Communication ability in cerebral palsy: A study from the CP register of western Sweden

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Abstract

Background: Communication is often impaired in cerebral palsy (CP). Tools are needed to describe this complex function, in order to provide effective support.

Aim: To study communication ability and the relationship between the Communication Function Classification System (CFCS) and CP subtype, gross motor function, manual ability, cognitive function and neuroimaging findings in the CP register of western Sweden.

Methods: Sixty-eight children (29 girls), 14 with unilateral spastic CP, 35 with bilateral spastic CP and 19 with dyskinetic CP, participated. The CFCS, Gross Motor Function Classification System (GMFCS) and Manual Ability Classification System (MACS) levels, cognitive impairment and neuroimaging findings were recorded.

Results: Half the children used speech, 32% used communication boards/books and 16% relied on body movements, eye gaze and sounds. Twenty-eight per cent were at the most functional CFCS level I, 13% at level II, 21% at level III, 10% at level IV and 28% at level V. CFCS levels I–II were found in 71% of children with unilateral spastic CP, 46% in bilateral spastic CP and 11% in dyskinetic CP (p = 0.03). CFCS correlated with the GMFCS, MACS and cognitive function (p < 0.01). Periventricular lesions were associated with speech and more functional CFCS levels, while cortical/subcortical and basal ganglia lesions were associated with the absence of speech and less functional CFCS levels (p < 0.01).

Conclusion: Communication function profiles in CP can be derived from the CFCS, which correlates to gross and fine motor function. Good communication ability is associated with lesions acquired early, rather than late, in the third trimester.

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1. Introduction

Cerebral palsy (CP) is the most common motor impairment in childhood, affecting about two per 1000 live-born children. More than half the children with CP have accompanying impairments, which may be more disabling than the motor impairment. Communication impairment may be one of them.

As described by the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF)
framework, communication involves sending and receiving oral and written messages with familiar and unfamiliar communication partners. Communication can be accomplished by using one of many possible methods (e.g. speech, written word, communication pictures and speech-generating devices). Communication is described within the ICF activity level, but successful communication via speech is facilitated by adequate motor speech, receptive/expressive language and hearing skills which are classified within the chapters of the ICF body structures and functions. Communication success can be supported or impeded by ICF environmental and personal factors, including the knowledge and skill of the communication partners, characteristics of home and community settings and the use of technology.

Children with CP may have problems with intelligible speech production. Reduced speech intelligibility may influence a child’s interaction with its mother and other important communication partners. To provide effective intervention, more knowledge is needed of the communication limitations of children with CP. Few CP registers collect information about communication in a standardised manner, which makes comparisons between studies difficult. In a report from the CP register of Western Australia, 20% had no speech. In a Norwegian study, 19% had no speech, while an Icelandic study reported that 16% of preschool children with CP had severe dysarthria and 16% were non-verbal. In a recent report on children with any type of CP born in 1991–1998 in Sweden, 49% had impaired speech and 30% did not use speech to communicate. In the population-based study of children with dyskinetic CP born in 1991–1998 in western Sweden, 20% of the children had reduced intelligibility due to dysarthria and 80% did not use speech. Speech ability has been shown to be associated with cognitive and gross motor function.

When speech or other communication skills are compromised, augmentative and alternative communication (AAC) can be used to supplement or replace oral communication. AAC includes the use of manual signs, gestures, pointing, pictures, boards, books and speech-generating devices. Communication, both with speech and with AAC, is dependent on other functions, such as cognition and language, as well as visual, auditory and upper limb function.

The need for early intervention with AAC has been increasingly recognised. Information about AAC availability and use is extremely limited in the literature. In the Norwegian study, 54% of children with significant speech problems used AAC in any form, while, in the Icelandic study, only 21 of 152 children used AAC, but no child had a speech-generating system.

