Empowering Caregivers of Alzheimer's Disease and Related Dementias (ADRD) with a GPT-Powered Voice Assistant: Leveraging Peer Insights from Social Media

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Abstract— **Caring for individuals with Alzheimer's Disease and Related Dementias (ADRD) is a complex and challenging task, especially for unprofessional caregivers who often lack the necessary training and resources. While online peer support groups have been shown to be useful in providing caregivers with information and emotional support, many caregivers are unable to benefit from them due to time constraints and limited knowledge of social media platforms. To address this issue, we propose the development of a voice assistant app that can collect relevant information and discussions from online peer support groups on social media. This app will use the collected information as a knowledge base and fine-tune a Generative Pre-trained Transformers (GPT) model to facilitate caregivers in accessing shared experiences and practical tips from peers. Initial evaluation of the app has shown promising results in terms of feasibility and potential impact on caregivers.**

Keywords— Alzheimer's Disease and Related Dementias (ADRD), voice assistant, caregiving, Generative Pre-trained Transformers (GPT), natural language processing.

I. Introduction

Alzheimer's Disease and Related Dementias (ADRD) is a chronic and progressive neurodegenerative disorder that affects millions of people worldwide. The disease is characterized by the gradual loss of cognitive and functional abilities, including memory, communication, and daily living skills. Individuals with ADRD often require intensive and ongoing care. Caregivers need to provide a significant amount of care including assistance with activities of daily living, medication management, and emotional support. On the other hand, caregivers of ADRD are typically family members or friends of the patient [1]. They are often unprofessional without formal training or certification in caregiving.

Caring for individuals with ADRD can be a daunting task for unprofessional caregivers, who face daily challenges in managing symptoms, dealing with challenging behaviors, and accessing appropriate resources and support services [2]. The emotional and physical toll of caregiving can lead to increased levels of stress, depression, and caregiver burden. To address these challenges, there is a growing need for caregiver support and information resources. These resources can include educational materials, support groups, respite care, and counseling services, among others. Research has found that peer support groups can be useful in providing emotional and practical support to caregivers[3], [4]. Many online platforms such as Reddit, Facebook, and Twitter have peer support groups where caregivers can participate in discussions, ask questions, and receive advice from others with similar experiences. These discussions can be incredibly helpful for caregivers who are looking for guidance or simply a sense of community. However, not all caregivers are able to benefit from these resources due to factors such as not much time or a lack of knowledge on how to use social media [5]. Older caregivers, in particular, may struggle to utilize these online resources effectively. Therefore, it is important to explore alternative ways to provide support and resources to caregivers who may not have access to online peer support groups.

We propose an innovative solution to alleviate the aforementioned challenges faced by the caregivers. Specifically, we design a voice assistant app that utilizes advanced machine learning, natural language processing, and human-computer interaction technologies to create a convenient way for caregivers to access information from social media, without the need for extensive knowledge or time-consuming browsing. The app leverages peer-based information collected from social media discussions and posts, allowing caregivers to ask questions related to their caregiving experience. It provides answers based on the experiences of other caregivers who have faced similar challenges, offering valuable insights from peers who share the same experiences and challenges. While the answers are not from professionals or authorities, they reflect real-life experiences, making them more convincing and relatable. Caregivers should understand that the information provided may not always be accurate or appropriate for their

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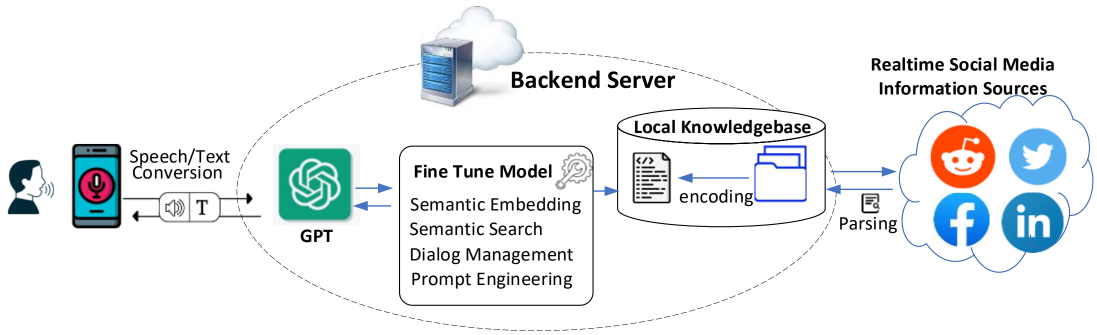

