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Are Epilepsy Patients Ready for the Use of Artificial Intelligence?

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Abstract

Objective: Artificial intelligence (AI) is increasingly applied in epilepsy care, yet little is known regarding patients' perspectives about its use in clinical practice. We aimed to assess the general knowledge, attitudes, and concerns of patients with epilepsy (PWE) and their caregivers regarding AI applications in epilepsy care.

Methods: A single-center cross-sectional survey was conducted at an epilepsy outpatient clinic between December 2024 and February 2025. Adult PWE or their caregivers completed a 13-question survey assessing knowledge about AI, attitudes toward its use in diagnosis and treatment, and concerns about privacy and the doctor-patient relationship.

Results: Responses from a total of 133 participants (mean age 34.65±12.44 years, 64.7% female) were analyzed. Although only 40.6% of participants had knowledge of AI, up to 55% expressed positive attitudes toward its use in seizure diagnosis and forecasting, medication adjustment, and interpretation of electroencephalography (EEG) and imaging. Most (77.4%) preferred AI to assist doctors in EEG interpretation rather than to analyze results autonomously. Privacy concerns were present in 52.6% of participants; 35.3% believed that AI applications will improve communication with their doctors; and 53.4% expressed concerns about doctor-patient relationships. Only 16.5% were comfortable with the idea of AI completely replacing their doctors.

Conclusion: Despite limited knowledge, PWE and their caregivers showed a generally positive attitude toward AI applications. Concerns regarding privacy and doctor-patient relationships remain prominent. Future studies involving larger cohorts are warranted to validate these results, and efforts to implement these technologies in clinical practice should consider these perspectives.

Keywords: Epilepsy, artificial intelligence, survey, privacy

INTRODUCTION

Artificial intelligence (AI) is a popular branch of computer science that refers to systems that were designed to perform tasks that typically require human intelligence.[1] Being one of the most popular and important topics nowadays, AI is poised to change the way medicine is practiced.[2] Epilepsy, a chronic neurological condition affecting more than 70 million people worldwide with a prevalence of 7.6 in 1000, is one of the fields where various AI applications have been explored.[3-5] There are many studies exploring the use of AI in analyzing medical images in epilepsy, especially with technologies such as deep learning, like other areas of neurology and other medical disciplines.[3,6] Similarly, there is a great interest in using AI to analyze electroencephalography (EEG), which constitute a vast amount of data, and represent a fundamental tool used in the diagnosis and follow-up of patients with epilepsy (PWE).[7,8] These studies highlight the opportunity to improve the care of PWE, especially for tasks such as interpreting EEGs, which take time and require expertise that is not readily available in many hospitals worldwide. Large language models, one of the most recent and practical advancements in AI, is also explored in different tasks in epilepsy-including but not limited to forecasting seizures using medical records and assisting in answering the health-related questions of PWE.[9]

In parallel with these advancements, several factors need to be addressed to integrate AI applications into the healthcare ecosystem. Trust in the AI systems by both patients and physicians, accountability for medical errors or misinformation, privacy of the data that is being used and generated, and the future of doctor-patient relationship are some of the pressing topics actively discussed in the literature.[2,10-14] However, there is a paucity of studies involving patients with neurological diseases. For example, a study conducted in a memory clinic showed that patients and their caregivers viewed computer-based tools as complementary to their physicians.[15] Similarly, in a neurosurgical population, patients favored partially autonomous surgery over fully autonomy surgery.[16] While these findings suggest that patients are open to AI integration

in healthcare, they also emphasize that human supervision and trust are essential for the successful implementation of these technologies. Recently, a qualitative study conducted in Australia explored the views of neurologists and PWE regarding AI-assisted antiseizure medication selection, showing that participants were generally supportive of such tools.[17] However, they perceived these tools as sources of advice for clinicians and believed that they could facilitate longer conversations between clinicians and PWE. To date, no quantitative study has evaluated the attitudes of PWE toward AI applications beyond treatment selection. Therefore, we aimed to explore the general knowledge of AI among PWE and their caregivers, as well as their perspectives and concerns regarding the use of AI applications in clinical practice.

