Selection and Visualisation of Outcome Measures for Complex Post-Acute Acquired Brain Injury Rehabilitation Interventions

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Abstract.

BACKGROUND: Outcome measurement challenges rehabilitation services to select tools that promote stakeholder engagement in measuring complex interventions.

OBJECTIVES: To examine the suitability of outcome measures for complex post-acute acquired brain injury (ABI) rehabilitation interventions, report outcomes of a holistic, neuropsychological ABI rehabilitation program and propose a simple way of visualizing complex outcomes.

METHODS: Patient/carer reported outcome measures (PROMS), experience measures (PREMS) and staff-rated measures were collected for consecutive admissions over 1 year to an 18-week holistic, neuropsychological rehabilitation programme at baseline, 18 weeks and 3- and 6-month follow-up.

RESULTS: Engagement with outcome measurement was poorest for carers and at follow-up for all stakeholders. Dependence, abilities, adjustment, unmet needs, symptomatology including executive dysfunction, and self-reassurance showed improvements at 18 weeks. Adjustment, social participation, perceived health, symptomatology including dysexecutive difficulties, and anxiety were worse at baseline for those who did not complete rehabilitation, than those who did. A radar plot facilitated outcome visualization.

CONCLUSIONS: Engagement with outcome measurement was best when time and support were provided. Supplementing patient- with staff-rated and attendance measures may explain missing data and help quantify healthcare needs. The MPAI4, EBIQ and DEX-R appeared suitable measures to evaluate outcomes and distinguish those completing and not completing neuropsychological rehabilitation.

Keywords: Brain Injuries, Health Services Research, Stroke, Outcome and Process Assessment, Neuropsychology, Rehabilitation

1. Introduction

Outcome measurement, incorporating patient reported outcome measures (PROMS), is an essential requirement of all areas of healthcare, including for those with long-term neurological conditions, such as stroke and traumatic brain injury (TBI). It facilitates comparisons of healthcare performance across countries and services. In Europe, key performance indicators of health including mortality statistics and PROMS for health and disability are published by the Organisation for Economic Co-operation and Development and European Commission (e.g. Organisation for Economic Co-operation and Development, 2012). Within the UK, the National Health Service (NHS) Outcomes Framework measures NHS performance to provide an accountability mechanism and support quality improvement throughout the service (Department of Health, 2013). This outcome framework sets out to measure not only survival rates and recovery, but also quality of life for people with long-term conditions. Within neuro-rehabilitation, outcome measures provide an indication of rehabilitation progress for people with long-term neurological conditions, their families and healthcare professionals. At a service level, improvement in average outcome measures also facilitates decision-making in healthcare commissioning in an increasingly competitive healthcare market.

One challenge posed by the need to carry out outcome measurement is to select the most appropriate measures for acquired brain injury (ABI) rehabilitation given the abundance of outcome measures available and the complexity of ABI rehabilitation interventions. In the UK, some of this selection is determined by statutory healthcare policies with associated outcome measure requirements. For example, an online dataset was developed to help services evidence their implementation of the UK National Service Framework (NSF) for Long-term Neurological Conditions (LTNC; Department of Health, 2005). This dataset distinguishes between measures required for different settings (e.g. neurology clinic or ward, neurosurgery, inpatient neuro-rehabilitation, community rehabilitation, vocational rehabilitation or palliative care) (Turner-Stokes, McCrone, Jackson, & Siegert, 2013). The NHS Outcomes Framework (Department of Health, 2013) also includes three domains pertinent to acquired brain injury rehabilitation. “Enhancing quality of life for people with long-term conditions” (domain 2) requires outcome measures of health-related quality of life for people with long-term conditions and their carers, the proportion of people feeling supported to manage their condition, the proportion in employment and reduction of time in hospital. “Helping people to recover from episodes of ill health or following injury” (domain 3) requires measurement of the proportion of people who recover from major trauma, stroke patients reporting an improvement in activity/lifestyle on the Modified Rankin Scale (Farrell, Godwin, Richards, & Warlow, 1991) at 6 months, patients recovering to their previous levels of mobility/walking ability at 30 and 120 days, and the proportion of older adults offered rehabilitation following discharge from acute or community hospital. “Ensuring that people have a positive experience of care” (domain 4) requires measures of patient experience.

In addition, several UK rehabilitation organisations have produced specific recommendations regarding outcome measures. The British Society for Rehabilitation Medicine (BSRM) publish a “basket” of recommended outcome measures for rehabilitation (British Society of Rehabilitation Medicine, 2005). They recommend that services select measures from this “basket” according to whether impairment, activity or participation is being evaluated, the condition treated, the treatment setting and purpose of measurement (e.g. clinical or research). The UK rehabilitation outcomes collaborative (UKROC) has also developed a national clinical database for rehabilitation to evaluate rehabilitation needs (complexity), inputs provided to meet needs and outcomes of specialist inpatient rehabilitation services (Turner-Stokes et al., 2012). UKROC recommends that in addition to the psychometric requirements of good reliability, validity and scaling, outcome measures require good feasibility (i.e. ease of application), responsiveness (i.e. sensitivity to changes over time and differences between clients), interpretability and engagement (Turner-Stokes et al., 2012).

Finally, there are also condition-specific recommendations for outcome measures. The US interagency Traumatic Brain Injury (TBI) Outcomes Workgroup has published a selection of outcome measures to evaluate natural recovery and treatment response and to predict and compare outcomes following TBI (Wilde et al., 2010). The Workgroup distinguish different tiers of measures: core (valid, robust, and widely applicable outcome measures with proven utility), supplemental (focussing on specific topics or populations) and emerging measures (under development or undergoing validation). The recommended measures are intended to cover outcomes relating to different levels of the International Classification of Functioning, Disability, and Health, e.g. function, activity, and participation (Ustün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003), target important domains affected by TBI, cover the time-course from acute to chronic and all levels of severity and include PROMS. Finally, the Center for Outcome Measurement in Brain Injury (COMBI), a collaborative project of the Traumatic Brain Injury Model Systems (funded by the National Institute on Disability and Rehabilitation Research, NIDRR) has also produced a web-based resource to provide information on outcome measures for ABI assessment and rehabilitation (http://www.tbims.org/combi/).

