MAIN ARTICLE

Full title:
Measuring changes in functional ability in older children and young people with acquired brain injury using the UK FIM+FAM

Short Title:
Responsiveness of the UK FIM+FAM in older children and young people with ABI

Keywords:

Functional ability, paediatrics, outcome measurement, brain injury, UK Functional Independence Measure + Functional Assessment Measure

Abstract:

Introduction: There is a need for validated and responsive measurement tools to demonstrate changes in functional ability. Existing outcome measurement tools have significant limitations for children and young people with acquired brain injury (ABI).

Aim: This study examines the potential of the UK Functional Independence Measure + Functional Assessment Measure (UK FIM+FAM) to detect clinical change in older children and young people with ABI.

Methods: Secondary retrospective pretest-post test analysis of 72 children and young people age 8-17 years. Internal responsiveness was examined using Wilcoxon signed-rank tests and effect sizes indices; external responsiveness was examined in relation to the Neurological Impairment Scale (NIS) using Spearman's correlation coefficient.

Results: Highly significant changes were detected from admission to discharge on Motor, Cognitive and total UK FIM+FAM scores ($p<0.001$). Medium to large effect sizes were found on the total scale indicating good internal responsiveness. There was a significant, negative correlation between UK FIM+FAM change scores and NIS change scores ($p<0.01$) indicating good external responsiveness.

Conclusion: The UK FIM+FAM was able to detect clinically meaningful change in functional ability in children and young people with ABI over 8 years. Further validity and reliability must be established before recommending its use in this client group.

Introduction

Acquired brain injury (ABI) is a major cause of childhood disability with around 40,000 children experiencing an ABI every year in the UK (National Health Service (NHS), 2013). ABI can be traumatic, resulting from a trauma to the head, or non-traumatic, caused by cerebral anoxia, brain tumour, stroke, toxic or metabolic damage, or brain infection (Royal College of Physicians (RCP) and British Society of Rehabilitation Medicine (BSRM), 2003). ABI in children is a complex condition and can impair motor, cognitive, social, and behavioural functions (College of Occupational Therapists (COT), 2015). These

impairments can affect a child's occupational performance, restricting their participation in their daily occupations and home, school, community and family life (COT, 2015; Anderson et al., 2012).

The role of occupational therapy in the rehabilitation of children and young people with ABI is to maximise participation in daily life (COT, 2015). Measurement of change in areas of relevance to occupational therapists using validated tools is important as it allows us to evaluate the effectiveness of our services and facilitates high quality research, which can demonstrate the value of occupational therapy to commissioners (COT, 2013). However there is still limited use of standardised outcome measures with children and young people with ABI, and a dominance of impairment-focused measures which do not capture changes in meaningful occupation (Gordon, 2014; Tal and Tirosh, 2013, Jones et al, 2007).

Occupational therapists face additional challenges when selecting outcome measures for older children and young people with ABI. Many existing child-specific measures are designed for, and validated on, children with congenital neurodevelopmental conditions, and are based on principles of typical child development. This affects their validity for use with children and young people

with ABI who have experienced a potentially lengthy phase of typical development prior to their injury (Wales and Dunford, 2011). The age of the child is another important consideration. The occupational engagement and priorities of teenagers and young adults, potentially including romantic relationships, higher study or work, differ widely from those of young children still primarily concerned with play and meeting their basic developmental milestones (Case-Smith, 2015). Outcome measures validated for use in adults with ABI merit consideration, as they may provide relevant and sufficiently challenging test items for older children and young people with ABI (Wales and Dunford, 2011).

