Why Do Some Parents Refuse Consent for Lumbar Puncture on Their Child? A Qualitative Study

abstract

OBJECTIVE: Qualitative analysis of the attitudes, beliefs, and perceptions of parents who refuse consent for lumbar puncture (LP) on their child.

METHODS: We performed prospective, semistructured, face-to-face interviews with 24 families declining consent for LP in their child (aged between 1 month and 10 years of age), in 2 hospitals, over a 1-year period in the United Arab Emirates. The questionnaire included open-ended questions to allow parents to discuss their beliefs, concerns, and expectations. Content analysis of the transcripts was performed on how parents experienced the issue: their behavior, perceptions, and beliefs, as well as their opinions on what might have made them consent. Identified themes resulting from that analysis were labeled and coded before reducing them into categories and generating a Pareto chart.

RESULTS: Seven (29%) families were unfamiliar with LP indications and 3 had the impression that LP was also therapeutic. The emerged themes were fear of complications by 18 (75%), perception that LP was unnecessary by 5 (21%), and distrust of the motives behind the request for consent. Fear of paralysis and conviction that LP is unnecessary encompassed 80% of the causes for refusal. Eleven families (46%) stated that nothing would have made them consent, and 10 (42%) would agree only if the child looked unwell or deteriorated.

CONCLUSIONS: A better understanding of parents’ perceptions, beliefs, and fears will help develop appropriate solutions to their refusal of LP consent.

INTRODUCTION

Although diagnostic lumbar puncture (LP) is a commonly performed procedure, some parents fear having it performed on their child and refuse to consent. This may result in admission of the child to hospital for empirical intravenous broad-spectrum antibiotic treatment or increase the duration of hospital stay, costs of hospitalization, and risk of resistance to antibiotics. There is also the lost opportunity to administer prophylaxis to contacts in cases of undiagnosed bacterial meningitis, as well as the additional psychological and emotional strain on the child and the family. The prevalence of parents’ refusal to give consent for LP and some of their underlying reasons have only been reported in 2 studies.1,2 Because there has never been a systematic, qualitative analysis of the underlying factors for this refusal, no effective strategies could be offered to remedy this problem.

In our hospitals in the United Arab Emirates, as shown in previous audits, at least one-third of parents refuse to give such consent (H.N., unpublished material, 2007). We undertook a qualitative analysis of their perspectives, beliefs, and attitudes behind such refusal in an exploratory and hypothesis-generating exercise.3-6 The results

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ABBREVIATION
LP, lumbar puncture

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would allow a detailed understanding of families’ experiences, motives, views, feelings, wants, needs, and concerns regarding the giving of consent, directly from their own perspective. The aim is to suggest appropriate solutions and strategies to minimize this refusal.

**METHODS**
This was a prospective study of children whose parents refused to give consent for a diagnostic LP, undertaken in the emergency and the inpatient pediatric departments of 2 teaching hospitals (Tawam and Al Ain hospitals) from October 2009 to October 2010. Previous parental consent is always required, and analgesia or sedation is not routinely offered. Ethical approval for the study was granted by the Al Ain District Human Research Ethics Committee (Ref: 09/62).

Parents of children (between 1 month and 10 years of age) who were offered diagnostic LP during their admission and who signed the informed consent form for the interview were included. Children who had already had a LP within 2 weeks and parents who did not consent to the interview were excluded.

The clinical and laboratory data were retrieved from the children’s medical charts. The coinvestigators, not directly involved with the clinical management of the children, were trained in the interview process and transcription before the start of the study. To minimize potential families’ response bias, they were interviewed 1 day after their child’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.

Those who discharged their child from the emergency department against medical advice were interviewed before their departure. After obtaining signed informed consent, a face-to-face semi-structured interview was conducted in English, or Arabic if necessary, by the coinvestigators (fluent in both languages). An interpreter was also available if needed. The duration of the interview did not exceed 20 minutes to minimize inconvenience to the families. The questionnaire was designed with open-ended questions to allow parents to openly discuss their beliefs, concerns, and expectations. The collected information was directly transcribed verbatim on the questionnaire form by the trained interviewers during the interview. No audio or video recordings were used, because this was not deemed acceptable by the local culture. The data were analyzed by the principal investigator (H.N.).

The data were anonymized, and qualitative analysis involved content analysis of the text with textual descriptions of how parents experienced the issue, their behavior, beliefs, opinions, and emotions. Recurrent themes were identified, labeled, and coded to identify differences and similarities between them before reducing them into categories. A Pareto chart was then generated: the identified themes on the horizontal axis, the frequency of their occurrence in descending order (their relative importance) as bars on the vertical axis, with a superimposed line showing their cumulative percentage. This chart, a tool of quality improvement, is based on the Pareto principle (the “80/20 rule”), stating that 20% of the causes (or themes in this study) are responsible for 80% of the results. This helps prioritize the few most important themes with the greatest cumulative effect on the problem.

