

ORIGINAL ARTICLE

Long term follow up after meningitis in infancy: behaviour of teenagers

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Aims: To determine the effects of meningitis in infancy on subsequent teenage behaviour.

Methods: A national postal survey of parents and teachers using an established standard behavioural questionnaire. Subjects were 739 of the surviving children from the national incidence study of infantile meningitis in England and Wales carried out between 1985 and 1987, together with a group of 606 matched controls that had been recruited when the index cases were 5 years old.

Results: 46% of parents of children who had had meningitis with complications in infancy, compared with 21% of parents of control children rated their children as having behavioural problems. When the children were rated by their teachers, 37% and 23% respectively, were scored as having behavioural problems. There was no significant difference in behaviour between the 103 children who had had meningitis during the first month of life and the 634 who had had postneonatal meningitis. Eight of the index children had been excluded from school compared to none from the control group.

Conclusions: The behaviour of teenage children who had meningitis in infancy is worse than that of control children who did not have infantile meningitis when rated by parents and teachers.

The subjects of this study were the survivors from a national incidence study of infantile meningitis in England and Wales, carried out by de Louvois and colleagues¹ between 1985 and 1987. The effects of meningitis on the overall health of these children at the age of 5 has been reported,² and also the cognitive outcome at 9 years of age of 111 children who had neonatal meningitis.³ The reluctance of some families to take part in the latter study, because of the adverse behaviour of their child, prompted us to review the behaviour of the whole group, and to compare the results with those from the controls who had been recruited at the time of the 5 year follow up study. There are no other published reports on behaviour following meningitis in such a large group of patients and none relating to a national cohort.

SUBJECTS AND METHODS

From our original study there were 1175 survivors on whom we had information from the parents and/or general practitioner (GP) when the child was aged 5 years. All of these children had had proven bacterial meningitis before their first birthday. A postal questionnaire about behaviour was sent to the parents and, following permission from the family, to the appropriate schoolteacher. The families were traced if necessary via their GP and relevant health authority.

The Strengths and Difficulties Questionnaire (SDQ) was used to evaluate behaviour.⁴ This is a brief form containing 25 questions, which can be completed in five minutes by the parents or teachers of children aged 4 to 16. The SDQ is based on the long established and highly respected Rutter behavioural screening questionnaire,⁵ and has been favourably compared with the widely used Child Behaviour Checklist.^{6,7} The 25 questions in the SDQ are divided into five categories: emotional symptoms; conduct problems; hyperactivity; peer problems; and prosocial behaviour; each category contains five questions. The first four of these groups rate negative aspects of behaviour and the fifth, the prosocial group, rates positive aspects, for example, being considerate, sharing, kind, or helpful. The person completing the form was asked to answer each question as "not true", "somewhat true", or "certainly true". "Somewhat true" was always scored as 1, but the scoring of "not true" and "certainly true" varies with each item, being equal to either 0 or 2.

The scores from the first four groups of antisocial behaviour were added to give a "total deviance" score. A total deviance score of between 0 and 13 was considered "normal" and between 14 and 40 was "not normal". The "prosocial" behaviour score was considered "normal" between 10 and 6 and "not normal" if 5 or less.

There were also questions relating to the impact the child's behaviour had on the family or classroom. Parents were asked if their child experienced difficulties that interfered with their life at home, with friendships, classroom learning, and leisure activities. They were also asked if these difficulties imposed a burden on family life. Questions on home life and leisure activities were omitted from the teacher's forms. Parents and teachers were asked to rate the extent of the difficulties on everyday life as "not at all", "only a little", "quite a lot", or "a great deal". "Not at all" and "only a little" were then scored as 0, "quite a lot" scored 1, and "a great deal" scored 2. The "total impact" was calculated as the sum of the five scores; the maximum burden being ten for parents and six for teachers.

The teachers were not told by us whether or not the child had had meningitis, although some had been told by the parents. At the time of the five year follow up, a cohort of matched (for age and sex) controls had been collected. The control children had been recruited by what was then known as the Family Health Services Agency. Each control child was selected from the same GP list as an index child. These control children were again traced and identical questionnaires sent to their parents and teachers.

