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Psychological problems in children with hemiplegia: a European multi-centre survey

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KEY WORDS:

[1] Hemiplegia
[2] Cerebral palsy
[3] Psychological problems
[4] Epidemiological study

ABSTRACT

Objective - to describe the prevalence and determinants of psychological problems in European children with hemiplegia.

Design – cross sectional survey.

Setting – home visits in nine European regions by research associates who administered standard questionnaires to parents.

Patients – 279 children with hemiplegia aged 8-12 years were recruited from population-based case registers.

Outcome measure – Strengths and Difficulties Questionnaire (SDQ) comprising emotion, conduct, hyperactivity, peer problems and prosocial domains. An 'impact score' (IS) measures the social and psychological impact of the child's difficulties.

Results – Children with hemiplegia had higher mean scores on the Total Difficulties Score (TDS) compared to a normative sample ($p<0.001$). 48% and 57% of children respectively had borderline-abnormal TDS and impact scores. Significant, independent associations were observed between intellectual impairment and an increased risk for hyperactivity (OR 8.4, 95% CI 3.4-20.8), peer problems (OR 3.1, 95% CI 1.7-5.5) psychological and social impact (OR 3.0, 95% CI1.6-5.6) when children with an IQ<50 were compared to those with IQ>70. Boys had an increased risk for conduct (OR 2.1, 95% CI 1.2-3.7) and hyperactivity disorders (OR 2.5, 95% CI 1.4-4.6). Poor self esteem was associated with an increased risk for peer problems (OR 5.8, 2.5-13.4) and poor prosocial skills (OR 7.5, 95% CI 2.4-23.2) compared to those with high self esteem. Other determinants of psychological adjustment were impaired communication, severe pain and living with a single parent.

Conclusions – Many of the psychological problems identified are amenable to treatment. Special attention should be given to those at highest risk of developing psychological difficulties.

INTRODUCTION

Spastic hemiplegia is a common subtype of cerebral palsy (CP), affecting approximately 1 in 500 children and accounting for 30-50% of CP cases. Recently we reported the psychological well-being of children with all types of CP[1] and found significant psychological problems present in more than a quarter of children: twice that of the general childhood population. This higher risk for psychological problems among children with cerebral disorders has been observed by others[2-5], particularly among boys and those with lower intellectual ability and with peer problems being a predominant issue for children with hemiplegia[5]. Contrary to these findings Trauner et al[6] found no excess of behavioural problems among 39 children with unilateral brain damage when compared to 54 'healthy' controls.

The aims of this paper are to describe the psychological problems and their determinants in a representative sample of European children with hemiplegia.

METHOD

Study design

A cross-sectional survey of parents of children with hemiplegia undertaken in nine European regions[7].

Participants

Population-based registers of children with CP[7] in eight European regions were used as sampling frames. In Germany a sample was constructed from multiple sources. Children born 31 July 1991 to 1 April 1997 were eligible to take part. In regions with sufficient numbers stratification by walking ability was undertaken before random sampling to ensure balanced numbers of children in each severity stratum. Of 1,174 children eligible to take part, 993 were traced and approached, 818 participated (70%)[8] of which 279 had hemiplegia.

Main outcome measure

The Strengths and Difficulties Questionnaire (SDQ PF-25)[9] is a behavioural screening measure, valid for 4-16 year olds and comprising five domains: emotion, conduct, hyperactivity, peer problems and prosocial. The first four domains form a total difficulties score (TDS). An 'impact score' (IS) measures the social and psychological impact of the child's psychological difficulties[10]. The domains, TDS and IS have a range of scores considered 'normal', 'borderline' or 'abnormal'. Higher scores indicate poorer outcomes on all domains except the prosocial. The SDQ has satisfactory psychometric properties[1,11].

Definitions

The definition of cerebral palsy and classification of hemiplegia was consistent with the Surveillance of Cerebral Palsy in Europe project[12.] Gross motor function was classified using the Gross Motor Function Classification System (GMFCS) and arm function using the Bimanual Fine Motor Classification System (BFMF) each of which have five levels ranging from I (the most able) to V (the least able)[13-15]. Intellectual impairment was defined as 'severe' if IQ<50; 'moderate' if IQ 50-70 and 'normal' if IQ>70. Child self-esteem and pain were captured using the Child Health Questionnaire (CHQ, PF-50)[16]. 'Low' self esteem was defined as scores <25th centile on the self esteem domain (CHQ); 'moderate' if 25th -75th centile and 'high' if >75th centile. Pain was defined as 'severe' for scores <30 on the pain domain of the CHQ; 'moderate' if 30-90 and 'no pain present' for a score 100. Psychological problems were considered present where scores were in the 'borderline to abnormal' range on the domains of the SDQ[9,11].

