

Towards Conversational Agents to support Informal Caregivers of People with Dementia: Challenges and Opportunities

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Abstract—People who have dementia (PwD) experience deteriorating executive functions, in particular their working memory, and therefore find it hard to complete multistep tasks or activities of daily living. There is no doubt that during the pandemic, PwD and their caregivers were particularly vulnerable, often isolated which affected their mental and physical health. Their ability to live independently was hampered, fomenting depression in the PwD and burnout on informal caregivers. Information technology can support dementia care improving the quality of life of PwD and easing the burden on caregivers. There is an increasing demand to support informal caregivers and improve their well-being by making dementia challenges less severe. This study uses qualitative techniques to design a model with technological strategies based on semi-structured interviews applied to seven informal caregivers from two different countries. Based on these interviews we developed design insights for implementing solutions to help informal caregivers take care of their PwD at home using conversational agents. We hope that the findings presented in this study will help researchers, and developers design solutions that can support PwD and informal caregivers.

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1. INTRODUCTION

According to the 2016 World Alzheimer Report it is expected that by 2050 there will be 131.5 million of People with Dementia (PwD). Between the 60 and the 70 percent of all dementia cases are estimated to have Alzheimer's disease. People who have dementia typically experience deteriorating executive functions, particularly their working memory, and therefore find it hard to complete multistep tasks or activities of daily living [1]. Currently, there is no known cure for dementia, with pharmacological and non-pharmacological interventions focused on improving the quality of life of patients, and caregivers [2].

There is no doubt that during the COVID-19 pandemic PwD and their caregivers were particularly vulnerable considering their mental-health and physical health [3]. Recent studies show that the elderly's mental health was affected by isolation, their ability to live independently was hampered, provoking in some

cases depression in the PwD and exhaustion in care providers [3].

Information technology can support dementia care easing the burden on caregivers [4]. Studies have explored the use of virtual assistants, robots, virtual reality, music technology, and Internet of Things to assist PwD [5]. Specifically, Intelligent voice assistants have been suggested as a potential source of assistance to caregivers, who are usually older adults themselves, and have limited technological skills [6].

Rugiano et al. [6] evaluated intelligent voice assistants from a usability perspective, assessing efficiency, effectiveness, and satisfaction. The voice assistants have shown to be useful not only for elderly people but for children with autism as well [7], [8].

There is an increasing demand to provide support to informal caregivers and improve their well-being by lessening the challenges associated to dementia. Devices such as smartphones, tablets, and computers

can be a helpful tool in alleviating the caregiver's psychological burden, encouraging social engagement, and easing the burden of daily activities [6], [9]. However, devices with a touch screen are harder to use for elderly people while voice assistant provide a more natural interface [8].

The objective of this study is to design a model with technological strategies based on a qualitative analysis of semi-structured interviews conducted with informal caregivers. The proposed model aims to support technological solutions to help informal caregivers take care of their PwD at home. The findings presented in this study mean to inform researchers and developers in the desing design solutions that can support PwD and informal caregivers.

The rest of the paper is structured as follows. Section 2 describes the related work, Section 3 explains the methodology that guided the interviews, and in Section 4 we present the model that resulted from its analysis. Then, Section 5 presents design insights derived from the study. Section 6 presents a pilot study and Section 7 concludes the study and suggests some lines of future work.

2. RELATED WORK

A qualitative study analyzed the experience of family caregivers for PwD in China [10]. The authors found that caregivers could positively interact with PwD by employing positive strategies, creating opportunities, and organizing meaningful activities [10]. Such methods are essential for maintaining harmonious family relationships. The authors suggested that nurses can implement or support these activities to the caregivers.

In a systematic review of technology-based interventions for dementia caregivers, it was reported that technology-based interventions often demonstrated efficacy in improving psychosocial outcomes but have not demonstrated efficacy in improving caregiving skills or care self-efficacy [6]. The benefits of using chatbots for healthcare have also been identified for patients and healthcare systems alike [6].

