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Causes of Parental Refusal for Lumber Puncture in Children and Adolescents

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ABSTRACT

Background: Lumbar puncture (LP) is an important procedure utilized in diagnosing and treating central nervous system (CNS) infections in individuals of all ages. This study was done to determine the causes of parental refusal for LP in children and adolescents.

Methods: This cross-sectional study was conducted at the Department of Pediatrics, Sheikh Khalifa Bin Zayed Al Nahyan Hospital, Rawalakot, Azad Kashmir, Pakistan, from July 2022 to December 2022. A total of 289 children, aged between 1 month to 12 years, and planned to undergo diagnostic LP were analyzed. Data about the parents included gender, residence, education level, and socio-economic status. Chi-square and logistic regression analyzed the impact on LP refusal taking $p<0.05$ as significant.

Results: Of a total of 289 study participants, 206 (71.3%) were mothers. There were 63 (21.8%) study participants (parents) who refused their children to undergo LP. The most dominant causes behind refusal for LP were fear of complications of LP, invasiveness nature of the LP procedure, LP procedure is unnecessary, wanted consultation with a family physician, close family relative influenced refusal, and history of LP related complications in a family member, reported by 27 (42.9%), 12 (19.0%), 9 (14.3%), 6 (9.5%), 5 (7.9%), and 4 (6.3%), respectively. Parents from low socio-economic status households demonstrated a statistically significant association with LP refusal ($p=0.008$).

Conclusion: A significant proportion of parents (21.8%) refused diagnostic lumbar puncture for their children. The most dominant causes behind refusal for LP were fear of complications, invasiveness nature, and perceived unnecessary need.

Keywords: Adolescent, Central Nervous System, Child, Infections, Interview, Meningitis.

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INTRODUCTION

Lumbar puncture (LP) is a critical procedure utilized in diagnosing and treating central nervous system (CNS) infections in individuals of all ages[1]. With a history spanning over a century, LP remains a fundamental method for accessing cerebrospinal fluid (CSF) without the need for invasive neurosurgery, enabling the diagnosis of conditions such as meningitis, tumors, and other CNS disorders[2]. Despite inherent risks, LP boasts a commendable safety profile when done rightly and is associated with relatively fewer contraindications.[3] Particularly in resource-limited settings, LP often emerges as the primary diagnostic and therapeutic option for various neurological disorders.

Although, huge advancements in neuroimaging and blood testing technologies have emerged in the last few decades, but CSF analysis remains irreplaceable in diagnosing CNS infections, tumors, and inflammatory conditions. The emergence of liquid biopsy techniques and the identification of CSF biomarkers have broadened the clinical utility of LP, extending its indications to encompass neurodegenerative diseases, neuroinflammatory disorders, and CNS malignancies[4]. LP continues to occupy a central role in the armamentarium of neurologists and other healthcare providers[3,4].

Previous studies have highlighted a concerning trend, reporting refusal rates ranging from 25% to 44% among parents when their child is indicated for LP evaluation[5,6,7]. Factors such as beliefs, fears, and misconceptions are believed to significantly influence parental attitudes toward LP[6,7]. Finding out the causes behind the refusal of parents' LP refusal could be important to form strategies aimed at addressing parental reluctance toward the procedure. Given the limited number of relevant studies in the literature and no study from Azad Kashmir Pakistan, the present study was planned to fill this research gap. Parental refusal of LP in children and adolescents presents a significant challenge in diagnosing critical conditions like meningitis, encephalitis, and certain cancers. LP is a key diagnostic tool for analyzing cerebrospinal fluid CSF, essential for timely and accurate diagnosis. Refusal can delay necessary treatment and complicate the management of neurological disorders, infections, and cancer staging. Addressing parental concerns and improving understanding of the procedure's importance is crucial to overcoming this barrier to diagnosis. The primary objective of this research was to determine the prevalence and causes of parental refusal for LP in children and adolescents.

