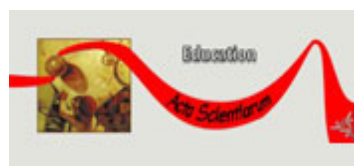


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Attitudes towards Augmentative and Alternative Communication for young children with cerebral palsy

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ABSTRACT. Considering that the use of Augmentative and Alternative Communication Systems (AACs) has been recommended for children who are severely impaired in their development of communicative abilities, it may be assumed that caregivers' attitudes toward AACs would be driven by children's degree of cognitive and linguistic impairments. To verify this, 40 dyads of children with cerebral palsy and their primary caregivers participated in this study evaluating children's degree of cognitive and linguistic impairments through the use of Battelle's questionnaire, and the caregivers' attitudes toward AACs by means of a Likert scale containing 15 items. Results showed that the provider's most negative attitudes toward the use of AACs were found among those caring for children with the most severe impairments.

Keywords: cerebral palsy, Augmentative and Alternative Communication Systems, primary care provider's attitudes.

RESUMO. As atitudes dos cuidadores em relação à utilização de Sistemas de Comunicação Alternativa e Aumentativa na interação com crianças com paralisia cerebral. Pode admitir-se que o grau de limitação cognitiva e linguística de crianças com capacidades comunicativas gravemente prejudicadas condiciona as atitudes dos respectivos cuidadores, no uso de Sistemas de Comunicação Alternativa e Aumentativa (SCAA) que têm vindo a ser recomendados para facilitar a relação com elas e promover o seu desenvolvimento. Para testar esta possibilidade, neste estudo averiguou-se qual a relação entre o grau de limitação cognitiva e linguística de 40 crianças com paralisia cerebral, avaliado por meio do questionário de Batelle, e as atitudes dos respectivos cuidadores primários perante os SCAA, determinadas através de uma escala de Likert com 15 itens. Os resultados mostraram que as atitudes mais negativas face ao uso de SCAA foram manifestadas por cuidadores de crianças com limitações mais drásticas.

Palavras-chave: paralisia cerebral, Sistemas de Comunicação Alternativa e Aumentativa, atitudes de cuidadores primários.

Introduction

Recommended practices support family participation on interdisciplinary teams for Augmentative and Alternative Communication Systems (AACs) to build consensus and make decisions (BEUKELMAN; MIRENDA, 1992; MCNAUGHTON, 1990; WARRICK, 1988). Two studies reporting parents as sources of information revealed children's limited use of resources at home and in community settings (ALLAIRE et al., 1991; CULP et al., 1986). Parents are often asked to share or to accept responsibility for the promotion of their children's linguistic, social, operational, and strategic competence (BEUKELMAN, 1991; LIGHT et al., 1988). In other words, parents are also required to accept responsibility for their children's technical skills in operating the communication systems (operational competence) and compensatory skills to

maintain effective communication beyond the communication systems' limitations (strategic competence). Because parents provide the essential social experiences and opportunities for children's learning, they play a key role as facilitators in children's language acquisition, communication, and social interaction skills (DUNST; LOWE, 1986; HUER; LLOYD, 1990). According to Berry (1987), family members often play an essential role in the transfer of information about technology, interaction styles, and other components of the children's AACs programs throughout the children's educational progress.

In interactions between a mother and her child with Cerebral Palsy (CP), it is important to take into account parents' attitudes. Attitude has been defined in social psychology as a psychological disposition shown by evaluating a particular entity with some

degree of favour or disfavour (EAGLY; CHAIKEN, 1993). Eiser (1986) highlighted three common assumptions about an attitude: (a) It involves some kind of evaluation about something or someone, (b) it can be conveyed through language, and (c) it is related to a social behaviour in a way that is predictable. A negative attitude towards the use of AACCS creates barriers that limit these children's opportunities for communication, full participation in society, and development (CLARKE; WILKINSON, 2008). It might, for instance, influence a person's willingness to interact with those using AACCS, thereby obstructing the formation of meaningful social relationships (MCCARTHY et al., 2002). An educator's negative attitude could lead children using AACCS to have low expectations and ultimately to have poor academic outcomes (POPICH; ALLANT, 1997).

