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Adaptation of the adult Functional Mobility Assessment (FMA) into a FMA-Family Centred (FMA-FC) paediatric version

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Abstract

Aim: The aims of this study were to adapt an adult wheeled mobility outcome measure, the Functional Mobility Assessment, for use with children (FMA-Family Centred) and establish the new measure's content validity, test–retest reliability, and internal consistency.

Background: Although several tools exist to measure a child's ability to operate and move a wheeled mobility device, none focus on the ability of the wheeled mobility device to support children and their families as they perform daily activities.

Methods: After adapting the FMA items with examples relevant to children aged 3–21, parent/caregiver and therapist stakeholder groups recommended adaptations relevant for families with children who cannot respond for themselves.

Results: Six of the initial FMA items were retained with child-appropriate examples, and 4 new items were developed.

Conclusion: The content validity of the FMA-Family Centred was strongly supported, and internal consistency and test–retest reliability met accepted psychometric standards.

KEYWORDS

caregivers, children, parents, wheeled mobility device

1 | INTRODUCTION

In 2011, the U.S. Census Bureau estimated that 12.1% of the population was disabled and ambulation disability had the highest prevalence at 6.9% (Erickson, Lee, & von Schrader, 2012). According to the World Health Organization (WHO), "the wheelchair is the most commonly used assistive device for enhancing person mobility" (WHO, 2010, p. 1). The WHO went on to address an individual's right to have an appropriate wheelchair and emphasized that the wheelchair provides benefits beyond enhanced mobility. Furthermore, in this era of evidence-based practice, there is pressure to prove that the recommended equipment is beneficial to the patient and to measure whether the user's needs have been met (Fitzpatrick, Davey, Buxton, & Jones, 1998). Such measures of user satisfaction with their devices, health care, or treatment are referred to as patient reported outcomes (PROs).

Welding and Smith (2013) reported that a "PRO directly reported by the patient" is best (p. 62); however, this is not always possible with children. When a child is the patient, family-centred decision-making and goal setting lead to greater participation in the intervention and follow through of the plan of care, with the end result being better outcomes (American Hospital Association, 2013). Current paediatric PRO tools that address mobility, such as the Patient-Reported Outcome Measurement System (PROMIS) Paediatric Bank, the PROMIS Paediatric Short Form v. 1.0 (mobility), the PROMIS Parent Proxy Bank v. 1.0 (mobility), the PROMIS Parent Proxy Short Form v. 1.0 (mobility), the National Institutes of Health Toolbox, and the Neuro-QOL Paediatric Scale v. 1.0 (Lower Extremity Function—mobility), tend to focus on specific movements or difficulty performing a task, rather than the wheelchair's ability to support wanted or needed task performance (Neuro-QOL, 2014; NIH Toolbox, 2014; PROMIS, 2014a; PROMIS, 2014b; PROMIS, 2014c; PROMIS, 2014d; PROMIS, 2014e).

Current paediatric PRO measures, including the PROMIS and NIH Toolbox, do not include adequate functional outcomes for children who require the use of a wheelchair for mobility. Although the

Neuro-QOL includes many items that address the use of a wheelchair for mobility, most focus on wheelchair movement rather than functioning with the wheelchair. Furthermore, proxy-reported outcomes, in which someone other than the patient responds for the patient, is not an acceptable method of reporting outcomes (U.S. Department of Health and Human Services, 2009). However, measurement of PROs of young children and/or adolescents who have cognitive impairments or are unable to communicate because of serious illness still needs to be addressed, and a family-centred approach is necessary. The aims of this study were to adapt an adult wheeled mobility outcome measure, the Functional Mobility Assessment (FMA; Kumar et al., 2012), for use with children and establish the new measure's content validity, test–retest reliability, and internal consistency. The FMA was selected as the parent measure because it is one of only a few instruments that focuses on the meaningful activities a wheelchair allows users to do rather than the movements users can do in the wheelchair (Mortenson & Auger, 2008). Furthermore, the FMA is widely used in practice and has been found to be a useful addition to wheelchair prescription for families and clinicians.

Key messages

- The Functional Mobility Assessment-Family Centred was adapted by two stakeholder groups (parents/caregivers and therapists) that are most relevant for recommending a wheeled mobility device that will support a child's daily activities.
- The Functional Mobility Assessment-Family Centred can be used to assess the type of wheeled mobility device that will best support children and their families and is stable enough to measure change.
- The content validity, internal consistency, and test–retest reliability all met acceptable psychometric standards.