METHODS

This cross-sectional study was performed at the Department of pediatrics, Sheikh Khalifa Bin Zayed Al Nahyan Hospital, Rawalakot, Azad Kashmir, Pakistan, from July 2022 to December 2022. Approval from "Institutional Research Ethical Committee" was acquired (No.603/SKBZ/CMHRKT). Informed and written consent were sought from parents explaining to them the aims and process of this research. A sample size of 289 was calculated taking the anticipated proportion of parents refusing LP as 25%, with a 95% confidence level and 5% margin of error5. Inclusion criteria were children aged between 1 month to 12 years, accompanied by at least one of the parents (either mother or father, or both), and planned to undergo LP due to febrile fits, suspected meningitis, or encephalitis. Contraindications to LP or parents refusing to be part of this research were excluded. Children who had undergone LP within the past 2 weeks were also not included. Non-probability consecutive sampling technique was adopted for sample selection.

The gender of the child, age, and indication for LP were noted. Data about the parents (either mother or father) included gender and education level. Parents accompanying the child during the admission were interviewed. In case, if both parents were available, the one who preferred to be part of the interview was involved. A face-to-face interview was planned in a quiet room in the pediatric unit after obtaining permission for an interview from the parents. Parents were counseled for the risks and benefits involved in LP. The clinical need for LP was elaborated in the local language to the participants, ensuring the secrecy of their data. Participants were assured that the care and overall treatment of their child was to proceed as per institutional protocols irrespective of whether them being part of this research or not. A structured questionnaire was administered, seeking socio-demographic data and causes behind the refusal of LP (if refused). The estimated time for each interview was between 10-15 minutes. Socio-economic status was labeled as low if the family's monthly income was below 18,000 PKR, middle 18,000 to 40,000 PKR, or high if >40,000 PKR8. Residential status was labeled as urban if living in a city above or equal to the district level, or rural if living in a city/town below the district level.

For the data analysis, "IBM-SPSS Statistics, version 26.0" was used. Quantitative data like age was represented as mean and standard deviation. Categorical variables like gender, indication for LP, residence, educational level, socio-economic status, and causes behind LP refusal (if yes) were shown as frequencies and percentages. Data was stratified concerning effect modifiers and post-stratification; a chi-square test was applied to see their effect on the outcome (refusal for LP [Yes or No]). Variables with p-values below 0.200 were further subjected to multivariate binary logistic regression after adjusting for confounders. P value below 0.05

was taken as significant.

RESULTS

Total of 289 study participants, 206 (71.3%) were mothers. The mean ages of the children and parents were 4.96±3.28 years (ranging between 1 month to 12 years) and 33.03±6.86 years (ranging between 18 to 52 years), respectively. The most common indication for LP was suspected meningitis, noted in 135 (46.7%) children. Table 1 shows sowing characteristics of children and parents involved in this study.

Table 1: Characteristics of Child and their Parents (n=289)

Characteristics			Number (%)
Children	Gender	Male	156 (54.0%)
		Female	133 (46.0%)
	Age (years)	<1	45 (15.6%)
		1-5	130 (45.0%)
		6-12	114 (39.4%)
	Indications for LP	Febrile fits	82 (28.4%)
		Suspected meningitis	135 (46.7%)
		Suspected Encephalitis	72 (24.9%)
Parents	Relation to the child	Mother	206 (71.3%)
		Father	83 (28.7%)
	Age (years)	<30	109 (37.7%)
		≥30	180 (62.3%)
	Residence	Urban	81 (28.0%)
		Rural	208 (72.0%)
	Education (either mother or father, who was involved in the interview)	Illiterate	32 (11.1%)
		Primary	91 (31.5%)
		Secondary	98 (33.9%)
		Matriculation	44 (15.2%)
		Intermediate	16 (5.5%)
		Graduation or above	8 (2.8%)
	Socio-economic status	Low	121 (41.9%)
		Middle	133 (46.0%)
		High	35 (12.1%)

There were 63 (21.8%) study participants (parents) who refused their children to undergo LP. The most dominant causes behind refusal for LP were fear of complications of LP, invasiveness nature of the LP procedure, LP procedure is unnecessary, wanted consultation with family physician, close family relative influenced refusal, and past history of LP related complication in a family member, reported by 27 (42.9%), 12 (19.0%), 9 (14.3%), 6 (9.5%), 5 (7.9%), and 4 (6.3%), respectively (figure-1).