Permission for this project was given by the research ethics committee of the Royal Postgraduate Medical School, and if required, permission was also obtained from other local research ethics committees.

Data analysis

Data handling and statistical analyses were carried out using EpiInfo (version 6) from the Division of Surveillance and Epidemiology, Epidemiology Program Office, Centre for Disease Control and Prevention, Atlanta, GA 30333, USA.

RESULTS

Of the 1175 post-meningitic children reviewed at 5 years of age, there were 178 who were lost to further follow up. Of

Table 1 Type of education received by index cases and controls at 13 years of age

Type of school	Complicated meningitis n (%)	Uncomplicated meningitis n (%)	Control n (%)
Mainstream	252 (85)	299 (90)	367 (98)
Help at school	14 (5)*	14 (4)	8 (2)
Special school	24 (8)†	15 (5)‡	1 (<1)
Excluded	5 (2)	3 (<1)	0
Subtotal	295	331	376
No information	53	60	104
Total	348	391	480

*RR=2.41, 95% CI=1.02 to 5.69, $\chi^2=4.3$, $p<0.05$.

†RR=33.1, 95% CI=4.5 to 243.5, $\chi^2=30.8$, $p<0.001$.

‡RR=18.4, 95% CI=2.4 to 138.8, $\chi^2=15.7$, $p<0.001$.

(All values are compared with controls)

these there were 81 on whom we had a GP response at age 5, but no permission to contact the family. There were 25 who did not reply when contacted for our nine year follow up. A further 69 could not be traced despite contact with the relevant health authority, and three had died. Completed questionnaires were received from 739 (74%) of the remaining 997 index cases and from 480/785 (61%) of the control parents; 84% of parents of index cases and 78% of control parents gave us permission to contact the child's school; 77% of teachers of index cases and 94% of control teachers replied. The mean ages of the children who had had meningitis (index cases) and the control children were both 13.3 (SD 0.4) years.

The study carried out when the index cases were 5 years old, allocated children to one of four categories of disability (severe, moderate, mild, or none). A classification of severe disability included children having multiple problems such as severe neuromotor impairment, significant intellectual impairment, severe seizure disorders, and severe visual or auditory impairment. Children were classed as having a moderate disability if their disability impaired their functioning but was not associated with severe intellectual or developmental impairment. This group included children with mild neuromotor disabilities, intellectual impairment, moderate sensorineural hearing loss, mild or moderate visual impairment, epilepsy that was controlled with treatment, and hydrocephalus without complications. Children classed as having mild disorders included those with middle ear disease, squint, febrile convulsions, and behavioural problems. Children were classed as having no disability if there was no evidence of developmental problems.

There were 436 index cases on which information had been collected at age 5, but for whom there was no behaviour assessment. The disability classification for these children at age 5 showed 242 (56%) to be normal, 121 (28%) to have mild disability, 36 (8%) to have moderate disability, and 37 (9%) to have severe disability. This compares with figures of 55%, 29%, 12%, and 4% respectively among the 739 subjects of this study. There is a significant difference in the proportion of severely disabled children whose parents did not respond or could not be traced and those who did respond (relative risk (RR) 1.51, confidence interval (CI) 1.20 to 1.90, $p < 0.05$).

Information collected in the incidence study¹ was used to divide the index children into two groups—"complicated" and "uncomplicated" meningitis. The criteria used for inclusion in the "complicated" group were one or more of the following: meningitis diagnosed at less than 28 days, together with a birth weight of less than 2000 g; coma; convulsions; hydrocephalus; a temperature of $>40^\circ\text{C}$; ventriculitis; relapse. There were 348 children with "complicated" and 391 with "uncomplicated" meningitis.

