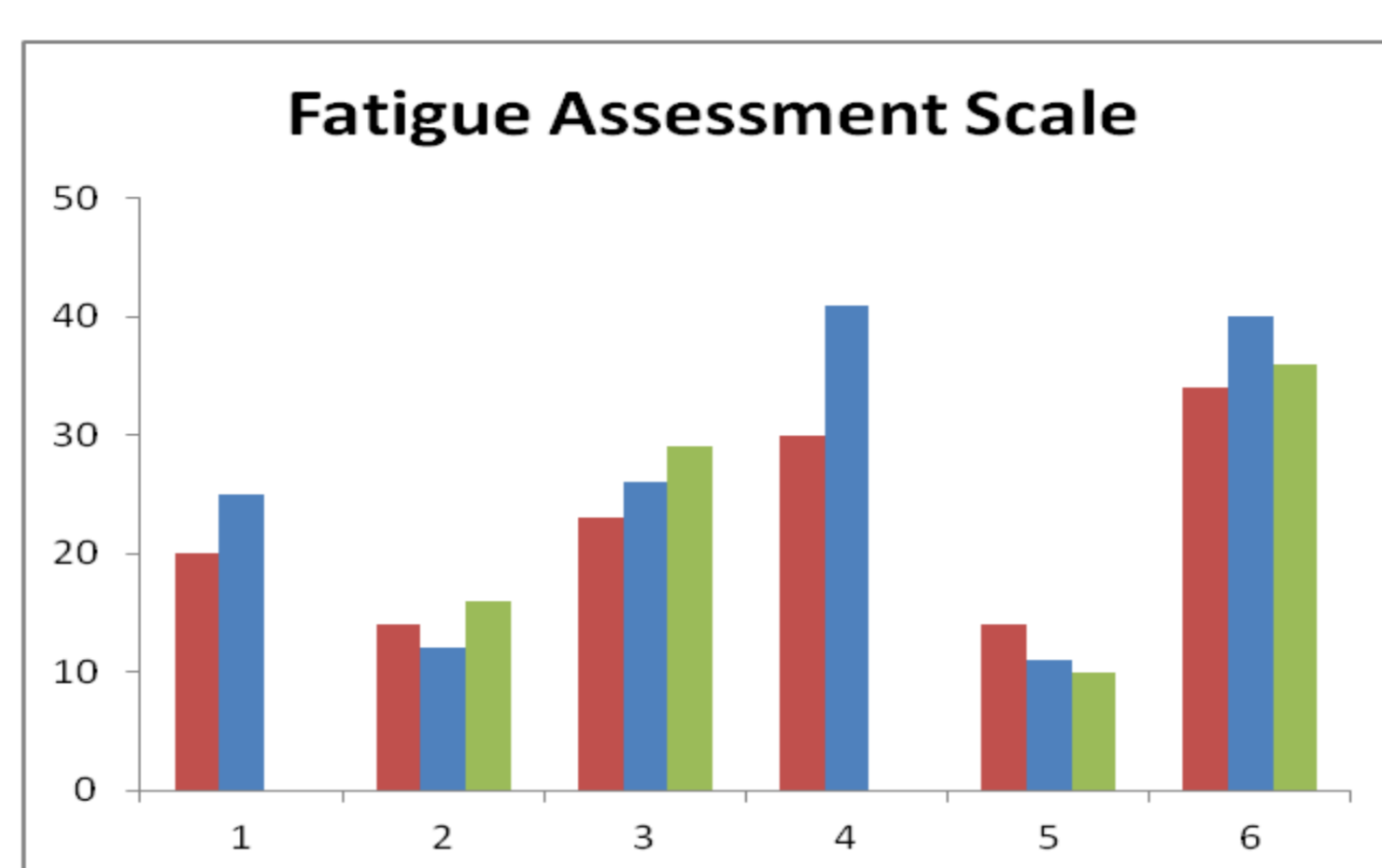
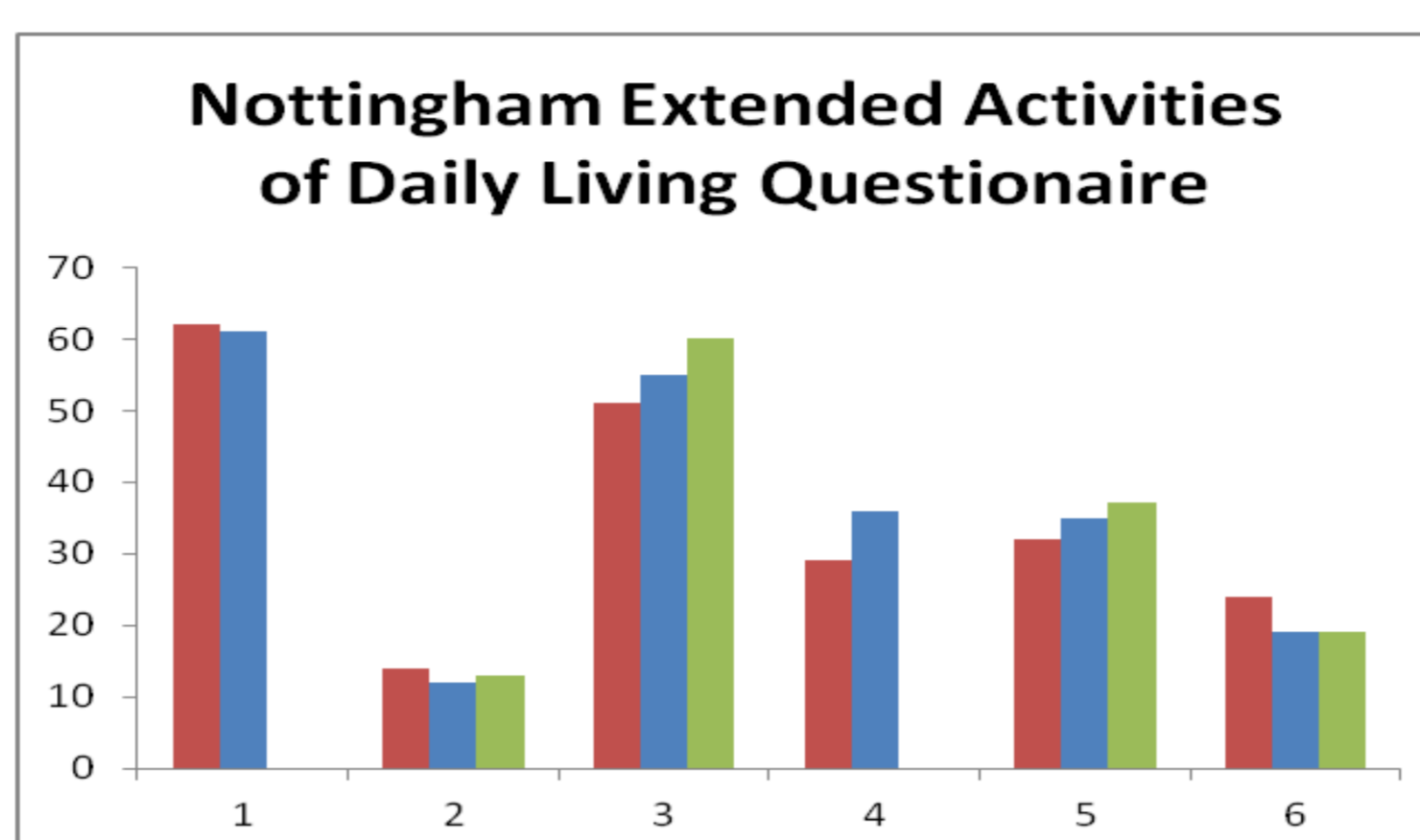
Quantitative data were analysed descriptively for this small sample and interview data were analysed thematically using an interpretative phenomenological³ approach

