

Systematic cognitive monitoring of children with cerebral palsy – the development of an assessment and follow-up protocol

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ABSTRACT

Cerebral palsy (CP) is associated with cognitive impairments, learning difficulties and reduced social participation. Individual assessment is necessary for individually tailored interventions. This paper describes the development of a systematic follow-up programme of cognition, and the challenges of integrating it into the regular follow-up of children with CP. Initiated by the Nordic users' organisations, a group of psychologists proposed a protocol of follow-up of cognition in children with CP – the *CP Cog*. This protocol consists of neuropsychological instruments covering general cognitive functioning, visuospatial and executive functioning. The article presents a natural experiment describing development and implementation of the cognitive protocol in three Scandinavian countries. This introduction illustrates challenges associated with implementation, especially how the success of the protocol hinges on structural backup within the different countries. In conclusion the *CP Cog* assessment protocol holds the promise of increasing the awareness among habilitation professionals that children with CP are in need of cognitive evaluation and educational support.

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Recent years have seen an increased focus on the cognitive difficulties children with cerebral palsy (CP) might experience. Intellectual impairments are frequent: at least 30% have an intelligence quotient (IQ) lower than 70 (Andersen et al. 2008). In the remaining group, an average full-scale IQ often masks an uneven profile with specific cognitive impairments.

Studies of children with CP applying more detailed neuropsychological examination reveal a cognitive profile characterized by both slower information processing (Shank et al. 2010) and specific impairments. Visual-perceptual and visuo-construction impairments, for example, the ability to copy or construct two- or three-dimensional figures, are common (Koeda and Takeshita 1992; Pagliano et al. 2007; Ego et al. 2015). Only a handful of studies have looked at attention and executive functioning, but the findings include impairments in focused, sustained and dual attention, reduced working memory capacity and impairments in impulse inhibition, supplemented with findings of impairment in a wide range of other executive functions such as shifting, emotional control and the ability to plan and monitor own behaviour (Kolk and Talvik 2000; Jenks et al. 2009; Boettcher, Flachs, and Uldall 2010). Memory impairments have been found in regard to inference and the use of spontaneous clustering (White and Christ 2005) and in learning of non-verbal associations,

even when controlling for deficits in visual-spatial ability. Language is generally considered an area of strength in children with CP, even in children with lesions in the left hemisphere (Frampton, Yude, and Goodman 1998).

The assessment of a child with CP always needs to be interpreted in the light of how neural and cognitive development has been compromised by the initial lesion. For example, impairments in attention will often affect the child's ability to participate in social and learning activities and thus cause secondary effects on reading and development of social skills. However, the extent and development of the cognitive and learning difficulties that the children experience also depend on the supportive and remedial practices that they meet in their everyday lives (Kozulin and Gindis 2007). Most children with CP are mainstreamed as part of the move towards more inclusive schooling. Often, they are expected to participate and learn similar to their peers. Conventional instructions build on a range of assumptions about the participating children's cognitive skills and abilities, for instance, that they are able to perceive visually presented material or to work at a particular speed or for a certain amount of time. Mainstreaming without knowledge of the child's cognitive profile increases the risk of the child being confronted with unwarranted assumptions about basic cognitive abilities in visual processing or the speed of information processing.

Children with learning difficulties need individually tailored interventions, and yet interventions are often provided in a standardized manner. For example, the dominant approach to children with reading problems has been based in the understanding of phonological problems as the underlying cause (Shaywitz and Shaywitz 2005). This assumption can be problematic because a second type of reading disabilities has been associated with deficits in visual-spatial processing (Vidyasagar 2012), deficits that are prevalent among children with CP. Traditional interventions based on a phonological approach will therefore not address the underlying problem. Instead, children with visual-perceptually based dyslexia will need a visually based training approach (Facoetti 2012). Compensatory techniques and aids may also be needed to address issues of slow reading pace and fatigue.

