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Design and Content Validity of a New Instrument to Evaluate Motor Abilities of Children with Severe Multiple Disabilities: Movakic (Part-I)

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Abstract

Aim: Evaluation of motor abilities of children with severe multiple disabilities is often based on subjective assessment or on instruments validated for other target populations. A practical instrument for the evaluation of change in motor abilities is needed. In this study such an instrument is constructed and its content validity and applicability are tested.

Methods: The instruments content was developed using an expert focus group and a systematic literature review. Experts were consulted in all stages of development. Content validity was assesses using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN). Applicability was assessed by experienced physical therapists in a pilot study among 53 children and adults with severe multiple disabilities.

Results: Movakic (**MO**tor e**VA**luation of **KI**ds with multiple and **C**omplex disabilities), a questionnaire consisting of 21 items on motor abilities, was constructed. Movakic scores are based on an assessment of motor performance of the child and have to be assessed by physical therapists. Movakic had adequate content validity and applicability.

Conclusions: Movakic's good applicability and content validity suggest that is has potential to be a useful instrument in clinical practice. Movakic's reliability is assessed in a prospective study, as reported in part II of this issue.

Keywords: Severe multiple disabilities; Motor abilities; Cerebral Palsy GMFCS V; Content validity; Evaluative instrument

Abbreviations

SMD: Severe Multiple Disabilities; COSMIN: COnsensus-based Standards for the selection of health Measurement Instruments; Movakic: **MO**tor e**VA**luation of **KI**ds with multiple and **C**omplex disabilities; GMFCS: Gross Motor Function Classification System; CFCS; Communication Function Classification System; MACS: Manual Ability Classification System; IQ: Intelligent Quotient; ICF-CY: International Classification of Functioning, Disability and Health for Children and Youth; CLA: The Chailey Levels of Ability; BSID III: Bayley Scales of Infant and Toddler-Third Edition; PEDI: Pediatric Evaluation of Disability Inventory; GMFM-88: Gross Motor Function Measure (88 items); MHFMS: Modified Hammersmith Function Motor Scale; LE 85: Lower Extremity physical functioning and mobility skills; MFM: Motor Function Measure scale; TDMMT: Top Down Motor Milestone Test; VAB: Vulpe Assessment Battery; WeeFim: Functional Independence Measure for Children.

Introduction

Children with severe multiple disabilities (SMD) are characterized by a severe or profound intellectual disability and severe motor impairments. There is no universal description of this group to be found in the current literature. Apart from "severe multiple disabilities", which we selected, the terms "severe generalized cerebral palsy", "profound and intellectual multiple disability", "severe motor and intellectual disability", "severe neurological impairment and intellectual disability" are used. Support for these children in acquiring or improving motor abilities is highly relevant for participation in general care situations and a sense of self-determination or autonomy. Availability of practical and reliable instruments for the measurement of motor abilities in these children is very important. However, instruments specifically designed for the measurement of motor abilities in this target group are lacking.

Children with SMD mostly have a level of motor abilities that is comparable to level IV/V of the Gross Motor Function Classification System (GMFCS) for children with cerebral palsy [1,2]: they typically are wheelchair-bound and only a few are able to move by crawling or using a physical aid [3,4,5]. They are usually severely limited in maintaining their body position or in transfers to another position. Communicative functions are highly limited; the children are only able to communicate non-verbally or through body language, which translates to Communication Function Classification System (CFCS) level V [6]. The child handles objects with difficulty or has severely limited ability to perform even simple actions. It requires support in almost all situations, which corresponds to Manual Ability Classification System (MACS) levels III-IV [7]. In addition, children with SMD are often diagnosed with sensory impairments, dysphagia

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Table 1: Cosmin Box D content validity [14].

	General requirements	Yes	No	?
1	Was there an assessment of whether all items refer to relevant aspects of the construct to be measured?	□	□	□
2	Was there an assessment of whether all items are relevant for the study population? (e.g. age, gender, disease characteristics, country, setting)	□	□	□
3	Was there an assessment of whether all items are relevant for the purpose of the measurement instrument? (discriminative, evaluative, and/or predictive)	□	□	□
4	Was there an assessment of whether all items together comprehensively reflect the construct to be measured?	□	□	□
5	Were there any important flaws in the design or methods of the study?	□	□	□

often leading to respiratory infections [8], gastro-oesophageal reflux disease, epilepsy, scoliosis and contractures [9,10,11]. As a result, these children are fully dependent on their caregivers and material in their immediate vicinity for all activities of daily life.