Another study presents a qualitative and quantitative analysis on the use and acceptance of technology in caregivers [3]. This study reveals that computer use decreases with age. And the higher the level of caregivers' education, the more often they use both smartphones and computers. Noteworthy, the level of education decreased as age increased, which could be an additional factor in technology use difficulties. According to [11] voice-based conversational agents are easier to use than touch interfaces, they were proved with autistic users.

Previous studies have highlighted that voice-based chatbots may be especially useful for older adults for health-related communication and information seeking, because they operate through voice-driven con-

versation, which may be helpful for those with low computer literacy [6].

As conversational agents become pervasive, studies are being conducted to assess its utility and adoption among older adults. A qualitative study with 37 community-dwelling older adults, for instance, found that they have a positive attitude towards the adoption of this technology, particularly to support their health management, although some concerns were raised regarding privacy [12]. Interestingly, a study on the adoption of voice interface technologies among patients with heart failure found that older participants used the technology more frequently [13]. There is increasing evidence that older adults with limited previous exposure to smart speakers adopt smart speakers without much concern, with playing music and asking health related questions among the most popular tasks [14].

While studies involving people with dementia are less frequent, some early evidence provide optimism about their adoption and their efficacy for caregivers. For instance, a 12-week trial conducted in Canada found that depression and anxiety among caregivers improved as a result of the intervention involving smart technologies with audio prompts to monitor the sleep of PwD [15]. Smart speakers have shown to improve intelligibility among adults with intellectual disability [16]. Solutions have also been proposed to address specific problems, such as a personalized diet voice-assistant implemented to support caregivers of people with Alzheimer's [17]. Finally, a recent systematic review of chatbots to support PwD and their caregivers found only 6 specifically designed for this audience, that while being easy to use the authors found them to have limitations in performance and content, suggesting that more research and development is needed in this area [6].

Speech is largely considered as the most powerful and effective communication mode for an assistive social robot to interact with its users. Recent technological developments and research results are contributing to solving the challenges that characterize the design and implementation of spoken dialogue systems for human-robot interaction with PwD [18].

Additional research has been conducted in addressing symptoms of dementia. For instance, in [13] an ontology is proposed for representing the domain knowledge for agitation in dementia. It represents the domain knowledge specific to non-pharmacological intervention for agitation in dementia, particularly in long-term care setting. In a similar direction [19] proposes an ontology nonpharmacological intervention for dementia to support a model proposed for ambient-assisted intervention systems (AAIS) that really on ambient computing to monitor symptoms and enact interventions.

Table 1. Characteristics of participants (P: participant no, AP: Age of Participant, TE: Techonology Experience, RPwD: Relationship with the PwD GPwD: Gender of PwD, APwD: Age of PwD)

P	P	GP	TE	RPwD	GPwD	APwD
1	45	Male	Y	Son	Female	80
2	74	Female	N	Daughter	Female	96
3	22	Female	Y	Grand daughter	Female	101
4	42	Female	Y	Daughter	Female	68
5	34	Male	Y	Grandson	—	—
6	43	Female	Y	Daughter	Male	80
7	33	Male	Y	Grandson	—	—

3. METHOD

This section presents the design of the qualitative study, describes the participants, data collection and data analysis.

3.1. Design

A descriptive phenomenological qualitative study was conducted [10], [20]. This approach lends to a deep understanding of the experiences and feelings of the caregivers who interact with Patients with Dementia (PwD). The questionnaire designed for data gathering included open-ended questions which let the interviewee describe daily activities, experiences, difficulties, and feelings of interacting with PwD.

3.2. Participants

Caregivers of patient with dementia (describe how these patients were diagnosed) were included. These participants should meet the following inclusion criteria: 1) age of 18 years and above, 2) main care for PwD for at least 6 months; and 3) currently living with the PwD. We contacted the participants through telephone, and seven caregivers completed the interviews. Four women and three men from Mexico and UK participated in this study. All were family caregivers for PwD. The duration of the experience taking care the patient varied from 1–10 years. All the caregivers lived with the PwD. Table 1 shows the characteristics of the participants.

