Reactions of Relatives of Epileptic Patients to Witnessed Seizures

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ABSTRACT

Raising awareness of appropriate actions to aid a person experiencing a seizure is essential because misinformed responses are common among the general public. This study aimed to evaluate the knowledge, awareness, and perceptions of non-medically trained relatives of epilepsy patients regarding epilepsy in Jeddah, Saudi Arabia. A cross-sectional analysis was conducted on a group of anonymous adults in Saudi Arabia, who participated in a survey distributed to relatives attending a single neurology clinic. In addition, an electronic questionnaire was administered via social media platforms. This study aimed to assess the level of awareness of witnessed seizures in prehospital settings from May 2020 to August 2020. A total of 212 individuals participated in the survey. Among them, 25.5% identified as spouses, and 31.6% fell within the age group of 19 to 29 years. The recommended correct response, involving placing the patient on their side with or without calling an ambulance, was selected by 53.3% of respondents. Notably, only 23.6% of those who chose this action did so without combining it with any other potentially harmful interventions. The most common incorrect action among participants was the attempt to insert a hard object into the patient's mouth, chosen by 37.7% of the participants. This was followed by an attempt to restrain the patients tightly to prevent them from seizing, selected by 13.2% of respondents. Furthermore, 32.1% of the participants believed that the typical duration of a seizure is less than two minutes. While patients' relatives demonstrate better awareness in certain areas than the general public, overall knowledge remains insufficient. The healthcare sector must intensify efforts to enhance epilepsy awareness among them.

INTRODUCTION

Epilepsy is one of the most common neurological disorders, affecting more than 50 million people worldwide. In Saudi Arabia, its prevalence is estimated to be 6.54 per 1000[1,2]. Unfortunately, it is associated with many misconceptions and myths, and given that it is one of the most common neurological disorders, it is extremely vital to raise public awareness toward it[3,4,5].

Relatives of epileptic patients are more likely to witness an actively seizing patient; therefore, raising awareness about epilepsy will improve their actions when witnessing seizing patients, which can be lifesaving on some occasions. Actions such as spraying water or holding the patient's tongue during active seizures may cause serious harm to both patients and rescuers. These actions, unfortunately, are common in the general population in Saudi Arabia[6,7].

This study aimed to evaluate the knowledge, awareness, and attitudes of patients' relatives with a non-medical background toward epilepsy in Jeddah, Saudi Arabia.

METHODS

A cross-sectional analysis was conducted on a group of anonymous adults in Saudi Arabia who participated in a survey distributed to attending relatives at a single neurology clinic. In addition, an electronic questionnaire was administered via social media platforms. This study aimed to assess the level of awareness of witnessed seizures in prehospital settings from May 2020 to August 2020.

The collected data included participant demographics, knowledge about epilepsy, professional background, general conception of the correct measures to follow, and expectations regarding the average time of a seizure attack (Table 1). No personal data that could identify the participants was required in this survey.

The correct answer was defined as choosing the answer of "putting the patient on their side" with or without choosing the answer "calling the ambulance" without picking any of the other wrong answers (e.g., spray water over the patient's face, put a hard object in the patient's mouth, try to hold the patient's tongue to prevent tongue swallowing or holding the patient tight and trying to prevent him from seizing).

Exclusion criteria were having no relatives or close friends diagnosed with epilepsy or if the participant had any medical field employment or experience.

Statistical analysis was performed using "IBM SPSS statistics ver. 20.0" to evaluate and test the hypotheses, simple/cross-tabulation frequency tables and percentages. The chi-squared test was used to test and describe the relationship between the two categorized variables. The level of $P<0.05$ was used as the cut-off value for significance.

Ethical approval was obtained from the Research Ethics Committee of the University of Jeddah (application number: UJ-REC-204). The committee reviewed the research project for compliance with the regulations and policies of bioethics scientific research of the University of Jeddah and principles of the national law of ethics of research on living things by the Bureau of Experts at the Saudi Council of Ministries and the National Committee of Bioethics at King Abdulaziz City of Science and Technology.

