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Psychological problems in children with cerebral palsy: a cross-sectional European study

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Objectives: To describe psychological symptoms in 8–12-year-old children with cerebral palsy; to investigate predictors of these symptoms and their impact on the child and family. **Design:** A cross-sectional multi-centre survey. **Participants:** Eight hundred and eighteen children with cerebral palsy, aged 8–12 years, identified from population-based registers of cerebral palsy in eight European regions and from multiple sources in one further region. **Main outcome measures:** The Strengths and Difficulties Questionnaire (SDQ)$^{P4-16}$ and the Total Difficulties Score (TDS) dichotomised into normal/borderline (TDS ≤ 16) versus abnormal (TDS > 16). **Statistical analysis:** Multilevel, multivariable logistic regression to relate the presence of psychological symptoms to child and family characteristics. **Results:** About a quarter of the children had TDS > 16 indicating significant psychological symptoms, most commonly in the domain Peer Problems. Better gross motor function, poorer intellect, more pain, having a disabled or ill sibling and living in a town were independently associated with TDS > 16. The risk of TDS > 16 was odds ratio (OR) = .2 (95% CI: .1 to .3) comparing children with the most and least severe functional limitations; OR = 3.2 (95%CI: 2.1 to 4.8) comparing children with IQ < 70 and others; OR = 2.7 (95% CI: 1.5 to 4.6) comparing children in severe pain and others; OR = 2.7 (95% CI:1.6 to 4.6) comparing children with another disabled sibling or OR = 1.8 (95%CI: 1.2 to 2.8) no siblings and others; OR = 1.8 (95% CI: 1.1 to 2.8) comparing children resident in a town and others. Among parents who reported their child to have psychological problems, 95% said they had lasted over a year, 37% said they distressed their child and 42% said they burdened the family at least 'quite a lot'. **Conclusions:** A significant proportion of children with cerebral palsy have psychological symptoms or social impairment sufficiently severe to warrant referral to specialist services. Care must be taken in the assessment and management of children with cerebral palsy to ensure psychological problems are not overlooked and potentially preventable risk factors like pain are treated effectively. The validity of the SDQ for children with severe disability warrants further assessment.
Keywords: Psychological problems, case registers.

Mental health problems in children are increasingly prevalent, with an estimated 10% of children over the age of five having a significant mental health disorder (Blair, Stewart-Brown, Waterston, & Crowther, 2003; Meltzer, Gatward, Goodman, & Ford, 2000). Children with disabilities, in particular those with 'chronic cerebral disorders', are at even higher risk of experiencing mental health problems compared to their non-disabled peers (Goodman, 2002; Rutter, Graham, & Yule, 1970). This increased risk may be partly explained by a direct link between brain and behaviour (Goodman & Graham, 1996) but it is also possible that negative social experiences like feeling excluded and being bullied could contribute to emotional and behavioural maladjustment (Yude, Goodman, & McConanchie, 1998; Yude & Goodman, 1999).

Cerebral palsy is a leading cause of motor impairment in childhood (Stanley, Blair, & Alberman, 2000) and affects about two children in every 1,000 (Surveillance of Cerebral Palsy in Europe Collaborative Group, 2002), with an estimated 10,000 newly diagnosed cases each year in the European Union before its expansion (Colver, for the SPARCLE group, 2006). The prevalence of psychological problems in children with hemiplegia – usually the mildest form of cerebral palsy – was found to be high, with over half the children experiencing problems at least as severe as those attending a psychiatric clinic (Goodman & Graham, 1996). However, little is known about the extent of psychological problems across all severities of cerebral palsy or their impact on the child and family. Moreover, the role of child, family and environmental factors has rarely been investigated simultaneously (Ford, Goodman, & Meltzer, 2004), thus limiting our

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understanding of where opportunities for treatment or prevention might lie. This paper reports on specific behavioural and emotional symptoms in a large sample of children with cerebral palsy in Western Europe. The data were obtained as part of a project (SPARCLE) investigating the role of environmental factors on participation and quality of life of children with cerebral palsy (Colver, for the SPARCLE group, 2006). The aims of this paper are to describe the prevalence, type and severity of behavioural and emotional symptoms in 8–12-year-old children with cerebral palsy; to investigate predictors of these symptoms and to report on their impact on the child and family.