Having selected appropriate measures, the second challenge is how to gather data that are meaningful for evaluating a service and monitoring individual patient progress with the patient, family and rehabilitation staff. To this end, client and staff completion of routine outcome measurement is necessary. Turner-Stokes and colleagues (2012) suggest that the likelihood of clinicians using standardised outcome measures is influenced by the time taken to administer and interpret measures, their perceived clinical relevance and utility and whether or not training has been provided in measure administration, scoring and interpretation. In addition, they comment on difficulties identified during the development of the UKROC such as the need for leadership, administration support and user friendliness in outcome measurement. The UKROC propose several solutions to these difficulties, including presenting measures in a user-friendly manner appropriate to those completing the measure. An example of this from UKROC is the Functional Independence and Assessment Measures (FIM-FAM; Turner-Stokes, Nyein, Turner-Stokes, & Gatehouse, 1999). The "FAM-splat" diagram is generated by presenting FIM-FAM results (for example at admission and discharge) on a radar chart, showing at a glance initial goals, progress made and where goals have not been met (Lynne Turner-Stokes et al., 2012). Such a user-friendly visualisation of complex data has been carried out before, most recently by the Outcome Stars^{TM} (http://www.outcomesstar.org.uk/), which develop radar charts showing change in key domains of PROMS to evaluate service user progress towards self-reliance or other goals.

A further challenge in community ABI rehabilitation is the wide range of type and complexity of needs, including physical, communication, cognitive, emotional and social needs. These needs can themselves challenge access to and engagement in rehabilitation, and can produce a range of valid outcomes, including return to work, reduced risk of harm to self or others, or improvements in family adjustment or self-awareness. Different measures and metrics may therefore be required for different patient subgroups (Gracey, Olsen, Watson, & Malley, 2015; Gracey, Malley, Wagner, & Clare, 2014) and different needs may impact upon the type of rehabilitation provided (Cocksedge, Gracey, Malley, & Wagner, 2014). On this basis we have described a model that seeks to characterise the basis on which such patients' needs and outcomes might differ (Gracey et al., 2015).

The current study focussed on outcome measure selection and completion in the context of an evaluation of outcomes for a holistic neuropsychological rehabilitation programme (Wilson, Gracey, Bateman, & Evans, 2009). Our focus was on clients in the community undergoing interdisciplinary neuropsychological rehabilitation in the chronic phase of ABI (e.g. one or more years post-ABI) at a national specialist centre. This is a group characterised by multiple neuropsychological and social challenges where selection of measures, change measurement, and measure completion can all be difficult. The first aim of the study was to pilot outcome measures to identify those that were feasible, well tolerated, easy to interpret and sensitive to the outcomes of the rehabilitation programme (i.e. responsive to improvements over time and differences between people who do and do not benefit from the programme). The second aim was to report rehabilitation outcomes. The third aim was to find a way to visualise the complex data collected, in a similar manner to the "FAM-splat" (Lynne Turner-Stokes et al., 2012) but for community-based neuropsychological rehabilitation clients rather than inpatient neuro-rehabilitation teams and incorporating PROMS alongside practitioner-rated measures. To achieve these goals a range of outcome measures were piloted on consecutive admissions over one year. Core and supplemental measures, as set out by the TBI Outcomes Workgroup (Wilde et al., 2010) and based on recommendations by the TBI Outcomes Workgroup, COMBI, the LTNC dataset, UKROC and the NHS Outcomes Framework, were selected by the service's rehabilitation team.

2. Method

2.1. Ethical Approval

The study was reviewed by the Chair of the local NHS research ethics committee and deemed to be service evaluation; it did not, therefore, require NHS research ethics review. Approval was provided from the NHS Trust Research & Development Department and Clinical Service Manager accordingly. All participants were able to, and did, consent to assessment for rehabilitation and relevant legal and ethical controls for confidentiality and anonymity of patient data were put in place.

2.2. Participants and Data Collection

Participants were included if they had been assessed by the multi-disciplinary clinical team as requiring the comprehensive neuropsychological rehabilitation programme offered by the service. The inclusion criteria for participation were: over 16 years of age at referral, one or more years post-acquired brain injury, difficulties with cognition, communication, emotion and function requiring an interdisciplinary team approach, independent in mobility and personal care needs, able to tolerate full therapy days (10:00-16:00), and free from significant severe and enduring mental illness and/or behavioural problems that would preclude engagement in group therapy. Participants were identified prospectively from consecutive admissions over a one-year period.

Measures were completed by clients, informants (a close family member or partner) and the staff team at baseline (week 1), the end of the programme (18 weeks except in cases where the programme was extended) and at 3- and 6-month review meetings. Clients were supported by a team member to complete questionnaires at weeks 1 and 18, but not at 3- and 6-month review meetings due to time constraints. A team member involved in the study (DM) provided support to staff if unfamiliar with particular measures.

