Original article

Comparison of underlying factors behind parental refusal or consent for lumbar puncture

Hassib Narchi, Ghassan Ghatasheh, Noura Al Hassani, Layla Al Reyami, Qudsiya Khan
Al Ain, United Arab Emirates

Background: **Although lumbar puncture (LP) is a safe procedure in experienced hands, some parents fear having it performed on their children and refuse consent. The factors associated with this refusal are unclear, and any differences with consenting parents might provide clues as to how to address them. Therefore, we compared the underlying factors between the parents who refuse and those who consent to this procedure, as well as their children's outcomes.**

Methods: **A prospective study of the two groups of parents was conducted by a face-to-face structured interview. Parents' demographic factors, knowledge, perceptions, beliefs and attitudes, as well as their children's outcomes, were compared. The odds ratio (OR) with 95% confidence intervals was calculated for significant associations.**

Results: **Consent was declined by 24 out of 55 families (44%). Alternative options were offered more often to those refusing consent (OR=5.7). Significantly more parents who refused consent also refused bladder catheterization (OR=18), knowing someone with complications following LP (OR=8.7), felt that it was not needed (OR=7.9) or that it induced complications (OR=12.5). A significantly higher proportion of the consenting parents were aware that meningitis might cause convulsions (OR=4.6), deafness or blindness (OR=2.9).**

Conclusion: **The differences in the understanding, perceptions, beliefs and fears between the parents who refused consent and those who agreed, can provide clues to the developing of appropriate strategies when requesting consent for LP.**

World J Pediatr 2013;9(4):336-341

Author Affiliations: Faculty of Medicine & Health Sciences (Narchi H); Tawam Hospital (Ghatasheh G, Hassani NA, Reyami LA); Al Ain Hospital, Al Ain, United Arab Emirates (Khan Q)

Corresponding Author: Hassib Narchi, Department of Pediatrics, Faculty of Medicine & Health Sciences, United Arab Emirates University, P.O Box 17666, Al Ain, United Arab Emirates (Tel: +971 3 7137414; Fax: +971 3 7672022; Email: hassib.narchi@uaeu.ac.ae)

doi: 10.1007/s12519-013-0419-z

Key words: **consent;**
lumbar puncture;
procedure;
spinal tap

Introduction

Lumbar puncture (LP) is a commonly performed procedure but some parents fear having it performed on their child and refuse consent. This often results in admission to hospital for empirical intravenous antibiotics, increasing the use of resources, the duration and the risk of complications while in hospital such as nosocomial infections and iatrogenic complications. There is also the added risk of potential increase of resistance to antibiotics as well as the lost opportunity to administer prophylaxis in case of undiagnosed bacterial meningitis. The public health impact is likely to be considerable.

The prevalence of parents' refusal to give consent for LP has only been reported in two studies from Asia, but without a systematic quantitative analysis of its reasons nor a comparison between the parents who gave and those who declined consent for the procedure.[1,2] As the underlying factors for refusal have not been systematically analyzed, no effective strategies could be offered to remedy this problem. Furthermore, the impact of such refusal on the use of antibiotics, duration of hospital stay or clinical outcomes has not been quantified. Differences in underlying factors between parents who refuse and those who consent may be instructive and may provide clues which will help tackle this refusal. Unfortunately, no such comparison has been undertaken previously.

In our hospitals, previous audits have shown that at least half of the parents refuse to give such consent (unpublished data). In this study we aimed to establish the true prevalence of this problem in our environment and compare the underlying factors between parents who refuse and those who consent to LP, as well as the differences in resource utilizations and outcomes. The results will help the development of appropriate solutions and strategies to minimize this refusal.

Methods

This was a prospective study of children whose parents were asked for consent for a diagnostic LP. The study was undertaken in the emergency department and the inpatient pediatric wards of two teaching hospitals (Tawam and Al Ain Hospitals) from October 2009 to October 2010.

Legally, parental consent is always required beforehand. Parents receive a detailed verbal explanation of the procedure and its advantages, potential common minor and rare but severe risks, as well as an explanation of alternatives to it, if applicable. In the absence of a current life-threatening emergency, the parent of a child under the age of 16 years has the legal right to refuse the procedure for his offspring and must sign the refusal of treatment form. Analgesia or sedation is not routinely offered in our institutions.

