

# A qualitative study of factors influencing ePHR adoption by caregivers and care providers of Alzheimer's patients: An extension of the unified theory of acceptance and use of technology model

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## Abstract

**Background and Aims:** As the nowadays provision of many healthcare services relies on technology, a better understanding of the factors contributing to the acceptance and use of technology in health care is essential. For Alzheimer's patients, an electronic personal health record (ePHR) is one such technology. Stakeholders should understand the factors affecting the adoption of this technology for its smooth implementation, adoption, and sustainable use. So far, these factors have not fully been understood for Alzheimer's disease (AD)-specific ePHR. Therefore, the present study aimed to understand these factors in ePHR adoption based on the perceptions and views of care providers and caregivers involved in AD care.

**Methods:** This qualitative study was conducted from February 2020 to August 2021 in Kerman, Iran. Seven neurologists and 13 caregivers involved in AD care were interviewed using semi-structured and in-depth interviews. All interviews were conducted through phone contacts amid Covid-19 imposed restrictions, recorded, and transcribed verbatim. The transcripts were coded using thematic analysis based on the unified theory of acceptance and use of technology (UTAUT) model. ATLAS.ti8 was used for data analysis.

**Results:** The factors affecting ePHR adoption in our study comprised subthemes under the five main themes of performance expectancy, effort expectancy, social influence, facilitating conditions of the UTAUT model, and the participants' sociodemographic factors. From the 37 facilitating factors and 13 barriers identified for ePHR adoption, in general, the participants had positive attitudes toward the ease of use of this system. The stated obstacles were dependent on the participants' sociodemographic factors (such as age and level of education) and social influence (including concern about confidentiality and privacy). In general, the participants considered ePHRs efficient and useful in increasing neurologists' information about

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their patients and managing their symptoms in order to provide better and timely treatment.

**Conclusion:** The present study gives a comprehensive insight into the acceptance of ePHR for AD in a developing setting. The results of this study can be utilized for similar healthcare settings with regard to technical, legal, or cultural characteristics. To develop a useful and user-friendly system, ePHR developers should involve users in the design process to take into account the functions and features that match their skills, requirements, and preferences.

#### KEYWORDS

Alzheimer's disease, caregiver, dementia, electronic personal health record, neurologists, UTAUT model

## 1 | INTRODUCTION

Dementia is a syndrome, which manifests as a set of symptoms, including memory loss and impaired thinking, language, problem-solving, and other capabilities of a patient.<sup>1</sup> The number of patients with this disorder is constantly growing day by day. In 2015, the Global Alzheimer's Association reported that the number of these patients will increase from 46 million to 150 million by 2050.<sup>2</sup> In the World Health Organization (WHO) report, the cost of caring for these patients was estimated to grow to 1.2 trillion dollars by 2030 worldwide.<sup>3</sup> Alzheimer's disease (AD) is the most common type of dementia named after the physician who first described it.<sup>4</sup> It has been predicted that the number of Alzheimer's patients will increase to 115 million by 2050 due to the growth in the elderly population worldwide.<sup>5</sup>

The main concern related to AD is that no definitive cure currently exists for this progressive disease. Delayed diagnosis as well as inadequate provision of resources, education about care and prognosis, and other home supports to meet the needs of patients/families are other challenges.<sup>6-8</sup> It is difficult to diagnose this incurable disease in the early phases, especially in the elderly.<sup>9</sup> One of the issues that makes AD challenging to diagnose is that it takes years for its symptoms to manifest themselves completely.<sup>10</sup> Moreover, to diagnose and manage its progression effectively, care providers should access information on several contributing factors such as the age of onset, level of education, and comorbidities (e.g., depression, hypercholesterolemia, and diabetes).<sup>11-17</sup> Therefore, all clinical information should comprehensively be made available to them in a timely manner to enable them to diagnose and control this disease as early as possible.<sup>18</sup> This will indeed be possible through the appropriate use of technology.

Nowadays, technology as a cost-effective method improves patients' quality of life in many healthcare solutions.<sup>19-21</sup> A personal health record (PHR) is a tool that was quickly developed into the electronic personal health record (ePHR) with the advent of the Internet.<sup>22</sup> This rapid development can be due to the reasons such as the low cost of ePHRs as an internet-based intervention for providing services to patients.<sup>23</sup> In addition, ePHRs can improve patients' relationships with health service providers by real-time sharing of patient medical records with them,<sup>24-26</sup>

and this in turn will improve the quality of care.<sup>27</sup> ePHRs are mainly used to address the care needs of patients with chronic diseases. They are considered promising tools for more effective coordination of health information between patients and their health service providers.<sup>21,28</sup> Unlike an EHR, an ePHR is accessible to patients. An ePHR attempts to give "agency" (to share and manage; and not just to access) one health information over patients' lifelong (records that might be amassed from perhaps multiple sources over time); and when done correctly, these functions are deliberately granted to the user (patient), not merely the health system or provider, in an ePHR.<sup>29</sup> By making personal health information available to patients, their caregivers, and even healthcare providers, ePHRs can improve patients' health and awareness, provide information support to caregivers, and as a result, increase caregivers' and healthcare providers' shared care provision to these patients.<sup>30-32</sup> Therefore, the need for technologies such as ePHRs is increasing in chronic diseases especially Alzheimer's to support patients, caregivers, and healthcare providers.<sup>33,34</sup> If ePHRs are not designed using user-centered design and user needs/requirements, due to patient's cognitive impairments, they are more likely to be of poor quality, not provide the needed support, cause more harm than benefit, compound the existing burden on care partners, and incur avoidable waste of financial and human resources.<sup>35-40</sup>

ePHRs are increasingly adopted in developed countries.<sup>41-46</sup> Despite the growth of ePHRs in developed countries, little experience is available in developing countries.<sup>47-49</sup> The reason for this is partly because there are more barriers (such as barriers related to health and technology infrastructures as well as human resources and expertise) to ePHR design/adoption in developing countries than in developed countries.<sup>44</sup> The results of numerous studies have indicated that ePHRs should primarily meet the individual needs and requirements of their users.<sup>29,50</sup> Many caregivers and care providers have access to their patients' health information through ePHRs, which plays an effective role in care provision.<sup>51</sup> Grabher argued that supporting caregivers is as important as providing direct care to Alzheimer's patients because the well-being of caregivers directly affects the quality of care they provide.<sup>52</sup> Furthermore, care providers would perform better when they are continuously provided

with information through ePHRs.<sup>53</sup> The many advantages of ePHRs prompted us to identify the needs and requirements of caregivers and care providers involved in the care of Alzheimer's patients to develop an ePHR in a developing country. Therefore, as the first step in developing an ePHR for Alzheimer's patients, we aimed to better understand the needs of the main users in care provision and the likely facilitators and barriers they may face for its adoption.