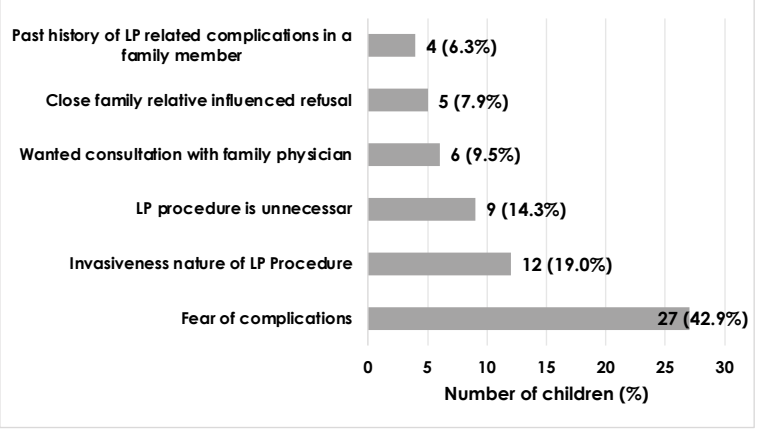

Figure 1: Causes Behind Lumbar Puncture Refusal (n=63)

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No significant association of LP refusal was found concerning gender (0.569), age (p=0.531), indications for LP (p=0.332), parent's relation to the child (p=0.775), or their age (p=0.417). Residential status (p=0.015), educational status of parents (p=0.012), and socio-economic status (p=0.016) were found to have significant association with LP refusal. Table 2 is shows details about the association of various children and parental characteristics with LP refusal.

Table 2: Association of Lumbar Puncture Refusal with Various Children and Parents-Related Characteristics (N=289)

Characteristics			Lumbar puncture refusal		P-value
			Yes (n=63)	No (n=226)	
Children	Gender	Male	36 (57.1%)	120 (53.1%)	0.569
		Female	27 (42.9%)	106 (46.9%)	
	Age (years)	<1	11 (17.5%)	34 (15.0%)	0.531
		1-5	31 (49.2%)	99 (43.8%)	
		6-12	21 (33.3%)	93 (41.2%)	
	Indications for LP	Febrile fits	23 (36.5%)	59 (26.1%)	0.332
		Suspected meningitis	28 (44.4%)	107 (47.3%)	
		Suspected Encephalitis	12 (19.0%)	60 (26.5%)	
Parents	Relation to the child	Mother	44 (69.8%)	162 (71.7%)	0.775
		Father	19 (30.2%)	64 (28.3%)	
	Age (years)	<30	21 (33.3%)	88 (38.9%)	0.417
		≥30	42 (66.7%)	138 (61.1%)	
	Residence	Urban	10 (15.9%)	71 (31.4%)	**0.015**
		Rural	53 (84.1%)	155 (68.6%)	
	Education (either mother or father, who was involved in the interview)	Illiterate	15 (23.8%)	17 (7.5%)	**0.012**
		Primary	20 (31.7%)	71 (31.4%)	
		Secondary	16 (25.4%)	82 (36.3%)	
		Matriculation	8 (12.7%)	36 (15.9%)	
		Intermediate	2 (3.2%)	14 (6.2%)	
		Graduation or above	2 (3.2%)	6 (2.7%)	
	Socio-economic status	Low	34 (54.0%)	87 (38.5%)	**0.016**
		Middle	27 (42.9%)	106 (46.9%)	
		High	2 (3.2%)	33 (14.6%)	

Chi-square test was applied.

Multivariate binary logistic regression analysis (Table 3) revealed that the parents residing in rural areas had an odds ratio of 1.92 with a 95% CI of 0.88-4.19, implying that parents from rural areas had nearly twice the odds of refusing LP compared to urban residents, though this association was not statistically significant (p=0.103). There was no statistically significant association between the education level of parents and LP refusal (p>0.05). Parents from low socio-economic status households demonstrated a statistically significant association with LP refusal (p=0.008) as the odds ratio of 8.20 (95% CI: 1.74-38.63) suggests that parents from low socio-economic backgrounds were over eight times more likely to refuse LP compared to those from high socio-economic backgrounds.

