



Epilepsy knowledge and attitudes: A large observational study among the Palestinian general public

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ABSTRACT

Background: Epileptic seizures are often misunderstood as supernatural power or satanic possession in different cultures around the world. Therefore, people with epilepsy (PWE) suffer discrimination, prejudice, and stigma. The epilepsy knowledge and attitude (EKA) of the Palestinian general public were not assessed before. Therefore, this study assessed the EKA of the Palestinian general public. In addition, the study identified the characteristics that were associated with EKA.

Methods: This was a large cross-sectional study that was conducted using a self-administered instrument. The study participants were invited and recruited from the Palestinian general public. The EKA were assessed using 16 knowledge items and 13 attitude items.

Results: In this study, responses were collected from 746 participants. Knowledge scores were significantly associated with having a university degree, satisfaction with household income, adequate knowledge about epilepsy, having acquaintances with epilepsy, and having witnessed someone experiencing epileptic seizures. Attitude scores were significantly associated with living in urban areas, being married, having a university degree, satisfaction with household income, adequate knowledge about epilepsy, having acquaintances with epilepsy, and having witnessed someone experiencing epileptic seizures.

Conclusion: Large knowledge gaps and negative attitudes toward PWE were identified among the Palestinian general public. These findings might be considered a call to increase knowledge and correct negative attitudes toward PWE. Decision-makers need to design and implement effective measures to increase knowledge and correct negative attitudes toward PWE. Further studies are still needed to assess the effectiveness of these measures in increasing knowledge and positive attitudes toward PWE.

1. Introduction

Epilepsy is one of the most common neurological disorders that is characterized by recurrent and unprovoked seizures. Globally, there are more than 65 million people with epilepsy (PWE), of whom the majority reside in low- and middle-income countries [1,2]. The number of PWE is projected to increase with the increasing number of people who are expected to survive head traumas, central nervous system infections, and strokes [3]. Previous epidemiological studies have reported that PWE belong to both sexes, different races, cultures, and socioeconomic classes [3–6].

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Previous studies have reported that epileptic seizures were often misunderstood as supernatural power or satanic possession in different cultures [4]. Although the pathophysiology of epileptic seizures is fairly understood today, epilepsy continues to be linked to superstition and possession by demons [5,7,8]. Therefore, PWE in different communities around the world often have to deal with myths, misconceptions, prejudice, discrimination, stigma, and negative attitude [4,5,7,9–13]. Because of these myths, negative attitude, misconceptions, stigma, prejudice, and discrimination, PWE are reported to be excluded from the general society. In addition, PWE have limited opportunities to participate and contribute to their societies [7,9]. It is widely thought that these phenomena could be alleviated by misconceptions or insufficient knowledge about why epileptic seizures occur, their recurrence, and their manifestations.

In Palestine, epilepsy knowledge and attitude (EKA) of healthcare professionals, healthcare students, and educators were previously assessed [9,14–18]. Similarly, previous studies have assessed the EKA of the general public in different countries [19–22]. These studies have reported gaps in knowledge and negative attitude toward PWE [9,14–22]. However, the EKA of the Palestinian general public were not assessed before. In addition, the characteristics that could be associated with a lack of knowledge or negative attitude toward PWE were not identified among the Palestinian general public. Therefore, this study was conducted to assess the EKA of the Palestinian general public. In addition, the study aimed to identify the characteristics that could be associated with EKA.

Assessing the EKA of the general public can contribute to combating ignorance, negative attitude, stigma, myths, prejudice, misconceptions, and discrimination against PWE. In addition, identifying the characteristics that could be associated with EKA can help design customized strategies and interventions to improve EKA. These customized strategies and interventions might reduce negative attitudes, stigma, myths, misconceptions, prejudice, and discrimination against PWE. In addition, these customized strategies and interventions might increase the inclusion, participation, and contribution of PWE to society.