The knowledge that children with CP are at risk of cognitive impairments is included in the most recent definition of CP (Rosenbaum et al. 2006). Several authors therefore recommend that cognition is examined in children with CP (Ashwal et al. 2004; Blair 2010). Despite the importance of having knowledge about the individual child's cognitive functioning, not all children with CP are formally assessed. Epidemiological studies have shown that less than one-third of children with CP had been formally assessed (Andersen et al. 2008). This is unfortunate, as the substantial variation in functioning means that group studies can only be used to outline typical areas of cognitive difficulties. Although CP subtype and the severity of motor impairments tend to correlate with cognitive functioning on a group level, such deductions cannot be done on the individual level (Blair 2010). Therefore, individual cognitive assessment is needed. And even though the brain damage that the children have sustained is non-progressive, the consequences may change over time. Thus, follow-up of cognitive functioning is needed to ensure the continued suitability of the interventions.

On this background, a Nordic initiative was taken to develop a systematic programme for detecting and remediating cognitive difficulties that children with CP might experience. The aim of this article is to present the development of the Scandinavian protocol for monitoring cognitive functioning in children with CP – the *CP Cog* – and the challenges of the implementation process.

Method

The data presented arose from a natural experiment, in which the idea of cognitive monitoring of children with CP was developed into a test protocol and initiated in three of the Nordic countries. A natural experiment observes possible effects of an independent variable in uncontrolled settings (Coolican 1994). Longitudinal data demonstrating the impact of a systematic follow-up is still years ahead. Nevertheless, the development and introduction of the monitoring protocol in three different sociocultural environments offer an opportunity to reveal challenges in applying research-based

knowledge about cognitive functioning in children with CP in tailored support in their everyday settings.

The historic background of the CP Cog initiative was the success of the programme for monitoring motor development and somatic status in children with CP in the Scandinavian countries through the CP follow-up programme (abbreviated CPUP in Sweden, CPOP in Norway and Denmark and CPEF in Iceland). This programme ensures that children are seen on a regular basis by physicians, physiotherapists and occupational therapists working in the regional habilitation units. CPUP/CPOP/CPEF started in Sweden in 1994, in Norway in 2006, in Denmark in 2010 and in Iceland in 2012. A growing awareness among clinicians, researchers and the users' organizations emerged that other areas – such as cognition – would benefit from similar systematic monitoring.

The users' organizations for CP in the Nordic countries (coordinated through the network *CP Norden*) initiated the development of the *CP Cog* programme in 2011. A Nordic conference with focus on cognition was held in 2011, followed by a meeting at Lund University Hospital in the spring of 2012 with representatives from the Nordic users' organizations, from CPOP/CPUP/CPEF, from the Swedish national quality registry for habilitation (HabQ) and from the Cerebral Palsy Register of Norway (CPRN). Psychologists from the Scandinavian countries were invited and asked to develop a systematic programme for monitoring cognitive functioning in children with CP. A proposal was sent to CPUP, CPOP, CPEF, HabQ, CPRN and CP Norden on 1 September 2012. Since then, the protocol has been presented in different professional settings in each of the Scandinavian countries and at a pre-conference symposium at the Annual Meeting of the European Academy of Childhood Disability in October 2013 in Newcastle.

Results

The protocol describes the rationale for areas to assess, instruments and time points, as well as recommendations for reporting data and the diagnostic practice and assessment of subgroups of CP.

Choice of areas to assess

The instruments had to be available and in use in all three countries. To give the new protocol a head start, the *CP Cog* aligned their selection of tests with the quality registry HabQ in Sweden and chose the Wechsler scales (Wechsler 2002, 2003) as the central test battery of the *CP Cog*. They provide a measure of general cognitive functioning, as well as measures of verbal understanding, perceptual reasoning, working memory and processing speed. A further reason for choosing the Wechsler scales is their widespread use in habilitation units and in the practices of educational psychologist in the Nordic countries. Choosing well-known tests was thought to facilitate the process of implementation. To address particular cognitive areas in greater depth, measures of visual-spatial and executive problems were added. The Beery–Buktenica developmental test of visual-motor integration (Beery, Buktenica, and Beery 2010) was chosen as it is easy to administer and gives separate scores for visual-constructional abilities, visual-spatial perception and fine motor skills. To control for fine motor problems when assessing visual-constructional abilities is especially important for children with CP. The questionnaire Behavior Rating Inventory of Executive Function (BRIEF) was added as it is a broad and widely used measure of executive functioning (Gioia and Isquith 2000).