2 | METHODS

2.1 | Study design

The study was conducted in two phases. In Phase I, the parent measure, the FMA, was modified by the authors so that item wording was consistent with a family-centred response approach that would be meaningful to parents. The stem of the question was modified to "My child's …" instead of the FMA stem for adults which began with "My." Item descriptions were also modified to be appropriate for children. To establish content validity, the Beta Version I of the FMA-Family Centred (FMA-FC) was discussed by parents/caregivers of children using wheeled mobility devices (WMDs) and therapists experienced in recommending WMDs, in dyads or small focus groups. In Phase II, the final beta version of the FMA-FC was administered to parents/caregivers of children using WMDs, and the data were used for the reliability studies. Both phases were approved by the University of Pittsburgh's Institutional Review Board and the Scientific Advisory Committee at Children's Specialized Hospital of New Jersey. Informed consent was obtained from all participants.

2.2 | Procedures

2.2.1 | Phase I, content validity

For inclusion in Study Phases I and II, parent/caregiver participants had to have a child, between the ages of 3 and 21 years (school age consistent with Public Law 94-142), with a nonprogressive disorder, whose primary means of mobility were a manual or power wheelchair or stroller. Additionally, the parents/caregiver had to be the primary caregiver for the child for at least 6 months, and the child had to have used a WMD for at least 6 months. Parents/caregivers, who required interpreter services, could not communicate over the telephone, or were unable to give consent or provide a legal representative to give consent, were excluded.

For Phase I, parent/caregiver participants were recruited from the Outpatient Services of Children's Specialized Hospital (CSH), Toms River, NJ. Flyers with participant criteria and the study's purpose were given to parents/caregivers attending outpatient therapy appointments by their treating therapists. The principal investigator (D. B.) explained the study in detail, including audio recording of the focus group sessions, to parents/caregivers expressing interest in the study. A time for focus group participation was scheduled for those agreeing to participate. To improve the generalizability of the FMA-FC, a gender balance and age distribution of the children were sought in recruitment. Parent/caregiver groups met before the therapist groups, and successive recommendations emerging from the discussions were incorporated into successive beta versions of the FMA-FC.

Inclusion criteria for therapist participants were being a licensed occupational or physical therapist, having current job responsibilities for evaluating and recommending WMDs for paediatric patients, and having a minimum of 1 year experience in paediatric seating and wheeled mobility. Therapist participants were recruited from the Therapy WMD Consortium of CSH and primarily through flyers, but this method was supplemented by word-of-mouth purposive sampling from therapist to therapist and durable medical equipment suppliers to therapists. Several focus groups were conducted to meet the scheduling needs of the therapists.

The research team modified each of the 10 items of the FMA to read "My child's" versus "My" (Kumar et al., 2012) so that each item was consistent with a family-centred response approach and was illustrated with child-appropriate examples. This modification yielded Beta Version 1 of the FMA-FC and was handed to or mailed to participating parents/caregivers along with a demographic questionnaire. Four focus groups were held for the parents/caregivers (N = 10). The PI began each focus group by reviewing the content of Beta Version 1 as needed to familiarize members with the instrument. Discussion then focused on (a) what is most important to you and your child concerning the activities the wheelchair should enable him/her to do? and (b) what items should be added? modified? deleted? Items were revised according to the group's suggestions. Each iteration of the FMA-FC and its modifications were described to the successive group. At the conclusion of the meeting, participants rated each item

for relevance, clarity, and ease of rating on 5-point scales (relevant/not relevant; clear/unclear; easy to rate/not easy to rate); recommended keeping, deleting, or modifying each item; and rank ordered the 10 items from least (1) to most (10) important for their child. The revised Beta Version 1 from the parent/caregiver focus groups became Beta Version 2 FMA-FC.

Beta Version 2 was distributed to the 10 therapist participants, who were recruited from the CSH facility and Therapy WMD Consortium, LADACIN Network, Lakeview School, and First Cerebral Palsy of New Jersey. Four focus groups were held for the therapists, who went through a discussion process analogous to that of the parents/caregivers, beginning with "what do you think is most important to parents/caregivers concerning the activities the WMD should enable their children to do?" and including item rating. The revisions to Beta Version 2 recommended by the therapists became Beta Version 3 FMA-FC.

