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Factors associated with the participation of children with complex communication needs

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ABSTRACT

The aim of this study was to conduct a preliminary analysis of relations between child and environmental variables, including factors related to communication aid provision, and participation in informal everyday activities in a sample of children with complex communication needs.

Ninety-seven caregivers of children provided with communication aids responded to a questionnaire survey. Child variables assessed were level of ability, trait emotional self-efficacy, and competence in communication aid use. Environmental variables assessed were the impact of childhood disability on the family, family socio-economic category, perceived reliability of electronic communication aids provided to children, and ease of use of the aid. The outcome measure was the intensity of child participation in informal activities.

Significant correlations were observed between participation scores and the following variables: child age, level of ability, trait emotional self-efficacy, and family impact of childhood disability. Regression analyses highlighted trait emotional self-efficacy and, to a lesser degree, family impact of childhood disability as the strongest potential predictors of participation.

While aspects of child personality may be difficult to disentangle from behaviours related to disability type or developmental age, this research highlights a clinical requirement to assess systematically child behaviours relating to their general emotional functioning.

1. Introduction

In recent years, studies using multivariate modelling techniques have made important inroads into identifying relations between child variables and environmental factors, and participation in everyday life activities, for children with disabilities. This research has focussed predominantly on children with a clinical description of cerebral palsy (CP; Fauconnier et al., 2009; Forsyth, Colver, Alvanides, Woolley, & Lowe, 2007; Hammal, Jarvis, & Colver, 2004; Imms, Reilly, Carlin, & Dodd, 2009; King et al., 2006; Morris, Kurinczuk, Fitzpatrick, & Rosenbaum, 2006; Voorman, Dallmeijer, Van Eck, Schuengel, & Becher, 2010). Findings from these studies suggest that communication impairment may be predictive of participation restriction in

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a general sense. However, increases in degree of communication impairment do not necessarily predict increases in level of participation restriction in a range of domains including home life, relationships, recreation (Fauconnier et al., 2009) and social participation (Hammal et al., 2004).

For example, Fauconnier and colleagues report an analysis of associations between features of child impairment and participation in a sample of 1173 children with CP. The sample comprised 32% of children with communication difficulties, 16% of whom were classified as children with communication difficulty but being able to use speech; 12% as using non-speech for formal communication, and 15% as having non-formal communication only. Participation was measured using the Life-H instrument (Noreau et al., 2007) which assesses the degree of difficulty an individual experiences in engaging in 11 activity domains relating to two general themes: daily activities (e.g., personal care and hygiene) and social roles (e.g., recreation and relationships). Overall, participation was shown to be associated with level of motor impairment, learning disability, pain, and communication difficulty. More specifically however, increases in degree of communication difficulty did not predict decreases in participation in six domains (health hygiene, home life, mobility, relationships, school, and recreation).

Work by Hammal et al. (2004) reported similar mixed findings in relation to association between degree of communication impairment and participation. In an examination of 443 children with CP, 54% were reported to have some form of communication difficulty, with 15% needing alternative formal methods (presumably including communication aids), and 14% having no formal communication. Participation was measured by the Lifestyle Assessment Questionnaire (LAQ; Mackie, Jessen, & Jarvis, 1998), which examines the impact of disability across six domains: physical dependence, education, social participation, mobility, clinical burden, and economic burden. While increases in severity of clinical and functional features of CP generally predicted greater participation restriction, communication problems had differential effects on the participation domains. Perhaps surprisingly, degree of communication difficulty was not associated with restriction of social participation.

Although difficulties are reported in identifying suitable measures of communication and participation in such research (Fauconnier et al., 2009; Hidecker, 2010), there is growing evidence to suggest that the relationship between communication ability and participation is not straightforward. Overall, it seems that capturing the complex relations between child and environmental factors and participation in populations of children with communication disabilities presents particular challenges for research.

