Perspective on everyday technologies for Alzheimer’s care: Research findings, directions, and challenges

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Abstract

The Everyday Technologies for Alzheimer’s Care (ETAC) initiative was launched by the Alzheimer’s Association and Intel Corporation in 2003 to identify and fund promising research in the use of technology—especially information and communication technologies (ICTs)—for monitoring, diagnosing, and treating Alzheimer’s disease (AD). Agilent Technologies joined the initiative in 2005. In October 2006, representatives of the three partners, together with ETAC award grantees, met to review the most recent research, and discuss how current and developing technologies can address growing needs in Alzheimer’s care.

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1. Introduction

By this century’s midpoint, global demographic changes will double or even triple the number of people over age 65 in many countries, putting healthcare systems and entire economies at risk as chronic conditions and age-related illness and injuries become even more pervasive. A fundamental question challenges all of us: how will we deliver quality care and quality of life to today’s and tomorrow’s aging population while reducing healthcare costs that already threaten to swamp national economies? Cross-discipline research centers that bring together computer scientists, engineers, gerontologists, social scientists, medical experts, and clinicians are emerging to explore how information and communication technologies (ICTs) might help answer this pressing social question. Small-scale, evidence-based pilots of ICTs that will promote a shift from hospital-focused or “mainframe healthcare” paradigms to home-based or “personal health” paradigms [1] are cropping up in many parts of the world, with many of them focused on Alzheimer’s disease (AD).

It is not surprising that the majority of these independent living technology centers focus on AD. Alzheimer’s disease is a debilitating and slowly progressing neurodegenerative disease that presents unique challenges to caregivers. Because many people suffering from AD remain physically able-bodied while gradually losing memory and cognitive ability, monitoring their behavior and activity becomes crucially important. Caregivers face overwhelming obstacles in assisting their loved ones with activities of daily living, in an effort to sustain a high quality of life for them as their memory declines. Simultaneously, caregivers must deal with their own burnout and declining health resulting from the extreme demands of caregiving. Professional caregivers, clinicians, and researchers face challenges in diagnosing and treating the disease. Often, people suffering from AD and their families avoid early diagnosis and intervention out of fear, stigma, and denial. Additionally, traditional diagnostics fail to provide much help in early diagnosis or differentiation.

Modern computing, consumer electronics, and telecommunications technologies have the potential to improve the quality of life for both AD patients and their caregivers. They also hold the promise of creating innovative approaches for detecting the disease and its progression. The Everyday Technologies for Alzheimer’s Care (ETAC) initiative was launched in 2003 to bring visibility to early, pioneering research efforts in this

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domain, and to accelerate multidisciplinary research approaches to investigating the potential of ICTs in four specific areas: disease diagnosis, tracking disease progression, disease treatment, and caregiver assistance. The portfolio of ETAC-funded grants thus far shows great promise in these four interrelated domains.

2. Technologies for disease diagnosis

Many AD patients consider the current neuropsychological tests very onerous, especially as their cognitive function declines. These tests also poorly distinguish different types of dementia. The ICTs offer promising new ways to diagnose and differentiate AD.

Virtual reality (VR) technology can be used to measure visuospatial ability, and may be both less burdensome and more probeable than traditional two-dimensional (2D) pen and pencil tests. Virtual reality can be used in two classic paradigms that assess visual-spatial memory. First, the classic Vandenberg shape-comparison test, in which one mentally rotates images of test shapes to determine which one matches a standard shape, can be performed through VR technology which allows the participant to “see” the objects in three dimensions (3D) and physically manipulate them. Second, the Morris water maze, a commonly used test of spatial learning and memory for animal models of dementia, can also be performed in 3D space (Fig. 1) [2,3]. These tests can be performed with relatively inexpensive VR machines that use special eyeglasses called shutter glasses that rapidly and alternately occlude the eyes. Virtual reality tests, in both 2D and 3D, are currently under evaluation to see if they can detect AD symptoms earlier than traditional pencil and paper tests, and if they can predict how well persons with AD can orient themselves in their environment.

