

ORIGINAL ARTICLE

CONSENT FOR LUMBAR PUNCTURE – FACTORS THAT INFLUENCE THE DECISION

AS Malik, MBBS (Punjab), DCH (Punjab), MCPS (Karachi), DTCH (Liverpool)

Paediatric Core Group, Faculty of Medicine and Health Sciences,
Universiti Malaysia Sarawak, Kota Samarahan, Sarawak

Abstract

Lumbar puncture (LP) is an important procedure both for diagnostic and therapeutic purposes. In Kelantan, Malaysia, on many occasions consent for this procedure is not granted by patients or guardians. The aim of this study was to find out the factors that influence the decision to grant or refuse the consent for LP.

This was a cross-sectional study in which 86 parents (who agreed or refused to give consent for LP on their child) were interviewed by using a standard questionnaire. A scoring system was used to assess their knowledge about the purpose and technique of the procedure.

Consent for LP was granted in 23 and refused in 27 children. The refusal rate was significantly higher when family members other than parents made the decision. The factors which did not play a statistically significant role in decision-making included: age of the child and parents; gender of the patient; number of children in the family; patient's birth order among the siblings; place of residence; monthly income of the family; parents' level of education; and number of days after admission when LP was requested. The factors that positively influenced the decision to give consent included knowledge about the purpose of LP and underlying disease.

In order to receive positive consent for LP it is concluded that the parents/guardians and other family members who may influence the decision-making should be explained the role of LP in (1) making diagnosis and (2) choosing right antibiotics for treatment. They should also be informed about the side-effects of antibiotics, which may be used

unnecessarily in unconfirmed cases of central nervous system infections.

Key words: *Complications; consent; lumbar puncture; Kelantan; Malaysia; parents; traditional healers*

Introduction

Lumbar puncture (LP) is a useful procedure both for diagnostic (e.g. meningitis) and therapeutic purposes (e.g. intrathecal medication, spinal anaesthesia). In children it is principally used for the diagnosis of meningitis, as there is no other appropriate alternative to the examination of cerebrospinal fluid (CSF) for establishing the diagnosis of this illness. The advantages of making a rapid diagnosis are obvious: pathogens can be identified and sensitivities established; treatment can be initiated; complications and sequelae of the illness can be anticipated and appropriate public health measures, when indicated, can be instituted. Delay in the diagnosis of meningitis is a recognised risk factor for disease sequelae.¹ However this procedure is not without risks. The adverse reactions of LP include: pain from the procedure itself; headache; bleeding into the tissues surrounding the spinal column or into the CSF; and herniation of the temporal lobe through the tentorium or the cerebellar tonsils through the foramen magnum.¹ Other reported risks include local infection, transient or persistent paraesthesiae, cranial nerve palsies and seeding of the organisms into the CSF in bacteraemic patients.²

Correspondence: Assoc. Prof. Alam Sher Malik, Faculty of Medicine and Health Sciences, Universiti Malaysia Sarawak, Kuching, Sarawak.

Every medical intervention is subjected to the rule of informed consent.³ The declaration of Lisbon states that the patient has the right to accept or to refuse treatment after receiving adequate information.⁴ In medical practice, to be valid, consent must be given by a person who has received all relevant information, who is competent, who has not been coerced into agreement or refusal, and who is not emotionally overwhelmed.⁵

Minor invasive investigations such as withdrawal of blood from the vein can, as a matter of practice, be undertaken on the basis of oral consent; they are no more than part of normal practice of patient care.

The process of informed consent in the paediatric population has important differences from the process with competent adults. Young children are not competent to consent to treatment or procedures. It is the responsibility of parents or guardians to provide informed consent for children. Refusal of consent for procedures and treatment in medical practice is not uncommon^{6,7} and paediatricians in Malaysia often find it difficult to obtain consent from parents to perform LP on their children (8 of 28 parents refused to give consent in a study from Kuala Lumpur).⁸ In this study we examined the factors that influence parent's decisions regarding giving consent for LP.