Table 1 shows the type of education the children were receiving at 13 years of age. Thirty nine index children (8% of

Table 2 Results of the Strengths and Difficulties Questionnaire—total deviance

	Complicated meningitis n (%)	Uncomplicated meningitis n (%)	Control n (%)
<i>Parent's response</i>			
Total deviance			
Not normal	158 (46)*	147 (38)†	101 (21)
Normal	187 (54)	244 (62)	379 (79)
Subtotal	345	391	480
No information	3	0	0
Total	348	391	480
<i>Teacher's response</i>			
Total deviance			
Not normal	98 (37)‡	101 (33)§	80 (23)
Normal	167 (63)	205 (67)	271 (77)
Subtotal	265	306	351
No information	83	85	129
Total	348	391	480

*RR=2.18, 95% CI=1.77 to 2.68, $\chi^2=57.0$, $p<0.001$.

†RR=1.79, 95% CI=1.44 to 2.22, $\chi^2=29.0$, $p<0.001$.

‡RR=1.62, 95% CI=1.27 to 2.08, $\chi^2=14.8$, $p<0.001$.

§RR=1.45, 95% CI=1.13 to 1.86, $\chi^2=8.5$, $p<0.05$.

the "complicated" cases and 5% of "uncomplicated" meningitis cases) compared to one control child attended a special school. There was a statistically significant difference between the "uncomplicated" meningitis group receiving extra help at school (14/348, 5%) and the control group (8/480, 2%) (RR 2.41, CI 1.02 to 5.69, $p < 0.05$). The difference between index and control children attending a special school was highly significant for both the "complicated" (RR 33.1, CI 4.5 to 243.5, $p < 0.001$) and the "uncomplicated" group (RR 18.4, CI 2.4 to 138.8, $p < 0.001$). Eight children had a school exclusion order; all were boys and all were from the index group. Permission to contact the child's school was refused by 113 parents of the index cases and 104 parents of control children.

Tables 2 and 3 summarise the overall results of the SDQ. It can be seen that the greatest difference was in the "total deviance", when rated by parents, between the "complicated" meningitis group and controls (table 2; RR 2.18, CI 1.77 to 2.68, $p < 0.001$), although the difference between the "uncomplicated" cases and controls was also significant (RR 1.79, CI 1.44 to 2.22, $p < 0.001$). The teacher rated total deviance score was "not normal" in 37% of the "complicated" cases (RR 1.62, CI 1.27 to 2.08, $p < 0.001$), and 33% of the

Table 3 Results of the Strengths and Difficulties Questionnaire—impact score

	Complicated meningitis n (%)	Uncomplicated meningitis n (%)	Control n (%)
<i>Parent's response</i>			
Impact score			
Not normal	118 (35)*	96 (25)†	47 (10)
Normal	215 (65)	287 (75)	414 (90)
Subtotal	333	383	461
No information	15	8	19
Total	348	391	480
<i>Teacher's response</i>			
Impact score			
Not normal	98 (38)‡	103 (35)§	82 (24)
Normal	158 (62)	195 (65)	259 (76)
Subtotal	256	298	341
No information	92	93	139
Total	348	391	480

*RR=3.48, 95% CI=2.56 to 4.73, $\chi^2=74.7$, $p<0.001$.

†RR=2.46, 95% CI=1.78 to 3.39, $\chi^2=32.8$, $p<0.001$.

‡RR=1.59, 95% CI=1.25 to 2.03, $\chi^2=14.0$, $p<0.001$.

§RR=1.44, 95% CI=1.13 to 1.84, $\chi^2=8.5$, $p<0.05$.

Table 4 Combined parent and teacher total deviance ratings

	Index n (%)	GP control n (%)	RR	95% CI	χ^2	p
Parent and teacher rate as normal	267 (36)	239 (50)	0.73	0.64 to 0.83	22.4	<0.001
Parent and teacher rate as not normal	134 (18)	40 (8)	2.18	1.56 to 3.04	22.8	<0.001
Parent rates as normal, teacher as not normal	61 (8)	40 (8)	0.99	0.68 to 1.45	0.00	0.96
Parent rates as not normal, teacher rates as normal	103 (14)	32 (7)	2.09	1.43 to 3.06	15.6	<0.001
No information	174 (24)	129 (27)				
Total	739	480				

Table 5 Numbers of children having normal prosocial scores

	Index n (%)	Control n (%)	RR	CI	χ^2	p
Parents	625/736 (85)*	437/480 (91)†	0.82	0.73 to 0.91	9.8	<0.05
Teachers	360/567 (63)	249/351 (71)	0.88	0.80 to 0.98	5.4	<0.05

Comparison between parents and teachers:
 *RR=1.82, CI 1.55 to 2.13, $\chi^2=79.6$, $p<0.001$.
 †RR=2.15, CI 1.66 to 2.78, $\chi^2=56.8$, $p<0.001$.