Consent to participate was included on the first page of the questionnaire provided to participants.

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Table 1: The survey given to participants.

Question	Response
What is your relationship to an individual diagnosed with epilepsy?	• Parent • Spouse • Son/daughter • Brother/sister • Close friend • Other
Would you be more likely to help a seizing patient?	• Yes • No • I don't know
Which of the following actions do you think is helpful when trying to help a seizing patient outside the hospital environment (you can choose more than one answer)	• Spray water over the patient's face • put a hard object in the patient's mouth like a piece of fabric • Try to hold the patient's tongue to prevent it from swallowing • Hold the patients tight and try to prevent them from seizing • Put the patient on his/her sides • Call the ambulance
How long do you think most epileptic convulsions lasts?	• Less than two minutes • Between 2 to 5 minutes • Between 5 to 10 minutes • More than 10 minutes

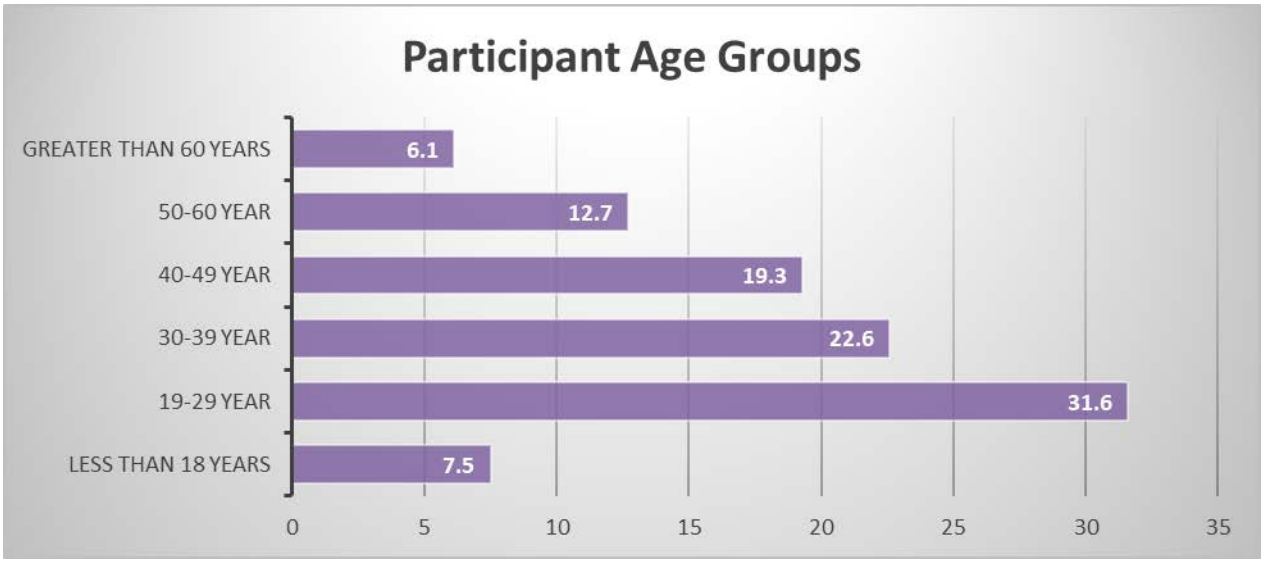


Figure 1. Age group distribution among participants.

RESULTS

A total of 212 participated in this survey, with 51% of them were males, 49% female. The age group was mostly between 19 and 29 years (31.6%), followed by 30 to 39 years (22.6%). Of these, 25.5% were spouses, followed by parents which were 21.7%; more details about demographics are provided in the Figure 1 and Figure 2.

One of the survey questions was "What is, in your opinion, a correct action to be taken when seeing an actively seizing patient?" The responses are listed in Table 2.

