Mapping Caregiver Needs to AI Chatbot Design: Strengths and Gaps in Mental Health Support for Alzheimer's and Dementia Caregivers

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Family caregivers of individuals with Alzheimer's Disease and Related Dementia (AD/ADRD) face significant emotional and logistical challenges that place them at heightened risk for stress, anxiety, and depression. Although recent advances in generative AI—particularly large language models (LLMs)—offer new opportunities to support mental health, little is known about how caregivers perceive and engage with such technologies. To address this gap, we developed Carey, a GPT-4o–based chatbot designed to provide informational and emotional support to AD/ADRD caregivers. Using Carey as a technology probe, we conducted semi-structured interviews with 16 family caregivers following scenario-driven interactions grounded in common caregiving stressors. Through inductive coding and reflexive thematic analysis, we surface a systemic understanding of caregiver needs and expectations across six themes—*on-demand information access, emotional support, safe space for disclosure, crisis management, personalization*, and *data privacy*. For each of these themes, we also identified the nuanced tensions in the caregivers' desires and concerns. We present a mapping of caregiver needs, AI chatbot's strengths, gaps, and design recommendations. Our findings offer theoretical and practical insights to inform the design of proactive, trustworthy, and caregiver-centered AI systems that better support the evolving mental health needs of AD/ADRD caregivers.

CCS Concepts: • **Human-centered computing** → *Empirical studies in collaborative and social computing*; • **Applied computing** → *Psychology*.

Additional Key Words and Phrases: alzheimers, wellbeing, social support, caregiving, aging, mental health, LLMs, AI chatbots

1 Introduction

Alzheimer's Disease and Related Dementias (AD/ADRD) is one of the most pressing public health challenges—as of 2024, 6.9 million people in the U.S. aged 65 and older living with AD/ADRD, a number projected to nearly double to 13.8 million by 2050 as the population ages [4, 102]. The progressive nature of these neurodegenerative conditions leads to cognitive decline, memory loss, and increasing dependence on others for daily functioning [14]. The majority of care is provided by informal caregivers [57, 61, 102]—primarily family members—who, in 2023, delivered over 18.4 billion hours, or nearly 31 hours per week, of unpaid care [115]. Family caregivers are essential to maintain the wellbeing and safety of individuals living with dementia, but they often do so under conditions of high emotional strain, minimal respite, and limited access to professional resources [38, 58, 134, 150, 151, 159]. Compared to formal caregivers, family caregivers face more pronounced challenges due to factors such as emotional attachment to the care recipient, lack of formal training, and insufficient resources and equipment [24, 48, 119]. As a result, they often struggle with high levels of stress, anxiety, and depression [34, 64, 93, 111]—at

least one in three family caregivers of AD/ADRD individuals suffer from clinical depression per prior meta-analysis [125, 167]. Additional challenges such as anticipatory grief, compassion fatigue, caregiver guilt, and role-related identity shifts [23] uniquely characterize caregivers'[1] mental health experience.

Despite the growing recognition of these mental health challenges, access to timely, affordable, and personalized support remained limited for most caregivers [27, 103]. Traditional mental health services can be costly, stigmatizing, or difficult to access due to time constraints and caregiving responsibilities [37]. In response, researchers and designers have begun exploring the role of technology in enhancing mental health support [50, 130]. Among these, conversational agents and AI-driven chatbots present a particularly promising avenue due to their accessibility, adaptability, and ability to simulate supportive dialogue [100, 175].

Recent advances in generative artificial intelligence (AI), especially large language models (LLMs), offer an opportunity to enhance caregiving support [148]. LLM-powered chatbots can provide always-available support, practical advice, and a sense of companionship [32, 67, 173]. However, little is known about how AD/ADRD caregivers perceive such technologies, and to what extent they trust, use, or feel supported by them—especially in the context of mental health and wellbeing. Prior work highlighted how user expectations of technology evolve alongside their needs and contexts [26]. Therefore, it is essential to examine not only whether AI can support caregivers, but also *how caregivers interpret, negotiate, and assess the role of AI in their mental wellbeing journey.* In fact, these needs and expectations are not merely preferences—they are foundational to designing human-centered AI systems that meaningfully support caregiver mental health.

To bridge the above gap, we investigate the research question (RQ): **What are the needs and expectations of AD/ADRD caregivers for an AI chatbot designed to support mental health?**

For our RQ, we developed a GPT-4o based AI chatbot, named Carey—which is aimed to provide informational and emotional support to AD/ADRD caregivers. We used Carey as a technology probe [65] to conduct semi-structured interviews with 16 AD/ADRD caregivers. These participants interacted with Carey on eight carefully designed scenarios from the literature, representing common caregiving stressors—1) disruptive care-recipient's behavior, 2) lack of support, 3) low self-efficacy, 4) emotional distress, 5) relationship tensions, 6) compassion fatigue, 7) lack of self-care, and 8) burnout. The participants shared their interaction experiences and perceptions about their expectations, desires, and concerns about Carey.

We analyzed the interview transcripts and chat history using inductive coding and reflexive thematic analysis [22] to examine both benefits and tensions in caregivers' interactions with Carey. We present a systemic understanding of the multifaceted ways caregivers seek, interpret, and evaluate AI-based support in response to specific emotional and logistical stressors. Our findings highlight both optimism and hesitation—while caregivers appreciated Carey's timeliness, ease of access, and nonjudgmental tone, they also raised concerns about personalization, initiative, information trust, and emotional over-reliance. Importantly, caregivers expressed that their mental wellbeing support needs are contextual, evolving, and relational—dependent not only on their own emotional states, but also on interactions with care recipients, family dynamics, and external resources. Our work offers the following key contributions:

- We provide a systemic understanding of how caregivers engage with an AI mental health chatbot, surfacing key needs and expectations across six major themes—*on-demand information access, emotional support, safe space for disclosure, crisis management, personalization capabilities,* and *data privacy*.
- For each of the above themes, we highlight the caregivers' nuanced perceptions of benefits and concerns.
- We present a comprehensive mapping of caregiver needs, current chatbot strengths, unmet gaps, and actionable design recommendations—centered around the caregiver experiences.

The above contributions collectively advance both theoretical understanding and practical approaches to supporting AD/ADRD caregivers' mental wellbeing. We discuss the implications of our work in informing the

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[1]Since our work focuses on family caregivers, the term "caregivers" will refer to family caregivers unless otherwise noted.

development of caregiver-centered AI tools that are proactive, trustworthy, and attuned to the emotional and informational complexities of caregiving. Our work underscores the importance of moving beyond technical feasibility toward context-sensitive, relationally grounded AI support for vulnerable populations.

2 Background and Related Work

2.1 Alzheimer's Disease and Related Dementias (AD/ADRD): Condition and Caregiving

Alzheimer's Disease and Related Dementias (AD/ADRD) is a group of progressive neurodegenerative conditions marked by cognitive decline, memory loss, and eventual loss of independence [76]. With no known cure, AD/ADRD remains a significant and growing public health challenge—currently the fifth-leading cause of death among older adults in the U.S. [14]. By 2050, it is estimated that 14 million people in the U.S. and 152 million globally will be living with these conditions [102].

Care for individuals with AD/ADRD is primarily provided by family and informal caregivers, most often within the home environment [57, 61]. In 2022, this unpaid caregiving was valued at over $339.5 billion in the U.S. alone [14]. This caregiving experience is marked by significant emotional, physical, and financial strain. Caregivers frequently report challenges in managing their own mental and physical health [38, 64, 159], navigating future care decisions [98, 151], and maintaining financial stability [58, 60, 150]. The intensity of AD/ADRD caregiving, including the need to supervise daily activities, manage behavioral symptoms, and make complex medical decisions, contributes to elevated stress levels and heightened risk of depression and burnout [9, 62, 86, 114, 120].

The daily routines of AD/ADRD caregivers are often tightly constrained by the needs of the care recipient, leaving limited time for self-care, social engagement, or accessing professional support [120, 158]. This localization of caregivers' lives—often physically, emotionally, and socially—further compounds their vulnerability, with many reporting isolation, limited mobility, and difficulty accessing even basic mental health resources [9, 62, 120]. They are at a heightened risk for clinical concerns such as suicidal ideation, complicated grief, trauma symptoms, and health-related anxieties [128, 139]. Without formal training or structured support, they must adapt to the evolving needs of the care recipient while contending with their own wellbeing challenges.

A growing body of research acknowledges that caregiving is not just a logistical challenge, but also an emotionally complex and socially entangled experience [14, 57, 61, 62]. Caregiving in AD/ADRD contexts is particularly complex, involving prolonged emotional labor, progressive memory loss, behavioral challenges, and shifting family roles [23, 30]. This complexity is well-documented in clinical frameworks such as Pearlin's Stress Process Model [108], which outlines how contextual stressors, mediators (e.g., social support), and outcomes (e.g., depression, burden) dynamically interact throughout the caregiving trajectory. Given these challenges, there is an urgent need for interventions that are accessible, affordable, immediate, and available around-the-clock—especially given caregivers' limited time and mobility, and the unpredictability of care demands. AI-driven tools, such as conversational agents, offer a promising direction for delivering low-barrier scalable support [156, 165]. However, there is limited understanding of what AI-driven mental wellbeing support should look like for AD/ADRD caregivers. Building on the above body of research, our work focuses specifically on the mental wellbeing of family caregivers in AD/ADRD contexts. We designed scenario-based interactions to surface caregiver' perspectives, exploring their expectations, concerns, and perceived value of AI-driven support through a chatbot interface.