Reporting data

It was decided to register scaled scores from all subtests and the sum of scaled scores for clusters of subtests. The reporting of IQ was not recommended, as it was viewed as inadequate for describing cognitive functioning in a nuanced manner. Instead, diagnoses of cognitive difficulties were to be reported. To make a diagnosis of intellectual impairment, the F70–79 diagnoses of the

ICD-10, it was recommended that the child's adaptive functioning was assessed with Vineland-II (Sparrow, Cicchetti, and Balla 2005) or Pediatric Evaluation of Disability Inventory (Haley et al. 1992).

Choice of time points

Scandinavian children start school at 6–7 years of age. For children with CP it is important that the educational setting is tailored to the child's needs from the beginning. The transition from primary to secondary school or from lower to higher classes of elementary school (depending on national ways of organizing schools) is another important time point, as the demands on cognitive functioning increase markedly in these years. The group therefore decided to recommend testing at 5–6 years and 12–13 years of age.

Scope of protocol

The CP group is diverse when it comes to functioning, and for children with the most severe gross motor impairments (Gross Motor Functioning Classification System (GMFCS) levels IV and V), the tests described above cannot be used without adaptations (Schiørbeck and Stadskleiv 2008). We recommended that adapted assessments are carried out by specialized psychologists/habilitation units.

Ethical considerations

Ethical consideration was given to the consequences of having systematic cognitive assessments. Even though the proportion of cognitive impairments is very high in the CP group, including them all makes it probable that some children with no need for interventions will also be assessed. There is no way to exclude groups beforehand, as cognitive impairments are found in all subtypes and at all GMFCS levels. The consequences of undetected cognitive deficits were considered to be more serious than going through a two to three hour assessment procedure, even if the result of that assessment is a confirmation that no cognitive deficits could be detected. It is, however, important that all parents are informed that all the different assessments offered are voluntary, that they can participate in the rest of the follow-up programme (CPOP/CPUP) and HabQ even if they do not opt for the cognitive assessment, that they can give consent to the cognitive assessment but not to reporting data to the national registries, and that they can withdraw their consent and get the information deleted from the registry at any time without consequences. The concessions of the Norwegian and Swedish CPUP/CPOP and HabQ registers explicitly state that data may be used in research.

Protocol

On the basis of the considerations above, the following protocol was proposed (Table 1).

Table 1. The proposed follow-up procedure of cognition – CP Cog – for children with CP.

Age	Rationale	Instruments	
		For GMFCS I–III	For GMFCS IV–V
5/6 years	Starting in school	WPPSI-III, VMI and BRIEF	Adapted assessment in specialized institutions
12/13 years	School transition	WISC-IV, VMI and BRIEF	

Notes: GMFCS, Gross Motor Functioning Classification System; WPPSI-III, Wechsler Pre-school and Primary Scale of Intelligence, third edition; VMI, Test of Visual-Motor Integration; BRIEF, Behavior Rating Inventory of Executive Function; WISC-IV, Wechsler Intelligence Scale for Children, fourth version.

Implementation

Although the Scandinavian countries all have welfare systems with the same principle of offering free habilitation services to children with disabilities, the services in themselves are differently organized. Accordingly, the implementation of the protocol followed different trajectories in each of the three Scandinavian countries.

Sweden

In Sweden, a multi-professional quality register for habilitation (HabQ) was introduced in south-east Sweden in 2005 to supplement CPUP with the monitoring of cognitive, communicative and social aspects of development. *CP Cog* is based on the HabQ, and 4 out of 21 counties in Sweden have started using the *CP Cog* protocol. Coverage of HabQ in the four counties has been estimated by using population statistics and epidemiologic data for children with CP since 2010. Coverage has increased substantially over the years, estimating that 51% of children with CP in the population of the counties were followed in HabQ in 2010 and 82% in 2013. Not all children participating in HabQ are assessed cognitively, but a relatively high percentage had cognitive assessments at 6 years (75–85%) and at 12 years (86–66%) over the years 2006–2013 (not shown). Assessments with Wechsler Preschool and Primary Scale of Intelligence, third edition (WPPSI-III) or Wechsler Intelligence Scale for Children, fourth version (WISC-IV) were lower, but rising over the years, from 20% to 52% at 6 years of age over the period 2006–2013 and from 9% to 33% at 12 years of age over the period 2008–2013

