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COVID-19 vaccine-related frequently asked questions (FAQs) by people with epilepsy and carers in Iran; educational video is included

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ARTICLE INFO

Article history:

Received 9 March 2022

Revised 21 April 2022

Accepted 17 May 2022

Available online 19 May 2022

Keywords:

Coronavirus

COVID-19

Epilepsy

Seizure

Vaccine

ABSTRACT

Objective: The aim of the current study was to inquire the questions and concerns of people with epilepsy (PWE) about COVID-19 vaccines in order to provide a more realistic list of their frequently asked questions (FAQs).

Methods: We surveyed all the consecutive PWE or their care-givers who were referred to our neurology clinics (Shiraz University of Medical Sciences) during January-February 2022. We collected their questions and concerns in relation to COVID vaccines based on a pre-designed brief questionnaire. Informed consent to participate in the study was obtained from the participants.

Results: In total, 452 people participated in the study; 291 people (64.4%) did not have any questions or concerns with regard to the COVID-19 vaccination. Having any questions or concerns about COVID-19 vaccination was significantly associated with not being vaccinated. Questions and concerns about the adverse effects of COVID-19 vaccines [seizure worsening, general adverse effects, long-term effects (e.g., infertility, cognitive dysfunction)] were by far the most common questions by people with epilepsy and their carers.

Conclusion: Our findings may be used by policy-makers to prepare appropriate educational materials to provide the best targeted and tailored information to people with epilepsy and their carers to convince them of the necessity and safety of COVID-19 vaccination. Such an educational material must include enough information on the associated adverse effects of COVID-19 vaccines and should also discuss some other important issues such as indications of these vaccines in special populations and drug-vaccine interactions.

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1. Introduction

COVID-19 is a serious and fatal disease. Vaccination against severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) infection is the best hope for preventing the serious consequences of COVID-19 (i.e., severe illness and death). However, a growing number of people in the world express vaccine hesitancy [1,2]. In a previous study (performed in late 2020 and before the start of the vaccination campaign in Iran), we observed that about 11% of the people had vaccine hesitancy [including about 6% of patients with epilepsy (PWE)] [1]. In another study of physicians (neurologists and psychiatrists) (conducted in September 2020 and before

COVID-19 vaccines became available in Iran), about 6% of the participants expressed that they would not recommend COVID-19 vaccines to PWE [3]. While COVID-19 vaccines became available in February 2021 in Iran, by February 2022 only 65% of the Iranian people have been fully vaccinated. So far, 12 different vaccines have been approved for use in Iran. Vaccination is done in people aged 5 years and above. People with epilepsy are not prioritized to receive COVID-19 vaccines in Iran [4,5].

In order to overcome the hesitations and doubts of people about vaccines, it is helpful and necessary to have a good knowledge of their questions and concerns. While many scientific organizations and support groups have tried to provide appropriate information for their target audience by providing educational materials, including COVID-19 vaccine-related frequently asked questions (FAQs), those materials are often prepared based on the presumptions of the experts about FAQs by patients; no one has actually

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Table 1
Characteristics of patients with regard to having questions about COVID-19 vaccination.

Clinical characteristics	Having questions (N = 161)	No questions (N = 291)	P value
Received any vaccines (patient)	102 (63.4%)	251 (86.3%)	0.0001
Sex (female: male)	96: 65	148: 143	0.077
Education (less than 5 grades, 5 to 12 grades, college)	21: 84: 56	61: 129: 101	0.085
Seizure free in the past 12 months	42 (26.1%)	93 (31.9%)	0.159
Contracted COVID-19 (responder)	51 (31.7%)	86 (29.6%)	0.670
Mean age (±SD), years	35 (±12)	35 (±13)	0.867

tried to perform a field study to identify the COVID-19 vaccine-related FAQs by people with epilepsy and their carers, to the best of our knowledge.

The aim of the current study was to inquire the questions and concerns of PWE about COVID-19 vaccines in order to provide a more realistic list of their FAQs. This may help health policy-makers understand the concerns of the people and to put in place appropriate educational strategies and materials to provide the best targeted and tailored information to the people to convince them of the necessity of COVID-19 vaccination.