2.2 HCI and Digital Health Technologies for Caregivers

Human-Computer Interaction (HCI) and digital health research have long examined how digital technologies can support the wellbeing of caregivers [20, 31, 52, 68, 85, 99, 126, 131, 176]. In the context of caregiving for AD/ADRD and older adults, prior work has examined the use of smartphone [135], wearables [80, 141], voice assistants [104, 112, 163], and online social platforms [71, 73, 87, 110, 124] to reduce caregiver burden, facilitate coordination, and enhance access to resources. Prior research has explored technologies such as memory aids,

context-aware home systems [152], and collaborative care platforms [71, 87] to assist both caregivers and care recipients. These technologies often aim to support caregiving tasks such as medication management [86], appointment scheduling [18], and activity monitoring, while also supporting emotional needs through self-tracking, social support, or reflective prompts [18, 73].

Beyond functional support, a rich body of work has emphasized the importance of addressing the emotional and psychological dimensions of caregiving [15, 83, 134, 136]. Lazar et al. demonstrated the value of fostering digital social sharing among AD/ADRD caregivers to combat isolation and enhance communal coping [71, 83]. Bhat et al. highlighted the caregiver's central role in mediating care and proposed caregiver-centric technological supports [15]. Similarly, Kim et al. pointed to the need for adaptive and personalized support strategies, given that caregiver needs often fluctuate across the progression of behavioral episodes [78]. Meyerhoff et al. advocated for user-centered digital mental health tools that flexibly adapt to individual support needs and empower users in their mental health journeys [97]. Most recently, Smriti et al. explored how technology might meaningfully address the emotional experiences of dementia caregivers [138].

Accordingly, recent research has called for digital interventions that center caregivers' wellbeing, relational dynamics, and long-term coping strategies [15, 134, 170, 171]. Mental health chatbots, journaling platforms, and peer support communities have shown early promise in reducing emotional burden. However, many of these tools remain generic in design and do not adequately account for the unique and evolving psychological challenges faced by AD/ADRD caregivers. Our work builds on this evolving literature by examining how an AI-powered mental health chatbot may fulfill—or fall short of—caregivers' expectations, with the goal of identifying actionable design considerations for human-centered technologies to support caregivers' mental wellbeing.

2.3 Designing Human-Centered AI for Wellbeing: Maximizing Benefits and Mitigating Harms

AI holds growing promise for addressing longstanding gaps in mental health and caregiving support [19]. Increasingly, AI systems are being leveraged to deliver mental and physical health support across diverse domains, including clinical decision support, health behavior change, symptom tracking, and emotional wellbeing [70, 94, 137, 148]. Among these, conversational agents and AI-powered chatbots have emerged as accessible, low-cost tools that aim to provide emotional support at scale [66, 67]. These tools can integrate techniques such as Cognitive Behavioral Therapy (CBT) [11, 132] and emotion regulation [137], and have shown early promise in reducing symptoms of depression and anxiety [50].

With advancements in large language models (LLMs), interest in AI-driven mental health technologies has expanded significantly [132, 166]. General-purpose LLM-based chatbots such as OpenAI's ChatGPT, Google's Gemini, and Microsoft's Bing are now being explored as companions or wellbeing coaches due to their ability to generate emotionally expressive and contextually adaptive responses [32, 173]. This technological shift has intensified hopes that generative AI could play a central role in expanding mental health support, particularly for caregivers whose lives are constrained by the continuous demands of care.

Yet, despite these advances, significant concerns remain [25, 45, 124, 168]. LLMs are known to hallucinate facts, produce inconsistent or overly generic responses, and simulate empathy without true understanding [12]. They struggle to detect psychological distress, adapt to evolving user needs, or maintain memory over time—capabilities that are crucial in emotionally sensitive, high-stakes domains like AD/ADRD caregiving. These limitations risk undermining user trust and may inadvertently cause harm. Further concerns around bias, safety, and ethical accountability highlight the need for careful, intentional design [21, 45, 92, 95].

As AI systems move beyond clinical settings into everyday wellbeing contexts, HCI and digital mental health researchers have emphasized the importance of human-centered design principles [28, 127, 140, 168, 169]. Prior work has called for tailoring AI to individual needs—not just to optimize outcomes, but also to support emotional processes such as expression, validation, and coping [13, 26]. Madaio et al. proposed participatory co-design

of ethical AI checklists, developed with stakeholders to address organizational challenges and surface hidden biases [96]. This approach fosters greater accountability and aligns with broader research on inclusive, value-driven AI design [2, 49, 74, 122, 171]. A rich body of research on AI alignment—ensuring that AI systems produce outcomes consistent with human values—has gained increasing attention, expanding from its roots in philosophy and machine learning to more human-centered design [53, 59, 133, 147]. Recent work highlights alignment both during development (e.g., annotation) and interaction (e.g., user feedback) [36, 89, 95], with concepts like bidirectional alignment emphasizing mutual adaptation between humans and AI [133]. However, in the domain of AD/ADRD caregiving, chatbot technology remains in its early stages and is not yet well aligned with caregivers' lived experiences, emotional labor, or evolving support needs [123, 163].

To fulfill the promise of AI for caregiver wellbeing, systems must be designed with deep consideration for trust, usability, emotional resonance, and harm reduction. Our study builds on this body of work by investigating how AD/ADRD caregivers engage with a prototype LLM-powered mental health chatbot. We provide a mapping of caregivers' needs, the chatbot's strengths and gaps, and resulting design considerations. This mapping can inform the development of AI systems that are not only effective but also ethically aligned with the lived experiences and needs of AD/ADRD caregivers. Our work draws inspiration from, and contributes to, the growing body of research on ethical AI design guidelines [5, 40, 41, 74, 91], offering empirical insights into how caregiver-centered values, emotional needs, and real-world contexts can shape the design of more caregiver-centered AI technologies.

3 Study Design and Methods

Our study used a scenario-based interview study with a technology probe [65]—Carey, a chatbot designed for AD/ADRD caregivers. This study was approved by the Institutional Review Boards (IRBs) at the researchers' institutions. In the following subsections, we describe our methodology.

3.1 Participant Recruitment

To access a diverse and digitally engaged caregiver population, we recruited participants from social media communities, where many AD/ADRD caregivers seek support and share lived experiences [73]. We first contacted the moderators of the online communities catering to AD/ADRD-related discussions on Reddit (*r/alzheimers, r/dementia, r/dementiaresearch, r/ParentsWithAlzheimers*, etc.), *alzheimersdisease.net*, and *alzconnected.org*, by briefly describing our research and if they were okay with recruiting from their respective platforms. In communities where the moderators granted permission, we posted recruitment information with an interest form. This form included a demographic questionnaire (collecting information on age, sex, race, U.S. state) and a section identifying their caregiving role. The form served as a screening tool to ensure participants met the eligibility criteria: 1) 18 years or older, 2) current or former caregivers for individuals with AD/ADRD, and 3) residing in the U.S. We received 205 responses to our interest form over three months from October 2024 to January 2025, and we invited a subset of participants to maximize diversity and balance across demographic attributes. Ultimately, we interviewed 16 participants, each of whom was compensated with Amazon gift vouchers of $25 USD. Table 1 summarizes our participant pool, reflecting a balanced distribution across demographic attributes. Our sample includes both recent caregivers with less than three years of experience (N=9) and more experienced caregivers with over three years of caregiving experience (N=7).

Before the interviews, participants were provided with the Rapid Caregiver Well-being Scale (R-CWBS) [146]. R-CWBS is a validated short-form rapid assessment instrument to infer key areas of support a caregiver needs [146]. Here each question is rated on a Likert-scale between 1 (Rarely) and 5 (Usually), and lower scores indicate a need for greater support. Table 2 provides a summary of participants' responses to this survey—we see that our pool of participants scored high on taking care of personal daily activities (mean=4.25), but scored low on treating or rewarding themselves (mean=2.75).

Table 1. Summary of participants, including type (current/former caregiver), years of caregiving (ys.), care-recipient, age, gender, race, education, and occupation. *Professional Caregivers* are marked with an '*' next to their ID.

ID	Type	Ys.	Care Recipient	Age	Sex	Race	Education	Occupation
P1	Current	4	Father	36-50	Transgender	Black or African American	Some college, no degree	Out of work
P2	Current	5	Father	25-35	Male	Black or African American	Associate degree	Employed for wages
P3	Current	3	Father	50-65	Female	White	Advanced degree	Employed for wages
P4	Former	4	Aunt	25-35	Female	Black or African American	Some college, no degree	Homemaker
P5	Current	5	Stepmother	25-35	Male	White	Advanced degree	Employed for wages
P6	Current	3	Father	25-35	Male	Hispanic or Latino	Some college, no degree	Employed for wages
P7	Current	7	Mother	25-35	Female	Black or African American	Bachelor's degree	Employed for wages
P8	Former	5	Uncle	36-50	Female	White	Advanced degree	Self-employed
P9	Current	1	Mother	50-65	Female	White	Bachelor's degree	Employed for wages
P10	Current	1	Wife	50-65	Male	White	Advanced degree	Employed for wages
P11	Former	3	Father	50-65	Male	Black or African American	Bachelor's degree	Employed for wages
P12	Current	3	Father	19-24	Female	White	Some high school, no diploma	Employed for wages
P13	Current	3	Mother	50-65	Female	White	Associate degree	Retired
P14	Current	2	Father	25-35	Male	Black or African American	Trade/technical/vocational training	Employed for wages
P15*	Current	19	Friend, Patients	50-65	Female	White	Bachelor's degree	Employed for wages
P16	Current	3	Mother	19-24	Female	Prefer not to say	Associate degree	Employed for wages

Table 2. Summary of participants' responses to Rapid-Caregivers' Well-being Scale (R-CWBS) [146]. Each question was rated on a scale from: 1 (Rarely), 2 (Occasionally), 3 (Sometimes), 4 (Frequently), and 5 (Usually).