Communication in children with CP is still poorly described, although some communication scales are being developed, e.g. in Australia, Portugal and North America. The most recently published classification is the Communication Function Classification System (CFCS), which has been developed on five levels to correspond to the well-known Gross Motor Function Classification System (GMFCS) and the Manual Ability Classification System (MACS). The CFCS is based on the concept of sending and receiving messages by the individual with CP interacting with familiar and unfamiliar partners (Table 1). The content validity has been demonstrated and very good test-retest reliability, good professional inter-rater reliability and moderate parent-professional inter-rater reliability were found in the original development study.

Reports on the neuroanatomical correlates to communication disability in children are scarce. Basal ganglia, perisylvian and rolandic cortices, the cerebellum and corticobulbar tracts have been associated with speech disorders. However, few population-based studies have as yet described this association regarding CP.

The CP register of western Sweden has been monitoring the prevalence, motor function and accompanying impairments of CP in a defined study area since 1954. Communication impairment is a recent addition to this follow-up.

The aim of this study was to examine the relationship of the CFCS with gross motor function, manual ability, cognitive impairment and AAC methods and to describe communication ability in relation to neuroimaging findings in children and adolescents with CP within a population-based register.

### 2. Materials and methods

#### 2.1. Participants

Sixty-eight children, born in 1991–1997, in the CP register of western Sweden participated in this study. The motor function and accompanying impairments of the total birth-year cohort have previously been described, with the exception of communication impairment. The CP definition according to Mutch et al. and the classification of CP suggested by the Surveillance of Cerebral Palsy in Europe (SCPE) were used. All the children were included in the European SPARCLE project (Study of Participation of children with cerebral palsy living in Europe).

Fourteen children had unilateral spastic CP, 35 had bilateral spastic CP and 19 had dyskinetic CP. All GMFCS and MACS levels were represented in the group.

In total the population-based register comprised 130 children with unilateral spastic CP, 170 with bilateral spastic CP and 48 children with dyskinetic CP from the birth years 1991–1997. None of the children had Worster Drought syndrome.
2.2. Procedures

Communication function was classified according to the CFCS, while gross motor function was classified according to the GMFCS and MACS. Cognitive impairment was defined as mild with an IQ of 50–70 and severe if the IQ was less than 50. The IQ or developmental quotient were measured by Wechsler or Griffith scales or estimated from clinical observation, as described previously in these cohorts. Interviews were conducted with the children and their families as part of the SPARCLE study. In conjunction with the interview, the child’s ability to communicate was classified by the second author using the CFCS. Age at assessment was 11–17 years. To study the inter-rater agreement of the instrument, a second CFCS classification was completed independently in 40 (59%) of the children by the first author. Communication methods were documented. Neuroimaging findings on computed tomography (CT) or magnetic resonance imaging (MRI) were classified into five categories: maldevelopment, periventricular white matter lesions, cortical and deep gray matter lesions, other lesions and normal, according to Krägeloh-Mann. The group of cortical and deep gray matter lesions were sub-divided into cortical/subcortical and basal ganglia lesions.

2.3. Statistics

Kappa was used to measure inter-rater agreement for the CFCS. Analysis included descriptive statistics and Fisher’s test for comparisons of several groups in the case of small numbers. Spearman’s correlation coefficient was used to study correlations. The Cochran–Armitage chi-square test for trend was used to detect trends.

2.4. Ethics

The study was approved by the Ethics Committee at the Medical Faculty at the University of Gothenburg.

3. Results

Results were obtained from 68 children in the CP register of western Sweden. CFCS inter-rater reliability between the first and second author was $\kappa = 0.905$.

3.1. Distribution of CFCS levels

Nineteen (28%) children were found at CFCS level I, 9 (13%) at level II, i.e. effective senders and receivers with unfamiliar partners, 14 (21%) at level III, i.e. effective senders and communicators with familiar partners, while 7 (10%) were at level IV and 19 (28%) at level V, i.e. not reliably effective communication partners even with familiar partners.