Fig. 1 System Architecture

specific situation. However, the app serves as a quick and easy resource for caregivers who may not have the time or ability to engage in more traditional peer support groups. It enables caregivers to access a wealth of peer-based knowledge and support, helping them navigate the unique challenges of caregiving for individuals with ADRD.

II. Related Work

Research in the field of peer support groups for helping patients manage their disease has shown promising results. Several studies have explored the effectiveness of peer support groups in various medical conditions, including mental health and chronic diseases such as diabetes, cancer, and cardiovascular diseases [6], [7], [8], [9]. In their work, Naslund et al. [10] found that people with serious mental illness benefit from online peer interactions, including increased social connectedness, group belonging, and sharing coping strategies. Similarly, Gavrila et al. [11] conducted qualitative interviews with caregivers and patients of diabetes to assess the impact of the online community on peer support. The interviews revealed online communities can provide multiple avenues for peer support, empowering individuals and fostering altruism within the community. Another study [12]investigated unmet needs of cancer patients that could potentially be addressed through peer support. The findings revealed that 83.3% of the participants in their study needed peer support, with the highest proportion of peer support needs in the information domain reported by patients who had been diagnosed with cancer for more than 5 years.

Many studies have explored the potential of voice assistants as a tool for improving patient care and enhancing healthcare outcomes. For instance, voice assistants have been used to facilitate remote patient monitoring [13], medication management [14], [15], appointment scheduling [16], and health information retrieval [17] . They have also been employed in telemedicine settings to enable virtual consultations [18], [19] and provide personalized health recommendations [20], [21] . Furthermore, voice assistants have been integrated into various healthcare devices, such as smart home systems and wearable devices, to assist patients with chronic conditions, elderly individuals, and individuals with disabilities. Overall, the application of voice assistants in healthcare holds promise for improving patient engagement, enhancing healthcare access and delivery, and promoting better health outcomes.

ChatGPT, as a large language model (LLM), has been trained on a massive dataset of text and code. It can be used to generate text, translate languages, and answer questions in an informative way. ChatGPT has the potential to be used in a variety of healthcare applications. Cascella et al.[22] explores the potential applications and limitations of ChatGPT in healthcare. While ChatGPT has impressive capabilities, its performance in real-world scenarios, particularly in medicine, is uncertain due to the high-level and complex thinking required in the field. A review by Sallam [23] focuses on ChatGPT's potential applications in healthcare education, research, and practice. Benefits of ChatGPT were identified in various areas, including improved scientific writing, efficient analysis of datasets, streamlined workflow in health care practice, and improved personalized learning in health care education. However, concerns regarding ethical, copyright, transparency, legal, and other issues were also raised in the majority of the reviewed records. In summary, ChatGPT is still under development, but it has the potential to revolutionize the way that healthcare is delivered. It can help to improve the quality of care for patients, to make healthcare more affordable, and to make it easier for patients to access the care they need.

III. Methodology

A. System Architecture

The proposed voice assistant, ADHelper, has three primary components, as shown in Fig. 1. The first component is dedicated to information retrieval from social media platforms such as Reddit, Twitter, and Facebook. Specifically, the system locates peer support groups and online discussions related to ADRD and retrieves relevant information from these sources. The retrieved information is then parsed and saved to our local knowledge base.

