Evaluating Awareness, Availability, and Implementation of Seizure Action Plans (SAP) in Schools of Karachi, Pakistan

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Abstract

Epilepsy, a neurological disorder characterized by recurrent seizures, affects millions globally, particularly in low- and middle-income countries like Pakistan. Despite its prevalence, stigma and misconceptions surrounding epilepsy persist, necessitating educational initiatives to enhance awareness and understanding. This cross-sectional study, conducted in Karachi, Pakistan, aimed to identify barriers to the awareness, availability, and implementation of Seizure Action Plans (SAPs) in schools. Thirty-two teachers from urban schools participated in structured interviews. Most participants, 65.6%, were aware of SAPs; however, their availability in schools was limited, with only 56.3% participants reporting their presence. Lack of awareness (68.8%), funding (15.6%), understanding (12.5%), and access to medical resources (6.2%) were cited as reasons for the absence of SAPs. Participants demonstrated limited knowledge of first-aid procedures, with only 53.1% knowing how to administer first aid during seizures. Moreover, only 6.25% were aware of emergency medication to be given during seizures. Discrepancies between perceived and actual responses to seizure incidents were evident, highlighting the urgent need for improving awareness and preparedness among educators. A comparison with international studies revealed similar challenges that educators face, emphasizing the importance of epilepsy awareness campaigns and comprehensive training initiatives. Addressing these barriers can lead to improved awareness, reduced stigma, and better outcomes for individuals living with epilepsy.

Keywords: *Seizure, epilepsy, awareness, seizure action plans, LMIC.*

INTRODUCTION

Epilepsy is a neurological disease characterized by recurrent seizures that occur as a result of synchronized, high-frequency neuronal firing and may happen without any provoking factors. According to WHO, 50 million people worldwide have epilepsy and approximately 80% of people with epilepsy live in low- and middle-income countries [1]. In Pakistan, it is estimated that 0.99% of the general population has epilepsy, with the highest prevalence seen in people younger than 30 years of age [2]. Previous studies conducted in Pakistan have found that the majority of participants believe that epilepsy is caused by supernatural causes (possession by jinn's), is a mental illness, or a hereditary disease. Moreover, most participants reported learning about epilepsy from friends and relatives [3]. Such findings highlight the need for educational initiatives and awareness campaigns to increase knowledge about epilepsy in Pakistan to reduce the stigma and discrimination faced by people living with epilepsy and to improve their quality of life.

A seizure action plan (SAP) is a document that provides parents, caregivers, and teachers with step-by-step instructions for managing prolonged seizures and administering rescue medications to patients with epilepsy. Currently, no standardized or official SAP documents are available in schools in Pakistan, and limited resources exist in Pakistan to train teachers regarding steps to take in the setting of an epilepsy episode. However, first aid training and emergency medication administration play an essential role in preventing physical trauma and long-term brain damage, which highlights the importance of the availability and implementation of standardized SAP in schools.

Our study aims to assess the key barriers related to awareness, availability, and implementation of the Seizure Action Plan (SAP) among schools in Karachi, Pakistan, to formulate targeted strategies for implementing SAP in educational settings.

METHODS

The study was conducted in three urban schools in Karachi, Pakistan. These schools were selected based on prior exposure to students with epilepsy. Data collection was conducted from January to December 2024. The study followed the STROBE guidelines for reporting observational studies [4].

A purposive sampling approach was employed. Schools that had reported seizure episodes among students were identified, and relevant staff, including teachers,

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school nurses, and special education staff, were invited to participate. Data was collected from 38 individuals, out of whom 6 had missing data and were thus excluded from the study. Hence, a total of 32 participants were included in the study.

Ethical clearance was obtained from the Ethical Review Committee at Aga Khan University (ERC Number: 2023-8929-27232), and informed consent was obtained from all participants and schools involved before the interviews were conducted.

A structured interview approach was utilized to investigate the relationship between various independent variables and respondents' knowledge, experiences, and perceptions regarding seizure management and epilepsy awareness within school settings. Our co-authors, who received formal training, conducted the interview, which lasted approximately 10 minutes.

The interview consisted of twelve questions divided into three sections focusing on awareness, availability, and implementation of Seizure Action Plans (SAPs). Trained interviewers conducted face-to-face interviews with participants.