3.2. Communication methods used

In 35 (51%) children, speech was reported to be the communication method. In one child, speech was supplemented with a talking device due to dysarthria. In 22 (32%), communication boards, books and/or pictures were used, with speech-generating devices used in parallel in six children. In eleven (16%) children, sounds, eye gaze, facial expression, gesturing and/or pointing were the only communication methods. One child, with neural deafness, used manual signs. Of the 35 children who used speech, 19 (54%) were at CFCS level I. In contrast, 14 of 22 (64%) children using communication boards were at CFCS level IV or V (Table 2). Children using speech were found at more effective communication levels than children using a communication board as the communication method, Fisher’s test $p < 0.01$. One child, at CFCS level III, used speech, sounds, eye gaze, facial expression, gesturing, pointing and pictures.

3.3. Communication by CP type

The children with unilateral spastic CP were at CFCS level I–II in 10 of 14 children (71%), while this was the case in 16 of 35 (46%) of the children with bilateral spastic CP. In the children with dyskinetic CP, only two of 19 (11%) had the ability to communicate with unfamiliar partners, while five of 19 (26%) were able effectively to communicate with familiar partners. All the children at CFCS level I had unilateral spastic CP or bilateral spastic CP. The differences in communication ability, expressed as CFCS levels, between the CP types were significant, with dyskinetic CP being the CP type with least effective communication, Fisher’s test $p = 0.03$ (Fig. 1).

<table>
<thead>
<tr>
<th>Communication method</th>
<th>CFCS level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech</td>
<td>I  II III IV V Total</td>
</tr>
<tr>
<td>Sounds</td>
<td>19 8 8 0 0 35</td>
</tr>
<tr>
<td>Eye gaze, facial expressions, gesturing and/or pointing</td>
<td>0 1 7 7 19 34</td>
</tr>
<tr>
<td>Manual signs</td>
<td>0 0 0 1 0 1</td>
</tr>
<tr>
<td>Communication boards, books, and/or pictures</td>
<td>0 1 7 6 8 22</td>
</tr>
<tr>
<td>Speech-generating device</td>
<td>0 0 3 1 4 8</td>
</tr>
</tbody>
</table>

Please note that each child may be counted in more than one category.

Fig. 1 – Distribution of CFCS levels by CP type in 68 children born in 1991–1997. USCP: unilateral spastic CP; BSCP: bilateral spastic CP.
3.4. Communication by gross motor function and manual ability

The level of communication ability correlated strongly with gross motor function expressed as GMFCS levels (Spearman’s correlation coefficient 0.776; \( p < 0.01 \)) (Fig. 2). All the children at GMFCS level I were at CFCS level I. Eleven (73%) of the children at GMFCS level II were at CFCS levels I–II. In contrast, 14 (82%) of the children at GMFCS level V were at CFCS level V, while three (18%) were at CFCS level III (effective communication with familiar partners). When the MACS was applied, the same pattern emerged (Spearman’s correlation coefficient 0.8; \( p < 0.01 \)) (Fig. 3).

3.5. Cognitive impairment and communication

The communication ability differed between the groups of cognitive function, Fisher’s test, \( p < 0.01 \). A more effective CFCS level was associated with a higher cognitive function (Spearman’s correlation coefficient 0.859; \( p < 0.01 \)). All the children at CFCS level V had severe cognitive impairment. However, children with cognitive impairment were found at every CFCS level (Table 3).

3.6. Neuroimaging and communication

Neuroimaging results (40 CT, 25 MRI) were available for 65 children. There was a difference between neuroimaging findings associated with the presence of speech (Fisher’s test \( p < 0.001 \)). In children without speech, cortical/subcortical lesions and basal ganglia lesions were more prevalent compared with the group with speech, where the periventricular lesions were more prevalent (Table 4). Regarding communication expressed as CFCS levels, there was a trend that lesions occurring later in gestation (cortical/subcortical and basal ganglia lesions) were associated with less functional CFCS levels (\( \chi^2 \) trend (1df) 6.81; \( p < 0.01 \)) (Table 5). Of the three children without neuroimaging data, one was at CFCS level I, one at level II and one at level III.