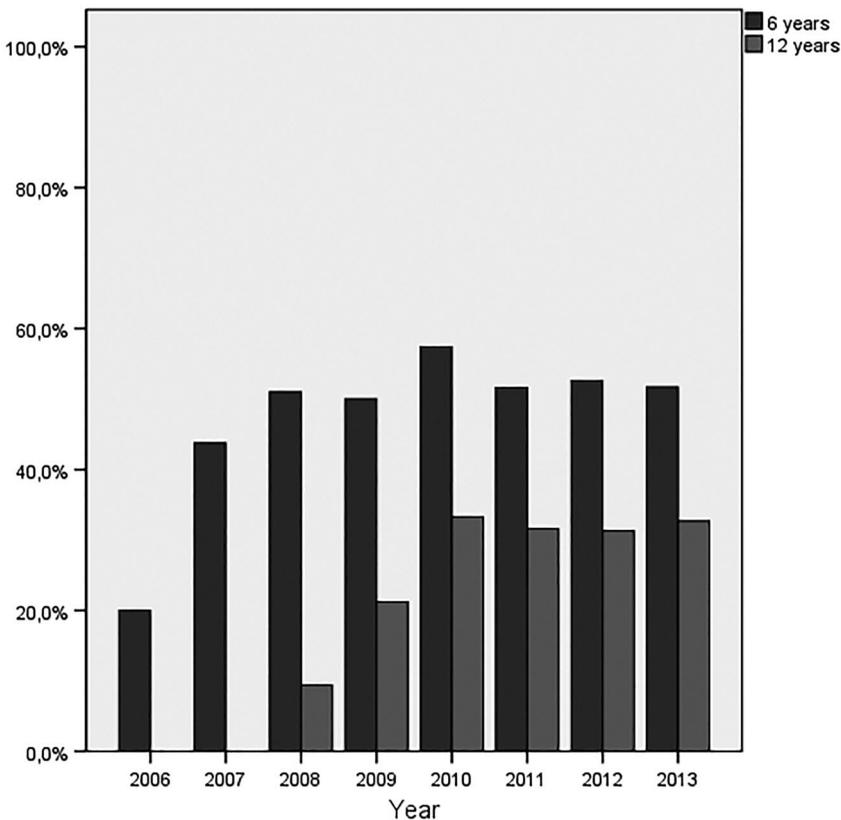


Figure 1. Results from Sweden. Percentage of assessments with a Wechsler test (WPPSI-III or WISC-IV) in HabQ of children with CP GMFCS I–V at 6 and 12 years of age, development over the period 2006–2013. From 2006 to 2013, a total of 365 out of 713 children (51.2%) were assessed at 6 years of age and a total of 188 out of 524 (26.6%) of the 12-year-olds were assessed.

(Figure 1). In CPUP, estimated or tested intellectual function according to the ICD levels F70–79 is reported by a neuropaediatrician at 4–5 years of age. One-third (273/945) of the children born 2000–2006 with such a report had had at least some formal assessment by a psychologist in 2012. CPUP has been running in all 21 counties since 2007 and will introduce the *CP Cog* during 2015 in cooperation with HabQ.

Norway

In Norway, the CPRN has been collecting data about cognitive functioning in children with CP for many years, but there has been no systematic procedure for how and when the children should be assessed. In 2012, the habilitation units in Norway expressed a positive attitude towards a standardized national follow-up procedure of cognition in children with CP (survey response rate 67%, 15 of 16 units positive). Implementing the procedure takes time. The 21 regional habilitation units are autonomous in deciding if they want to add cognition to the areas that children with CP are followed up on, and if they want to submit the data to the national Norwegian quality register for cerebral palsy (CPRN). At present, the CPRN only receive information about cognition following the new *CP Cog* procedure from one regional habilitation unit on a regular basis, but several others are in the process of starting up. To increase the likelihood of data being reported to the CPRN, the registry form was made available on the CPRN webpage in December 2014. The CPRN concession to store data from the protocols runs until 2030, when permission will need to be renewed.