In the awareness section, participants' understanding of seizure management and SAPs was assessed through questions covering awareness of SAPs, experience with seizure incidents, and perceived steps in an SAP. These steps included providing first aid, taking the child to a nearby hospital, calling parents, calling an ambulance, adjusting the child's position, allowing the child to settle independently, and taking the child to the school doctor or sickroom.

The availability section evaluated the presence of a seizure plan at school and reasons for its absence, such as lack of awareness, understanding, funding, or availability of doctors/hospitals to provide SAP documents.

Finally, the implementation section measured participants' confidence in adhering to SAPs, familiarity with first aid procedures, understanding of emergency medication administration, awareness of when to call emergency services, opinions on the necessity of SAPs, exposure to epilepsy awareness campaigns, and beliefs about epilepsy treatability. The survey included closed-ended questions with predefined response options and a few open-ended questions for detailed insights.

These questionnaires were reviewed for content validity by practicing neurologists; however, due to the exploratory design and limited sample size, formal reliability and validity analyses were not conducted.

All data were analyzed using IBM Statistical Package for Social Sciences (SPSS) version 26. Descriptive analysis was employed to examine the data gathered from structured interviews. Frequency and percentages were computed for categorical variables.

RESULTS

Awareness was determined through three closed-ended and two open-ended questions. The respondents included 17 teachers, four physiotherapists, four occupational therapists, two speech therapists, two behavior therapists, one psychologist, one special educator, and one occupational intern (**Fig. 1**).

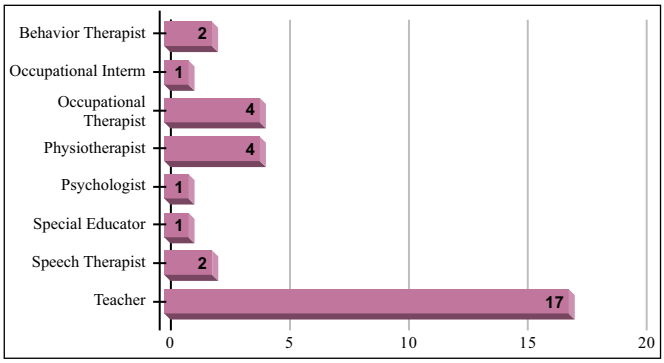

Fig. (1): Designation of study participants (n=32).

21(65.6%) participants reported that they were aware of what a seizure action plan meant (**Table 1**), and 18 (56.3%) participants stated that a plan was available within their schools to deal with a child suffering from a seizure (**Table 1**). 17 (53.1%) participants had prior episodes of a child suffering from a seizure in their schools. In 7 instances, the child was given first aid, whereas in 9 instances, the child's position was adjusted. In 2 cases, the child was taken to a nearby hospital, and in one case, an ambulance was called. The child's parents were called in 8 cases, whereas in 2 cases the child was allowed to settle independently (**Table 1**).

Table 1: Awareness, availability, and responses to seizure events among school staff (n=32).

Variables	Frequency	Percentage
Aware of what a Seizure Action Plan (SAP) is	21	65.6
SAP available in their school	18	56.3
Prior episode of seizure in school	17	53.1
Actions Taken During Seizure Episodes		
Provided first aid	7	41.2*
Adjusted child's position	9	52.9*
Taken to a nearby hospital	2	11.8*
Ambulance was called	1	5.9*
Child's parents were called	8	47.1*
Child allowed to settle on their own	2	11.8*

*Percentage of actions taken are calculated based on 17 participants who reported an encounter to prior seizure episode in their school.

The participants were also asked about their opinion regarding steps to take in a seizure action plan, and varying responses were received. Ten participants (31.2%) stated safety and support measures should be taken, nine participants (28.1%) stated medical assistance should be provided, and 13 participants (40.6%) reported that positioning and adjustment should be done (**Table 2**).

Table 2: Understanding of seizure action plans (SAPs) among participants (n=32).

Suggested Steps in SAP	Frequency (n)	Percentage
Safety and Support	10	25.6
Medical Assistance	16	41.0
Positioning and Adjustment	13	33.3

*Multiple responses allowed.

When inquired regarding Barriers to SAP Availability. The lack of availability of seizure action plan in schools was attributed to lack of awareness by 22 (68.8%) participants, a lack of funding by 5 (15.6%) participants, a lack of understanding by 4 (12.5)% participants and a lack of hospital and doctors to provide SAP documents by 2 (6.2%) participant (**Fig. 2**).