We included all families of children (one month to 10 years of age) who were offered diagnostic LP during their current admission and who gave signed, informed consent for the interview. We excluded children who had already had a diagnostic LP within two weeks of that presentation or whenever their parents did not consent to the interview.

We estimated that 50% of parents in our study population would refuse LP on their children. Therefore, to have a precision of 10% with 95% confidence interval (CI) for a study sample to be representative of this population and, anticipating the possibility that up to 20% might provide incomplete data, the required sample size was 55 families (Epi Info statistical package, version 6.04, Centers for Disease Control and Prevention, Atlanta, GA, USA and the World Health Organization, Geneva, Switzerland).

The co-investigators, not directly involved with the clinical management of the children, were trained in the interview process before the start of the study. To minimize potential families' response bias, they were interviewed one day after their children's admission. This was when their anxiety was less, and they were less likely to fear management bias by the physician, should they not participate in.[3-7] For those who discharged their children from the emergency department against medical advice, they were interviewed prior to their departure. After obtaining the informed consents, a face-to-face structured interview was conducted in English, or Arabic if necessary, by the co-investigators (fluent in both languages). An interpreter was also available, if needed. The questionnaire included demographic information, parental beliefs, behaviors and attitudes. Confidentiality was assured and the duration of the interview did not exceed 20 minutes to minimize inconvenience to the families. The clinical and laboratory data were retrieved from the children's charts. This included demographic data, details of admission to hospital, antibiotic therapy, complications while in hospital and clinical outcomes.

Statistical analysis was performed with the software Stata version 11.0 (StataCorp, College Station, Texas). Proportions were compared with the Chi-square test or Fisher's exact test for small numbers (<5). Continuous variables were compared with Student's *t* test, if normally distributed, or the Kruskal-Wallis test, if not. A 2-tailed *P* value <0.05 was considered statistically significant. Odds ratio (OR) with 95% CI was calculated when statistically significant associations were found.

Ethical approval for the study was granted by the Al Ain District Human Research Ethics Committee (Ref: 09/62). The procedures followed were in accordance with the ethical standards of the Al Ain District Human Research Ethics Committee and with the *Helsinki Declaration* of 1964, revised in 2000.

Results

Fifty-five eligible families were enrolled during the study period and none refused consent for interview. All interviews were in English, and no interpreter was needed. For families refusing consent, clinicians attempted to encourage consent by suggesting analgesia or sedation but were unsuccessful.

The demographic data are displayed in Table 1. The interviewee was most often the father (*n*= 42, 76%). Consent was declined by 24 parents (44%, 95% CI: 30-57) and there was no significant difference whether consent was declined by fathers (*n*=3, 12%) mothers (*n*=5, 21%) or both (*n*=16, 67%). The age and gender of the children and the age of the fathers and mothers were not significantly different between the families who consented and those who did not, nor were the parent's education level, employment status, nationality (*P*=0.7) or religion (*P*=0.9).

The indications for LP were not significantly different between the groups (Table 1). The analysis of the process for the consent procedure revealed no significant difference between the groups in neither the location where consent was requested nor the grade of the requesting physician. Although alternatives to LP were offered significantly more often to families who refused consent for the procedure (*P*=0.006), there was no significant difference even if the parents were told they could stay with their children during the procedure. For the families who refused consent, the number of attempts to obtain consent was significantly larger (*P*=0.02) but not the median time spent to obtain it (*P*=0.1).

The information discussed with the families during

the consent procedure (Table 2) revealed no significant difference between the groups if the parents had been informed of the advantages, the risks of the procedure and if they had received an explanation that it was the only reliable way to diagnose or rule out meningitis, nor in their understanding of advantages or disadvantages of performing it or not.