2.2.2 | Phase II, reliability studies

Phase II parent/caregiver participants met the same criteria as Phase I participants. They were recruited from the Outpatient Services of Children's Specialized Hospital of New Jersey and the school population at LADACIN Network, also of New Jersey, using the same procedures as for Phase I. For test–retest, the FMA-FC Beta Version 3 was first administered on site (Time 1), and participants were given a copy of the measure to take with them. Retesting was done via telephone within 2 weeks (Time 2). As with Phase I, the gender and ages of the children using the WMDs were taken into account in recruitment. Time 1 data were used to examine internal consistency.

2.3 | Data analyses

Descriptive statistics were used to describe participants and their children and the FMA-FC item ratings for relevance, clarity, and ease of rating. To establish content validity, ratings for each respective version of the FMA-FC (Version 1, parents/caregivers; Version 2, therapists) were dichotomized. For the relevance of the item, completely relevant, mostly relevant, and slightly relevant were collapsed and labelled relevant. Mostly irrelevant and completely irrelevant were collapsed and labelled not relevant. For clarity of the item, completely clear, mostly clear, and slightly clear were collapsed and labelled clear, and mostly unclear and completely unclear were collapsed and labelled not clear. For ease of rating the item, completely easy, mostly easy, and slightly easy were categorized as easy, and mostly not easy and completely not easy were categorized as not easy. Content validity was established for each item using the percentage of raters deeming the item relevant, using the principle proposed by Lawshe (1975): "The more panelists (beyond 50%) who perceive the item as 'essential', the greater the extent or degree of its content validity" (p. 567). The recommendation for each item was keep, delete, or modify, with percentages recommending keep reported, as well as any recommended modifications. Parents were asked to rate the priority of each item for their children, with 10 being the most important and 1 being the least important.

Cronbach's alpha was used to assess the internal consistency of Beta Version 3 FMA-FC, with a target of 0.70–0.90 for acceptable internal consistency without redundancy. Intraclass correlation coefficients (ICCs (3,k)) were used to calculate the test–retest reliability for each item and the total score of the Beta Version 3 FMA-FC, with a target of $\geq$0.75 (Portney & Watkins, 2008).

3 | RESULTS

3.1 | Participants

3.1.1 | Children

Although the average age of children in Study Phases I and II was in the early teen years, the age range of the children in the reliability studies was broader (ages 7–20) than in the content validity study (ages 9–18; see Table 1). Gender and age distributions were equivalent for both groups. On average, both groups of children spent about $8\,^{1}/_{2}$ hr per day in their WMD, which they had used for 3–4 years. Equal numbers of children in the validity study used manual and power WMDs; however, the majority of children in the reliability studies used manual WMDs, with fewer using power WMDs and several relying on strollers. The primary diagnosis leading to WMD use was cerebral palsy and its associated respiratory and musculoskeletal impairments. Family group size ranged from 3 to 9, with their child with a disability most often being the first born.

3.1.2 | Parents/caregivers

As seen in Table 2, the largest number of parents/caregivers, in both studies, was in the 31- to 50-year age range. A small number in both groups had respiratory, musculoskeletal, or neuromuscular impairments that might make it difficult to manage a child using a WMD. Parents/caregivers in both groups were primarily concerned with postural support when seeking a WMD for their child, but device mobility, transportability, and independent use by their child were of concern by at least half of the participants.

3.1.3 | Therapists

The therapist validity participants consisted of nine physical therapists and one occupational therapist. They had practiced for an average of 27.1 (16–36 range) years, including an average of 19.8 (4 to 36 range) years recommending WMD. The primary age ranges for their caseloads were 3 to 6 years and 13 to 18 years. The majority indicated that the families of their paediatric clients were very involved in the evaluation and selection of the WMD for their child.

3.2 | Content validity

Like the parent measure, the FMA, Beta Version 3 FMA-FC consisted of 10 items. The content of six items on the FMA-FC was comparable with six companion items on the FMA (carry out daily routines, meets comfort needs, access different surface heights, transfers, complete personal care tasks, and transportation). The content of four FMA-FC items (postural support, manage daily supplies, move indoors and outdoors, independence from caregiver for social activities) differed from the original FMA. No changes were indicated for the response scale. Hence, the Beta Version 3 FMA-FC uses a