To enhance the accuracy and appropriateness of the responses provided by the voice assistant, we utilize the local knowledge base to retrain and fine-tune a pre-trained GPT model. This approach ensures that the voice assistant has a solid knowledge foundation and is capable of providing effective responses to user inquiries.

To interact with the voice assistant, we provide a user-friendly front-end app that offers a multi-modal input-output interface for ADRD caregivers. Users can simply speak to the voice assistant or type their questions into the system. The voice assistant is capable of providing responses in both voice and text formats, enabling users to choose the most suitable communication mode for their needs.

B. Information Retrieval from Social Media Sources

The initial implementation of ADHelper relied on Reddit as its primary data source. However, our system's modular nature allows for easy integration with other social media platforms such as Twitter or Facebook. In our data collection phase, we selected two of the most popular sub-Reddits related to Alzheimer's and Dementia, namely, "Alzheimer's" and "Dementia," which had 23.7k and 11.8k members, respectively. We collected posts from the top section of each subreddit, posted between January 1, 2014, and March 2023. In addition to the posts, we collected comments on these posts, which provided further insights into the online conversations surrounding ADRD. To effectively analyze the large amount of text data collected, we employed natural language processing (NLP) to identify the most frequently used words and phrases, as well as the topics that were being discussed. By doing so, we were able to exclude irrelevant posts, such as spam or unrelated content, and focus solely on the relevant data.

C. Local Knowledgebase Construction

After collecting information from social media, the data is processed to prepare it for use by our voice assistant. The posts collected from social media are combined with comments or response text to create a single, combined text. Irrelevant content such as advertisements, spam, and off-topic conversations are removed through data cleaning and preprocessing. The text is then indexed using semantic embeddings, which represent text data in a continuous vector space where similar or related text items are positioned close to each other. This allows for efficient comparison and retrieval of similar text items, while capturing contextual information and relationships between words and phrases. By encoding text into semantic embeddings, the original text data can be compressed into a lower-dimensional representation, saving storage space and computational resources while preserving semantic meaning.

Pre-trained embedding models such as BERT, Huggingface Embedding or Word2Vec can be used to generate embeddings for the combined text, resulting in a single vector embedding. These embeddings are then utilized in semantic search, enabling efficient and cost-effective searching through all posts and comments. The use of semantic embeddings in our local knowledgebase construction process enhances the accuracy and efficiency of information retrieval for our voice assistant, providing caregivers with relevant and helpful insights from social media peer support groups.

D. GPT-powered Conversation Management

- Designing Dialog Flow for User-Directed Conversations

Managing conversation flow is a critical aspect of creating an effective conversational system for AD caregivers. The dialog flow refers to the structure and sequence of interactions between the user and the voice assistant. By carefully designing the dialog flow, we can ensure that the conversation is coherent, relevant, and provides valuable information to the caregiver.

We employed the GPT model to enable natural and flexible conversations with users. As a state-of-the-art language model, GPT is widely used for a variety of tasks. However, using GPT directly may result in imprecise or irrelevant outcomes for specialized domains such as ADRD, especially in the context of social discussions: GPT has limitations in real-time discussions, follow-up questions, and directing conversations. Furthermore, it's worth noting that the training data for the current version of GPT (GPT3.5) only goes up to September 2021, which means that some answers may not reflect the latest information. To address these issues, we customize and fine-tune a pretrained GPT model to better suit the needs of ADRD caregivers. This involves defining dialog flow and retraining the model for the designated domain of ADRD to enhance its performance.

We prioritize user-directed conversations, where users have control over the conversation flow. Our voice assistant is designed to answer users' questions and engage in dynamic interactions based on the context of the conversation. Users can initiate conversations, and our voice assistant responds accordingly, taking into account the conversation context and local knowledge. The voice assistant may ask follow-up questions to clarify queries, provide additional information, or introduce new topics related to the conversation. This user-directed approach allows for dynamic and flexible interactions, empowering users to steer the conversation based on their needs and preferences.