## 2 | METHODS

The present qualitative, exploratory study was conducted in Kerman Province, the largest province in Iran, from February 2020 to August 2021. This study follows the Standards for Reporting Qualitative Research (see Appendix S1).<sup>54</sup> We invited AD patient caregivers living in Kerman and the neurologists working in Shafa hospital, affiliated with Kerman University of Medical Sciences (KUMS), to participate in this study using purposive sampling. Thirteen interviews were conducted with Alzheimer's patient caregivers (whose patients were in different stages of the disease) and seven interviews with neurologists involved in AD care. The inclusion criteria for the neurologists was their involvement in treating Alzheimer's patients. Caregivers were selected from the two WhatsApp groups, "Dardashna" and "Bargozidegan" having 315 members in total. These two groups covered almost all caregivers in Kerman because the neurologists of Kerman added patients and their family members to them. They had been active for almost 9 years and were the only support groups for Iranian Alzheimer's patients and their caregivers on the WhatsApp platform.<sup>55</sup> We invited the family members of community-dwelling AD patients, who were living in urban areas of Kerman and had at least 5 years of care experience, whose patients were still alive at the time of this study to participate. Participation was voluntary without providing them with any incentives.

In order to conduct the interviews, first, two interview question guides were designed: one for caregivers and another for neurologists. The details of these two question guides are shown in Table 1. The interviews were conducted over the phone because face-to-face interviews could increase the possibility of transmission of the coronavirus disease of 2019 (COVID-19) at the time of this study. The first author, who held a master's in medical informatics and was one of the main study investigators with more than 3 years of qualitative studies performed the interviews. In total, 13 caregivers

accepted our invitation from which we interviewed 13 people mainly because the saturation of data was reached after the 11th interview (i.e., no new information was provided in the last three interviews). The mean length of interviews with caregivers and neurologists was 1 h (minimum of 40 and maximum of 80 min) and 20 min (minimum of 10 and maximum of 30 min), respectively.

### 2.1 | Research framework

Several theories and models were examined in the present study in order to identify the factors affecting the adoption of ePHR with the possibility of remote consultation (see Appendix S2). We chose the Unified Theory of Acceptance and Use of Technology (UTAUT) as a suitable and widely used theory to examine the acceptance of an ePHR system in our study population based on other studies.<sup>55-58</sup>

The research team members obtained a general understanding of the content of the interviews by reading them multiple times. Then the content of the interviews was analyzed using the Elo and Kyngas method in three stages, including preparation, organization, and reporting (Table 2).<sup>59,60</sup> The initial codes were extracted using this method, and groups were formed under the subthemes on the bases of the UTAUT model.

### 2.2 | The UTAUT model

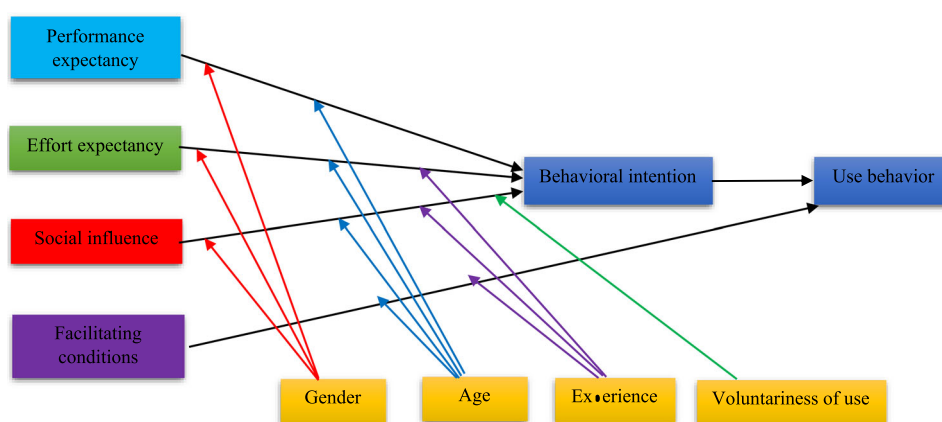
The UTAUT combines theories based on the technology acceptance model to explain users' intentions to adopt technology and their subsequent usage behavior.<sup>61</sup> So far, the UTAUT has been used to evaluate the acceptance and use of technology in various mobile and information technology fields.<sup>62,63</sup> Figure 1 provides a summary of effective factors in the UTAUT approach. The behavioral intention in the UTAUT is a subjective probability of how a person acts in relation to a certain behavior.<sup>64</sup> The three key factors for "behavioral intention" in the UTAUT were "performance expectancy," "effort expectancy," and "social influence." "Performance expectancy" is defined as the perception or belief that adopting a system will increase or enhance the quality of a person's life performance. "Effort expectancy" is defined as the level or degree of ease associated with using a system. "Social influence" is defined as the degree to which an

**TABLE 1** Interview question guide.

Question of caregivers	<ol style="list-style-type: none"> <li>1. How can the use of an ePHR with the possibility of remote consultation help you?</li> <li>2. Recording and remembering what kind of information can help you the most?</li> <li>3. In your opinion, what barriers will prevent you and others from using such systems?</li> <li>4. What solutions do you suggest to overcome these barriers?</li> </ol>
Questions of neurologists	<ol style="list-style-type: none"> <li>1. In your opinion, who (among the healthcare providers) can be the main users of an ePHR for AD, responding to patients and their caregivers, possibly in the form of remote consultations?</li> <li>2. What general categories of information must be available in an ePHR with the possibility of remote consultation so that you can better manage the patient's condition?</li> <li>3. What stage-specific information about the AD should be included in this ePHR?</li> </ol>

**TABLE 2** The qualitative data analysis process based on the Elo and Kyngas method (47).

Preparation	Selecting the unit of analysis	After converting the interviews into texts, the transcripts were analyzed, and the semantic units were identified.
	Finding a logical relevance between the data and the topic	The researchers read the transcripts several times to achieve a continuous and prolonged engagement with the data.
Organization	Creating an analytical matrix	Determining the main classes based on the UTAUT model.
	Data extraction from content based on classes	The main classes were formed based on conceptual and logical relationships with other classes, and finally, the classes were identified based on the research framework.
	Grouping	The number of codes was reduced by integrating similar codes based on their differences and similarities in more general codes.
	Classification	The formed groups were classified based on differences and similarities (integration of similar groups).
	Abstract	The identified classes were placed in the main and primary classes of the analytical matrix.
Reporting	The participants' characteristics, data collection, data analysis, and each of the main classes were reported in details in the findings section.	