2.3. Client Rated Core Measures

2.3.1. The EuroQOL-5D-3L (EQ-5D-3L, Rabin & de Charro, 2001)

The EQ-5D-3L is a questionnaire measure of health-related quality of life. The descriptive system measures the presence and severity of health-related difficulties via ratings on 5 dimensions (Mobility, Self-Care, Usual Activities, Pain/Discomfort and Anxiety / Depression) each of which has 3 levels: no problems, some problems, extreme problems. The EQ-VAS is a vertical, 20 cm visual analogue scale (0-100) used to rate self-reported health where the endpoints are labelled ‘Best imaginable health state’ and ‘Worst imaginable health state’. The EQ5D is the tool recommended by the NHS Outcomes Framework (Department of Health, 2013) to assess the impact of service provision on enhancing quality of life for people with long-term conditions (domain 2 in the Outcomes Framework). It is also the preferred measure for economic evaluations of healthcare interventions by the UK National Institute for Health and Care Excellence (NICE) and recommended as a core measure by the TBI outcomes workgroup (Wilde et al., 2010). It was used to identify the perceived health status of participants during the rehabilitation programme.

2.3.2. The General Self-Efficacy Scale (GSE, Schwarzer & Jerusalem, 1995)

This is a freely available 10-item self-report measure of general self-efficacy, someone’s belief in their ability to cope with a range of stressful situations. Each item is rated on a four-point scale (1 = not at all true and 4 = exactly true). There are no cut-off points but normative data are available from large samples, including a sample of N = 1,594 US-American adults (mean = 29.48/40, SD = 4.0) (http://userpage.fu-berlin.de/~health/faq_gse.pdf). This measure has been used in studies of ABI identifying self-efficacy as a predictor of outcome (Rutterford & Wood, 2006) and correlate of response to a similar comprehensive rehabilitation programme (Cicerone et al., 2008). In addition, this measure has been used extensively in research into models of health behaviour change such as the Theory of Planned Behaviour (Ajzen, 1991).

2.3.3. Satisfaction with Service Questionnaire

Improving patient experience of healthcare, measured by PROMS and PREMS, is a UK government objective (Department of Health, 2013). We modified a local patient satisfaction survey to create a 5-item scale with 4 questions each rated on a 4-point scale. The question topics were: “Quality of Clinical Service” (Very Poor, Poor, Good or Excellent), “Having Confidence in Staff”, “Being treated with Respect and Dignity” and “Being Involved in Decision-Making” (all rated as, Strongly Disagree, Tend to Disagree, Tend to Agree, or Strongly Agree) and whether the rater would “Recommend the Service to Friends and Family” (Yes, No, Maybe).

2.4. Family / Partner Rated Core Measures

2.4.1. Modified Carer Strain Index (mCSI)

This is a modified version of the Caregiver Strain Index (Robinson, 1983). The original CSI has 13 yes/no questions about caregiver strain (Yes = 1, No = 0) with a cut-off of 7. Our modified version includes 11 of the original questions (items 1-6 and 9-13) with minor rewording and adds five new items (“I get tired”, “I feel emotionally drained”, “There is a strain on our relationship”, “I have a lot more responsibility” and “I worry about what will happen in the future”). Each item is rated on an 11-point scale (0 = never/not at all to 10 = always/very much) (Simblett & Bateman, 2011).

2.5. Staff Rated Core Measures

2.5.1. The Glasgow Outcome Scale–Extended (GOS-E, Wilson, Pettigrew & Teasdale, 1998)

This measure classifies global outcome following TBI using an ordinal scale (range 1-8) from Death (1) to Upper Good Recovery (8). It has excellent test-retest reliability (Pettigrew, Wilson, & Teasdale, 2003; Wilson et al., 1998), good to excellent inter-rater reliability (Lu, Marmarou, Lapane, Turf, & Wilson, 2010; Pettigrew et al., 2003; Wilson et al., 1998), and shows medium correlations with length of post-traumatic amnesia and the Barthel Index of Activities of Daily Living (Wilson, Pettigrew, & Teasdale, 2000). It is recommended as a core measure for global outcome for traumatic brain injury by the US National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements Project (Hicks et al., 2013) and the TBI Outcomes Workgroup (Wilde et al., 2010).

2.5.2. The Mayo-Portland Adaptability Index-Fourth Edition (MPAI4, Malec, Kean, Altman, & Swick, 2012)

This is a 35-item measure of post-acute ABI rehabilitation outcome. Items relate to common post-ABI difficulties and are rated on a 5-point rating scale from 0 (difficulty not present) to 4 (severe problem that interferes with activities more than 75% of the time). There are three outcome subscales: Abilities (range 0-52), Adjustment (range 0-36) and Participation (range 0-32). There is also a subscale measuring pre-existing and associated conditions (range 0-24). It can be completed by a single practitioner, consensus of those working with the person with brain injury, the injured person or a significant other. In this rehabilitation programme it is completed by professional consensus. Normative data are available from a large sample of people with ABI. The MPAI4 has been found to be a valid, reliable measure of outcome following traumatic ABI (Kean, Malec, Altman, & Swick, 2011) and stroke (Malec et al., 2012). It is recommended by COMBI and the TBI Outcomes Workgroup (Wilde et al., 2010).

2.5.3. The Needs & Provision Complexity Scale (NPCS, Turner-Stokes, McCrone, Jackson, Siegert, 2013)

This questionnaire from the LTNC dataset (UK Department of Health, DOH, 2005) quantifies unmet needs following ABI using an ordinal scale (range 0-50) with five main domains (Healthcare, Personal Care, Rehabilitation, Social and Family Support and Environment) and fifteen subscales (e.g. Number of Carers, Care Frequency). It is divided into two parts, part A (NPCS-Needs) which assesses service needs and Part B (NPCS-Gets) which assesses service provision. The difference between the two is used to quantify unmet needs. Ratings are used to determine the number of staff required and the frequency of intervention needed. The NPCS includes a costing algorithm to estimate the cost of meeting unmet needs. It has been found to have excellent internal consistency (Cronbach's $\alpha = 0.94$), acceptable test-retest reliability (intraclass correlation coefficients ranging from 0.66 to 0.84) and demonstrates concurrent validity with expected relationships to other measures of need (Lynne Turner-Stokes et al., 2013).