METHODS

We conducted a single-center, cross-sectional survey between December 1st, 2024, and February 28th, 2025, in our epilepsy outpatient clinic. Patients aged 18 years or older were included in the study. Surveys were administered during routine clinic visits. In cases where the patient was unable to complete the survey because of illiteracy or intellectual disability, their primary caregiver completed the survey on their behalf. Demographic information, including age, sex, and education level, was collected from participants. Epilepsy type of the patients was inferred from their electronic health records, either as focal, generalized, or unknown, according to the classification proposed by the International League Against Epilepsy.[18]

The survey consisted of 13 questions. Two yes/no questions were asked to assess the participants' general knowledge about AI. The remaining questions were 5-point Likert-scale items (5=strongly agree, 4=agree, 3=not sure, 2=disagree, 1=strongly disagree), designed to explore the participants' perspectives on the use of AI applications in key domains, including diagnosis, treatment, privacy, and the doctor-patient relationship. All responses were analyzed as frequencies and percentages. The survey was developed by the authors specifically for this study and was not previously validated. It was administered in Turkish, and the English translations of all questions are presented in Table 1 for reference.

Statistical Analysis

All statistical analyses were performed using SPSS version 21. Data visualization was performed in R using the tidyverse (v2.0.0), scales (v1.3.0), ggplot2 (v3.5.1), and ggnewscale (v0.4.10) packages. Participant type (patient, caregiver), sex (female, male), education level (literate, primary school, high school, college, postgraduate), and epilepsy type (focal, generalized, unknown) were reported as frequencies and percentages. The normality of the age distribution was assessed using skewness and kurtosis, and the mean age and standard deviation were calculated. For analytical purposes, participants were grouped into younger and older age groups based on the mean age. In addition, the responses "strongly agree" and "agree" were grouped as positive, while the remaining responses were classified as negative. Age was compared between groups using an independent-samples t-test and a one-way analysis of variance (ANOVA). Tukey's test or Games-Howell test was used for post-hoc analyses in one-way ANOVA, depending on the homogeneity of variance. Positive response rates were compared between groups using the chi-square test. A p-value of <0.05 was considered statistically significant.

Ethical approval was obtained from the University of Health Sciences Türkiye, Kartal Dr. Lütfi Kırday City Hospital Scientific Research Ethics Committee (approval number: 2024/010.99/10/17, date: 29.11.2024). Written informed consent was obtained from all participants at the time of the survey.

MAIN POINTS

- Knowledge of artificial intelligence (AI) among patients with epilepsy and their caregivers is limited.
- Despite this, almost half of the participants expressed positive attitudes toward the use of AI in epilepsy care.
- Concerns related to privacy and the doctor-patient relationship should be considered when implementing AI.
- Future studies involving larger cohorts and a more structured survey design are needed to validate these results.

Table 1. All questions administered in the survey. The survey was conducted in Turkish, and the English translations of all questions are provided here for reference

Number	Question
1	Do you have knowledge about artificial intelligence applications (e.g., ChatGPT, Gemini, Apple Intelligence, Midjourney, DALL-E, Copilot)?
2	Have you ever used any artificial intelligence application (e.g., ChatGPT, Gemini) for any issue related to your epilepsy (e.g., about seizures, medication side effects, or test results)?
3	I support the use of artificial intelligence to evaluate whether the episodes I experience are seizures.
4	I support the use of artificial intelligence to predict the risk of seizure recurrence or when my next seizure will occur.
5	I would like artificial intelligence to be used in selecting the most appropriate medication for me.
6	I would like artificial intelligence to guide the adjustment of my medication dosages.
7	I support my electroencephalography (EEG) test results being interpreted entirely by artificial intelligence.
8	I would prefer artificial intelligence to assist my doctor in interpreting my EEG test results, rather than interpreting them entirely on its own.
9	I would like artificial intelligence applications to be used in interpreting my imaging tests such as magnetic resonance imaging or computed tomography scans.
10	I believe that artificial intelligence applications accessing my personal health information would raise privacy concerns.
11	I believe that artificial intelligence applications will improve communication between my doctor and me.
12	I am concerned that the increasing use of artificial intelligence applications will weaken the human bond between my doctor and me.
13	I would not feel uncomfortable if artificial intelligence applications completely replaced my doctor for follow-ups and treatment of my disease.