Cruz (2006) observed that primary care providers' attitudes toward AACCS are measurable and are related to the efficacy of AACCS. Taking into account that the use of AACCS has been advocated for children with severe impairments in the development of their communicative abilities (severe deficits in language and cognitive development), it seemed reasonable to suppose that primary care providers' attitudes toward AACCS would be regulated by children's level of cognitive and language impairments, with caregivers of children with more cognitive impairment having a more positive attitude towards AACCS. In a general sense, the primary care providers' attitudes shape their perception of the AACCS efficacy. Besides, primary care providers with more positive attitudes would develop behaviours that would facilitate interaction.

Udwin and Yule (1991) observed that primary care providers tended to show a less favourable attitude towards Blissymbols (SILVERMAN et al., 1978) at home when the child had severe problems with language comprehension and consequently tended to make limited use of Blissymbols. Additionally, these primary care providers reported that they did not have the time to commit themselves to children or to acquaint themselves with the systems. According to Beck et al. (2001), professionals reported more positive attitudes when they watched a highly competent person, according to the cognitive sub-scale of the Professionals' Attitudes Regarding Children who Communicate Augmentatively (PARC-CA), using AACCS than when they watched a less competent person using AACCS.

Researchers and practitioners have repeatedly stressed the need to provide approval and support to AACCS training for users in schools and home environments and also to train parents and teachers to use the systems with their children (e.g., GRINNELL et al., 1976; KIERNAN, 1977; KOPCHICK et al., 1975). The use of AACCS has been recommended for children who have severe impairments in their development of communicative abilities. Questions of parental attitudes toward AACCS and their willingness to use the systems with their children with disabilities have received scant attention in the literature. The aim of this study was to investigate whether there was a relationship between the level of cognitive and linguistic impairment of children with CP and their primary care providers' attitudes toward AACCS.

Material and methods

Participants

Participants were selected from a population of children attending the Portuguese Cerebral Palsy Centres in Lisbon, Oporto, Coimbra, Viseu, Guimarães, Setúbal, and Fafe, and satisfying the following criteria: (a) diagnosed as having CP, (b) having complex communication needs, (c) 2-7 years old, (d) severe dysarthria, and (e) users of some kind of AACCS. Considering those five criteria, the health teams from each of the respective Centres selected all the children that fulfilled those requirements.

Attempts were made to make the groups more homogeneous by consulting children's clinical records to determine their level of motor and speech deficits and also to assess their communication skills to guarantee similar abilities that would allow the dyads to be contrasted. Based on these criteria, children whose official certification established deficits of at least 80% were selected (Legislative Act 360/97), however, four primary care providers reported that, officially, their children presented functional limitations of at least 60% and one caregiver referred that, officially, the child presented a percentage of limitation greater than 40%. Despite the fact that these five children were not officially considered to have 80% functional limitation, their performance in the linguistic and cognitive evaluations carried out by one of the authors showed significant functional limitations and, as such, these cases, even the last one, after close consideration of these children's linguistic (quotient = 82) and cognitive (quotient = 83) deficits, were not dropped as outliers.

Based on the already described inclusion criteria, 40 dyads were selected. The representatives from the already mentioned centres informed the primary care providers about the content of the study and requested their informed consent to participate. Thus, this was a convenience sample of volunteer participants.

The participating children consisted of 21 males and 19 females, with 70% of them aged 3 to 5 years-old, 20% primary school children aged 6 to 7 years-old, and 10% aged 2 years-old to 2 years and 11 months-old. Seventy-five percent of the 40 primary care providers were 20-40 years of age. Fifty percent of all the caregivers were in their 30s. Most of the primary care providers were the children's mothers (87.5%).

Many of these children with CP were living at home with their parents and one or two siblings. Fifty-five percent of the primary care providers had at least secondary education. Only two primary care providers reported lack of education or only primary education. Thirty percent of the mothers were housewives, 60% were working mothers, and 10% were in unemployment.