2.6. Client Rated Supplemental Measures

2.6.1. The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983)

This is a 14-item measure of anxiety and depression in the context of physical health conditions. Seven items relate to anxiety and seven to depression. Items are rated on a four-point rating scale (0-3), with totals for both subscales ranging from 0 to 21. A score of 0-7 is considered within the normal range, 8-10 suggestive of borderline symptomatology and 11 or higher indicating the probable presence of a mood disorder. Reliability and validity (Whelan-Goodinson, Ponsford, & Schönberger, 2009) and two factor structure (anxiety and depression, Dawkins, Cloherty, Gracey, & Evans, 2006; Schonberger & Ponsford, 2010) have been established for the HADS with brain injured populations.

2.6.2. The Rosenberg Self-Esteem Scale (RSES, Rosenberg, 1965)

This is a 10-item questionnaire measure of self-esteem with established reliability and validity in use with people with acquired brain injury (Anson & Ponsford, 2006; Carroll & Coetzer, 2011; Cooper-Evans, Alderman, Knight, & Oddy, 2008). Items are rated on a four-point rating scale (strongly agree – strongly disagree) and scores are summed to provide a total score. Scores below 15 are indicative of clinically significant low self-esteem.

2.6.3. Forms of Criticism/Self Attacking and Self-Reassuring Scale (FSCRS, Gilbert, Clarke, Hempel, Miles, & Irons, 2004)

This is a 22-item measure of tendencies to respond to things going wrong with self-criticism or self-reassurance. Items are rated on a 5-point scale (0 = not at all like me to 4 = extremely like me). There are three subscales: inadequate self, hated self and self-reassurance. It has been found to have excellent internal consistency

(Cronbach's α = 0.90 for inadequate self and 0.86 for both hated self and reassured self) (Gilbert et al., 2004). The validity of the scale has been established for people with brain injury (Ashworth, Bauch, & Bateman, 2012).

2.6.4. Measure of Social Fit (Haslam et al., 2014)

A visual social fit scale with two items was designed for the study based on that used by Haslam et al. (2014) to measure change over time in the sense of fitting with social groups, both within rehabilitation and elsewhere. Sense of fit or belonging has been identified as a moderator of improvements in well-being in group-based intervention (Haslam et al., 2014) and the group 'milieu' has been identified as a core component and feature of this type of rehabilitation programme (Wilson et al., 2009). Both items were rated on a 7-point scale illustrated by pairs of circles (1 = no overlap between circles labelled "me" and "the OZC group" or "my groups" and 7 = maximum overlap between circles).

2.7. Client and Family / Partner Rated Supplemental Measures

2.7.1. The European Brain Injury Questionnaire (EBIQ, Teasdale et al., 1997)

This is a 63-item questionnaire measuring acquired brain injury symptoms. The frequency with which particular symptoms occur is rated on a 3-point rating scale: 1 (not at all), 2 (a little) or 3 (a lot). Scores can be calculated for subscales identified by a previous Rasch analysis: Somatisation, Cognition, Motivation, Impulsivity, Depression, Social Isolation, Physical symptoms, Communication, as well as a Global subscale (Bateman, Teasdale, & Willmes, 2009). There are parallel versions for self- and informant-report. A close family member or partner was asked to complete the informant rated version.

2.7.2. Revised DEX Questionnaire (DEX-R; Simblett & Bateman, 2011)

The original DEX questionnaire is a 20-item questionnaire measuring the frequency with which a number of dysexecutive behaviours occur on a five-point scale (0 = never and 4 = very often) with parallel versions for self- and informant-report (Burgess et al., 1996). A close family member or partner was asked to complete the informant rated version. The revised version of the DEX reorders the original 20 items and includes an additional 17 items. Scores on the revised DEX can be calculated for three subscales identified by a previous Rasch analysis: Behaviour, Cognition and Emotion (Simblett & Bateman, 2011). As with the EBIQ the difference between self- and informant-ratings is calculated to serve as a proxy for awareness of difficulties.

2.8. Data Preparation and Analysis

Prior to analysis of rehabilitation outcomes, variables with more than 40% missing data (8 of 20 patients) were excluded from analysis. The distribution of data for the remaining variables was examined using the Shapiro-Wilk test of normality and visual inspection. When Shapiro-Wilk tests showed data distributions deviated significantly from normality or they were visibly non-normal, Wilcoxon signed rank tests were used for paired samples analyses, otherwise paired samples t-tests were used. Mann-Whitney U tests were used to analyse differences at baseline between clients who subsequently completed the programme and those who did not. Effect sizes corrected for the degree of intercorrelation between variables were calculated for parametric tests.

3. Results

3.1. Demographics

Demographic data are summarised in Table 1. The rehabilitation clients ranged in age from 18 to 56 years and were predominantly white British (70%), men (75%), with further or higher education (65%), who were employed at the time of injury (65%) and who had suffered a TBI (70%), which was likely to have been classified as severe (71%).

Five clients did not complete the rehabilitation programme. They had all experienced TBI. They had acquired their injuries earlier (median age at injury = 18 years, IQR = 11 years) than had those who completed the programme (median age at injury = 39 years, IQR = 26 years) (Mann-Whitney $U = 13$, two-tailed $p = .032$). They had also been referred to the centre at a younger age (median age = 20 years, IQR = 11 years) than had those who completed the programme (median age = 40 years, IQR = years 23.5) (Mann-Whitney $U = 10$, two-tailed $p = .016$). The majority of clients who did not complete the programme did not engage with completion of the service satisfaction questionnaire. It is therefore not possible to assess whether they were less satisfied with the service than ‘completers’.