In clinical practice, evaluation of motor abilities in children with SMD is often based on subjective assessments or on instruments developed for other target groups with motor disabilities. An instrument for this specific group, with the aim of longitudinal evaluation of progression, stabilization, or deterioration of motor abilities, which could then be applied in clinical physical therapeutic practice, was needed.

A systematic review of available instruments on motor abilities in children with severe disabilities [3], showed that eight instruments might be potential candidates for application in children with SMD. One instrument (TDMMT) was developed specifically for this population [12]. The seven other instruments were developed for children with cerebral palsy, other neurologic conditions, or motor disabilities in general. Although evaluation of psychometric properties of all eight instruments appeared incomplete, one or more of them might be suitable for children with SMD after some adaptation. Therefore, an expert focus group formulated suitability criteria and systematically judged the clinical suitability of the identified instruments for this group. The expert focus group determined the clinical suitability of the eight instruments based on five established criteria; 1) Low level of motor abilities, children with SMD are classified in level V (GMFCS) and can at best crawl. 2) Grading of scoring because of the subtle changes in motor abilities. 3) Manual and/or device support is a functional element in using motor abilities. 4) Non-verbal instruction, children with SMD have an Intelligent Quotient (IQ) <25 and do not understand verbal instruction. 5) Capability versus capacity and performance, which means the possibility, and not quality, of performing a motor ability is important. The suitability criteria were further specified in appendix A. As a result of the judgment, consensus was reached for all instruments; none of the selected instruments was found to be completely suitable in the target group. Therefore the focus group decided that development of a new instrument was needed. The procedure of the judgment is described in appendix A.

In this study we present the development of an instrument to evaluate motor abilities of children with severe multiple disabilities. The formulated suitability criteria were the starting point of the construction of the new instrument. We tested its applicability and content validity. In a companion publication in the current issue of this journal the reliability of the new instrument will be presented.

Methods

Expert focus group

The joint development and application of new suitability criteria and growing insights into wishes for an ideal instrument for children with SMD led to a strong motivation of the expert focus group to proceed and design a new instrument. Members of the focus group were selected from therapists of the Ipse de Bruggen Care Organisation with ten years or more experience with the target population. The expert focus group consisted of six well-trained physical therapists and an occupational therapist, each with over 15 years [range 15-30 years] of specialist experience in working with children with SMD. They were trained in the use of different instruments such as the Gross Motor Function Measure (GMFM), the Bayley Scales of Infant and Toddler-Third Edition (BSID-III) and the Pediatric Evaluation of Disability Inventory (PEDI). In addition, all have specific specializations in the field of intellectual disability and physical therapy interventions.

Theoretical framework

The content of the instrument was based on the next theoretical starting points: the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) [13], multidisciplinary treatment goals and monodisciplinary treatment goals. Using the ICF-CY we can distinguish the levels of 'body function and structure', 'activities', and 'participation'. Multidisciplinary treatment goals for children with disabilities are usually defined at the participation level of the ICF-CY, where as mono disciplinary treatment goals may concern the level of activities. In physical therapy, motor abilities (level of activity) are the primary focus for treatment, among other goals such as contracture management (level of body function and structure). This new instrument had the aim to evaluate motor abilities on the level of activities, and the users of the instrument had to be physical therapists working with children with SMD. Logically, the theoretical framework of the new instrument had to comply with the established criteria for clinical suitability.

Content validity

In the development of the new instrument, we used the general requirements (Table 1) on content validity of the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN). Assessing content validity is an important step in developing an instrument that aims to be relevant and comprehensive. An appropriate method might be to let experts judge the relevance and comprehensiveness of the items. The focus and detail of the items of the instrument need to be specifically designed to match the target

population [14]. Since the COSMIN criteria are designed to assess content validity of an instrument in a certain study, only the first four criteria needed to be met to deem the items suitable for obtained adequate content validity.