Parents' prior knowledge (Table 3) revealed no significant difference between the two groups in their prior knowledge of LP indications or technique, nor on the process of CSF analysis. Their knowledge source about LP, or if they personally knew somebody who had a LP in the past, was not significantly different between both groups, but a significantly higher proportion of the parents who refused to consent knew of someone who had had complications following a LP (P=0.004). Although significantly more consenting parents were aware that bacterial meningitis might cause convulsions or epilepsy (P=0.01), deafness or blindness (P=0.05), there was no significant difference if they knew that

Table 1. Comparison of the characteristics in the children and their families and indications for lumbar puncture

Variables	Consent obtained	Consent refused	Total	P
Children				
Number	31 (56)	24 (44)	55 (100)	
Males	16 (51)	15 (62)	31 (56)	0.4
Age (mon)	11.9±26	6.2±10	9±21	0.4
Fathers				
Age (y)	34±8	32±9	33.5±8	0.2
Employed	28 (93)	19 (82)	47 (89)	0.2
Secondary education	21 (68)	15 (63)	35 (66)	0.7
University degree	5 (16)	4 (18)	9 (17)	0.8
Mothers				
Age (y)	30±6	27±6	28.5±6	0.2
Employed	6 (19)	4 (17)	10 (18)	0.8
Secondary education	11 (37)	14 (63)	25 (48)	0.09
University degree	13 (43)	5 (23)	18 (34)	0.2
Indications for lumbar puncture				
Fever	14 (63)	15 (88)	29 (74)	0.08
Convulsions	5 (16)	4 (17)	9 (16)	0.9
Convulsions with fever	3 (18)	3 (27)	6 (21)	0.5
Drowsiness, lethargy	2 (6)	2 (8)	4 (7)	0.8
Irritability	2 (6)	2 (8)	4 (7)	0.8
Sick looking	10 (32)	3 (13)	13 (24)	0.1

Values are n (%) or mean±standard deviation.

Table 2. Comparison of the procedure for lumbar puncture (LP) consent and the information discussed with the families during the consent process

Items	Consent obtained, n=31	Consent refused, n=24	Total, n=55	P
Consent request in ward	18 (60)	12 (52)	30 (56)	0.5
Grade of requesting physician				
Resident	7 (23)	3 (13)	10 (19)	0.3
Specialist	20 (66)	19 (74)	39 (70)	0.6
Attending physician	3 (10)	3 (13)	6 (11)	0.7
Other alternatives offered to family	4 (14)	11 (50)	15 (30)	0.006*
Parents offered to be present during procedure	7 (23)	1 (4)	8 (15)	0.06
Median number of attempts to obtain consent	2 (1, 5)	3 (1, 6)	2 (1, 6)	0.02
Median time in minutes spent to obtain consent	10 (1, 30)	13 (5, 60)	12 (5, 60)	0.1
Advantages of performing LP explained	28 (93)	21 (95)	49 (94)	0.7
LP is the only way to diagnose meningitis explained	26 (84)	17 (71)	43 (78)	0.2
Family fully understood advantages of performing LP	24 (77)	13 (54)	37 (67)	0.06
Risks of LP explained	12 (43)	6 (27)	18 (36)	0.2
Family fully understood disadvantages of not performing LP	17 (57)	12 (50)	29 (54)	0.6
Parents told that LP carries no risks at all	7 (22)	5 (21)	12 (22)	0.8

Values are n (%) or median (range). *: odds ratio=5.7 (95% confidence interval: 1.3-28.5).

Table 3. Comparison of the families' prior knowledge of lumbar puncture (LP)

Families' prior knowledge	Consent obtained, n=31	Consent refused, n=24	Total, n=55	P
Source of prior knowledge				
Doctors	1 (3)	2 (9)	3 (5)	0.4
Relatives	6 (19)	10 (43)	16 (29)	0.07
Friends	4 (13)	3 (13)	7 (13)	0.9
Media	3 (10)	1 (4)	4 (7)	0.4
Prior knowledge of indications	22 (71)	14 (58)	36 (65)	0.3
Prior knowledge of technique	27 (87)	16 (66)	43 (78)	0.07
Prior knowledge of CSF analysis	6 (19)	4 (16)	10 (18)	0.7
Prior knowledge of potential bacterial meningitis complications				
Lethal	16 (52)	12 (50)	28 (51)	0.9
Convulsions or epilepsy	17 (55)	5 (21)	22 (40)	0.01*
Developmental delay	12 (39)	4 (16)	16 (29)	0.07
Paralysis/spasticity	10 (32)	5 (21)	15 (27)	0.3
Deafness and/or blindness	21 (68)	10 (42)	31 (56)	0.05†
Knowing somebody who had had a LP	14 (47)	12 (50)	16 (45)	0.7
Knowing somebody who had complications after LP	2 (15)	9 (75)	11 (44)	0.004§

Values are n (%). OR: odds ratio; CI: confidence interval; CSF: cerebrospinal fluid. *: OR=6.6 (95% CI: 1.2-19.4); †: OR=2.9 (95% CI: 1.0-10.3); §: OR=8.7 (95% CI: 1.4-89).

bacterial meningitis could be lethal or might result in neuro-developmental delay, paralysis or spasticity.