One tool which has potential to be clinically useful for this client group is the UK Functional Independence Measure + Functional Assessment Measure (UK FIM+FAM) (Turner-Stokes et al., 1999). The UK FIM+FAM is a measure of functional ability across two domains, motor and cognitive, which was originally developed for adults with ABI. A recent mapping exercise of the UK FIM+FAM demonstrated that the items of the measure primarily map onto the “Activities and Participation” domains of the International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) (World Health Organization, 2007) supporting its potential as an outcome measure of

functional ability (Dunford et al., 2013). The UK FIM+FAM is one of the most extensively researched and used outcome measures in adult neurorehabilitation services in the UK (Skinner and Turner-Stokes, 2006). It is valid, reliable and responsive for adults in inpatient settings (Nayar et al., 2016; Turner-Stokes and Siegert, 2013) and community settings (Wilson et al, 2009). Outcome data from this measure is currently used to influence NHS funding decisions for neurorehabilitation services across the UK (Turner-Stokes et al., 2012), including some services for children and young people with ABI (Dunford et al., 2013). Given these implications for funding and commissioning of ABI services for children and young people with ABI it is important to establish whether the UK FIM+FAM is valid, reliable and able to capture clinical change in a younger client group.

At present there is little published evidence supporting the psychometric properties and clinical utility of the UK FIM+FAM for older children and young people with ABI. There is evidence that the UK FIM+FAM is valid and responsive in adults and young people with ABI aged 15+ (Turner-Stokes and Siegert, 2013), however younger participants were a minority within the study. Therefore the extent to which these findings apply to young people with ABI is unclear. In addition to the mapping exercise detailed above, some initial work

has been completed which supports the clinical utility of the tool in children and young people with ABI aged 8-17 years (Wales, Dunford and Grove, 2014). More recently work has been completed on the concurrent validity of the tool compared with the School Functional Assessment (SFA), a standardised measure for children, which found significant correlations between the UK FIM+FAM and SFA at item by item level, motor and cognitive subscales and for the total scores demonstrating concurrent validity (Callen et al., 2017). Reliability of the UK FIM+FAM has been well established within the adult population (Turner-Stokes and Siegert, 2013). However there have been no studies which establish reliability of the measure when used specifically with older children and young adults, as confirmed in a database search performed by the authors between 1999 and August 2017.

The current study examines the ability of the UK FIM+FAM to detect clinical change over time in children and young people with ABI, a property commonly referred to as responsiveness. The study uses retrospective data obtained through routine clinical practice. Typically validity and reliability are established prior to examining responsiveness however it was not possible to examine these properties with existing data. For this reason an exploratory study into responsiveness was carried out with a view to planning subsequent prospective studies on validity and reliability if the results from this study indicate that the

UK FIM+FAM merits further investigation. This is in line with recommendations by the College of Occupational Therapists for occupational therapists to examine routine clinical data (COT, 2013) and ethical considerations that restrict access to this client group for prospective research studies (Donders, 2013).

There are several dimensions of responsiveness which can be examined. Internal responsiveness is "the ability of a measure to change over a pre-specified time frame", and external responsiveness "the extent to which changes in a measure over a specified time frame relate to corresponding changes in a reference measure of health status" (Husted et al., 2000, p. 459). Another aspect of responsiveness to consider is the level of floor and ceiling effects, which considers the number or percentage of participants with the lowest or highest possible score on the measure respectively (Laver-Fawcett, 2007). Ceiling effects may indicate that the assessment did not capture all clinical change, whilst floor effects may imply that the measure is not sensitive enough to detect minimal clinical changes (*ibid.*).

Aim

The overall aim of this study was to explore the ability of the UK FIM+FAM to detect clinically meaningful changes in older children and young people with acquired brain injury. To meet this aim the following three aspects of responsiveness were explored:

1. The internal responsiveness of the UK FIM+FAM
2. The external responsiveness of the UK FIM+FAM
3. The presence of floor and ceiling effects of the UK FIM+FAM

Methods

Design

This study examined clinical data using a retrospective one group pretest-posttest design (Portney and Watkins, 2009).