To achieve this, we employ a conversation policy that guides the dialog flow and ensures that the conversation remains relevant and coherent. The conversation policy is designed to provide a framework for how the voice assistant should respond to user inputs and prompts. It includes rules for handling different types of queries, determining when to ask follow-up questions, and identifying new topics related to the conversation context and local knowledge. The conversation policy is designed in our backend service and can direct the conversation with the user and pass the necessary context to the GPT trained model.

Prompt engineering plays a crucial role in implementing the conversation policy effectively. We carefully design prompts or queries that align with the conversation policy and guide GPT towards providing meaningful and relevant responses. These prompts are crafted to provide clear instructions to users on how to phrase their questions or requests, encourage follow-up questions, and incorporate contextual information from previous interactions. By leveraging prompt engineering and the conversation policy, we aim to create a conversational system that enables effective communication between the user and the voice assistant.

- Leveraging Local Knowledge for Accurate Responses

As a generative model, GPT has the potential to generate responses that may not always be accurate or relevant. To mitigate this challenge, we utilize our local knowledge base as a reliable source of information to guide GPT's responses. Instead of solely relying on GPT's pretrained knowledge, we leverage our local knowledge base to ensure that the information provided to users is accurate and reliable.

When a user query is received, we convert the query into semantic embeddings, which are vector representations that capture the meaning of the query. These embeddings are then matched with the embeddings in our local knowledge base using cosine similarity, a measure of similarity between two vectors. This allows us to identify the most relevant or information sources in our knowledge base that are related to the user's query. Once we have identified the most similar embeddings in our local knowledge base, we use them as the context or query input for GPT model. This context provides GPT with relevant information from our local knowledge base, allowing it to generate responses that are informed by the accurate information from our domain-specific knowledge base.

IV. EVALUATION

While the ADHelper system has not yet been deployed to final users, we have employed a combination of use case studies and research evaluation to assess its performance and gather valuable insights to ensure its effectiveness and suitability for real-world applications.

A. *Prototype System*

We developed a mobile application using Flutter that included a voice assistant feature. The application uses Google's voice API to convert voice to text and text to voice. The user can provide prompts or ask questions through voice, which are then forwarded to the GPT backend services for a response. We used Langchain, a Python package that provides a simple interface for OpenAI's GPT language models, to transform the data we collected into training data for GPT. LangChain is a framework developed for large language models (LLMs). The framework is built around the concept of "chaining" different components together to create more complex use cases for LLMs.

The local knowledge base is represented as an index file. To create an index for GPT, we used the GPTSimpleVectorIndex class and huggingface embedding for indexing. We set several parameters for the index, including the maximum input size, number of output tokens, maximum chunk overlap, and chunk size limit. We also defined the GPT language model to use for the index, which was set to the gpt-3.5-turbo model. We used the LLMPredictor class to define the GPT language model and the PromptHelper class to define the input prompt format for the index.

Fig. 2 shows the screenshot of the app. A user can communicate with the assistant through voice or typing based on their preference.

B. *Use Case Study*

One key approach we employ for system evaluation is the use of case studies. A use case study involves the in-depth examination of specific scenarios or situations where our system is deployed and used by real ADRD caregivers. These scenarios are carefully selected to represent real-world caregiving situations that our system is designed to address. Use case studies provide us with data on the performance of our system in real-world scenarios. We can assess how well our system is able to provide accurate and relevant information, support caregivers in their decision-making process, and facilitate effective communication with care recipients.