2. Methods

2.1. Recruitment of the study participants

The study participants were invited and recruited from the Palestinian general public. The study participants were invited and recruited when they met the following inclusion criteria: 1) being 18 years or older, 2) living in Palestine, 3) willing to answer the EKA items that were included in the study instrument, and 4) providing informed consent. PWE were not included in this study.

The sample size was estimated based on the current Palestinian population. A freely accessible sample size estimator was used to calculate the sample size (www.raosoft.com). The sample size was estimated at a 95 % confidence interval (95 % CI). While computing the sample size needed for this study, a margin of error of 5 % was tolerated.

2.2. Study design and instrument

This was a large cross-sectional study that was conducted using a self-administered instrument among the Palestinian general public. The self-administered instrument was developed to assess the EKA of the Palestinian general public. The items in the study instrument were based on previous studies that assessed the EKA of the general public and those who deal with PWE [9,14,15,18,23–28]. The study instrument contained 3 parts. The 1st part collected the demographic characteristics of the participants including, age, marital status, gender, place of residence, and educational level. The educational level was collected as school education regardless of the grade or university education regardless of the degree program that was completed. The participants were also requested to self-rate their satisfaction with their household income and social status. In addition, the participants were also requested to self-rate their knowledge about epilepsy, state whether they had acquaintances (close friends or family members) who had epilepsy, and state whether they had witnessed someone experiencing epileptic seizures. The 2nd part of the study instrument contained a 16-item knowledge test to which the participants were asked to respond. For each item, the participants had to answer by either: 1) true, 2) false, or 3) I don't know. The 3rd part of the study instrument contained 13 attitude items. On each item, the participants were asked to express their attitude by either: 1) strongly agree, 2) agree, 3) neutral, 4) disagree, or 5) strongly disagree. The questionnaire is provided as Supplementary Material.

2.3. Pilot testing of the study instrument

The study instrument used in this study was pilot-tested before it was used in the larger study among 50 participants who were recruited from the general population. The pilot testing aimed to assess the study instrument for clarity, comprehensibility, and readability. In the pilot test, the participants were requested to respond to the study instrument on two occasions. A period of 24–72 h was left between each round. To ensure the stability of the answers, the rest-retest reliability approach was used. Pearson's correlations were used to correlate the responses of the participants in both rounds. A Pearson's correlation coefficient (Pearson's r) of >0.80 indicated acceptable test-retest reliability [9,14,15,18,23–35]. To ensure that the items used in the study instrument were internally consistent, Cronbach's alpha was used as an indicator of item-relatedness. A Cronbach's alpha of $>70\%$ indicated acceptable internal consistency. In this study, Pearson's r was 0.91 and the Cronbach's alpha was 0.72.

2.4. Analysis of the collected data

The data collected in this study were entered into MS Excel and were then transferred into IBM SPSS v. 21.0. The participants

received 1 point for each correct answer and 0 points for each incorrect answer. In the knowledge test, the scores ranged from 0 to 16. The knowledge scores were expressed in percentages that ranged from 0% to 100 %. A higher score indicated a higher knowledge.

On the other hand, strongly agree, agree, neutral, disagree, and strongly disagree for each attitude item were replaced by 1, 2, 3, 4, and 5, respectively. The attitude scores were summed and converted into percentages. Like knowledge scores, a higher attitude score indicated a more positive attitude toward epilepsy and PWE. Because a large sample size was used in this study, the data were assessed for normal distribution using skewness and kurtosis. As the kurtosis was within the range of -7.0 and $+7.0$ and the skewness was within the range of -2.0 and $+2.0$, the data were considered normally distributed [36–38]. The EKA scores were compared using t-tests. A p-value of <0.05 indicated a statistically significant difference.

Ethical approval

This study adhered to the local and international ethical standards including those in the Declaration of Helsinki. The study was approved by the local ethics committee (Institutional Review Board of An-Najah National University). Participation was completely voluntary and those who participated in the study provided informed consent.