Similarly, music technologies may offer valuable diagnostic information because they probe neuropsychological markers for the episodic domains shown to be sensitive to early detection of cognitive decline [4], while offering unique opportunities for community-wide use. Music was shown to arouse individuals in late-stage AD who were otherwise not very responsive [5]. Hyperscore, a computer application that allows people with no musical education to compose their own music, has spurred people suffering from AD to overcome physical limitations and start using fine motor control to interact with the interface [6]. New music tools are being developed to move neuropsychological testing into the auditory domain, where melodies are being used to probe associative memory and thereby help distinguish early AD from other diseases such as semantic dementia or depression.

3. Technologies for tracking disease progression

Wireless audiovisual networks and pocket personal computer (PC) technology can be used both to monitor people’s activity over time, and to look for behavioral changes that might be indicative of dementia or show progression of disease. These monitoring systems can be combined with simple magnetic switches on appliances and pressure pad switches on furniture to get a picture of the types of activity that people engage in during their daily routines. Such systems offer many advantages to people suffering from the disease and to caregivers. When those affected by AD are living alone, the systems can provide caregivers and family members with the peace of mind that comes from knowing there is a system in place to monitor their loved one [7]. In an institutional or nursing-home setting, these systems can also provide valuable backup, since they operate 24 hours a day, 7 days a week. In nursing homes, where professional caregivers are often overworked or may be unfamiliar with the medical history of their charges, monitoring systems have the potential to identify anomalous behavior that might otherwise be missed. Families and facilities will have the option of choosing monitoring technologies that vary along a continuum of intrusiveness. For example, once installed and activated, in-home sensors will monitor movement, room use, and device use. This tends to be intrusive, although the opportunity to turn off the sensors may be available. Data entry devices such as the PocketPC Buddy system will only accumulate and transmit information that a caregiver has entered, thus falling on the noninvasive end of the continuum (Fig. 2) [8].

Feasibility studies indicate that monitoring systems are very beneficial. For example, in a small pilot trial conducted on eight adults over 10 days in a nursing home, video camera technology found three episodes of aggressive behavior that had been missed by staff members, and six attempts to wander outside the building that had gone unnoticed. In the first in-home usability test of the Pocket-Buddy system, one caregiver’s responses identified him as extremely stressed, resulting in the recruitment of additional support [9].

A substantial amount of information may be gleaned from these systems. Basic individual welfare can be ascertained. Medication status can determine if persons being monitored are taking their prescription medications at the appropriate times and correct dosages. The system can potentially recognize a problem indicative of dementia, e.g., repeatedly opening and closing a refrigerator door, or some other activity that would not be expected of cognitively normal individuals. Disease monitoring could also warn if behavior is indicative of disease progression. For example, more frequent aggressive symptoms may signal a significant change in health status. This type of monitoring can be fine-tuned to both gradual and dramatic behavioral changes. These systems can be used to detect household maintenance such as running faucets and showers, to detect blocked or overflowing toilets, and to monitor household appliances. Systems and technologies have the potential to detect behaviors and events that warn of global safety issues and
dangerous risks. For example, doors left open, backed-up toilets, or stove burners left operating may all pose a significant risk. Actual reports of falls, wandering, and other behaviors through interactive systems provide similar safety alarms.

However, potential problems exist with these systems. One of the major difficulties with this type of technology is mapping, i.e., it can be difficult to pinpoint the precise location of the participant. With video-based systems, this can be overcome by using multiple cameras to build a 3D picture of the living space. With radiofrequency-based systems, which are not very accurate at measuring distances, one can focus on the shape of the trajectory of participants in their environment rather than on their exact location. This allows the identification of frequently occupied locations within the “trajectory shape,” which can then be calibrated to exact locations by comparing reported activity (e.g., watching television, sleeping, or eating in the kitchen) with the position of a participant in the trajectory map at that time.

Several other technical difficulties with electronic monitoring exist, including signal interference, technology incompatibility, and data-review limitations. Signal interference from a variety of household electronics and radiofrequency transmitters can be troublesome for monitoring systems. Appliances such as microwaves, household heating and cooling sensors, wireless phones, and wireless computer networks cause problems and can result in false alarms. This problem is likely to become worse as more appliances and applications become wireless. For radiofrequency-based systems, the selection of a frequency band that is interference-free is important. In the case of systems that rely on off-the-shelf software and hardware, updates from manufacturers can often be detrimental because they may introduce incompatibilities or new interference patterns. Dedicated systems such as the pocket PC-based PocketBuddy use custom-written software with automatic updating [9]. With video monitoring systems, the amount of data collected can be too cumbersome for manual review. Software-based reviews will need to be developed that can handle trillions of frames of video per day. Likewise, systems need careful adjustment to reduce the number of false positives. With video-based surveillance systems, privacy is of primary concern [10]. A possible future solution, allowing monitoring systems to maintain an individual’s privacy, is to monitor infrared wavelengths only.