Question	Mean	Std. Dev.	Distribution
Activities			
Taking care of personal daily activities (meals, hygiene, laundry)	4.25	0.77	
Taking time to have fun with friends and/or family	3.00	1.46	
Treating or rewarding yourself	2.75	1.29	
Needs			
Receiving appropriate health care	3.75	1.18	
Feeling good about yourself	3.44	1.41	
Feeling secure about your financial future	3.19	1.44	

Participants were also asked to respond to a survey questionnaire on the different mental health concerns of AD/ADRD caregivers drawn from the literature (the eight scenarios) on a Likert scale of 1 (not at all concerning) to 5 (very concerning). Table 5 summarizes their responses—we see that lack of support (mean=3.89) and burnout (mean=3.75) scored the highest, whereas low self-efficacy (mean=2.94) scored the least in our participant pool.

3.2 Carey: Technology Probe for AR/ADRD Caregivers' Mental Health

Understanding the mental health challenges faced by AD/ADRD caregivers requires an approach that captures their caregiving experiences while interacting with AI-driven mental health tools. To explore this, we developed a technology probe named Carey—a GPT-4o-mini-based chatbot—designed to provide emotional support, practical caregiving advice, and self-care recommendations. Carey serves as both an intervention and a research tool, allowing us to examine how caregivers perceive and engage with AI-based mental health support, and to explore how future technologies can better support them. However, due to the sensitive and complex nature of ADRD caregiving and mental health, we opted not to deploy Carey in a real-world setting. Instead, participants interacted with Carey during a guided one-hour interview session. During the interviews, each participant was presented with eight caregiving-related scenarios—derived from the literature—which are known to significantly impact

Table 3. Summary of participants' responses to prompts on mental wellbeing concerns from literature. They responded to these prompts based on their level of concern, on a scale of 1 (not at all concerning) to 5 (very concerning).

Question	Mean	Std. Dev.	Distribution
Disruptive behaviors by care-recipient	3.19	1.42	▪▄▄▌▪▄
Lack of support	3.89	1.20	▁▁▄▪▌
Low self-efficacy	2.94	1.29	▁▁▄▪▄
Emotional distress	3.44	1.42	▄▄▄▪▁
Relationship tensions	3.38	1.20	▄▄▄▌▄
Compassion fatigue	3.56	1.31	▁▁▄▌▁
Lack of self-care	3.56	1.46	▁▄▄▌▌
Burnout	3.75	1.00	▄▄▄▄▌

AD/ADRD caregivers' mental health. They were asked to select four to five of these scenarios as time permitted. By engaging with Carey within these scenarios, participants shared their perspectives in a controlled setting, allowing for in-depth exploration of their needs and concerns. In the following subsections, we elaborate on the design of the scenarios and chatbot interactions.

3.2.1 Scenario Design. We adopted a scenario-based design to guide our participants in interacting with Carey for mental health support. These theory-driven scenarios provided realistic caregiving situations that reflect common mental health stressors. For ethical reasons, interviewers monitored emotional cues and offered breaks or termination options when signs of distress emerged. Participants were also reminded that Carey is not a crisis resource. We developed the scenarios based on prior literature on AD/ADRD caregivers' mental health challenges, identifying eight key stressors: 1) disruptive behaviors by care-recipient [47, 81, 143], 2) lack of support [69, 107, 129], 3) low self-efficacy [39, 54, 145], 4) emotional distress [6, 27, 56], 5) relationship tensions [118, 154], 6) compassion fatigue [42, 43, 109], 7) lack of self-care [105, 155, 157], and 8) burnout [3, 144, 149].

For each of the above scenarios, we crafted descriptions to help participants understand the context, along with the specific tasks that encouraged them to engage with our AI chatbot—as presented in Table 4. During the interviews, scenarios were presented in random order, and participants were asked to choose one that they related with their own experience. They would then choose a scenario and interact with Carey with a query. The number of scenarios each participant engaged with varied depending on their interaction pace, within the stipulated total interview time of one hour.

3.2.2 Development of Carey. To develop Carey, we used the Flask web framework for its simplicity and flexibility in web applications, enabling seamless integration with the OpenAI API [1]. Carey was implemented within a Python virtual environment, ensuring secure management of the OpenAI API key. For the back end, we selected GPT-4o-mini—the state-of-the-art generative AI model at the time of this research—known for its advanced natural language capabilities and optimized response times. The API was incorporated into the Flask application with careful attention to constructing messages that defined the chatbot's role, the specific caregiving scenario, and the ongoing chat history.

The chatbot function processed scenario descriptions, chat logs, and prompts to generate relevant and contextually appropriate responses. We experimented with several prompts and caregiver queries (gathered from the body of work on identifying the scenarios as well as from online communities [73, 124]) to arrive at a final prompt which led to generating most relevant responses—"You are a peer-supporter chatbot designed to support the mental wellbeing of caregivers of Alzheimer's Disease and Related Dementias. The caregiver wants to seek your advice and support related to the [S], which is described as [D]"—here [S] refers to the particular scenario and [D] consists of the scenario description (ref: Table 4).

Table 4. Descriptions and tasks for each scenario in the study.

Scenario	Description	Task
Disruptive behaviors by care-recipient	Your care recipient has disruptive behaviors, such as aggressive behaviors (verbal outbursts, physical aggression), restlessness, and heightened irritability over minor triggers. You are seeking to better understand your care recipient's behavior.	Start chatting with Carey about strategies for handling disruptive behaviors by your care-recipient. Ask for advice on managing verbal outbursts, physical aggression, and restlessness. Seek tips on identifying triggers and creating a calming environment.
Lack of support	You're facing challenges due to a lack of support systems to help manage your mental health. You have difficulties getting help from senior centers, professionals, and services like home health aides and respite care.	Chat with Carey about handling caregiving with limited support. Ask for tips on finding resources and support systems.
Low self-efficacy	You're experiencing doubt in your ability to manage caregiving challenges. This lack of confidence affects your motivation and resilience.	Start a chat with Carey to discuss strategies for boosting self-efficacy. Seek advice on building confidence, staying resilient, and developing coping mechanisms.
Emotional distress	You're struggling with emotional wellness, finding it difficult to stay positive and manage stress related to caregiving, including depression, guilt, and embarrassment.	Start a chat with Carey about strategies for maintaining emotional wellness. Ask for tips on managing guilt, depression, and other challenging emotions while staying resilient.
Relationship tensions	You're struggling to manage family relationships due to the uneven distribution of caregiving duties, causing stress, tension, and conflict.	Start a chat with Carey about managing family relationships while caregiving. Ask for advice on handling conflicts, communicating with family, and sharing responsibilities more equally.
Compassion fatigue	You're feeling emotionally drained and struggling to stay empathetic, especially as your care recipient's condition worsens.	Start a chat with Carey about handling compassion fatigue. Ask for tips on recharging emotionally, coping with burnout, and rekindling empathy.
Lack of self-care	You're struggling to find time for self-care, feeling overwhelmed with caregiving responsibilities, and lacking personal space or privacy.	Start a chat with Carey about making time for self-care. Ask for tips on balancing responsibilities, setting boundaries, and incorporating self-care into daily life.
Burnout	You're feeling overwhelmed and exhausted, showing signs of burnout from caregiving demands. Persistent stress is impacting your emotional wellbeing and sense of accomplishment.	Start a chat with Carey about coping with caregiver burnout. Ask for advice on managing stress, improving emotional resilience, and regaining a sense of control.

Carey's front-end interface followed a minimalist and simple design for clarity and ease of use, with the left part displaying the scenario number, title, description, task, and example questions, and the right part facilitated participant interactions (see Fig. 1). The participant had options to go back to the scenario page and navigate between different scenarios. The participant chatlogs and scenario selections were automatically stored on a secure server, which was later used for analysis alongside interview transcripts.

3.2.3 Safety Measures. Given the emotional and psychological demands of caregiving for individuals with AD/ADRD, we implemented several safety measures to ensure participant wellbeing throughout the study. We carefully considered potential risks related to discussing caregiving challenges and emotional distress, taking proactive steps to minimize any negative impact on participants.

To ensure a safe interaction with AI chatbot Carey, we rigorously tested its responses across multiple caregiving scenarios before participant engagement. These scenarios were derived from existing literature on caregiver support needs and emotional wellbeing [78, 84, 117]. We rigorously tested several queries to ensure that the responses did not contain distressing or misinformation content.