TABLE 1 Demographic/health/family—child data

Demographic/health/family data	Focus group participants (*N* = 10)	Test–retest participants (*N* = 28)
Demographics/health—child		
Age of child using WMD (mean, years)	13.50	12.78
(Range in years)	(9–18)	(7–20)
Gender and ages		
Males <13 years	2	8
Males ≥13 years and <22 years	3	6
Females <13 years	2	7
Females ≥13 years and <22 years	3	7
Age of child's WMD (mean, years)	3.75	2.67
(Range in years)	(1–12)	(1–6)
Hours child spends in WMD per day (mean)	8.71	8.54
(Range in hours)	(4–14)	(1–16)
My child's current WMD (*n*)		
Manual	4	20
Power	4	5
Stroller	2	3
My child's diagnostic condition (*n*)		
Cerebral palsy	9	20
Traumatic brain injury	1	2
Genetic disorder	0	2
Seizure disorder	0	2
Diagnosis unknown	0	2
My child's impairments (*n*)		
Child has respiratory impairment[a]	0	1
Child has musculoskeletal impairment[a]	6	13
Child has neuromuscular impairment[a]	6	9
Child has cardiac impairment[a]	0	0

Note. WMD = wheeled mobility device.

[a]For impairments, children can have more than one impairment.

TABLE 2 Demographic/health/family-parent/caregiver data

Demographic/health/family data	Focus group participants (*N* = 10)	Test–retest participants (*N* = 28)
Age of parent/caregiver (*n*)		
19 or younger	1	0
20–30 years	0	1
31–40 years	3	6
41–50 years	4	13
51–60 years	1	4
61+ years	1	3
Parent/caregiver impairments (*n*)		
Respiratory impairment	1	2
Musculoskeletal impairment	1	2
Neuromuscular impairment	1	1
Cardiac impairment	0	0
Important factors for my child's mobility device (*n*)		
Postural support	9	22
Mobility of the device in the environment	6	16
Transportability of the device	6	17
Independence of my child using the device	7	14

6-point scale ranging from completely agree to completely disagree. The option "Does not apply" was also retained. To access the FMA-FC, see www.fma.pitt.edu.

The average ratings of item relevance by parent/caregiver and therapist participants indicate that content validity was excellent. Except for the personal care item, ratings were ≥90%. Similarly, all ratings for the clarity and ease of rating items were ≥97% (see Table 3).

3.3 | Reliability

3.3.1 | Test–retest

Beta Version 3 FMA-FC demonstrated an overall ICC(3,k) of 0.85 (CI [0.81, 0.89]), $p < .001$, which exceeded our target of 0.75 for degree of correspondence and agreement between test and retest (see Table 4). Item ICCs ranged from 0.63 (Posture) to 0.92 (Daily Routines; see Table 4).

3.3.2 | Internal consistency

Internal consistency of Beta Version 3 FMA-FC achieved a standardized alpha of 0.87. Inter-item correlations ranged from −0.12 to 0.88. Low correlations were associated with items that were not logically related (e.g., daily routines and posture, $r = 0.18$; comfort and personal care, $r = -0.12$). The majority of inter-item correlations were within a range that indicates internal consistency of FMA-FC items without redundancy (Briggs & Cheek, 1986).

4 | DISCUSSION

A primary aim of this study was to develop a WMD assessment tool appropriate for use with paediatric patients who require manual wheelchairs, power wheelchairs, or strollers. A measure specifically oriented toward children, and focused on the extent to which WMDs facilitate children's functional performance in needed and desired activities and community participation, would fill a void in outcome tools. Building on our tool development process of the FMA, an adult instrument recognized for its functional orientation (Kumar et al., 2012) and tested in practice, was parsimonious. Thus, item wording and descriptions were modified to make items appropriate for measuring the functional activities of young children and adolescents, and a family-friendly item format (e.g., My child…) was introduced to facilitate responses by parental and other caregivers. Content validity was established through critique and modification by two groups of stakeholders—parents/caregivers who are responsible for children needing WMDs and therapists who are responsible for recommending WMDs and their features.

Like the parent measure (FMA), Beta Version 3 FMA-FC and all prior versions consisted of 10 items. Except for changes in item wording and descriptions, the content of 6 of 10 FMA items was comparable on the FMA-FC. These items focused on the degree to which the child's WMD enabled the child to participate in daily routines,

TABLE 3 Relevance (content validity), clarity, and ease of rating FMA-FC items

Items	Relevance of the item for supporting child's use of WMD		Clarity of the item		Ease of rating the item	
	Parents/caregivers (*N* = 10) (%)	Therapists (*N* = 10) (%)	Parents/caregivers (*N* = 10) (%)	Therapists (*N* = 10) (%)	Parents/caregivers (*N* = 10) (%)	Therapists (*N* = 10) (%)
1 Daily routines	100	100	100	100	100	100
2 Comfort	100	100	100	100	100	100
3 Health/*posture*	100	100	100	100	100	100
4 Independent/*manage daily supplies*	90	*100*	100	*100*	100	*100*
5 Reach	90	90	100	90	90	100
6 Transfer	90	100	100	100	90	100
7 Personal care	60	100	90	100	90	100
8 Indoor and outdoor/*indoor-outdoor*	100	*100*	100	*100*	100	*100*
9 *Social independence*	90	*100*	100	*100*	100	*100*
10 Transportation	100	100	100	100	100	100
Averages	92	99	99	99	97	100

Note. Items in *italics* represent changes to FMA-FC based on focus group feedback. FMA-FC = Functional Mobility Assessment-Family Centred; WMD = wheeled mobility device.