Ethics approval

Permission to conduct the study was obtained in each country and complied with the local requirements[7].

Statistical analysis

The significance of group differences was established with chi-square and t tests. Prevalences (%) were adjusted to take account of the sampling strategy and response rates[8]. Significant univariate predictors ($p<0.2$) of psychological problems were entered into a multivariable, logistic regression using a forward stepwise procedure ($p<0.01$) adjusting for centre and checked using a backwards elimination procedure ($p<0.01$). The percentage reduction in deviance relative to the null model is reported. Goodness of fit was assessed using Bayesian Information Criterion and was adequate in all models. The stability of models with and without outliers was checked. Analyses were performed in STATA[17].

RESULTS

The majority of children with hemiplegia had mild motor impairment, higher intellectual ability and attended mainstream schools (see Table 1).

Symptoms and impact

Tables 2 and 3 show the distribution of psychological problems. The mean scores on TDS for children with hemiplegia differed significantly from a normative sample (British children aged 5-10 years; n=5,855, mean 8.6, SD 5.7; $p<0.001$); as did the proportion with borderline/abnormal TDS (46% versus 10%; $p<0.001$).

Parents were asked if their child had '*any difficulties in the areas of emotions, concentration, behaviour or getting on with other people*': 29% (80/278) reported none, 37% minor, 30% definite and 4% had severe difficulties. In parents reporting 'minor difficulties' or worse (n=198), 95% said difficulties

were present for a year or more. The level of social impairment experienced by the child and burden to the family as a result of the child's difficulties is shown in Figure 1.

Predictors of psychological problems and social impairment

Table 4 shows the final models of predictors for 'borderline-abnormal' scores on the domains of the SDQ. Associations of variables shown in Table 1 but not in the final models were assessed but found to be not significant ($p<0.01$).

(i) Emotional symptoms
The odds for emotional symptoms increased significantly with the presence of severe pain which accounted for 6% of the observed variation.
(ii) Conduct problems
The odds for conduct problems was higher in boys and accounted for 4% of the observed variation.
(iii) Hyperactivity
Children with intellectual impairment, boys and children of a lone parent had increased odds for hyperactivity compared to those with an estimated IQ>70 and compared to girls, respectively. Sex-specific effects were checked using tests of interaction but were not significant ($p>0.05$). The model explained about 16% of the observed variation.
(iv) Peer problems
The odds of having peer problems were significantly higher among those with moderate-low child self esteem and were higher among children with intellectual impairment compared to those with high self esteem and without intellectual impairment respectively. The model accounted for about 13% of the observed variation.
(v) Prosocial skills
Children with communication problems and with poor self esteem compared to those without communication difficulties and high self esteem respectively, had significantly increased odds for prosocial difficulties. The model accounted for about 26% of the observed variation.
(vi) Impact
Children with intellectual impairment and those with moderate to low self esteem had significantly increased odds for experiencing high impact scores compared to children without intellectual impairment and with high self esteem respectively. The model accounted for about 12% of the observed variation.

DISCUSSION

We report the psychological problems of children with hemiplegia. The reports are consistent with the important paper by Goodman & Graham[5] but our study looked at children across western Europe using standardised, descriptions of motor severity and random sampling from population-based registers of children with cerebral palsy. Our study is therefore, more generalisable and will allow more precise comparisons with future studies.

We found significant differences in the rate of psychological problems in children with hemiplegia compared to norms based on the TDS. Children with

hemiplegia had more than double the rate of borderline/abnormal TDS and more than treble the rate on the IS compared to able-bodied peers. The most common issue was peer problems. Overall these findings are similar to the report for the total group of children with CP[1] and to other reports[5,18] but the rate of hyperactivity is higher than that reported by Uvebrandt[4]. The findings are also different to Trauner et al[6] who reported no statistically significant differences between mean scores on the Child Behaviour Checklist[19] in children with unilateral brain damage, confirmed on scan compared to normative controls. However not all children in Trauner's study had a clinical finding of hemiplegia – the inclusion criteria for our study. Furthermore Trauner used a small convience sample identified from clinical referrals, known to be an incomplete source of information on children with cerebral palsy[20]. The methodological strengths of our study provide more convincing evidence about the prevalence of psychological problems in children with hemiplegia.