**FIGURE 1** The unified theory of acceptance and use of technology (UTAUT) (49).

individual perceives that others feel she or he should use new technologies. The degree to which a person thinks there is a technical and organizational foundation to enable the usage of the system is known as the facilitating condition. The main factors determining the actual “use behavior” and continuous use of the technology are “behavioral intention” and “facilitating conditions.”<sup>64</sup> Fitrianie et al.<sup>65</sup> showed that both “behavioral intention” and “facilitating conditions” can affect users’ “usage behavior” in mobile applications. Gender, age, experience, and voluntariness of use are considered user characteristics that might affect “use behavior” by influencing “performance expectancy,” “effort expectancy,” and “social influence.”

### 2.3 | Data analysis

In the present study, qualitative analysis of the interviews was performed using the thematic analysis method.<sup>66</sup> In this method, the recorded and noted information was written down verbatim and typed in Microsoft Word 2020 at the first opportunity. Then, these

files were entered into ATLAS.ti8 for coding using thematic categories from the four core constructs of the UTAUT model (performance expectancy, effort expectancy, social influence, and facilitating and impeding conditions). The first investigator systematically coded the data to identify and categorize key themes based on the above-mentioned framework. The corresponding investigator closely supervised the whole analysis. Any disagreement was solved by a discussion among the authors of this manuscript. Finally, the qualitative findings were placed in the form of themes and subthemes of the UTAUT model.

### 2.4 | Rigor

To evaluate qualitative data, Lincoln and Guba created criteria including credibility, transferability, dependability, and confirmability in 1994.<sup>67</sup> These criteria can be applied by researchers concerned about the acceptability and usefulness of their research to a variety of stakeholders. Credibility was achieved through the interaction

between the researchers and at least 5-month interactions with the data. Transferability refers to generalizability, for which the characteristics and experiences of the study participants were described in detail. In order to achieve dependability, academic supervisors familiar with qualitative studies supervised the study stages. Finally, the confirmability of the study was maintained by stringent attempts to sustain neutrality by the researchers. For maintaining confirmability in this study and to sustain neutrality by the researchers, we mentioned the exact exemplary participant quotes in a dedicated table (please see Section 3.2).

## 2.5 | Ethical considerations

Before starting the study, the necessary permissions were obtained from the Ethics Committee of KUMS to conduct the research. The participants were assured of their information confidentiality. After explaining the study objectives and the voluntariness of their participation, the participants gave their consent to participate in the study. With their consent, the interviews and conversations were recorded.

## 3 | FINDINGS

### 3.1 | Study participants

The participating caregivers and specialists in this study were aged 27–80 and 43–65 years, respectively ( $n = 20$ ). Most caregivers were

female ( $n = 11/13$ ), and most specialists were male ( $n = 5/7$ ). Out of 13 patients under the care of participating caregivers, 6 patients were in Stage<sup>1</sup> 4, 4 were in Stage 3, and 3 were in Stage 2 of AD. Eight caregivers were the patients' children, and five were the patients' spouses. Tables 3 and 4 provide the details of our study participants.

### 3.2 | Findings on the bases of the UTAUT model

After continuous analysis and comparison of codes and removing duplicates, the final codes obtained from the interviews with the participants to determine the factors affecting the adoption of ePHR with the possibility of remote consultation by caregivers and neurologists were categorized under five categories of behavioral

**TABLE 4** The characteristics of specialists who participated in the study.

Neurologist number	Age (years)	Gender	Work experience (years)
1	43	Male	10
2	54	Male	17
3	47	Male	19
4	48	Female	10
5	55	Male	21
6	50	Female	16
7	65	Male	30

**TABLE 3** The characteristics of caregivers who participated in the study.

Caregiver number	Age (years)	Gender	Marital status	Education level	Relationship with AD patient	Length of caregiving experience (years)	Disease stage of an AD patient
Caregiver 1	65	Male	Married	Bachelor's degree	Husband	10	4
Caregiver 2	30	Female	Single	Master's degree	Daughter	5	2
Caregiver 3	43	Female	Married	PhD	Daughter	8	3
Caregiver 4	27	Female	Single	Master's degree	Daughter	3	3
Caregiver 5	50	Female	Married	Master's degree	Daughter	11	4
Caregiver 6	35	Female	Married	Master's degree	Daughter	1	2
Caregiver 7	80	Male	Married	Bachelor's degree	Husband	25	4
Caregiver 8	42	Female	Married	Master's degree	Daughter	9	3
Caregiver 9	56	Female	Married	High School Diploma	Wife	6	4
Caregiver 10	40	Female	Single	Master's degree	Daughter	4	2
Caregiver 11	53	Female	Married	High School Diploma	Wife	7	4
Caregiver 12	48	Female	Married	Associate Degree	Daughter	5	3
Caregiver 13	55	Female	Married	High School Diploma	Wife	7	4

intention, performance expectancy, effort expectancy, social influence, and facilitating conditions based on the UTAUT and the participants' sociodemographic factors (Figure 2).

The analysis results indicated that, in general, the participants had positive attitudes toward using an ePHR. All participants believed that such an electronic record is necessary to achieve a higher quality of care. According to the interviews, many goals can be achieved using such a system. The participants considered an ePHR with the possibility of remote consultation as an efficient and useful tool to increase neurologists' information about their patients and manage their symptoms in order to provide better and timely treatment. However, some factors, such as the specialists' lack of trust in the information exclusively provided by caregivers (e.g., incorrect, false, or misleading information because of their low level of literacy and problems in understanding ePHR content), the possibility of errors and mistakes in remote consultation, and concerns about the principle of confidentiality and privacy, have made neurologists skeptical about its use. From the caregivers' point of view, this system can play an effective role in reducing their work, mental, and financial burdens. For example, they considered the informational/educational support of caregivers by means of an ePHR as an incentive to use it in order to reduce the workload (e.g., self-management tasks) and mental burden (e.g., anxiety). While they stated that the lack of support provided by some insurance companies would be a barrier to the acceptance of these systems. Some of our participants' quotes are marked with Q# in the text, which corresponds with the direct quotes presented in Table 5.

### 3.2.1 | Performance expectancy

Performance expectancy was considered a criterion of users' belief that using this system would improve their lives because of, for example, saving time and reducing workload and mental pressure. Based on the analysis of participants' interviews, the performance expectancy was divided into the three subcategories of usefulness expectancy, service quality, and usability (Table 5).

#### *Usefulness expectancy*

During in-person visits, the patients themselves or their companions may forget the medical recommendations of care providers due to their mental preoccupations or may not be able to convey them completely and accurately to other family members, especially when several family members take turns taking care of a patient. Clinician recommendations on such as lifestyle, diet, or medications can be recorded using an ePHR, and this can prevent forgetting to follow medical orders. Our participants believed that an ePHR can also increase coordination between caregivers themselves and reduce their workload (Q1 and Q2). Furthermore, when referring to medical centers, many patients or their caregivers cannot provide comprehensive information about patients' conditions. This can lead to unnecessary extra steps in treatment and diagnosis, and then, clinicians would spend more time reaching an appropriate decision (Q3).

