Evaluation of Saudi Arabian Parent’s Attitude towards Lumbar Puncture in Their Children for Diagnosis of Meningitis

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ABSTRACT

Background: although lumbar puncture is a safe procedure in experienced hands, some parents fear having it performed in their children and refuse consent. The factors associated with this refusal are unclear and any differences between consenting and non-consenting parents might provide clues as to how to address them.

Objective: this study aimed to predict the underlying factors that affect parent’s refusal of consent for lumbar puncture in their children with meningitis in southern Saudi Arabia.

Methods: We conducted a cross-sectional study, of 750 children with meningitis, who visited either the emergency department or the pediatric wards in three teaching hospitals (Khamis Mushait Maternity and Children Hospital, Abha Maternity and Children Hospital and Military Hospital (Khamis Mushait) in the southern region of Saudi Arabia from 20th February 2016 to 6th January

Results: his study included 751 patients with meningitis. Their ages ranged between one month and 13 years (3.9±3.3 years); 42.7% presented with other symptoms (cough, sore throat, dyspnea and pneumonia); 28.7% had fever, 10% vomiting, 12.1% dyspnea, and 6.5% convulsions. Fifty-one per cent of children were accompanied by their fathers, 41.9% by their mothers and 6.9% by others. Accompanying people were asked for consent for lumbar puncture in their children; 44.3% disagreed and 55.7% agreed. Factors influencing disagreement were relative’s opinions (35.1%), media (30.4%) and their previous experience (12.3%).

Conclusion: based on the results of this study, the main reason for refusal of consent for LP in the children of the majority of parents was fear of side effects such as paralysis, as well as lack of awareness about the usefulness of LP in diagnosis and treatment of children. Informing parents of affected children is very important in the counseling for such diagnostic tests. Therefore, it seems that it is necessary to pay more attention for training in national health plans.

Keywords: lumbar puncture, pediatrics, meningitis, parents, consent.

INTRODUCTION

One of the indicators of child health is public health reducing the incidence, early diagnosis and treatment of disease is an important objective of global health plans. Viral and bacterial infections are common in infants and children and these may spread to the central nervous system (CNS), causing primary or secondary infection in nervous tissue. One of the diagnostic tests is concerning the cerebrospinal fluid and the benefits of lumbar puncture (LP).

The prevalence of parent’s refusal to give consent for LP and some of their underlying reasons, have only been reported in 2 studies [1, 2]. When a child presenting with apparent febrile convulsions is suspected of having meningitis, parent’s refusal of LP can put the doctor in a difficult position. A firm diagnosis of meningitis cannot be made without a cerebrospinal fluid sample[3]. The refusal of a diagnostic LP was 25% at Mulago Hospital in Kampala [3]. LP refusal is commonly encountered and it is impractical to obtain court orders in all these cases. Additionally, this may cause the public to avoid hospital attendance for fear of being forced to have procedures performed against their wishes. Patients who refused LP were significantly more likely to discharge themselves from hospital.

This would put them at risk as the diagnosis and treatment of meningitis might be further delayed [1].

A study by Wong et al. in 2010 showed the main reasons for refusal of LP by parents was fear of paralysis in 48% and fear for mental retardation in 6; 16% were influenced by the recommendations of relatives and friends[4]. Similarly, Deng et al. studied the parental views on LP in their children with febrile convulsions, and the authors reported that the main reasons for refusal were fear of paralysis, mental retardation, child death, painfulness and weakened kidneys, which is consistent with some our findings [2]. A study evaluated parent’s beliefs about LP in their children showed that the usual reason for refusal or disagreement is fear of probable paralysis, confusion due to incorrect popular guidance, fear

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of losing the child during the LP, and painfulness of the procedure [2, 3]. 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. Lack of uniform practice for this consent in hospitals has been identified [4]. Therefore, our study is of universal interest and of relevance to other settings. Many attempts were made to persuade parents who had declined consent and they were offered 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]. Our study aimed to evaluate the underlying factors affecting parent’s disagreement with the LP procedure.

METHODS
Participants and study
This study was undertaken in the emergency department and the inpatient pediatric wards of three teaching hospitals (Khamis Mushait Maternity and Children Hospital, Abha Maternity and Children Hospital and Military Hospital (Khamis Mushait) in the southern region of Saudi Arabia from 20th February 2016 to 6th January On 751 children.

Legally, parental consent is always required before performing an LP on a minor. Parents received 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. To minimize potential family’s response bias, parents were interviewed one day after their children's admission. This was when their anxiety was thought to be less and they were less likely to fear management bias by the physician, should they not participate. 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.

For those who discharged their children from the emergency department against medical advice, they were interviewed prior to their departure. After obtaining informed consent, a face-to-face structured interview was conducted in Arabic, or English if necessary, by the co-investigators (Fluent in both languages).

An interpreter was also available, if needed. The questionnaire included demographic information, parental beliefs, and sources of information on which their refusal might be dependent. 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, and details of admission to hospital.

Inclusion and Exclusion criteria
We included all families of children one month to 13 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 already had a diagnostic LP within two weeks of that presentation, or if their parents did not consent to the interview.

Statistical analysis
All data were entered, coded and analyzed using statistical package for social science (SPSS, version 22). The distribution of the data was evaluated for normality with. Qualitative variables were reported as proportions, with the mean ± standard deviation calculated for quantitative variables. For all analyses, a p-value <0.05 was considered significant.

Ethical Approval:
Our study was approved by The Research Ethics Committee at King Abdulaziz City for Science and Technology. The parent(s)/guardian(s) provided informed consent as appropriate for age.