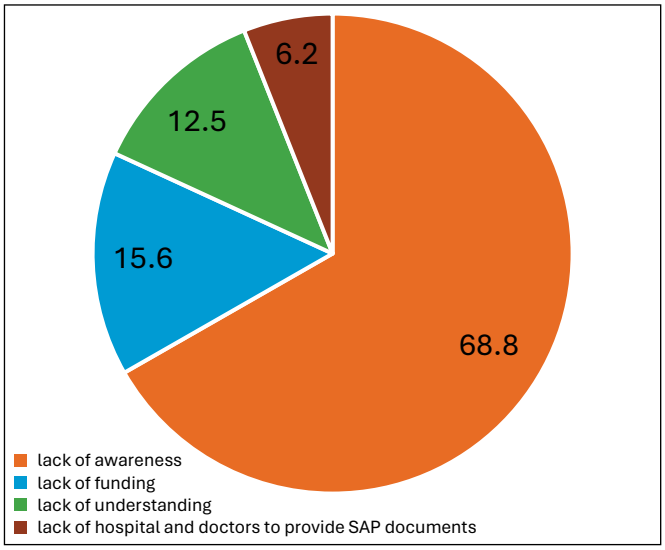

Fig. (2): Reported barriers to SAP availability.

21(65.6%) participants stated that they could manage a seizure at their school according to the seizure action plan; however, only 17 (53.1%) participants knew how to give first aid during the event of a seizure. 2 (6.25%) participants were aware of the emergency medication to be given during the event of a seizure. They acquired this information from a healthcare professional in 1 case and a parent in the second case. 20 (62.5%) participants reported that emergency ambulance service should be called immediately in case of a seizure, whereas 10 participants (33.3%) stated ambulance should be called if the seizure lasts more than 5 minutes. All 32 participants agreed that a seizure action plan should be available in their schools. 8 (25%) participants reported hosting an epilepsy awareness campaign in their schools. 22 (68.75%) participants considered epilepsy to be an ailment that can be treated, whereas 10 participants (31.25%) considered epilepsy to be untreatable. These results have been presented in Table **3**.

Table 3: Participants' responses on implementation and emergency readiness of seizure action Plans (n=32).

Participants' Responses	Yes n (%)	No n (%)
Confident in managing a seizure according to a Seizure Action Plan (SAP)	21 (65.6)	11 (34.4)
Know how to administer first aid during a seizure	17 (53.1)	15 (46.9)
Believe SAP should be available even if not currently implemented	32 (100)	0 (0)
I have previously hosted an epilepsy awareness campaign in school	8 (25.0)	24 (75.0)
Believe epilepsy is a treatable condition	22 (68.8)	10 (31.3)
Know when to call emergency services (Rescue 1122)	Immediately	If seizure lasts more than 5 minutes
Total	20 (62.5)	10 (31.3)

DISCUSSION

Education regarding epilepsy has been effective in decreasing stigma and misconceptions surrounding epilepsy. Studies conducted by Kaddumukasa *et al.* [5], Hermann *et al.* [6], and Musekwa *et al.* [7] have highlighted the importance of strengthening epilepsy education, as it leads to a reduction in stigma and misconceptions, and equips individuals with the skills to manage epileptic attacks. Hashemi *et al.* [8] further highlighted the significance of education in equipping individuals with the knowledge and skills needed to manage epileptic episodes. Our study echoes these findings, revealing a notable gap in knowledge among teachers despite the recognized benefits of epilepsy education.

Previous literature has also underscored the lack of formal training among teachers in epilepsy management. A study conducted in Sudan reported that none of the teachers had received prior training on epilepsy, a significant percentage (58.5%) were unaware of the etiology, more than 65% believed that epilepsy could not be cured, and 33.1% thought that it could not be controlled even by medical treatment [9]. A study conducted in Zimbabwe reported that 89% of the teachers had heard or read about epilepsy, 4.2% respondents had observed epileptic seizures in their pupils in the class setting; however, none of the teachers had had a formal teaching or lecture on epilepsy, about half (49.1 %) of the teachers believed that seizures could be reduced with medical intervention [10]. The results of our study align with those of the studies mentioned above. Among the participants, 17 individuals (53.1%) reported prior episodes of a child suffering from a seizure in their schools. However, only seven instances (24.1%) were reported where first aid was administered during the event of a seizure. This discrepancy highlights educators' need for improved awareness and training regarding proper first-aid procedures for managing seizures in school settings.