The child factors found to be significant included sex, intellectual impairment, pain and self-esteem. Boys were more likely to have conduct disorders similar to other reports on child mental health[21]. Intellectual impairment was associated with hyperactivity, peer problems and higher impact scores. Low self-esteem was related to peer problems, poor prosocial skills and higher impact scores. However a high proportion of children had normal scores on the prosocial domain indicating a capacity for kindness and consideration to other children. Indeed children with hemiplegia were found to be less likely than their classmates to initiate aggressive or bullying behaviour suggesting that peer problems are not entirely their 'fault'[22].

We can only speculate about the direction of these relationships because of the cross-sectional nature of the data. For example children with hemiplegia in pain may be prone to an underlying emotional disorder; conversely children with emotional problems may have a psychosomatic origin to their pain. In a post hoc analysis of the emotion domain, severe pain was significantly ($p<0.05$) related to three out of five items on the domain including psychosomatic complaints. Some pain may have a psychosomatic origin and this should be considered in the assessment of such children and in future research.

An important 'family determinant' of psychological problems was lone parenthood which was significantly related to hyperactivity in the child. Lone parenthood, which may be a marker for family adversity and stress, is a risk factor for poor child mental health[23]. Single parenthood and caring for a child with hemiplegia may test parental skills to the limit leading to feelings of stress and isolation[24]. Evidence from a longitudinal study supports the idea that the child's difficulties place stress on the family and not the family's stress which creates the child's problems[18].

A strength of this study was our ability to account for the impact of non-response or refusal to take part on our study by analysing the baseline characteristics available from the registries and assigning sampling weights. A limitation is that in-depth psychiatric interview is necessary to make a reliable diagnosis; however the high correlation between psychiatric interview and use of a screening questionnaire[5] gives confidence about the results reported here. Finally it is important to note that

while this study confirms earlier findings, the final models explain relatively little of the observed variation in children with and without psychological problems.

Conclusions

Interventions aimed to improve child self-esteem and social skills using a family-centred approach[25,26] could help children with hemiplegia with or at high risk for psychological problems. The high prevalence of psychological problems, their impact and potential for treatment justifies screening for psychological problems as part of routine care for children with hemiplegia.

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Competing interests

None

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WHAT IS ALREADY KNOWN ON THIS TOPIC

- British children with hemiplegia, compared to their able-bodied peers, are at increased risk for psychological problems.
- Lower intellectual ability and being male is a risk factor for psychological problems and difficulties with peers and friendships are predominant issues.

WHAT THIS STUDY ADDS

- Psychological problems are common in a representative sample of children with hemiplegia from western Europe, with peer problems the most common difficulty.
- Over 70% of children with hemiplegia have difficulties in the areas of emotion, concentration, behaviour and getting on with others. Important determinants for psychological problems include lower child self-esteem, intellectual impairment, the presence of child pain, and being in a lone parent family though the direction of effect is unclear.

Table 1: Characteristics of children with hemiplegia in nine European regions (n=279)

Characteristics		*n*	**%**
Centre	North England, UK	*46*	**16**
	West Sweden	*33*	**12**
	Northern Ireland, UK	*33*	**12**
	South east France	*22*	**8**
	South west Ireland	*49*	**18**
	East Denmark	*34*	**12**
	Central Italy	*20*	**7**
	South west France	*21*	**8**
	North west Germany	*21*	**8**
Age (years)	7/8	*65*	**23**
	9	*48*	**17**
	10	*60*	**22**
	11	*56*	**20**
	12/13	*50*	**18**
Sex	Male	*161*	**58**
	Female	*118*	**42**
Gross motor function (GMFCS level)	I (functionally most able)	*162*	**58**
	II	*78*	**28**
	III	*17*	**6**
	IV	*11*	**4**
	V (functionally least able)	*11*	**4**
Bimanual fine motor function (BFMF level)	I (functionally most able)	*145*	**52**
	II	*72*	**26**
	III	*47*	**17**
	IV	*8*	**3**
	V (functionally least able)	*7*	**3**
Intellectual impairment	IQ>70	*178*	**64**
	IQ 50-70	*63*	**23**
	IQ<50	*36*	**13**
Vision	Has useful vision	*270*	**97**
	No useful vision	*9*	**3**
Hearing	Does not need hearing aid	*272*	**97**
	Needs hearing aid	*7*	**3**
Seizures	No seizures no medication	*213*	**76**
	No seizures on medication	*26*	**9**
	Seizures <1/month	*19*	**7**
	Seizures ≥1/monthth <1/week	*12*	**4**
	Seizures ≥1/week	*9*	**3**
Feeding	No problems	*253*	**91**
	Feeds orally with problems	*21*	**7**
	Tube fed	*5*	**2**
Communication	Normal	*219*	**78**
	Difficulty but uses speech	*39*	**14**
	Alternative formal methods	*11*	**4**
	No formal method	*10*	**3**