Instrumentation

UK FIM+FAM

The UK FIM+FAM has 30 items, divided into a motor domain and a cognitive domain, as well as an optional Extended Activities of Daily Living scale. The FAM (12 items) is an adjunct to the FIM (18 items) to address cognitive,

communication and psychosocial functional domains of importance in ABI rehabilitation, which were inadequately covered by the FIM (Turner-Stokes et al., 2009; Turner-Stokes et al., 1999). Each item is rated on a 7-point scale, from a score of 1 indicating total assistance to 7 indicating complete independence (see table 1).

Table 1. Content of the UK FIM+FAM (Each item rated on score range 1-7)

Motor domain (16 items)	Eating; Swallowing*; Grooming; Bathing; Dressing Upper Body; Dressing Lower Body; Toileting; Bladder management; Bowel management; bed/chair/wheelchair transfer; Toilet transfer; Tub/Shower Transfer; Car Transfer*; Locomotion: walking/wheelchair; Stairs; Community mobility*
Cognitive domain (14 items)	Comprehension; Expression; Reading*; Writing*; Speech Intelligibility*; Social interaction; Emotional Status*; Adjustment to Limitations*; Leisure Activities*; Problem Solving; Memory; Orientation*; Concentration*; Safety Awareness*
Optional scale: EADL items (6 items)	Meal Preparation; Laundry; Housework; Shopping; Home Finances; Work/education

*FAM items

Neurological Impairment Scale (NIS)

The NIS is a standardised measure that provides information on the nature and level of impairment of patients with neurological conditions. This tool can assist clinicians in controlling sample characteristics and identify differences in functional progress after rehabilitation. It consists of 17 items rated 0-2 or 0-3, with a possible total score range of 0-50. A score of 0 indicates no impairment, and a score of 50 indicates the most severe level of impairment. The NIS is a valid and reliable measure for use in the ABI population and is widely used clinically (Turner-Stokes et al., 2014). Whilst it has not yet been specifically validated for children and young people, the NIS was selected as a comparison measure with the UK FIM+FAM due to availability of data from the two time-points pre and post intervention and reasonable assumption that there would be a relationship between impairment (as measured by the NIS) and functional ability (measured by the UK FIM+FAM).

Data Collection

Use of a retrospective design facilitated access to data difficult to gather

prospectively due to challenges gaining informed consent from children with ABI (Donders, 2013). Data for this study were obtained from the existing database of one neurorehabilitation service for children and young people with ABI located in the UK. Two sets of de-identified data were provided by the neurorehabilitation service. The data consisted of UK FIM+FAM scores and NIS scores, taken pre- and post-clinical intervention, as well as descriptive data of participants' characteristics (see table 2). No data cleaning was performed prior to the authors obtaining the data. The UK FIM+FAM and NIS are routinely administered to patients aged over 8 years admitted to the service, within approximately 2 weeks of admission and 2 weeks of discharge. Several multidisciplinary team members collaborate to administer different areas of these measures: occupational therapists, speech therapists, physiotherapists, and sometimes, clinical psychologists, teachers and members of the play team. Team members received training for administering the UK FIM+FAM and NIS and cascaded the training to other staff. An internal developmental norms guide was made available to clinicians to assist in administering the UK FIM+FAM. The guide provides a reference for judging the level of occupational performance skills and independence typically expected at different developmental stages in childhood and young people.

Data Analysis

Several analysis methods were used to examine internal responsiveness. Firstly admission and discharge data were analysed descriptively by comparing median admission and discharge scores to observe trends. Inferential statistical analyses were then performed. A Wilcoxon Signed Rank test was used to establish whether changes observed were significant. Cohen's effect sizes *d*, Standardised Response Means (SRM) and non-parametric effect sizes were subsequently calculated to identify the magnitude of the change. These three types of effect sizes were calculated to provide further confidence in findings, due to the lack of consensus on which effect size is the most appropriate measure of responsiveness (Corder and Foreman, 2009). Both Cohen's effect size and SRM indices are usually interpreted as value of .20 or less = small amount of change; .50 or higher = medium; and .80 or higher = large. The non-parametric effect size is usually interpreted as .10 = small amount of change; .30 = moderate, and .50 = large (Cohen, 1988).