3.3. Data Collection

A semi structured interview guide was developed and then refined via discussion with the study team. The final guide included the following sections: 1) demographic information, 2) experience in the use of technology, 3) experience in caring the PwD, 4) faced difficulties. The instrument has 27 questions, the following are some examples of the questions that we applied:

- How was your experience taking care of the PwD?

- What were the insights that motivates you to search medical help?

- Can you mention a recent situation of frustrations recently?

- Thinking about the last year, what were the most challenging situations that you faced with the PwD related to his/her behavior?

- What was your reaction in the previously mentioned situations?

- Does the PwD faced repetitive questioning or behaviors? Explain them.

- What was the context when the PwD experimented the repetitive behaviors?

- How do you think that a chatbox like Alexa could help in the caring of the PwD?

The interviewer explained the purpose of the interview and discussed the caregiver right to discontinue at any time for any reason. Interview data were collected by audio recording for future analysis. The interviews were conducted at the preferred time of the caregivers to respect their schedules and provide a suitable environment to share their thoughts and experiences. Data were collected from September 2021 to March 2022. The interviews lasted an average of 22 mins (max = 40 min, min = 12 min).

3.4. Data Analysis

Interviews recordings were transcribed, and the transcripts were read and analyzed by the team. A coding framework was developed through thematic analysis (Braun & Clarke, 2006). The researchers became familiar with the information by listening to the interview's recordings during the transcription and repeatedly reading the transcripts. The data were then stored and coded in Atlas.ti. To maintain qualitative rigor, two researchers refined the coding categories.

4. RESULTS

After the interview data were analyzed to identify core categories which describe the family caregivers experience of interacting with PwD. In each one of the

categories, we present some of the interviewee answers, also we suggest how the conversational agents could help the PwD and the family caregivers.

4.1. Challenging behaviors of the PwD

It is well known that all the PwD have different behaviors and symptoms and frequently unexpected things happen. For that reason, it is difficult for the family caregivers to be prepared for all the different challenging situations she/he might experience. However, they start knowing the PwD and detecting the most common situations. For instance, in the interviews the participants mentioned:

P1: “*She forgets her things like money and medications*”.

P4: “*She forgets to take her medication, or she takes the medication twice, she is affecting her health and I do not know how to control that*”.

P5: “He is asking the same questions again and it became frustrating”.

Forgetting things and repetitive questioning were common challenging behaviors mentioned by the interviewees. As we mentioned before the patients are different and each family faces different situations, for that reason the caregivers need strategies to face these specific problems.

4.2. Strategies to Face Challenging Behaviors of PwD

Informal caregivers learn about the disease and start implementing different positive strategies to face the challenging behaviors they experience. For instance, they try to distract or entertain the PwD by incorporating activities that they like to do.

P1: “I go out with her and try to make her feel busy”

Frequent greetings and presentations are important to situate the PwD know and made her aware of who are the people around. One informant suggested that:

P6: “it is important to greet him, ask him some questions”

Formal caregivers and doctors suggest making the patients remember things so they can train their minds, having conversations about their youth will help too. The main goal is to keep their minds working. As one participant commented:

P6: “just ask him questions, I often start the conversation about something from his youth, or his teachings in school, so I just do that now, it definitely works, and it helps him”

It is important to follow the conversation with the patient and answer their questions as many times as needed. The participants shared some of their strategies to handle difficult situations with the PwD.

P2: “I repeat the things over and over again”

P3: “We follow the conversation; it does not matter if it makes no sense, we tried to make her talk because sometimes she is not talking at all”

P5: “People with dementia tend to ask things, if you tell them to do something they ask why I should do that, so you must explain to them why it is good for them to do that. Basically, give them a short answer”

The idea is to make them feel comfortable and loved but not patronize them making them feel as kids.