During the study, one participant showed signs of emotional distress while discussing the caregiving experience. The interviewer provided space for them to process their emotions, offered a break, and reiterated the availability of support services. No other participants reported distress following the interviews.
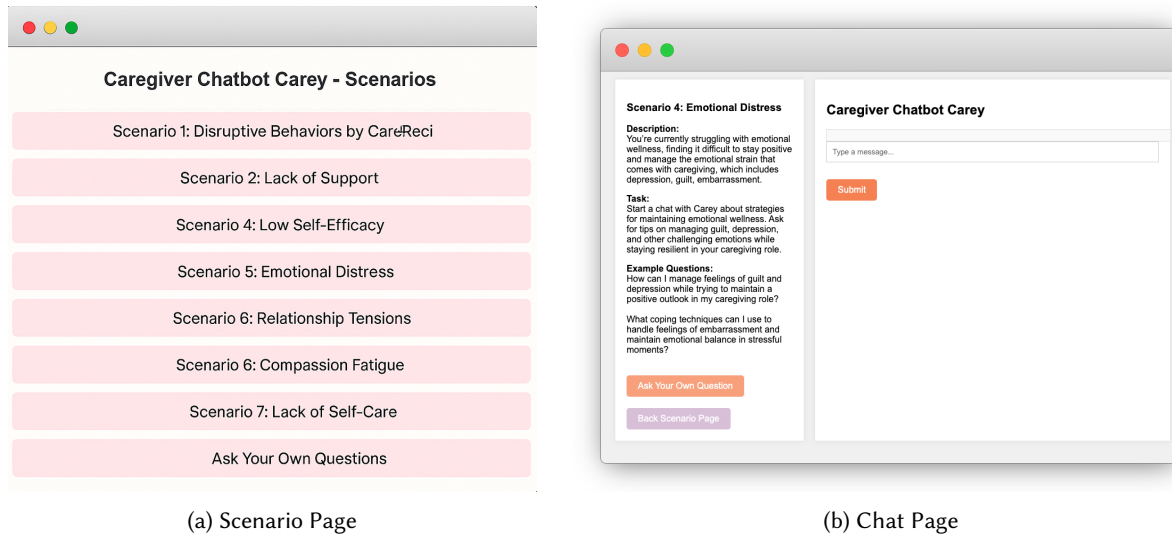
(a) Scenario Page   (b) Chat Page

Fig. 1. Screenshots of the scenario and chat page of our prototype chatbot, Carey.

3.3 Interview Procedure

We conducted semi-structured interviews with caregivers to explore their experiences and mental health throughout the caregiving journey. These interviews were conducted via video calls (Teams) and lasted approximately 60 minutes. The research team alternated between interviewing and note-taking during the sessions, which were recorded for research purpose. At the beginning of the interview, we introduced the study by explaining its purpose—exploring caregiving opinions on using an AI-based chatbot, Carey, for mental wellbeing support. We aimed to investigate the needs, desires, and concerns of an AI chatbot catering to the mental health of AD/ADRD family caregivers. We informed participants that Carey was designed based on prior research that identified eight major causes of caregivers' mental health concerns. Before proceeding, we addressed any questions they had and sought permission to record the session.

The interview was structured into three main sections. First, we asked participants about their general caregiving and mental health experiences. We inquired about their care recipients, the duration of their caregiving experience, the impact on their mental health, specific mental health challenges they had encountered, and which aspects of caregiving they found particularly stressful or overwhelming [17]. In the second section, we focused on participants' experiences with AI-based chatbots. We asked whether they had previously used chatbots such as OpenAI's ChatGPT, Google's Gemini, or Microsoft's Bing, their motivations for doing so, their first impressions, and whether they had ever used chatbots for mental health support. If applicable, we asked them to describe their experiences using AI for mental health purposes, including the effectiveness and limitations of such tools. Finally, in the third section, participants engaged in direct interaction with Carey by selecting scenarios that resonated with their caregiving experiences. During these interactions, we encouraged them to think aloud—sharing their intentions behind each prompt and their reactions to Carey's responses. Wherever applicable, we also prompted them to elaborate on their thoughts and personal experiences.

3.4 Data Analysis

After the interviews, we used the default transcription feature on Teams for all interviews conducted. The recordings were anonymized by redacting any identifiable data such as personal names and locations. The data set was then treated as a corpus for comprehensive analysis. We analyzed our data, including transcriptions from the interview recordings, notes taken during the interviews, and chat history between the participants and Carey, using reflexive thematic analysis [22]. Four co-authors participated in reviewing the transcripts and engaged in an interactive process of open coding, where codes were grouped, initial subthemes were identified, and subthemes were refined into higher-level themes.

To further elaborate on our process, four co-authors were involved in the open coding process. The first author led the coding effort, completing the majority of coding on raw interview transcripts, while senior co-authors (who have extensive experience in qualitative research) provided feedback and suggestions during hybrid (in-person and screen-sharing-based) co-working sessions. To ensure coherence in the analysis, we carefully reviewed and refined the themes through an iterative process. This involved merging related themes into broader categories, separating overlapping themes into distinct categories, and discarding themes that were not directly relevant to our core research questions. While we allowed flexibility in our coding and theme development, we applied thematic analysis [22] as our primary methodological approach, guided by prior research on social support in online dementia communities [71]. We initially obtained 420 codes, which were grouped into 24 lower-left subthemes and five higher-level themes that aligned with our research question.

3.5 Privacy, Ethics, and Reflexivity

Our study was approved by the Institutional Review Boards (IRBs) at the researchers' institutions. Given the sensitive nature of caregiving experiences, we implemented several ethical and privacy considerations to protect participants' wellbeing and confidentiality. Each participant was assigned a unique participant ID to anonymize their responses, and all personally identifiable information was removed during transcripts and analysis. Throughout the interviews, we adopted a respectful and empathetic approach to discussing caregiving experiences. We used language that prioritized the caregiver's perspective and emotional well-being, referring to their loved ones as "care recipients" rather than clinical terms such as "AD/ADRD patients." During the interviews, we closely monitored participants' emotional states, paying attention to verbal and nonverbal cues. If a participant became emotional while sharing their experiences, we paused the session, offered them the option to take a break, and reminded them that they could discontinue at any time without consequences.

Our research team comprises researchers holding diverse gender, racial, and cultural backgrounds, including people of color and immigrants with interdisciplinary expertise in HCI, digital health, AI ethics, and psychology as well as experience in studying caregiving technologies and social support. The team includes a clinical psychologist with experience in mental health and caregiver wellbeing, as well as researchers with personal caregiving experiences—though not specifically related to AD/ADRD. Although we have taken great care to faithfully analyze and represent participants' perspectives, we acknowledge that our positionality as researchers and, in some cases, as caregivers may shape our interpretations. We remain committed to presenting participants' experiences authentically and recognizing the diverse and complex nature of caregiving.

4 Results

Overall, our analysis revealed predominantly favorable opinions of Carey among AD/ADRD caregivers (N=16). Nearly all participants (93.75%) described the prototype Carey as "helpful" or "very helpful" in addressing caregiver-related mental health challenges. First, our scenario-based analysis revealed that caregivers most frequently engaged with scenarios they found personally relevant and emotionally resonant. These usage patterns reflect caregivers' prioritization of mental health concerns that are often overlooked in general-purpose wellbeing tools.

Table 5. Summary of participants' interactions with Carey.

Scenario	Num. Participants	Num. Interactions
Disruptive behaviors by care-recipient	8	15
Lack of support	2	4
Low self-efficacy	3	6
Emotional distress	12	28
Relationship tensions	5	11
Compassion fatigue	4	9
Lack of self-care	5	8
Burnout	7	12

Second, our reflexive thematic analysis [22] revealed that although caregivers appreciated Carey's accessibility, emotional validation, and neutrality, they also identified key limitations in its current design. These insights underscore caregivers' desire for AI tools that are not only empathetic and nonjudgmental but also proactive, trustworthy, and attuned to the complex realities of caregiving. In this section, we elaborate on our findings.

4.1 Characterizing and Understanding Caregiver–Carey Conversations

Participants in our study interacted with Carey through eight theory-driven scenarios known to be challenging for caregivers' mental health [153]. They prioritized interacting with scenarios that appealed the most to their lives—at an average of 3.25 scenarios per participant, and Table 5 presents the frequency of occurrence of each scenario. The scenario most chosen was emotional distress (by 12 participants), followed by disruptive behaviors by care-recipients (8 participants) and burnout (7 participants). We describe the observations per scenario below:

Scenario 1: Disruptive behaviors by care-recipients (N=8). Caregivers sought strategies for handling care refusal situations, improving care-recipients' receptiveness to suggestions, managing verbal aggression, navigating public perception of inappropriate comments, and calming agitated care-recipients during outbursts. Some common questions included—"How do I calm my recipient when they are aggressive?" (P12) and "How can we manage inappropriate comments by patients?" (P03). Carey responded with de-escalation techniques, person-centered validation approaches, and practical recommendations for explaining AD/ADRD-related behaviors to others. P3 noted that Carey's advice aligned closely with the guidance they had previously received from an AD/ADRD caregiving support group they participated in. They found the responses helpful and expressed interest in continuing to engage with Carey for future support.

Scenario 2: Lack of Support (N=2). Although this scenario was only chosen by two participants, it reflected interactions on frustration with institutional and social support. For instance, P1 expressed, "I am not getting enough help from the Veterans organization. How do I navigate through this situation?" Carey validated P1's struggle, suggested persistence, and offered guidance on alternative advocacy options and caregiver networks, highlighting the limitations of AI when institutional change is needed.

Scenario 3: Low Self-Efficacy (N=3) In this scenario, caregivers asked questions like, "What tips are available to help me decide if treatments are the correct thing to do?" (P13) and "What practical tips can help me feel more capable and confident when facing new caregiving challenges?" (P1). Carey responded with frameworks for shared decision-making, conflict resolution strategies for family discussions, and permission-giving language that emphasized the connection between caregiver wellbeing and care quality.

Scenario 4: Emotional Distress (N=12). In this scenario, example questions consisted of "How do I manage my depression while taking care of my dad?" (P3) and "How do I deal with feeling low emotionally when caregiving

seems endless?" (P7). Carey provided validation-first responses, followed by reflective prompts and coping suggestions such as journaling, breathwork, and emotional boundary-setting.

Scenario 5: Relationship Tensions (N=5**).** In this scenario, participants voiced challenges like, "How do I get closer to my family when I care for my dad?" (P4) and "How can I talk to my siblings about their lack of involvement?" (P1). Carey emphasized empathetic communication, boundary-setting, and collaborative planning, often providing sample scripts to reduce confrontation while advocating for shared responsibility.