To examine external responsiveness, a Spearman correlation test was performed to identify any correlation between NIS and UK FIM+FAM scale. The use of the NIS alongside UK FIM+FAM has been recommended to assist in

interpreting change, and to inform a case-mix adjustment for clinical studies (Turner-Stokes et al., 2014).

To establish floor and ceiling effects, proportions of children scoring lowest and highest possible scores on the UK FIM+FAM, at admission and discharge were examined using frequencies analysis.

Data analyses were performed with IBM SPSS Statistics Package for Mac OS Version 20.0.00 (Armonk, NY).

Ethical Approval

Ethical approval of this research was granted by <BLINDED>. Consent was not required since this was a retrospective study.

Results:

Participants

The sample consisted of 72 children and young people aged 8-17 years (median=13 years), admitted for neurorehabilitation between October 2010 and December 2014. Demographic and clinical characteristics of the sample are described in Table 2.

Table 2. Sample characteristics

Number of participants	72
Age at admission (months)	
Mean (SD)	161 (32.4)
Median	161.5
Range	97-214
Length of rehabilitation stay (weeks)	
Mean (SD)	24.2 (17.6)
Median	17
Range	3-90
Time from Injury to Admission (weeks)	
Mean (SD)	28.7 (31.6)
Median	17.5
Range	7-190
Injury Type *n, (%)*	
TBI	34 (47.2)
NTBI	38 (52.8)
Brain Tumour	11 (15.3)
Vascular Accident	18 (25)
Infection	7 (9.7)
Other	2 (2.8)
Impairment severity* (NIS Admission score)	
Median (IQR)	26 (20)
Range	5-44

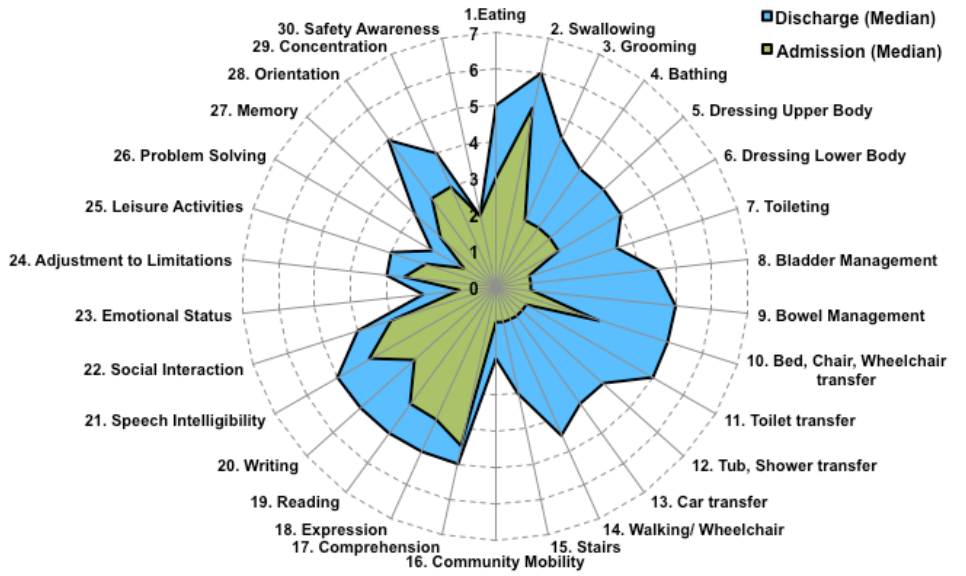
SD: Standard Deviation; TBI: Traumatic Brain Injury; NTBI: Non-traumatic Brain Injury; NIS: Neurological Impairment Scale; IQR: Interquartile Range

*Data available for 67 patients only

Internal responsiveness of the UK FIM+FAM

A “FIM+FAM Splat” was generated to illustrate median scores at admission and discharge (see Figure 1). The splat provides an initial indication of the clinical change that was captured for each FIM+FAM item at sample level. Items are displayed around the outside of the dial, and scores are plotted from zero in the centre to seven outwards. The green area represents average baseline data and the blue area represents average clinical change. On average, the tool detected an increase in scores pre and post intervention.