4.3. Support Family Caregivers’ Emotions

The family caregivers try to make the PwD feel as comfortable as possible, and sometimes they are not taking care of themselves [21]. They expressed that most of the time they feel sad to see how the disease is progressing. They also experience frustration facing all the repetitive behaviors and questioning. However, they are happy to have their loved one with them no matter the circumstances. For that reason, it will be important to provide some solutions that help the family caregivers to take care of the PwD.

P2: “*She is my mother, it does not matter the conditions I want to have her*”

P3: “*Sometimes I get tired and stressed, but we have good times too*”

P4: “*I feel frustrated and desperate*”.

In the next section, we present some design insights based on the results of the interviews proposing a caregiver assistant. The proposal is presented as a conceptual meta-model.

5. DESIGN INSIGHTS

In this section we propose how a caregiver assistant can support PwD and informal caregivers. Conversational agents are powerful tools because of their popularity, usability, and persuasiveness. Figure 1 explains the interaction between a caregiver assistant that integrates specific strategies, a PwD and an informal caregiver.

It is important that the solutions provided to the PwD and the caregivers consider several aspects of both types of user such as: mental health, emotions, physical health, medication and personality. All these aspects could be used by the caregiver assistant to personalize or tailor the tasks.

All the tasks where the caregiver assistant can help are non-pharmacological interventions for example, playing music, telling jokes, or executing relaxation routines. In the medical service interventions, the caregiver assistant will be more limited because it won't be able to diagnose the disease or provide medication, but it could be useful providing medication alarms and reminders, also it has the option of calling 911 in case of an emergency.