Method

Study design

The SPARCLE study was a cross-sectional survey of 8–12- year-old children with cerebral palsy and their families in seven countries or nine regions of the European Union (see below).

Participants

The children were identified from eight population-based cerebral palsy registers covering the north of England, west Sweden, Northern Ireland, Isere County in south-east France, south-west Ireland, east Denmark, central Italy, and Haute Garonne County in south-west France. A further centre in north-west Germany followed study protocols but its sample was constructed from referrals from multiple sources in a defined geographic area. The details of recruitment, sampling procedures and inclusion criteria are described elsewhere (Colver, for the SPARCLE group, 2006). In summary, children with a diagnosis of cerebral palsy, born 31 July 1991 to 1 April 1997 and resident in one of the geographical areas, were eligible to take part. A total of 1,174 children were identified as potentially eligible; of these 993 (85%) were traced and approached and 818 families participated (82% of those approached; 70% of those eligible to participate) (Dickinson et al., 2006).

Definitions

All regions shared the Surveillance of Cerebral Palsy Collaborative Group definition of cerebral palsy (Surveillance of Cerebral Palsy in Europe Collaborative Group, 2000). The Gross Motor Function Classification System (GMFCS) was used to classify gross motor function (Palisano et al., 1997); the Bimanual Fine Motor Function (BFMF) to classify the use of arms and hands (Beckung, & Hagberg, 2002); the presence of intellectual impairment was assessed using a standardised technique based on IQ (White-Koning et al., 2005); severe visual impairment was defined as visual acuity <6/60 in the better eye; severe hearing impairment as >70 decibels in the better ear. Definitions of child and family characteristics are described elsewhere (Colver, for the SPARCLE group, 2006). Parental employment and parental educational qualifications were grouped into three categories, as was area of residence.

Measures

Pain was measured using the algorithm for the questions about pain in the Child Health Questionnaire (parent form 50) (Landgraf, Abetz, & Ware, 1995) and categorised into none (score = 100), moderate (score = 50–90) and severe (score = 0–40).

Emotional and behavioural symptoms were captured using the parent-form Strengths and Difficulties Questionnaire (SDQ) whose psychometric properties have been tested extensively and found to be satisfactory (Goodman, 1997, 1999, 2001). The SDQ is suitable for children aged 4–16 years and the reference period for this standard version is 'the last six months or this school year'. The SDQ is a behavioural screening instrument and functions well at detecting emotional, conduct, attention deficit and hyperactivity disorders (Goodman, 1999). The questionnaire contains 25 items based on four symptom scales (conduct, hyperactivity, emotion and peer problems) yielding a 'total difficulties score' (TDS). This score represents the extent of behavioural and emotional symptoms and was dichotomised using established cut-offs into normal/borderline (TDS ≤ 16) versus abnormal (TDS > 16). Scores in the abnormal range (TDS > 16) provide a reasonable estimate of 'symptom caseness' (Goodman, 1999), although it should be noted that this is not the same as 'psychiatric caseness' which requires more detailed information, including reports from multiple informants (parents, teachers and self-report) as well as in-depth psychiatric interview. An additional prosocial scale (not included in the total score) reflects social competence and maturity. There is also an 'Impact supplement' (IS) which evaluates the overall, everyday distress experienced by the child and family related to the child's mental health problems. It is possible to compute an 'impact score' using established cut-offs where a score of two or more is indicative of significant social impairment. The IS also includes a question about parent-perceived difficulties in the areas of 'emotion, concentration, behaviour and getting on with others' which can be used as a one-item screen and is a better predictor of clinical status than symptoms alone (Goodman, 1999); the chronicity of problems, overall distress to the child and burden on the family.