Our study also highlights the importance of epilepsy awareness campaigns conducted by medical professionals in schools. While only a quarter of participants reported exposure to such campaigns, the majority (68.8 %) believed that epilepsy was treatable.

This emphasizes the need for more widespread and comprehensive educational initiatives to address misconceptions and improve teachers' knowledge about epilepsy.

Comparison with other studies, such as those conducted in Campina Grande, Brazil [11], Thailand [12], reveals similar challenges in epilepsy education and management among educators worldwide. These studies demonstrate varying levels of knowledge and preparedness among teachers regarding seizure management, with many lacking awareness of proper first-aid measures. Most respondents (86.4%) did not know the appropriate measures for first-aid management of seizures. Many gave potentially harmful interventions for first-aid seizure management, including inserting a spoon or a gag or cloth into the mouth of a seizing person (73%), trying to hold the person down (30.2%), and putting patients on their backs (18.9%) [12]. This was also highlighted in our study, in which the participants reported how the child's position was adjusted (31%) and the child was allowed to settle independently (6.9%) during a seizure. Thus, the need for comprehensive training on identifying seizure symptoms and implementing seizure rescue procedures is evident.

Yang *et al.,* in their study conducted in 2021 in Shanghai, found that, due to the lack of professional knowledge, teachers were inclined to be afraid that their wrong measures could cause damage and would instantly ask people around to find the school doctor for professional help [13]. Moreover, teachers believed that they needed training in accurately identifying the symptoms of seizure and implementing seizure rescue correctly [13]. This need for proper training and guidance in seizure management is echoed in our study, where all participants emphasized the importance of having a Seizure Action Plan (SAP) available in schools. This underscores the significance of SAPs in guiding appropriate seizure management and highlights the importance of comprehensive training for educators.

STRENGTHS AND LIMITATIONS

To the best of our knowledge, the study is among the first to explore the knowledge, attitude, and practice of Seizure Action Plans (SAPs) among teachers, both regionally and in broader literature. However, the study does acknowledge several limitations. Firstly, the small sample size of only 32 participants may affect the generalizability of the results. Secondly, the cross-sectional design restricts the establishment of causal relationships between variables. Additionally, the study did not consider confounding variables such as teachers' prior training or experience managing seizures. Moreover, although the questionnaires were reviewed for content validity by a practicing neurologist, formal reliability and validity analysis were not conducted due to the study's exploratory design and limited sample size. Despite these limitations, the study serves as a crucial initial step in highlighting the importance of implementing SAPs in educational settings. It lays the groundwork for future population-based studies that could provide further insights into seizure management practices among teachers and inform the development of comprehensive intervention strategies.

CONCLUSION

This study aimed to identify the barriers related to awareness, availability, and implementation of the Seizure Action Plan in Pakistan. The findings underscore the importance of awareness regarding epilepsy and seizures and highlight the need to implement the Seizure Action Plan in schools by addressing the underlying factors, such as lack of awareness, funding, understanding, *etc.*, contributing to the lack of implementation to ensure individuals with epilepsy receive proper first aid during seizure episodes and to target any misconceptions regarding the ailment.

ETHICS APPROVAL

Ethical clearance was obtained from the Ethical Review Committee at Aga Khan University (ERC Number: 2023-8929-27232)

CONSENT FOR PUBLICATION

Informed consent was obtained from all participants and schools involved before the interviews were conducted.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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AUTHORS' CONTRIBUTION

Syeda Samnita Batool Zaidi: Literature review, data analysis and manuscript writing, Mehreen Taufiq: Conceptualization, data collection, Aqsa Amjad: Literature review, data analysis and manuscript writing, Yusra Tariq: Manuscript reviewing and editing, supervision, Jay Kumari: Manuscript reviewing and editing, supervision, Muhammad Shahzad Zafar: Manuscript reviewing and editing, supervision, Wajeeha Khalid: Manuscript reviewing and editing, supervision, Prem Chand: Conceptualization, Manuscript reviewing and editing, supervision, project administration.

DISCLAIMER

The views expressed in the submitted article are our own and not the official position of the institution.

GENERATIVE AI AND AI-ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

During the preparation of this work the authors limitedly used ChatGPT (GPT-4, OpenAI) to get language

suggestions and do minor proofreading in some parts of the manuscript. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

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