Fig 3. shows a use case conversation between an ADRD caregiver and the voice assistant. The user initially asks about activities that their loved one may enjoy, and the bot provides a

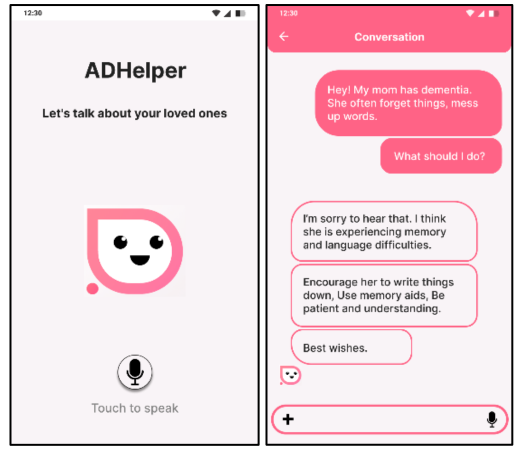

Fig. 2. App interface

comprehensive list of potential activities. The bot also emphasizes the importance of activities that may help delay the progression of the disease. When the user expresses an interest in camping, the bot acknowledges it as a potentially beneficial activity and highlights its positive aspects. The bot also mentions two medications that may delay the progression of the disease, but cautions about potential side effects. It encourages the user to consult with the doctor before starting any medication. When the user indicates they haven't talked to the doctor yet, the bot reinforces the importance of consulting with the doctor and provides additional information about the need for a thorough assessment of the cognitive abilities and symptoms. Overall, the conversation demonstrates the voice assistant's ability to provide relevant information and guidance to the caregiver, and emphasizes the importance of consulting with a healthcare professional for personalized medical advice.

In contrast, Fig. 4 illustrates how the user poses the same question to ChatGPT. It is apparent that the question provided by ChatGPT lacks context, user-specific information, and is overly general in nature.

In addition to the examples mentioned, we have evaluated numerous other use cases with our voice assistant. However, due to space limitations, we are unable to report them all. Nevertheless, these cases further highlight the feasibility and effectiveness of our system in providing support and guidance to caregivers. Our use cases demonstrate the effectiveness of our voice assistant in providing comprehensive and informative responses to users. The bot asks relevant follow-up questions, offers strategies and resources, and shows empathy towards users. However, it is not a substitute for professional medical advice.

C. *Qualitative Assessments*

We conducted a series of experiments to perform qualitative assessment. To generate questions, we utilized a generic version of ChatGPT. We prompted ChatGPT to imagine itself as a caregiver for a patient and provided categories to generate a set of questions. The purpose of using ChatGPT was to obtain a neutral set of questions that real users might ask. This allowed us to evaluate the voice assistant's ability to answer questions in a diverse range of scenarios, beyond the questions already present in the knowledge base. Our voice assistant was