Denmark

Denmark lacks an organizational structure similar to the habilitation units. A presentation of the protocol at a national CPOP meeting and for groups of interested professionals did raise interest. However, it also revealed that assessments currently take place in an uncoordinated and thus non-systematic fashion. At the municipal level, educational psychologists at the local schools assess children when necessary to address school-related issues. While the WPPSI-R and WISC-IV are in use, shorter screening instruments are also applied. At the intermediate level, five regions exist with responsibility for hospitals. At least one paediatric unit is known to offer a thorough 'developmental profile' prior to school start. However, this option is only available to children from that particular region and only around the age of five. At the national level, the central organization VISO (the national organization for knowledge and specialized counselling) offers high-specialized assessment and counselling, mainly in complicated cases. No central registration of assessments takes place.

The success of the original CPUP programme in Sweden, decreasing the amount of children with CP developing hip dislocation, has led to the implementation of the CPOP in Denmark, despite the lack of habilitation units. Thus it is our hope that a similar process of implementation of the *CP Cog* will take place as the Swedish and Norwegian *CP Cog* programmes begin to show positive results.

Discussion

Implementing a protocol for assessment of cognition in all children with CP will ensure that the strengths and difficulties of each individual child will be known. The protocol contributes to systematic follow-up of all children with CP, and is a safeguard against cognitive challenges being overlooked in the part of the CP population with less severe impairments. The daily effort of keeping up with demands in mainstream practices without the necessary support and accommodation of the school and teaching practices might be a stressor for many children with CP and part of the explanation for why a substantial part of children with CP experience social and emotional problems (Bjorgaas et al. 2013; Bøttcher and Dammeyer 2013), alone or together with learning difficulties. In Denmark, a law-based division have been made between children in need of at least nine hours of support and those in need of less (Law no. 379 from 28 April 2012). The law states that children

with need of less than nine hours of support are supposed to function within the mainstream teaching practices that may include dividing the class into smaller groups and smaller adaptations of the curriculum (within general educational acts regarding the curriculum). However, approximately 35% of parents of mainstreamed children with CP report that their child lacks consideration of the consequences of having CP, while this is less often the case of children with CP in special classes or special schools (Michelsen et al. 2010). Psychological assessment can be requested by the leader of the school, eventually on requests from the child's parents and/or teachers. However, a recent qualitative study of assessment procedures of children with CP in Denmark revealed a need for more systematic assessment procedures. Many children with mild CP were not seen by a psychologist and their parents received no counselling regarding their child's educational needs. They felt left alone in the choice of school for their child. In addition, children with cognitive difficulties started school without awareness at the school and among their teachers that they might have special educational needs (Bøttcher, Falkenstrøm, and Nielsen 2014).

A standard protocol offered to all children with CP could be a safeguard against inequality of services. Results from the Swedish HabQ registry indicate that having a systematic protocol leads to more children being assessed. For clinical as well as educational purposes, it is important that not only children with obvious difficulties are tested. A standardized protocol including all children with CP will also ensure that children's cognitive capabilities and challenges are correctly described. In children with CP where evaluations of cognition are based on clinical observations or only a few subtests, more are evaluated as having general intellectual impairment and less as having specific learning disabilities than when children are properly assessed (Stadskleiv et al. 2015). On the other hand, standardized assessment cannot stand alone but need to be followed up with counselling and recommendations for interventions in teaching that will enable the child to participate in teaching/learning activities with better outcome. In Norway and Sweden all children with need for specialized educational support are entitled to an individual learning plan, while individual learning plans in Denmark are part of the educational practices mainly in specialized school settings and does not figure as a right in the educational act regarding children with special educational needs. Research have shown how children with CP (and children with other types of disabilities as well) experience increasing difficulties with participation over time (Wendelborg and Tøssebro 2010). The tendency towards increasing exclusion was explained as due to alterations in the relation between the child's characteristics and the demands of the environment. In addition, cooperation between the parents and the teachers were reported to decrease over the years as teachers tended to marginalize their pupils with special educational needs and hand over the responsibility for their learning to a special educational teacher. Thus part of the participation problems are possibly due to social marginalization processes such as tendencies to attribute learning problems as due to factors within the child only rather than to see them as related to lack of necessary accommodations at the schools to embrace a wider range of students including those with CP. However, participation problems of children with disabilities are not equally distributed across all activities, but are in particular seen in math, practical subjects and science (Erikson, Welander, and Granlund 2007). Thus, knowledge about the particular learning challenges of children with CP is relevant in order to address the learning needs and concretize *which* types of accommodations are needed. Learning problems and social and emotional problems need to be understood in relation to the incongruence between expectations and demands in particular activities within the school setting and the individual capacities of the child. To be met with correct demands and expectations is the basis of coping, of optimal development, of feelings of self-confidence and self-esteem. Offering the child the right amount of cognitive challenges, at the same time providing the necessary amount of support, in what Vygotsky termed the zone of proximal development (Vygotsky 1998; Kozulin and Gindis 2007), will also contribute towards each child reaching his potential. Even if assessment results are not reported nationally, the protocol as a foundation for an individual learning plan may thus be of clinical and educational value as a base for interventions that are tailored to each child's individual needs. Thus the protocol in its current form supplements the current procedures for educational counselling,

