ORIGINAL ARTICLE

Parents' Views of Lumbar Puncture in Children with Febrile Seizures

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Summary

A study was carried out to ascertain the views of parents regarding the performance of lumbar punctures on their children admitted for febrile seizures. One hundred and seventeen (117) children with febrile seizures were recruited over nine months. Either one of the parents was interviewed a day after admission. In most cases, this was usually the mother. The ethnic groups of the patients were Malays (62.4%), Indians (26.5%), Chinese (8.5%) and others (2.6%). Lumbar punctures were requested by the doctor in attendance in only 28 (23.9%) patients This showed that the rate of request for lumbar punctures in febrile seizures was low. Parents of eight of them refused. The main reasons for the refusal were: fears that the child might be paralysed, advice from relatives and fear that the child might die from the procedure, or might find it too painful. All the parents who refused were Malays. A lumbar puncture was also more likely to be refused in a girl. Those who consented to lumbar puncture did so because they wanted the doctor to get to the diagnosis. Another reason given was that it might be therapeutic.

Parents whose children did not require a lumbar puncture also thought that lumbar puncture may cause paralysis.

The main sources of information on lumbar punctures for the parents were their relatives and/or friends. In only 85% of the cases were the reasons for the lumbar puncture explained to the parent. In 71.4% of the time the explanation was done by the medical officer, and in only 4.8% of the time was the consultant involved. Of the lumbar punctures requested, 75% were in those 18 months and younger. Knowledge of this information would aid doctors in counselling and advising their patients' parents. Parents have a lot of misconceptions about this procedure which need to be cleared up.

Key Words: Febrile seizures, Lumbar punctures, Parents' views

Introduction

The prevalence of febrile seizures in various countries is between 2% to 4%[1]. It is a common childhood condition with controversies regarding its definition and prognosis[2-7].

One major area of controversy in febrile seizures is the role of lumbar puncture. More than half of paediatricians in a survey do not do routine lumbar punctures[8]. The yield from routine lumbar punctures is not very good and meningitis may still be missed even if lumbar punctures were done routinely[8-10]. There have been suggestions that a lumbar puncture itself may be the cause of meningitis if done in a child with bacteremia[11-13]. There has been much debate regarding the risk of coning if lumbar puncture was done in the presence of raised intracranial pressure[14-28].

Paediatricians in Malaysia have long had a common experience of having patients' parents refuse a lumbar puncture. From our experience in the wards we found that many parents have reservations and fears particularly of death and paralysis arising from lumbar punctures. We wanted to study what the parents' perception of lumbar punctures were and what their fears were. Furthermore we wanted to see if there were any factors that might predispose parents to refuse a lumbar puncture for their child. This information would be useful to paediatricians as they counsel parents[30-31].

Methodology

This was a prospective uncontrolled study in which the parents of consecutive children, admitted for febrile seizure in the paediatric wards of Universiti Kebangsaan Malaysia were interviewed using a questionnaire.

For the purpose of this study, a febrile seizure was defined as a seizure which occurred with a fever in a child aged more than one month and up to 12 years old. The seizure might be generalised or focal. It could be of any duration. The seizure might be single or recurrent. There should not be evidence of any intracranial infection. Fever was deemed to be present based on parents' history or documented temperature. Children with previous history of afebrile seizures or who had neurological or developmental impairment were excluded.

We decided to include children outside the usual age range of six months to six years because children outside this range have been known to have febrile seizures. Ouelette in her review[32] stated that one to two per cent of febrile seizures occurred in children below six months of age and one to six per cent were in those above five years old. We excluded children with neonatal seizures from our study. Our upper age limit was 12 years as that was the upper age limit for all admissions to the paediatric wards.

Data collection was by interview and extracting clinical information from ward notes. A prepared questionnaire was used to interview the parents. The interviews were all performed by the first author. If the mother was present she was the preferred parent to be interviewed as the mother is usually the one who knows the child better and is almost always the parent who stays with the child in the ward. The father was interviewed for a very small number of patients when the mother was unavailable. The interview was usually conducted on the first or at the latest, the second day after admission.