“uncomplicated” meningitis cases (RR 1.45, CI 1.13 to 1.86, $p < 0.05$), compared with 23% of controls. Results of the “impact scores” (table 3) showed that parents whose children had “complicated” meningitis were three times more likely to report a negative impact on home and social life than parents of control children (RR 3.48, CI 2.56 to 4.73, $p < 0.001$). The teacher rated impact scores showed a less marked, but significant difference between the “complicated” meningitis group and control children (RR 1.59, CI 1.25 to 2.03, $p < 0.001$), and between the “uncomplicated” meningitis group and controls (RR 1.44, CI 1.13 to 1.84, $p < 0.05$).

The behaviour of those children attending a special school was worse than that of those in mainstream education (with or without extra help). Parents of 60% of index children in mainstream schools rated their child as having normal behaviour compared with 31% of those at special school (RR 1.07, CI 1.02 to 1.12, $p = 0.001$). Similarly, when assessed by teachers, 68% of index cases in a mainstream school were scored as normal compared with 34% at special schools (RR 1.11, CI 1.04 to 1.17, $p < 0.001$).

There was no significant difference in the behaviour between the 103 children who had had meningitis during the first month of life and the 634 who had had postneonatal meningitis. There was no difference in behaviour between boys and girls, except that all eight children excluded from school were boys.

Comparing the total deviance scores where both teachers and parents had replied (table 4), 36% of teachers and parents rated the index child as normal compared with 50% of those of a control child ($p < 0.001$). Index children (18%) were more than twice as likely to be rated as not having normal behaviour by both parents and teachers compared with controls (8%) ($p < 0.001$). Twice as many index children (14%) were rated as normal by teachers but not normal by their parents compared with the control group (7%) ($p < 0.001$).

The “prosocial” scores (table 5), given by the parents, showed that 85% of index children and 91% of controls were rated by their parents as having normal positive social attributes, (RR 0.82, CI 0.73 to 0.91; χ^2 9.8 and $p < 0.05$). These values fell to 63% and 71% respectively when scored by teachers (RR 0.88, CI 0.80 to 0.98; χ^2 5.4 and $p < 0.05$). There was a significant difference between the parent (85%) and teacher (63%) rating of the index cases (RR 1.82, CI 1.55 to 2.13, χ^2 79.6, $p < 0.001$) and a similar difference between control parent (91%) and teacher (71%) ratings (RR 2.15, CI 1.66 to 2.78, χ^2 56.8 and $p < 0.001$).

Table 6 has been compiled from the classifications of disability at age 5 and information from the present study on the type of school attended. Of the 517 index children who had no or mild problems aged 5, 94% are in a mainstream school without extra help, 20 are receiving extra help at school, and three are in a special school. Of the 77 who were

Table 6 Relation between outcome at age 5 years and type of schooling at age 13 years

Outcome at 5 years	Type of schooling at age 13 years				
	Mainstream school n	Help at school n	Special school n	Excluded n	No information n
Index children					
No problems	314	11	1	6	72
Mild	172	9	2	2	31
Moderate	61	5	11	0	9
Severe	3	3	25	0	0
Total	550	28	39	8	112
Control children					
No problems	283	3	1		82
Mild	83	4	0		22
Moderate	1	1	0		0
Total	367	8	1		104

classified as having moderate problems aged 5, 61 are in a mainstream school without extra help, five are receiving extra help at school, and 11 attend a special school. Of the 31 severely affected children, 25 (81%) are at a special school and six attend a mainstream school (three with and three without extra help). Of the 64 children who were classified as moderately or severely affected at age 5 but who attend a mainstream school, 52% were rated as having behavioural problems by their parents and 35% by their teachers. The eight excluded children had been assessed as having no or mild problems. Of the 39 in a special school, 36 were assessed as having severe or moderate problems at age 5.