TABLE 4 Test-retest reliability of the FMA-FC Beta Version 3 (*n* = 28)

FMA-FC items	ICC(3,k) [CI]
1 Daily routines	0.92 [0.83, 0.96]
2 Comfort	0.83 [0.64, 0.92]
3 Posture	0.62 [0.17, 0.83]
4 Daily supplies	0.86 [0.66, 0.94]
5 Reach	0.80 [0.55, 0.91]
6 Transfer	0.89 [0.75, 0.95]
7 Personal care	0.78 [0.42, 0.92]
8 Indoor & outdoor	0.88 [0.74, 0.95]
9 Social independence	0.89 [0.71, 0.96]
10 Transportation	0.91 [0.79, 0.96]
Total	0.85 [0.81, 0.89]

Note. FMA-FC = Functional Mobility Assessment-Family Centred.

meet comfort needs, access and complete tasks at different heights, complete transfers with or without help, complete personal care tasks, and use school, personal, or public transportation. From a measurement perspective, this is advantageous because it will allow for continuity of measurement as the children mature into adult WMD users. Stakeholders recommended four substantive item changes to the FMA to more effectively serve the needs of children. Meeting postural support needs replaced a more general item related to health needs and responded to the importance of postural support to paediatric mobility. "My current means of mobility allows me to be as independent, safe and efficient as possible" was changed in the FMA-FC to "My child's current means of mobility allows for managing daily supplies (medical and personal)." To accommodate a new item and retain the 10 item structure, the FMA items related to moving indoors and outdoors were combined. Sensitive to children's social needs and privacy concerns, the new item "My child's current means of mobility allows for independence from family/caregiver for social activities" was strongly endorsed by both stakeholder groups. Although item similarity between the child and adult FMA measures will facilitate outcome reporting as children physically mature and require new WMDs, the unique items address concerns relevant to families of children using WMDs.

Having established content validity, internal consistency, and test–retest reliability, the FMA-FC meets the basic psychometric criteria for a new PRO tool. Methods used to establish the content validity of the FMA and the FMA-FC differed. For the FMA, it was based on its parent tool, Functioning Everyday with a Wheelchair (Mills, Holm, & Schmeler, 2007), whose content validity was established by cross-validating items with patient goals. The FMA-FC content validity was validated by the two stakeholder groups having the most input into WMD selection—parents/caregivers and therapists. The test–retest reliability of the parent tool, the FMA, ranged from 0.85 to 0.89, with an ICC of 0.87, and the test–retest reliability of Beta Version 3 FMA-FC was comparable with an ICC of 0.85 and a range of 0.81 to 0.89. Internal consistency was not reported for either of the parent tools; hence, no comparisons can be made.

Several limitations should be taken into account when interpreting the study findings or using the FMA-FC. First, the children being reported on by the parent/caregiver participants were primarily in their teens, leaving the possibility that additional adaptations may be required for younger children. Parents/caregivers of younger children were reluctant to participant in the study because of time constraints; however, clinical use of the FMA-FC indicates that the proposed instrument adequately addresses younger children. Second, some of the focus groups were only dyads, which may have limited cross-pollination of ideas among parents/caregivers and therapists. Nonetheless, the content of the FMA-FC was strongly endorsed by all stakeholders. Third, the psychometric investigations of the FMA-FC carried out in this study need to be supplemented by studies of its ability to record change. For example, when new WMDs are recommended and obtained, therapists and parents/caregivers expect that they will enable their children's functioning. The FMA-FC should be able to record this improvement. Because no changes were made in the response format of the FMA and the FMA has demonstrated ability to discern change (Kumar et al., 2012), we anticipate that the

FMA-FC will also be responsive. However, the FMA-FC's responsiveness needs to be examined.

In conclusion, the FMA-FC is a valid and reliable measure for assessing the use and support of children's WMDs as the children and their families engage in daily living tasks.

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