3.7. Pattern of function by CP type

The majority of the children with unilateral spastic CP had CFCS level I, no cognitive impairment, MACS level I and GMFCS level I respectively. Most of them used speech.

In the children with bilateral spastic CP, 16 of 35 were effective senders and/or receivers with unfamiliar and familiar partners, albeit sometimes slow paced (i.e. CFCS level I–II), and were at both GMFCS and MACS level I–II, 75% had no cognitive impairment and all used speech. In the 19 children with BSCP and a less functional CFCS level (III–V), all had GMFCS level IV–V and almost all had MACS level III–V and cognitive impairment.

The group with dyskinetic CP was characterised by a less functional CFCS level (III–V) in 89%, GMFCS and MACS at levels IV–V and most had cognitive impairment.

Comparing the children with bilateral spastic CP and dyskinetic CP with more severe motor impairment (GMFCS IV–V), eight of 22 (36%) of the children with bilateral CP used speech as compared with none of the 16 children with dyskinetic CP, Fisher’s test \( p = 0.012 \). However, according to CFCS levels, there was no statistical difference between these two subgroups in the ability to communicate, Fisher’s test \( p = 0.3 \). Nor was there any difference in the percentage of severe cognitive impairment between bilateral spastic CP and dyskinetic CP at GMFCS IV–V.

3.8. Representativeness of the total cohort by CP type

The children in this study constituted 20% of all children with spastic or dyskinetic CP born in 1991–1997 in the population-based register. The distribution of GMFCS levels was representative of the total group of unilateral spastic CP and dyskinetic CP, while, in bilateral spastic CP, there were more children at GMFCS levels IV–V in the investigated group than in the total group (62% and 41% respectively, \( p = 0.026 \)). The distribution of cognitive level was representative of the total group regarding all three CP types.

Applying the CFCS distribution by CP type derived from this study, 175 of 348 children in the total group (92 with unilateral spastic CP, 78 with bilateral spastic CP and 5 with dyskinetic CP) would be able to communicate with unfamiliar partners (CFCS levels I–II) in the total group, while 78 (9 with unilateral spastic CP, 49 with bilateral spastic CP and 20 with dyskinetic CP) would be at CFCS level V (seldom effective senders and receivers even with familiar partners).
The ability to communicate is important to everyone. This ability may be hampered in several ways for individuals with CP. In the present study, a new classification, the CFCS, was used to obtain an overview of communication ability in a group of children and adolescents with different CP types and severity of impairment within a population-based CP register. The professional inter-rater reliability for CFCS classification was excellent and the researchers were able easily to classify the children using the CFCS.

Children were found on every level of the CFCS. Of the 51% who used speech to communicate, half were not classified as CFCS Level I, i.e. effective communicators with familiar and unfamiliar partners, but on levels II and III. This lack of effective speech may indicate the need for other methods of communication, such as a speech-generating device. In spite of this, only one of the children using speech also used a speech-generating device.

The ability to communicate was associated with cognitive level, gross motor function and manual ability, which is in line with previous research. If there was severe cognitive impairment, the child was more likely to have less functional communication ability.

Due to the complexity of communication, it is described and studied in many ways. In addition, the complexity of CP itself must be taken into account. Different patterns may emerge for various subgroups. A recent study by Hustad et al. revealed four groups of speech and language profiles in 34 children with CP, based on language development, cognition and severity of speech impairment. There was no information on CP type in that study. In the present study, differences in the communication patterns of the different types of CP emerged. Children with unilateral spastic CP were characterised by good communication ability, matched by good gross motor function and manual ability. Children with bilateral spastic CP and dyskinetic CP were more scattered across the CFCS levels, with the majority of children with dyskinetic CP depending on AAC. It is worth noting that there were children with a severe motor impairment, who had a good ability to communicate.