*Register of Exercise Professionals

Participants

The 6 participants were aged between 57-72 years and were 14 months to 16 years since their stroke. Four people completed the programme; two people dropped out early, reporting fatigue and that they did not want to continue due to the demands of the programme, both had complex co-morbidities.

Results: Outcome Measures



The four figures are individuals' scores for selected measures at baseline (red), post-intervention (blue) and 3 month follow up (green) for all cases (1-6). Missing data were due to early drop outs (1 and 4) and a wheelchair-user (2) who was not assessed on Timed Up and Go (gait).

Quantitative outcomes varied considerably between individuals. The improvements among completers were in daily activities, SF36 physical function and gait but fatigue levels also increased for 2 programme completers. No adverse events were reported.

Completers and those reporting greater benefits had higher pre- and post-stroke activity levels, supportive partners, and higher socio-economic status.

Even those reporting high levels of motivation did not report maintenance of increased physical activity once supervised training ceased.

Results: Interview findings

Small steps of improvement: all completers experienced personally significant improvements in physical ability and psychological factors such as confidence and self-efficacy. These were not always reflected in quantitative measures.

'I've really noticed is how much easier it is to move around in bed, rolling over left and right and getting up' (CS5, T2)

'Initially cautious but...not so worried about falling' (CS2, T2)

'I'm less scared about walking out the front door and striding towards town' (CS3, T2)

Hopes and expectations: the positivity, high expectations and non-medicalised approach of the trainers were important elements of the programme. Hopes were raised and realised for some but not others, resulting in varying levels of on-going commitment to exercise.

'My mind wanted me to do it but my body didn't, and I wasn't happy with that at all' (CS4, T2)

'I got a lot out of it and I am still buoyed up by it you know. I don't think there's any danger of me slipping back. I don't want to slip back' (CS3, T2)

'I suppose if I could have stuck at it I would have got stronger and you know I could have done probably a little bit better than what I'm doing now, but I've gone back to my old, my walking and all that now, which I can't help.' (CS4, T2)

'Some hope to recover some of the things that I thought were lost forever' (CS5, T3)

The personalised one-to-one format was highly valued by the completers:

'The disciplining effect of having to go [to a programme], or having someone coming can't really be overestimated.' (CS5, T3)

Discussion & Conclusions

- A high intensity, personalised, functionally-oriented training programme can bring physical and psychological benefits to selected long-term stroke survivors.

- Small physical improvements were noticed and can have major significance for the individual. Some of these important benefits were not necessarily registered by our range of commonly-used outcome measures.

- Ongoing forms of support may be necessary to sustain the commitment to higher levels of exercise.

- Participant selection is important: our interviews revealed that those reporting an existing commitment to exercise were also those who completed the programme and gained the most.

- Further work is required to finalise the parameters of the research. The next step is a feasibility study with a pilot randomised controlled trial (RCT) prior to a full RCT to evaluate the efficacy of the ReTrain programme.

References

1. Graven C, Brock K, Hill K, Joubert L. (2011). Are rehabilitation and/or care co-ordination interventions delivered in the community effective in reducing depression, facilitating participation and improving quality of life after stroke? *Disability and Rehabilitation*, 33 (17-18): 1501-1520.
2. Medical Research Council (MRC) (2008). *Developing and evaluating complex interventions: new guidance*. London, MRC.
3. Smith JA, Flowers P, Larkin M. (2009). *Interpretative Phenomenological Analysis Theory, Method and Research*. London, Sage.

We acknowledge support from the National Institute for Health Research Collaborations for Leadership in Applied Health Research and Care. The views and opinions expressed in this poster are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