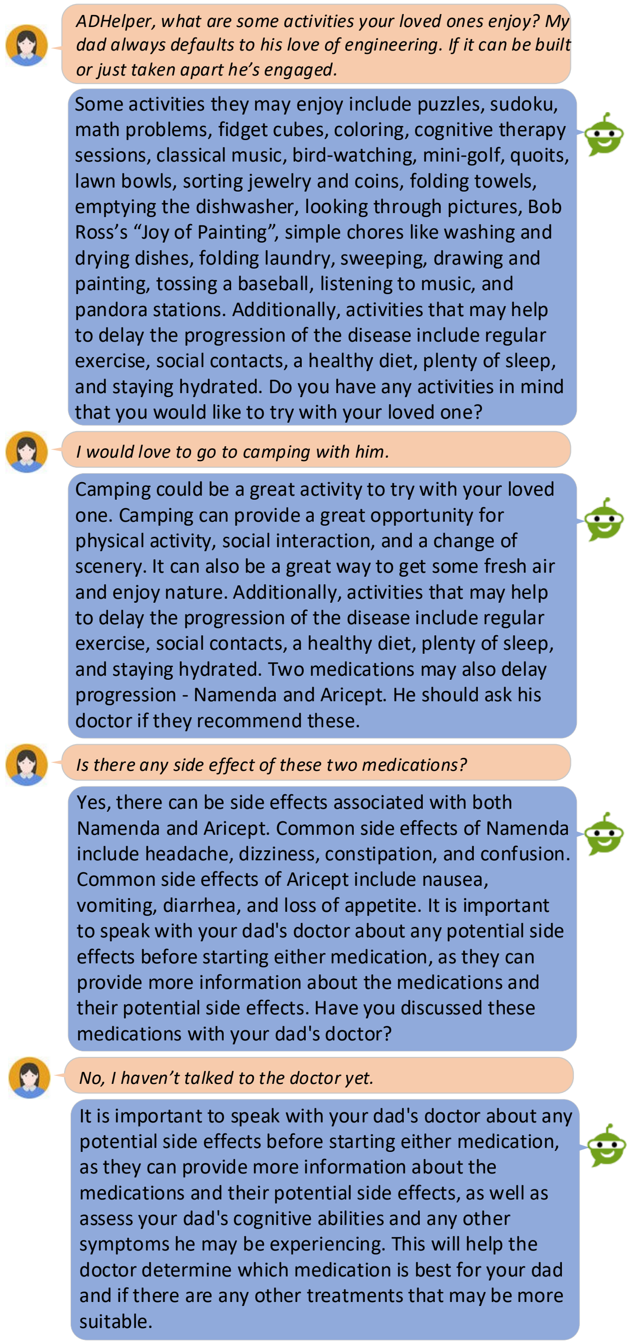

Fig. 3. Example case

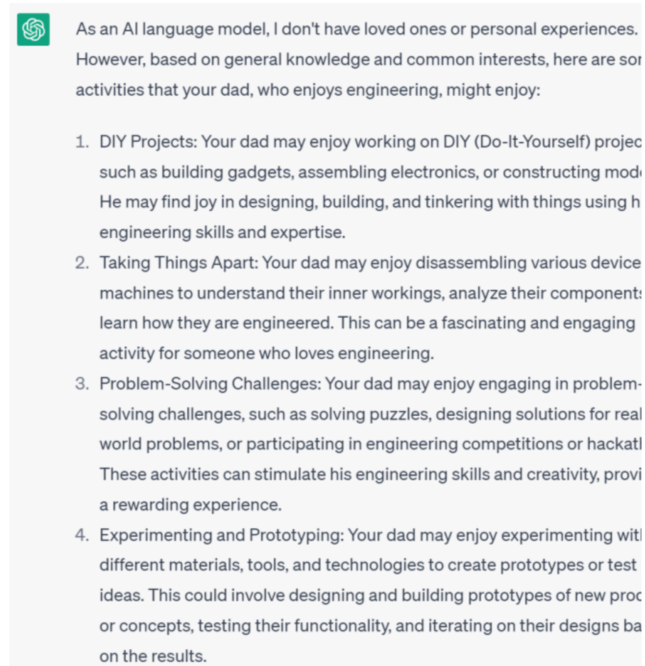

Fig. 4. Example case answered by ChatGPT

evaluated on five categories of ADRD-related questions: Symptom, Diagnosis, Treatment, Caregiving, and Resource. A total of 360 questions were used, with 232 questions covered by our local knowledge base and 128 questions not covered.

First, we evaluate the accuracy of the factual information provided by our knowledge base. Since users may seek information based on what peers have shared on social media, it is crucial for our voice assistant to avoid generating responses based solely on its own learning experiences, as is common with generative models. Instead, our approach focuses on organizing and summarizing what people say on social media. To evaluate this, we posed questions that may or may not be sourced from social media and assessed whether the voice assistant relied solely on social media as a source for generating responses.

Table I illustrates the results of our evaluation. For questions in all five categories, the voice assistant was able to answer all questions that were covered in the local knowledge base and provided appropriate responses using local knowledge. For questions that were not covered in the local knowledge base, the voice assistant acknowledged its lack of local knowledge to answer the question, but offered to provide information based on its pretrained general knowledge. The voice assistant also asked if the user would like to hear that information. This indicates that the voice assistant is capable of providing accurate factual information based on local knowledge with high accuracy.

Table I: Accuracy of providing factual information from local knowledgebase.