Scenario 6: Compassion Fatigue (N=4**).** Participants expressed questions regarding compassion fatigue and emotional withdrawal, "I feel blank when I think about my life—how do I fix that?" (P8) and "How can I take care of my emotional needs while caring for someone who won't address theirs?" (P14). Carey acknowledged the cumulative toll of caregiving and recommended micro-restoration practices, re-framing caregiver fatigue as a valid and treatable experience tied to prolonged emotional labor.

Scenario 7: Lack of Self-Care (N=5**).** Questions in this scenario included, "How do I balance caregiving with personal time?" (P16) and "What small self-care activities can I actually do between all my responsibilities?" (P10). Carey offered actionable self-care strategies grounded in feasibility, such as incorporating mindful breathing into daily routines. These recommendations align with micropractices that accommodate time constraints while supporting gradual restoration.

Scenario 8: Burnout (N=7**).** This scenario captured caregivers expressing ambivalence or emotional collapse, "I love her, but I'm exhausted. I don't want her to die, but I'm relieved of the thought" (P15). Another participant asked, "How do I manage work and caregiving when both demand everything from me?" (P11). Carey responded with layered support—validation, time-sensitive coping plans, and referrals to external resources—recognizing burnout as both a psychological and practical challenge of caregiving.

Own Questions (N=6**).** Six participants chose to engage with Carey by asking their own questions. These interactions reflected caregivers' personal interests, concerns, and curiosity, often extending into more medically or genetically specifically inquiries. For example, P3 asked a detailed question about hormone replacement therapy (HRT) in the context of carrying the Apolipoprotein E epsilon 4 (APOE4) gene variant: "I have the APOE4 gene. Are there specific things people with this allele can do to reduce their risk of Alzheimer's? What's the latest research on hormone replacement therapy for women with APOE4?". P3 noted that Carey's responses surfaced new lines of inquiry they had not initially planned to explore: "I didn't come in thinking I wanted to ask more about HRT and APOE4, but seeing what Carey provided prompted more questions, which I really liked.". It illustrate how Carey can enable discovery-oriented dialogue by supporting relevant knowledge-especially in areas they might not have otherwise explored.

Overall Insights. Across all scenarios, participants used Carey to navigate both emotional validation and practical scaffolding. Emotional needs were particularly prominent, with participants often initiating conversations from moments of vulnerability, seeking reassurance, and meaning-making. Participants also desired for trustworthy, situation-specific guidance that felt personalized and realistic within the constraints of caregiving. We observed that participants frequently commented on Carey's tone, appreciating its non-judgmental, calm, and empathetic voice. However, the expectations varied. Some participants sought proactive guidance or more emotionally rich engagement, while others expressed skepticism about AI's ability to truly "understand" caregiving.

4.2   Needs and Expectations of Caregivers from Carey

Our analysis revealed that while participants generally found value in their interactions with Carey, they also recognized areas where the tool could more effectively address their caregiving challenges. In this section, we present key themes related to participants' needs and expectations, highlighting the tensions between the perceived benefits and concerns of interacting with Carey.

4.2.1 AI chatbots as a source of on-demand information access. **Participants appreciated Carey's potential as a tool for on-demand practical guidance, emphasizing the need for credible and contextual information.** Participants responded positively to Carey's ability as a source of immediate information access for diverse caregiving scenarios, e.g.,:

> "[The information provided by Carey] is practical and useful."—P16

That said, participants also expressed concerns about the verifiability and trustworthiness of the information provided. In fact, the AD/ADRD caregivers may need evidence-based guidance for complex care decisions. For example, P3 expressed a preference for information certified directly from trusted sources:

> "Personally, I just know the concept is that it pulls data from a variety of sources. But I would always want to go to an original source or a doctor, or the Alzheimer's website. I'd be worried about it pulling dirty data, like I'd be worried about it pulling information that's not accurate."—P3

This highlights a fundamental tension—although Carey can aggregate information from multiple sources, caregivers fear potential misinformation that could impact critical care decisions. Beyond trustworthiness concerns, participants also identified issues with information quality and relevance. For example:

> "It seems like recycled content from the previous questions that is only marginally relevant and useful"—P10

It indicates frustration with repetitive responses lacking novel insights or contextual adaptation—this suggests that caregivers also expect content that demonstrates an understanding of specific caregiving context and avoid generic, templated responses that fail to address their evolving needs.

4.2.2 AI chatbots as a "safe space" for disclosure. **Participants valued Carey as a judgment-free, always-available outlet for emotional venting, but desired more natural conversational reciprocity.** They described Carey as a space where they could openly process emotions—such as guilt, frustration, or exhaustion—without the fear of judgment. This sense of psychological safety was essential, given that societal norms often discourage caregivers from voicing emotional strain. Much like journaling or expressive writing, Carey offered participants a private, stigma-free outlet for candid self-reflection and disclosure—particularly valuable when caregivers face complicated decisions regarding behavioral management or long-term planning, as P4 expressed:

> "It's not going to judge you, with humans, sometimes you feel like people see everything you do, and at some points, it might feel like, "*OK, you're way too emotional.*" But with AI, it doesn't judge you like that."—P4

Therefore, the AI's neutral stance allowed participants to articulate their thoughts that they might otherwise suppress for fear of disappointing others or being perceived negatively. Further, P1 emphasized that AI provided the freedom to express without social consequences:

> "Sometimes it's hard to share emotions with another human being. But with an AI chatbot, you don't have to worry about being judged because it's just an AI—it doesn't have biases or personal opinions."—P1

Likewise, P9 described how Carey made it easier to express sensitive thoughts than in real-world relationships shaped by power dynamics:

> "It actually is easier [to share] to Carey than to someone who may be my boss." —P9

That said, participants expressed a desire for more natural conversational turn-taking—which was lacking in Carey in its current form. They found the interactions to be one-sided, placing the burden on caregivers to sustain engagement. P14 expressed frustration at needing explicit prompting:

> "I told it to talk like a human, and it did. But I wish it would do that without me having to ask."—P14

Therefore, Carey's reactive conversational approach fell short of creating the dynamic and back-and-forth rhythm that typically exists in supportive human interactions, as P3 noted:

> "I wish Carey would ask me questions too. That's what I like in a real conversation—it keeps me engaged."—P3.

4.2.3 AI chatbots for emotional support. Related to the above, **participants recognized and acknowledged Carey's ability to offer emotional support, but also desired a depth of human connections.** Caregiving often involves deep emotional labor, including compassion fatigue, anticipatory grief, emotional exhaustion, and role-related guilt, as noted in prior work [42, 43, 109, 161]. Our interviews revealed that Carey showed strengths in providing emotional support that resonated deeply with caregivers—supporting prior work on AI's capabilities in emotional support and empathy [13, 26]. In particular, participants valued Carey's ability to validate their complex feelings, and offer empathetic, emotionally attuned responses—something participants identified as a core unmet need in their caregiving experience. For example, P8 expressed:

> "Being a caregiver, at times, you need support. You need someone to hear you, someone actually to understand how you feel."—P8

Interestingly, participants also interpreted certain system behaviors—such as a pause between input and response—as signs of thoughtful engagement rather than technical delay. For example, P13 said:

> "I felt it was thinking. I asked a hard question, and it took a moment. That made it feel more intelligent."—P13

However, Carey's support often felt limited to isolated exchanges and lacked the dynamic, emotionally rich engagement that human-human supportive interactions provide. P3 remarked:

> "I bet it can't do this with following up like "*which of these are you more interested in?*" Like something you know when you're in human conversation."—P3

While some participants recognized the benefits of AI in offering low-risk emotional expression, they also voiced a clear preference for authentic, human interactions. P3 emphasized:

> "If I am going to interact with anything, I want it to be human. So for example, I'm very involved in my Alzheimer's support group. I find the human interaction very valuable."—P3

Therefore, we found a nuanced tension in participants appreciating AI's supportive qualities and maintaining a strong preference for human interactions. Beyond preference, some participants voiced ethical and emotional concerns about growing too attached to AI-based support. P15 reflected:

> "In general, I feel a bit suspicious of AI. I don't want it to replace human interaction, and honestly, I don't want to grow too fond of it."—P15

4.2.4 AI chatbots for crisis management. Our interviews revealed that **although the participants appreciated Carey's ability to provide timely and round-the-clock interactions and support, it needs better crisis response.** To begin with, Carey's potential 24/7 availability strongly aligned with caregivers' need for on-demand assistance during unpredictable caregiving situations. Participants consistently valued the immediate accessibility of guidance that mitigated waiting times experienced with human support systems. This was particularly valuable given the irregular and often crisis-driven nature of AD/ADRD caregiving, where challenges frequently emerge during off-hours when professional support may be unavailable. This shows an AI's potential to address a critical vulnerability in the caregiving journey—isolation during moments of urgent need. For example:

> "Using an AI chatbot gives you that 24/7 availability. They're always accessible and sometimes provide resources you didn't even know existed."—P8

This "always available" nature of Carey was considered to be "emotionally stabilizing" for multiple participants. This contrasted with participants' experiences trying to contact healthcare professionals, family members, or support groups during moments of need, as P9 expressed:

> "Instead of waiting for responses from professionals who may be available, I get an immediate answer. It's a real-time interaction."—P9

Despite these strengths, Carey showed limitations in differentiating between routine inquiries and situations requiring professional intervention. Carey—in its current form—lacked sophisticated mechanisms to recognize crisis indicators and escalate accordingly. Some participants noted that while generic information was readily

available, the system needed more contextually relevant guidance for complex or emergency situations. For instance, P3 expressed concern that delays in receiving a response could pose risks in urgent situations.