Validation of the SDQ instrument

A validation of the SDQ on the SPARCLE data was undertaken by examining internal consistency within countries and overall using Cronbach's alpha. The coefficients were generally satisfactory (mean .69) and all coefficients were similar to Goodman's (2001) with the exception of the conduct domain which was lower (.46 compared to .63) and the prosocial behaviour domain which was higher (.81 compared to .65). Convergent and divergent validity were checked using correlations between and within domains. All items were more strongly correlated to their own domain (scores calculated omitting the item under study) than to other domains of the SDQ, with three exceptions:

item 5 '*often has temper tantrums or loses temper*' correlated more strongly with the Emotions and Hyperactivity domain than its own domain (Conduct); item 7 '*generally obedient, usually does what adults request*' correlated more strongly with the Prosocial and Hyperactivity domain than its own domain (Conduct); and item 11 '*has at least one good friend*' correlated more strongly with the Prosocial domain than its own domain (Peer Problems). Confirmatory factor analysis then established that the main factors identified in the SPARCLE data were consistent with the domains used. All 25 items loaded strongly onto the predicted factors, with only two items loading better onto additional factors: item 7 '*generally obedient, usually does what adults request*' loads more strongly onto the Prosocial and Hyperactivity factor than onto the Conduct factor (of which it is part); and item 11 '*has at least one good friend*' loads more strongly onto the Prosocial factor than onto the Peer Problems factor (of which it is part).

Data collection

In each of the regions, Research Associates interviewed families at home during 2004–5, if possible when the child was between 8 and 12 years, using a standardised procedure (Colver, for the SPARCLE group, 2006).

Ethics approval

Ethics approval to conduct the study was obtained in each of the countries and complied with the local requirements (Colver, for the SPARCLE group, 2006).

Statistical analysis

To facilitate comparison with normative data, the mean and standard deviations of the domains of the SDQ are presented even though the data are not normally distributed. Prevalence (expressed as proportions with 95% confidence intervals) was estimated using sampling weights which took account of the sampling strategy (Dickinson et al., 2006). Prevalence estimates excluded children in North West Germany, as their children were not identified from a population-based register.

The determinants of children's symptoms (as measured by the total difficulties score dichotomised into normal/borderline versus abnormal) were studied using multilevel, multivariable logistic regression. Multilevel modelling was used as it was considered likely that children from the same region would be more similar than children from different regions. Initially, multilevel univariate logistic regression was performed, considering each covariate in turn. Covariates associated below the 20% significance level in the univariable analysis were then entered into the multivariable analysis using forward stepwise regression, and included in the final model if they were significant below the 5% significance level. All variables significant in the multivariable analysis were tested for removal with a backwards step at each stage. Where significant, categories within variables were collapsed after including the factor in the model if the 95% confidence intervals overlapped substantially. The final multivariable model excluded children with missing values on the included covariates, explaining why the model was based on 774 out of the possible 818 subjects. Goodness-of-fit as assessed by the Bayesian Information Criterion was adequate. Models were rerun excluding influential observations and found to be stable. The reduction in deviance resulting from the multivariable model was used as an indicator of the variation explained by the model.

All analyses were checked with and without north-west Germany (centre 9) as their recruitment method differed. As the results were very similar their data were included in the models presented here. We checked the possible effect of non-response bias by rerunning a weighted model allowing for non-response: results were not affected. All analyses were performed in Stata Release (StataCorp, 2005) version 9. Multilevel modelling was performed using the gllamm programme (Hesketh & Skrondal, 2005).

Results

Emotional and behavioural symptoms

Table 1 shows the extent and type of emotional and behavioural symptoms experienced by the children. Almost a quarter of children were in the abnormal range on the TDS, indicating significant emotional and behavioural symptoms. After allowing for the sampling strategy and non-response, this corresponds to an estimated population prevalence of 26% (95% CI 24% to 28%). The most common

Table 1 Mean, standard deviation (SD), median, inter quartile range (IQR), % normal, borderline and abnormal (using established 'cut-offs') on SDQ domains (total sample) ($N = 818$)