Statistical analysis was performed on an IBM compatible personal computer. Univariate statistical analysis of Chi-squared test and Fisher's exact test were done using the SASv6 statistical package.

Results

There were 117 children recruited into the study over a period of nine months. There were 70 boys and 47 girls giving a male to female ratio of 1.5:1. The majority of patients were Malays (62.4%) followed by Indians (26.5%), Chinese (8.5%) and others (2.6%). Muslims formed the largest religious group (66.4%) followed by Hindus (26.7%), Buddhists (8.6%), Christians (2.6%) and others (1.7%).

The age range at presentation was from one month to 119 months with a mean age of 20.9 months (SD = 19.5 months). Most of the patients were aged six months to 24 months (66.7%), with the largest number 33 (28.2%) in the age group six months to 12 months.

Lumbar punctures were requested in 28 (23.9%) out of 117 patients in our study. All of the lumbar

Table I
Reasons for refusal of lumbar puncture (n=8)

Reasons	Number	(%)
Fear of paralysis	6	(75.5%)
Fear of death	3	(37.5%)
Too painful	2	(25.0%)
May cause child's illness to worsen	1	(12.5%)
Religious	1	(12.5%)

punctures were requested for suspected meningitis. The majority (75%) of the lumbar punctures were requested in those below 18 months of age.

Of the 28 requested, 20 gave their consent resulting in a consent rate of 71.4%. The reasons for refusal were frequently more than one. The most frequent answers encountered were the fear of the child being paralysed after the lumbar puncture, the fear of death resulting from the procedure, anxiety about pain to the child and advice from relatives or friends. The other fear was that the child's condition might worsen after the procedure. One parent gave a religious reason. (Table I)

We looked at the possible variables that might influence the consent for lumbar puncture. The girls in our study were less likely to have a lumbar puncture done compared to the boys (p=0.044). The Malays and the Muslims were also less likely to agree to a lumbar puncture (p=0.025 and p=0.011 respectively) (Table II)

The parents who consented to the procedure were asked to give their reasons for consenting. (Table III) The most common reason given was that it would help to make the diagnosis; 12 out of 20 (60%). Eight (40%) believed that the lumbar puncture was therapeutic and would help the child to get better. Twenty per cent (20%) of the parents gave the reason of following the doctor's advice or trust in the doctor.

The reason for doing the lumbar puncture was explained to the parents in only 24 out of the 28 requested (85%). In order of decreasing frequency, the explanation was done by the medical officer (71.4%), house officer (4.8%), lecturer (9.5%) and consultant (4.8%).

The parents whose children did not require a lumbar

Table II
Factors associated with parental consent for lumbar punctures in their children

Factor	Prevalence of factor (%) Refuse (n=8)	Consent (n=20)	p value
Low maternal education@	0	40	0.060
Low paternal education@	0	25	0.119
Family income ≤ RM500.00 per month	63	40	0.400
Belief in traditional medicine	75	65	0.375
Muslim	100	50	0.010
Malay race	100	50	0.010
Girl	75	31	0.044
Past history of febrile seizures	12	10	1.000
History of lumbar in siblings	0	10	1.000
History of seizures in siblings	25	10	0.555

@ nil or primary education

Table III
Reasons for consenting to a lumbar puncture (n=20)

Reasons	Number	(%)
For diagnosis	12	(60.0%)
Child may improve	8	(40.0%)
Follow doctor's advice	4	(20.0%)

puncture were also interviewed regarding their opinions on it. Since it was an open-ended question the responses were very varied. The most common fear expressed was the fear of paralysis in the child. The fears of mental retardation or death in the child were also the major concerns of the parents. Other worries were that it was too painful, the child was too small for the procedure, it was a dangerous procedure and the kidneys might be weakened. Favourable comments were few and the most common answer was that it would help in getting to the diagnosis in 14 parents. (Table IV)

The parents' important sources of information about lumbar puncture were their friends (52.1%) and relatives (41.9%). Not much information was obtained from the television, newspaper, magazines or even medical staff. (Table V)

Discussion

Our study has shown that the rate of request for lumbar puncture in febrile seizures is low at 23.9%. This reflects our practice of assessing the need for lumbar puncture individually for each child with febrile seizure. We do not do routine lumbar punctures.