The approach in this study consisted of three steps, in which we aimed to satisfy the requirements for strong content validity: (1) listing of relevant motor abilities, (2) design of a structure and layout and (3) a first pilot study on applicability in children and adults with SMD.

Step 1: Listing of relevant motor abilities: To identify motor abilities that are most relevant to children with SMD, we listed common treatment goals formulated in clinical practice using a survey. Twenty-five physical therapists, working with clients with SMD at a care provider service, were asked to collect all therapeutic long-term and short-term goals from their client files, formulated during the last five years.

Step 2: Structure and layout of the instrument: As mentioned before, the five formulated suitability criteria as shown in appendix A, were the starting point for constructing the new instrument. Furthermore, the structure of the newly designed instrument was partially based on that of other instruments (e.g. start with the main positions of lying, sitting and standing) taking into account the relevance of specific situations and activities. These situations and activities were selected in concordance with collected therapeutic goals from the first step using the collective experience of the expert focus group. For the development of the structure and layout of the instrument, the expert focus group followed a repeated consensus procedure.

Step 3: Pilot study on applicability: Physical therapists working with children and adults with SMD from different care-organisations in the Netherlands were asked to participate in a pilot study. In total, twenty-six physical therapists evaluated the instrument's applicability and whether test items met the criteria for good content validity. None of these physical therapists were members of the expert focus group. They received a four-hour training on the web based computer application used to complete all items and on the user manual. After applying the instrument to their own clients, the therapists answered questions on applicability, addressing the comprehensibility of the user manual, the layout (questionnaire and score-form), the items (relevance, comprehensibility, difficulty, number, and suggestions for other questions), the clarity of the answer categories and scoring procedure, and time needed to complete the instrument. There was room for written remarks per item, additions and further tips. The questionnaire also included a question on whether the instrument score measured corresponded to the therapist's clinical judgement, on a scale of 1 = not at all, to 10 = completely.

Results

The proposed approach for the development of the new instrument outlined in the methods section of this paper was followed.

Step 1: Listing of relevant motor abilities

The survey resulted in 355 therapeutic goals for 75 clients. After removal of duplicates and goals on the levels of body function (such as pain, contractures, dyspnoea) and participation, the remaining goals on the level of activity were translated into motor abilities by the expert focus group.

We illustrate this process with the example of the following therapeutic goal 'Client x is able to sit in his wheelchair during playing'. In this case, the generic motor ability on the level of activities is 'maintaining body position' and the specific motor ability is 'maintaining the sitting position'. This motor ability can be specified for different situations and activities of daily life. In our example, the specific situation is 'sitting in a wheelchair', whereas 'during playing' concerns the level of participation.

Table 2: Structure of Movakic.

Positions	Lying	Sitting	Standing
Situations → **Grouping of motor abilities** ↓	1 Supine 2 Supine with device* 3 Prone 4 Prone with device 5 Side 6 Side with device	7 Flat surface 8 Dangling legs 9 Chair/ sitting device 10 Feet on subsurface	11 Without device 12 With device
Maintaining position	Items (see table 3) with questions (table 4) on 1 Intensity manual or support by device 2 Activity of the child 3 Intensity of manual facilitation/ stimulation		
Activities			
Changing body position			
Moving around			

*Device: Assistive devices such as prostheses, orthese and specialized tools and aids for personal mobility such as canes, walkers and wheelchairs [13].

Step 2: Structure and layout of the instrument

The discussions within the expert group during the repeated consensus procedure resulted in a structure and the layout of the instrument (Table 2); 1. Main body positions ('Positions'). 2. Specific situations in each body position ('Situations'). 3. Specific motor abilities in each situation ('Grouping of motor abilities'). 4. Items with questions ('Items').

Based on the relevance, the items consisting of motor abilities were clustered within the 12 situations (Table 3).

In addition, the expert focus group decided that most of the items should include three questions; 1. Required level of manual support i.e. the level of palpable support that was given, or support by a device. 2. Level of activity of the child itself. 3. Level of manual facilitation, meaning active stimulation, i.e. provocation of the child with your hands. These questions address relevant elements in the actual use of motor abilities by these children during daily functioning. All questions could be scored using a four-point Likert scale (Table 4).