RESULTS

A total of 135 surveys were administered during the study period. Two surveys completed by caregivers were excluded because of missing demographic information. Detailed demographic information for all participants is presented in Table 2. A total of 111 (83.5%) participants were patients. Among all participants, 86 (64.7%) were female, and the mean age was 34.65±12.44. The youngest and oldest participants were 18 and 76 years old, respectively. Education levels were grouped due to low sample sizes in some categories: literate and primary school levels were combined, as were college and postgraduate levels. A total of 38 (28.6%) participants were literate or had a primary school education, 42 (31.6%) had completed high school, and 53 (39.8%) had a college or postgraduate degree. As for epilepsy classification, 63 patients (47.4%) had focal epilepsy, 34 patients (25.6%) had generalized epilepsy, and the epilepsy type was unknown in 36 patients (27.1%).

The mean age was significantly higher in male participants than in female participants [38.55 (12.42) vs. 32.52 (11.99), p=0.007]. No significant differences in mean age were observed between other comparison groups. When compared based on the epilepsy type, patients with focal epilepsy had a significantly higher mean age (40.11±11.09) than those with generalized epilepsy (mean difference =14.14 years, p<0.001) and unknown epilepsy type (mean difference =6.80 years, p=0.011). Participants who were literate or had completed primary school were significantly older (44.42±10.72) than those who had completed high school (mean difference =12.06 years, p<0.001) and those with a college or postgraduate degree (mean difference =14.49, p<0.001).

Fifty-four (40.6%) participants reported knowledge of AI applications. Among all participants, only 11 (8.3%) reported using an AI application for their epilepsy at least once. A total of 54 (40.6%) participants expressed a positive attitude toward the use of AI applications to evaluate whether their attacks were epileptic. In total, 74 (55.6%) participants were positive about using AI applications to determine recurrence risk or forecast the next seizure. Positive attitudes toward AI applications for choosing the most appropriate medication and for tailoring medication doses were present in 62 (46.6%) and 55 (41.4%) of participants, respectively. While 35 (26.3%) participants were comfortable with AI evaluating their EEGs independently, 103 (77.4%) participants preferred AI to assist their physicians in reading their EEGs. Overall, 58 (43.6%) participants had a positive attitude toward the use of AI to evaluate their imaging. Seventy participants (52.6%) expressed concerns about privacy due to AI applications accessing their personal health information. A total of 47 (35.3%) participants believed that AI applications would improve communication with their doctors, whereas 71 (53.4%) expressed concern that the human connection with their doctors would weaken. When asked whether they would be comfortable with AI applications completely replacing their doctors, 22 (16.5%) responded affirmatively. All responses are presented in detail in Figure 1.

Table 2. Demographic characteristics of all participants (n=133)

Characteristics	
Participant category	
Patient, n (%)	111 (83.5)
Caregiver, n (%)	22 (16.5)
Age, mean (SD)	34.65 (12.44)
Female sex, n (%)	86 (64.7)
Epilepsy type	
Focal, n (%)	63 (47.4)
Generalized, n (%)	34 (25.6)
Unknown, n (%)	36 (27.1)
Education level	
Literate, n (%)	1 (0.8)
Primary school, n (%)	37 (27.8)
High school, n (%)	42 (31.6)
College, n (%)	50 (37.6)
Postgraduate, n (%)	3 (2.3)

