In This Issue. . .

From the Coordinator by Amy Goldman ................................................................. 2

Early AAC Intervention: Some International Perspectives by Mary Jo Cooley Hidecker .... 3-4

AAC Use by Young Children at Home by Mary Jo Cooley Hidecker .............................. 5-11

Prevalence of Speech Problems and the Use of Augmentative and Alternative Communication in Children With Cerebral Palsy: A Registry-Based Study in Norway by Guro Andersen, Tone R. Mjøen, and Torstein Vik ................................................................. 12-20

Clinical Impressions of How Young Children Use AAC at Home and in Child-Care Settings: A Canadian Perspective by Kathryn Wishart ...................................................... 21-28
Prevalence of Speech Problems and the Use of Augmentative and Alternative Communication in Children With Cerebral Palsy: A Registry-Based Study in Norway

Guro Andersen, MD
Norwegian Cerebral Palsy Registry, Tonsberg, Norway
Habilitation center, Vestfold Hospital, Tønsberg, Norway
Department of Laboratory Medicine, Children’s and Women’s Health, Norwegian University of Science and Technology, Trondheim, Norway

Tone R. Mjøen, OT
Habilitation Center, Vestfold Hospital
Tønsberg, Norway

Torstein Vik, MD
Department of Laboratory Medicine, Children’s and Women’s Health, Norwegian University of Science and Technology
Trondheim, Norway
Department of Women’s and Children’s Health, St. Olav University Hospital
Trondheim, Norway

Abstract

This study describes the prevalence of speech problems and the use of augmentative and alternative communication (AAC) in children with cerebral palsy (CP) in Norway. Information on the communicative abilities of 564 children with CP born 1996–2003, recorded in the Norwegian CP Registry, was collected. A total of 270 children (48%) had normal speech, 90 (16%) had slightly indistinct speech, 52 (9%) had indistinct speech, 35 (6%) had very indistinct speech, 110 children (19%) had no speech, and 7 (1%) were unknown. Speech problems were most common in children with dyskinetic CP (92%), in children with the most severe gross motor function impairments and among children being totally dependent on assistance in feeding or tube-fed children. A higher proportion of children born at term had speech problems when compared with children born before 32 weeks of gestational age 32 (p < 0.001). Among the 197 children with speech problems only, 106 (54%) used AAC in some form. Approximately 20% of children had no verbal speech, whereas ~15% had significant speech problems. Among children with either significant speech problems or no speech, only 54% used AAC in any form.

Introduction

Cerebral palsy is the most common cause of childhood motor disability, affecting about 2 per 1,000 live born children per year (Blair & Watson, 2006). CP is a clinical diagnosis, and the motor problem is the hallmark of the diagnosis. However, associated impairments often
accompany the motor disorder, and in 2007 a new definition of CP was proposed. In addition to the description of CP as a group of disorders of the development of movement and posture that cause activity limitation and are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain, the new definition added that the motor disorders are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder (Rosenbaum et al., 2007).

However, few studies have described the prevalence of speech and communication disorders among children with CP. In the Western Australian cerebral palsy register, the prevalence of children unable to speak was approximately 21% for children born during the period 1975-99. (Watson, Blair, & Stanley, 2006). A similar proportion of children with non-verbal communication was reported from Hong Kong by Chan et al. (Chan, Lau, Fong, Poon, & Lam, 2005).

In a systematic review, Pennington et al. estimated that approximately 20% of children with CP had severe communication impairment, and these were classified as being non-verbal (Pennington, Goldbart, & Marshall, 2005). For non-verbal children, various devices for augmentative and alternative communication (AAC) have been developed, including hand signs, pictograms, graphic communication, and speech machines. However, in the study by Chang et al., only 3% of the children used AAC devices (type not specified), and another 3% used hand signs (Chan et al., 2005). In Norway, a national cerebral palsy register (Andersen et al., 2008) has recorded data on spoken language and non-verbal communication among 5-year-old children born since 1996.

In this study, we want to describe the prevalence of speech problems in children with CP in Norway and the use of augmentative and alternative communication. The main hypothesis was that the prevalence of speech problems is similar to the 20% reported in previous studies. Moreover, based upon our clinical experience, we hypothesized that the use of AAC is too low, introduced too late, and may be used inappropriately among those in need of it.

**Participants and Method**

In this registry based study, data were abstracted from the Norwegian Cerebral Palsy Registry (CPRN; Andersen et al., 2008). This is an informed consent based registry that records detailed information on cerebral palsy subtypes, severity, and associated problems, including speech problems. Data are provided by the 20 public habilitation centers caring for children with CP.

The individual data were collected by a senior pediatrician in a standardized form. Virtually all Norwegian children with CP are cared for in these institutions. The habilitation centers also provide summary data on all children with CP. In a previous study, we reported that detailed information was available for nearly 80% of the children with CP in Norway for children born between 1996 and 1998. Using the 11-digit number unique to each Norwegian citizen, we linked the detailed information in CPRN with data from the Medical Birth Registry of Norway (MBRN). The latter registry has recorded all births in Norway since 1967, and reporting to this registry is mandatory. The combination of data from these two registries allowed us to study the relation between speech abilities and known CP risk factors in pregnancy and at birth.