DISCUSSION

The Strengths and Difficulties Questionnaire (SDQ)^{4,7} provides a quick and effective means of measuring behaviour in teenage children. In the present study, where direct assessment of the 997 children would not have been possible, the SDQ enabled parents and teachers easily to report their observations. It is clear, given the high response rate, that neither parents nor teachers had difficulty in completing the questionnaire. It is noteworthy that only 84% of index case parents and 78% of control parents gave permission for us to send the questionnaire to the child's teacher.

The educational requirements of children who have suffered from meningitis in infancy are clearly different from those who have not (table 1). The division of index cases into "complicated" and "uncomplicated" meningitis shows that there is an additional burden carried by children who had pyrexia (>40°C), convulsions, relapse, etc during their meningitic episode.

SDQ responses by parents and teachers of control children gave very similar results for total deviance: 79% and 77% respectively classified the control children as "normal". The total deviance scores for index cases were significantly higher than for the controls when assessed by either parent or teacher. Parents of the index cases, whether "complicated" or "uncomplicated", perceived problems more often than the teachers. When assessed by teachers, 65% of index children were scored as normal compared to 77% of control children.

Impact score results for the control group—that is, how the children function in their surroundings, gave a different picture. While 10% of responses from parents gave their child a "not normal" score, the corresponding teachers classified 24% as "not normal". A similar situation existed in the assessment of index cases, but the differences between parents and teachers were not so marked. Both parents and teachers recognised significantly more problems in index children.

Among control children 91% had normal social skills at 13 years of age (prosocial scores) as judged by their parents (table 5). In contrast the teachers of these children only considered 71% to have normal skills. A similar difference existed among the index cases where 85% of parents and 63% of teachers considered them to have normal social skills. The difference between index cases and controls was less marked for social skills than for total deviance and impact scores.

Teenage behaviour is a complex issue, but of great importance to the families it affects. This is borne out by the fact that 74% of families replied to our questionnaire 13 years after their child's initial illness. No account has been taken of any changes to the child's home circumstances that may have occurred in the families since the child's birth, or of the possible effects such changes might have had on their behaviour. We have assumed that as the numbers of children studied are large, these life changes would have been equally frequent in each group. There were 64 index children who had been identified as having moderate or severe problems at 5 years and who were attending a mainstream school at age 13 years. Parents rated 52% of these children as having behavioural problems, and teachers 35%. This would indicate that perhaps some of these children needed extra help at school.

There were 258 index families who were traced, but declined to participate in this study. Twenty nine children (11%) had been assessed as having moderate or severe problems at the five year follow up. These problems may have burdened the families sufficiently to have discouraged them from participating in the study. There are very few published reports on the long term effects of infantile meningitis on child behaviour, and these involve only a small number of cases. Grimwood and colleagues^{8,9} reported on a longitudinal study of 158 cases of paediatric meningitis. At a mean of 8.4 years after the acute episode, 130 survivors, together with grade and sex matched controls, were assessed for a wide range of sequelae. The authors concluded that a quarter of index cases, compared to 7% of controls, had either serious or disabling sequelae or a functionally important behaviour disorder that affected academic progress. In a second follow up study at a mean of 12 years after the meningitic episode the index cases were still at a greater risk of disability than the controls. Children who had had acute neurological complications had more sequelae than uncomplicated cases or controls ($p < 0.001$). Behaviour scores of the index cases deteriorated between the first and second follow up study. Thus the results reported by Grimwood *et al* are in close agreement with those of the present study. Klinger and colleagues¹⁰ suggested that most infants at risk of an adverse outcome following bacterial meningitis could be identified within 12 hours of admission. The predictive factors which they suggested are largely those that are associated with "complicated" meningitis. The implication that cases of "uncomplicated" meningitis do not also suffer from serious sequelae, albeit at a lower frequency, is at variance with our findings.

This study shows that 13 year old children who suffered from bacterial meningitis during the first year of life have significantly more behavioural problems than matched controls when assessed by both parents and teachers. When it comes to social skills the differences between the two groups are less marked.

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