The population of children with profound and persistent difficulties producing functional speech are confronted with very significant challenges to participating in everyday life. For such children, augmentative and alternative communication (AAC) tools, including for example the provision of voice output communication aid (VOCA) technology, are intended to support and enhance communication skills development, with the ultimate aim of promoting participation in society (e.g., Clarke & Wilkinson, 2008). Evidence from users of communication aids and their families, clinical experience and research has established the benefit of communication aid provision for many. While research in the AAC field has provided invaluable insights, it is typically fairly narrow in focus, with single-case and small sample studies predominating (typically with fewer than 30 participants), and relatively limited in scope, commonly analysing a single domain of interest. To date, large-scale research studies have yet to establish an integrated understanding of factors affecting participation specifically for children with complex communication needs who are provided with communication aids. The purpose of this study therefore was to make an initial examination of relations between child and environmental variables, including communication aid related factors, and participation in informal everyday activities in a substantial sample of children with complex communication needs.

The data presented here are drawn from a study examining outcomes for children with complex communication needs. Framed within the World Health Organisation's International Classification of Functioning, Disability and Health (World Health Organisation, 2001), this paper presents a preliminary analysis of relations between selected child and environmental factors, and children's participation in everyday informal activities.

2. Methods

2.1. Participants

A questionnaire survey was sent to 360 caregivers of children attending either: (a) The Augmentative Communication Service (ACS), Great Ormond Street Hospital (GOSH), or (b) the ACE Centre Advisory Trust, Oxford – both in the UK – between March 2006 and March 2008. The ACS and ACE Centre offer multi-disciplinary assessment services, including investigation of AAC options for children with complex communication needs. We aimed to investigate within-group variation across the whole population of children attending these clinics. Therefore, we excluded only families of children with profound and multiple learning difficulties for whom face-to-face spoken interaction with their child is not an everyday expectation, and families of children with progressive conditions – primarily because interventions, including AAC provision, within this population are generally designed to manage a decline in skills over time. Caregivers of 97 children returned questionnaires. Table 1 illustrates child and family characteristics.

2.2. Measures

The independent variables selected for analysis were derived from a review of the research literature, and the research team's longstanding clinical practice experience. Child variables were level of ability, personality, age, and competence in aid use. Communication aids are designed and promoted as tools to enhance participation by augmenting or replacing speech.

Table 1
Participant characteristics.

	Mean	SD	Frequency	%
Age (y:m)	10:02	4:08		
Level of ability[a]	0.11	0.29		
Cognition[b]	0.71	0.31		
Speech[b]	0.32	0.34		
Ambulation[b]	0.38	0.45		
Dexterity[b]	0.45	0.39		
Pain[b]	0.91	0.16		
Gender				
Male			64	66
Female			31	32
Unknown			2	2
Communication aid[c]				
Electronic communication aid			77	79
Paper based communication aid only			20	21
Child primary reported condition				
Cerebral palsy			50	51.5
Autism/ASD			9	9.3
Down syndrome			1	1.0
Dyspraxia			6	6.2
Severe learning disabilities (not associated with CP or Downs)			10	10.3
Cerebral palsy and autism			3	3.1
Other (e.g., Worster–Drought Syndrome, Dandy Walker Syndrome)			15	15.5
Unknown			3	3.1
Total			97	100.0
Child's ethnicity				
White—UK heritage			75	77.3
White—other			6	6.2
Pakistani			2	2.1
Bangladeshi			2	2.1
Black—African Heritage			2	2.1
Indian			1	1
Black—Caribbean Heritage			1	1
Other			4	4.1
Unknown			4	4.1
Total			97	100
Family socio-economic classification				
Managerial and professional occupations			55	56.7
Intermediate occupations			6	6.2
Small employers and own account workers			4	4.1
Lower supervisory and technical occupations			10	10.3
Semi-routine and routine occupations			4	4.1
Never employed			5	5.2
Unknown			13	13.4
Total			97	100.0
Languages spoken at home				
English only			86	88.7
English + 1 other			9	9.3
English + 2 other			1	1
Unknown			1	1
Total			97	100

[a] Possible range from minimum score of −0.36 (most impaired) to 1.00 (no impairment).

[b] Possible range from minimum score of 0 (most impaired/in pain) to 1.00 (no impairment/pain).

[c] Children with electronic aids may also be provided with paper-based systems. In these instances, caregivers responded to the questionnaire in relation to the electronic aid only.

The provision of communication aids constitutes one element of a broader total communication approach, whereby all possible communicative modalities (speech, signing, aided communication and non-verbal methods) are considered as potentially useful. An underlying principle of intervention therefore is that greater individual competence in communication aid use is likely to contribute to more frequent and diverse opportunities for participation in everyday life.