> "At first, it felt like one of those dead ends you hit when searching online. But then it rebounded and gave me the information I wanted. Still, it took a moment, and that made me wonder how it would handle something more serious or urgent."—P3

4.2.5 AI chatbots' personalization capabilities. **A cross-cutting theme was that participants appreciated Carey's personalization capabilities; however, they also sought a deeper depth of engagement for complex caregiving situations.** In particular, they frequently described Carey as helpful in offering seemingly tailored responses that resonated with their situations. Many were surprised by how personally relevant the chatbot's suggestions felt. As P9 described:

> "I was surprised by [Carey's responses]. It felt like it was a tailored, real-time self-help book or support group, which is especially [helpful as] caregiving needs [to increase]."—P9

Participants pointed to small psycholinguistic cues—such as the use of personal pronouns and conversational tone—as contributing to a sense of individualized interaction. P2 noted:

> "I just like [Carey] using "I" and being more personalized. It gradually resonates with me."—P2

P13 further noted that Carey could adapt its general knowledge to address specific queries.

> "General responses, but it's specific to what I type."—P13

Despite these strengths, caregivers consistently pointed to limitations in depth and contextual understanding. While initial interactions felt responsive, many participants found the personalization to be surface-level and not well attuned to the complexity of their caregiving situations. For instance, P8 remarked:

> "So I think this is not as personalized as it could be, probably because I just started chatting with it."—P8

Others expressed that responses often felt mismatched in tone, length, or emotional nuance. P10 explained:

> "I'm asking sophisticated questions–personal questions that I believe are complicated–but [Carey's] answers are too long for what I need."—P10

Beyond functional assistance, participants emphasized the need for emotional support that felt attuned to the complexity of their caregiving roles. In high-stress moments, generic reassurance often fell short, underscoring the importance of deeper personalization. Participants also expressed a desire for AI tools to facilitate meaningful real-world connections—such as recommending peer support groups or strategies for carving out time for self-care. They valued support that acknowledged both their emotional challenges and their social isolation, offering not just empathy but concrete avenues for connection. For example, P8 appreciated that the system did not just validate their loneliness but offered actionable strategies across multiple scenarios, such as taking regular breaks and engaging with caregiving communities:

> "[Carey] literally gave me ways what to do to: manage my feeling of loneliness and it actually gave a whole lot of scenarios I can connect with others. I can schedule regular breaks and join a caregiving community."—P8

This illustrates how effective AI support bridges emotional reassurance with practical guidance, helping caregivers feel both understood and empwered through connections to real-world support networks.

4.2.6 AI chatbots and perceptions of privacy. **Participants expressed complex and contrasting perspectives on privacy in their interactions with Carey, revealing a nuanced tension between perceived comfort and hesitation around disclosing to an AI.** For many participants, Carey, being an AI agent created a reassuring sense of protection. Multiple participants described feeling less concerned about privacy because Carey lacked personal knowledge of them or their care recipients. As P15 described:

> "My perception is that there is a degree of privacy here because Carey doesn't know me. Carey doesn't know my [care-recipient]."—P15

Likewise, several participants expressed preference to disclose sensitive information to an AI versus humans. P7 optimistically commented, "AI, unlike humans cannot steal information," and P4 noted about being more open to an AI rather than a human:

> "I prefer going in depth with AI chatbots because I believe there is privacy."—P4

Similarly, P2 appreciated that Carey *respected* personal boundary by not asking for unsolicited personal details:

> "It doesn't ask anything about my personal life or anything to do with me personally [..] It doesn't have an effect on my personal private life. I am more concerned about people knowing me, my identity, and my questions."—P2

However, the above comfort was not universal. For instance, P15 was comfortable in sharing their own mental health struggles, but expressed caution in discussing about others (e.g., their care-recipient):

> "I don't mind talking about myself and my own mental health, but when it comes to [my care-recipient], I will protect their privacy 100%."—P15

Similarly, P10 noted that they would share sensitive information under a veil of anonymity:

> "I feel comfortable enough to sufficiently describe my situation to Carey without identifying myself."—P10

Some participants expressed a sense of resignation regarding data security in the digital age, with P9 stating, "At this point, I feel like the cat's out of the bag." However, the desire for immediate support sometimes conflicted with privacy concerns, as more personalized crisis assistance would require sharing more detailed personal information. Some participants recognized the need to share more detailed and sensitive information during crises or when seeking behavior-specific guidance. This introduced a dilemma—while privacy was valued, there was also an urgent desire for actionable, tailored help, e.g.,:

> "I'm comfortable sharing sensitive info with Carey to get a more specific answer."—P1

Relatedly, P4 shared that they were comfortable sharing more personal information, but explicitly emphasized the expectation of protecting the privacy of the chat history—drawing comparison with therapist sessions:

> "Yeah, I'm asking if conversations and the interaction with the taskbar is protected and quite private. Like when you are going for therapy, you wouldn't want people outside to hear the things that you say to your therapist. It's a personal thing."—P4

Together, these reflections suggest that privacy in AI-mediated support is not just about data protection—it is about control, context, and conditional trust. Anonymity enabled emotional openness for many, but the limits of trust surfaced when participants encountered moments requiring deeper, more personalized engagement. Moreover, the diversity of participants' views on data privacy underscores the need for greater attention to privacy-sensitive design in future AI systems.

5 Discussion

5.1 Designing Human-Centered AI for AD/ADRD Caregiver Wellbeing

Our work bears implications for designing human-centered AI technologies that support the wellbeing of AD/ADRD caregivers. Grounded in established frameworks such as Pearlin's Stress Process Model [108] and the Caregiver Appraisal Scale [142], we highlight the importance of accounting for the evolving and multifaceted nature of caregiver burden over time. Designing for the complexity of caregiving requires AI tools that are not merely responsive, but relational and clinically attuned—sensitive to the emotional, cognitive, and systemic stressors caregivers face [88, 164]. These include decision fatigue from navigating fragmented care systems, anticipatory grief during cognitive decline, and role captivity—the sense of being trapped in caregiving responsibilities—all of which are central components of caregiver stress trajectories [29, 33, 75]. To be truly supportive, AI tools must engage not only with the logistical content of caregiving but also with the lived psychological toll it imposes.

Table 6. Mapping caregivers' needs and Carey's strengths, gaps, and design recommendations. Specific future explorations where the HCI/design community may have the biggest impact in developing such AI tools are highlighted using **bold-face**.

Caregivers' Needs	Carey's Strengths	Carey's Gaps	Design Recommendations
• Immediate, actionable information • Context-specific guidance	• On-demand access felt practical • Responses were tailored to caregiving scenarios	• Trust and source verifiability concerns • Repetitive or generic responses • Limited information verification and source attribution.	• Enhance trustworthiness through **transparent source citation and expert verification**. • Adapt responses to caregiving context • Reduce redundancy, provide more novel (but safe) insights.
• Private space to vent emotions	• Offered a safe and judgment-free space for candid self-disclosure and self-reflection • Helped reduce stigma around expressing frustration, guilt, and exhaustion • Enabled caregivers to plan difficult decisions	• One-sided interactions • Lack of conversational initiative	• Design for **conversational turn-taking and add proactive follow-up questions** • Support stigma-free emotional expression through emotionally aware prompts. • Balance ethical objectivity with empathy for caregiving dilemmas. • Design tools to facilitate **AI-powered interactive personal journaling that leverages evidence-based pyschoeducation**.
• Emotional support • Feeling understood and supported	• Validated complex emotions • Demonstrated empathy and emotionally attuned responses.	• Support seemed superficial and in isolated interactions • Lack of dynamic feedback • Fell short of human-human supportive interactions	• Model sustained emotional engagement • Support empathetic interaction loops • Design tools to combine and complement AI- and human- driven support. • **Exploring scaling up evidence-based therapies (e.g., CBT, DBT) using chatbots.**
• Crisis management and interventions • Real-time guidance in urgent situations	• 24/7 availability and no wait times in times of need. • Felt emotionally stabilizing.	• No crisis escalation mechanism • Risk of false assurance in emergencies.	• Integrate crisis detection features • Enable **tiered response systems** with clear escalation pathways. • Design tools for **triaging crises and routing to professional interventions**.
• Personalized interactions • Facilitate real-world connections	• Responses felt personalized and well-adapted to queries. • Use of personal tone and language (e.g., first-person pronouns)	• Only surface-level adaptation • Not adapted to complex caregiving situations	• Personalize chatbot interactions based on user's long-term, evolving caregiving needs. • Position AI as a complement to human support rather than a replacement. • Better integrate with **real-world resources and referral mechanisms** to support communities.
• Privacy and data-security assurance • Comfort in anonymous disclosures	• Perceived as non-intrusive. • Did not prompt for unsolicited personal information • Felt safer to share to an AI than a human	• Unclear data handling policies • Hesitation to share identifiable information, especially about care recipients • Tension between desire for personalization and privacy concerns	• Clearly communicate data usage and retention policies • Enable user-controlled data sharing/storage. • Include opt-in and ephemeral data-sharing mechanisms. • Support **pseudonymous** use and boundary-setting features. • Practices to enhance digital and AI literacy and awareness.

Our analysis of caregivers' interactions with Carey revealed that AI chatbots can fulfill certain unmet needs of caregivers, but also has key areas for improvement. For each theme identified in Section 4.2, we map caregiver needs, Carey's strengths and gaps, as well as design recommendations to advance human-centered AI

for AD/ADRD caregivers' mental wellbeing. We summarize this information in Table 6 and describe these recommendations by theme below:

5.1.1 *Transparent and credible information delivery, integrated with reliable sources of information.* Caregivers valued Carey's on-demand access and context-sensitive guidance. However, concerns about information credibility and repetitive responses indicate a need for transparent sourcing, expert validation, and adaptive content generation. For instance, P3's concerns about "dirty data" and "pulling information that's not accurate" highlight a fundamental tension—unlike general mental health chatbots where users may seek emotional validation, AD/ADRD caregivers need evidence-based guidance for complex care decisions that directly impact both their and their loved one's wellbeing.