Figure 1: FIM+FAM Splat: Median admission and discharge scores at sample level



Wilcoxon Signed Rank tests showed that highly significant change was detected from admission to discharge in the UK FIM+FAM total scale and both Motor and Cognitive subscales (see table 3). Therefore the UK FIM+FAM was sensitive to change in this population. Large effects were observed on all scales (Cohen, 1988). Overall, less change was detected on Cognitive subscales than

Motor subscales.

Table 3: Internal Responsiveness of the UK FIM+FAM

Scale	Median Change Scores (IQR)	Wilcoxon Signed Rank Test	Effect Size *d**	SRM**	Non-parametric effect Size***
FIM+FAM Motor	11.5 (29)	z = -6.49, p < 0.001	0.54	0.89	0.54
FIM+FAM Cognitive	7 (12)	z = -6.38, p < 0.001	0.42	0.86	0.53
FIM+FAM Total	19 (39)	z = -6.90, p < 0.001	0.54	0.95	0.58

FIM+FAM: Functional Assessment Measure; IQR: Interquartile Range; SRM: Standardised Response Mean

*Effect size d = difference between discharge and admission scores, divided by the standard deviation of admission scores (Cohen, 1988)

**SRM: Standardised Response Mean = difference between discharge and admission scores, divided by the standard deviation of change scores (Husted, 2000)

***Non-parametric effect size = absolute Wilcoxon z score, divided by the square root of the total number of observations on which z is based (Field, 2013)

External responsiveness of the FIM+FAM

There were moderate to strong negative correlations between NIS change scores and the UK FIM+FAM total change scores (Spearman's rho = -.741, p < .01), Motor change scores (Spearman's rho = -.736, p < .01) and Cognitive change scores (Spearman's rho = -.646, p < .01); and these correlations were all significant. This means an increase in functional ability (indicated by an

increase in UK FIM+FAM scores), was associated with a decrease in impairment (indicated by a decrease in NIS scores). This confirms that the UK FIM+FAM was able to detect change when the NIS identified change in this sample, indicating good external responsiveness.

Floor and ceiling effects

For the total UK FIM+FAM, there was a floor effect of 15.3% at admission and 6.9% at discharge. This implies that the UK FIM+FAM was too challenging for 15.3% of children at admission and 6.9% at discharge. No ceiling effects were found. This implies that there was a large scope for detecting further clinical change in functional ability using the UK FIM+FAM. There were floor and ceiling effects on the UK FIM+FAM Motor subscale (11.1% and 1.4% respectively) at discharge. This implies that some children may have improved further in their performance of motor task than was detected by the FIM+FAM. For example the measure would show that a child improved from requiring assistance for dressing to being able to dress independently at discharge, however the measure would not detect any further improvements in task performance such as less time or effort required for the task. There were higher floor effects on the UK FIM+FAM Cognitive subscale at discharge (13.9%) than the Motor subscale; and no ceiling effects. There were no floor or ceiling effects on the NIS scale at admission and discharge.

Discussion and implications:

This exploratory study sought to investigate the responsiveness of the UK FIM+FAM for older children and young people, to consider whether this tool merits further investigation as an outcome measure for a younger population.