Table 1 continued

Characteristics		*n*	**%**
Pain (parent reported)	None	*86*	**31**
	Moderate	*158*	**57**
	Severe	*34*	**12**
Self-esteem (parent reported)	High (≥ 75th centile)	87	**32**
	Moderate	138	**51**
	Low (<25th centile)	44	**16**
Area of residence	Big city	*51*	**18**
	Suburbs/outskirts	*41*	**15**
	Town/small city	*94*	**34**
	Country village	*60*	**22**
	Farm/country	*31*	**11**
Type of school	Mainstream	*170*	**61**
	Mainstream and visits special unit	*27*	**10**
	Special unit in mainstream	*20*	**7**
	Special school	*60*	**22**
Family structure	Married	*201*	**72**
	Living with partner	*26*	**9**
	Single/sep. with partner	*9*	**3**
	Single and living alone	*43*	**15**
Siblings	One or more, none disabled	*194*	**71**
	One or more disabled	*34*	**12**
	None	*45*	**16**
Parent qualifications	University degree	*50*	**18**
	Above lowest qualification	*164*	**59**
	None	*63*	**23**
Parent employment	Full-time professional	*82*	**30**
	Full-time trade/professional	*142*	**51**
	Part-time trade/professional	*21*	**8**
	Neither partner working	*32*	**12**

Table 2: Descriptive statistics (unweighted) for the SDQ for children with hemiplegia (n=279)

		Summary statistics											
	SDQ	Responders		Mean	SD	Median	IQR	n (%) normal		n (%) borderline		n (%) abnormal	
		n	%										
All regions	Emotion	279	100	13.3	2.4	3	1-5	162	(58.1)	29	(10.4)	88	(31.5)
	Conduct	279	100	2.0	1.6	2	1-3	188	(67.4)	46	(16.5)	45	(16.1)
	Hyperactivity	279	100	4.7	2.8	5	3-7	175	(62.7)	26	(9.3)	78	(28.0)
	Peer problems	279	100	2.8	2.2	2	1-5	144	(51.6)	34	(12.2)	101	(36.2)
	Total difficulties	279	100	12.8	6.3	13	8-17	152	(54.5)	49	(17.6)	78	(28.0)
	Prosocial	279	100	7.8	2.3	9	6-10	234	(83.9)	18	(6.5)	27	(9.7)
	Impact score	278	99.6	1.7	2.3	1	0-3	126	(45.3)	47	(16.9)	105	(37.8)

Table 3: Prevalences of psychological problems (with 95% confidence intervals) in children aged 8-12 years with hemiplegia in eight regions weighted for sampling strategy (n=245)*

			Population prevalences					
	SDQ	Responders n	Normal %	95% CIs	Borderline %	95% CIs	Abnormal %	95% CIs
All regions	Emotion	245	59.0	55.3-62.7	10.1	7.8-12.3	30.9	27.4-34.4
	Conduct	245	64.9	61.3-68.6	17.9	15.0-20.8	17.2	14.3-20.0
	Hyperactivity	245	60.4	56.7-64.1	10.5	8.2-12.8	29.1	25.7-32.5
	Peer problems	245	53.1	49.3-56.9	11.2	8.8-13.5	25.7	32.1-39.4
	Total difficulties	245	51.9	48.1-55.7	19.3	16.3-22.2	28.8	25.4-32.3
	Prosocial	245	83.7	80.9-86.5	7.7	5.6-10.0	8.6	6.5-10.7
	Impact score	244	43.2	39.4-46.9	16.1	13.3-18.9	40.7	36.9-44.4

* Exclusions: 21 children from north west Germany; 10 children aged >12 years and 3 children aged <8 years at the time of interview.