Environmental variables included the impact of childhood disability on the family, and family socio-economic category. Environmental variables relating specifically to the communication aid used were also selected (reliability and ease of use). While a boom in micro-computer technology continues to provide a growing range of options for non-speaking children and their families, lack of technical reliability can markedly limit the potential for communication aid use to mitigate participation restrictions (Shepherd, Campbell, Renzoni, & Sloan, 2009). Equally, it is important that communication aids are designed effectively such that they can support users in carrying out activities. Effective communication aids are, for example, easy to learn to use and easy to utilize in conversation. Within the context of this study therefore, reliability of the communication aid, and ease of use, were considered important factors for examination.

2.2.1. Child ability

Level of ability was assessed by caregivers using the Health Utilities Index (HUI; Feeny, Furlong, Boyle, & Torrance, 1995). The HUI is a multi-attribute measure covering vision, hearing, speech, ambulation, dexterity and cognition. It may be used to derive individual attribute scores and a global summary score. Lower scores indicate greater severity of impairment with a score of one indicating full health. Evidence of its reliability and validity (face validity, content validity, construct validity, convergent validity, discriminative validity, predictive validity) has been established from multiple studies across a broad range of clinical conditions (see: http://www.healthutilities.com), and it has been used successfully as a measure of child impairment in multivariate modelling (Forsyth et al., 2007).

2.2.2. Child personality

Child personality was assessed by caregivers' judgements of their children's trait emotional self-efficacy (or trait emotional intelligence), which refers to perceptions of emotional abilities (Petrides, Pita, & Kokkinaki, 2007). This construct was assessed through caregiver ratings on the short form of the Trait Emotional Intelligence Questionnaire 360° (TEIQue 360° – SF; Petrides, Niven, & Mouskounti, 2006). The TEIQue 360° – SF consists of 15 distinct facets. These are presented with a brief explanation, and caregivers were requested to provide percentage scores (between 0% and 100%) for their child, with higher percentages indicating greater perceived ability. Evidence of good reliability and construct validity is available from numerous papers (e.g., Mikolajczak, Luminet, Leroy, & Roy, 2007; see also http://www.psychometriclab.com for an annotated bibliography). Its use with parents of children with complex communication needs has revealed excellent internal consistency ($\alpha = 0.91$) (Clarke et al., 2010).

2.2.3. Family impact of childhood disability

The Family Impact of Childhood Disability measure (FICD; Trute & Hiebert-Murphy, 2002) was used to capture the impact on the family of a child with developmental disabilities. The caregiver-report measure presents 15 items incorporating both positive and negative subscales related to raising a child with a disability. The FICD total score is represented as the discrepancy between the positive and negative subscale scores with higher scores reflecting more positive assessment. Trute and Hiebert-Murphy (2002) report good internal consistency for the positive and negative subscales with alphas of 0.71 and 0.88, respectively, and evidence of discriminant and predictive validity derived from a sample of 87 families of children with developmental disabilities.

2.2.4. Socio-economic category

Socio-economic category was assessed in this study using the five-class self-completion version of the UK Government's National Office of Statistics Socio-economic Category measure (NS-SEC; National Office of Statistics, 2010). The classification was derived from caregivers' responses to questions concerning occupation and employment status.

2.2.5. Communication aid related measures

Suitable published measures were not available for competence, reliability, and ease of communication aid use, and consequently had to be constructed specifically for this study. The qualitative aspect of the development of the scales involved peer review from senior specialist clinicians working in the neuro-disability and AAC fields, as well as a focus group discussion with caregivers of children provided with VOCAs. Written feedback was also provided by two caregivers unable to attend the focus group. Cronbach's alpha coefficients for competence, reliability, and ease of use were excellent (0.93, 0.82 and 0.87, respectively).

2.2.6. Participation

The dependent variable was children's participation in everyday activities outside formal settings, such as school. Twenty-six items from the self-improvement (10 items), recreational activities (6 items), and social activities (10 items) subscales of the Children's Assessment of Participation and Enjoyment questionnaire (CAPE; King et al., 2004) were used as our participation measure. The CAPE was deemed to be appropriate for this study because it establishes a profile of child/family activities. King et al. (2004) report good test stability (test re-test reliability scores assessed by random effects intra-class correlation on a group of 48 children) for intensity and diversity scores. We asked caregivers to report on the intensity and diversity of participation of the children under their care. Caregivers provided a rating in the form of a percentage score (between 0% and 100%) to indicate the degree to which their child had participated in each activity in the last four months. Higher percentages indicated greater degree of participation. The full CAPE measure incorporates scales representing five activity domains: recreational, social, self-improvement, active physical and skill based. While active physical (e.g., water sports) and skill based (e.g., dancing and singing) activities are relevant aspects of participation for all children, activities of primary interest to the current study were encompassed in the recreational, social and self-improvement scales (e.g., pretend/imaginary play, hanging out, and doing homework, respectively).