		Summary statistics					
		Responders					
Centre	SDQ domains	*n* (%)	Mean (SD)	median (IQR)	*n* (%) normal	*n* (%) borderline	*n* (%) abnormal
All centres							
	Emotion	808 (99)	3.1 (2.3)	3 (1–5)	497 (61.5)	92 (11.4)	219 (27.1)
	Conduct	802 (98)	1.9 (1.6)	2 (1–3)	543 (67.7)	138 (17.2)	121 (15.1)
	Hyperactivity	806 (98)	4.8 (2.7)	5 (3–7)	489 (60.7)	95 (11.8)	222 (27.5)
	Peer problems	807 (99)	2.7 (2.1)	2 (1–4)	420 (52.1)	126 (15.6)	261 (32.3)
	Total difficulties	799 (98)	12.4 (6.0)	12 (8–16)	466 (58.3)	142 (17.8)	191 (23.9)
	Prosocial	796 (97)	7.2 (2.7)	8 (6–9)	604 (75.9)	65 (8.2)	127 (15.9)
	Impact score	810 (99)	1.9 (2.4)	1 (.3)	361 (44.6)	123 (15.2)	326 (40.2)

problems encountered were in the domain Peer Problems (prevalence 32%, 95% CI 30% to 35%), followed by hyperactivity (prevalence 31%; 95% CI 29% to 33%) and emotion (prevalence 29%, 95% CI 26% to 31%). Problems with conduct were less common and about half the rate of peer problems (prevalence 17%; 95% CI 15% to 19%).

Predictors of symptoms (TDS > 16)

Table 2 shows the univariable logistic regression analyses of the influence of child and family characteristics on the presence of TDS > 16. Children with hearing impairment, intellectual impairment or pain were more likely to have TDS > 16, as were children with no siblings or disabled siblings, children attending special schools or special units in mainstream schools and children living in a small town or city. In contrast, those who needed total assistance with moving about (GMFCS Levels IV and V) were less likely to have TDS > 16. However, most of the factors describing impairment and pain were correlated, so the findings cannot be interpreted without recourse to a multivariable model which allows for these correlations. The following variables were associated with symptoms at a significance level ≤20% and were tested for inclusion in the multilevel, multivariable model: gross motor function, hearing, seizures, communication, intellectual impairment, pain, schooling, siblings, family structure, parental qualification, parental employment and area of residence.

The following variables comprised the final, adjusted model (see Table 3) and remained significantly associated with an increased risk of TDS > 16 in children with cerebral palsy: gross motor function, intellectual impairment, siblings, pain and area of residence. Children with severe functional limitations had significantly reduced odds of experiencing TDS > 16 compared to children in GMFCS Level I: OR = .4 for Level IV; OR = .2 for Level V. The presence of intellectual impairment (moderate to severe/profound) was associated with a significantly increased risk of TDS > 16 (OR = 3.2) compared to children with an IQ over 70. Having at least one disabled or chronically ill sibling significantly increased the risk of TDS > 16 in the child (OR = 2.7) as did being an only child (OR = 1.8) compared to those children with cerebral palsy who had well, able-bodied siblings. Children with severe pain were also significantly more likely to have TDS > 16 (OR = 2.7) than children without. Finally those living in a town/small city had a significantly increased risk of TDS > 16 (OR = 1.8) compared to those living in a big city or its suburbs. After allowing for these covariates, variance between regions was low (3% of total variance) but statistically significant ($p = .02$), suggesting country-specific differences in the psychological well-being of children with cerebral palsy. We found no significant interactions between

Table 2 Multilevel, univariate logistic regression model of TDS > 16 in relation to child and family characteristics (ORs > 1 indicate a higher risk of symptom caseness in that group)