The correct answer was to place the patient on his/her side with or without calling the ambulance, without choosing any of the other wrong answers.

Of the sample, 53.3% chose to place the patient on their side, but those who chose the correct answer without picking any wrong answers were only 23.6% of the sample. There was no statistically significant difference in obtaining the correct answers among different age groups or sexes.

The most incorrect answer chosen by the participants was put a hard object in the patient's mouth (piece of fabric), which was chosen by 37.7% of the participants, followed by holding the patient tight and try preventing them from seizing (13.2%) (Figure 3).

The participants were asked also about the expected time for seizure duration; 89 of the participants (42%) answered between 2 and 5 minutes, followed by 68 of the participants (32.1%) who thought it is less than two minutes (the correct choice), more details in Figure 4.

DISCUSSION

Epilepsy awareness is challenged by widespread misconceptions and cultural biases within general public realization, which is observed globally across various cultures. Therefore, the healthcare sector bears the responsibility for correcting these misperceptions while adapting to the digital age to effectively disseminate accurate information to the public. Moreover, fostering an inclusive environment that incorporates patients and their families as essential components of the community is paramount to this overarching objective[3,4,8,9,10,11].

Irrespective of their prior experiences, a noteworthy 85% of the participants in this study demonstrated a willingness to offer help during an active seizure episode. This contrasts with the response

