Background

Feedback from users of assistive devices is essential to enable evidence based practice. Device users are in the best position to meaningfully evaluate the functioning of their devices as it relates to several International Classification of Function (ICF) categories [1]. Patient reported outcomes measures (PRO) - questionnaires designed and validated for the purpose of assessment of the subject/patient’s well-being - are increasingly seen as key in the assessment of medical interventions of any kind, along with frameworks being developed for appropriate use [2, 3]. Feedback from users of wheelchairs and other mobility devices is essential to the development of more functional devices. The Functional Mobility Assessment (FMA) is a brief and well validated PRO for adult users of wheeled mobility devices [4, 5].

The development or modification of PROs for the pediatric population provides a unique challenge because a child’s ability to respond to questionnaires differs from that of an adult [6, 7]. Caregivers have often been asked to complete questionnaires on behalf of younger children unable to read well or respond in an adult manner [8]. One tool utilized in questionnaires designed for children is a Visual Analogue Scale (VAS) with anchors that include emoticons [9]. There are indications that even very young children can respond in a valid meaningful way through the use of such emoticons or anchors on a visual analogue scale format [8, 9].

Sensitivity to detect differences is a necessary attribute of effective PRO metrics [10]. An additional benefit of the VAS format is increased sensitivity, as VAS format questionnaires often produce continuous parametrically normal data enabling the use of more sensitive parametric statistical analysis methods [11]. Many pediatric PROs include methods of collecting input from caregivers as well as from pediatric subjects though there are indications these two sources of feedback may not always perfectly agree [7, 12]. Because children often have better listening skills than reading comprehension, questionnaires are often done in an oral as well as written format[9]. Cognitive interviewing methodology can reveal and ameliorate any lack of understanding on the part of a child [6].

Questionnaires are often tested for reliability using test/re-test study design analyzed by calculating intra-class correlation coefficients [5]. For pediatric questionnaires, ICC values of 0.41-0.61 have been designated poor to fair agreement; 0.61 – 0.80 good or excellent agreement; and 0.81 – 1.00 excellent agreement [8, 13].

We could not find any validated and reliable PRO enabling wheelchair evaluation for a pediatric population. To meet this need, investigators have made a preliminary modification of the FMA for pediatric use. The objective of this study was to test that modification for test/re-test reliability in a school aged pediatric population of wheelchair users in Africa.

Methods

Investigators have devised a version of the FMA modified for use by school children and their caregivers. Because the questions are simple and straightforward, the text has not been changed. Question format has been modified for pediatric use with VAS format with emoticons at each end, with “grades” acting as “anchors.” Investigators chose to use emoticons because these are often utilized in VAS for children and chose to augment these with letter “grades” because school aged children are almost universally familiar to the concept of “grades” or academic scores which are essentially a rating system for school work[9].

Our protocol for the FMA modified for children includes both oral and written formats of this questionnaire: A researcher sits with the child and the child’s caregiver; the participant is given the chance to read the question; the question is then read aloud by the researcher; and then the subject, caregiver and researcher will discuss the question and interview the child to facilitate comprehension and to determine if the child is fully understanding the question. Researcher and caregiver are instructed to take great care not to “lead” the child in any way. An oral spoken response and explanation is sought from the child, and the child is asked to “grade” the specific item on the VAS. The subject’s comments are thus solicited and recorded. Both the caregiver and researcher are required to gauge whether the child had understood and meaningfully responded. If not, the caregiver listens to and interacts with the child again, and then indicates a meaningful response on the VAS for that question. The data collection sheet includes a line for a comment from the subject and another line for a comment from the caregiver.

Subjects wheelchair users attending a boarding school for children with special needs in Kenya where children with special needs are generally not able to attend main stream classes. Such children may begin school quite late because their parents may not initially know of special needs boarding schools. English is the spoken language in school and the questionnaire was administered in English though the questions were also translated into other languages the subject was familiar with as part of the cognitive interview.