TABLE 1 ABOUT HERE

3.3. Engagement with Measure Completion

The proportion of missing data was examined for each outcome measure as an index of engagement with measure completion. Measures with greater than 40% missing data were identified as informant (i.e. family member or partner) rated measures (carer strain, EBIQ and DEX), client-rated measures taken at the 3- and 6-month follow-up meetings and baseline client-rated measures (with the exception of the Forms and Functions of Self-Criticism) for people who subsequently did not complete rehabilitation.

3.4. Rehabilitation Outcomes: Change Over Time

Change over time from week 1 to week 18 (end of programme) was analysed for the 15 clients who completed the programme. Significant positive changes were found in three of the seven core measures, as summarised in Table 2. At week 18, by comparison with week 1 there was a lower mean level of disability and dependency on the GOSE, statistically significant improved abilities and adjustment, and a trend to improved participation on the MPAI-4 and fewer unmet needs recorded on the NPCS. Three of the six supplemental measures also showed statistically significant positive changes, as summarised in Table 2. At the end of the programme there was a reduction in reported brain injury symptoms on the EBIQ, dysexecutive symptoms on the DEX-R and increased self-reassurance on the Forms and Functions of self-criticism questionnaire. There was also a trend towards lower levels of self-criticism expressing self-hatred on the Forms and Functions of self-criticism questionnaire.

Given the very small sample for conducting such comparisons, there is a risk of the analysis being underpowered to identify any effect. Effect sizes (Cohen's *d*, corrected for intercorrelations) are also shown in Table 2. This highlights medium sized effects for MPAI-4 Participation, Rosenberg Self-Esteem and Generalized Self-Efficacy that did not reach significance.

TABLE 2 ABOUT HERE

3.5. Differences between People Completing and Not Completing Rehabilitation

Table 3 shows the core and supplemental measures that identified differences at baseline in clients who subsequently completed or did not complete the rehabilitation programme. As well as having experienced TBI earlier than those subsequently completing the programme, the five clients who did not complete the programme had greater difficulties at baseline with adjustment and participation on the MPAI-4, perceived health on the EQ5D-3L, self-reported brain injury symptoms on the EBIQ, self-reported dysexecutive difficulties on the DEX-R and self-reported anxiety on the HADS. We have previously identified a subgroup including clients represented within the present data, who present with very high self-ratings of cognitive and emotional problems, low self-esteem, TBI, injury during childhood or adolescence and male gender (Gracey et al., 2014) .

TABLE 3 ABOUT HERE

3.6. Visualising Outcomes

A star-shaped radar plot was designed to simplify visualisation of outcome measurement for clients, staff and funders for key measures of rehabilitation (see Figure 1) following the example of the “FAM-splat” used to capture outcome measurement in inpatient rehabilitation (Lynne Turner-Stokes et al., 2012). The diagram simplifies visualisation of outcome measurement by focussing on a small number of key domains (attainment of client-centred goals, staff-rated MPAI4 subscales measuring abilities, adjustment and participation, self-reported perceived health and mood and service satisfaction), shown on a common 4-point scale represented using simple differences in colour (represented by grayscale shading in this paper) and position (severe difficulties/goals not achieved, moderate difficulties/goals started, mild difficulties/goals partially achieved, no difficulties/goals achieved). We chose to describe the outer points of the star to represent positive outcomes (e.g. happiness rather than depression) in order to present change in terms of progress towards a positive construct, rather than reduction of a negative construct, although recognise that this may be conceptually problematic as ‘absence of depression’ is not necessarily the same as ‘happiness’. We present this as an illustration of how selected measures might be represented to enhance engagement and perceived usefulness to clients, carers and staff. Therefore, additional or alternative measures could be included, depending on the nature of the service and client or carer’s preferences.

FIGURE 1 ABOUT HERE

4. Discussion

The current study focussed on the selection and completion of formal outcome measures for complex post-acute ABI rehabilitation interventions provided for a group of people with ABI whose needs are not routinely met in community rehabilitation services (Gladman et al., 2007). A key finding is that there were high rates of missing data indicating variable engagement with outcome measurement. Rather than affecting particular outcome measures, however, non-completion was associated with certain time-points and raters. Informants showed the highest level of non-completion. This may reflect the absence of a close family member to complete measures, staff engagement of family members in the rehabilitation process, time constraints due to carer burden, a lack of understanding of the importance of the role of family informants or the impact of relationship difficulties, which are relatively common after ABI (Kieffer-Kristensen & Teasdale, 2011). Rates of missing data for family informants were particularly high at baseline for clients who subsequently did not complete rehabilitation and it is possible that family or relationship factors contributed directly or indirectly to completion of rehabilitation. The particular mix of cognitive, emotional and social challenges for this client sub-group may have also been a factor in completion of measures. Non-completion of measures by family / partner informants limits the interpretation of measures intended for completion by both clients and family members, such as EBIQ and DEX. It also restricts informant-rated measurement to those carried out by staff in dedicated rehabilitation settings, rather than everyday environments. This risks underestimating the scale of the client's difficulties and the strain experienced by family carers or partners.

Rates of missing data were also high for client-rated measures completed at 3- and 6- month review meetings after rehabilitation. Measures at these time-points and by family informants at all time-points were completed without staff support. It is possible that, consistent with Turner-Stokes et al (2012) staff support or training might be required to understand and help address difficulties affecting measure completion. It is also noticeable that rates of missing data in staff-rated measures increased after rehabilitation, possibly due to competing time pressures once rehabilitation has been completed. This may limit the evaluation of the maintenance of gains over time after rehabilitation.