Query answering performance	**Question Categories**				
	Symptom	Diagnosis	Treatment	Caregiving	Resource
# of query	80	80	80	80	40
queries in KB	66	54	48	78	33
answers of queries in KB	66	54	48	78	33
query not in KB	14	26	32	2	7
answers with lack of knowledge acknowledged	14	26	32	2	7

To evaluate the appropriateness, relevance, and completeness of the voice assistant's answers, we employ a human manual verification method. It's important to note that answers are verified solely based on our local knowledgebase. We have informed the users that the answers provided are reorganized and summarized using peer support information, not from authoritative organizations or experts. Therefore, the appropriateness, relevance, and completeness of the answers are measured solely based on the local sources. The quality of answers was shown in Table II. Most answers were appropriate and relevant, but there were some incomplete answers, particularly in the resource category. Overall, the voice assistant provided appropriate, relevant, and complete answers for most questions, with limitations in treatment and resource categories, possibly due to limited information in the knowledgebase. Further development may be needed to improve the voice assistant's abilities in these areas.

Table II: Evaluation of answer quality

Question Categories	**# of questions**	**Appropriate answers**	**Relevant answers**	**Complete answers**
Symptom	66	66	66	65
Diagnosis	54	54	54	50
Treatment	48	48	48	40
Caregiving	78	78	78	77
Resource	33	32	32	30

Table III: Comparison between ADHelper and ChatGPT

Metric	**ADHelper**	**ChatGPT**
Accuracy of response	High accuracy as fine-tuned on reddit caregiver dataset.	Generalized, not tailored for specific domain.
Empathy towards caregiver and patient	Shows empathy and support towards the caregiver	Display of empathy varies: sometimes demonstrating contextual understanding and empathy, while other times not
Context	Consistently understands the context, even when the question does not include keywords related to ADRD.	may not understand the context if specific keywords are not used in the question.
User Experience	Presents users with an easy-to-use multi-modal mobile app interface	Accessible through a web interface, limited to text-based interactions.
Follow-up questions	Supports multi-turn conversations and can ask follow-up questions during interactions	Does not ask follow-up questions and provides only single responses for specific questions
Customizability	Highly customizable with prompt engineering from the backend.	No customizability is provided.
Real Time information support	Training data can be regularly updated, with options for frequency such as weekly or monthly.	Training data cutoff is September 2021.

Table III provides a comparison between ADHelper and ChatGPT in terms of various factors including accuracy of response, empathy towards caregiver, context understanding, user experience, follow-up questions, customizability, and real-time information support. ADHelper, which is fine-tuned on a caregiver dataset from Reddit, demonstrates high accuracy in response. It shows empathy and support towards the caregiver and understands the context even if ADRD keywords are not included in the question. It presents a mobile app interface that is easy to use and can be utilized with voice conversation. ADHelper can engage in multi-turn conversations and follow-up questions, and it is highly customizable with prompt engineering from the backend. ADHelper's training data can also be updated on selected frequency, such as weekly or monthly.

On the other hand, ChatGPT is a generalized model that is not tailored for a specific use case. The generalized version of ChatGPT sometimes understands the context and shows empathy, but other times it doesn't get the context and lacks empathy. If specific keywords are not used in the question, ChatGPT struggles to understand the context. It can only be used through a web interface and supports only text. ChatGPT does not ask any follow-up questions and provides only single responses for specific questions. Customizability is not provided in ChatGPT, and its training data cutoff is up to September 2021, which means it may not have the most up-to-date information.

V. Conclusions

We proposed the development of a voice assistant app, ADHelper, that can collect and summarize relevant information and discussions from online peer support groups on social media. The app uses a GPT model to provide caregivers with answers to their questions based on peer experiences. The initial evaluation has shown promising results in question answering regarding to ADRD care. Future work could focus on expanding the knowledgebase of the voice assistant to improve coverage. Further refinement of the answer quality evaluation criteria could also be explored to ensure that the responses provided by the voice assistant are appropriate, relevant, and complete. Additionally, user feedback and input could be gathered to continuously improve the voice assistant's performance and user experience.

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