Characteristics	*n*	OR	95%CI
Gender			
Boys	471	1	
Girls	328	.8	.6–1.2
Age (yrs)			
7/8	178	1	
9	157	1.0	.6–1.6
10	161	1.1	.6–1.8
11	153	.9	.5–1.5
12/13	150	1.0	.6–1.6
GMFCS			
I (no limitation)	256	1	
II	164	1.3	.8–2.0
III	138	.9	.6–1.5
IV	109	1.0	.6–1.7
V (total assistance)	132	.5	.3–0.8
BFMF			
I (no limitation)	280	1	
II	205	1.2	.8–1.8
III	131	1.3	.8–2.1
IV	84	.8	.4–1.5
V (total assistance)	99	.6	.3–1.2
Vision			
Has useful vision	748	1	
Blind or no useful vision	51	.9	.4–1.8
Hearing			
Does not need hearing aids	782	1	
Needs hearing aids	16	3.3	1.2–9.1
Seizures			
No seizures, no medication	569	1	
No seizures, with medication	72	.9	.5–1.7
Seizures < 1/month	61	2.4	1.4–4.2
Seizures ≥ 1/month < weekly	46	1.0	.5–2.1
Seizures ≥ 1/week	50	1.5	.8–2.9
Feeding			
No problems	579	1	
By mouth with difficulty	166	1.2	.8–1.8
Tube feeding	53	.6	.3–1.4
Communication			
Normal	462	1	
Difficulty but uses speech	132	1.8	1.2–2.8
Alternative formal methods	96	1.0	.6–1.8
No formal communication	108	.9	.5–1.5
Intellectual impairment			
None-mild (IQ > 70)	385	1	
Moderate-severe (IQ ≤ 70)	428	3.0	2.1–4.2
CP subtype			
Spastic unilateral	279	1	
Spastic bilateral	407	.7	.5–1.0
Dyskinetic	83	.6	.3–1.1
Ataxic	29	1.2	.5–2.8
Pain (parents' report on CHQ)			
None (score = 100)	224	1	
Moderate (score 50–90)	426	1.3	.9–2.0
Severe (score 0–40)	139	2.0	1.2–3.2
School type			
Mainstream	315	1	
Mainstream & visits special unit	109	1.5	.8–2.8
Special unit in mainstream	67	2.1	1.0–3.8
Special school	297	1.6	1.0–2.3
Siblings			
One or more, none disabled/ill	548	1	
One of more, one or more disabled/ill	83	2.7	1.7–4.4
None	158	1.9	1.2–2.8

Table 2 (*continued*)

Characteristics	*n*	OR	95%CI
Family structure			
Married, living with partner	564	1	
Living with partner	82	1.5	.9–2.6
Single/separated, living with parents	18	1.4	.5–4.0
Single alone	134	1.5	1.0–2.4
Parent qualifications (median)			
University degree	113	1	
Above lowest qualifications but below university degree	494	1.4	.8–2.3
None/lowest formal qualification	187	1.8	1.0–3.3
Parent occupation			
Full-time professional	223	1	
Full-time trade trade/professional	394	1.5	1.0–2.3
Part-time trade/professional	63	1.6	.9–3.1
Neither partner working	116	1.5	.8–2.5
Area of living			
Big city or its suburbs	243	1	
Town or small city	286	1.7	1.1–2.5
Village, farm or home in the country	286	1.0	.7–1.5

Table 3 Multilevel, multivariable logistic regression model of predictors of TDS > 16 by child and family characteristics (n = 774)

Characteristics	n = 774	OR	95% CI
GMFCS			
Level I (no limitations)	252	1	
Level II	160	.9	.6–1.5
Level III	127	.6	.3–1.1
Level IV	106	.4	.2–.8
Level V (total assistance)	129	.2	.1–.3
Intellectual impairment			
None-mild (IQ > 70)	376	1	
Moderate-severe (IQ ≤ 70)	398	3.2	2.1–4.8
Siblings			
One or more, none disabled/ill	542	1	
One of more, one or more disabled/ill	79	2.7	1.6–4.6
None	153	1.8	1.2–2.8
Pain (parent report)			
None (score = 100)	222	1	
Moderate pain (score 50–90)	414	1.4	.9–2.1
Severe pain (score 0–40)	138	2.7	1.5–4.6
Area of living			
Big city or its suburbs	233	1	
Town or small city	273	1.8	1.1–2.8
Village, farm or home in the country	268	.9	.6–1.5

GMFCS, IQ and pain. The relationship between GMFCS and intellectual impairment and GMFCS and pain by TDS > 16 is shown in Figures 1a & 1b. Overall the final, adjusted model accounted for only 10% of the variation between children with TDS > 16; impairment (GMFCS and intellectual) accounted for only 5% of the variation.

Impact of difficulties

Using the Impact Supplement, parents were asked if they perceived their child had any difficulties in the areas of emotions, concentration, behaviour or getting on with other people (the 'one-item screen').