Analysis of parents' attitudes, perceptions and beliefs (Table 4) showed that 11% felt that LP was not needed, with a significantly higher proportion in those refusing consent (21% *vs.* 3%, *P*=0.04). In addition, 43% of the families also feared complications related to the procedure, with a significantly higher proportion in those refusing consent (75% *vs.* 19%, *P*<0.001). There was no significant difference between the two groups in their perception that the risks of not performing LP were higher than those of the procedure itself nor in the parents' preference to seek the opinion of another family member or another doctor.

There were no LP related complications in any of the children who underwent the procedure. The comparison of clinical outcomes (Table 5) showed a significantly higher rate of refusal of other procedures (all bladder catheterizations) when LP consent was refused (*P*=0.002). There was no significant difference in discharge against medical advice, in the proportion of children who received antibiotics, in the duration of therapy, in the duration of hospital stay, in the number of reinsertions of the intravenous cannula, and in the number of in-hospital complications. *Streptococcus pneumoniae* bacteremia was diagnosed in two children (neither of whom underwent LP) and urinary tract infection in three children (one of whom did not undergo LP) but the differences were not statistically significant. Viral meningitis was diagnosed in two children (both had LP) and presumed partially treated meningitis in one child who underwent LP (with sterile blood and CSF culture), but the difference was not statistically significant.

Discussion

Comparing the beliefs, fears, concerns and expectations of parents consenting or not to LP provides clues to helping develop strategies and solutions to tackle this problem.

Our results confirm that the prevalence of parents' refusal to give consent to LP for their children is elevated (44%), higher than that in other studies (25% to 28%) which focused exclusively on febrile convulsions.[1,2] They also confirm that the main sources of information for the parents were their relatives and friends, that the justification for LP

Table 4. Comparison of the families' attitude and perceptions of lumbar puncture (LP)

Families' attitudes	Consent obtained *n*=31	Consent refused *n*=24	Total *n*=55	*P*
Felt that LP was not needed	1 (3)	5 (21)	6 (11)	0.04*
Feared complications of LP	6 (19)	18 (75)	24 (43)	<0.001†
Prefer opinion of another relative before consenting	18 (58)	14 (58)	32 (58)	0.9
Prefer opinion of another physician before consenting	11 (35)	7 (30)	18 (33)	0.7
Believe that the risk of not performing the procedure outweighs the risk of its complications	12 (40)	15 (62)	27 (50)	0.1

Values are *n* (%). OR: odds ratio; CI: confidence intervals. *: OR=0.12 (95% CI: 0.002-1.3); †: OR=0.8 (95% CI: 0.02-0.33).

Table 5. Comparison of children's clinical outcomes

Clinical outcomes	Consent obtained, *n*=31	Consent refused, *n*=24	Total, *n*=55	*P*
Other procedures refused	1 (4)	9 (39)	10 (20)	0.002*
Discharge against medical advice	1 (3)	3 (12)	4 (7)	0.2
Antibiotic therapy started	30 (97)	17 (71)	47 (85)	0.06
Duration of antibiotic therapy (d)	5.4±3.7	7.6±3.9	6.2±3.9	0.06
Duration of hospital stay (d)	6±4.1	6.1±4.1	6±4.1	0.9
Complications in hospital	7 (22)	4 (16)	11 (20)	0.6
Intravenous fluid extravasation	5	4	9	
Allergic rash	1	0	1	
Nosocomial infection	1	0	1	
Number of intravenous cannula reinsertions	2.4±1.8	8.2±18.9	4.4±11.2	0.1
Meningoencephalitis	3 (9)	0 (0)	3 (5)	0.1
Viral	2 (6)	0 (0)	2 (3)	
Partially treated bacterial	1 (3)	0 (0)	1 (2)	
Streptococcus Pneumoniae bacteremia	0 (0)	2 (8)	2 (3)	0.1
Urinary tract infection	2 (6)	1 (4)	3 (5)	0.7

Values are *n* (%) or mean±standard deviation. *: odds ratio=18 (95% confidence interval: 2-214).

was not always explained to some of them and that consultants sought consent only in a minority of cases.