### RESULTS
From a total of 55 families who were asked to give consent for an LP on their child, 24 (44%) declined to give consent. All agreed to be interviewed, including the only one (4%) who left the emergency department despite medical advice. All interviews were conducted in English, and no translator was required.

The demographic data are shown in Table 1. The indications for LP and the details of the consent procedures are shown in Table 2. Whereas the majority of respondents were males, there were no differences in responses noted by gender.

Parents’ knowledge, understanding, and beliefs are shown in Table 3. Seven families (29%) had no previous knowledge of the indications for LP, and 3 had the impression that LP was also therapeutic. When asked about the

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<th>Table 1 Demographic Data of Families Refusing LP Consent</th>
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<td>Child’s median age (range), mo</td>
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Values given are numbers unless stated otherwise.
reasons for not consenting, 18 (75%) said that it was because of fear of complications from the procedure: 14 (58%) feared paralysis, 4 feared pain (16%), and 1 feared scoliosis. The total exceeds 18, because some families cited >1 cause. Illustrative comments made are as follows:

“I was scared that inserting the needle in his back could cause damage to the spinal cord.”

“My child is very young and putting a needle in his back could hurt him and injure his nerves.”

“We were afraid that the procedure would leave him with a deformed and twisted back (scoliosis) as he is very young and his spine has not fully grown yet.”

“The brain is very sensitive to injury; putting a needle in the back, which is connected to the brain nervous system may lead to development delay and epilepsy.”

Five families (21%) also felt that the procedure was unnecessary, as stated below:

“My son had no signs of meningitis and the whole family felt that LP was not necessary.”

“My daughter was not sick, she only had a cold with fever when she had the convulsion and was not looking sick.”

“I felt that it would have been better to observe my son first, do some tests for infection and discuss LP only if there was evidence of meningitis.”

“All my 3 other children had a cold like my daughter, she was not sick, and we all felt that she also only had a cold.”

“My 2 other children also had febrile convulsions when they were young and did not require LP.”

One family stated:

“If the doctors truly believe that LP is very safe and is done routinely, why do they then ask us to sign a consent form? If this is to protect themselves, it must be because they know that complications may occur sometimes without telling us about them.”

Another family said:

“Why have we been asked for consent if the LP was so important for the diagnosis and carried no significant risks? We would not have objected if we were not explicitly asked for consent.”

The main themes that emerged included: fear of complications such as (1) paralysis, (2) pain, (3) the perception that LP was unnecessary, and (4) distrust of the motives behind the request for consent (see Fig 1). Three categories summarized these themes: fear, unconvinced, and distrust.

Eleven families (46%) stated that nothing would have made them change their mind to consent to LP. Ten (42%) would have changed their minds if the child looked unwell or if the condition deteriorated, 1 family if they were convinced that the child had something other than a cold, 1 if they knew somebody who had had a LP and had no complications, and 1 if the physician requesting consent was more convincing. Some of their comments included:

“Nothing at all would have made us change our mind to give consent.”

“I might have given consent if my son looked very sick or if his condition became worse while in hospital.”

“We might have agreed for LP if our other children did not have a cold as our daughter may not have the same condition.”

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The issue of informed consent for procedures, in general, is not unique to our environment. It is a universal theme, some aspects of which continue to be debated in the United States. Some studies have identified a lack of uniform practice for this consent in hospitals, and others have tried to define a scope for implied consent in the emergency department setting. Providing a universal consent form for procedures in critically ill adults has also been suggested. The specific issue of consent for LP in adults has also generated a debate. More directly relevant to our discussion, informed parental consent for LP in their child has also been an ongoing subject of discussion for the past 2 decades in the North American literature. Because there are also similar reports from Asian countries, the universal nature of this problem is obvious. It is clear, therefore, that, although this study was performed in the United Arab Emirates, it is also relevant to other settings.

The main reasons behind parents’ refusal to consent to LP in this study included fear of complications, their distrust of the physician’s motives behind seeking consent, and their perception that LP was unnecessary. Fear of paralysis or severe pain has also been found in other studies.1,2

Parental perception that LP is unnecessary and their distrust of the physician’s motives behind seeking consent must also be addressed. Distrust of the physician’s motives is illustrated by the 2 families who wondered why it was necessary to ask for consent if the procedure carried no risks and was so important for the diagnosis. They also specifically stated that they would not have objected if they had not been explicitly asked for consent. The way physicians approach the issue of LP with parents

These themes were summarized in 2 categories: fear and unconvinced.

**DISCUSSION**

Obtaining consent for a procedure involves an interaction between parents’ beliefs, perception or understanding of their child’s illness, and doctors’ skills at convincing them of the necessity of the procedure. A balance must be struck between the robustness of the indication and the advantages versus the risks of performing that procedure or not. Exploration of the beliefs, fears, concerns, and expectations of parents refusing to consent to LP directly provided us with their personal perspective on this process, which should help us develop strategies and solutions to tackle this problem.