With regards to internal responsiveness, significant change was found with medium to large effect sizes on all scale. This suggests that the UK FIM+FAM had a good level of internal responsiveness with the population studied. Previous studies of adults and young people over 15 years also show the UK FIM+FAM's ability to detect highly significant change over time with its motor, cognitive and total scales ($p < 0.001$) (Turner-Stokes et al., 2013; Turner-Stokes et al., 2009; Wilson et al., 2009). Effect sizes, however, were lower in this study than those found in Turner-Stokes et al. (2013; 2009), and the floor effects observed at discharge have not been reported in any other study of the UK FIM+FAM. Both these findings may be due to developmental differences. It is feasible that younger participants are not old enough to be expected to complete tasks without full adult assistance, which may have contributed to the floor effects found in this study. An examination of other potential variables

which may have affected responsiveness levels, including age, is necessary to further interpret these differences.

Although findings of internal responsiveness are encouraging, some authors claim that this type of responsiveness only relates to statistical change on the measure, which may not always be clinically meaningful to clinicians, patients and commissioners (Stratford et al., 2005; Husted et al., 2000). For this reason external responsiveness was also examined as a better measure of clinically meaningful change. Moderate to strong negative correlations were found between NIS change scores and the UK FIM+FAM total change scores. Given that a decrease in impairment is associated with an increase in functional ability in this population these results provide strong support for the ability of the UK FIM+FAM to detect clinically meaningful change.

Floor and ceiling effects were investigated as these can limit the responsiveness of a measure (Laver-Fawcett, 2007). Slight floor effects were observed at discharge for the total UK FIM+FAM scale: 5 children (6.9%) remained fully dependent at discharge in the performance of their everyday activities. If their functional ability deteriorated, this was not detected by the UK FIM+FAM, as they already scored at the lowest point on the scale (Portney and

Watkins, 2009). Perhaps the tool may be less relevant for children or young people at early stages of rehabilitation, with higher level of impairments, or with certain types of brain injury. Meanwhile, there were no ceiling effects at discharge indicating that the UK FIM+FAM would be able to detect further improvements in functional ability. This suggests the tool also has potential to be responsive for children and young people with ABI with a higher functional ability at baseline. These may include older children, those with less severe injuries or children in later stages of rehabilitation of such as in community settings.

The UK FIM+FAM detected more change in the motor domain than in the cognitive domain. These findings may be interpreted in several ways. The UK FIM+FAM may be less sensitive in the cognitive domain, meaning that another, more responsive measure would have identified more change in same sample. However, previous studies of responsiveness of the UK FIM+FAM in adults and young people over 15 years with ABI, and of paediatric measures in children with ABI, also found less change detected over time in cognitive functioning than motor functioning (Bedell, 2008; Thomas-Stonell et al., 2006). Research indicates that the recovery of social and cognitive skills tends to be more gradual, and deficits emerge later, sometimes years after the injury, as

environmental demands become greater (Limond et al., 2014). This suggests that the UK FIM+FAM may have detected all cognitive change that occurred despite this being a lower level of change than those observed in the motor domain. It is worth noting that a smaller improvement on this scale in areas such as concentration or problem-solving at this stage of rehabilitation may be equally meaningful to the child or young person as motor skills such as being able to use a wheelchair (Hammond et al., 2004).

Overall, the examination of several dimensions of responsiveness: internal responsiveness, external responsiveness and the presence of floor and ceiling effects, indicates that the UK FIM+FAM was able to detect meaningful clinical change in this sample, with only a relatively small floor effect noted. The range of analysis methods used to examine responsiveness supports the robustness of these findings. Although a convenience sample was used the sample was relatively large (>50) (Husted et al, 2000) and heterogeneous in terms of demographic and clinical characteristics increasing the likelihood that it is sufficiently representative of the target population (Dunford et al., 2013). These findings indicate the potential of the UK FIM+FAM to be a responsive measure for the wider population of child and young people with ABI. There are key limitations to this study, notably around validity and reliability of the tool, which

mean that results must be interpreted with caution and further research is recommended before the tool can be recommended for routine clinical practice.