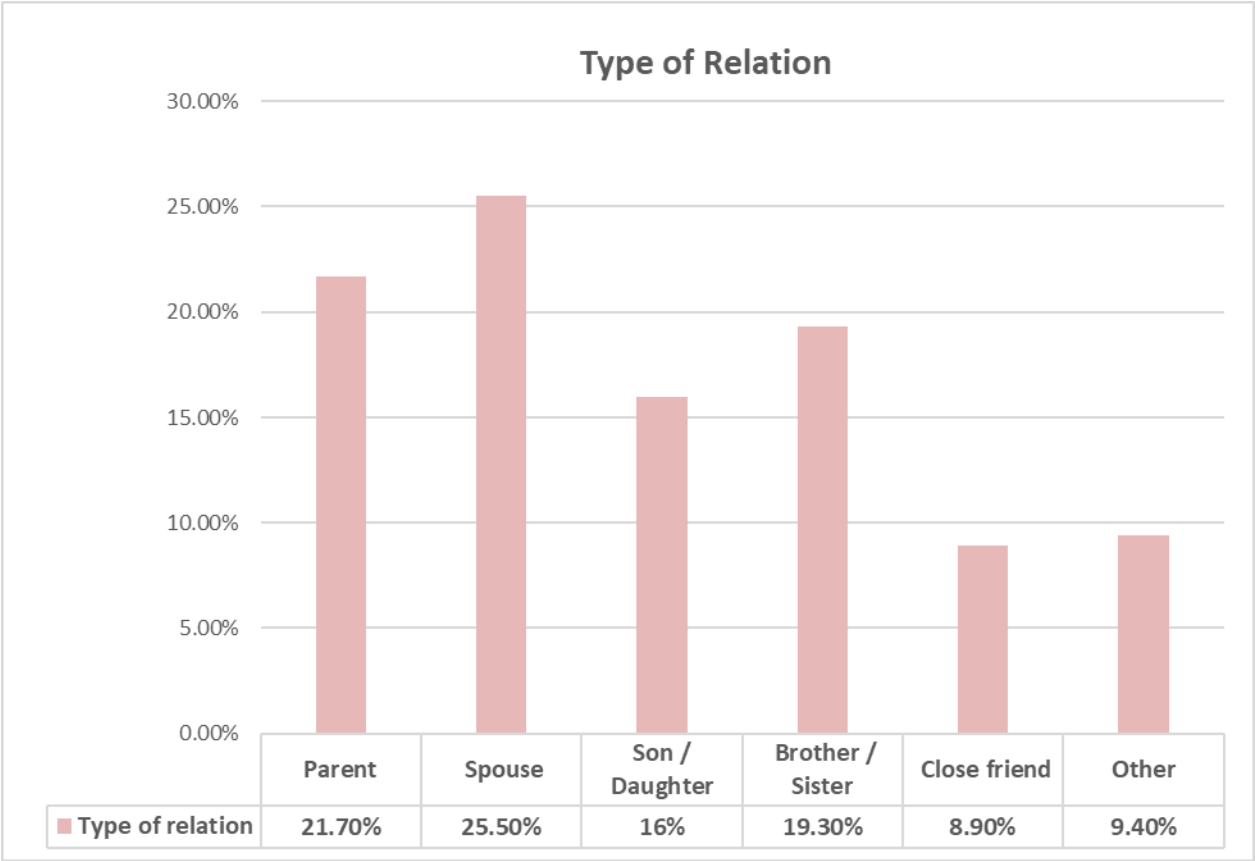


Figure 2. The relationship of participants with epilepsy patients.

Table 2. Responses of participants of correct actions in their views to be taken when witnessing an actively seizing patient (more than one option can be chosen).

Response	Yes	No
Spray water over the patient's face	12 (5.7%)	200 (94.3%)
Put a hard object in the patient's mouth (piece of fabric)	80 (37.7%)	132 (63.3%)
Try to hold the patient's tongue to prevent tongue swallowing	33 (15.6%)	179 (84.4%)
Holding the patient tight and trying to prevent him from seizing	28 (13.2%)	184 (86.8%)
Put the patient over his/her side	113 (53.3%)	99 (46.7%)
Call the ambulance	149 (70.3%)	63 (29.7%)
Put the patient on his side without picking any other wrong answer	50 (23.6%)	162 (76.4%)
Put the patient on his side without calling the ambulance	15 (14%)	197 (86%)

observed in the general public when facing a similar situation as a prior study conducted within the general public in Jeddah revealed that only 58% expressed a willingness to assist during a seizure. This may reflect the confidence that relatives have regarding their ability to help in these situations in contrast to the general public[12,13].

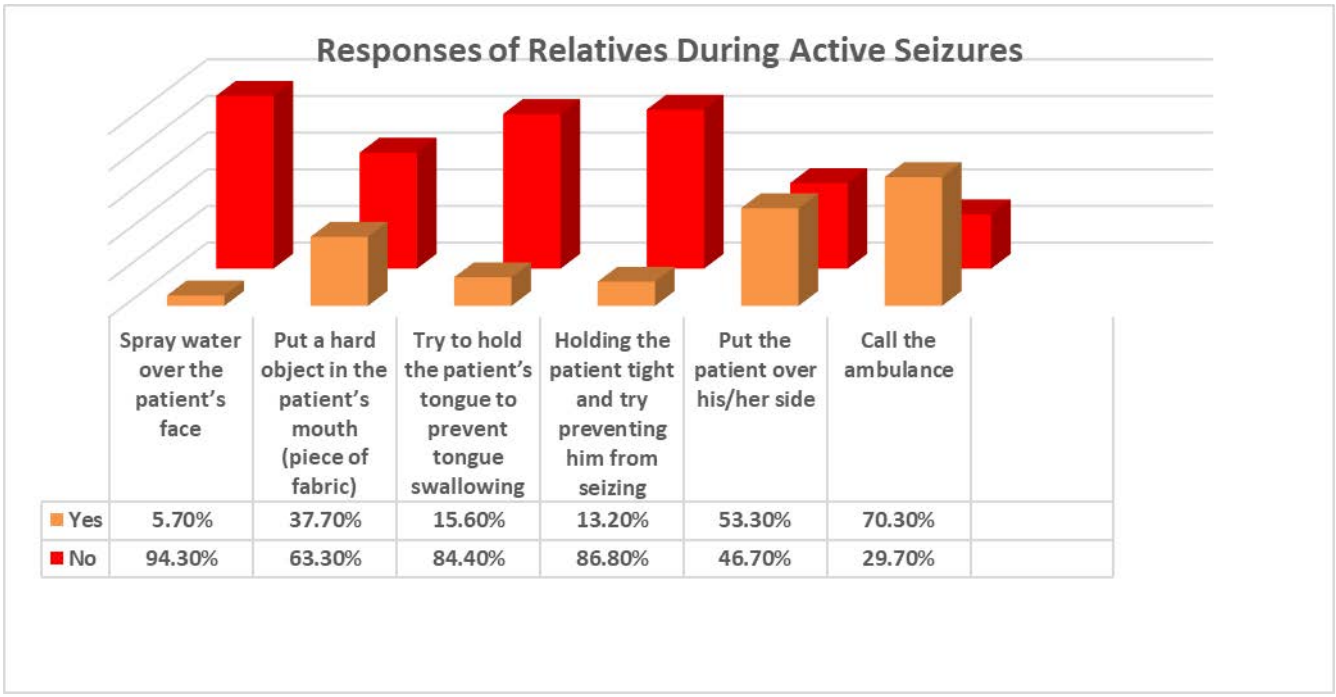
The most prevalent misconception concerning the response to an actively seizing patient is the misguided attempt to insert rigid objects into the patient's mouth, often to prevent tongue biting. This study has revealed a striking statistic where 37.7% of the participants expressed a willingness to engage in this potentially harmful action. This result differs from the findings for the general public facing the same circumstances, as shown by a different study conducted in Saudi Arabia. Although this percentage is numerically better, it is crucial to highlight its significance, particularly when it concerns individuals who are more likely to witness a seizure[1,14,15].