Figure 1: The level of social impairment experienced by the child and burden to the family as a result of the child's difficulties (taken from the Impact Supplement of the SDQ) (n=198)

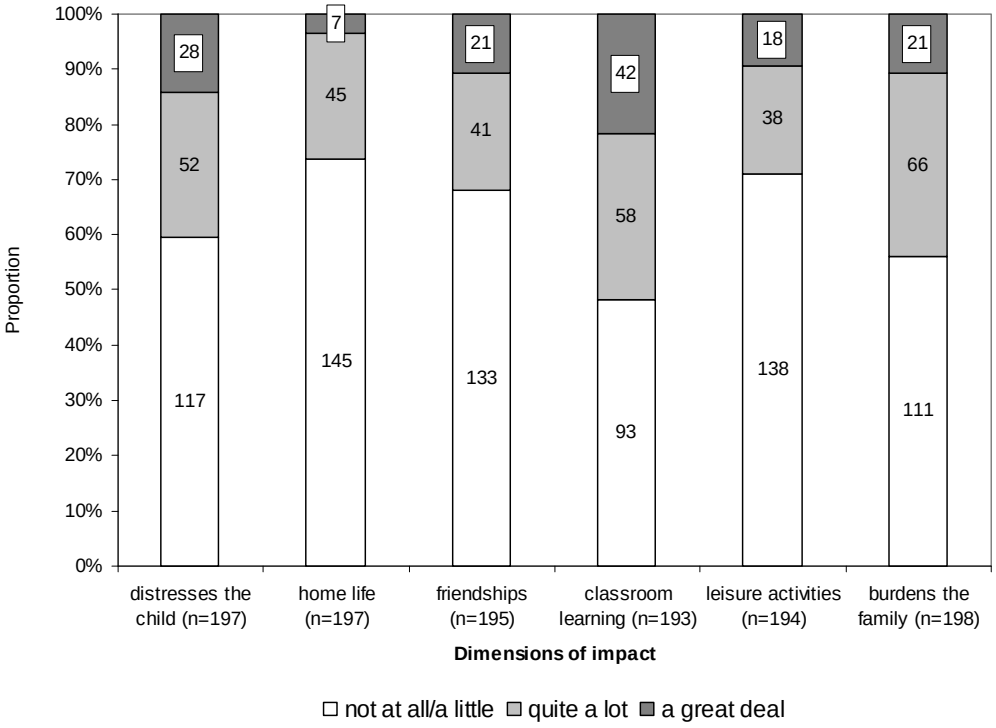

Table 4: Adjusted ORs and 95% confidence intervals of the multivariable logistic regression across six domains of the SDQ (normal=0 versus borderline/ abnormal=1) by child and family characteristics*

SDQ domains		Child and family characteristics	ORs	95%CI	p value
Emotion (n=272)	Pain	Absence of pain (reference category)	-	-	
		Moderate pain	1.2	0.7-2.2	
		Severe pain	5.5	2.2-13.8	<0.001
Conduct (n=275)	Sex	Female (reference category)	-	-	
		Male	2.1	1.2-3.7	<0.01
Hyperactivity (n=264)	Intellectual impairment	Normal/mild (reference category)	-	-	
		Moderate	2.3	1.2-4.5	
		Severe	8.4	3.4-20.8	<0.0001
	Sex	Female (reference category)	-	-	
		Male	2.5	1.3-4.6	<0.01
	Family status	Parent married with partner (reference category)	-	-	
		Parent with partner	2.1	0.9-4.9	
		Lone parent	3.1	1.5-7.1	<0.01
Peer problems (n=273)	Self esteem	High self-esteem (reference category)	-	-	
		Moderate	2.3	1.2-4.3	
		Low self esteem	5.8	2.5-13.4	<0.001
Prosocial (n=271)	Communication	No difficulties (reference category)	-	-	
		Some problems–no communication	8.9	3.7-21.5	<0.0001
	Self esteem	High self esteem (reference category)	-	-	
		Moderate self esteem	1.4	0.5-3.9	
		Low self esteem	7.5	2.4-23.2	<0.001
Impact Score (n=271)	Intellectual impairment	Normal/mild (reference category)	-	-	
		Severe	3.0	1.6-5.6	<0.001
	Self esteem	High self esteem (reference category)	-	-	
		Moderate self esteem	1.8	1.0-3.3	
		Low self esteem	4.8	2.1-11.0	<0.001

* All models were adjusted for region