The main themes that emerged and that might make the parents consent to LP included the following: (1) fear that their child was sick or worsening, (2) a physician who was more convincing regarding that LP is truly necessary because meningitis is suspected, (3) a physician addressing their unfounded beliefs, such as their child did not have a cold, as well as (4) knowledge of somebody who did not have a complication after LP (see Fig 2).

“The doctor who informed me that LP was needed was not convincing when explaining why it was needed”

“I think that I might have given consent if I personally knew somebody who had LP in the past and did not develop any complications.”

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**TABLE 3 Parents’ Knowledge, Understanding, and Beliefs Regarding LP**

| Had no previous knowledge on why LP is done | 7 (29) |
| Knew specifically that LP involved laboratory studies to diagnose meningitis | 11 (46) |
| Knew that LP allows the diagnosis of convulsions or infections | 6 (25) |
| Knew that bacterial meningitis could result in 1 or more of the following complications | 18 (75) |
| Death | 12 (50) |
| Paralysis or spasticity | 5 (21) |
| Deafness | 5 (21) |
| Blindness | 5 (21) |
| Convulsions or epilepsy | 5 (21) |
| Developmental delay | 4 (16) |
| Knew that the procedure involved inserting a needle in the back | 16 (66) |
| Heard of the risks of LP from 1 or more of the following | 8 (33) |
| Relatives | 13 (54) |
| Friends | 8 (33) |
| Other doctors | 2 (8) |
| Televised program | 1 (4) |
| Knew somebody who had a LP before | 12 (50) |
| A relative | 11 (46) |
| A family friend | 1 (4) |
| Knew of 1 or more complication occurring after LP in that individual, such as | 9 (37) |
| Paralysis or spasticity | 2 (8) |
| Severe pain | 4 (16) |
| Spinal deformity, scoliosis | 3 (12) |
| Delayed walking or abnormal gait | 4 (16) |
| Understand the advantages of doing a LP | 13 (54) |
| Diagnosing or ruling out meningitis | 13 (54) |
| Normal CSF results would result in decreases hospital stay and alleviate the need for antibiotic therapy | 4 (16) |
| Understand the disadvantages of not doing a LP | 11 (46) |
| Believe that the risks of performing LP outweigh the risk of not diagnosing meningitis | 15 (62) |
| Prefer seeking the opinion of a relative before deciding to consent or not | 14 (58) |
| Prefer to have a more senior doctor involved in requesting consent | 7 (29) |

Values are given in number (%) unless stated otherwise. CSF, cerebrospinal fluid.
is, therefore, an important determinant of their acceptance. Explaining the very low risks of the procedure must be mentioned, but, more importantly, the risks of not performing it must also be stressed. Other potential causes of refusal to give consent were given less emphasis by parents. Although the language barrier makes obtaining informed consent more difficult, we do not believe that it is an issue, because all interviews were undertaken in English. Although most parents wish to be present when invasive procedures are performed on their child, not offering them that option was not found to be a cause for refusal of the procedure. Similarly, offering parents alternative options when consent was declined was not found to be an issue.

Our study has some potential 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, it remains possible that other unexplored reasons might still exist. All interviews were in English, which is the second language for most families. However, we feel that the parents’ perspective was adequately expressed to the interviewers who were also fluent in Arabic. Although unlikely, it remains possible, however, that this might not have fully reflected some of the families’ opinions as it would have, if the interview had been conducted in their mother tongue. There is also the possibility of recall bias by parents when the interview occurred on the day after the request for consent, because they may have forgotten some of their beliefs and feelings when interviewed. However, we feel that this is very unlikely, because their thoughts and concerns had been present for quite some time and were unlikely, therefore, to have significantly changed over that very short time frame. It might also be argued that all families should have been interviewed shortly after consent.

FIGURE 1 Pareto chart. Reasons for parental refusal of consent to LP.

FIGURE 2 Pareto chart. What might have made parents consent to LP?
was sought. However, it is known that the timing of an approach to parents’ consent for research can be crucial, because their judgment and capacity might be clouded by the child’s acute condition. Pressure can also be unwittingly placed on them through a wish to please the physician or to ensure that their child has priority in treatment. It is advised, therefore, that parents be given time to consider information so that their decision is made away from the clinically acute situation. It is also recommended that they should not be made to feel that they have a duty to participate and should be free to withdraw from the research project without fear that medical care of their child might be jeopardized. We also analyzed whether cultural aspects in this society might have influenced the results. Although the United Arab Emirates is a male-dominated society, both parents together made the decision to refuse consent in 66% of the cases. In addition, 12% of refusals were made by the father alone (considered to be the decision maker in this society), when the mother alone (considered the principal caregiver in this society), when the father was not present. Unfortunately, our data do not allow a detailed analysis of the degree of discordance in the decision-making by the 2 parents which could shed some light on this cultural aspect in this particular society.

CONCLUSIONS
A better understanding of parents’ perceptions, beliefs, and fears will help develop appropriate solutions to their refusal of LP consent. Because it addresses such a universal issue, this study might be of practical interest in other settings.

REFERENCES