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ORIGINAL ARTICLE

Knowledge, Attitude and Practice (KAP) Study of Pediatricians on Infantile Spasms: An online survey from Pakistan

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ABSTRACT

Objective: To assess the knowledge, attitude, and practices (KAP) of Pakistani pediatricians regarding infantile spasms (IS).

Study Design: Descriptive cross-sectional study.

Place and Duration of Study: An online survey across Pakistan, conducted from January 2023 to March 2023.

Material and Methods: This study enrolled 117 practicing pediatricians via an online survey shared through pediatricians' Whats App groups. The survey captured data on KAP regarding IS. Data analysis was performed using SPSS version 26. Frequencies and percentages were calculated for the KAP variables.

Results: A majority of participants, 109 (93.2%), correctly identified IS as a type of seizure. Jerks occurring in clusters were recognized as a hallmark feature by 92 (78.6%) participants, while only 2 (1.7%) identified Salaam Seizures. About 89 (76%) pediatricians reported encountering at least one IS case per month. EEG and MRI facilities were available in 84 (71.8%) and 74 (63.2%) setups, respectively. Etiology was considered "very important" by 64 (54.7%) respondents. Most participants had correct knowledge of the first-line treatment. However, only 33 (28.2%) correctly identified "spasm cessation for four weeks" as a complete treatment response. Nelson's Textbook of Pediatrics was cited as a primary guideline by 89 (76.1%) pediatricians.

Conclusion: While Pakistani pediatricians are managing IS cases, there are gaps in their knowledge and understanding of its diagnostic and therapeutic aspects. Enhancing the KAP of pediatricians through targeted educational interventions is crucial to improve outcomes for children with IS

Key Words: *Infantile spasm, Pediatrician, West Syndrome, Knowledge, Attitude, Practice*

INTRODUCTION

Infantile spasm (IS) is a condition that primarily affects infants and young children. It is one of the most severe childhood epilepsies and is indicative of a true epileptic encephalopathy.[1,2] The incidence ranges from 1 in 2400 to 5500 live births. Infantile spasms typically appear between

the ages of 2 and 9 months, though they can appear as late as 2 years of age. Rapid detection and treatment of infantile spasms is a top priority since prompt administration of adequate medication increases the likelihood of epileptic spasm resolution and improves cognitive results.[3]

IS has a diverse etiology, in part because it can be the clinical manifestation of a number of hereditary or acquired disorders. Extrinsic brain traumas, metabolic encephalopathies, brain deformities, and chromosomal abnormalities are major causes of IS; nonetheless, roughly 30% of cases remain unexplained. Pathogenic variations in over 30 genes have been discovered in patients with unexplained IS, several of which are also connected with other seizure types.[4]

Infantile spasms have been diagnosed using neuroimaging and genetic testing.[5] Children with infantile spasms benefit from early diagnosis and treatment with appropriate conventional drugs such as hormone therapy (ACTH or prednisolone) or vigabatrin.[6,7] Contrary to widespread belief, even patients with recognised etiologies or prior developmental delay benefit from proven standard therapy. After two weeks, electroencephalography should be used to check treatment efficacy, and if epileptic spasms or hypsarrhythmia have not resolved, an alternate therapy should be considered. Collaboration with primary care providers is essential for mitigating the potentially serious adverse effects of standard treatments as well as providing developmental interventions.[7]

South Asian resources are insufficient to fulfil current recommendations for investigating etiology of IS. The two most common impediments to a thorough etiological examination are a lack of money for investigations and inadequate laboratory support. In the ILAE 2017 classification, only around half of pediatric neurologists can attempt to classify etiology according to etiological subgroups. Including the incompletely researched etiological subcategory was considered an alternative to decrease the limitation posed by the "Investigation Gap".[8]

Developing countries face difficulties in managing infantile spasm at different stages starting from level of awareness, availability and accessibility of diagnostic facility and poor adherence to prescribed treatment.[9] There is a scarcity of data on pediatricians' knowledge, attitudes, and practise in developing countries. The knowledge, attitude, and practise (KAP) study provides an informative diagnosis of the population under research. As a result, the current study was designed to determine pediatricians' knowledge, attitude, and practise (KAP) regarding infantile spasms in Pakistan.

