



FOCUS ON RESEARCH

MEASURING OUTCOMES IN COMMUNITY-BASED STROKE REHABILITATION: ENHANCING INCLUSION AND PARTICIPATION

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Aim

To assess the relevance and inclusivity of outcome measures used to evaluate community-based rehabilitation from the perspective of service users and rehabilitation professionals.

Project Outline/Methodology

Phase 1: In-depth interviews with 34 community-dwelling stroke survivors, six with communication difficulties (aphasia) used Talking Mats™.

Phase 2: Web-based survey of 113 rehabilitation therapists in 12 Scottish health boards (51 Physiotherapists (PTs), 39 Occupational Therapists (OTs), 23 Speech and Language Therapists (SLTs) and 13 in-depth follow-up interviews.

Phase 3: Synthesis workshop with 8 rehabilitation professionals and 5 stroke survivors to prioritise the most important areas for outcome measurement.

Key Results

Phase 1: a. Outcomes that are relevant to stroke survivors. Stroke survivors identified 89 areas of 'importance to life' (e.g. family, community life) and 56 'recovery goals' (e.g. driving). Goals, hopes and expectations, support from others, loss of previous activities, mobility, family and participation in community and civic life mattered most. Relationships and mobility were most endorsed by those with aphasia.

b. Making outcome measurement inclusive

Stroke survivors emphasised the importance of positive, meaningful and culturally/linguistically and personally sensitive measures.

Phase 2: a. Outcome measures currently used by therapists in community stroke rehabilitation

Therapists used 80 different outcome measures. Only 11% of measures were used by all 3 professions. These were generic (e.g. goal attainment scaling). All therapists selected measures they deemed 'relevant to patient goals' and 'easy to use'. Assessing change, planning treatment, and illustrating progress to patients were the principal uses reported. Only 15 therapists (13.6%) used measures to elicit patient views. Accessibility, and aphasia-friendliness were rarely cited as reasons for selection.

b. Differences by location

There were no significant differences in measurement choice between groups (i.e. urban vs.

remote/rural), practice model (uni-disciplinary, multi-disciplinary vs inter-disciplinary) or case mix (stroke only vs neurology, mixed). PTs were more likely than other therapists to cite 'to assess functional change' and 'enable patients to see progress' among their top 3 reasons for selection.

c. Mapping stroke survivor needs onto the WHO ICF

Survey data showed that most outcome measures used were activity and body structure/impairment based. Only 11% of measures focused on activities and participation outcomes. Interestingly, 78% of areas of 'importance to life' and 66% of 'recovery goals' from the service user interviews mapped onto ICF Activities and Participation domains, highlighting that participation in meaningful life roles and activities matter most to stroke survivors but the use of outcome measures in this area was limited.

Phase 3. Synthesis workshop

Professionals and stroke survivors prioritised 3 areas of importance for measurement: (a) relevance to stroke survivors' goals; (b) encouragement to reach goals; (c) inclusive of all stroke survivors irrespective of disability.

Conclusions

Participation in meaningful life roles matters most to stroke survivors in community rehabilitation. This is in contrast to the predominantly impairment focused measures used frequently by therapists.

What does this study add to the field?

This study demonstrates a disconnection between what is meaningful for stroke survivors (i.e. activities and participation) and what is currently being assessed in community rehabilitation (i.e. function).

Implications for Practice or Policy

Outcome measurement should be more inclusive and aligned with stroke survivors' priorities.

Where to next?

Outcome measurement in community stroke rehabilitation requires (a) greater emphasis on context-sensitive, individualised goal setting measures; (b) direct involvement of stroke survivors in assessment processes; and (c) development and validation of accessible versions of outcome measures that reflect participation goals.

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