This is the first time any study has been done locally regarding parental consent for lumbar puncture and their views about this procedure. Despite the negative views of parents regarding lumbar punctures the consent rate is still high at 71.4%. Experienced

Table IV
Parents opinion of lumbar punctures (n=89)

Opinion	Number	(%)
Cause paralysis	53	(59.5%)
Don't know	25	(21.4%)
Cause mental retardation	22	(24.7%)
Will help in diagnosis	14	(15.7%)
Too painful	12	(13.5%)
Cause death	10	(11.2%)
Other responses of parents to lumbar punctures:		
– Cause illness later on	6	(6.7%)
– Will weaken kidneys	3	(3.4%)
– Procedure is acceptable if done properly	2	(2.2%)
– Dangerous	2	(2.2%)
– Child is too small	1	(1.1%)
– Child will suffer	1	(1.1%)

practising paediatricians have for some time noted that the Malays tend to refuse lumbar puncture. This study has shown, though in a very small number of patients (n=28) that refusal of lumbar puncture was significantly associated with the Malays. We postulate that this arises mainly from the belief among the community that lumbar punctures in some way will cause weakness or paralysis. However further studies among the Malay community are needed to discover whether these views are peculiar to the community.

Most parents obtained their information on lumbar puncture from friends and relatives. Hence these unfavourable views on lumbar puncture were passed from person to person by word of mouth. This form of information dissemination is extremely effective in entrenching certain beliefs within a community. The mass media seemingly has not had an effect on parental views. This could either be because there has not been much information regarding lumbar puncture in the mass media or that parents have chosen to ignore what is said.

Table V
Parents sources of information on lumbar puncture

Source	Number (%)
Friends	69 (59.0%)
Relatives	55 (47.0%)
Medical personnel	30 (25.6%)
Magazines	30 (25.6%)
Newspaper	29 (24.8%)
Television	28 (23.9%)
Radio	20 (17.1%)
Books	16 (13.7%)
Traditional medicine	11 (9.4%)

Paediatricians are now very cautious about doing a lumbar puncture in every child with febrile seizure. Reports of coning and death from lumbar punctures in meningitic patients cannot be ignored even though this complication is rare[24]. The other complications like headache, paresthesia of the legs and pain are minor and resolve spontaneously[31].

The decision whether or not to do a lumbar puncture still lies with the individual clinician. However if the belief that lumbar punctures is harmful becomes widespread in the community, then the decision whether or not to do a lumbar puncture will depend not on clinical grounds but parents' erroneous beliefs. This may make the diagnosis of meningitis extremely difficult to confirm and treatment and prognostication would also be affected.

Lumbar puncture should be a safe and useful procedure when done with definite indications and after examination by an experienced doctor. It should follow clear guidelines when it is contraindicated[33]. We need to inform parents and convince them regarding the safety of this procedure.

There are not many studies regarding febrile seizures in children in developing countries[23]. As far as we know there has been no study in a developing country regarding parental views and reactions to lumbar punctures in their children.

We conclude that lumbar punctures are associated with negative connotations, such as death and paralysis, in the minds of many Malaysian parents. Since we know their fears and worries, clinicians may be better able to counsel and advise parents.

Acknowledgement

We wish to acknowledge with thanks the lecturers and consultants of the Department of Paediatrics, Faculty of Medicine, Universiti Kebangsaan Malaysia for allowing us to interview the parents of their patients.

References

1. Wallace SJ. Prevalence. In: Wallace SJ. The child with febrile seizures. London: Butterworths & Co. 1988 : 10-4.

2. Hauser WA. The natural history of febrile seizures. In: Nelson KB, Ellenberg JH (eds.) Febrile Seizures: Consensus Statement on Febrile Seizures. New York: Raven Press 1981 : 7-16.

3. Verity CM, Butler NR, Golding J. Febrile convulsions in a national cohort followed up from birth. II-Medical history and intellectual ability at 5 years of age. Br Med J 1985; 290 : 1311-5

4. Verity CM, Butler NR, Golding J. Febrile convulsions in a national cohort followed up from birth. I-prevalence and recurrence in the first five years of life. Br Med J 1985; 290 : 1307-10.