2.3. Procedure

Caregivers were invited to complete a paper-and-pencil questionnaire and return it by post, or to complete the questionnaire on-line via the project website hosted by University College London. Ethical review of the study protocol was undertaken by the Oxfordshire REC B NHS National Research Ethics committee, and approval was given for all procedures. Information provided to caregivers explained the project in detail and that the return of the questionnaire was deemed an act of consent to participation in the research. The initial mail-out was followed up by two reminders. The first reminder included a second copy of the questionnaire. The third mail-out reminded families of the on-line facility for completing the questionnaire.

2.4. Statistical analysis

Associations between key variables were explored using Pearson correlations. In addition, two regression analyses were conducted: (i) a theoretically driven analysis, whereby participation was regressed onto five selected predictors (age, level of ability, trait emotional self-efficacy, competence in aid use, and impact of childhood disability on the family), and (ii) a stepwise regression whereby participation was regressed onto all of the variables in the dataset (the aforementioned five plus reliability of aid use, ease of aid use, and socio-economic classification). The aim of this analysis was to determine the optimal combination of statistically significant predictors in this particular dataset. We replaced missing values by the mean for those variables in which they did not exceed 10% of the total. In all other cases they were left blank.

3. Results

Table 2 presents the correlations among the variables examined. Where correlations are significant they are fairly weak or moderate, with r values ranging from .236 to .576. Most notably perhaps, family impact of childhood disability was negatively associated with participation ($r = -.305$, $p < 0.01$). Participation scores also correlated moderately with children's trait emotional self-efficacy ($r = .474$, $p < 0.01$), level of child impairment ($r = .261$, $p < 0.05$), and child age ($r = -.226$, $p < 0.05$).

The theoretically driven regression model yielded a statistically significant result ($F[5,56] = 4.098$, $p < 0.005$), with an adjusted R square = 0.268. Only trait emotional self-efficacy reached significance (beta = 0.386, $p = 0.002$). See Table 3 for details.

The model to emerge from the stepwise analysis ($F[2,49] = 8.578$, $p = 0.001$; adjusted R square = 0.229) contained two predictor variables only: trait emotional self-efficacy (beta = 0.379, $p = 0.004$) and impact of childhood disability on the family (beta = −0.266, $p = 0.04$). None of the other variables available for selection (age, level of ability, competence in communication aid use, socio-economic category, reliability of the communication aid, and ease of use) reached levels of statistical significance (see Table 4 for details).

4. Discussion

The aim of this paper has been to present an initial analysis of the links between key child and environmental factors and children's participation in everyday activities. We focused specifically on children with little or no functional speech who have been provided with communication aids. Trait emotional self-efficacy and, to a lesser degree, family impact of childhood disability are highlighted as factors that may account for the intensity of children's participation.

Table 2
Correlations between participation, child, environmental and communication aid related variables.

		1	2	3	4	5	6	7	8	9
1	Participation	–								
2	Age	−.226*	–							
3	Child ability	.261*	−.069	–						
4	Trait emotional self-efficacy	.474**	−.116	.236*	–					
5	Socio-economic classification	−.037	.118	.180	−.105	–				
6	Impact on the family	−.305**	.251*	−.159	−.171	−.028	–			
7	Competence in aid use	.137	.215	.206	.240*	.311*	.030	–		
8	Reliability of electronic aid	.031	−.257*	.112	.045	−.027	−.280*	.060	–	
9	Ease of use of aid	.224	.020	.084	.074	−.121	−.178	.576**	.258*	–

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Table 3
Standard multiple regression coefficients.