SD: Standard deviation

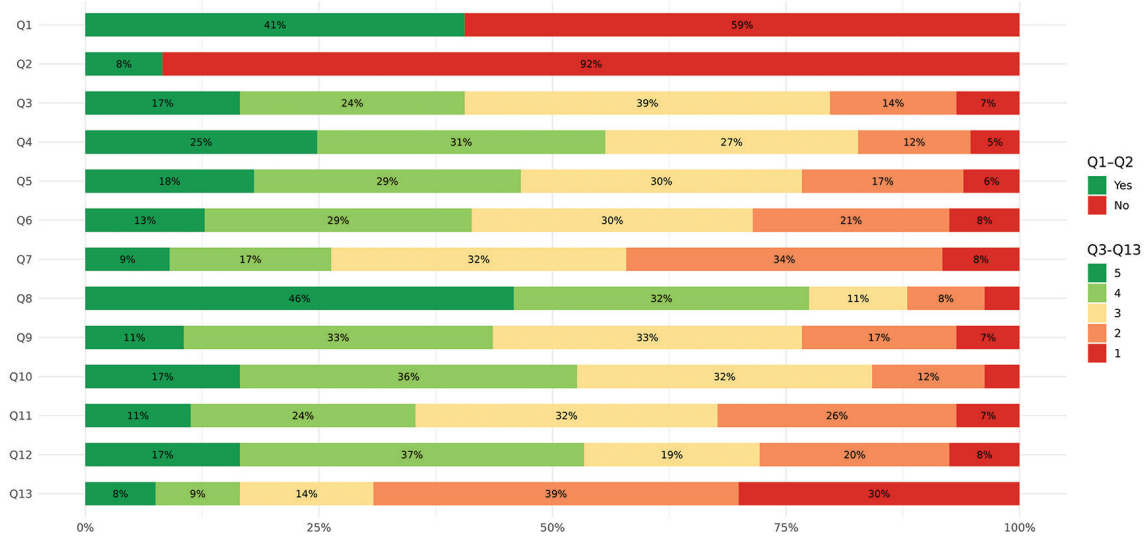

Figure 1. Distribution of responses to all survey questions. Q1-2 were yes/no questions; Q3-13 were rated on a 5-point Likert scale (5=strongly agree, 4=agree, 3=not sure, 2=disagree, 1=strongly disagree). Percentages were rounded to the nearest whole number

Percentages of positive responses were compared between groups. No significant differences were observed between patients and caregivers or between males and females. Participants younger than the mean age had higher knowledge of AI than participants older than the mean age (48.6% vs. 31.1%, p=0.041). All other responses were comparable between groups. Participants with a college or postgraduate degree had higher AI knowledge than other participants (literate and primary school: 21.1%; high school: 21.4%; college and postgraduate: 69.8%; p<0.001). Participants who completed high school had a less favorable attitude toward the use of AI applications in interpreting medical images (literate and primary school, 42.1%; high school, 28.6%; college and postgraduate, 56.6%; p=0.023). Participants who were literate or had completed primary school expressed greater concern about the possibility of weakening the human connection between patients and their doctors compared with other participants (literate and primary school: 73.7%, high school: 42.9%, college and postgraduate: 47.2%, p=0.011). No significant differences were observed in other responses across education levels. Patients with generalized epilepsy expressed lower levels of concern about privacy related to AI applications accessing their medical information than did other patient groups (focal 55.6%, generalized 35.3%, unknown 63.9%, p=0.046). Other responses were similar across epilepsy types.

DISCUSSION

The present study demonstrated that PWE and their caregivers had limited knowledge of AI applications. Notably, almost half of the participants favored the use of AI applications in their care. However, many participants expressed concerns about privacy regarding their personal health information and the potential weakening of their relationship with their doctors. Although attitudes toward AI applications were generally positive, the majority were uncomfortable with the idea of AI completely replacing their doctors. Despite a single-center design and a moderate sample size, this is, to the best of our knowledge, the first quantitative study to assess the attitudes of PWE and their caregivers about AI applications.