The issue of informed consent for procedures is not unique to our environment but is a universal theme that continues to be debated in many countries. A lack of uniform practice for this consent in hospitals has been identified,[8] suggesting the need for implied consent in the emergency room setting[9] or providing a universal consent form for procedures in critically ill adults.[10] Consent for LP has also been looked into in adults[11] and parental consent for LP in their children has also been extensively debated.[12-14] It is clear, therefore, that our study is of universal interest and of relevance to other settings.

We found some significant differences between the parents who consent, and those who do not. There was a large number of attempts to persuade the parents who had declined consent and they were offered more alternatives to LP, reflecting the efforts of medical staff to convince them. They were also more likely to fear complications caused by the procedure or to know of someone who reportedly suffered from them, as shown in other studies as well.[2] Some of these perceived risks may be associated with the underlying disease and not the procedure itself. The parents' fears might be alleviated; and the consent rate improved if they are informed of the common complications with the procedure and offered, when indicated, a proper explanation of the exact nature of some perceived complications and the circumstances surrounding them, without the need to enumerate all known or rare complications.[11]

Families declining consent perceived that the procedure was not needed. Those who consented were more aware of the serious complications of bacterial meningitis, making this a major determinant for their consent in order to avoid these feared complications. Highlighting, in a sensitive way, the risks of not performing LP may enhance the chance of consent.[14]

Parents refusing LP consent were also significantly more likely to refuse bladder catheterization for urine culture. Following the introduction of vaccination against *Streptococcus pneumoniae*, urinary tract infection (UTI) has become much more common as the main cause of febrile illness without a focus in young infants than occult bacteremia with the former. Refusal of bladder catheterization will therefore have, in addition, a major negative impact on the diagnosis of UTI in these situations.[15,16]

Surprisingly, we observed no significant differences in clinical outcomes, perhaps because in both groups the etiology was most often a viral illness except for three children with a bacterial infection. Although we did not analyze this, there remains the possibility of unjustified requests for LP in some children with febrile convulsions, considering that the prevalence of bacterial meningitis has been dramatically reduced by vaccination.[17-20] In such instances, when the indication for the procedure is not evidence-based, the physician may not try hard to obtain consent after the failed initial request but offers instead a hassle-free approach of using empirical antibiotic therapy. Surprisingly, the majority of children empirically treated with antibiotics, whether an LP was performed or not, had a lengthy hospital admission and antibiotic therapy duration. This may reflect, once again, lack of adherence to guidelines stating that such children can be safely discharged after 48 hours if bacterial cultures are negative and their clinical assessment is normal.[21]

Our study has some limitations. Although we found no significant difference in the perceptions or concerns between parents who refused consent in the emergency department and those who refused after admission, other subtle and undetected differences might still exist. Although all interviews were in English, the second language for most families, we feel that their opinion was adequately expressed to the interviewers. Another potential weakness is a possible recall bias by parents but we feel it is very unlikely, as they were interviewed one day after the attempt at consent and their thoughts and concerns are unlikely to have significantly changed in that brief period. Although the study sample size was calculated based on an estimated prevalence of 50% refusal rate of consent to LP in our population, it might not have been large enough to specifically detect a statistically significant difference for some of the less common associations we analyzed. We also caution that the observed differences between the two groups of parents might not necessarily be causal for their decision, but merely associations.

We acknowledge that this quantitative analysis is unlikely to provide all the information affecting parental decision-making. For this reason, a qualitative study of those refusing consent is currently underway. We also recognize that the results of this geographically centered study may not be necessarily directly applicable to other countries or cultures. We believe, however, that the study concept and design provide a useful framework which can be used to analyze the refusal of consent to LP in other settings where the cause for refusal and the strategies required to tackle them might not necessarily be similar.