RESULTS
The study included 750 children. Their ages ranged between one month and 13 years, with a mean of 3.9 and standard deviation (SD) of 3.3 years. The majority of children (41%) were between 1 and 5 years of age as shown in table 1 with those less than 1 year accounting for 28.7%, between 5 and 10 years 21.9% and over the age of 10 years 8.4%. The distribution of presenting symptoms showed non-meningitic symptoms (cough, sore throat, dyspnea and pneumonia) in 47.2% of the children, fever in 28.7%, vomiting in 10%, dyspnea in 12.1% and convulsions in 6.5%. Slightly more than half of children (51.1%) were accompanied by their fathers, while 41.9% were accompanied by their mothers, and 6.9% by other relatives.

Parents or guardians were interviewed regarding their opinions on the performance of lumbar punctures in their children. As illustrated in figure 1, 44.3% (333) disagreed and 55.7% (418) agreed. The prevalence of LP agreement among mothers was 59.4%, with 40.6% disagreeing, while 51% of fathers agreed and 49% disagreed. In the case of other accompanying persons, 67.3% agreed, while
32.6% disagreed (Table 2). Influencing factors in those who disagreed were relative’s opinions 262 (35.1%), media 228 (30.4%) and previous experience 92 (12.3%) as shown in figure 2.

Table: 1. Demographic data of 751 patients in southern Saudi Arabia with presenting symptoms and accompanying parent/guardian

<table>
<thead>
<tr>
<th>Variables</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s age (years)</td>
<td></td>
</tr>
<tr>
<td>≤1 year</td>
<td>N=215 (28.7%)</td>
</tr>
<tr>
<td>&gt;1-&lt;5 years</td>
<td>N =309 (41%)</td>
</tr>
<tr>
<td>&gt;5-&lt;10 years</td>
<td>N =164 (21.9%)</td>
</tr>
<tr>
<td>≥10 years</td>
<td>N =63 (8.4%)</td>
</tr>
<tr>
<td>Presenting symptom</td>
<td></td>
</tr>
<tr>
<td>Fever</td>
<td>N =215 (28.7%)</td>
</tr>
<tr>
<td>Vomiting</td>
<td>N =75 (10%)</td>
</tr>
<tr>
<td>SOB</td>
<td>N =91 (12.1)</td>
</tr>
<tr>
<td>Convulsions</td>
<td>N =49 (6.5%)</td>
</tr>
<tr>
<td>Others</td>
<td>N =321 (42.7%)</td>
</tr>
<tr>
<td>Nature of the accompanies</td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>N =384 (51.1%)</td>
</tr>
<tr>
<td>Mothers</td>
<td>N =315 (42%)</td>
</tr>
<tr>
<td>Others</td>
<td>N =52 (6.9%)</td>
</tr>
</tbody>
</table>

Table 2-Consent or refusal to performance of lumbar puncture by parents of 751 children in southern Saudi Arabia

<table>
<thead>
<tr>
<th>Variables</th>
<th>Yes N (%)</th>
<th>No N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>187 (59.4)</td>
<td>128 (40.6)</td>
</tr>
<tr>
<td>Father</td>
<td>196 (51.0)</td>
<td>188 (49.0)</td>
</tr>
<tr>
<td>Other</td>
<td>35 (67.3)</td>
<td>17 (32.6)</td>
</tr>
</tbody>
</table>

Figure 1. Agreement or disagreement of accompanying person to performance of lumbar puncture

DISCUSSION

Refusal of consent to perform an LP by parents due to anxiety is a universal issue that complicates medical diagnosis and adequate management. Although this problem is common, there are few studies dealing with the subject, especially in our country. In other study [7], consent was declined by 24 parents (44%), which is consistent with our result and higher than that in other studies (25% to 28%) [1, 2, 7].

On the other hand, in a study consistent with our result performed in the United Arab Emirates, which was a male-dominated society, both parents together made the decision to refuse consent in 66% of the cases [7]. Furthermore, 12% of refusals were by the father alone; he is considered the decision maker in this society [7]. In our study, refusal of consent to LP was related to some factors that gave the wrong impression of the importance of the LP procedure. This is clearly shown in another study [8] in which 58.2% of parents had received the necessary information about the LP previously. There was a statistically significant difference between the proportion of parents who had received the necessary information and those who had not (p=0.04).

Information about LP was received from doctors by 81.3% of parents, and 2.2% had some experience of LP in their friends and relatives [8]. In the same study, parent’s views on the importance of LP for their children's diagnosis, were that 14.3% expressed that this was very important, 6.28% believed too much importance, 19.8% believed it important to some extent, 2.2% slightly important, 7.7% expressed that this method had no effect, and 27.5% were unaware of the necessity of LP for their child's diagnosis [8,9].
Some studies showed that reasons why parents refused LP included fear of paralysis, mental retardation, child death, painfulness, weakened kidneys and worsening of the child’s condition after the procedure \[2-5,8,10\].

These fears were dependent on parental knowledge of the LP procedure, and this in turn depended on the parent’s sources of information. In this study, information was obtained from friends in 52.1% of cases, and relatives in 41.9% \[2\]. In this study no much information was obtained from the television, newspaper, magazines or even medical staff \[2\].

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

CONCLUSION

Based on the results of this study, the main reason for refusal of consent for LP in the children of the majority of parents was fear of side effects such as paralysis, as well as lack of awareness about the usefulness of LP in diagnosis and treatment of children. In addressing such a universal issue, this study might be of practical interest in other settings. Informing parents of affected children is very important in the counseling for such diagnostic tests. Therefore, it seems that it is necessary to pay more attention for training in national health plans.

REFERENCES