Limitations and future research

For this study a pragmatic decision was made to carry out an exploratory examination of responsiveness of the UK FIM+FAM using available clinical data as a first step in the process of validating this tool for use with older children and young people. Validity and reliability of this measure, whilst well established in the adult population, are yet to be established sufficiently for a younger population. In this particular study, one factor that may have further affected reliability is the use of a developmental norms guide to assist with rating items. Due to use of retrospective data it is not possible to establish whether clinicians were using it consistently. Without evidence of intrarater and interrater reliability, it cannot be guaranteed that ratings at the two time points have not been affected by large measurement errors (Portney and Watkins, 2009).

Similarly there is insufficient evidence of the validity of the UK FIM+FAM with this population. If a tool's validity is not adequate for a specific purpose, it may

still be responsive but will not capture relevant outcomes (Portney and Watkins, 2009). This is an important consideration for occupational therapists who are seeking a measure that captures changes in domains of relevance to our profession.

Furthermore, the concept of meaningful change is different for each individual with ABI due to the heterogeneity of impairment level, brain injury and life circumstances (Turner-Stokes et al., 2009). As the UK FIM+FAM does not capture personal satisfaction regarding performance, the use of an outcome measure of personal goals alongside the tool may contribute to a more informative representation of change. It is also not possible to get the maximum score if the child or young person uses an assistive device. Measuring personal goals may provide an additional opportunity to capture change in the minority of older children or young people whose score remained at the floor of the UK FIM+FAM at discharge. Other measures may also complement the UK FIM+FAM by measuring relevant domains not covered, or insufficiently covered by the tool. Further research is required to examine which other measures could be recommended for use alongside the tool as part of a basket of measures.

There are also some minor limitations to this study with regards to data analysis. Several effect size indices have been proposed in the literature to assess internal responsiveness, albeit with the same criteria for interpreting results (Cohen, 1988). The lack of consensus makes it difficult to fully establish the appropriateness of the methods used and their interpretation. Furthermore it should be noted that there were missing data for NIS scores of 5 participants. These issues may have affected the data analysis and affect the reliability of the findings.

Due to the limitations of this study the authors recommend that further research would be required before recommending the use of the UK FIM+FAM in routine clinical practice with this population. Most importantly the psychometric properties of the tool need to be further established with a younger population. Research examining interrater and intrarater reliability is required to support the findings from this study and increase confidence that changes are attributable to clinical changes rather than measurement error. Further research regarding other aspects of validity would also strengthen validation of the measure in this client group (Laver-Fawcett, 2007).

Should validity and reliability be established in the future data from the UK FIM+FAM could assist in demonstrating the value and cost effectiveness of occupation-focused interventions, and support further research to increase the evidence-base for this client group. For this reason it is recommended that occupational therapists and others using this tool in clinical practice with a younger population interpret the data from it with caution and complement it with the use of other tools validated for children and young people.

Conclusion

This study evaluated the responsiveness of the UK FIM+FAM, a measure of functional ability, in a sample of older children and young people with ABI within a neurorehabilitation setting. Several methods found the tool to have good levels of internal and external responsiveness, indicating that the tool can detect clinically meaningful change in this client group. This supports potential use of the UK FIM+FAM by occupational therapists and multidisciplinary teams to capture change in functional ability and participation in everyday life. However the lack of evidence on validity and reliability of the measure is a

significant limitation to recommending its use in this client group. Publication of findings on the validity of the measure is underway, however reliability must be addressed in further research.

Key findings:

- The UK FIM+FAM was responsive to changes in functional ability in older children and young people with acquired brain injury
- Further validation of the UK FIM+FAM is recommended with this population

What the study has added:

This exploratory study supports potential use of the UK FIM+FAM as a tool to measure change in functional ability for older children and young people with acquired brain injury.

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Research ethics: Ethical approval was obtained from Brunel University Research Ethics Committee (14/11/MOT/24, 2015) and the neurorehabilitation centre's Research Committee (TCT007, 2014).

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