Audio Autonomy: An Ambient, Interactive Audio Companion System for Dementia Patients and Caregivers

Renu Bora  
School of Information  
UC Berkeley  
Berkeley, CA 94720, USA  
renubora@ischool.berkeley.edu

John Chuang  
School of Information  
UC Berkeley  
Berkeley, CA 94720, USA  
chuang@ischool.berkeley.edu

Andrew McConachie  
School of Information  
UC Berkeley  
Berkeley, CA 94720, USA  
andrewm@ischool.berkeley.edu

Benjamin Shapiro  
Geffen School of Medicine  
UC Los Angeles  
Los Angeles, CA 90095, USA  
shapiro@ucla.edu

Abstract  
Audio Autonomy is an audio companion system designed for both dementia patients and their caregivers. A broad range of audio experiences can help with the primary challenges of independent living, and an integrated technology can help the caregiver manage these experiences. Interactive Voice Response (IVR) technologies, traditionally used in call centers, can be used to build the system to manage voice, music and other audio content.

Author Keywords  
ambient assisted living; activities of daily living; Alzheimer’s; VoiceXML; fraud training; healthcare companion

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H.5.1 [Information interfaces and presentation (e.g., HCI)]: Audio input/output; H.5.2 [Information interfaces and presentation (e.g., HCI)]: voice I/O

Introduction  
As the world’s population grows and ages, the number of global dementia cases is on track to triple by the year 2050. Current estimates predict 35% of the adult population 85 years and older will meet the clinical criteria for dementia, impacting societies and economies worldwide [1]. Prevention, treatment, and management of every kind will be needed and relief of caregiver burden will be essential [2].
Dementia patients have quality-of-life and clinical needs that require effective management. Both sets of needs typically increase over time, often overwhelming caregivers and taxing medical care systems. Yet quality of life is routinely unmet and highly dependent on the individual’s environment [3]. Caregivers also have support needs, since caring for individuals with dementia can be exhausting, leading to high rates of caregiver burnout and depression [4].

Activities of daily living (ADLs) are basic skills fundamental to functioning in everyday life, such as eating, bathing, dressing, and toileting. ADLs are central for independent living, which is vital in fostering well-being and quality-of-life among older adults. This is particularly true for demented individuals, where maintaining independent living for as long as possible decreases morbidity while also limiting social, health system, and caregiver burdens [5].

Audio Autonomy is an ambient, interactive audio system designed for dementia patients and their caregivers. We make three contributions in this work. First, we perform needs assessment for both the dementia patients and their caregivers. Second, we design Audio Autonomy to address the assessed needs, particularly support for ADL, fraud protection, safety, and caregiver relief. Third, we demonstrate the design feasibility by implementing an open-source, fully-functional prototype system using industry-standard VoiceXML and Interactive Voice Response technologies.

At its heart, Audio Autonomy is designed to augment comfort, enhance safety, increase life-engagement, and support and maintain activities of daily living in dementia patients. It represents one component of a more advanced personal healthcare companion utilizing gerontechnologies of Ambient Assisted Living (AAL). It has the dual purpose of enhancing and maintaining independence of dementia patients while diminishing caregiver burden and burnout.

The audio system goes in the home. It resembles the ship’s computer on Star Trek, or HAL 9000 of 2001 Space Odyssey, because its main interface is audio and the identity of its primary voice remains distinctly non-human. From the patient’s perspective, it listens, and can talk or play audio content. It is an ‘audio assistant’ that can respond to commands, music requests, and questions. It can play scheduled audio content, such as music, voice reminders, and interactive programs like fraud simulation training exercises. Certain utterances may use secondary, pre-recorded human voices of loved ones. It can also serve as a supplementary emergency response service.

Similar, more complex voice response prototype systems for smart homes have been built and tested in a wide array of user and technical assessments [6], [7]. Our system has a different emphasis in that it is tailored for specific dementia challenges, in a social context where a caregiver is truly another user, with the need to continually manage the delegation of support features, with increasing responsibility for the patient relationship itself.

The system is managed by the caregiver using a web browser interface, and helps the caregiver design care activities and experiences for the patient. The caregiver uses a scheduling calendar to curate the activities, including music and question-answer responses. It can relieve the caregiver’s burden of answering repetitive and routine questions, foster generative thinking and activities by the patient, and provide information and insights to the caregiver regarding patient interactions with the system.