The expert focus group decided that the instrument should take the form of a questionnaire instead of an observational test. This was decided because execution of motor abilities of children with SMD may vary considerably under the influence of attention, fatigue, health, medication use, or unfamiliar circumstances. The questionnaire has to be completed by a therapist that has long-lasting experience with the child in a naturalistic setting instead of a therapist that does not know the child and uses the instrument in an isolated testing situation. Most other observational instruments are based on using a specific testing situation. Based on the difficulty to test execution of motor abilities in standardized situation, the judgment on being able to perform the motor ability in whatever shape or form in spontaneous situations during the last three months will be used to measure the motor abilities of the children with SMD.

Table 3: Items of Movakic.

		Situations (see Table 2)											
	Items	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
1	Maintaining position	x		x		x		x	x	x	x	x	x
2	Duration maintaining position					x		x	x	x	x	x	x
3	Turning head	x	x	x	x	x	x	x	x	x	x	x	x
4	Upright head	x	x	x	x	x	x	x	x	x	x	x	x
5	Maintaining upright head position	x	x	x	x			x	x	x	x	x	x
6	Reaching with the arms	x	x	x	x	x	x	x	x	x	x	x	x
7	Take support (fore)arms			x	x								
8	Take support hands			x	x			x	x			x	
9	Grasping with the hands	x	x	x	x	x	x	x	x	x	x	x	x
10	Roll over to the left	x		x									
11	Roll over to the right	x		x									
12	Roll over to prone	x				x							
13	Roll over to supine			x		x							
14	Transfer from lying to sitting	x	x	x		x							
15	Transfer from sitting to lying							x	x				
16	Transfer from sitting to standing							x		x	x		x
17	Transfer from standing to sitting									x	x	x	x
18	Pivoting							x					
19	Minor voluntary postural changes								x	x	x		
20	Move on	x		x				x		x		x	x
21	Distance	x		x				x		x		x	x

A score-form was added to the questionnaire, containing separate pages for each specific situation and an overview page with total situation scores. The maximum total scores of the 12 situations will differ because of a different cluster of items. Because all children have different abilities or disabilities and different therapeutic goals, only situations that are relevant to the child need to be scored. Therefore, on the score-form, individual scores for evaluated situations have to be converted into percentages of the maximum scores. Apart from standardized scoring, there is room for written detail information too, because execution of motor abilities may vary in different specific situations (e.g. different types of wheelchairs). The users' manual instructs the user to write down examples of such detail information are added to the items.

The instrument was named Movakic (**MO**tor e**VA**luation of **KI**ds with multiple and **C**omplex disabilities). Information for therapists was written in a first draft of a user manual, in which the guiding principles, structure and application of the instrument are explained. Descriptions of the most common terms are given, such as reaching, grasping and different forms of support. The scoring procedure is explained.

Step 3: First evaluation of applicability

Movakic was completed for 53 children, 35 boys and 28 girls, mean age 8.1 (range 2-17) years. The mean number of situations scored was 7 out of 11 (range 6-8). Mean completion time per situation was 9 minutes (range 6-15) and mean total completion time was 61 minutes (range 46-90 minutes). The content (validity) of the test items and relevance of the items was good according to all therapists. On a scale of 1 (very easy) to 10 (very difficult), mean difficulty score of the questionnaire was 2.8 (range 1-7). The mean therapists' judgment score of the correspondence of Movakic total score with the therapists' own clinical judgement was 8.5 (range 8-9). In addition, for assessing Movakic's applicability in adults, Movakic was completed by 10 physical therapists for 15 adults with SMD, seven women and eight men with a mean age of 40 years (range 19-65). Mean completion time for two situations was 18 minutes (range 10-30 minutes). The content of the test items and relevance of the items was good according to all therapists. On a scale of 1 (very easy) to 10 (very difficult), mean difficulty score of the questionnaire was 4.2 (range 2-7). The mean therapists' judgment score of the correspondence of Movakic total score with the therapists' clinical judgement was 8.1 (range 7-9).

Table 4: Questions and answer categories of the items.