2. Methods

We surveyed all the consecutive PWE (adults and adolescents older than 16 years of age) or their care-givers [in case of younger patients (<16 years) and people with intellectual disability] who referred to our neurology clinics (Shiraz University of Medical Sciences) during January-February 2022. Either the patient (in case of adults and adolescents older than 16 years of age) or the carer [in case of younger patients (<16 years) and people with intellectual disability] responded to the survey. We collected their questions and concerns in relation to COVID vaccines based on a pre-designed brief questionnaire (Appendix 1); it was a self-declared survey. The inclusion criteria included all PWE, 5 years of age or older (the COVID-19 vaccination age in Iran is 5 years of age or older). The exclusion criteria included unwillingness to participating in the study and less than five grades of education (the responder).

Statistical analyses were performed using independent t-test, Fisher’s Exact test, and Pearson chi-square test. A p-value (2-sided) less than 0.05 was considered as significant. All the statistical analyses were conducted with SPSS version 25. The Shiraz University of Medical Sciences Review Board approved this study. Informed consent to participate in the study was obtained from the participants. The dataset is confidential and could not be shared per the regulations of Shiraz University of Medical Sciences.

3. Results

In total, 452 people participated in the study and completed the questionnaire. The responders included: self (305; 67.5%) and carer (147; 32.5%); female (244; 54%) and male (208; 46%). The mean age of the responders was 35 years (minimum: 13; maximum: 78; standard deviation: 12; median: 34; interquartile range: 17 years).

In total, 291 people (64.4%) did not have any questions or concerns with regard to COVID-19 vaccination. Table 1 shows the characteristics of patients with regard to having questions or concerns about COVID-19 vaccination. Having any questions or concerns about COVID-19 vaccination was significantly associated with not being vaccinated; people, who did not have any questions or concerns, were more often vaccinated against the COVID-19 compared with those who had any questions. The most common COVID-19 vaccine-related questions or concerns by people with

epilepsy and their carers are included in Table 2. Questions and concerns about the adverse effects of COVID-19 vaccines [seizure worsening, general adverse effects, long-term effects (e.g., infertility, cognitive dysfunction)] were by far the most common questions by people with epilepsy and their carers.

4. Discussion

In the current survey of patients with epilepsy or their carers, we observed that more than one-third of the participants had questions or concerns with regard to COVID-19 vaccination. Importantly, questions and concerns about the adverse effects of COVID-19 vaccines were the most common questions by people with epilepsy and their carers; this should be the main focus of any educational material. In other words, by definition, questions and concerns about the adverse effects of COVID-19 vaccines should be considered as FAQs by people with epilepsy and carers. However, any educational material should also address and discuss other important issues such as indications of these vaccines in special populations (pregnancy, children, underlying illnesses), drug-vaccine interactions (with antiseizure medications), and efficacy of various vaccines. In an observational study examining the public’s most FAQs regarding COVID-19 vaccines using search engine analytics in the United States (conducted in January 2021; not a field study), the authors observed that the most COVID-19 vaccine-related FAQs were seeking factual information (78.6%), specifically about safety and efficacy (40.9%) [6]; this is similar to our observation.

Scrutinizing the webpage of the “International League Against Epilepsy (ILAE)” (COVID-19 Vaccines and People with Epilepsy [7]) shows that while some of the adverse effects of COVID-19 vaccines have been discussed (e.g., fever, seizure), some others that were important to the participants of the current study were not discussed [e.g., long-term effects (e.g., infertility, cognitive dysfunction)]. Furthermore, some other important issues such as indications of these vaccines in special populations and drug-vaccine interactions were not discussed on this important resource at all [7]. “Epilepsy Foundation” has discussed various aspects of the COVID-19 vaccination more comprehensively than that by the ILAE [8]; however, this resource has also ignored some of the important

Table 2
COVID-19 vaccine-related questions by people with epilepsy and their carers.