In emotionally charged decision-making contexts (e.g., medication management, behavioral symptoms, or transitions to institutional care), caregivers may not want approximations or general advice. These moments often coincide with clinical touch-points such as post-diagnosis counseling, care plan reviews, or medication reconciliation visits, where caregivers may feel overwhelmed or under-informed. AI systems like Carey could serve as supplementary supports in these moments by reinforcing clinical guidance, answering follow-up questions, and scaffolding health literacy outside of brief provider interactions.

Therefore, a major design recommendation involves prioritizing traceable credible sources. This could additionally be achieved by integrating direct connections to established mental health and Alzheimer's caregiving resources such as from Alzheimer's Association and credible research findings enabling caregivers to access original sources if needed—as P3 preferred. Additionally, caregivers valued the need for delivering information that is contextually relevant to their situations. Accordingly, future designs can incorporate scoring mechanisms that evaluate both the reliability and relevance of content in relation to the user's query, enabling more effective filtering of responses prior to delivery.

5.1.2 *AI-mediated interactive personal journaling.* Our findings revealed that AI chatbots can serve as a safe space for self-disclosure, helping caregivers express complex emotions without fear of judgment. Participants consistently emphasized the emotional utility of Carey, particularly its capacity to offer nonjudgmental listening and space to "say the hard things." This aligns with evidence that caregivers of people with AD/ADRD experience high rates of depression, anxiety, and complicated grief—particularly when social support is lacking or when emotional processing is suppressed [113]. Supportive journaling, as facilitated by Carey, may offer a low-barrier emotional outlet that complements—but does not replace—structured interventions like caregiver psychoeducation or Cognitive Behavioral Therapy (CBT). Integrating prompts grounded in these clinical frameworks may enhance their relevance and impact [55].

Yet, the one-sided nature of interactions often limited emotional depth and reflection. To better support caregivers' mental wellbeing, AI systems can incorporate emotionally aware prompts, converstional turn-taking, and interactive journaling to foster more supportive and meaningful self-reflection and expressive writing. In particular, interactive personal journaling exemplifies this approach—Kim et al. noted how generative AI can effectively facilitate such technologies [77].

Future technology designs can involve both voice- and text-based tools, drawing on evidence-based frameworks such as CBT [11], Acceptance and Commitment Therapy (ACT) [63], and Dialectical Behavior Therapy (DBT) to support stress management, emotional regulation, and resilience building. These AI systems can be designed to recognize themes such as burnout, isolation, and compassion fatigue, and offer personalized strategies such as CBT-based thought reframing, ACT-oriented values journaling, and DBT-informed distress tolerance exercises. Importantly, this journaling feature goes beyond simple documentation. Through AI-assisted summaries and reflection prompts, it can help caregivers process their experiences in deeper, more constructive ways—transforming emotional expression into opportunities for therapeutic insight and coping [23].

5.1.3 Deepen emotional engagement beyond surface-level empathy. Building on established therapeutic mechanisms listed above, emotional supoprt in AI tools can be improved by incorporating sustained, context-aware engagement rather than relying on fragmented, surface-level empathy. While caregivers appreciated Carey's emotionally supportive tone, many found the interactions to be fragmented or overly generic. Emotional validation without continuity can fall short in addressing long-term psychological needs of caregivers navigating chronic stress and social isolation.

Designing for deeper emotional connection requires dynamic empathy loops—where the AI can reference prior interactions, recognize emotional patterns over time, and respond with consistency and sensitivity. For instance, P14 noted that they had to explicitly instruct the system to "talk like a human," suggesting the need for algorithms capable of proactively detecting distress through psycholinguistic cues and adapting tone or strategy accordingly. Future tools can implement memory features—combined with user-controlled consent—to reduce conversational management burden, and make the interactions feel more relational and human-like. However, our findings also emphasized that *AI should complement—not replace—human support*. While some, like P1, valued the emotional safety of sharing with a nonjudgmental AI, others like P15 cautioned against over-reliance. Therefore, technology designers must be attuned to this tension, when building tools for caregivers' wellbeing self-management.

Our scenario-based study design revealed future technologies can involve scenario-based guidance that helps caregivers navigate through challenging decisions, such as transitioning to professional care or managing difficult behavioral symptoms. By integrating case-based reasoning with healthcare ethical principles, AI could provide more sophisticated support for the moral dilemmas caregivers frequently described. This approach would preserve psychological safety while helping caregivers navigate moral dilemmas with contextualized, nonjudgmental support. Notably, many of Carey's responses organically resembled micro-skills from established psychotherapeutic models. Without being explicitly clinical, Carey's responses incorporated reflective listening, non-judgmental affirmation, and strengths-based reframing—principles consistent with CBT [11], ACT [63], and other evidence-based frameworks. This unintentional therapeutic alignment suggests that generative AI systems may resonate with users' emotional needs even in non-clinical contexts. However, this also raises critical design questions—How can we harness the benefits of therapeutic resonance while avoiding misrepresentation of AI as a mental health provider? Balancing emotional attunement with clear boundaries around the AI's role is essential. Importantly, our findings critically highlighted the need of human connection to help the support feel authentic. Overall, tranparent disclaimers, consent-driven personalization, and integration with human supoprt networks in technology design, can help ensure that AI complements—not substitutes—the complex ecosystem of caregiving.

5.1.4 Prepare for crises with tiered intervention mechanisms. Caregivers appreciated the 24/7 availability of AI support, particularly during unpredictable situations. This constant accessibility filled a critical gap when human support was unavailable. However, the absence of escalation pathways raised concerns about false reassurance and ethical risk—as P9 shared, while immediate answers were appreciated, the system lacked contextual awareness during emergencies. In particular, caregivers often operate in crisis-adjacent conditions—managing aggression, elopement risk, sundowning, or other behavioral escalations [23]. When left unsupported, such moments can result in clinical consequences such as emergency room visits due to caregiver burnout, psychiatric decompensation, or missed signs of elder abuse or neglect. AI systems in this space must therefore be designed not only to react to crises but to also proactively anticipate them.

Therefore, future design of such tools needs to distinguish between routine queries and crisis situations in real-time. Additionally, tiered mechanisms and referral protocols that guide users toward appropriate human interventions would be necessary in such sensitive use cases. Natural language classifiers could flag distress signals and trigger supportive actions, while location-aware features—with user consent—can help connect caregivers to nearby emergency resources. These interventions must be guided by transparent and ethical data practices. Although some participants valued the option to share anonymously, others hesitated without clarity on

data use. Giving caregivers control over their data—what is shared and how it is handled—is essential. Integrating proactive crisis detection and responsible escalation pathways can ensure AI tools provide meaningful support without exceeding their clinical scope.

5.1.5 Personalize for the long-term caregiving journey. Caregiving is not a static task, but rather an evolving process marked by shifting emotional, informational, and logistical demands. Although participants appreciated personalization in Carey, they often described it as flat and moment-specific—failing to reflect the progression of their caregiving responsibilities or emotional states over time. To remain relevant and supportive over time, AI tools need to go beyond short-term personalization and also adapt to the *caregiving journey.* Such tools can incorporate mechanisms for persistent, consent-driven memory that enables the AI to recall prior conversations, track ongoing concerns, and tailor support as caregivers' needs change. This can reduce repetitive explanation, build emotional rapport, and offer contextually relevant guidance reflective of a user's caregiving trajectory. AI tools can be attuned to the temporal dynamics of caregiving—early, active, and late-stage care—adapting tone, resources, and goals accordingly. For example, early-phase caregivers can benefit from basic education and emotional validation, while long-term caregivers may require burnout mitigation strategies or grief preparation.

Moreover, personalization should not happen in isolation and must extend beyond the AI interface. These tools can improve utility by integrating with existing healthcare infrastructures—such as patient portals, caregiver support networks, or care coordination tools used in memory clinics, home health, or hospice settings. For example, tracking emotional burden over time could trigger alerts to case managers, while content modules could adapt to the stage of dementia or care plan milestones.

Yet, a recurring theme was caregiver ambivalence about Carey's role. This mirrors broader patterns seen in digital mental health, where users form prosocial bonds with AI companions (e.g., Woebot, Replika) [46, 106]—relationships that offer comfort but also risk emotional dependency, especially among those experiencing isolation or anticipatory grief. For distressed caregivers, this raises critical design and clinical questions—*How can AI systems offer emotional resonance without undermining connections to real-world support?*

To balance this depth of personalization with user trust, systems can implement tiered data-sharing models. These would give caregivers control over what information is shared, how much, with whom, and under what conditions—particularly when personal or clinical data is involved. For instance, lightweight personalization might rely on general patterns, while more detailed recommendations (e.g., crisis planning or localized resources) can require explicit consent for deeper data sharing. This tiered approach helps navigate the privacy-personalization tradeoff in sensitive caregiving contexts. Overall, designing for the long-term caregiving journey means building systems that are adaptive, ethically aware, and deeply connected to broader human support ecosystems.

5.1.6 Designing with more flexible privacy features. To support the diverse privacy expectations of caregivers, especially in emotionally charged and high-stakes caregiving contexts, AI chatbots must go beyond static data protection. Caregivers in our study often appreciated the sense of anonymity, yet this comfort was conditional—challenged when disclosures involved others or when situations demanded more personalized assistance. With this in mind, designing flexible privacy features such as opt-in data sharing and ephemeral memory can help balance greater personalization without a compromise of loss of privacy. Drawing on the success of online communities [7, 44, 73, 110, 174], AI chatbots can facilitate pseudonymous interactions and boundary-setting tools (e.g., disclosure warnings, redaction options) to help reinforce a sense of control and safety.