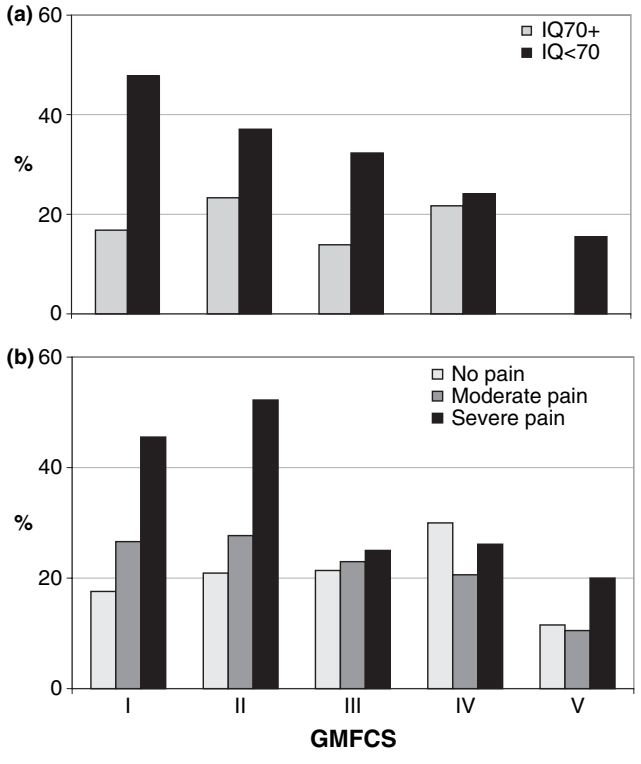

Figure 1 Proportion of children with TDS > 16 by GMFCS and intellectual impairment (1a) and by pain (1b) (n = 774)

Twenty-seven percent (216/810) reported no difficulties, 34% (277/810) reported minor difficulties, 32% (257/810) definite difficulties and 7% (60/810) severe difficulties. Almost all parents (97%; 186/191) whose child had TDS > 16 reported their child had at least minor problems on the one-item screen question. Table 1 shows the impact score (social impairment) experienced by the child as a result of their emotional or behavioural difficulties. The estimated population prevalence of significant social impairment was 41% (95% CI 39% to 44%).

Those parents reporting minor difficulties or worse on the 'one-item screen' (n = 594) were asked for how long their child's difficulties were present and 95% said over a year. The extent to which these difficulties upset the child and family and impacted on their everyday life is summarised in Figure 2. Parents perceived the child's classroom learning to be the most disrupted aspect of the child's life and their home life the least disrupted. Forty-two percent of parents reported the child's difficulties burdened the family at least 'quite a lot'.

Discussion

Our results indicate that a significant proportion of children with cerebral palsy are at high risk of poor mental health, as over 40% of children scored in the borderline to abnormal range on TDS, with more than a quarter with TDS > 16 on the parent version

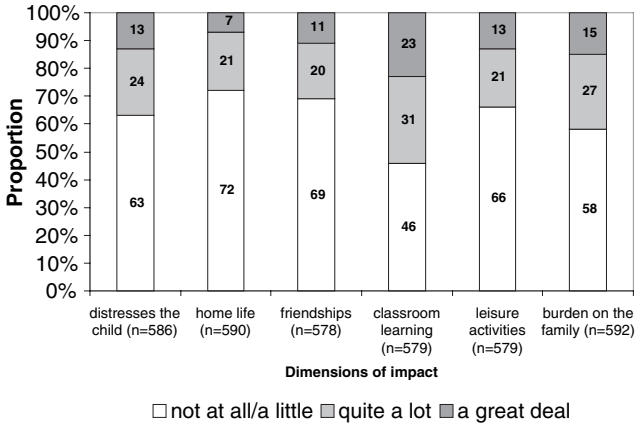

Figure 2 Impact of parent perceived difficulties on the child (social impairment) and the family (burden) ($n = 594$)