The children and their caregivers completed the questionnaire once, and then completed it again one week later. Researchers for the test-retest reliability study were undergraduate students who had received a briefing, read the protocol, observed the PI administering the FMA in this format to a subject and caregiver, and then administered the FMA to a subject and caregiver under supervision.

As with other 100 mm-VAS format questionnaires, the distance between the left hand end of the line and the vertical mark made by the subject was measured using a millimeter ruler with each question will produce a score between 0 and 100 for each subject. The data was tested for normalcy using the Shapiro Wilks test. Intra-class correlation coefficients
(ICC) for the data for each question from the two sessions were calculated to ascertain test-retest reliability.

Results

Investigators completed test-retest reliability testing for this format of the FMA with a cohort of 44 school children who were full time manual wheelchair users (Age 13 ± 3.2). Three subjects were in classes for academically challenged children, the others were in normal academic curriculum spread quite evenly from kindergarten to grade eight. Their disabilities included nine different diagnoses, the three most common being cerebral palsy (40%), spina bifida (17%) and muscular dystrophy (17%).

Among the ten items in the questionnaire, eight of the items had ICC values greater than 0.6 while one item, Item 3 – ‘Health Needs’, had an ICC value of 0.47 (Table 1). The ICC value for item 10 - ‘Transportation’ was not calculated because over 60% of the subjects had never experienced traveling in vehicles with their wheelchairs.

Table 1. Intra-class correlation coefficients values for the test-retest results of the FMA questions modified for use by school aged children.

<table>
<thead>
<tr>
<th>Item</th>
<th>ICC average measures values (Confidence Interval)</th>
</tr>
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<tbody>
<tr>
<td>1. My current wheelchair allows me to carry out my daily routine: (tasks I need to do, am required to do)</td>
<td>0.86 (0.74 - 0.92)</td>
</tr>
<tr>
<td>2. My current wheelchair meets my comfort needs: (heat/moisture, sitting tolerance, pain, stability)</td>
<td>0.66 (0.37 - 0.81)</td>
</tr>
<tr>
<td>3. My current wheelchair meets my health needs: (pressures sores, other injury, breathing)</td>
<td>0.47 (0.03 - 0.71)</td>
</tr>
<tr>
<td>4. My current wheelchair allows me to operate it as independently and safely as possible: (do what I want to do when and where I want to do it)</td>
<td>0.73 (0.51 - 0.85)</td>
</tr>
<tr>
<td>5. My current wheelchair allows me to reach and carry out tasks at different surface heights: (table, bed, chair)</td>
<td>0.67 (0.40 - 0.82)</td>
</tr>
<tr>
<td>6. My current wheelchair allows me to transfer from one surface to another: (bed, toilet, chair)</td>
<td>0.80 (0.61 - 0.89)</td>
</tr>
<tr>
<td>7. My current wheelchair allows me to carry out personal care tasks: (dressing, eating, washing, toilet care)</td>
<td>0.70 (0.44 - 0.83)</td>
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<tr>
<td>8. My current wheelchair allows me to get around indoors: (bedroom, schoolroom, at home, shops)</td>
<td>0.74 (0.52 - 0.86)</td>
</tr>
<tr>
<td>9. My current wheelchair allows me to get around outdoors: (uneven surfaces, dirt, gravel, ramps, obstacles)</td>
<td>0.68 (0.42 - 0.83)</td>
</tr>
<tr>
<td>10. My current wheelchair allows me to travel in vehicles efficiently such as cars, buses, taxis: (load wheelchair)</td>
<td>N/A: Many children had never traveled with their chair</td>
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</tbody>
</table>

Discussion

The results of this study indicate that our protocol for this modification of the Functional Mobility Assessment provided a reliable tool for use with school aged wheelchair users. Eight out of the ten FMA items had good to excellent agreement whereby one items, health needs, had moderate agreement. This was the case even though our subjects did not speak English as their first language. Further validation with subjects who speak English as a first language may indicate even stronger reliability. With further validation, this version of the FMA could provide a much needed tool for those looking for a patient reported outcomes measure for pediatric wheelchair users.

References