Instrumentation

A questionnaire was submitted to primary care providers to gain information on their attitudes about the use of AACs. This questionnaire was prompted by the work of Udwin and Yule (1991) and by the professional experience of one of the authors (Appendix 1). In addition to demographic and personal data, it consisted of 15 items, 8 positively and 7 negatively worded. A 1 (in total disagreement) to 5 (totally in agreement) Likert scale was used. The maximum possible score was therefore 75 points and the minimum possible score was 15 points, indicating a totally positive attitude or a totally negative attitude, respectively. The psychometric properties of this scale for the 40 participants included a very acceptable internal consistency for the scores: Cronbach's alpha = 0.87; standardized alpha = 0.872; average inter-item correlation = 0.324; and M = 57.275, SD = 8.057.

The Battelle Developmental Inventory (BDI) (NASCIMENTO, 2003) is an instrument for assessing children's developmental skills from birth to 8 years of age. Specially designed for professional use with infants and primary school children, the BDI has adaptations for administering the test to children with visual, auditory, or physical disabilities. Nascimento (2003) adapted and validated the BDI for Brazilians, and this was the

version used in the current study with Portuguese children. In this study, however, only communication and cognitive domains were used. The communication domain contained 59 items pertaining to receptive and expressive communication and verbal and nonverbal communication. The BDI's cognitive domain contained 56 items that were grouped into four sub-domains: perceptual discrimination, memory, reasoning and academic skills, and conceptual development. Results were converted into four quotients - for expressive language, receptive language, total language, and cognitive development - by dividing the mental age derived from the Battelle scores by the chronological age and multiplying by 100. The BDI was administered individually during only one session varying from 60 to 90 minutes, depending on the participant. Primary care providers' attitude toward AACs was also assessed on an individual basis. While the BDI was being administered to the children by a researcher, the primary care provider completed the questionnaire on attitudes.

Results

The scores on the attitude scale, for all 40 participants, varied between 38 and 73, and its mean was 57.275 (SD = 8.057). That score shows a fairly positive attitude towards the use of AACs. Table 1 shows frequencies for those values (scores) resulting from the primary care providers' answers to the 15 items questionnaire adopted to evaluate their attitudes.

Table 1. Frequencies of the scores for the attitude scale.

Item	Count	Cumulative	Percent	Cumulative
38	2	2	5.00	5.00
43	1	3	2.50	7.50
44	1	4	2.50	10.00
47	1	5	2.50	12.50
50	4	9	10.00	22.50
51	1	10	2.50	25.00
53	1	11	2.50	27.50
54	1	12	2.50	30.00
55	1	13	2.50	32.50
56	2	15	5.00	37.50
57	1	16	2.50	40.00
58	3	19	7.50	47.50
59	2	21	5.00	52.50
60	5	26	12.50	65.00
61	2	28	5.00	70.00
62	3	31	7.50	77.50
63	2	33	5.00	82.50
64	1	34	2.50	85.00
65	2	36	5.00	90.00
67	1	37	2.50	92.50
68	1	38	2.50	95.00
71	1	39	2.50	97.50
73	1	40	2.50	100.00

Table 2 shows the mean chronological age, mean age equivalents, and mean quotients for Battelle scores.

Table 2. Statistics regarding children's studied characteristics.

	Valid N	Mean	Median	Minimum	Maximum	Std. Dev.
Age	40	56.625	57.500	25	85	16.397
Linguistic Age	40	20.225	18.000	3	49	11.844
Cognitive Age	40	28.225	31.500	3	50	15.034
Impairment	40	81.300	82.500	40	100	12.441
Language	40	35.275	32.000	8	81	17.713
Linguistic IQ	40	37.590	32.738	8	90	23.853
Cognition	40	36.975	37.500	6	82	18.806
Cognitive IQ	40	51.812	50.595	6	108	29.645

These results show considerable delays in development. Children's age was not associated neither with their caregivers' attitudes ($r = 0.24$), nor with children's language ($r = 0.11$), cognition ($r = 0.23$) or impairment ($r = 0.18$). These data suggest the participants indeed had functional limitations and that scores were not based simply on their age.

In order to detect possible relationships between the primary care providers' attitudes toward the AACs and child characteristics, linear correlations were calculated (see Table 3).

Table 3. Correlations between primary care providers' attitudes and children's studied characteristics (N = 40).