but there is reason to assume that the procedures for translating assessment of the child into educational practices still rest too much on local procedures for follow-up rather than systematic and research-based inclusion practices.

Assessment protocols that are meant to be implemented in everyday clinical practice will only be successful if there is an appreciation of why they are needed and how they are important in clinics. The *CP Cog* procedure is based on an initiative from user organizations, reflecting an expressed need for more focus on cognition from parents of children with CP. In addition to assessment, the parents are also requesting guidance about intervention strategies. In the future, it would therefore be desirable for the *CP Cog* to include not only areas and instruments of assessment, but also suggestions for interventions when difficulties are detected following assessment. The awareness of minor or more extensive cognitive difficulties and how to circumvent them will help teachers and other educators in both mainstream and specialized settings. Assessments serve to identify and raise attention to the existence of special educational needs of a particular child with CP otherwise overlooked or not noticed until later on when learning problems have grown due to greater demands on the child or the development of psychological or psychiatric problems. Second, the assessment and the subsequent presentation and discussion of the assessment results at a joint meeting between psychologist, parents' and teachers hold the potential to open up for discussions about possible barriers to the child's participation in learning activities by providing a mutual vocabulary in which to understand the child and his or hers way of acting in the classroom and at home (Bøttcher, Falkenstrøm, and Nielsen 2014). The use of a standardized assessment protocol does not need to be in opposition to the current move within educational psychology towards consultative practices (Lambert, Hylander, and Sandoval 2004). Rather, psychological assessments and consultative practices hold the promise to supplement each other in knowledge-based counselling of the teacher and parents about the individual child educational needs considered in relation to situational practices.

Further development in the clinical setting

The proposed follow-up programme *CP Cog* is a core battery, as the aim was to propose a battery that was both manageable and realistic to introduce in the clinical setting. However, it is strongly recommended that the core battery is supplemented if difficulties in areas that it does not cover are suspected, to ensure that counselling is based on a comprehensive foundation.

The plan is to introduce an expanded battery once the core battery has been firmly implemented. There are two ways in which the core battery should be expanded: areas assessed and time points of assessment.

The protocol only recommends assessment at two time points. Usually it will be desirable to assess children with CP at a younger age, especially if they do not develop speech as expected for their age. We therefore propose that children are assessed with a developmental scale (Bayley or Griffiths) at two years of age. It is also advisable to assess for visuospatial difficulties between the two time points of the core protocol. At the age of 5/6 years, more subtle difficulties might be difficult to spot, while visuo-perceptual difficulties and a lack of educational support may have caused the child to develop learning difficulties in academic subjects such as arithmetic at the second time point. Likewise, difficulties with attention and executive functioning might be underestimated at 5/6 years of age and might have had a large and negative impact on academic and social functioning if they are not detected and adjusted for by the time the child reaches the end of primary education. We therefore propose the assessment of visuospatial abilities, attention and executive functioning at 9/10 years of age; especially if the child is born prematurely or has diplegic CP (Koeda and Takeshita 1992). As children continue to develop after 12/13 years of age, a thorough assessment before entering higher educational levels is also recommended. The purpose of this assessment would be to guide children towards realistic job opportunities as well as forming the basis for discussions about possibilities and obstacles in adulthood.