Importantly, because both individuals with AD/ADRD and their caregivers often belong to older age groups, many may have limited familiarity with AI and digital technologies. As such, privacy features must not only exist—they must also be easily understandable and accessible. Clear, jargon-free explanations of what data is stored, how it is used, and when it is discarded should be embedded within the interface. Additionally, integrating lightweight AI literacy supports—such as inline prompts, FAQ-style guidance, or optional onboarding tutorials—can empower users to make informed choices. In fact, designing for conditional trust requires not just technical

safeguards, but an empathetic, transparent, and accessible interface tailored to a population that may be less digitally fluent yet highly vulnerable.

5.2 Theoretical and Clinical Implications for Caregiver-Focused Digital Mental Health

Our research builds on and contributes to theoretical understandings within HCI, digital mental health, and caregiving research by foregrounding the affective and relational dimensions of AI-mediated support in AD/ADRD caregiving contexts. Extending prior work in HCI which explored task-oriented caregiving support (e.g., scheduling, remote monitoring [8, 160]), our study reveals how AI systems can also act as *relational agents*—mediating emotional expression, reflection, and companionship. This reinforces emerging theories that position AI not merely as a tool but as an individual's "companion" to vent out and navigate through decision-making [51, 138].

Our work also supports the conceptual shift toward emotionally attuned technologies that center emotional labor as integral to user experience and design. Rather than treating emotions as secondary to caregiving logistics, our study reveals how technologies like Carey can scaffold caregivers' emotional processing around guilt, grief, isolation, and burnout, as similarly noted in prior HCI and chatbot literature [138, 159]. This aligns with broader efforts to reconceptualize caregiving as a dynamic, socially embedded, and emotionally demanding experience.

This work contributes to theoretical models of epistemic trust and risk perception in health communication [72, 79]. Unlike conventional users, AD/ADRD caregivers often interpret chatbot responses through the lens of high-stakes responsibility for another person's health. Their desire for accurate, evidence-backed, and context-aware responses highlights the need to theorize AI credibility and trustworthiness as situational, emotional, and ethical problems—particularly in domains like caregiving, where inaccurate and misleading information may carry negative consequences for both the caregiver and the care-recipient [12, 21, 67]. These insights suggest that emotional and informational trust in a technology are deeply intertwined in caregiving contexts, especially when emotional vulnerability and clinical uncertainty intersect.

From a clinical science perspective, our findings raise important considerations for how AI-mediated journaling and conversational agents might be thoughtfully integrated into mental health care ecosystems for caregivers. Although Carey was not designed to serve as a therapeutic tool, participants frequently reported emotional relief, catharsis, and a sense of being heard, which are hallmarks of early engagement in emotional processing. This suggests that AI tools may offer low-barrier, adjunctive supports to structured interventions like caregiver CBT, psychoeducation, or grief counseling, especially in under-resourced settings [23, 60, 151].

These dynamics can be interpreted through the Stress Process Model [108] and the Caregiver Appraisal Model [82]. Both of these models emphasize how caregivers' subjective appraisals—such as perceived role captivity, relational strain, and self-efficacy—shape emotional outcomes. In this light, an AI tool such as Carey may help surface and regulate these appraisals in real-time, offering a digital outlet for emotional self-expression that supports coping and adaptation. Furthermore, Carey's journaling features could serve as early warning systems by identifying patterns associated with distress, grief severity, or burnout. When integrated into clinician dashboards, these features could facilitate timely referrals or adjustments in care planning—though doing so responsibly would require robust ethical safeguards around data use and consent.

Finally, our findings invite interdisciplinary dialogue about the role of AI in emotional meaning-making. Rather than merely acting as information conduits, AI tools like Carey may function as *co-constructors* of emotional narratives. This reframing encourages collaboration across clinical psychology, HCI, and implementation science to better align emerging technologies with standards of ethical and effective care. Taken together, our study contributes to a more nuanced theoretical account of how AI can support not only logistical but also emotional and relational aspects of caregiving. It underscores the value of conceptualizing AI as a mediator of affective experience and inspires further interdisciplinary theorizing across HCI, digital mental health, clinical psychology, and aging studies to better understand the evolving role of relational technologies in caregiver wellbeing.

5.3 Ethical Implications

As AI becomes more integrated into caregiving support, our study surfaces several critical ethical implications. Caregivers expressed concerns about data security and privacy, particularly given their desire for personalized support—creating a fundamental tension where increased personalization requires sharing more sensitive personal information, aligning with prior work on personalization-privacy tradeoff [10, 90, 168, 172]. We also caution against interpreting participants' comfort with Carey as a blanket endorsement of AI technologies. Their trust was shaped within a researcher-guided setting, where perceived risks were low and interactions were somewhat bounded. In real-world or commercial applications—technologies may request more personal information for personalization or even for basic functionalities—additional privacy concerns may arise. These contexts demand greater transparency, user consent, and ethical data practices beyond what our study captured [35].

The use of generative AI in caregiving tools also raises concerns about potential bias, reliability, and harm. AI systems are likely to reflect or amplify existing biases [12, 16], and may not fully comprehend the nuances of clinical conditions or caregiving contexts, leading to inappropriate recommendations that could harm both the caregivers and care-recipients. These harms must be weighed against the risks of therapeutic drift—where users begin to treat emotionally supportive AI as a substitute for clinical care. To prevent and mitigate these harms, AI should include clear disclaimers, escalation pathways, and integration with referral networks to ensure they are positioned as complementary rather than curative supports—drawing on the body of work on AI ethics [5, 40, 116]. Effective oversight mechanisms should include clinical review boards, caregiver feedback systems, and regular assessment of user outcomes to ensure AI tools maintain appropriate therapeutic boundaries. Maintaining this distinction is crucial to safeguarding caregiver safety while maximizing the technology's benefits.

Additionally, there is a risk that AI and technological solutions may widen existing digital inequalities between those who have access and those who do not [121], necessitating efforts to ensure that technologies are inclusive and accessible for caregiving. Our study also highlights the ethical dilemma of AI over-reliance—while AI can supplement caregiving challenges and provide valuable emotional support, it cannot replace the empathy and nuanced understanding that human interaction offers. Therefore, striking a balance between AI automation and human support is crucial to maintaining the dignity and emotional wellbeing of both caregivers and care recipients, ensuring that AI serves as a complement to, rather than the replacement for, human-centered care.

5.4 Limitations and Future Directions

Our work has limitations, which also suggest interesting future directions. First, the caregiver participants in our study are not a representative sample. However, our primary goal is not to obtain generalizable findings, but to motivate the design and development of AI tools centered around caregivers' needs and expectations. Then, our study design consisted of scenario-driven interactions with Carey—a technology probe designed to elicit user perceptions rather than serve as a high-fidelity prototype or be evaluated for effectiveness. As such, we did not evaluate Carey's long-term usability or sustained impact. Our findings inspire the design of future tools, as well as future research on longitudinal deployment studies to assess the feasibility, benefits, and user experience of these AI chatbots in long-term settings. The design of such deployments should also employ and evaluate natural interaction patterns and the integration of these tools into caregivers' daily routines. Along similar lines, our work did not measure changes in caregiver burden, psychological distress, or other clinical outcomes before and after interaction with the chatbot. Future research should incorporate validated outcome measures (e.g., PHQ-9 for depression [101], Zarit Burden Interview [162] for caregiver burden) to rigorously evaluate the mental health benefits of AI-based support. Additionally, future research can adopt multi-stakeholder approaches that involve not only caregivers, but also clinicians, community health workers, family members, and local support networks. Such inclusive studies can surface diverse perspectives on caregiving needs, assess implementation barriers, and promote the design of AI tools that are contextually appropriate, clinically relevant, and socially acceptable

across different caregiving ecosystems. Finally, while our findings highlight the potential of conversational AI to support caregiver wellbeing, current limitations underscore the need for more integrated approaches. Future feasibility trials should explore pairing AI journaling or check-in tools with clinician dashboards or caregiver support staff. Such hybrid systems may enable real-time responsiveness and continuity of care—key elements in evaluating both the acceptability and clinical effectiveness of these tools in practice.

6 Conclusion

In this work, we explored how family caregivers of individuals with Alzheimer's Disease and Related Dementias (AD/ADRD) engaged with Carey—a GPT-4o–based AI chatbot—designed to provide mental health support to caregivers. Through scenario-driven interactions and semi-structured interviews with 16 caregivers, we examined their needs, expectations, and perceptions of AI-based support. Our reflexive thematic analysis revealed five core areas of caregiver expectations—*on-demand information access, emotional support, safe space for disclosure, crisis management*, and *personalization*—each accompanied by nuanced tensions between perceived benefits and concerns. While caregivers appreciated Carey's accessibility, nonjudgmental tone, and responsiveness, they also expressed concerns around trust, initiative, emotional over-reliance, and the limits of personalization. We contributed a systemic understanding of how caregivers interpret AI support, alongside a mapping of their needs, current chatbot strengths, unmet gaps, and design recommendations. Some of the major design implications involve providing transparent source citation, conversational turn-taking, interactive personal journaling, tiered response systems for crisis support, alongside balancing personalization with privacy-sensitive features. Our findings underscore the importance of designing caregiver-centered AI systems that are context-sensitive, emotionally attuned, and capable of evolving with users' changing needs. This work highlights the potential and limitations of generative AI-driven chatbots in caregiver mental health support and calls for future efforts that center relational, trustworthy, and ethically grounded design.

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