Our participants highlighted that AD treatment is costly and as the disease progresses, treatment costs continue to increase. Many caregivers believed that by accessing patients' medical records through ePHRs, such as test results and reports of radiographic images, they can reduce medical service costs, especially when patients change their physicians or consult several others (Q8). In addition, with the help of ePHRs, caregivers and patients in the early AD stages can get much information about the disease, which may enable them to solve their problems without referring to a specialist and paying for visits. The information support to manage this disease in ePHRs can motivate them to use such systems (Q9). According to the caregivers, using an ePHR can increase their awareness of their patients' condition through easier access to information, patient medical records, and appropriate educational materials and, thereby, help reduce the side effects of the disease (Q4). The caregivers also stated that timely access to information through an ePHR with the possibility of remote consultation could greatly increase their access to care. Consequently, when something happens, the caregivers would benefit from the guidance available in this system (Q5).

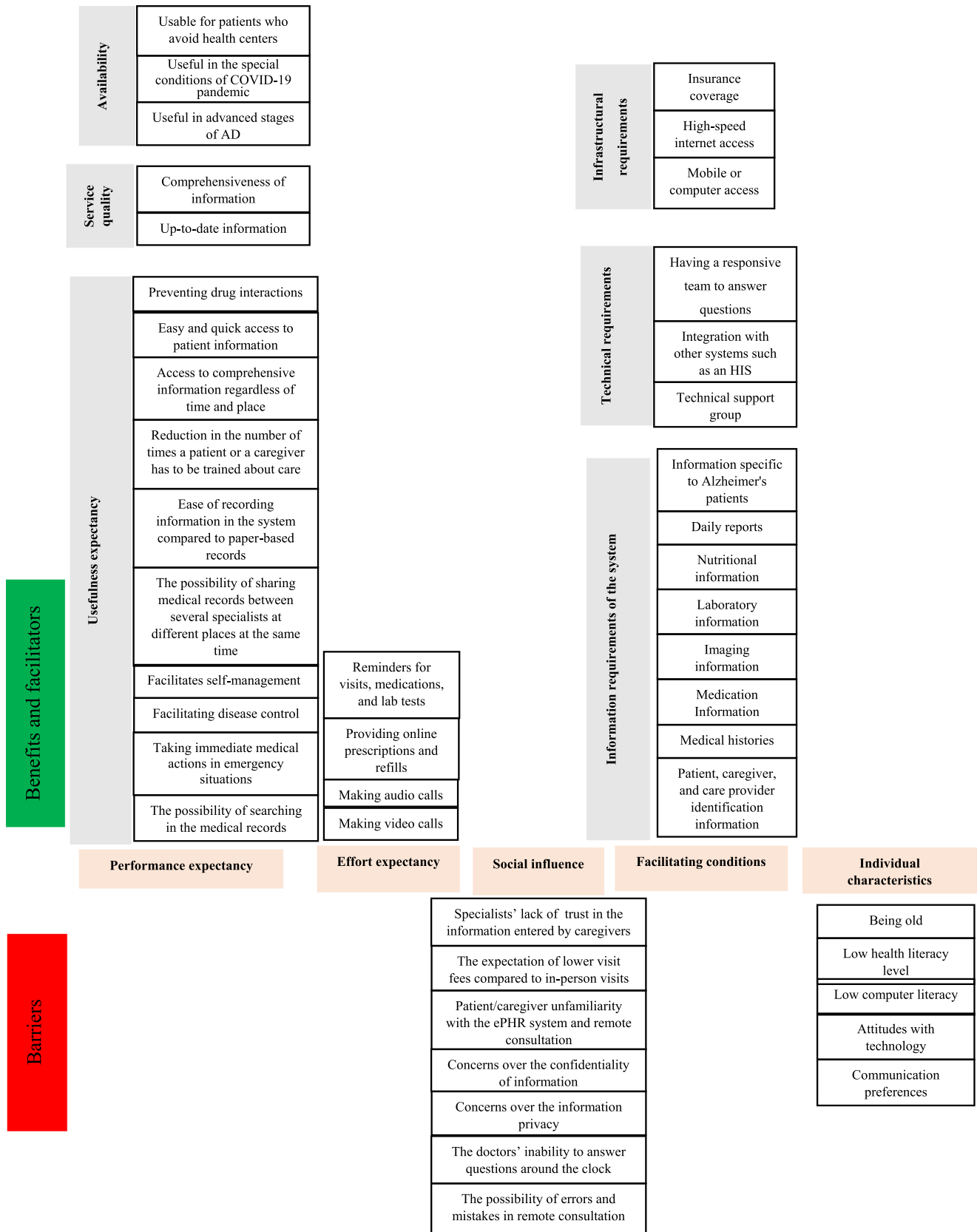
Providing comprehensive care to Alzheimer's patients seemed difficult. Caregivers reported that controlling behavioral changes in these patients requires information and caregiver expertise and professional behavior to cope with the changes. By providing information, such systems can train caregivers to acquire the necessary skills in dealing with behavioral changes (Q6). By using the educational content in ePHRs, caregivers would be able to control and manage patients' conditions by choosing the best dealing strategy when behavioral changes occur (Q7).

Some caregivers considered Alzheimer's a challenging and complicated disease, which imposes a huge burden on them, and also negatively affects their patients' quality of life. They mentioned that using an ePHR at home would be one of the solutions to reduce this care burden. The analysis indicated that the caregivers considered this system effective in their self-efficacy in providing better care (Q10 and Q11).

Our caregivers reported that as the disease progresses, their patients need more and different types of care in different stages. Due to the chronic and progressive nature of AD, the caregivers requested tailored information related to each stage of the disease to increase their knowledge (Q12). Some caregivers stated that while caring for patients, various complex conditions might occur (such as the one mentioned in Q13). These cases are difficult to solve without enough prior information and knowledge. Sharing caregivers' experiences through this system can make the care processes easier and more understandable for other caregivers.

#### *Service quality*

Many healthcare providers stated that they do not have proper access to health documents and patient records when patients visit medical centers. This problem can be due to time-consuming access to paper-based medical records and the unavailability of the hospital's medical records unit during holidays. Accordingly, they valued using ePHRs to access patients' medical records (Q14).



**FIGURE 2** An overview on the factors impacting the adoption of an ePHR with the possibility of remote consultation for Alzheimer's disease.