MATERIAL AND METHODS

This descriptive cross-sectional study was conducted across Pakistan from January 2023 to March 2023 and was designed at the Pediatric Neurology Department, Children Hospital & Institute of Child Health, Faisalabad, Pakistan. Ethical permission was obtained from Hospital ethical committee. Participants' willingness to fill the survey was considered as consent. All the practicing pediatricians from Pakistan were invited to participate in the study by sharing the google form in WhatsApp group of pediatricians. Non response was considered as exclusion criteria. A total of 117 pediatricians filled the survey. Data of knowledge, attitude and practices regarding Infantile Spasm was collected.

Questionnaire was prepared by extensive literature search, face and content validity was achieved by review from pediatrician and pre-testing was done before sharing this questionnaire as a study tool. It consists of 18 questions and meant to collect information regarding knowledge (Question No.1-9), attitude (Question No.16-18) and practice (Question No.10-15) for infantile spasm.

Data was exported from CSV file to SPSS version 26 and descriptive statistics was applied. Mean and standard deviation was calculated for numerical data whereas frequency and percentages were measured for categorical data.

Data analysis was performed by SPSS version 26 using descriptive statistics to determine the frequency and percentages for of Knowledge, Attitude and Practices towards Infantile Spasm.

RESULTS

A total of 117 respondents filled the online questionnaire mean age of the participants was 37.97 $\pm$ 10.27. Among respondents 50 (42.7%) were female and 67 (57.3%) were male. Subjects

belonged to different provinces of Pakistan. Majority were from Punjab 91 (77.8%) followed by KPK 15 (12.8%). There was a small representation from Sindh 5 (4.3%), Baluchistan 4 (3.4%) and GB 2 (1.7%).

Majority of the participants had <5 years' experience 75 (64.1%) and 42 (35.9%) had experience >5 years. Regarding work settings 67 (57.3%) were working in government sector, 35 (29.9%) in Private sector and remaining 15 (12.8%) were working at both government and private sector.

Frequency and percentages of the responses of questions regarding knowledge, attitude and practice are presented in table 1.

TABLE 1: Knowledge, Attitude and Practice of Pakistani Pediatricians about Infantile Spasm

Q. No	Questions	Majority Responses f (%)	Minority Responses f (%)
	Questions regarding Knowledge N=117		
1	What is infantile spasm?	Type of seizure109(93.2%)	Extra-pyramidal movement disorder 4 (3.4%) Non-epileptiform disorder 4 (3.4%)
2	Pointers towards infantile spasms?	Jerks occurring in clusters 92 (78.6%) Developmental delay 21 (17.9%)	Inconsolable cry 2 (1.7%) Salaam Seizures 2 (1.7%)
3	How often do you see cases of infantile spasms per month?	1-5 cases 72 (61.5%) Rarely 28 (23.9%)	>5 cases 17(14.5%)
4	What is the average number of children you would newly diagnose with WS per year?	<10 cases 85(72.6%) 11-20 cases17(14.5%)	>20 cases 10(8.5%) Rarely 5 (4.3%)
5	What facilities are available in your hospital to investigate the etiology of infantile spasms?	EEG 84 (82.9%) MRI 74 (63.2%) Tests for Inborn Errors of Metabolism 21(17.9%)	Genetic Studies 17 (14.5%) Facility not available 14 (12%) Immunological Testing 8 (6.8%) CT 1(0.9%)
6	Underlying etiologies of infantile spasms, that you have come across till now?	Idiopathic 70(59.85%) Perinatal asphyxia 61(52.1%) Tuberous sclerosis 55(47%) Structural brain defects 50(42.7%) Inborn errors of metabolism 42(41.7%)	Hypoglycemic brain injury 15(12.8%) Prematurity 1(0.9%) No experience 1(0.9%)
7	Etiologic classification of infantile spasms, that you have come across till now, during your clinical practice?	Idiopathic 84 (71.7%) Symptomatic 57(48.7%) Cryptogenic 38 (32.4%)	Congenital brain malformation1 (0.9%)
8	Types of infantile spasms, that you have managed till now?	Flexor spasms 76(64.9%) Mixed spasms 57(48.7%) Extensor Spasm 41(35%) Subtle infantile spasms 29(24.7%)	Hemi infantile spasms 5 (4.3%) None 2 (1.7%)
9	How important it is to classify the etiology of infantile spasms in your opinion?	Very Important 64 (54.7%) Important 40 (34.2%)	Unsure 12 (10.3%) Not Important 1 (0.9%)