During rehabilitation a subset of outcome measures proved feasible to use and responsive to the impact of rehabilitation. Statistically significant improvements between the beginning and end of rehabilitation were shown on both self-report measures of symptoms and impairments (EBIQ and DEX) and team-rated measures of ability (or disability) and adjustment, (GOSE and MPAI4). These results suggest that clients felt that rehabilitation was successful in reducing the perceived level of impairments more than one year after injury, even in areas traditionally viewed as challenging, such as executive functioning. The GOSE results indicate an average improvement from upper severe disability to lower moderate disability. The MPAI4 results indicate a significant improvement from moderate-to-severe to mild-to-moderate limitations affecting adjustment to ABI and a smaller, but statistically significant, improvement in ability within the mild-to-moderate range. There was also a trend towards significance for the improvement in social participation from mild-to-moderate limitations to a good outcome, with effect size indicating that the analysis may have been underpowered to detect a statistically significant difference. Self-reassurance increased on the Forms and Functions of Self Criticism Scale and the level of unmet needs reduced on the NCPS at the end of rehabilitation, suggesting that improvements in outcome may be underpinned by changes in response to difficulties and targeting previously unmet needs. Although no statistically significant changes were found in measures of mood or social fit (which showed a possible ceiling effect), self-esteem or self-efficacy, medium effect sizes were found for the latter two measures which are also viewed as underpinning the success of rehabilitation (Wilson et al., 2009). It is possible that larger samples are required to detect small but clinically relevant changes in these measures, raising concern about their responsiveness to rehabilitation, and especially their interpretation when reported for a single client. Services reporting outcome data may need to consider issues of effect size and power, rather than relying on statistical significance testing, or make use of single case data analysis approaches, and carefully consider interpretation of change in scores when providing a clinical report for an individual client.

A subset of measures proved to be responsive to baseline differences between those who did and did not complete rehabilitation. Clients who did not complete rehabilitation were characterised by having experienced TBI at a younger age and having been referred closer to the date of their injury than those who completed rehabilitation. At baseline the ‘non-completers’ did not differ in team-rated disability (GOSE) but were rated by the team as having significantly greater difficulties with adjustment and social participation (MPAI4). They also differed in showing worse self-rated health (EQ5D3L), brain injury symptoms (EBIQ), executive functioning difficulties (DEX) and anxiety (HADS-A). These findings are consistent with studies highlighting risk of particularly poor executive, emotional and social outcomes for those who sustain TBI in childhood or adolescence. The findings also partially overlap with Cocksedge et al. (2014) who identified high social vulnerability as rated on the MPAI-4 and impaired executive functioning (in addition to lack of capacity to make one or more personal decisions) to be significant predictors of the need for indirect rehabilitation work (i.e. case management activity, liaison between agencies and with other professionals within the service, and providing carer support). Cocksedge et al. (2014) also found HADS scores correlated significantly with the number of rehabilitation sessions the client failed to attend. The ability to distinguish patient sub-groups at initial assessment suggests that it might be possible to use outcome measures to stratify patients in terms of rehabilitation needs, to select goals, and outcomes accordingly, and adapt the service provision to reflect what is required to address such complex needs.

A post-acute ABI radar plot similar to the “FAM-splat” (Lynne Turner-Stokes et al., 2012) was designed to illustrate how complex information from key outcome measures might be represented simply. This includes established and recommended measures of post-acute community-based rehabilitation in line with the WHO ICF, such as goal achievement, ability, adjustment and social participation, supplemented with measures of mood and perceptions of health and service satisfaction to include the wider impact of rehabilitation and patient experience. The post-acute ABI star facilitates visualisation of data from a selection of key outcome measures, rather than a single measure as shown in the “FAM-splat”, providing a reflection of the scope of changes resulting from post-acute rehabilitation. At this stage in the pathway of recovery it is realistic to attempt to use visualisation of outcomes as a means to improve engagement in outcome measurement not only for staff, as with the “FAM-splat”, but also with clients and their families, because they are likely to be interested in a range of variables, including, but not limited to, traditional rehabilitation outcomes such as social participation and also emotional well-being. Reframing of the constructs being measured as positive statements may also help foster focus in rehabilitation on the development of strengths and hope for the future, rather than absence of negatives, which may help with motivation. However, issues of conceptual clarity and ecological validity need to be considered here. We are currently piloting the use of the post-acute ABI radar plot with clients and their families.

This study concerns a small sample of people with ABI treated at a national tertiary specialist centre for significant, complex difficulties that had persisted despite input from their local primary and secondary services. Further research is required to test the extent to which the results generalise to other services and whether simple visualisation of outcomes in post-acute rehabilitation facilitates engagement with outcome measurement. Outcome items included in the visualisation figure reflect a subset of those that might be pertinent in community neuro-rehabilitation. For instance the measure of social belonging was not sensitive to change, however, belonging is a key aspect of subjective positive outcome for many. Our study highlights the potential relevance of service process measures (such as completion of outcome measures, attendance at planned rehabilitation sessions) as potentially informative. Staff factors in the completion of outcome measurement were not systematically studied, and our conclusions are also limited to the specific rehabilitation model being delivered by a single service. Nevertheless, the results suggest that there may be an interaction between the delivery of rehabilitation, collection of meaningful and analysable outcome data and the rehabilitation change process, for at least some clients. For example, it may be that someone with a pre-injury psychiatric history before a severe TBI in childhood may present with difficulties that present a challenge for participation in rehabilitation and collection of meaningful assessment and outcome data, challenges that might further effect the smooth delivery of rehabilitation, with further consequences for the client and their family. It is important to conceptualise the factors that might impact upon accessing rehabilitation (including outcome measurement) from a systemic perspective, such that the relevant staff, family or client supports can be put in place. Such ‘indirect’ service activity needs to be studied further and recognised by funders. The current study also provides evidence that specific client, family and staff measures of impairment, ability and social participation recommended by at least one review or government agency (e.g. GOSE, MPAI4, EBIQ, DEX) are responsive to improvements following rehabilitation in a real-world service evaluation context, some of which also distinguish those completing rehabilitation from those who do not (e.g. MPAI4, EBIQ, DEX). Process measures of self-esteem and self-efficacy showed medium effect sizes and should therefore be considered important aspects of the change process as found previously, but the small sample size here meant that these changes did not reach statistical significance. Outcome measures that are not specific to ABI, such as the EQ5D and HADS proved useful for making this distinction, but they did not show improvements as a result of this particular rehabilitation programme.