**TABLE 5** Structure of the UTAUT with relevant quotes from our study participants.

Themes	Subthemes	The participants
Performance expectancy	Usefulness expectancy	<p>Q1: "Each patient may have several caregivers, one of whom accompanies them each time. When I ask if they have followed the recommendations from the last visit, they say that they could not come, and their sister or brother or someone else had come last time." (<i>Neurologist No. 3, October 20, 2020</i>)</p> <p>Q2: "It helps a lot because the exact type and stage of the disease and the medications are recorded, and during the visits, if any of us accompany the patient, the others can see the doctor's recommendations and medication changes using this system" (<i>Caregiver No. 7, April 2, 2020</i>)</p> <p>Q3: "At least one caregiver usually accompanies our patients when they visit our office. The caregivers are their wives, husbands, daughters, etc., i.e. family members. We don't expect these patients to tell us about their treatment. However, it would be great if their caregivers could provide us with information such as radiographic images, test results, and the medications that they have taken. This can make the treatment process faster and more accurate." (<i>Neurologist No. 5, May 15, 2020</i>)</p> <p>Q4: "... Because we have a lot of patients, training their caregivers takes time indeed (each time a different caregiver accompanies them). Moreover, if the information and records of the disease are available, the treatment will be faster and easier, and the disease will progress more slowly." (<i>Neurologist No. 3, October 20, 2020</i>)</p> <p>Q5: "I'd like this system to be able to guide me whenever there is a problem (in care matters)." (<i>Caregiver No. 13, June 22, 2020</i>)</p> <p>Q6: "Medication information and behavioral changes [following the use of medications] should be in the records because the behavior usually changes after taking a new medication. Using the system is like having the doctor with me all the time, and I can control my patient by reading the information and guidance provided in the system." (<i>Caregiver No. 8, December 14, 2020</i>)</p> <p>Q7: "I'd like this record to help me with behavioral changes. There are lots of behavioral changes. I always want to tell the doctor about them Sometimes I wish there was something that could teach me what to do at times like that. (For example) these patients have sun downing and feel stressed at sundown." (<i>Caregiver No. 2, April 23, 2020</i>)</p> <p>Q8: "I'm tired. Any time we visit a new doctor, I have to pay a lot of money for new tests. The imaging is costly. We also have to wait for so long to get an MRI appointment at public centers with this system we do not have to pay for new images each time." (<i>Caregiver No. 11, August 2, 2020</i>)</p> <p>Q9: "The most important problem of Alzheimer's patients is hallucinations and restlessness. Caregivers often ask questions about these problems. I think if the system had a section that includes frequently asked questions, this would help reduce some of these problems." (<i>Neurologist No. 2, September 3, 2020</i>)</p> <p>Q10: "It is very useful for me to get informed about my patient's condition and the treatment process. Using the system, I can learn about my patient's condition and make the best decision to continue the treatment." (<i>Caregiver No. 3, August 10, 2020</i>)</p> <p>Q11: "The information in this system can help provide better care. For example, if my patient has trouble sleeping, the system suggests options to solve my problem, so I don't need to visit the doctor every time. This system can be very helpful at the macro level." (<i>Caregiver No. 9, February 21, 2020</i>)</p> <p>Q12: "The information included in the records would be very helpful to the patients in the early stages of the disease. They can know the disease more easily and try to cope with it." (<i>Caregiver No. 6, June 7, 2020</i>)</p> <p>Q 13: "When dad went to the bathroom he put a lot of pressure on their throat when clearing it. He stayed there for about 4-5 hours until his throat started bleeding. After a year, I found out that diphenhydramine could solve his problem. For times like this, I like to have access to a doctor." (<i>Caregiver No. 4, March 7, 2020</i>)</p>



TABLE 5 (Continued)

Themes	Subthemes	The participants
	Service quality	<p>Q14: "The department secretary spends much time every day separating the patients' files for me. Sometimes a file isn't in the department, which wastes a lot of time. The information in the file is usually not coherent, and we always have to look for information to write a correct prescription." (<i>Neurologist No. 7, September 9, 2020</i>)</p> <p>Q15: "My patients are from different cities. They usually have at least one chronic disease besides Alzheimer's, for which they constantly refer to other doctors. These records help us to know about these diseases." (<i>Neurologist No. 5, May 15, 2020</i>)</p> <p>Q16: "It'll be easier to keep the records with this system. Reviewing past events will become possible and all stages and changes during the disease can be easily observed. If a record like this is made and the information is recorded correctly, maybe the next stage of Alzheimer's disease can be predicted with artificial intelligence." (<i>Neurologist No. 6, June 15, 2020</i>)</p> <p>Q17: "This system should consider all aspects of the process like medical history, medication history, tests, imaging records, care observation records prepared at the patient's home, an archive of daily events, patient changes in the progress of the disease, and care measures. This way, I have all the information in one place, and I feel at ease." (<i>Caregiver No. 13, June 22, 2020</i>)</p>
	Usability	<p>Q18: "I don't take my father to the doctor. I describe his condition because It is too difficult to take him out. If there is a system that gives me complete information, I prefer not to go to the doctor." (<i>Caregiver No. 12, July 8, 2020</i>)</p>
Effort expectancy		<p>Q19: "This system has provided a good opportunity for doctors to visit more patients. The doctors can communicate with their patients through audio or video calls, review patients' real opinions about themselves using the comment section of the system and read the patient's medical records in their documents." (<i>Neurologist No. 2, September 3, 2020</i>)</p> <p>Q20: "The reminders for visits, medications, and tests in this system can be helpful." (<i>Caregiver No. 1, October 20, 2020</i>)</p> <p>Q21: "Sometimes I worry that I will forget the medication or doubt if I've given the medication or not. This system can remind me of my tasks with an alarm or have a checklist so that I can check my completed tasks." (<i>Caregiver No. 5, July 11, 2020</i>)</p> <p>Q22: "It would be great if the system had reminders for appointments and tests." (<i>Caregiver No. 6, June 7, 2020</i>)</p> <p>Q23: "Without features like daily report forms, online communication with the doctors, etc. people won't use ePHRs." (<i>Caregiver No. 7, April 2, 2020</i>)</p> <p>Q24: "The daily report form (specific to Kerman Alzheimer's Association) should be included in this system because it is difficult for me to complete the paper-based form. I suggest that the doctors check this form in the online consultation section and advise us based on it." (<i>Caregiver No. 3, August 10, 2020</i>)</p> <p>Q25: "I have to remember everything, like the tests and medications, which stresses all the time. My brain has to work for two people this system provides alarms and reminders so that it can reduce my stress." (<i>Caregiver No. 12, July 8, 2020</i>)</p> <p>Q26: "Each caregiver's brain has to work for two people. I'm old myself, and I forget things like the medications well, this system should help me not to forget these things." (<i>Caregiver No. 5, July 11, 2020</i>)</p>
Social influence		<p>Q27: "Two of the most important problems of Alzheimer's patients are hallucinations and restlessness, which are the subject of many caregivers' questions. If the system has a section that includes frequently asked questions, we can focus more on treatment rather than answering repetitive questions." (<i>Neurologist No. 4, May 19, 2020</i>)</p> <p>Q28: "The university must approve this project." (<i>Caregiver No. 1, October 20, 2020</i>)</p> <p>Q29: "If doctors don't work with the ePHR, this system will be incomplete, and caregivers may not use it." (<i>Caregiver No. 9, February 21, 2020</i>)</p>