	Questions regarding Practice		
10	First Drug of Choice (DOC) in your opinion? n=117	ACTH 41 (35.0%) Oral Corticosteroids 36 (30.8%) Oral Vigabatrin 30 (25.6%)	Oral Valproate 4(3.4%) Oral Phenobarbitone 3 (2.6%) Levetiracetam 2 (1.7%) Depend upon Cause 1 (0.9%)
11	Preferred reason for the chosen Drug of Choice (DOC)? [ACTH] n= 42	Efficacy 34 (80.9%) Safety 13 (30.9%)	Availability 6 (14.2%) Tolerability 1 (2.4%)
11	Preferred reason for the chosen Drug of Choice (DOC)? [Oral Corticosteroids] n=52	Availability 48 (92.3%) Efficacy 23 (44.2%) Safety 14 (26.9%)	Tolerability 11(21.1%)
11	Preferred reason for the chosen Drug of Choice (DOC)? [Oral Phenobarbitone] n=9	Efficacy 5 (55.5%) Availability 3 (33.3%) Safety 3 (33.3%) Tolerability 3 (33.3%)	
11	Preferred reason for the chosen Drug of Choice (DOC)? [Oral Valproate] n=10	Availability 7 (70%) Tolerability 4 (40%) Safety 3 (30%)	
11	Preferred reason for the chosen Drug of Choice (DOC)? [Oral Vigabatrin] n=32	Efficacy 23 (71.8%) Availability 14 (43.75%) Safety 12 (37.5%)	Tolerability 6(18.75%)
11	Preferred reason for the chosen Drug of Choice (DOC)? [Other] n=6	Availability 4 (66.6%) Safety 2 (33.3%) Tolerability 2 (33.3%)	Efficacy 1(16.6%)
12	Do you make a treatment decision following an EEG? n=117	Yes 72 (61.5%) No 37 (31.6%)	Unsure 8 (6.8%)
13	What do you mean by treatment response? n=117	Spasms are reduced by 50%. 49 (41.9%) Spasms have completely stopped. 48 (41.0%)	Reversal of EEG findings 12 (10.3%) Achievement of developmental milestones 8 (6.8%)
14	What exactly do you mean by "complete response"? n=117	Spasms are no longer occurring for 4 weeks (Cessation of spasm) 33 (28.2%) Frequency of spasms once /month 33 (28.2%) Frequency of spasms once/year 21 (17.9%) Cessation of spasms for 2 weeks 15 (12.8%)	Cessation of spasms for 1 week 6(5.1%) Not sure 4 (3.4%) Cessation of spasm 2(1.7%) No seizures for consecutive 2 years 1(.9%) Continued cessation For 3 months 1(.9%) achievement of milestones1 (.9%)
15	What do you understand by treatment failure? n=117	Failure of clinical response in 14 days 56 (47.9%) Failure of clinical response in 28 days 41 (35.0%)	Failure to complete response 13 (11.1%) Spasms reoccurrence after complete response 7 (6.0%)