In conclusion, a better understanding of the differences in the perceptions, beliefs and fears, between the parents who consent for LP on their children and those who do not, is useful for developing appropriate solutions to this refusal. Addressing such a universal issue, this study might be of practical interest in other settings.

Acknowledgements

We are grateful to all colleagues whose patients were included in the study.

Funding: This study was supported by a research grant (NP/10/06) from the Faculty of Medicine & Health Sciences, United Arab Emirates University.
Ethical approval: This study was approved by the Al Ain District Human Research Ethics Committee (Ref: 09/62).
Competing interest: None.
Contributors: Narchi H reviewed the literature, designed the study, analyzed the results and wrote the manuscript. Ghatasheh G, Hassani NA, Reyami LA and Khan Q collected the data and contributed to the writing of the report. All authors read and approved the manuscript. Narchi H is the guarantor of the study.

References

1 Ling SG, Boey CC. Lumbar puncture refusal in febrile convulsion. Singapore Med J 2000;41:485-488.
2 Deng CT, Zulkifli HI, Azizi BH. Parents' views of lumbar puncture in children with febrile seizures. Med J Malaysia 1994;49:263-268.
3 Perneger TV, Chamot E, Bovier PA. Nonresponse bias in a survey of patient perceptions of hospital care. Med Care 2005;43:374-380.
4 Krause N. Stress, control beliefs, and psychological distress: the problem of response bias. J Human Stress 1985;11:11-19.
5 Cooke RW. Good practice in consent. Semin Fetal Neonatal Med 2005;10:63-71.
6 Diekema DS. Ethical issues in research involving infants. Semin Perinatol 2009;33:364-371.
7 Wilson S, Draper H, Ives J. Ethical issues regarding recruitment to research studies within the primary care consultation. Fam Pract 2008;25:456-461.
8 Manthous CA, DeGirolamo A, Haddad C, moateng-Adjepong Y. Informed consent for medical procedures: local and national practices. Chest 2003;124:1978-1984.
9 Easton RB, Graber MA, Monnahan J, Hughes J. Defining the scope of implied consent in the emergency department. Am J Bioeth 2007;7:35-38.
10 Davis N, Pohlman A, Gehlbach B, Kress JP, McAtee J, Herlitz J, et al. Improving the process of informed consent in the critically ill. JAMA 2003;289:1963-1968.
11 Beresford HR. Informed consent before lumbar puncture. N Engl J Med 1980;303:1534.
12 Botkin JR. Informed consent for lumbar puncture. Am J Dis Child 1989;143:899-904.
13 Avner JR, Selbst SM. Informed consent for lumbar puncture: an alternative. Am J Dis Child 1990;144:272.
14 Habiba A. Parental attitude to lumbar puncture for children with fever and seizure. Pediatrics 2007;120:1220.
15 Rudinsky SL, Carstairs KL, Reardon JM, Simon LV, Riffenburgh RH, Tanen DA. Serious bacterial infections in febrile infants in the post-pneumococcal conjugate vaccine era. Acad Emerg Med 2009;16:585-590.
16 Waddle E, Jhaveri R. Outcomes of febrile children without localising signs after pneumococcal conjugate vaccine. Arch Dis Child 2009;94:144-147.
17 Offringa M, Beishuizen A, Derksen-Lubsen G, Lubsen J. Seizures and fever: can we rule out meningitis on clinical grounds alone? Clin Pediatr (Phila) 1992;31:514-522.
18 Narchi H. Febrile convulsions: When is a lumbar puncture indicated? J Pediatr Neurol 2007;5:87-92.
19 Kimia AA, Capraro AJ, Hummel D, Johnston P, Harper MB. Utility of lumbar puncture for first simple febrile seizure among children 6 to 18 months of age. Pediatrics 2009;123:6-12.
20 Kimia A, Ben-Joseph EP, Rudloe T, Capraro A, Sarco D, Hummel D, et al. Yield of lumbar puncture among children who present with their first complex febrile seizure. Pediatrics 2010;126:62-69.
21 Durongpisitkul K, Gururaj VJ, Martin CF. The appropriateness of early discharge of hospitalized children with suspected sepsis. J Fam Pract 1997;44:91-96.

Received February 4, 2012
Accepted after revision June 18, 2012