(Continues)

TABLE 5 (Continued)

Themes	Subthemes	The participants
		<p>Q30: "We dedicate time to patients both in-person and virtually, so a visit fee must be paid. If the visit is free in your system, I don't think the doctor will be willing to cooperate." (<i>Neurologist No. 2, September 3, 2020</i>)</p> <p>Q31: "Many caregivers are elderly and may enter information incorrectly. Sometimes they're not careful and enter the wrong information, so we may write wrong prescriptions, and the patient's life will be in danger." (<i>Neurologist No. 5, May 15, 2020</i>)</p> <p>Q32: "In-person visits are much better because doctors can see the patients. While seeing the patients, the doctors add information to the records and provide the best treatment, but in virtual visits, caregivers may accidentally record or convey incorrect information. Doctors may not accept your system for this reason." (<i>Caregiver No. 7, April 2, 2020</i>)</p> <p>Q33: "We used to tell the doctor about the patient's condition over the phone, and the doctor increased the dose of the medicine. Then, my loved one went into a coma because of drug allergy." (<i>Caregiver No. 6, June 7, 2020</i>)</p> <p>Q34: "Separating patients and doctors is to the last resort. This record is not usable sometimes. For example, when we do not know the caregiver, but it's OK for patients with a history of 5 years or more." (<i>Neurologist No. 1, April 9, 2020</i>)</p>
Facilitating conditions	Information requirements of the system	Q35: "All the patient's information such as name, surname, national ID number, etc., and the information related to their illness should be included in these records. There should be a record in which doctors can find everything about their patient's illness to diagnose the disease." ( <i>Neurologist No. 4, May 19, 2020</i> )
	Technical requirements	<p>Q36: "Nowadays, electronic systems are used for test results, radiographic images, and many other things. Maybe in the future, all those things will be linked to the records, so users won't have to enter all the data." (<i>Neurologist No. 3, October 20, 2020</i>)</p> <p>Q37: "The doctor visits parent online, but the problem is that the information cannot be shared with the doctor; it would be great if this system could share treatment and medication information with the doctor." (<i>Caregiver No. 12, July 8, 2020</i>)</p>
	Infrastructural requirements	<p>Q38: "In our country, with the poor network connection, which is often interrupted, it is risky to rely only on these records, there must be paper-based records." (<i>Neurologist No. 3, October 20, 2020</i>)</p> <p>Q39: "The problem with virtual visits is the poor audio quality (because of lack of access to high-speed internet), but in-person visits are more reliable." (<i>Caregiver No. 8, December 14, 2020</i>)</p> <p>Q40: "Online visits without any paper-based documents cause difficulties for insurance companies. Without the support of insurance companies many users will stop using this system." (<i>Caregiver No. 10, May 26, 2020</i>)</p>
The participants' sociodemographic factors		<p>Q41: "Many elderly caregivers are afraid to use these systems, maybe because of low vision and sometimes distraction; they may enter wrong information and put the patient's life at risk." (<i>Caregiver No. 9, February 21, 2020</i>)</p> <p>Q42: "Because I'm old, I've somehow forgotten how to work with computers or do things like installing apps. If installing the app is complicated, I won't use it." (<i>Caregiver No. 1, October 20, 2020</i>)</p> <p>Q43: "I only have a high school diploma. If the record is in English, it will be difficult for me to use it I don't know English terms I can't use many applications because of this." (<i>Caregiver No. 13, June 22, 2020</i>)</p> <p>Q44: "Well, it is clear that many caregivers do not have a university degree or are illiterate [therefore] they may not know how to work with computers or smartphones, or it might be difficult for them the care itself takes the caregivers energy. They don't have the time and energy to learn these things (working with computers and smartphones)." (<i>Caregiver No. 2, April 23, 2020</i>)</p>

TABLE 5 (Continued)

Themes	Subthemes	The participants
		Q45: "If the caregiver does not understand the medical content in this system, it'll definitely be useless. The information should be very simple and comprehensible your system shouldn't have difficult medical terms." (Caregiver No. 10, May 26, 2020)
		Q46: "I have a master's degree in computer science it's easy for me to work with these systems if the record works properly, there is no need for an in-person visit. I can see the patient's condition in this file. Especially when they run out of medications and the medications prescribed by the doctor are not available in the pharmacies, the pharmacy offers a replacement medication. The pharmacist tells me to consult the doctor first; if the doctor allows, I'll buy it. In this situation, if this system allows us to consult the doctor, it would be great." (Caregiver No. 10, May 26, 2020)
		Q47: "Because caregivers have little time (due to caring for the patient), they may not be able to complete this record but still, an incomplete record on our mobile phone or computer is much better than paper-based ones." (Caregiver No. 2, April 23, 2020)

Alzheimer's patients usually suffer from other chronic diseases due to their old age. Therefore, in addition to referring to a neurologist, they also refer to other specialists in special treatment centers. The medical records of these patients should cover the entire patient's medical history, not just AD, and be shared between different specialists (Q15). Therefore, the participants requested an ePHR to provide a complete report of the patients' condition because the most crucial goal of this system is to collect detailed records of each Alzheimer's patient in different stages of their disease (Q16). Based on the participants' opinions, access to patient records through technologies such as mobile phones may help manage the progression of AD and provide better care (Q17).

#### Availability

Caregivers stated that using ePHRs with the possibility for remote consultation has many advantages compared to in-person visits. For instance, when the patient cannot move, using the ePHR system can be more acceptable and feasible to caregivers than in-person visits.

### 3.2.2 | Effort expectancy

The neurologists generally stated that it can be easy to learn to use this system due to their positive attitudes towards virtual visits and the convenience of being visited at home using online platforms. Based on the neurologists' opinions, it seems that the implementation of telemedicine projects has recently encouraged doctors to use such online technology. Neurologists considered a visit using this system almost similar to an in-person visit, referring to some features, such as the possibility of making audio or video calls, providing prescriptions online, reviewing patients' views and opinions, and seeing other physicians' actions in the care of patients (Q19).

Another advantage of such systems was perceived as helping caregivers to perform care tasks. These perceived advantages included reminders with a pop-up notification or marking completed

tasks with checkmarks. Some caregivers highlighted that they forget the time of visits, tests, and medications and found such a system useful for remembering the time of these tasks (Q20, Q21, and Q22). Other caregivers also stated that the daily report form of the Kerman Alzheimer's Association and the possibility of online communication with physicians through an ePHR would be effective in their ePHR adoption. Caregivers also expected to get motivation from care providers to use this system (Q23 and Q24).