Needs Assessment
The three pillars of dementia care that foster independent living are: support for activities of daily living, fraud protection, and safety. These three elements are fundamental to
reducing intensive caregiving and keeping dementia patients out of full-time supervised care settings and are three primary goals of Audio Autonomy.

Dementia patients regularly struggle with ADLs and have particular difficulty with activity transitions such as changing or bathing. These moments can precipitate anxiety, agitation, and even anger. Cognitively intact individuals have learned mechanisms or heuristics to get over motivational hurdles for things they don’t always want to do. Dementia patients often lose these mental and behavioral techniques due to impairments in several cognitive systems. Caregivers therefore need to create comforting structures to anticipate and facilitate activity transitions for the patients.

Voice over IP, robocalling, and international calling have facilitated a rise in phone scams. Over 86.2 million calls per month in the US are phone scams [8]. The elderly are highly targeted for telemarketing fraud and those with dementia are particularly susceptible. A typical trick is to refer to some event or meeting that never took place, hoping the victim will be too embarrassed they do not remember it, thereby baiting obedience to requests. Dementia sufferers are still capable of learning to recognize fraudulent calls and maintain privacy over the phone, so there is an opportunity to assist them with anti-fraud training [9].

American seniors are 60% more likely to experience a consumer product-related injury that results in an emergency room visit than persons between the ages of 25-64 [10]. Dementia patients often present hazards by failing to attend to basic safety, such as forgetting to turn off a stove or to close and lock a primary entryway door.

Audio autonomy also attempts to address several primary causes of caregiver stress — behavioral symptoms of dementia, which include agitation and disruptive behavior, and difficulty with transitions [4], [5]. Dementia patients experience long-term, on-going decline of their cognitive functions and individual impairments and disruptive behavior patterns can vary widely. Research indicates that music can uniquely diminish agitation and disruptive behavior and improve the quality of life for dementia patients, especially in regards to improving mood, and promoting calmness and engagement [11], [12]. This may be due to the preservation of music as a form of communication among persons with dementia [13]. Audio Autonomy has been designed to provide salutary effects of music for individuals with dementia as well as to adapt to their changing needs over time.

Furthermore, as an AAL system Audio Autonomy employs multiple modalities and channels to increase redundancy and breadth in conveying information, given that particular impairments typically increase and accumulate.

Caregivers are equally important as a user group for AAL systems since they must orchestrate the daily schedules of the patients. As patients lose their cognitive functions over time, caregivers have to assume more decision-making, provide intensive supervision, and manage physical and psychological demands. The continuous emotional and psychological stress of managing such demands can create caregiver burnout. For example, a patient may ask “What time is dinner?” repeatedly within a few minutes. The burden of responding to repeated questions may frustrate the caregiver, cause them to communicate annoyance, and ultimately agitate the patient. Having an automated tool answer these repetitive questions can be very helpful.

Through expert interviews, we learned the importance of initiating early dialogue between caregivers and patients. Sometimes a tool’s primary purpose is to act as a conversation starter between two family members who are grappling with the newfound reality of dementia, or to prepare for situ-
ations in which a parent loses the ability to make decisions for themselves. In advanced stages, families can become desperate to have any connection or shared experience at all, and music can provide that sharing [14], [15].

Even though memory declines, patients retain the ability to learn many kinds of things, and be trained, especially in relatively simple motor tasks. An AAL system can exploit a patient's intact ability to learn, even if diminishing or rudimentary [16]. However, it is important not to design learning activities with unrealistic goals that would frustrate the patient or the caregiver. A demoralizing sense of failure or even safety risks could result.

Family members may consider the sharing of stories and personal memories via audio content to be a compelling use case for the system. However, great care must be exercised in the design of these activities. As memory declines, reminiscence activities can create a sense of failure and lead patients to shut down their communication [17]. Instead of inviting participation or pressuring patients to remember beyond their abilities, it may be better to offer alternative experiences, such as singing along, or other forms of creative participation that give patients confidence in their ability to communicate and make meaning [18].

System Architecture
The Audio Autonomy system comprises three parts: a web interface, an audio interface, and a database (Figure 1). The web interface is used by the caregivers, while the audio interface is used by the patients. While the web interface reads and writes to the database, the audio interface only reads from the database.

The concept of an event is important for the Audio Autonomy system. Caregivers configure two types of events for patients, listener events and scheduled events.