Questions	Number	Percent
None	291	64.4%
Adverse effects [seizure worsening, general adverse effects, long-term effects (e.g., infertility, cognitive dysfunction)]	136	30.1%
Indications in special populations (pregnancy, children, underlying illnesses)	22	4.9%
Efficacy of vaccines (are they really effective?)	16	3.5%
Manufacturer (brand; which one is a better option?)	12	2.7%
Drug-vaccine interactions (with antiseizure medications)	11	2.4%

issues for the participants of the current study [e.g., long-term effects of vaccines (e.g., infertility), indications of these vaccines in special populations, and drug-vaccine interactions]. It seems that the scientific community should pay more attention to the real needs, questions, and concerns of people with epilepsy and their carers when providing educational materials for them.

In a study of the COVID-19 vaccine take-up rate in 491 adult patients with epilepsy from China (conducted in August 2021), 42% of those with epilepsy had had the first dose of a vaccine, compared with 93% of the controls and 84% of the people with other neuropsychiatric conditions ($p < 0.0001$). The main reasons for vaccine hesitancy were potential adverse effects of the vaccines and concerns about losing seizure control [9]; these are similar to our observations. It is important to highlight that the incidence of the COVID-19 vaccine adverse events in the epilepsy group was similar to that in the controls in that Chinese study; they found no evidence suggesting seizure worsening after vaccination [9]. In another study of 111 PWE from Kuwait (conducted in April 2021), COVID-19 vaccines showed a good safety profile and a low risk of epilepsy worsening [10]. A German study had similar observations and suggested that vaccination against COVID-19 appears to be well tolerated in PWE [11]. Having said all the reassuring observations above, in a study of COVID-19 vaccine hesitancy among people with epilepsy in Lithuania, only less than half of the participants (47%) showed willingness to receive a COVID-19 vaccine [12]; this rate was 69% in a study from China [13]. In order to overcome the hesitations and doubts of people about vaccines, the scientific community should address their questions and concerns.

5. Limitations & conclusion

We do not know how many people refused to participate. We did not have a control group to compare the COVID-19 vaccine-related FAQs in PWE and their carers with those in the general public or other chronic conditions. However, similarity of our observations with those from the USA [6] and China [9] implies that our findings may be generalizable to other populations and therefore, may be used by policy-makers to prepare appropriate educational materials to provide the best targeted and tailored information to people with epilepsy and their carers to convince them of the necessity and safety of COVID-19 vaccination. Such an educational material must include enough information on the associated adverse effects of COVID-19 vaccines and should also discuss some other important issues such as indications of these vaccines in special populations and also drug-vaccine interactions (if any). Considering the aim of the current study, we decided not to discuss the adverse effects of COVID-19 vaccines, their indications in special populations (pregnancy, children, underlying illnesses), their efficacy, and any potential drug-vaccine interactions (with anti-seizure medications) in the current manuscript; these issues deserve a comprehensive expert review.

Note: Following this study, we have produced an educational video clip (in Farsi with English subtitle) to encourage everyone to get their COVID-19 vaccine as soon as possible. Important people (i.e., well-known physicians, athletes, and celebrities) helped us to develop this educational material and by this we hope to influence a broad spectrum of people from various backgrounds (Appendix 2).

Acknowledgements

We thank Shiraz University of Medical Sciences. We confirm that we have read the Journal's position on issues involved in ethical

publication and affirm that this report is consistent with those guidelines.

Role of the funding source

This work was supported by Shiraz University of Medical Sciences. The funding source had no involvement in study design; in the collection, analysis and interpretation of data; in writing of the report; and in the decision to submit the article for publication.

Author contributions

Ali A. Asadi-Pooya, M.D.: Designed and conceptualized the study; analyzed the data; drafted and revised the manuscript.

Others: Data collection and revised the manuscript.

Availability of data and material

The data used in this study are confidential and will not be shared.

Conflict of interest disclosures

Ali A. Asadi-Pooya, M.D.: Honoraria from Cobel Daruo, RaymandRad, Sanofi, and Tekaje; Royalty: Oxford University Press (Book publication). Others: none.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2022.108763>.

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