Materials and methods

Fifty children, admitted consecutively to the paediatric medical wards of Hospital Universiti Sains Malaysia, for whom the attending paediatrician requested LP to be performed, were selected for this study. The attending doctor briefed parents about the purpose and technique of the procedure. Both parents of the selected children were interviewed by the author (with the help of an interpreter if necessary). These parents were interviewed separately, using a questionnaire, within two days after their decision to give or refuse consent for this procedure to be carried out on their child. The

following data were collected:

Patient: age, sex, birth order of the patient among the siblings, number of days after admission when LP was requested, provisional and final diagnosis.

Parents: age, residence (urban or rural), number of children, education, occupation, monthly income, understanding of technique of LP (site of LP, posture of the child during procedure, use of local anaesthesia, amount of CSF collected) and understanding of the purpose of LP (diagnosis, treatment, side-effects of drugs used for treatment of suspected illness, if LP is not done).

A scoring system (one score for every appropriate answer) was used to assess the parent's knowledge about the technique and purpose of LP.

Statistical analysis was performed using Chi square test. Statistical significance was defined as $p < 0.05$ (Mantel-Haenszel values). It was computed using program STATCALC in package Epi Info version 6.04.

Results

A total of 86 parents (38 fathers and 48 mothers) were interviewed. Of the 50 families, 30 resided in an urban area and 31 came from a middle socio-economic group. The number of children in these families ranged from 1 to 9. The average age of mothers was 30 years (range 19 to 60) and 43 of them were educated (at least primary education). The majority of the mothers (32) (66.6%) were housewives. The average age of fathers was 26 years (range 20 to 48) and all of them were educated. The majority of the parents had had secondary level education (33 mothers and 29 fathers). The average age of patients was 29.5 months (2 months to 12 years) and 29 of them were males. Meningoencephalitis was the most common provisional diagnosis (40) (78%) followed by leukaemia (6) and others (Table I). In 25 children LP was requested on the day of admission, in 11 on the second day and the rest 3 days or more after admission. Most of the

parents were well aware (score 100%) of the purpose of LP (28 mothers and 19 fathers), but only a few of them (6 mothers and 6 fathers) knew the technique of the procedure (Table I). The most common complication parents attributed to LP were paralysis (66.6%) and mental retardation (33.3%), followed by deafness, blindness, loss of speech, worsening of disease, shortness of life span, death, infection, injury to nerves, backache, and loss

of CSF which could not be replaced. Consent for LP was granted in 23 and refused in 27 patients. In 36 (72.0%) patients the decision was made by parents alone, whereas in the rest (28%) the decision was made by other family members. When parents were the sole decision makers they gave consent in 20 (55.6%) patients and refused it in 16 (44.4%), but when other family members made the decision they gave consent in 3 (21.4%) and refused in 11 (78.6%) patients

Table I. Relation of consent to parents' awareness about the lumbar puncture and provisional diagnosis

	Agreed (n=23)*	Refused (n=27)	Relative Risk (#)	Chi Square***	P Value***
Decision Makers					
Parents alone (36)*	20	16	2.59	4.63	<0.032**
Others (14)	3	11	(0.91-7.37)		
Purpose Score					
<i>Mother</i>					
3	18	10	2.83	8.39	<0.004**
< 2	5	17	(1.25-6.41)		
<i>Father</i>					
3	14	5	2.54	9.27	<0.003**
< 2	9	22	(1.38-4.68)		
Procedure Score					
<i>Mother</i>					
3	11	5	1.95	4.80	<0.03**
< 2	12	22	(1.11-3.42)		
<i>Father</i>					
3	6	5	1.25	0.41	<0.53
< 2	17	22	(0.66-2.39)		
Provisional Diagnosis					
Meningitis (32)	12	20	0.61	2.53	< 0.12
			(0.34-1.10)		
Encephalitis (8)	3	5	0.79	0.27	<0.61
			(0.30-2.03)		
Leukaemia (6)	6	0	2.59	7.84	<0.006**
			(1.78-3.76)		
Others (4)	2	2			

* = Number of patients; # = 95% confidence interval; ** = Statistically significant; *** = Mentel-Haenszel values

($p < 0.032$) (Table I).