3. Results

3.1. Characteristics of the participants

In this study, responses were collected from 746 participants. Of those, 379 (50.8 %) were 40 years or older, 396 (53.1 %) were male, 398 (53.4 %) lived in rural areas, 422 (56.6 %) were married or ever married, and 464 (62.2 %) had university degrees. Additionally, 511 (68.5 %) participants expressed satisfaction with their social status, and 487 (65.3 %) participants expressed satisfaction with their household income. On the other hand, 465 (62.3 %) participants self-rated their knowledge of epilepsy as adequate, 63 (8.4 %) had acquaintances (family members or close friends) with epilepsy, and 57 (7.6 %) had witnessed someone experiencing epileptic seizures. The variables of the participants who were surveyed in this study are shown in Table 1.

3.2. Responses of the participants on the knowledge test

The responses of the participants on the knowledge test are shown in Table 2. In this study, large knowledge gaps about epilepsy were identified among the participants. More than 70 % of the participants did not know that epilepsy was a curable disease (item #11), PWE are not dangerous to others while experiencing seizures (item #4), the majority of PWE can lead normal lives (item #14),

Table 1
Characteristics of the participants ($n = 746$).

Characteristic	n	%
Age (years)		
<40	367	49.2
≥40	379	50.8
Gender		
Male	396	53.1
Female	350	46.9
Place of residence		
Rural	398	53.4
Urban	348	46.6
Marital status		
Single/never married	324	43.4
Married/ever married	422	56.6
Educational level		
School	282	37.8
University	464	62.2
Self-reported satisfaction with social status		
Unsatisfied	235	31.5
Satisfied	511	68.5
Self-rated satisfaction with household income		
Unsatisfied	259	34.7
Satisfied	487	65.3
Self-rated knowledge of epilepsy		
Inadequate	465	62.3
Adequate	281	37.7
Having an acquaintance with epilepsy		
No	683	91.6
Yes	63	8.4
Having witnessed someone experiencing epileptic seizures		
No	689	92.4
Yes	57	7.6

and the majority of PWE have normal intelligence (item #8). On the other hand, 434 (58.2 %) participants correctly answered the knowledge item about the cause of epileptic seizures (item #10).

3.3. Attitude of the participants toward epilepsy

The responses of the participants on the attitude items are shown in Table 3. In this study, the participants expressed negative attitudes toward epilepsy and PWE. Of the participants, 393 (52.7 %) agreed or strongly agreed that PWE were frightening, 391 (52.4 %) agreed or strongly agreed that they would object to the marriage of their children to PWE, 387 (51.9 %) agreed or strongly agreed that they would hide a diagnosis with epilepsy from friends, 378 (50.7 %) agreed or strongly agreed that they would never marry PWE, and 374 (50.1 %) agreed or strongly agreed that they would feel uncomfortable working with PWE.

3.4. Association between characteristics of the participants with their EKA toward epilepsy

Knowledge scores were significantly associated with having a university degree, satisfaction with household income, adequate knowledge about epilepsy, having acquaintances with epilepsy, and having witnessed someone experiencing epileptic seizures. Differences in the knowledge scores are shown in Table 4. On the other hand, knowledge scores were not associated with age, gender, place of residence, marital status, and satisfaction with social status.

Attitude scores were significantly associated with living in urban areas, being married, having a university degree, satisfaction with household income, adequate knowledge about epilepsy, having acquaintances with epilepsy, and having witnessed someone experiencing epileptic seizures. Differences in the attitude scores are shown in Table 4. On the other hand, attitude scores were not associated with age, gender, and satisfaction with social status.

