Using the MACS to facilitate communication about manual abilities of children with cerebral palsy

The heterogeneity of disorders covered by the term cerebral palsy (CP) may severely hinder communication between families on the one hand and health professionals, such as physiotherapists, paediatricians, and occupational therapists on the other. Common ground for communication about the child with CP is crucial for aspects such as diagnosis, treatment, care, management, and research. In his later work, Ludwig Wittgenstein introduced the concept of ‘language games’ (Sprachspiele) to underline that our use of language is permanently governed by rules, but not always by the same rules. On a daily basis we are involved in a large number of ‘language games’, where confusion and misunderstanding usually arise when a statement in one ‘language game’ is interpreted according to the rules of another. Speaking the same language, i.e. being engaged in the same ‘language game’ was one of the primary goals in the development of the Gross Motor Function Classification System, the recent redefinition of CP, as well as the recent development of the Manual Ability Classification System (MACS; also see Morris et al. p 950). This commentary focusses on the communication aspect of the MACS.

Potentially, the MACS can become an important and widely used classification system to assess manual abilities in children with CP. To attain this, it is important that the reliability of the evaluation is assured. Morris et al. tested the reliability of the MACS for children with CP in the UK. Families (n=91) and health professionals (n=60) scored manual ability of the children by completing postal surveys. Intraclass correlation coefficients ranged from 0.7 to 0.9 indicating reliable results for population-based research. Still, perfect agreement between families and health professionals was not present for every child which may be the result of two possible causes outlined below.

First, families and professionals observed children perform tasks in different environments and contexts. Consequently, evaluations may be based on tasks that differ in complexity. As an example, tasks observed by families may be closely related to activities of daily living (e.g. grasp a cup and place it upside down in a dishwasher), whereas the tasks observed by professionals may be more standardized and simple (e.g. dexterity tests). Taking this example one step further, the tasks evaluated by families may be more complex and sequential in nature, thereby adding a substantial (cognitive) motor planning component. Recently, we showed that disorders in motor planning may limit the performance of activities to a similar extent as disorders in the execution of motor tasks in the subgroup of hemiplegic CP. Thus, the level of cognitive impairment may have a significant impact on performance outcome over and above the manual abilities proper. It is, therefore, advisable to have some degree of standardization of the tasks and to avoid tasks that place a large burden on (cognitive) motor planning, particularly so because Morris et al. indicated that cognitive functioning was low in a substantial number of the children (39% had an IQ<70, and 28% had an IQ<59).

Second, Morris et al. report two conditions by which manual ability of the children was evaluated, direct observation or referral to previous records. The latter was often used by professionals: physiotherapists (40%), paediatricians (44%), and occupational therapists (61%). However, a record was most likely put together for another purpose and by another person (who did not have the MACS in mind when creating the record) and it may, therefore, not be a very reliable source. This argument is supported by the observation that the reliability was slightly higher for physiotherapists, of whom a greater proportion used direct observation, and slightly lower for paediatricians and occupational therapists, a greater proportion of whom had depended on the medical records.

In conclusion, standardization of task complexity and evaluation method should be communicated clearly to families and professionals as this will most likely increase the already good reliability of the MACS. As Morris et al. indicated, the instructional leaflet has been edited to allow for better communication and this may be extended to the particulars of tasks and methods used. Eventually, these efforts will create a common playground where families and parents are involved in the same ‘language game’, such that communication about the manual abilities of the child with CP is facilitated.

Bert Steenbergen

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References