Subsequently, 15.6% of participants demonstrated a propensity to hold the patient's tongue to prevent swallowing, aligning with findings from prior research conducted within the general public, where 14.7% chose to do the same[13].

The act of holding the patient tightly to prevent the limb movements was selected by 13.2% of participants, a finding that closely compares with previous studies conducted in Saudi Arabia, where 15.9% of respondents indicated a willingness to perform this action[1,14]. From these previous observations, it is noteworthy that relatives of patients, who are expected to have a higher level of awareness regarding seizures, adopt a significant proportion of particular practices, which makes raising overall awareness imperative.

Of the participants 53% opted to position the patient on their side; however, a higher proportion tended to engage in at least one incorrect action. This response was significantly better than the observed behaviors of the general public in similarly designed questionnaires (26%), reflecting a more favorable response than the general public[13].

Only 23.6% of participants correctly positioned the patient on their side without engaging in any incorrect actions. Among this group, 30%



	Spray water over the patient's face	Put a hard object in the patient's mouth (piece of fabric)	Try to hold the patient's tongue to prevent tongue swallowing	Holding the patient tight and try preventing him from seizing	Put the patient over his/her side	Call the ambulance
Yes	5.70%	37.70%	15.60%	13.20%	53.30%	70.30%
No	94.30%	63.30%	84.40%	86.80%	46.70%	29.70%