4. Discussion

Inadequate EKA is thought to nourish stigma, myths, misconceptions, prejudice, and discrimination against PWE [4–6,9–13]. This study assessed the EKA of the participants toward epilepsy. This is the first study among the Palestinian general public. The findings of this study identified large knowledge gaps and serious negative attitude toward PWE among the Palestinian general public. The large knowledge gap was indicated by the number of incorrect answers and low knowledge scores of the participants and the negative attitude was indicated by the low attitude scores. The main knowledge gaps were related to the curability of the disease, helping patients while experiencing seizures, the ability of PWE to lead normal lives, and the intelligence of PWE. The main negative attitude was related to marriage, staying, and working with PWE. The findings of this study could inform strategies and policies to combat ignorance, negative attitudes, stigma, myths, misconceptions, prejudice, and discrimination against PWE.

In this study, the participants had relatively low knowledge about the curability of the disease. It is well-established that seizures can be controlled by adherence to taking antiseizure medications [39]. Previous studies have shown that even some future healthcare providers and educators also thought that seizures could not be controlled [14,15,18]. Probably, this misconception could have nourished embarrassment about having epilepsy, willingness to hide a diagnosis of epilepsy, and refusal to marry a person with epilepsy. Previous studies reported hiding a diagnosis of epilepsy during marital negotiations because of the felt and enacted stigma [40, 41]. This could be associated with inadequate adherence to taking antiseizure medications, less frequent visits to seek healthcare, and poor marital outcomes [41]. Further studies are needed to understand the reasons for the lack of knowledge about epilepsy and PWE. Probably, decision-makers might consider advertising the importance of seeking a diagnosis, timely prescription of, and adherence to

Table 2
Responses of the participants on the 16-item knowledge test.

#	Item	Correct answer	Incorrect answer		Correct answer	
			n	%	n	%
1	Seizures come in different forms	True	344	46.1	402	53.9
2	The majority of PWE can work	True	431	57.8	315	42.2
3	The majority of children with epilepsy can go to school	True	459	61.5	287	38.5
4	PWE are dangerous to others while experiencing a seizure	False	585	78.4	161	21.6
5	Many seizures can last for a few seconds	True	352	47.2	394	52.8
6	The majority of PWE can control their seizures using antiseizure medications	True	396	53.1	350	46.9
7	Some epilepsies can be treated with brain surgeries	True	494	66.2	252	33.8
8	The majority of PWE have normal intelligence	True	543	72.8	203	27.2
9	The majority of PWE can be as successful as others at work	True	508	68.1	238	31.9
10	Abnormal functioning of brain nerve cells can cause epileptic seizures	True	312	41.8	434	58.2
11	Epilepsy is incurable	False	592	79.4	154	20.6
12	Alcohol, lack of sleep, and stress can provoke seizures	True	336	45.0	410	55.0
13	Seizures can be stopped by smelling onion	False	445	59.7	301	40.3
14	The majority of PWE can lead normal lives	True	557	74.7	189	25.3
15	Some seizures can be hardly noticed	True	466	62.5	280	37.5
16	Seizures can be stopped by spilling water on the face of the patient	False	438	58.7	308	41.3

PWE: people with epilepsy.

Table 3
Answers of the participants on the 13 attitude items.

#	Item	Strongly disagree		Disagree		Neutral		Agree		Strongly agree	
		n	%	n	%	n	%	n	%	n	%
1	Having epilepsy is embarrassing	119	16.0	152	20.4	162	21.7	161	21.6	152	20.4
2	One should stay away from PWE	0	0.0	88	11.8	334	44.8	84	11.3	240	32.2
3	One should feel uncomfortable working with PWE	77	10.3	134	18.0	161	21.6	126	16.9	248	33.2
4	One should be embarrassed when someone in the family has epilepsy	70	9.4	214	28.7	98	13.1	84	11.3	280	37.5
5	One should break friendships with PWE	28	3.8	210	28.2	147	19.7	49	6.6	312	41.8
6	PWE are frightening	14	1.9	199	26.7	140	18.8	49	6.6	344	46.1
7	PWE are not physically attractive	7	0.9	119	16.0	259	34.7	49	6.6	312	41.8
8	I would refuse to work with PWE	42	5.6	112	15.0	299	40.1	77	10.3	216	29.0
9	I would hide a diagnosis of epilepsy from friends	112	15.0	120	16.1	127	17.0	203	27.2	184	24.7
10	I would not trust PWE	49	6.6	160	21.4	228	30.6	133	17.8	176	23.6
11	I would never marry a person with epilepsy	168	22.5	128	17.2	72	9.7	226	30.3	152	20.4
12	I would object to the marriage of my child PWE	133	17.8	104	13.9	118	15.8	231	31.0	160	21.4
13	I feel uncomfortable staying in a room with PWE	84	11.3	158	21.2	168	22.5	112	15.0	224	30.0

PWE: people with epilepsy.