The factors, which did not play a statistically significant role in decision-making included: age of the child and parents; gender of the patient; number of children in the family; patient's birth order among the siblings; place of residence; monthly income of the family; parent's level of education; and number of days after admission when LP was requested. The factors that positively influenced the decision to give

consent included: knowledge about the purpose of LP and underlying disease (Tables I, II, III). Parents who knew that LP helps in making the diagnosis and in choosing the right drugs for treatment were more willing to give consent as compared to less informed parents (Table II). Knowledge about the side-effects of antibiotics that might be used unnecessarily in unconfirmed cases also helped to give consent (Table II).

Table II. Consent for lumbar puncture (LP) – relation to parents' knowledge about the purpose of the procedure (1)

Question: Do you know that LP is helpful to make a diagnosis?

	Mother		Father	
	Correct answer	Incorrect answer	Correct answer	Incorrect answer
Agreed	20	2	16	1
Refused	15	11	9	12
Relative risk (#)	3.71 (1.01–13.72)		8.32 (1.24–55.96)	
Chi square***	6.52		10.68	
P-value***	< 0.011**		< 0.002**	

Question: Do you know that LP helps to choose the right drugs for the treatment?

	Mother		Father	
	Correct answer	Incorrect answer	Correct answer	Incorrect answer
Agreed	22	0	16	1
Refused	15	11	9	12
Relative risk (#)	–		8.32 (1.24–55.96)	
Chi square***	11.82		10.68	
P-value***	< 0.0006**		< 0.002**	

Question: If we are not sure about the diagnosis your child may be treated unnecessarily with antibiotics. Do you know that the antibiotics likely to be used for treatment may have adverse affects on your child?

	Mother		Father	
	Correct answer	Incorrect answer	Correct answer	Incorrect answer
Agreed	18	4	15	2
Refused	12	14	8	13
Relative risk (#)	2.70 (1.08–6.72)		4.89 (1.30–18.39)	
Chi square***	6.33		9.63	
P-value***	< 0.02**		< 0.002**	

** = Statistically significant; # = 95% confidence interval; Agreed = Consent given; Refused = Consent refused; *** Mantel-Haenszel values

Table III. Consent for lumbar puncture (LP) – relation to parents' knowledge about the technique of the procedure (2)

Question: Do you know the exact part of the body from which the fluid would be obtained during LP?

	Mother		Father	
	Correct answer	Incorrect answer	Correct answer	Incorrect answer
Agreed	17	5	10	7
Refused	11	15	8	13
Relative risk (#)	2.43 (1.07–5.49)		1.59 (0.77–3.28)	
Chi square***	5.87		1.58	
P-value***	< 0.02**		< 0.21	

Question: Do you know the exact posture of the child during the procedure of LP?

	Mother		Father	
	Correct answer	Incorrect answer	Correct answer	Incorrect answer
Agreed	7	15	7	10
Refused	3	23	4	17
Relative risk (#)	1.77 (1.01–3.12)		1.72 (0.88–3.34)	
Chi square***	2.91		2.18	
P-value***	< 0.09		< 0.15	

Question: Do you know that local anaesthetic is used to prevent pain due to the procedure?

	Mother		Father	
	Correct answer	Incorrect answer	Correct answer	Incorrect answer
Agreed	15	7	8	9
Refused	9	17	8	13
Relative risk (#)	2.14 (1.07–4.30)		1.22 (0.61–2.47)	
Chi square***	5.26		0.30	
P-value***	< 0.022**		< 0.59	

Question: Do you know how much spinal fluid is collected for testing?

	Mother		Father	
	Correct answer	Incorrect answer	Correct answer	Incorrect answer
Agreed	13	9	8	9
Refused	10	16	5	16
Relative risk (#)	1.57 (0.83–2.96)		1.71 (0.87–3.36)	
Chi square***	1.99		2.20	
P-value***	< 0.16		< 0.14	

** = Statistically significant; # = 95% confidence interval; Agreed = Consent given; Refused = Consent refused; *** Mantel-Haenszel values

Discussion

Refusal of consent for any procedure or treatment in medical practice is not uncommon in Malaysia.⁶⁻⁸ In this study consent for LP was refused in 54% of cases which is higher than a previous report in adult patients from Kota Bharu.⁷

The refusal rate was significantly higher ($P < 0.032$) when family members other than parents made the decision (Table I). These family members were not briefed about the procedure. Among the parents the acceptance rate was significantly higher in well-informed than those who were less well-informed (Tables II, III). This clearly shows the importance of a detailed discussion and explanation of the purpose and technique of the procedure to the parents and other family members who may be involved in decision making.