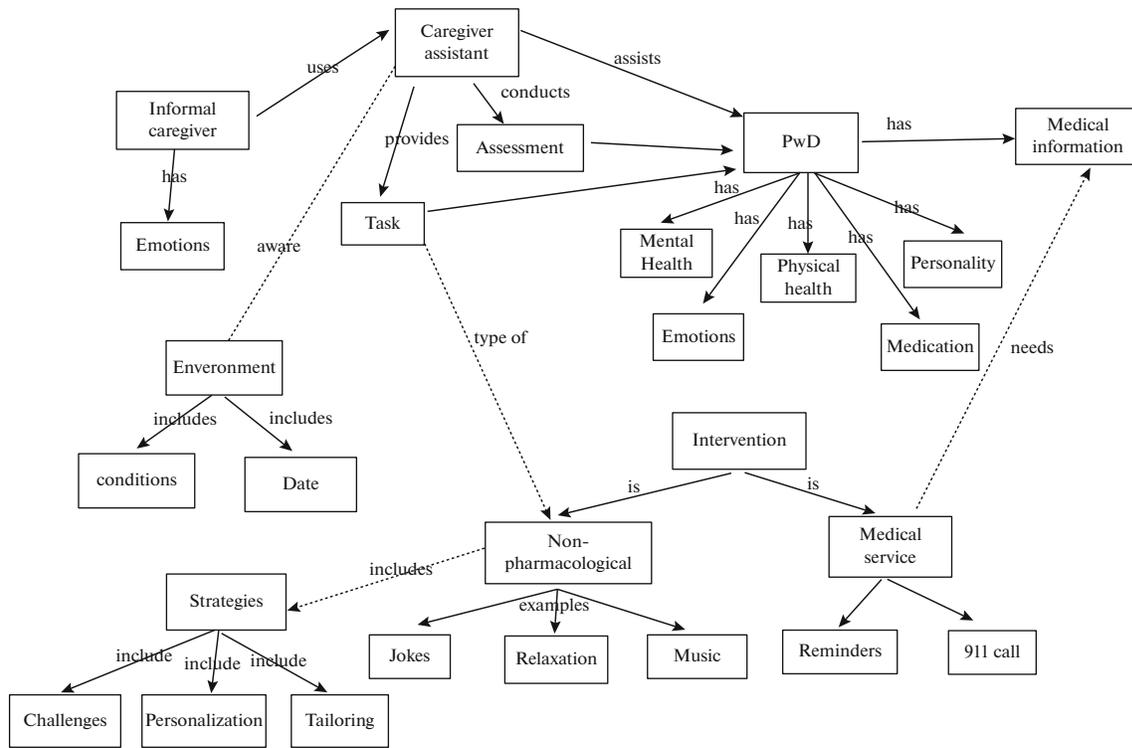


Fig. 1. Conversational agent, Patient with Dementia and Informal Caregiver interaction.

The caregiver assistant can also assess the PwD asking specific questions or tasks to evaluate the PwD’s performance and the progression of the disease. These assessments could be helpful for the family caregivers and as well as the physician.

The conversational agents can interact with the patients answering repetitive questions (Fig. 2). They can also act as medication reminders or other scheduled activities. All these activities can be easily handled by these agents helping the caregivers on the support to the PwD and reducing the stress and frustration. There are several attempts on including conversational agents in the activities of daily life like playing music, some relaxation activities, but to the best of our knowledge these conversational agents have not been used to address the phenomena of repetitive questions.

This model suggest that the caregiver assistant should be aware of the environment. For example it needs to know if the informal caregiver left the house, if the PwD is moving around the house or if the PwD left the house so it can send a message or call the caregiver to alert the situation. Also, the awareness can be useful for pattern recognition in the future understanding when, where and why the PwD experiences those behaviors.

It is important to understand how the conversational agents will help informal caregivers so we can evaluate how helpful and useful the system is for the caregivers. The evaluation could be performed con-

ducting interviews, questionnaires, and usability evaluation. It is important that the informal caregiver uses the caregiver assistant to relax and reduce the negative emotions mentioned by the caregivers in the interviews (Fig. 3). The conversational agents can provide some relaxation routines to the family caregivers and answering some of the PwD’s repetitive questions reducing the frustration of the family.

The incorporation of persuasive strategies such as personalization, challenges, tailoring can be an additional value (Fig. 4). These strategies can keep the caregivers and PwD using the conversational agent, because as researchers and developers we want to keep the attention of the users, but also, we want to change their attitudes and eventually impact in the behaviors.

Conversational agents can help informal caregivers provide personalized greetings and some specific clarification to the PwD every morning to start the day or at the end of the day. In specific cases the agent can play some greeting with the voice of the caregiver or

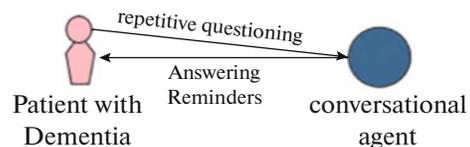


Fig. 2. Patient with Dementia and Conversational Agent Interaction.

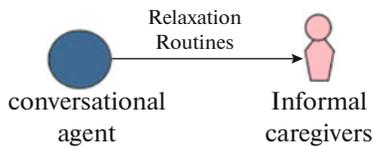


Fig. 3. Informal caregiver and conversational agent interaction.

with a different voice depending on their needs. Thus, we suggest the following persuasive strategies.

4.2.1. Personalization. The users should be able to personalize the system according to their preference, including name, nickname, gender of voice. Caregivers can modify to its convenience some of the features of the conversational agents.

4.2.2. Challenges. In these cases, the conversational agents could be a useful tool by reading audio-books, playing music, or other recreational activities such as games.

4.2.3. Tailoring. Informal caregivers can let the conversational agent know that they are going to go out or when they are going to get the meal, so when the PwD asks about it, the conversational agent will answer what is happening or will happen next. The agent can then suggest calling the caregiver or someone else if the PwD feels anxious.

