Manual Ability Classification System (MACS): development, evaluation and applicability

AKADEMISK AVHANDLING
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ABSTRACT

The ability to use our hands affects how we carry out almost all daily activities. Children with cerebral palsy (CP) have varying degrees of difficulties using their hands, ranging from minor clumsiness to major problems with any voluntary movements. There has not been any standardized, reliable method available for describing how children with CP use their hands.

The aims of this thesis was to develop a system to classify hand function among children and adolescents with cerebral palsy, to evaluate the validity and reliability of the results, and to investigate whether the use of this classification system could increase knowledge about the ability of these children to use their hands, and how this correlates with self-sufficiency in daily activities.

Study I describes the development of the Manual Ability Classification System (MACS). The central concept “manual ability,” is defined as the ability to handle objects in daily activities. The classification system consists of five levels. The MACS levels are based on the self-initiated ability of the children/adolescents to handle objects in their daily environment, i.e. when engaged in activities such as eating, dressing, playing, or doing schoolwork. The criteria for the different levels also include descriptions of the need for help or adaptations. The MACS is described in a brochure available on the Internet (www.macs.nu).

The validity of the MACS content and concept have been evaluated using different methods and from various perspectives in each of the four studies in the thesis. This was accomplished by interviewing parents of children with CP, occupational therapists and physical therapists, and other experts in the field (Studies I and II). In addition, the correlation between MACS and other instruments of hand function was examined, using a questionnaire to measure the degree of difficulty children have using their hands in daily activities (ABILHAND-Kids), as well as a test of manual dexterity (Box and Block Test) (Study III). MACS was also compared with a classification of gross motor function (Gross Motor Function Classification System, GMFCS) (Studies I and IV). The outcome of MACS was then compared with measures of independence of performance of daily activities (Pediatric Evaluation of Disability Inventory, PEDI) (Study IV). The reliability between different observers (two therapists, or one therapist and a parent, respectively) was reported in Study I.

The overall results show that both parents and therapists found MACS to be a meaningful method of describing how children handle objects in daily life (Study I and II). The comparison between MACS and other instruments, ABILHAND-Kids and the Box and Block Test, showed a strong correlation (rs = -0.88, p < 0.05 and rs = -0.81, p < 0.05) among the different assessment methods, even though they describe different aspects of hand function. By linking the meaningful concepts of the instruments to categories of the International Classification of Functioning, Disability and Health (child and youth version) (ICF-CY), it was shown that the instruments cover various aspects of activity and participation within ICF-CY. MACS provided a significantly broader representation of activity and participation (linking to seven chapters) than the other two instruments (linking to two and one chapters, respectively) (Study III). A high correlation was also found between MACS and GMFCS (rs = 0.77, p < 0.05) (Study IV). Nevertheless, only half of these children were classified into analogous levels of MACS and GMFCS indicating the complementary nature of the instruments. Inter-rater reliability for MACS was studied in two ways: in part by having two therapists classify 168 children, and in part by having both parent and therapists classify 25 children. In both situations, inter-rater reliability was excellent (intraclass correlation coefficient 0.98 and 0.96, respectively) (Study I).

Study IV investigated 195 children aged 3–15 years with different types of CP, using the PEDI functional skill scale for self-care and mobility. The results were compared to the children’s MACS and GMFCS levels. Stepwise multiple regression analysis verified that MACS was the strongest predictor of self-care (66%), while the GMFCS was the strongest predictor of mobility (76%). Moreover, children in MACS levels I and II demonstrated an age-related increase of skills, achieving complete or almost complete self-sufficiency in self-care, albeit at a later point than children without disabilities. Children with more severely affected hand function, MACS levels III–V, did not achieve self-sufficiency, and no age-related increase of self-care skills was observed. A similar picture was seen with regard to mobility based on GMFCS levels.

In summary, the studies in this thesis show that MACS is a classification system that provides a valid and reliable functional description of manual ability in children and adolescents with CP.