Table 3: Multivariate Binary Logistic Regression Analysis Showing Details About the Predictors of LP Refusal

Characteristics		P-value	Odds Ratio	95% CI (Lower-Upper)
Residence	Urban	Reference		
	Rural	0.103	1.92	0.88-4.19
Education (either mother or father, who was involved in the interview)	Illiterate	0.451	2.04	0.32-12.97
	Primary	0.460	0.51	0.09-3.03
	Secondary	0.280	0.37	0.06-2.23
	Matriculation	0.471	0.50	0.08-3.29
	Intermediate	0.219	0.24	0.24-2.34
	Graduation or above	Reference		
Socio-economic status	Low	0.008	8.20	1.74-38.63
	Middle	0.049	4.69	1.01-21.87
	High	Reference		

DISCUSSION

In the present study, 21.8% parents refused their children to undergo LP. In research done by Ahmad and colleagues, 32.6% families declined LP procedure for their children9. Acoglu et al revealed that 28.5% parents refused for LP10. Samreen et al in a local study documented that 26.4% parents refused for LP[11]. Another study from Sub-Saharan Africa reported that 25% of parents refused LP for their children[12]. Our study along with others report that a significant proportion of parents refuse LP for their children which can delay the diagnosis and overall treatment of these children[9,10,11,12]. The long-term impact of complications related to sub-optimal treatment of neurological diseases in the pediatric population might be impacting the healthcare system of a developing country like Pakistan.

It was noted in this study that the most dominant causes behind refusal for LP were fear of complications of LP, invasiveness nature of the LP procedure, LP procedure being unnecessary, wanted consultation with family physician, close family relative influenced refusal, and past history of LP related complication in a family member, reported by 42.9%, 19.0%, 14.3%, 9.5%, 7.9%, and 6.3%, respectively. Ahmed and colleagues noted the primary reason behind LP refusal to be fear of limb paralysis (64.2%). Additionally, 31.3% of the parents expressed fear of death as a reason for declining LP[9]. Alhebshi et al from Saudi Arabia reported that fear of complications like paralysis or pain was the most frequent cause behind parental refusal of LP[13]. Previous studies revealed that fear of complications (mainly paralysis) was the most common reason behind parental LP refusal[14]. A local study by Riaz et al revealed that 70% of the parents refused LP because they thought it was risky[15]. Anwar et al also showed that 36% of the parents refused LP because they thought it might cause paralysis[16]. Asif et al described that fear of side effects related to LP was the most frequent reason (25.2%) behind parental LP refusal[17]. A study conducted in Saudi Arabia found that 44.3% of parents refused LP, while the primary reasons for parental refusal of LP were relative's opinion (35.1%) [18]. A study conducted in a teaching hospital in Ireland reported a higher percentage of parents expressing fear of complications associated with LP[19]. High refusal rates raise several questions regarding the reasons behind LP refusal. It prompts investigation into whether these refusals are region, sex, or disease-specific, and whether they stem from patients' perceptions or practitioners' discomfort with the procedure. It has been observed that fear and misconception related to LP are major hindrances behind parents' decision to refuse LP in their children so future research should address these barriers and may seek to devise strategies to handle these hurdles[20,21]. The literature reports a wide range of reasons behind LP refusal but misunderstanding about the need for LP and procedure stands out as a common reason[22,23,24,25].

As LP is considered an essential modality for evaluating many CNS-related disorders, clinicians may not avoid the approach due to its importance in guiding clinical judgment. There is a need to create more awareness among the general population about LP and its related advantages and risks. Addressing fears and beliefs barring parents from refusing LP may reduce the proportion of parents refusing their children to undergo LP[17]. There is also a need to address underlying causes due to which parents refuse LP as parents might not see the potential benefits of LP. Local research should also be planned to evaluate the effectiveness of counseling while acquiring informed consent from parents for LP which can ultimately facilitate informed decision-making and optimizing patient care. Being a single-center study, our findings

cannot be generalized and need further verification in large multicentric studies.

CONCLUSION

A significant proportion of parents (21.8%) refused diagnostic lumbar puncture for their children. The most dominant causes behind refusal for LP were fear of complications, invasiveness nature, and perceived unnecessary need. Parents from low socio-economic status households demonstrated a statistically significant association with LP refusal. There is a need to create more awareness among general population about LP and its related advantages and risks.

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ETHICAL APPROVAL

The permission was obtained from the Research Ethical Committee of the HH Sheih Khalifa Bin Zahyed Al Nahyan / Combined Military Hospital, AK CMH Rawlakot, with letter number 6.0/SKB2/CMH RKT, dated: 03-06-2022.

CONFLICT OF INTEREST

The authors have no conflict of interest.

AUTHORS CONTRIBUTIONS

SI: Data collection, drafting, responsible for data's integrity, approved for publication
RIA: Designed, conceived the idea, supervised, proofreading, approved forpublication

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