of the SDQ. Approximately 18% of a British community sample could be expected to have symptoms in this band of scores, about 10% scoring in the abnormal range, although this may vary by country, age and gender (Goodman, 1999). Furthermore, the mean TDS for children with cerebral palsy (12.4) was high compared to reports of normative data from children resident in Britain (8.4) (http://www.sdqinfo.com/b8.html), Denmark (5.4), parts of Sweden (6.3, 7.2) (Obel et al., 2006) and Germany (8.1) (Becker, Woerner, Hasselhorn, Banaschewski, & Rothenberger, 2004). Goodman and Graham (1996) found a higher rate of psychological disturbance among children with hemiplegia aged 2–16 years (54%) and 6–10 years (55%) based on parent-report in a single centre (Greater London). However, our study extends to all types of cerebral palsy in children aged 8–12 years resident across nine regions of western Europe. It should be noted that a high frequency of emotional and behavioural symptoms is not always associated with psychiatric disorder, although depressed mood has been identified as an important correlate (Fombonne, 1992, 2003). More than a quarter of children with cerebral palsy in this sample experienced abnormal scores (5–10) on the emotion domain of the SDQ.

Around 40% of parents perceived their child to have definite or severe difficulties in relation to emotion, behaviour, concentration and getting on with others. This is a similar proportion to those reporting symptoms, although the children may not be the same ones. An 'impact score' of two or more is a stronger predictor of clinical status than symptoms scores alone, with an estimated 13.5% of a British community sample having scores in the abnormal range, based on reports from multiple informants (Goodman, 1999). Just over 40% of children with cerebral palsy in this study had an impact score of two or more, indicating significant social impairment as a result of emotional or behavioural problems reported by their parents.

This study helps to clarify the relationships between the risk of experiencing psychological problems and child and family factors. Children with greater intellectual impairment or pain had a higher risk of TDS > 16 but those with greater functional impairment had a lower risk. In our sample, GMFCS and intellectual impairment were positively correlated, i.e., children with lower functional abilities tended to have lower intellectual ability. However, gross motor function and intellectual impairment had different associations with the presence of TDS > 16. It is possible that the apparently lower risk among children with greater functional impairment, which was more marked in the multivariable model than the univariable model, may be partly an artefact due to the lack of sensitivity of the SDQ to psychological problems in more severely disabled children. Indeed Goodman and Graham (1996) suggested that it made little sense to ask severely disabled children or their parents about certain conditions related to psychological adjustment. It is also important to note that some of the variables studied were based solely on parent-report (the SDQ and pain) whereas others were classified by trained Research Assistants (GMFCS, intellectual impairment). Child self-report of the SDQ and pain might have produced different results.

Some of this relationship may also be explained by children with more severe motor impairment being less able to participate in poor behaviours – like stealing, fighting, cheating or fidgeting, being restlessness or easily distracted – and so are at lower risk of conduct or hyperactivity disorders. There was some evidence from our psychometric evaluation of the SDQ that certain items, mainly related to the conduct domain, correlated more strongly with other domains. On the other hand, it is possible that differences in functional ability are more stressful for children with milder forms of cerebral palsy if they are more similar to their able-bodied peers than when these differences are greater, as in children with severe cerebral palsy. Goodman and Yude (2000) describe how school life for children with milder cerebral palsy (hemiplegia) can be stressful as they feel conspicuous and uncomfortable as a result of always being last, never picked for sports, needing help during mealtimes or with self-care.

The higher risk of emotional or behavioural symptoms in children with intellectual impairment has been reported before (Rutter et al., 1970; Goodman & Graham, 1996; Davies, Heyman, & Goodman, 2003) and is considered evidence of a brain–behaviour link (Goodman & Graham, 1996). Further, it is clear that living through the difficult experience of pain is associated with psychological adjustment, although it is not possible to infer the direction of causality from cross-sectional data (Yude & Goodman, 1999). Our multivariable model also showed that children with disabled/chronically ill siblings or no siblings, and children living in a