Kelantan is a relatively poor state of Malaysia and has a mainly rural population, only a quarter of which is educated beyond the primary level. However it is interesting to note that the financial and educational level of parents did not appear to influence the decision to perform LP in this study. Use of herbal medicine is popular in this state⁹ and the "Bomoh" (traditional healer) is usually the primary health care provider. In Kelantan "Bomohs" who are considered to be the "specialists" in treating a person with fits, usually advise against LP. The higher rate of acceptance of LP reported from Kuala Lumpur⁸ may be due to the minimal influence of traditional healers in that city. The acceptance rate was high in cases of malignancies. This might be due to the fact that in these cases LP was done not only for diagnostic purposes but also for intrathecal medication and the parents were required to give consent for the whole management plan as a package which include LP.

Most of the complications which parents attributed to LP are the known complications of

meningoencephalitis, the most common diagnosis for which LP is requested. Therefore it is important to clarify to the parents and the family members that the complications seen are not due to LP but because of the underlying disease.

It is interesting to note that overall (in both well-informed and less-informed groups) the rate of giving consent was higher in mothers (72.9%) than in fathers (65.8%) (Tables I, II, III). In Kelantan, during hospitalisation, mothers generally spend more time with children than fathers; whether it plays a role in decision-making needs to be further studied.

Limitations of this study include the small sample size and inherent problems of questionnaire based interviews and their translations, which may not fully convey the exact message to the interviewee.

Conclusion

To get consent for LP in the practice of paediatric medicine, the following steps may be of help:

- (i) Inviting the other family members who may play a crucial role in decision-making about the consent for LP, along with the parents, to the sessions for explanation of the purpose and technique of LP.
- (ii) Explanation should clarify the role of LP in: (1) making the diagnosis; (2) choice of appropriate medication and duration of treatment; (3) side-effects of drugs which may be used unnecessarily in cases of suspected but unconfirmed diagnosis (e.g. meningitis).
- (iii) Education of the traditional healers about the advantages of LP and its side-effects.

References

1. Klein JO, Feigin RD, McCracken GH. Report of the task force on diagnosis and management of meningitis. *Pediatrics*. 1986; 789 (supp): 977.
2. Marton KI, Gean AD. The spinal tap: a new look at the old test. *Ann Intern Med*. 1986; 104: 840-8.

3. Garneau Y, Diener JM. The law of informed consent and its impasses in psychiatry. *Can J Psychiatry*. 1989; 34: 759–64.
4. Deutsch E. The right not to be treated or to refuse treatment. *Med Law*. 1989; 7: 433–8.
5. White BC. Ethical issues surrounding informed consent. Part II. Components of a morally valid consent and conditions that impair its validity. *Urol Nurs*. 1989; 9: 4–9.
6. Hishamuddin HM, Baba AA, Azmi MNN, et al. Patterns of haemato-oncologic conditions and outcome in Hospital Universiti Sains Malaysia – January 1990 – December 1994. Abstract, Chapter of Physicians Annual Combined Scientific Meeting, 11–12 February 1995, Singapore, p22.
7. Haniffah AG, Hishammudin HM, Aziz M. Refusal of consent for lumbar puncture in Hospital Kota Bharu, Kelantan. Abstract, Academy of Medicine Scientific Meeting, Kuala Lumpur, Malaysia, 28–30 October 1994, p231.
8. Deng CT, Zullkifli HI, Azizi BHO. Parents' views of lumbar puncture in children with febrile convulsions. *Med J Malaysia*. 1994; 49: 263–8.
9. Salleh MR. The consultation of traditional healers by Malaysian patients. *Med J Malaysia* 1989; 44: 3–13.