1 How much support does the child need?	(0) Complete support (1) A lot of support (2) Moderate support (3) Barely support
2 Is the child active?	(0) Completely passive (1) Has intention to stand up (2) Active during part of the movement (3) Completely active
3 If you use facilitation, how much do you use?	(0) In spite of full facilitation there's no intention (1) A lot of facilitation (2) Variable facilitation (3) Only during start of movement

All physical therapists were satisfied with the structure and contents of the instrument and offered practical suggestions for improvement, including the addition of an extended training. As a result of the practical suggestions for improvement the answer category is modified into a five-point likert scale, items about moving around were added and a group consisting of a cluster of items on motor abilities specific used in care-situations was added. In the appendix B the modified version of Movakic is adapted.

Content validity

From the general requirements on content validity (Table 1) all answers of item one till four were scored as yes, item five was scored as no. The relevance of the Movakic items to the construct of measuring motor abilities, to the study population and to the purpose of the instrument (item 1, 2, 3 and 4) were positively assessed using the expert focus group, by formulating the clinical suitability criteria and by using the results of the pilot study on applicability in which experts, others than the expert focus group, participated. Extraordinary care was taken to follow a comprehensive step-by-step procedure to insure good content (item 5). Movakic's content validity was thus scored as adequate.

Discussion

Strengths of our approach to instrument development include highly experienced therapists, structuring the instrument and using a repeated consensus procedure, participated in the development of Movakic. By using this approach, it is highly likely that all relevant items of all relevant measurement properties are included, contributing to the content validity of the new instrument [14]. However, since content validity is a subjective judgment, the developers cannot

perform a completely unbiased judgment. Evaluation of content validity by a separate expert panel would contribute to the quality of the validity [15,16,17] of Movakic. Therefore other experts, who were not involved in the development of Movakic, participated in a pilot study and were asked to evaluate the relevance and comprehensiveness of the items of the new instrument.

The design of Movakic takes group-specific characteristics into account, which positively impacts the construction of the test. In addition the clinical criteria are formulated by clinical experts and based on the activity level (ICF-CY) [13]. Completion of a questionnaire by the therapist based on the child's performance during a longer time frame has the advantage of no extra burden of separately testing the child.

It might be argued that flaws in caregiver recall, on which much of the judgments in this study are based, may lead to inaccuracies in caregiver judgments. However, the contact between caregiver and child is very intensive, and anecdotal evidence suggests that in the care for this target group, caregivers are able to recall many (often minute) details about the care for and the condition of their clients. Experience of the physical therapist with this specific group of children and longer familiarity with the child are playing an essential role in effective application of Movakic. We do not expect that recall bias played an important role.

This study made an important step in the availability of an applicable, relevant and complete instrument. Movakic can be applied in a clinical setting because the construct is based on consensus of experts working in the field. In the Netherlands, most of these children visit day-care centers, where specialized on-site treatment is offered on a more or less daily basis. In such a situation, the requirements of the instrument can easily be met. We are not familiar with the involvement of physical therapists with children with SMD in other countries, but presume that most therapists treat their children often.

This study does not provide other psychometrics properties of Movakic. A prospective study that would prevent recall bias is recommended. Our study on Movakic's reliability, in collaboration with physical therapists in different care provider services, is reported in this issue in part II. Since we have demonstrated satisfactory psychometric properties, it will now be possible to use Movakic to evaluate effectiveness of current physical therapeutic interventions in children with SMD, and assess the effect of change in motor ability score on health and participation goals and quality of life.

Conclusion

The clinical suitability of the eight existing tests of motor abilities of disabled children for children with severe multiple disabilities (SMD) proved inadequate and as a result led us to design a new instrument. Using consensus criteria developed by an expert focus group of physical therapists a comprehensive instrument for the measurement of motor ability for children with SMD was developed: Movakic. Movakic is a questionnaire, containing of items on motor abilities, which can be objectified in a standardized procedure. Using a set of consensus based suitability requirements, Movakic was found to be applicable in clinical practice. In addition, Movakic has strong content validity.

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Appendix

http://austinpublishinggroup.com/physical-medicine/fulltext/appendix-id1068.pdf

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