In the future, the plan is also to expand the assessment battery to include recommendations for assessing children with the most severe motor impairments; those classified as having GMFCS levels IV and V. For this group, assessment needs to be adapted in order to evaluate their level of understanding appropriately (Visser et al. 2013). A recent study showed that adaptations may be necessary for as many as one-third of the CP population (Sherwell et al. 2014).

Possibilities for research

For research purposes, the *CP Cog* protocol holds promise as a way to gather large-scale data about cognitive functioning and cognitive development of children with CP. Especially the last point is in need of further research as only a few studies of cognitive development exist. There are three recent studies with a longitudinal design, all of them only including children with unilateral spastic CP. Furthermore, the three studies disagreed about the development of general cognitive functioning. Muter, Taylor, and Vargha-Khadem (1997) found that IQ remained stable, Levine et al. (2005) found that IQ declined with age, while the third study by Gonzalez-Monge et al. (2009) found that the mean (full-scale) IQ was close to the normal reference score at all their three points of measurement (time 1 at 7 years of age, time 2 at 7 and time 3 at 14). Differences between the results of the three studies may be related to their different designs regarding the age of the participating children, follow-up age and longitudinal versus cross-sectional design. Still, studies of general intellectual development (IQ) can only be used to point to overall trends in cognitive development. The general IQ measure may cover up developmental increases or decreases in specific cognitive functions that might be more informative about the developmental trajectories of cognition. White and Christ (2005) analysed the development of verbal learning and inhibition using a cross-sectional design. Analysis included the interaction between age and group and revealed that the difference between the CP group and the control group was more pronounced in the younger than the older children in the CP group. The study pointed to a developmental *delay*. Such a delay has also been proposed in another cross-sectional study, but this time in relation to development of Theory of Mind and executive functioning (Li et al. 2014). Opposite to what was found in studies of general cognitive functioning, younger children showed greater impairment compared to same-aged peers and older children revealed a catch-up. In contrast, the two papers from Dahlgren Sandberg (2001, 2006), where the second represent a follow-up of the first one, point to a decline in the development of both literacy skills and working memory. Even though the children were behind same-aged peers at T1 and T2, they showed progress in literacy skills. However, the follow-up study revealed that the progress in the first study was followed by a developmental arrest between T2 and T3. The children participating in Dahlgren Sandberg's studies all had severe speech and motor impairments. Smits et al. (2011) found that in children with CP those with the most severe motor impairments had a slower development of visuospatial reasoning than those with less severe motor impairments. Taken together, studies of general as well as specific cognitive functioning might reveal different developmental trajectories of specific cognitive functions and that the developmental trajectories might be different for different subgroups of children with CP. The two assessment points of the protocol will enable studies using a longitudinal design. Furthermore, the large-scale standardized data from *CP Cog* following cohorts of children with CP at at least two time points could provide research material for registrar-based research of developmental trajectories that combine data about cognitive functioning with other types of large-scale data already being collected. The Danish Cerebral Palsy Registry and other registries in Denmark collect data on CP diagnosis, parents education and income and school performance in national tests. In Norway, *CP Cog* is embedded in the CPRN, thus providing similar opportunities. In Sweden, register-based research combining healthcare security identification of participants with diagnosis of CP and other types of data, for example, national attainment data on educational outcome, is also possible.

Limitations

Presentations of the implementation process in the three Scandinavian countries show that there is still some way to go before the *CP Cog* protocol is implemented and that there are substantial differences between the three countries. This situation which will probably continue due to structural factors such as coordination with existing quality registries and the organization of the social and health sector. For research purposes, it is crucial that data are systematically collected and registered, and a protocol like *CP Cog* holds the potential to increase knowledge about CP and its consequences in an unparalleled manner. This of course requires that results are reported to national quality registries for as many children as possible at the assigned time points.

The group will continue to work towards a higher implementation rate, as well as expansion into the other Nordic countries Iceland and Finland, as we believe this is of value for both research and clinical purposes. In this connection, it is essential to inform national political decision-makers about the soundness of providing resources for assessment and support for all children with CP. Patient organizations remain important partners.

Disclosure statement

No potential conflict of interest was reported by the authors.

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