Figure 3. Responses of Relatives During Witnessed Active Seizure

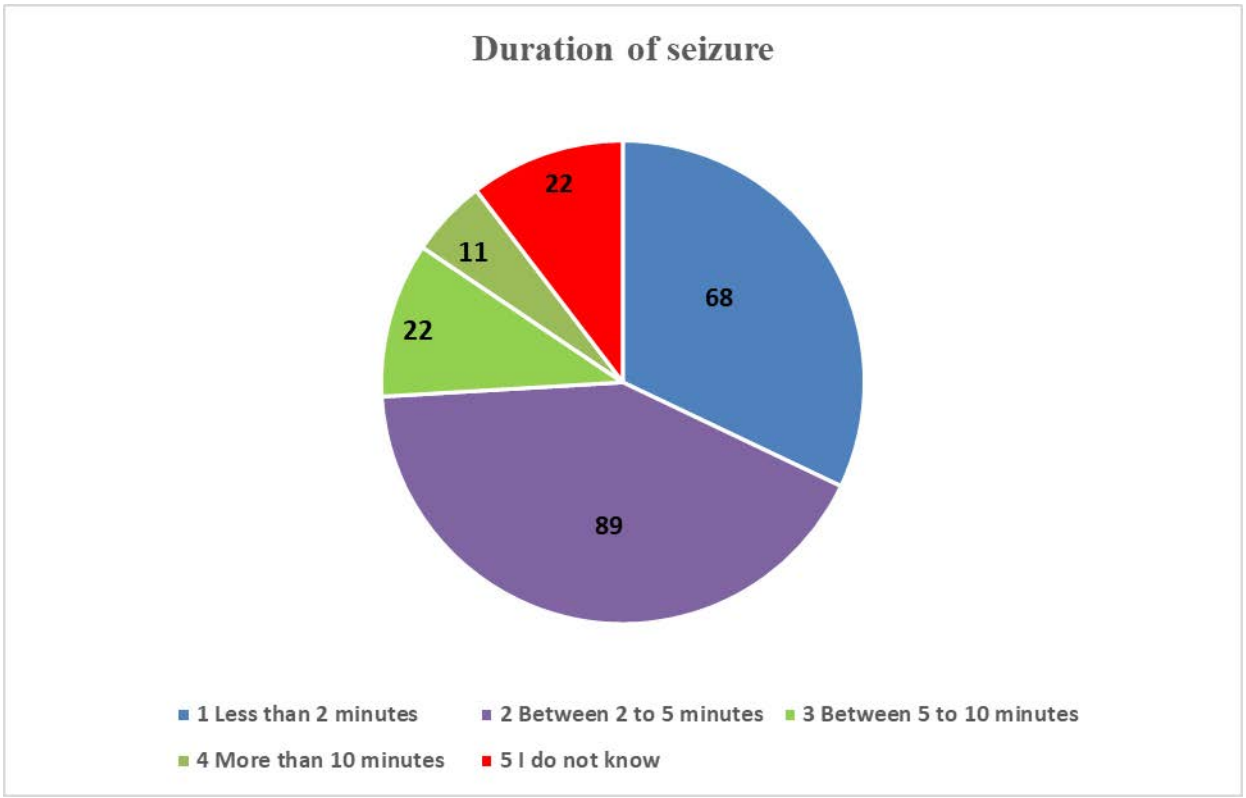


Figure 4. Participants Responses Concerning Seizure Duration.

recognized the necessity of seeking professional assistance. While the majority of these individuals were familiar with the nature of seizures, their decision to call for an ambulance highlights their awareness of the severity of the seizure episode.

Lastly, it is worth noting that 42% of the participants estimated seizure durations to be between 2 and 5 minutes, which is longer than the medically accurate assessment[16]. This perception of a longer duration may be influenced by emotional stress, leading to an overestimation of time by observing relatives.

The study limitation is that it was conducted through an electronic questionnaire during the COVID-19 pandemic because of the lockdown at that time.

CONCLUSION

The findings discussed above emphasize the urgent need for the healthcare sector to enhance epilepsy awareness among relatives of patients. While there are certain areas where knowledge appears better than that of the general public, the overall level of awareness is insufficient to achieve the optimum goal of ensuring the safety of both patients and their relatives. This goal can be attained through concentrated efforts utilizing modern and innovative approaches through social media, in conjunction with traditional educational methods at schools and universities.

Authorship Contribution: All authors share equal effort contribution towards (1) substantial contributions to conception and design, acquisition, analysis and interpretation of data; (2) drafting the article and revising it critically for important intellectual content; and (3) final approval of the manuscript version to be published. Yes.

Potential Conflicts of Interest: None

Competing Interest: None

Acceptance Date: 05 September 2025

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