Declaration of Interest

All authors declare they have no financial and personal relationships with other people or organizations that could inappropriately influence their work.

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Tables

Table 1 Demographic Characteristics and Service Satisfaction

	Clients completing programme (N = 15)		Clients not completing programme (N = 5)		Total	
Age at referral (median)	40		20		32.5	
Age at referral (interquartile range)	25		12		26.0	
Sex						
Men	11	73%	4	80%	15	75%
Women	4	27%	1	20%	5	25%
Ethnicity						
White UK	11	74%	3	60%	14	70%
Black UK	0	0%	1	20%	1	5%
Mixed race UK	0	0%	1	20%	1	5%
Black African	2	13%	0	0%	2	10%
Missing	2	13%	0	0%	2	10%
Education						
No qualifications	1	7%	1	20%	2	10%
School qualifications	3	20%	2	40%	5	25%
Further Education	4	27%	2	40%	6	30%
Degree or above	7	47%	0	0%	7	35%
Occupation (at time of injury)						
Employed	10	67%	3	60%	13	65%
Studying	3	20%	0	0%	3	15%
At school	1	7%	2	40%	3	15%
Volunteering	1	7%	0	0%	1	5%
Pre-injury Psychiatric History (Primary problem counted, all had co-morbidities)						
Drug misuse	0	0%	1	20%	1	5%
Alcohol misuse	4	27%	1	20%	5	25%
Mental health history	2	13%	1	20%	3	15%
Age at injury (median)	39		18		27.5	
Age at injury (interquartile range)	27		13		27	
Type of acquired brain injury						
Traumatic Brain Injury	8	53%	5	100%	13	65%
Stroke	5	33%	0	0%	5	25%
Neurosurgery	1	7%	0	0%	1	5%
Infection	1	7%	0	0%	1	5%
Severity of Traumatic Brain Injury						
Severe	6	40%	4	80%	10	50%
Not classified / not appropriate	3	60%	1	20%	10	50%
Service Satisfaction at week 18 (rated good or excellent or agree / strongly agree)						
Quality of Clinical Service	11	73%	1	20%	12	60%
Confidence in staff	10	67%	0	0%	10	50%
Treated with respect and dignity	9	60%	0	0%	9	45%
Involved in decisions	10	67%	1	20%	11	55%
Would recommend service	11	73%	1	20%	12	60%
Missing	4	27%	4	80%	8	40%

Table 2 Rehabilitation Outcomes: Change Over Time (baseline to 18 weeks)

	Baseline (week 1)		End of Rehabilitation Programme (week 18)		Statistical significance of differences over time			Effect size (Cohen’s *d* corrected for intercorrelations – parametric tests only)
	Mean or Median	SD / IQR	Mean or Median	SD / IQR	Statistic	*df*	*p*	
CORE MEASURES								
1. Glasgow Outcome Scale – Extended (GOSE)	4.43	1.09	4.86	1.29	$t = -2.482$	13	0.028*	0.34
2. Mayo-Portland Adaptability Inventory – 4 (MPAI4)								
Abilities (standard score)	46.00	5.97	41.00	8.50	$t = 3.516$	13	0.004*	0.62
Adjustment (standard score)	52.71	6.90	45.93	9.08	$t = 3.960$	13	0.002*	0.81
Participation (standard score)	42.79	5.65	38.79	7.22	$t = 2.048$	13	0.061	0.61
Total	46.79	5.75	39.64	8.88	$t = 4.051$	13	0.001*	0.88
3. The Needs and Provision Complexity Scale (NPCS) for Long Term Neurological Conditions (LTNC)	7.67	5.60	4.13	3.56	$t = 2.352$	14	0.034*	0.74
4. The Euroquol EQ5D-3L visual analogue scale (0-	64.69	19.26	59.62	23.45	$t = 0.689$	12	0.504	0.24

100)								
5. The Euroquol EQ5D-3L index value	0.71	0.51	0.71	0.25	*Z* = -.979		0.328	
6. General Self Efficacy Scale (GSE)	27.00	4.71	29.00	5.41	*t* = -1.720	13	0.109	0.39
7. Modified Carer Strain Index (mCSI)	76.83 (N = 12)	41.81	57.63 (N = 8)	38.70				.
SUPPLEMENTAL MEASURES								
8. The European Brain Injury Questionnaire (EBIQ								
Self	116.92	17.92	106.23	25.39	*t* = 2.132	12	0.054*	0.46
Informant	122.71	23.05	103.29	28.60				
9. DEX Questionnaire Revised								
Self	54	36	43	42	*Z* = 2.045		0.041*	
Informant	69	57	34	27				
10.The Hospital Anxiety and Depression Scale								
Anxiety	9	8	5	6	*Z* = -.868		0.385	
Depression	8	4	8	8	*Z* = -.494		0.621	

11. Rosenberg Self-Esteem Scale (RSES)	17.62	5.01	19.54	4.46	$t = -1.286$	12	0.223	0.40
12. Forms of Criticism/Self Attacking and Self-Reassuring Scale								
Inadequacy	18	15	13	11	$Z = -0.416$		0.678	
Self-hatred	5	5	0	1	$Z = -1.739$		0.082	
Self-reassurance	16	9	23	9	$Z = -2.048$		0.041*	
13 Social Fit								
With rehab peers	5	3	6	3	$Z = -1.091$		0.275	
With other social groups	5	4	6	4	$Z = -0.762$		0.446	