	Questions Regarding attitude n=117		
16	For what purpose do you consider referral to a pediatric neurologist?	Failure of response to treatment 67(57.3%) For treatment purpose 20 (17.1%)	For diagnostic purpose 18 (15.4%) For EEG 8 (6.8%) For follow up 4 (3.4%)
17	Which treatment guidelines you use for infantile spasms?	Nelson's Textbook of Pediatrics 89(76.1%) Evidence Based Guidelines 47 (40.2%) Pediatric Journals 20 (17.1%)	Up-to-date 1 (.9%) Consult with Pediatric Neurologist1 (.9%)
18	Do you think more awareness is required among pediatricians regarding infantile spasms?	Yes 115 (98.3%)	No 1(0.9%) Unsure 1(0.9%)

DISCUSSION

Infantile spasm (IS) is a severe epileptic encephalopathy that occurs in infancy. Historically, West syndrome was defined by clinical seizures (epileptic spasm, ES), an abnormal interictal electroencephalogram (EEG) pattern (hypsarrhythmia), and developmental issues.[10] However, developmental delay and hypsarrhythmia are not always apparent at the start of the disease. IS requires a high index of suspicion as well as a prolonged EEG. Time to treatment and drug choice may influence short- and long-term outcomes more than any other epilepsy syndrome.[11,12] A survey similar to the present study was conducted in India and had similar results.[9] Another similar study was conducted in Turkey with similar findings but majority of the respondents referred patients to pediatric neurologist while in our study most of the patients were treated by pediatricians themselves due to less number of pediatric neurologist.[13]

In the present study majority of the pediatricians correctly identified infantile spasm as a type of seizure. Jerks occurring in clusters were recognized as pointers by many subjects whereas Salaam seizures by only few subjects. Atlesat 1 case per month was seen by 76% pediatricians. EEG and MRI were present largely at many setups but detailed workup was available less frequently. Most of them had knowledge about etiology and had come across idiopathic, symptomatic and cryptogenic causes in practice. Knowing etiology was considered very important by half of the participants only. Most of the subjects had correct idea regarding first drug of choice.[9,13,14] Few wrongly selected oral valproate, oral phenobarbitone, levetiracetam as first choice

Regarding treatment response almost 60% of the subjects had understanding, complete cessation of spasms was reported by 41.0% and Reversal of EEG findings by 10.3%.[9,13] None of the subject correctly mentioned that both of them are required.

Complete response was correctly identified as cessation of spasms for 4 weeks by 28.2% subjects only. Treatment failure was correctly identified as failure of clinical response in 14 days by 47.9% subjects only. Majority mentioned that they use Nelson's Textbook of Pediatrics as a source of guidelines[9] which is not correct as this may not be updated. Peer reviewed journals, up to data were used as guidelines by few subjects. Most of them believe that more awareness is required for infantile spasm.[9,13] Another study concluded that lack of awareness leads to delayed diagnosis and poor prognosis.[2] Early diagnosis is one of the key factor is the management of infantile spasm.[15] A review on South Asian countries reported that delayed diagnosis, limited availability of ACTH which is the first line drug,[7] few resources and more burden are the challenges for this particular region in the management of infantile spasm. It was reported that a considerable knowledge gap exist and by creating awareness among first contact point persons which are pediatricians in such cases will help.[16]

Limitations of the study are; sample size was not calculated, convenient sampling, those who do not use social media could not reach and may have different knowledge.

Recommendations of the current study are that in our country where there are only few pediatric neurologists and first point of contact, diagnosis and often treatment is offered by a pediatrician and referral is either not feasible or affordable, pediatricians must be trained in early recognition, timely and appropriate management as per accepted guidelines and where needed appropriate referral. Training may be done through workshops and seminars and local guidelines may be developed to facilitate the pediatricians and the patients.

CONCLUSION

Pediatricians are managing children with infantile spasm. They have some knowledge but to make is more precise there is dire need to improve knowledge, attitude and practices of pediatricians of Pakistan.

Conflict of Interest: Nil

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