**Study Population**

Children with a diagnosis of CP born between January 1, 1996 and December 31, 2003 were eligible for registration. All children were at least 4 years when diagnosis and subtype were confirmed for this register. By June 2009, 571 children were included in the registry. In seven cases, the reporting clinicians did not know whether the child had speech problems, and an additional seven children had no information on communication provided to the registry.
Study Variables

Cerebral palsy was defined and classified according to the recommendations by the Surveillance of Cerebral Palsy in Europe in 1999 (Surveillance of Cerebral Palsy in Europe [SCPE] Collaborative Group, 2000). In brief, SCPE divides CP into a spastic, a dyskinetic, or an ataxic subtype. The spastic subtype is further divided into a unilateral and a bilateral type. Gross motor severity of CP is based upon walking and sitting ability, and, during 1996–1998, this was recorded in the registry on a four level scale: normal walking without restrictions (level 0), walking with restrictions but without assistive devices (level 1), walking with assistive devices (level 2), and completely unable to walk (level 3). For children born during this period, we used this information on walking and sitting ability to estimate gross motor function according to the Gross Motor Function Classification System (GMFCS; Andersen et al., 2008; Palisano et al., 1997; Palisano et al., 2000; Rosenbaum et al., 2002). For children born between 1999 and 2002, the GMFCS levels were recorded directly by the individual clinicians.

Outcome Variables

A classification of speech problems was developed in cooperation with an occupational therapist and a special educator. Communication was recorded on different scales as verbal communication (i.e., speech), sign language, and graphic communication. Speech was classified on a scale from zero to four, where zero indicated normal speech, one indicated slightly indistinct speech, two indicated obviously indistinct speech, three indicated severely indistinct speech, and four indicated children without any speech ability. Children with obviously indistinct, severely indistinct, or no verbal speech were defined as having speech problems. Sign language was recorded as “using sign language,” “not using sign language,” or “unknown.” Graphic communication was recorded as “writing,” “using pictograms,” “using pictures,” “using bliss,” “does not use graphic communication,” and “unknown.”

Covariables

Feeding ability was classified on a scale from being independent (0), in need of some assistance (1), totally dependent on assistance (2), partly tube fed (3), or mainly tube fed (4). Information on gestational age at birth was abstracted from the MBRN for children born between 1996 and 1998.

Statistical Methods

The statistical package for social sciences (SPSS) for Windows version 12.0.1 (SPSS Inc., Chicago, IL) was used for data analysis, and a significance level of 0.05 was chosen. The test or Fisher’s exact test were used to analyze differences in proportions between groups. Confidence intervals (CI) were calculated according to the method recommended by Newcombe and Altman (2000).

Results

Background Data

In all, individual data were available for 571 children in the CP registry. Median age at recording in the registry was 6.6 years (range 0.21-10.22). There were 318 (55.7%) boys and 253 (44.3%) girls.

A total of 212 (37%) had the spastic unilateral, 271 (48%) had the spastic bilateral, 36 (6%) had the dyskinetic, and 24 (4%) had the ataxic subtypes. In 28 (5%) children, the CP could not be classified into any of these subtypes by the referring centre.

Prevalence of Speech Problems
Among the 564 (99%) children with available information on speech, 270 children (47%; CI: 44–52%) had normal speech, 90 (16%; CI: 13.2–19.2%) had slightly indistinct speech, 52 (9%; CI: 6.7–11.6%) had obviously indistinct speech, 35 (6%; CI: 4.3–8.2%) had severely indistinct speech, 110 (19%; CI: 16.2–23.2%) had no speech, and in 7 (1%, CI: 0.6–2.5%) the reporting clinician did not know if speech problems were present. Of these, 197 (35%; CI: 31–39%) were considered to have speech problems (obviously indistinct, severely indistinct, or no speech) at a level where they might benefit from AAC.

Figure 1. Number of children with speech problems among children with cerebral palsy (CP) according to CP subtype.

Children with missing (7) and children (7) in which the reporting clinicians did not know if the child had speech problems are not shown in this figure.

The cerebral palsy subtypes are shown on the x-axis. The y-axis shows the number of children with obviously indistinct, severely indistinct or no speech (red color) and the number of children with normal or slightly indistinct speech (blue color), indistinct speech (blue color).