According to the caregivers, using an ePHR would reduce their workload, mental burden, and cognitive overload preventing fatigue. For example, one of its most important advantages was expected to be providing caregivers with reminders for due visits, tests, and medications because each caregiver acts as her/his patient's external memory (Q25 and Q26).

### 3.2.3 | Social influence

Participants cited some social influences as barriers to ePHR adoption. The analysis of interviews showed that care providers would not be able to answer the patients' or their caregivers' questions through ePHRs regularly due to their high workload. The non-acceptance of the system by the care providers will affect the non-acceptance of the system by the patients and their caregivers. As a result, they suggested a section for frequently asked questions and their answers through the system to reduce the number of questions (Q27). Some caregivers found the social influence of care providers while supporting the use of the system to be effective in ePHR adoption. They claimed that the support of physicians and medical sciences universities would be a determinant of whether or not they use such a system. In contrast, ignoring these matters could undermine system adoption (Q28 and Q29).

On the other hand, the care providers stated that if insurances support this system, users will be encouraged to use it. Otherwise, this may become an obstacle and prevent them from supporting the

system (Q30). Care providers also expressed concerns about some incorrect information in ePHRs. They argued that providing wrong information to care providers through an ePHR for any reason could lead to serious medical risks for patients (Q31 and Q32).

As no definitive treatment is available for Alzheimer's, the medications prescribed by physicians can only control the progress of this disease to some extent. Using these medications has complications so that their management requires close communication and collaboration between a caregiver and physicians. According to some caregivers, due to the complexity of the treatment regimens of these patients, an ePHR system cannot be used to convey a patient's condition correctly because this system cannot convey a thorough picture of a patient's condition to physicians (Q33). In addition to the above-mentioned issues, concerns about the privacy and confidentiality of patients' information were among the most important barriers frequently mentioned by neurologists (Q34).

### 3.2.4 | Facilitating conditions

The participants mentioned some necessary conditions that would facilitate the ePHR adoption. These conditions were classified into informational, technical, infrastructural, and environmental requirements.

#### *Informational requirements*

Our analysis showed that the main set of data elements required for the design of an Alzheimer's specific ePHR should include a total of 216 information elements, which can be set in eight main categories, including identification information, clinical records, information specific to Alzheimer's patients, laboratory information, medication information, nutritional information, educational information, and daily patient reports (Q35).

#### *Technical requirements*

The main technical requirements for the smooth implementation of an ePHR for AD could be divided into the following categories: a team to answer user questions, integration with other available information systems, and a technical support team.

Every ePHR requires data entry by the user. As caregivers are commonly busy taking care of their patients, they should not be expected to enter too much data into poorly organized and complicated pages. ePHRs should be connected to other existing information systems in clinical laboratories, pharmacies, radiology departments, and so forth to avoid the extra burden of data entry. This would make working with the ePHRs much easier (Q36 and Q37).

#### *Infrastructural requirements*

According to our analysis, there were three requirements related to infrastructure. These requirements were high-speed internet access, mobile phone or computer access, and full insurance coverage of services through ePHRs (Q38 and Q39). One of the caregivers stated

that some insurance services do not cover online visits and then forcing the patients to pay the full costs themselves would be a serious challenge for ePHR adoption (Q40).

### 3.2.5 | The participants' sociodemographic factors

As mentioned by our participants, factors such as older age, low level of education, inadequate computer literacy, attitude towards technology, and communication preferences could also impact ePHR adoption.

Some caregivers considered older age to be a barrier because aging is considered a factor for forgetting to work with computers and the Internet. They also expressed that problems in vision and other senses in the elderly may lead to the stress of entering the wrong data into the system (Q41 and Q42). The participants believed that the lack of an understanding of how the system works would be a barrier for Alzheimer's patients or their caregivers. Three participants considered the low level of education as one of the factors influencing their comprehension of the system (Q43). They stated that they might not be able to work with smartphones or computers due to their low literacy (Q44). Moreover, the caregivers expected the information in these records to be presented in simple and understandable language without using complex medical terminology and jargon (Q45).

The communication preferences of different caregivers for using the ePHR system depended on their sociodemographic factors such as education level. Caregivers who had a high level of education and computer literacy preferred the use of the ePHR system over paper records. Understanding the expectations and preferences of caregivers can help to design strategies in the ePHR system according to the individual needs of caregivers, such as using simple and non-medical terms. In addition, considering and addressing the caregivers' expectations or communication preferences can promote them to use this system (Q46).

The workload, mental overload, and responsibilities of Alzheimer's caregivers increase exponentially as the disease progresses. Therefore, these caregivers may experience unique challenges compared to other chronic patients' caregivers. Therefore, they may not have enough time to enter a complete set of information into these systems. However, they preferred computer-based records in ePHRs over paper-based ones (Q47).

## 4 | DISCUSSION

In the present study, the requirements, content, and structure of an ePHR for AD with the possibility of remote consultation were identified from the perspective of caregivers and neurologists. Several studies have shown that user-centered design is one of the methods that can facilitate the smoother implementation and adoption of ePHRs.<sup>48,68,69</sup> Using the UTAUT, we extracted the effective factors in the adoption and implementation of these

systems in AD care. Several barriers and facilitators for ePHR implementation were also identified. Our study showed that caregivers and physicians generally had positive attitudes toward using such a system in AD care. The participants stated that such a system can be a promising tool to improve the quality of current AD. Although, they also acknowledged the role of a number of barriers to hinder that, including provider/health system adoption of an ePHR as well as healthcare costs associated with additional clinical services necessary to maintain/add to such an ePHR.

In our study, from the participants' point of view, several factors will encourage users to apply an ePHR. Since the main users to adopt ePHRs are patients with chronic diseases,<sup>22,70</sup> the benefits of using ePHRs for the care they receive have been expressed in numerous articles so far.<sup>71-73</sup> These benefits, which are in line with those identified in the present study include reducing healthcare costs, empowering patients, timely access to reliable and understandable health information, providing better continuity of care, and communication between patients and healthcare providers.<sup>74-76</sup> In the present study, the participants envisioned further benefits for an AD-specific ePHR with the possibility of remote consultation (e.g., physician-patient communication through audio/video calls), getting online prescriptions, helping reduce drug interactions through warnings, and providing reminders for the time of medication use, appointments, performing follow-ups, biomedical tests, and radiography investigations. Some of these can be achieved due to the possibility of an ePHR to provide remote consultation. Nowadays, ePHRs have some advanced technological and functional features. For instance, Genitsaridi et al.<sup>77</sup> showed that drug interactions can be reduced with the help of decision support systems embedded in ePHRs. Such capabilities for ePHRs can play a vital role in encouraging users to use them in order to minimize the long-term health risks associated with their chronic diseases and their associated treatments.<sup>78,79</sup>