In our study, 40.6% of participants reported having knowledge about AI. Despite having limited knowledge about AI applications, up to 55% of participants expressed a positive attitude toward the use of these applications in diagnosing and forecasting seizures, adjusting medications, and interpreting EEGs and images. This may reflect greater receptiveness to AI as a physician-supporting rather than an autonomous tool; however, as the underlying reasons were not directly assessed, this interpretation remains speculative and warrants further qualitative investigation. Busch et al reported that 13.4% of patients had no knowledge, and 58.6% had little knowledge about AI.[19] This study also showed that 57.6% of participants were positive about the general use of AI in medicine. In another study where patients rated the responses of health-related questions, they were unable to distinguish the AI-generated responses from doctors' responses, they understand the meaning better even when the response had low accuracy, and they stated that they would follow the AI-generated medical advice similar to the ones that were given by doctors.[20] Overall, these studies highlight patients' lack of knowledge about AI and underscore the need to improve both AI-specific and general health literacy. Improving knowledge about AI will affect their attitudes toward the use of these applications, help them understand the limitations of these technologies, and enable them to foresee potential medical risks.

The knowledge of AI was significantly higher in participants younger than 35 years of age and in those with a college or postgraduate degree compared to participants older than 35 years of age and those with lower education levels, respectively. The attitude toward AI was more positive in people who were experts in AI or had higher technological literacy (measured by the number of technological devices used weekly).[19] It is plausible that interaction with technology is greater among younger individuals and those with higher education. However, this highlights both the heterogeneity of AI knowledge across different groups and the importance of raising awareness, especially among older adults and individuals with lower education levels.

Participants in our study were more comfortable with AI assisting their doctors in interpreting the EEG results than with AI applications used alone. This is in line with findings from another study conducted in a memory clinic, where more than 80% of patients and their caregivers thought that the computer programs should be complementary, not a replacement for the current way of working.[15] Similar attitudes have been observed in other clinical settings, such as neurosurgical patients, who favored partial autonomous surgery rather than fully autonomous surgery.[16] Beyond acceptance, several potential benefits of using AI in interpreting EEG results, such as preventing misreading and decreasing the high time burden of reading EEGs, have been identified.[21] Furthermore, several studies have shown that doctors using AI tools achieve better performance than doctors alone.[2] Thus, future approaches are likely to evolve toward a collaborative model between doctors and AI, and integrating AI into EEG training should be considered to improve the epilepsy care and patient trust.[21]

In our study, 43.6% of participants responded positively to AI analysis of their imaging data. The literature reports various findings on AI and image interpretation. In a neurosurgery patient population, 76.7% of all patients reported feeling comfortable about the use of AI in preoperative imaging interpretation.[16] In contrast, another study exploring the views of patients on the use of AI in radiology reported a general distrust for AI in diagnostic interpretation tasks.[13] Additionally, the same group reported that majority of patients wanted the radiologist to check the results after AI had examined the mammography.[22] They also showed that the need for human oversight of AI results decreased with increasing education level.[22] This aligns with our findings, in which participants with the highest level of education had the most favorable attitudes toward using AI for image interpretation. Enhancing patient literacy, both about AI and more generally, may positively affect their attitude towards the use of AI in this context.

The study found that half of the patients had concerns about the privacy of personal information related to the use of AI applications. It has been shown in various studies that patients have concerns about privacy, and it is one of the most important barriers in the implementation of AI applications.[13,23] Anonymizing the datasets used in the training of the models and using federated models to store patient data locally for decentralizing are some of the proposed solutions for data safety.[2] In addition to these technical privacy- and security-oriented approaches, healthcare professionals, including neurologists, and patients, who are the

primary individuals affected by the outcomes of the use of these applications, should also be present in the process.[11,12] Active participation of patients in the process would make sure that their expectations are considered, as well as help gain their trust that will enable the implementation of these applications in clinical care.[24] Indeed, patients have a high expectation for explainable AI and value transparency.[19] Ensuring transparency and validation during the training of the AI models is one of the key factors in building trust.[2,19] Additionally, the implementation of effective monitoring measures, along with clearly defined boundaries of accountability, is essential for building a safe and reliable system both for doctors who use these applications and patients who are directly affected by their outcome.[10] Our study findings build on these views by sharing the expectations and concerns of both PWE and their caregivers.