Listener events are active throughout the day, and are activated by a patient's voice. The primary example of a listener event is the Question and Response event. Via the web interface a caregiver enters both the question text and the response text. At any time during the day, when the patient says the question text, the audio interface will answer with the response text and/or execute the response action. For example, a caregiver might enter the question “What time is dinner?”, and the response “Dinner is at 6pm.”

The listener event can also support a response action instead of, or in addition to, a response text. For example, the caregiver can set up a listener event with the question text “Play music”, and select the response music. The listener event can also be used to provide a supplementary emergency response service. For example, the event can be configured with a question text of “Help Help!”, a response text “Okay, help is on the way!”, and one or more response actions such as dialing for emergency services, as well as dialing the phone of the caregiver.

The second event type is the scheduled event. These events fire at the times specified by the caregiver. There are many possible examples of scheduled events. In our prototype, we implemented three classes of scheduled events: scheduled reminders (e.g., medication, daily tasks, home safety), playing of a patient's favorite song, and activating a fraud prevention training exercise. Other possibilities include: time announcements, playing a curated therapeutic music playlist, and scheduled phone calls to family or friends.

Prototype Implementation
We have built a functional prototype of the system, and software source code is available at: https://github.com/renubora/audio-autonomy under the GPLv2 License.

The web interface allows the caregiver to schedule events
for their patient using a grid-based calendar (Figure 2). Caregivers can drag, drop, update, and delete various events and listeners, as well as enter the verbal responses. Additional menu items for new event classes can easily be added to the web interface with HTML code, and menu items for more complex interactions or events can be added with some additional PHP and VoiceXML code. Voxeo’s voice platform is used to process the VoiceXML logic [19].

**Future Work**

There are a number of promising future directions. First, pilot testing and clinical trials could verify the value for patient and caregiver experiences. These may include a placebo-controlled assessment of therapeutic music to reduce agitation and assist behavioral transitions, assessment of different voice reminder schemes, assessment of impact on caregiver distress, needs assessment and qualitative survey of users’ experience with the system, and test analytics and caregiver feedback to modulate program function.

Second, several important design dimensions can be tested. There are many possible voice types spoken by the system. The utterances can be pre-recorded or dynamically generated by text-to-speech algorithms. Our current system presents a primary or ‘master’ identity voice that is distinctly non-human, but uses the recorded voice of a loved one and caregiver for reminders. Patients may be more likely to listen to someone they have a relationship with, and that may even strengthen the familiarity of the relationship itself [20].

Audio Autonomy may be integrated with an interactive TV health monitoring system such as [21]. Their system is clinical in emphasis, as per the Distributed Diagnosis and Home Healthcare framework (D2H2). Dementia patients are typically already highly engaged and familiar with TVs.

As robot companions develop affective capabilities, emotional bonds between patient and technology may form which alienate the caregiver and negatively impact the relationship [22]. Audio Autonomy may take a ‘computer assistant’ approach to interacting with patients where it explicitly identifies itself. For reassurance, it could say “I am your Audio Assistant. I am on and listening.” The system may regularly engage the patient, by stating the time every hour, or engaging in reminiscence exercises or games. The regular, repetitive audio prompts could help orient dementia patients. It may also strengthen the relationship between caregiver and patient, perhaps with creative expression exercises such as sing-a-longs [23], [24].

**Conclusion**

The convergence of Internet of Things (IoT) and Ambient Assisted Living (AAL) technologies can bring about new opportunities in supporting dementia patients and caregivers. Intelligent personal assistants like Apple’s Siri and Amazon’s Echo have already shown that audio-based interfaces backed by cloud-based intelligence can offer tremendous utility to users in a variety of real-world contexts. Personal robots like Jibo, Pepper, and PARO seek to form even more intimate relationships with their human owners through visual, tactile, social, and emotional connections.

The design of Audio Autonomy points to a larger vision of leveraging these or similar consumer-oriented platforms to deliver support to patients and caregivers. Specialized modules implementing the functionalities described in this paper could extend the platform’s capabilities.

Through this study, we have derived user needs, as well as design principles and lessons, such as the importance of designing for both patients and caregivers; and the power and versatility of audio in dementia care. These insights
can inform the design of future systems, regardless of whether we call them virtual assistants, therapeutic robots, or healthcare companions.

References