In addition to the above-mentioned benefits, participants in our study mentioned several barriers to ePHRs. For example, some factors, such as specialists' lack of confidence in the information provided by caregivers, lack of clarity about who would pay these visits' costs, physicians' inability to answer patients' and caregivers' questions around the clock, and concerns about non-compliance with the principles of privacy and confidentiality, etc., can discourage users from applying an ePHR in AD care. Similar to our study, several studies have investigated the barriers to adopting ePHRs.<sup>22,50</sup> For instance, users worry about sharing their health information online through ePHRs because there are not enough standards in this field. Since Health Insurance Portability and Accountability Act (HIPAA) is mostly limited to paper-based health records,<sup>22</sup> there are concerns about the adequacy of its standards for ePHRs.<sup>80</sup> Overcoming these barriers in the adoption and implementation of ePHRs can lead to increased efficiency and improved quality of patient care.<sup>81</sup> Therefore, to devise strategies to overcome barriers, it is necessary to recognize and understand the nature of such barriers.

The participants in the present study stated that some factors such as integrating ePHR with other systems such as a Hospital

Information System (HIS), access to the high-speed internet, insurance coverage of services received through an ePHR, having a responsive team to regularly answer user questions, and the possibility of getting a report could facilitate its adoption by users. In fact, with the help of these facilitators, some ePHR barriers can be alleviated. For instance, using the facilitators of "having a team to respond to the users' questions" and "integrating the given ePHR with other systems such as an HIS" can help overcome the barriers of "physicians' inability to answer caregivers' questions around the clock" and "specialists' lack of confidence in the information entered by caregivers," respectively. Several studies have investigated the facilitators for accepting ePHRs such as integration and connection between HIS systems, proper training on ePHR use, adequate technical support, and so forth.<sup>77-79,82</sup> However, some facilitators are sometimes not feasible. For example, in many developing countries, integrating an ePHR with other health information systems requires funding and also the support of their developers.<sup>83</sup> Insurance coverage of ePHRs is also one of the facilitators that, if not fulfilled, can be a huge barrier to the adoption of these systems due to imposing higher costs on patients and their families. For this purpose, studies have highlighted that the payment method for ePHR-related services for patients and insurance should be clearly defined under different circumstances.<sup>70,84</sup> Addressing facilitators can increase motivation to use it.

Like any other new technology, ePHRs may fail due to a lack of adequate planning, design, and implementation with consumer involvement. In order to prevent ePHR failures and encourage users to adopt them, training should be provided about how to use ePHRs, computers, and smartphones. This could contribute to their optimal use and the reduction of health inequity due to low health and computer literacy in societies. In our study, the level of education and the level of computer literacy were among the participants' socio-demographic factors that played a role in the acceptance of ePHR. Our findings are also consistent with the findings of others in which system interfaces tailored to users' education and computer literacy levels are recommended for ease of use.<sup>85</sup> Furthermore, studies have shown that short training sessions have increased interest in computers, improved self-efficacy, and decreased computer anxiety among elderly patients and their caregivers.<sup>86,87</sup> We suggest that potential barriers to user compliance with ePHRs must be addressed before any design and implementation, otherwise, its deployment may be threatened.

The present study had several strengths. One of the strengths of this study was the use of a qualitative approach. The qualitative approach allows exploring concepts and experiences in more detail. Therefore, more facts can be obtained with a qualitative method. Another strength was choosing the thematic analysis based on the well-known UTAUT model in this study. The main difference between thematic analysis and content analysis lies in the opportunity for quantification of data with content analysis, which was out of the scope of our study.<sup>67</sup> In thematic analysis, a more goal-oriented reading was used with time advantages compared to content analysis. This study was conducted with the help of caregivers and

neurologists with experience in caring for Alzheimer's patients in Kerman. Therefore, caution should be taken in generalizing the results of this study to the whole country. Although very good information was obtained about the study objectives, for the generalizability of these findings at the national level or their application at a higher level, we suggest that researchers conduct future studies in care systems and different cultural structures and medical working models outside Kerman. As mentioned, this study provides insights into AD-specific ePHRs. We suggest that after the implementation of ePHRs, studies address the gap between interest in and use of ePHRs and how to close this gap.

## 5 | CONCLUSION

The present study is one of few ePHR studies specific to Alzheimer's patients to understand the factors affecting the implementation and adoption of an AD-specific ePHR by Alzheimer's caregivers and care providers, specifically focused on the requirements for easy and smooth system implementation. The identified factors should be considered when designing and implementing ePHRs for these user groups. We highly recommend that ePHR developers involve users early in the system design process to understand and include functions and features that match users' preferences, requirements, and skills while creating a useful and user-friendly ePHR system. These AD-specific requirements include, but are not limited to, recording daily reports, behavioral changes or caregiver behavior type with the patient. Following this study, a tailor-made ePHR system was designed given into account the identified requirements and perceived facilitators and barriers mentioned by the participants. This system is currently under usability evaluation. The plan is to implement and evaluate it in AD clinics in future research formally. Besides these main users of such systems, there are also other stakeholders such as medical professional societies, healthcare policy-makers, and insurance companies whose their opinions and concerns should also be heard and considered when implementing such systems. The contribution of main stakeholders in the healthcare sector can facilitate the adoption and use by chronic patients and their caregivers and care providers.

### AUTHOR CONTRIBUTIONS

**Parastoo Amiri:** Conceptualization; data curation; software; validation; writing—original draft; writing—review and editing. **Habibollah Pirnejad:** Formal analysis; funding acquisition; investigation; project administration; resources; software; writing—original draft. **Kambiz Bahaadinbeigy:** Data curation; investigation; resources. **Mahdie Shojaei Baghini:** Data curation; investigation; resources. **Parviz Rashidi Khazae:** Data curation; investigation; resources; software. **Zahra Niazkhani:** Investigation; methodology; project administration; supervision; visualization; writing—original draft.

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### CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

### DATA AVAILABILITY STATEMENT

Our data or material may be available from the first or corresponding author upon reasonable request.

### ETHICS STATEMENT

This article was extracted from an independent research project performed as part of a PhD dissertation in the field of Medical Informatics at Kerman University of Medical Sciences without any organizational support (ethical code: IR.KMU.REC.1400.587), the study followed appropriate ethical standards. All methods were performed in accordance with the relevant guidelines and regulations. The manuscript does not contain any individual person's data in any form. Therefore, there was no need for consent. All authors have read and approved the final version of the manuscript. All authors had full access to all of the data in this study and take complete responsibility for the integrity of the data and the accuracy of the data analysis.

### TRANSPARENCY STATEMENT

The lead author Zahra Niazkhani affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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### ENDNOTE

<sup>1</sup> Stages were based on AD clinical consensus criteria

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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