5. Hirtz DG. Generalized tonic-clonic and febrile seizures. Pediatr Clin North Am 1989;36 : 365-82.

6. Livingston S, Berman W, Pauli LL. Febrile convulsions. Lancet 1973;2 : 1441-2.

7. Livingston S, Pauli LL. Febrile fits. Br Med J 1976;1 : 1530.

8. Asnes RS, Novick LF, Nealis J, Nguyen M. The first febrile seizure: A study of current pediatric practice. J Pediatr 1975; 87 : 485-8.

9. Surpure JS. Febrile convulsions: What happens to the infant admitted to the hospital. Clin Pediatr 1980;19 : 361-2.

10. Rutter N, Smales ORC. Role of routine investigations in children presenting with their first febrile seizure. Arch Dis Child 1977;52 : 188-91.

11. Chamberlain M, Gorman RL. Occult bacteremia in children with simple febrile seizures. Am J Dis Child 1988;142 : 1073-6.

12. Teele DW, Dashefsky B, Rakusan T, Klein JO. Meningitis after lumbar puncture in children with bacteremia. N Engl J Med 1981;305 : 1079-81.

13. Shapiro ED, Aaron NH, Wald ER, Chiponos D. Risk factors for development of bacterial meningitis among children with occult bacteremia. J Pediatr 1986;109 : 15-8.

14. Richards P, Towu-Aghantse E. Dangers of lumbar puncture. Br Med J 1986;292 : 605-6.

15. Harper JR, Lorber J, Smith H, Bower BD, Eykin SJ. Timing of lumbar puncture in severe childhood meningitis (clinical topics). Br Med J 1985;291 : 651-2.

16. Stephenson JBP. Timing of lumbar puncture in severe childhood meningitis (letter). Br Med J 1985;291 : 1123.

17. Bourne WRP. Timing of lumbar puncture in severe childhood meningitis (letter). Br Med J 1985;291 : 1123.

18. Clarke MA. Timing of lumbar puncture in severe childhood meningitis (letter). Br Med J 1985;291 : 899.

19. Clark SA, Campbell AN. Timing of lumbar puncture in severe childhood meningitis (letter). Br Med J 1985;291 : 898.

20. Thomson APJ. Timing of lumbar puncture in severe childhood meningitis (letter). Br Med J 1985;291 : 898.

21. Jaffe IP. Timing of lumbar puncture in severe childhood meningitis (letter). Br Med J 1985;291 : 898.

22. MacVicar D, Symon DNK. Timing of lumbar puncture in severe childhood meningitis (letter). Br Med J 1985;291 : 898.

23. Noah PK, Archer EY. Routine investigations in first febrile seizures. West Indian Med J 1987;36 : 236-40.

24. Lorber J, Sunderland R. Lumbar puncture in children with convulsions associated with fever. Lancet 1980;1 : 785-6

25. Joffe A, McCormick M, DeAngelis C. Which children with febrile seizures need lumbar puncture: A decision analysis approach. Am J Dis Child 1983;137 : 1153-6.

26. Joint Working Group of the Research Unit of the Royal College of Physicians and the British Paediatric Association. Guidelines for the management of convulsions with fever. Br Med J 1991;303 : 634-6.

27. Donald PR, Kibel MA. When not to do a lumbar puncture (letter). Arch Dis Child 1988;63 : 569-75.

28. Neville BGR, When not to do a lumbar puncture (letter). Arch Dis Child 1988;63 : 569.

29. Wallace SJ, Convulsions and lumbar punctures (letter). Dev Med Child Neurol 1985;27 : 69-79.

30. Wallace SJ. Supportive family management. In: Nelson KB, Ellenberg JH. Febrile seizures: Consensus statement on febrile seizures. New York. Raven Press 1981 : 226-8.

31. Botkin JR. Informed consent for lumbar puncture. Am J Dis Child 1989;143 : 899-904.

32. Ouelette EM. The child who convulses with fever. Pediatr Clin North Am 1974;21 : 467-87.

33. Addy DP. When not to do a lumbar puncture (Annotation). Arch Dis Child 1987;62 : 873-5.