Table 4
Association between the characteristics of the participants and the EKA scores.

Variable	n	%	Knowledge score (%)			Attitude score (%)		
			Mean	SD	p-value	Mean	SD	p-value
Age (years)								
<40	367	49.2	37.1	41.3	0.167	67.4	19.2	0.252
≥40	379	50.8	41.3	41.6		69.0	18.4	
Gender								
Male	396	53.1	39.7	42.8	0.734	68.8	18.9	0.329
Female	350	46.9	38.6	40.0		67.5	18.7	
Place of residence								
Rural	398	53.4	37.5	41.8	0.225	66.9	16.6	0.046
Urban	348	46.6	41.2	41.0		69.7	21.0	
Marital status								
Single/never married	324	43.4	39.7	45.7	0.787	66.6	20.1	0.045
Married/ever married	422	56.6	38.8	38.0		69.4	17.7	
Educational level								
School	282	37.8	26.1	39.4	<0.001	66.1	20.3	0.017
University	464	62.2	47.2	40.7		69.5	17.7	
Self-reported satisfaction with social status								
Unsatisfied	235	31.5	38.7	48.8	0.834	69.4	26.4	0.252
Satisfied	511	68.5	39.4	37.7		67.7	13.9	
Self-rated satisfaction with household income								
Unsatisfied	259	34.7	26.5	37.4	<0.001	66.3	18.3	0.049
Satisfied	487	65.3	46.0	42.0		69.2	19.0	
Self-rated knowledge of epilepsy								
Inadequate	465	62.3	27.5	39.9	<0.001	66.8	19.0	0.009
Adequate	281	37.7	58.6	36.5		70.5	18.3	
Having an acquaintance with epilepsy								
No	683	91.6	35.5	41.1	<0.001	66.9	18.0	<0.001
Yes	63	8.4	79.2	18.1		82.0	21.5	
Having witnessed someone experiencing epileptic seizures								
No	689	92.4	37.0	41.4	<0.001	67.8	19.2	0.038
Yes	57	7.6	66.0	32.3		73.1	12.0	

EKA: epilepsy knowledge and attitudes.

taking the appropriately prescribed antiseizure medications to control seizures. In addition, there is a need to increase the knowledge of the general public on the ability of PWE to lead normal lives. Probably, this might increase the acceptance and inclusion of PWE into the general society.

Similarly, a considerable percentage of the participants thought that PWE could be dangerous to others while experiencing seizures. Again, this misconception could affect willingness to help PWE while experiencing epileptic seizures. Moreover, this could have encouraged staying away and refusing to work with PWE. Less than optimal willingness to help PWE while experiencing seizures was previously reported [42]. The reasons for unwillingness or hesitation to help included lack of knowledge of how to help, difficulty identifying seizures, apathetic attitude toward PWE, fear of providing unprofessional help, and fear of getting hurt. Recent studies among school teachers identified gaps in first aid knowledge and practices for students with epileptic seizures [43,44]. In another