	Age	Attitude	Language	Linguistic IQ	Cognition	Cognitive IQ	Impairment
Age	1.000						
Attitude	0.243*	1.000					
Language	0.110*	0.362	1.000				
Linguistic IQ	-0.278*	0.327	0.892	1.000			
Cognition	0.228*	0.361	0.859	0.706	1.000		
Cognitive IQ	-0.235*	0.390	0.814	0.916	0.798	1.000	
Impairment	0.175*	-0.298	-0.546	-0.593	-0.368	-0.480	1.000

*All but marked correlations are significant at $p < 0.05$.

A weak but positive association between attitude scores and child development scores was found. Child development scores were all highly inter-correlated, as expected, but negatively associated with impairment scores. That is, the better children performed on the Battelle, the less impaired they were.

Discussion

Theoretically AACs are appropriate to be used by children with communication difficulties commonly associated with CP, such as difficulties in sending or receiving messages. These children's motor, cognitive, visual and hearing impairments might limit the intelligibility of their speech and gestures, delay their spoken and written language development, and also might affect their interpersonal interactions and impact on their

speech perception. Their whole development may be affected by the contingencies imposed by the impairments themselves. AACs are mainly used by children communicating with their primary care providers and represent a powerful means through which children can produce basic requests, expressive language and communication of ideas, feelings and thoughts. It may be assumed that owing to the characteristics of such systems, caregivers would develop highly positive attitudes towards their use.

Taking into account the benefits in using those systems with children with a high degree of impairment in their development, it would be expected that the greater the impairment the better the caregivers' attitudes towards AACs. Data showing that caregivers' attitudes are somewhat more positive when children score higher on developmental tests might reflect (a) an overall positive attitude towards any intervention when children make better progress (although these are one-time data, so 'better progress' is inferred) or (b) a potential efficacy attribution – that children's progress might have been caused by the AACs. The present data cannot confirm either of these possibilities, but future studies could.

On the other hand, those results just presented pointed out what Clarke and Wilkinson (2008) had already highlighted, that is, that asymmetries registered in adult-child interactions may occur due, partly, to adults' expectations that these conversations would happen in a speed of progress or change that would match or be compatible, similar or consistent, and coincide in their characteristics to the pacing of turn taking in interactions between natural speakers. Such imbalances may negatively impact exactly on those parents interacting with the most severely impaired children since these parents need a higher level of resilience, which may be difficult to sustain considering that, for any form of reinforcement to come, parents may probably need a higher response rate, what may have negative implications on the caregivers' attitudes toward AACs. In other words, because attitudes are so interwoven with the level of resilience required in order to achieve success and because working with deeply impaired children does require greater resilience, what will affect willingness, the deeper the impairment the lower the attitudes favouring AACs or any communication means.

Undoubtedly it is necessary to work more intensively with primary care providers who are planning to use AACs with children with a high degree of impairment in their development, not only in terms of a technical training but also the

psychological readiness needed to grasp the advantages and possibilities of the systems. At the same time, depending on children's degree of impairment, the difficulties involved should be emphasised so that primary care providers do not give up easily, since with such children progress would be slower and less considerable although in the long run positive results will become quite clear.

Conclusion

Undoubtedly it is necessary to work more intensively with primary care providers who are planning to use AACs with children with a high degree of impairment in their development, not only in terms of a technical training but also the psychological readiness needed to grasp the advantages and possibilities of the systems. At the same time, depending on children's degree of impairment, the difficulties involved should be emphasised so that primary care providers do not give up easily, since with such children progress would be slower and less considerable although in the long run positive results will become quite clear.

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APPENDIX 1**Scale of primary care providers' attitudes toward the use of AACs**

- A better use of AACs helps the interaction between me and my child
- Using AACs has improved my understanding of what my child is trying to express
- Using AACs has improved the understanding by other members of my family of what my child is trying to express
- Using AACs has improved the understanding of people outside my family of what my child is trying to express
- Using AACs has relieved the frustration felt by my child in trying to express him/her self
- AACs has stimulated my child's development of speech
- AACs has improved my child's motivation to communicate
- AACs promotes visual contact
- AACs inhibits my child's development of speech
- AACs restricts the communication between family members
- My child is not motivated to use AACs
- The use of AACs is tedious and slow
- I have found physical difficulties in using AACs
- Family members find it difficult to learn how to use AACs
- AACs underlines my child's deficiencies