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Review article

Instruments for the evaluation of motor abilities for children with severe multiple disabilities: A systematic review of the literature

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ABSTRACT

Based on a systematic review, psychometric characteristics of currently available instruments on motor abilities of children with disabilities were evaluated, with the aim to identify candidates for use in children with severe multiple (intellectual and motor) disabilities. In addition, motor abilities are essential for independent functioning, but are severely compromised in these children.

The methodological quality of all studies was evaluated with the Consensus Based Standards for the Selection of Health Status Measurement Instruments (COSMIN) Checklist; overall levels of evidence per instrument were based on the Cochrane Back Review Group strategy.

As a result, 18 studies with a total of eight instruments, developed for children with cerebral palsy (CLA, GMFM-88 and LE85), spinal muscular atrophy (MHFMS), neuromuscular diseases (MFM), disabilities 0–6 years (VAB, WeeFIM), and one developed specifically for children with severe multiple disabilities (TDMMT) were found.

Strong levels of evidence were found for construct validity of LE85 and MFM and for responsiveness of WeeFIM, but reliability studies of these instruments had a limited methodological quality. Up to now studies of the TDMMT resulted in limited and unknown evidence for structural validity due to the poor methodological quality of reliability studies.

In a next step, the clinical suitability of the instruments for children with severe multiple disabilities will be evaluate.

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1. Introduction

The need for a specific evaluation instrument for motor abilities of children with severe multiple disabilities (SMD) has both nationally and internationally been recognized by physical therapists. Children with severe multiple disabilities (SMD) suffer from profound intellectual disabilities (IQ < 25) and have a level of motor abilities comparable to level IV/V of the Gross Motor Function Classification System (GMFCS) for children with cerebral palsy (Palisano et al., 1997; Veugelers et al., 2005): they typically are wheelchair-bound and only a few are able to crawl or move with a physical aid (Mergler et al., 2012; Rieken et al., 2011). These children are most often severely limited in maintaining their body position or transferring into another position. In addition, children with SMD may have multiple sensory disorders and other co-morbidity such as swallowing and respiratory problems, epilepsy and contractures. As a result, children with SMD are fully dependent on their social and material environment for all activities of daily life.

Motor abilities are essential for independent functioning, but are severely compromised in these children. Optimal development requires a highly structured environment with constant aid, supervision, extensive support technology and physical assistance (American Psychiatric Association, 2000). Independent mobility is only achieved if the child can learn how to operate a powered wheelchair (Palisano et al., 1997). Children with SMD often have to be manually activated and supported by caregivers to use their motor abilities. It has to be stressed that in the opinion of clinicians working in this field, even subtle motor abilities provide these children with a degree of control over their environment and may as such have influence on their quality of life.

For the purpose of evaluation of interventions, measurement of motor abilities is essential. In current clinical practice, the evaluation of motor abilities by physical therapists is mostly based on subjective assessments in children with SMD or on instruments developed for other target groups. Nevertheless, standardized instruments developed for children with SMD with adequate psychometric properties are lacking. For this reason, an overview of psychometric properties is presented in this article of instruments that are not specifically developed for children with SMD, but for generic groups of children with severe disabilities.

2. Method

We performed a systematic review of published articles evaluating psychometric characteristics of instruments for the measurement of gross motor abilities of children with severe disabilities (age range 2–18).

2.1. Search strategy

A literature search in Pubmed (1966–January 2014), Embase (1980–January 2014), Web of science (1975–January 2015), and PsycINFO (1985–January 2015) was performed in February 2015. Keywords were used alone or separately and if available medical subject heading (MeSH) terms were used. In order to maximize the chance of finding all relevant instruments, a generic set of keywords with a wide range of search terms was chosen to describe the group of persons with disabilities (disabled persons[mesh] OR disabil*[tw] OR disabl*[tw] OR retard*[tw] OR handicap*[tw] (AND (child*[tw] OR infan*[tw] OR pediatr*[tw] OR paediatr*[tw] OR juven*[tw] OR newborn*[tw] OR neonat*[tw] OR (adolescen*[tw] NOT (adult[mesh] OR adult*[tw]). Instruments with different aims such as 'evaluative', 'predictive', 'population specific' and 'disease specific' were searched, in order to provide a complete overview of available information on existing instruments (measurement*[tw] OR measuring[tw] OR measure[tw] OR scale*[tw] OR scaling*[tw] OR evaluat*[tw] OR assess*[tw] OR questionnaire*[tw] OR checklist*[tw] OR protocol*[tw]) AND (psychometr*[tw] OR reliab*[tw] OR valid*[tw] OR responsiv*[tw] OR sensibilit*[tw]). The focus of the search was based upon instruments evaluating motor abilities on