Figure 1 shows that speech problems were most prevalent in children with the dyskinetic subtype (N=33 of 36; 92%; CI: 78–97%) and least prevalent in children with unilateral CP (N=22 of 208; 11%; CI: 7.1–15.5%). In the bilateral group, speech problems were reported in 112 of 262 (43%; CI: 37–49%) children. Figure 2 shows that speech problems were most common among children with the most severe gross motor function impairments (GMFCS IV-V) (N=119 of 146, 82%) and least common among children with the least severe gross motor function impairments (GMFCS I-II; N=23 of 311, 7%; GMFCS IV-V). Figure 3 shows the association between speech problems and feeding ability. Among children being totally dependent on assistance in feeding or tube-fed, 137 of 157 (82%) children had indistinct, very indistinct, or no spoken language.
Figure 2. Speech problems in children with cerebral palsy according to gross motor function. GMFCS levels are not shown for children with missing information on speech problems (7) or children in whom the clinician did not know if the child had speech problems (7)

Gross motor function is shown in three categories on the x-axis. GMFCS (Gross motor function classification system) I-II, GMFCS III and GMFCS IV-V. The y-axis shows the number of children with obviously indistinct, severely indistinct or no speech (red color) and the number of children with normal or slightly indistinct speech (blue color)

In children with spastic bilateral CP (N= 88) born between 1996 and 1998, we also looked at the association between gestational age and spoken language. We found that a higher proportion of children born at term had very indistinct or no spoken language than children born very preterm (i.e., gestational age < 32 weeks). (p < 0.001)
Use of AAC

Among the 197 children with speech problems, 106 (54%; CI: 47–61%) used AAC in some form. Of these 106 children, 61 (58%; CI: 48–67) used graphic communication. We do not have specific information about the quality or the quantity of graphic signs used by these children. However, among the 64 of 197 (33%) that used hand signs, 36 (56%) had indistinct or very indistinct hand signs. (Results are not shown.) Figure 4 shows the use of AAC among children with speech problems. Among the children with dyskinetic CP, AAC was used by 86%, whereas AAC was used by only 53% of children with the bilateral subtype.
Discussion

In this study, we found that 35% of all children with CP had indistinct, very indistinct, or no speech. Such speech problems were associated with more severe subtypes of CP and with feeding problems. Speech problems were also more common among children born at term than preterm. Despite the fact that children with such speech problems would most likely benefit from some kind of AAC, only 54% of them in fact used AAC.

Strengths of this study are the size of the study population providing relatively precise estimates and the standardisation of the recordings. Even if at the time of this study, our recordings were not complete for the last 5-year period, we consider the study population to be representative of the total population with CP in this age group (Andersen et al., 2008).

The classification of speech problems was developed in cooperation with an occupational therapist and a special educator working with children with CP and speech problems, and it is possible that there may have been some misclassification of children with obvious or severe speech problems and between children with slight and obvious speech problems. However, it is less likely that children without any spoken language were misclassified, and, because this group constituted the major proportion of children classified as having speech problems, we consider the main results to be unbiased.

Our results are thus consistent with the few other studies describing the prevalence of speech problems (Chan et al., 2005; Pennington et al., 2005; Watson et al., 2006). In these studies, approximately 20% of children with CP had no verbal communication, well comparable to our findings. In addition, we found that 15% had indistinct or very indistinct spoken language, and we consider these children to be in need of some kind of AAC. Thus, our results suggest that 35% of children are in need of AAC. However, more than 40% of these children did not use any AAC, and only a very small proportion of the children with obviously indistinct, severely indistinct, or no speech used graphic communication. Hand signs were the most
commonly used type of AAC. However, the quality of hand signs was poor, which is not surprising in this patient group.

The finding that children who were preterm had less occurrences of no speech and very indistinct speech is most likely explained by the fact that periventricular leucomalacia, a result of ischemia in the watershed areas, in children born very preterm mainly affects corticospinal tracts to the lower extremities (watershed areas localized periventricular). In contrast, in children born at term, basal ganglia are more often affected, and this damage may also explain poor coordination of speech. We think that the most likely reason for this is that children born at term often obtain more extensive brain injuries than preterm born children.

**Implications**

Knowing how important communication is for the early cognitive and social development of a child, it is worrying how few children used AAC, and that a significant proportion of them used hand signs of poor quality. In order to ensure an optimal development for all children with CP, it seems mandatory to identify such problems early. Based upon the above results, we have proposed a method for early identification of AAC needs in these children. Our hypothesis is that a few central items on a standard registry form may identify children in need of AAC at the time of the CP diagnosis. These items include CP subtype, early feeding difficulties, information of gestational age at birth, interaction with the child, and language understanding and development. In 2007, the Norwegian Cerebral Palsy Registry developed a registration form suitable for this purpose.

We will use the information on communication recorded in the registry as a screening instrument. Through this, we will identify children that may be in need for AAC, and we will provide feedback to the local habilitation centres on this in order to ensure children with CP optimal development and good quality of life. We are now implementing this protocol and early intervention guidelines in the habilitation centres in the southern part of Norway. The project is funded by the Norwegian health department. Thus, we now hope to identify speech and communication problems at the time when CP is diagnosed, enabling us to intervene and offer necessary counselling and appropriate AAC.

In conclusion, we have found that a significant proportion of Norwegian children with CP had speech problems and that such problems were associated with CP subtype and gross motor function, as well as with feeding difficulties and with being born at term. Most troublesome was the finding that only 50% of the children with obvious speech problems or without spoken language used any type of AAC, and, among those who used AAC, the method mostly chosen (hand signs) is probably not optimal for children with CP. A program for early identification of speech problems has therefore just started.

**Acknowledgments**

We would like to express our thanks to all colleagues at the pediatric and habilitation departments in Norway, who provided the data.

**References**