* = Statistically significant at $p \leq .05$

Table 3 Differences Between People Completing and Not-Completing Rehabilitation

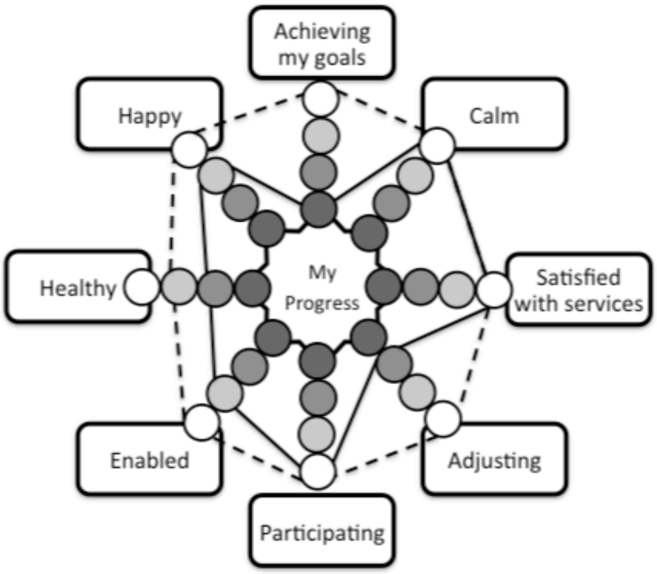
	Completing programme (N = 15)		Not completing programme (N = 5)		Statistical significance of between group differences		Clinical interpretation and significance of between group differences
	Median	IQR	Median	IQR	Z	*p*	
Core Measures	4	1	4	0	-0.509	0.611	
1. Glasgow Outcome Scale – Extended (GOSE)							
2. Mayo-Portland Adaptability Inventory – 4 (MPAI4)							
Abilities (standard score)	47	7.5	75	5	-0.700	0.484	
Adjustment (standard score)	55	6	67	10	-2.547	.011*	Greater difficulties with adjustment and participation at baseline in people who went on not to complete the programme.
Participation (standard score)	43	7	53	8	-2.273	.023*	
Total (standard score)	47	4.5	53	4	-2.497	.013*	
3. The Needs and Provision Complexity Scale (NPCS) for Long Term Neurological Conditions (LTNC)	6	7.5	12	7	-1.098	0.272	
4. The Euroquol EQ5D-3L visual analogue scale (0-100)	70	29.5	40	11.25	-2.410	0.016*	Worse perceived health status at baseline in people who went on not to complete the programme.
5. The Euroquol EQ5D-3L index value	0.73	0.15	0.26	0.64	-1.926	0.054*	
6. General Self Efficacy Scale (GSE)	28	5	25	2.25	-1.504	0.133	
7. Modified Carer Strain Index (mCSI)	77	77.5	87	20.5	-0.215	0.830	
Supplemental Measures							
8. The European Brain Injury Questionnaire (EBIQ)							

Self	114	27	145	8	-2.201	0.028*	Higher levels of self-reported brain injury symptoms in those going on not to complete the programme.
Informant	131	28	144	5	-1.504	.133	
9. DEX Questionnaire Revised							
Self	51	27	82	22	-2.503	.012*	Higher levels of self-reported dysexecutive difficulties in those going on not to complete the programme.
Informant	66	47	84	12	-0.987	0.324	
10 The Hospital Anxiety and Depression Scale							
Anxiety	7	6	12	2	-2.055	0.040*	Higher self-reported anxiety in those going on not to complete the programme.
Depression	8	4	13	8	-1.614	0.106	
11 Rosenberg Self-Esteem Scale (RSES)	15	8	15	4	-0.552	0.581	
12 Forms of Criticism/Self Attacking and Self-Reassuring Scale							
Inadequacy	15	15	22	7	-1.268	0.205	
Self-hatred	2	5	5	1	-0.748	0.455	
Self-reassurance	17	9	15	4	-1.006	0.314	
13 Social Fit							
With rehab peers	5	2	4	3	-0.822	0.411	
With other social groups	5	4	4	4	-0.916	0.360	

* = Statistically significant at $p \leq .05$

Figure Captions

Figure 1. Post-acute ABI Rehabilitation star radar plot, illustrating one client’s outcome (solid line week1, dashed line end of programme)



	●	◉	◍	○
Achieving my goals	Rehabilitation goal/s not achieved	Rehabilitation goal/s started	Rehabilitation goal/s partially achieved	Rehabilitation goal/s achieved
Happy	Severe low mood (HADS D 15-21)	Moderate low mood (HADS D 11-14)	Mild low mood (HADS D 8-10)	Normal / Happy (HADS 0-7)
Calm	Severe anxiety (HADS A 15-21)	Moderate anxiety (HADS A 11-14)	Mild anxiety (HADS A 8-10)	Normal / Calm (HADS A 0-7)
Healthy	0-24% self-rated health (EQ5D)	25-49% self-rated health (EQ5D)	50-74% self-rated health (EQ5D)	75-100% self-rated health (EQ5D)
Satisfied	Not satisfied with service	Satisfied with few aspects of service	Satisfied with most aspects of service	Highly satisfied with all aspects of service
Enabled	Severe limitations compared to others with ABI (MPAI4 T > 60)	Moderate to severe limitations compared to others with ABI (MPAI4 T 50-59)	Mild to moderate limitations compared to others with ABI (MPAI4 T 40-49)	Relatively good outcome / mild limitations compared to others with ABI (MPAI4 T < 39)
Adjusting	,,	,,	,,	,,
Participating	,,	,,	,,	,,