6. PILOT STUDY

The previous theoretical model is supported by the qualitative analysis conducted from the interviews with family caregivers. However, it is important to implement and test the framework to evaluate the feasibility of the model.

6.1. Methodology

We conducted a pilot study with one female elder user aged 72 years old who does not have an official dementia diagnosis. Firstly, we applied a questionnaire to determine the preferences of the user so the device could be adapted and prepared for her. Then, we set a list of activities she prefers such as: ask for the weather, ask the news in the city, tell a joke, play music and play the radio.

Table 2. Interactions between the user and the Alexa conversational agent

Topic	Interactions %
Weather	6.25
News	6.25
Time	6.25
Music	12.5
Jokes	18.75

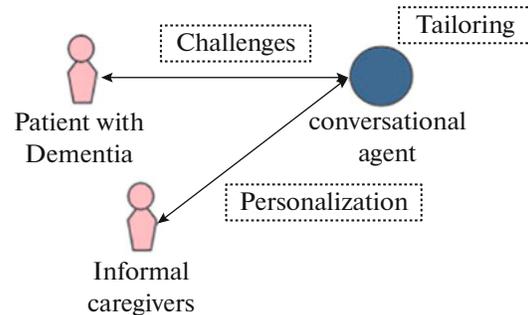


Fig. 4. Strategies in the use of conversational agent.

The device was installed in the living room where the user spends most of the time during the day. The list of activities was transformed into a list of commands that we provided to the user in a printed cheat sheet, so she can remember which commands can be used. A short training was conducted to explain how to interact with the device and which are the commands that the user can execute. The user interacted with an Alexa conversational agent for a period of three days.

To follow all the ethical considerations, we had no direct access to the log, a family member reported how many times each of the commands was activated.

6.2. Results

During the three days the user interacted with the device 16 times, and only 50% of them were effective (they triggered the intended response). Most of the interactions took place from 10:00 am to 2:00 pm. Table 2 shows the interactions between the user and the device.

We identified two main types of errors. The first one is when the user said “Alexa” followed by a long pause and then the instruction; the device could not execute those instructions. The second one was when the users said the instructions without invoicing “Alexa” first.

It is important to note that the user did not have previous experience in the use of technology, she only have a cell phone that used for making/receiving voice calls. She never used streaming platforms. Even though the effectiveness was only 50% at least she could interact with the device and execute some instructions. After the pilot study and data analysis we interviewed the user and she said that asking for the time of day and playing music were the commands she asked the most and she felt odd because she had never talked to an electronic device before.

7. CONCLUSION AND FUTURE WORK

In this paper, we presented a qualitative study based on interviews to seven informal PwD caregivers from two different countries. The results suggest that

the most challenging behaviors of the PwD are forgetting things and repetitive questioning. Caregivers have faced these problems and have developed different strategies to deal with them such as: follow the conversation, go out with the PwD to distract him/her, ask questions for the patient to reflect on where he is and who he is with, and for mental stimulation.

In all the informal caregivers' interviews, the caregivers expressed that taking care their loved ones trigger negative emotions like frustration and stress.

Based on these results, we suggest a model that describes the ecosystem of PwD assistance and how a caregiver assistant can support informal caregivers with some activities. The conversational agents can be an effective tool to support PwD answering repetitive questions, monitoring and evaluating the PwD. The evaluation could be useful for the assessment of disease progression. These patterns can detect specific situations in specific days or with specific context.

The proposal includes some persuasion strategies can help on change the PwD attitude and eventually change their behaviors.

This study suggests the next lines for future work:

1) Design an ontology using the conceptual model presented in this paper. The conversational agents can be developed taking advantage of such ontology.

2) Design a conversational agent that implements the strategies presented in this model.

3) Use a commercial conversational agent such as Alexa, Siri or Cortana to determine the acceptance and impact on PwD and informal caregivers.

The proposed model can be a basis for researchers and developers for implementing strategies and suggestions to support PwD and informal caregivers.

CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.

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