A similar pattern has been described by Andersen, who reported a difference in speech ability between bilateral spastic CP and dyskinetic CP. Children born preterm, assumed to have a periventricular brain lesion, had less speech impairment than children with dyskinetic CP, who typically have basal ganglia lesions, affecting the coordination of speech. To further explore the neuroanatomical basis for communication, neuroimaging data were included in the present study. Speech and affiliation to the most effective CFCS levels (I–II) were more prevalent in children with periventricular white matter lesions, derived late in the second or early in the third trimester, than in children with cortical/subcortical and basal ganglia lesions, derived later in the third trimester. These results are in accordance with recent reports by Martinez-Biarge et al. and Liégeois and Morgan. The lesions derived late in gestation were associated with a poorer ability to communicate according to the CFCS.

One limitation of this study is the relatively small sample size, albeit to some extent representative of the total group of children with CP in these birth-year cohorts. Based on the distribution of communication ability by CP type in the present study and the distribution of CP types in the total group of children born 1991–1997 in the register, the data suggest that more than 50% of children with CP are able to communicate not only with familiar, but also with unfamiliar partners. In contrast, 22% would only seldom be effective communicators even with familiar partners. These findings need to be confirmed in larger groups. The importance of attentive and informed communication partners is also highlighted by these results.

**Table 3 – Communication and cognitive level in 68 children born in 1991–1997.**

<table>
<thead>
<tr>
<th>Cognitive level</th>
<th>CFCS level</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I (n=19)</td>
<td>II (n=9)</td>
<td>III (n=14)</td>
<td>IV (n=7)</td>
<td>V (n=19)</td>
</tr>
<tr>
<td>No cognitive impairment</td>
<td>17 (89%)</td>
<td>7 (78%)</td>
<td>5 (36%)</td>
<td>1 (14%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Mild cognitive impairment</td>
<td>2 (11%)</td>
<td>2 (22%)</td>
<td>7 (50%)</td>
<td>4 (57%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Severe cognitive impairment</td>
<td>0</td>
<td>0</td>
<td>2 (14%)</td>
<td>2 (29%)</td>
<td>19 (100%)</td>
</tr>
</tbody>
</table>

**Table 4 – Neuroimaging and the presence of speech in 65 children born in 1991–1997.**

<table>
<thead>
<tr>
<th>Neuroimaging finding (n=65)</th>
<th>Speech</th>
<th>No speech</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maldevelopment</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Periventricular white matter lesion</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>Cortical/subcortical lesion</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Basal ganglia lesion</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Normal finding</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>31</td>
</tr>
</tbody>
</table>

**Table 5 – Neuroimaging and communication in 65 children born in 1991–1997.**

<table>
<thead>
<tr>
<th>Neuroimaging finding (n=65)</th>
<th>CFCS level</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I</td>
</tr>
<tr>
<td>Maldevelopment</td>
<td>2</td>
</tr>
<tr>
<td>Periventricular white matter lesion</td>
<td>10</td>
</tr>
<tr>
<td>Cortical/subcortical lesion</td>
<td>5</td>
</tr>
<tr>
<td>Basal ganglia lesion</td>
<td>0</td>
</tr>
<tr>
<td>Normal finding</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
</tr>
</tbody>
</table>
Future research could explore relationships between CFCS levels and different combinations of speech and language ability. Furthermore, the use of neuroimaging findings to predict future communication impairment in children with CP may be complementary to functional performance profiles constructed from CP type, gross motor function, manual ability, speech, language and communication ability. Common tools such as the CFCS are needed to include communication in the understanding of strengths and weaknesses that characterize individuals with CP, to achieve the goal of maximum participation.

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