town or small city were at higher risk of abnormal psychological symptoms. It is difficult to explain the association with place of residence and it could be a chance finding but it could also be related to differences in access to specialist services. Despite the statistically significant associations of TDS > 16 with impairment, pain and some socio-demographic characteristics, the multivariable model explained little of the overall variation in the TDS, indicating that other, unrecorded factors must have a major influence. For example, family adversity, including parental depression, is a recognised risk factor for psychological problems in children (Goodman & Graham, 1996) and can also negatively influence parental perceptions and report. However, Goodman (1998) concluded that adverse family circumstances are more likely to be a consequence than a cause of difficulties in the child, as evidenced by data from longitudinal studies of childhood hemiplegia. In disabled children as in non-disabled children, psychological problems are likely to be largely determined by social, environmental, genetic and other family factors not studied here. It is noteworthy that schooling, parental education, employment and cerebral palsy subtype were not independently related to the risk of a high TDS. Cerebral palsy subtype may be too broad or insensitive a proxy of 'neuroseverity' to be useful in discriminating between subgroups of children in this type of analysis. Furthermore, despite the registries involved in the study using standardised guidelines to classify children by subtype, this approach still aims to capture the 'predominant' clinical picture for epidemiological research and may be subject to poor or uncertain inter-rater reliability. In the dedicated studies of childhood hemiplegia Goodman (1998) notes that 'the presence of some bilateral signs in a substantial minority of children with a clinical diagnosis of hemiplegia is well recognised' (p. 348). By contrast, various studies have found the GMFCS to have excellent inter-rater reliability (Palisano et al., 1997; Morris, Galuppi, & Rosenbaum, 2004; Wood & Rosenbaum, 2000).

Some caution is needed in the interpretation of our findings as we used a screening questionnaire when in-depth interview is necessary for reliable psychiatric diagnosis (Goodman & Yude, 2000). However, we used cut-offs in the abnormal range of the TDS to increase the likelihood of identifying a clinical problem. Another reason for caution is that the SDQ might have poor face validity for parents of severely disabled children and our Research Assistants did report that the questionnaire was difficult for parents of severely impaired children to complete. There is also some evidence for this in other studies using the Child Health Questionnaire in children with severe cerebral palsy (Liptak et al., 2001; Schneider, Gurucharri, Gutierrez, & Gaebler-Spira, 2001; Wake, Salmon, & Reddihough, 2003). While the SPARCLE study was not set up primarily to investigate psychological problems, it offered a number of methodological advantages over other observational studies of psychological well-being in children. Firstly, in eight out of nine centres, the participants were identified from existing population-based case registers, thereby allowing analysis of those who took part as well as those who did not and avoiding bias resulting from clinic recruitment (Parkes, Kerr, McDowell, & Cosgrove, 2006). Secondly, we investigated the relative importance of a number of recognised risk factors simultaneously – child, family and environmental factors – and were thus able to draw more comprehensive conclusions. Finally, the analysis allowed for clustering within regions, assuming that children resident in the same region were likely to be more similar than children resident in different regions.

Our findings suggest that a significant proportion of children with cerebral palsy may have symptoms sufficiently severe to warrant referral to mental health services. We did not collect data on service use in SPARCLE and hence cannot comment on the extent of unmet need in this European sample, although under-use of mental health services in a community sample of British children has been reported (Meltzer et al. 2000; Glazebrook, Hollis, Heussler, Goodman, & Coates, 2003). The extent to which the child's difficulties burden the family has been found to be a good predictor of service use (Goodman, 1999), as has a 'definite' or 'severe' response to the one-item-screen on the Impact Supplement (Bourdon, Goodman, Rae, Simpson, & Koretz, 2005).

Professionals and parents need to be aware that children with cerebral palsy are at higher risk of psychological problems than their non-disabled peers and this may be attributable to problems in adjustment to their adverse circumstances as well as having an organic basis. Attention should be paid to the effective management of pain, particularly in children unable to self-report for whom a reliable instrument for assessing pain now exists (Hunt et al., 2004). The difficulties most commonly reported here were peer problems; as these may have implications for later psychological adjustment (Yude et al., 1998), follow-up work into adolescence and beyond will be important. It may be that for many children with cerebral palsy and their families, chronic psychological problems will have a greater impact than the physical impairments and this possibility also needs to be investigated in longitudinal studies.

Conclusions

Although psychological problems are more common in children with cerebral palsy than in other children and are related to functional abilities and pain, other factors – such as those which cause problems in

non-disabled children – are likely to be the most important determinants of such problems in children with cerebral palsy. Goodman and Graham (1996) have proposed that many of these psychological problems are amenable to treatment but require specialist support. Incorporating a reliable and easy-to-use screening tool into routine assessment of children with cerebral palsy would help to ensure that the psychological aspects of the condition are not overlooked. However, the validity of the SDQ for children with severe disability requires further assessment.

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