Our study found that most participants were uncomfortable with the idea of AI replacing their doctors completely, and more than half of them believed that it would weaken their communication with their doctors. Similarly, an international multicenter study reported that 61.8% of the patients believed AI would reduce the interaction with their physicians, 61.7% had a fear that AI would replace their doctors, and only 4.4% supported a fully autonomous AI for diagnosis.[19] Additionally, 69.6% of participants in another study stated that AI would result in spending less time with their doctors.[14] While some patients thought that AI could enhance communication with their doctors in a recent study, others worried that it could interrupt the consultation.[17] Nevertheless, they sought sensitive, clear, two-way communication with their doctors for establishing trust, which is essential for their willingness to follow the advice of their doctors and continue follow-ups.[17] Therefore, these attitudes should be considered when developing AI applications, ensuring that the doctor-patient relationship remains central rather than sidelined.

Study Limitations

Our study has several important limitations. First, it was conducted at a single center with a moderate sample size, thereby limiting the generalizability of our findings to the broader population of PWE. Second, the survey was developed by the authors for this study and was not formally validated. While it covered key domains, its preliminary nature may not have fully captured the detailed perspectives of the participants. A third significant limitation is that more than half of the participants reported no knowledge of AI, and our assessment was based on a single dichotomous question. This means that responses may be based on assumptions rather than informed opinions, making it difficult to draw conclusions about the reasons for participants' responses. Fourth, although including caregivers, who are generally involved in the decision-making process for the PWE, allowed us to represent real-life situations, it may have made it harder to reflect the attitudes of the participants, especially those with limited literacy. Although patients and caregivers had comparable responses across all survey questions, the relatively small number of caregivers limits the statistical power of this subgroup comparison. The surveys were administered by participants' treating doctors, which may have influenced their responses and introduced response bias. Despite these limitations, our study provides valuable preliminary insights into the literature and represents the first quantitative study conducted in an epilepsy outpatient clinic to explore the attitudes of patients and their caregivers toward AI applications, complementing the findings by Reeder et al.[17] in a different sociocultural population. Further studies with larger, multicenter cohorts and more structured surveys that explore knowledge about AI in more detail would build upon these findings.

CONCLUSION

Our study shows that nearly half of participants have positive attitudes toward AI applications in epilepsy practice, despite limited knowledge of these technologies. However, concerns related to privacy and doctor-patient relationships remain prominent. Future studies involving larger cohorts are needed to validate these findings, and efforts should incorporate these perspectives to develop trustworthy, reliable, and patient-centered AI applications.

Ethics

Ethics Committee Approval: Ethical approval was obtained from the University of Health Sciences Türkiye, Kartal Dr. Lütfi Kırday City Hospital Scientific Research Ethics Committee (approval number: 2024/010.99/10/17, date: 29.11.2024).

Informed Consent: Written informed consent was obtained from all participants at the time of the survey.

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For transparency, the authors note that an artificial intelligence-assisted language model (ChatGPT, OpenAI) was utilized to support language correction, data analysis, literature assistance. This assistance was limited to linguistic refinement; all scientific content, critical analysis, and final editorial decisions were made exclusively by the authors.

Footnotes

Authorship Contributions

Surgical and Medical Practices: M.E., S.F.Ö., Concept: M.E., S.F.Ö., Design: M.E., S.F.Ö., Data Collection or Processing: M.E., S.F.Ö., Analysis or Interpretation: M.E., S.F.Ö., Literature Search: M.E., S.F.Ö., Writing: M.E., S.F.Ö.

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