Variable	Beta	CI	p
Level of ability	4.11	−9.42 to 17.63	0.55
Trait emotional self-efficacy	0.316	0.12 to 0.51	0.002
Age	−0.27	−0.74 to 0.21	0.26
Competence in AAC use	1.14	−3.5 to 5.78	0.63
Impact on the family	−0.38	−0.95 to 0.20	0.19

Table 4
Stepwise regression coefficients.

Model 1	Beta	CI	*p*
Trait emotional self-efficacy	0.323	0.14 to 0.51	0.001
Model 2			
Trait emotional self-efficacy	0.28	0.09 to 0.47	0.004
Impact on the family	−0.597	−1.16 to −0.29	0.04

Research examining relations between aspects of personality and participation by children with disabilities has revealed mixed results. For example, feelings of self-consciousness or social awkwardness do not appear to account for participation by children with neuro-developmental disabilities (King et al., 2006). In contrast, task persistence, described as an element of child temperament, has been shown to be associated with diversity of participation, albeit fairly weakly (Imms et al., 2009). In this study, trait emotional self-efficacy was an important predictor of participation. Personality traits are independent of intelligence, and can be relatively stable over time, although variability is evident in children and young adults, especially before the age of 30 (Terracciano, Costa, & McCrae, 2006). Clinical experience suggests that, for some families of children with communication disabilities, manifestations of personality may be difficult to separate from behaviours that are indicative of disability type, or developmental profile. For example, young children with complex needs may not display significant evidence of intentional sociability on which judgements of trait emotional self-efficacy may be reliably made. Thus, aspects of child personality may be over-or under-represented in clinical and family decision-making. Nevertheless, within the context of this study, analysis of caregivers' responses to the TEIQue-SF revealed excellent internal consistencies, indicating that the measure is reliable for use with caregivers of non-speaking children. This finding emphasises a requirement for clinicians to examine and describe systematically aspects of children's trait emotional self-efficacy, including the pre-requisite communicative skills for demonstrating this trait, such as emotional responsiveness and use of referential expression by augmented or kinesic modalities. More broadly, the results of the study strongly underscore the clinical significance of issues concerning children's emotional functioning and well-being.

Caregiver response to childhood disability is known to vary between individuals. Some caregivers are at increased risk of personal stress and maladjustment, while others appear to cope more effectively. Our study revealed tentative evidence that caregiver assessment of the impact of childhood disability on the family may predict intensity of participation. That is, greater perceived negative impact is suggestive of greater participation restriction. This finding echoes observed negative associations between caregiver stress, and aspects of social participation in children with physical disability (King et al., 2006; Voorman et al., 2010). Caregiver response to childhood disability is itself likely to be an outcome of multiple, integrated factors, including those related to the person, child, family and environment. In this study, no relationship was observed between caregiver response to childhood disability and level of child ability, or child personality, as might have been anticipated.

Caregivers' perceptions of their children's competence in communication aid use, the reliability of communication aids, and their ease of use, did not predict participation as measured by our chosen CAPE subscales. Competence in aid use did correlate with perceived ease of use, although not with the reliability of the device provided. None of these factors correlated with the participation score. Strong evidence exists for the potential of communication aid provision to benefit significantly the lives of people with complex communication needs in a variety of ways. However, there remains a lack of empirical understanding concerning the relative influence of communication aid related factors, amongst other child and environmental factors, on children's informal everyday participation.

Like every study, the work presented here has limitations. A general point concerns the need to replicate the results with a larger sample size. Particularly vulnerable may be the results from the stepwise regression, whose well-understood limitations (especially capitalization on chance) (Pedhazur, 2010) are compounded in our case by the relatively low sample size, and the heterogeneity of the sample. It is, therefore, important to keep in mind the exploratory nature of these findings. The sample size also imposed a restriction on the range of independent variables we were able to examine. More variables could have been entered into the analyses had there been sufficient numbers of participants. The generalizability of findings is limited also by our selection of three subscales from the CAPE. We note also that, although this paper and its findings have been couched in terms of children's social, recreational and self-improvement activity participation (as defined by the CAPE), child participation may be difficult to disentangle from family participation (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006). The theoretical relevance of family impact of childhood disability as a potential predictor of participation for children with communication disabilities is highlighted here. Indeed, further research should aim to examine theoretical inter-relationships between a broader range of child and environmental variables that may also be sensitive to well-designed interventions at policy or individual family level. The testing of such multi-dimensional models, including factors related to communication aid provision, is a priority for clinicians and researchers in the field.

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