study, the majority of the Ethiopian general public reported unsafe practices while managing epileptic seizures [45]. Consistent with the findings of this study, the participants who had low education had poor knowledge about and negative attitude toward epilepsy. In this study, having higher education was significantly associated with higher knowledge of epilepsy and a more positive attitude toward epilepsy and PWE. These findings were consistent with those reported in previous studies [14,15,46–48]. Probably, the participants who had university education could have read more about epilepsy and the nature of seizures. Similar to previous studies, the participants who had a university education were more satisfied with their household income. Taken together, these findings indicate that decision-makers should dispel the misconception that people are dangerous to others while experiencing epileptic seizures, rather, they might require help. The general public might benefit from first-aid training sessions on how to help PWE while experiencing seizures. In a previous study, an appropriately designed health education program was shown to be effective in bringing significant improvements to the responses of school teachers to epileptic seizures [49]. Additionally, the program also improved the knowledge of the school teachers in all aspects of epilepsy. Recently, standardized seizure first aid training programs destined to train the general public and students were developed [50,51]. Such programs help improve self-efficacy in seizure first aid.

Similarly, a lack of knowledge about the normal intelligence and ability of PWE to lead a normal life could have nourished feeling embarrassed about epilepsy, refusal to marry a person with epilepsy, and staying away from PWE. Lack of knowledge and misconceptions about epilepsy were previously reported [19,52]. These findings indicate that there is a need to increase the knowledge of the general public about the nature of epilepsy. Knowledge-increasing campaigns on epilepsy are likely to increase knowledge, correct attitude, and improve practices [9,23,53]. Based on the findings of this study, the knowledge-increasing campaigns might notably target the general public who have low education, live in rural areas, have low household income, and do not have acquaintances with epilepsy. Many previous studies have reported that having interacted with PWE was associated with higher knowledge and more positive attitudes toward epilepsy [14,15,18,23,37]. Probably, encouraging successful PWE to share their stories in knowledge-increasing campaigns can help improve knowledge and correct attitude.

4.1. Strengths and limitations

This large cross-sectional study had many strengths. First, this study was the first to report on the EKA of the Palestinian general public toward epilepsy. The findings of this study should enrich the literature on EKA of the different communities toward epilepsy. The findings of this particular region could help in efforts to combat ignorance, negative attitude, misconceptions, stigma, myths, prejudice, and discrimination against PWE. Second, a sufficiently large sample size was used in this study. The findings reported from studies with large sample sizes are more reliable and robust compared to those reported in smaller studies. The large sample size used in this study should have improved the external validity and generalizability of the findings to the entire Palestinian public. Third, the participants in this study were diversified in terms of gender, age group, educational level, place of residence, and socioeconomic status. Additionally, the participants included those who had acquaintances with epilepsy and those who did not. This should have improved the representativeness of the entire population. Fourth, the study instrument used in this study was previously used in different settings elsewhere [25,26,28,46–48,54–58]. This should have ensured the suitability of the study tool in generating meaningful findings that could be compared to those previously reported. Finally, the study instrument was pilot-tested before being used in the larger study. This pilot testing ensured that the study instrument was clear, readable, and comprehensible. Additionally, the pilot testing ensured that the study instrument had high test-retest reliability and the items used in the study instrument were internally consistent.

The study had also some limitations. First, this study was conducted in a cross-sectional design. Compared to interventional studies, observational studies are less robust and useful. In this study, no intervention was undertaken to correct knowledge or negative attitudes. Second, the knowledge items were answered using true, false, and I don't know options. It is likely that some respondents guessed some answers. Therefore, knowledge scores could have been overestimated. Third, many of the data collected in this study were self-reported. Self-reported data are subject to recall and desirability bias.

4.2. Conclusion

Large knowledge gaps and negative attitudes toward PWE were identified among the Palestinian general public. These findings might be considered a call to increase knowledge and correct negative attitudes toward PWE. Decision-makers need to design and implement effective measures to increase knowledge and correct negative attitudes toward PWE. Further studies are still needed to assess the effectiveness of these measures in increasing knowledge and positive attitudes toward PWE.

CRediT authorship contribution statement

Ramzi Shawahna: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Validation, Visualization, Writing - original draft, Writing - review & editing.

Declaration of competing interest

The author declares that he has no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.heliyon.2023.e23707>.

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