4. Technologies for treatment

People with AD may benefit from modern technologies in many ways, from multimedia to help with identity retention, and to interactive body and mind exercises that can help with cognitive rehabilitation.

4.1. Multimedia

Interactive websites that offer online support groups are under development to help families, caregivers, and people with neurodegenerative diseases. These websites provide educational videos and handbooks. In addition, multimedia technology is being developed to assist people with cognitive and memory problems. The initial projects focus on remembering and reminiscing in people with mild cognitive impairment and mild to mid-stage AD. The aim is to develop multimedia DVDs that store and play patient biographies. By regularly viewing these DVDs, participants better retain their sense of identity, and the multimedia format also provides nurturing and emotional support for family members. These DVDs also have the advantage of giving caregivers who are not family members a better understanding of the persons for whom they are caring [11,12]. There are some hurdles to overcome in the production of these relatively short (40-minute) biographies. Determining how to summarize a person’s life can be challenging, and conflicts can arise in families over content.

4.2. Interactive exercises

Interactive programs under development fall into two main categories: video-based and electrophysiological. The video system relies on a television and monitoring system to show and monitor exercises, respectively. This system faces the same problem as other video monitoring technologies, i.e., the difficulty in accurately tracking the participant. One solution currently being explored is to dovetail the camera to a computerized model of the human torso that has 14 jointed segments (Fig. 3). By mapping these segments on the person, and then comparing their actual movements with how they should be moving, the system can decipher how well the person is performing the exercise. Robust prompts
are being developed that will help this system provide feedback to the participant. Algorithms are also being designed so that the system can cope with extraneous body movements that could otherwise confuse and crash the interface.

Magnetoencephalography (MEG)/electroencephalogram (EEG)-based systems that measure brain activity noninvasively are also being developed for cognitive training. The MEG/EEGs can record the full spatiotemporal orchestration of the brain while it is occupied with a specific task, and can identify networks of brain areas that are essential to fundamental cognitive processes such as attention and working memory [13]. These approaches also allow measurement of two or more different brain processes simultaneously, which is something that behavioral tasks cannot do. A prime example of this is attending-and-ignoring. People who are paying attention to one object while ignoring another may have two different types of activity going on in different parts of the brain at the same time, reflecting the processes for attending something of interest while simultaneously ignoring other things that are distracting. Until recently, there was no physiological evidence for a separate process related to ignoring irrelevant or distracting information [14,15]. Now there is evidence that aging (and perhaps AD) may differentially influence our ability to ignore irrelevant information more than it affects our ability to attend to relevant information [16].

The MEG/EEG measures can help tailor cognitive training. For example, they could be used to identify and help AD patients whose brain networks do not interact robustly during cognitive tasks. This may be used to identify sensory networks, sensory-motor networks, and cognitive-control networks that are engaged during specific tasks, and by recording how the brain is responding, may help track progress during cognitive therapies.

Currently, the main focus for this technology is on developing the interface and algorithms needed for complex signal detection and brain network identification [17,18].

5. Technologies for caregiver assistance

Monitoring can be a two-way street. In addition to receiving monitoring information about a person with AD, everyday technologies can also be used to contact and assist people in managing their everyday lives, thus giving their caregivers respite. Technologies that are actively being explored include verbal live systems, digital television, and simple cell-phone interfaces that give individuals prompts to help them cope with activities of daily living.

Live systems based on video monitoring are designed to track people engaged in specific tasks (e.g., making tea), to recognize if they get stuck at a particular point, and then give them a verbal prompt. The development of software for this type of system can be extremely challenging. Consider a simple task such as drying one’s hands, for example. The hands will often be covered by the towel or by each other,
making it extremely difficult for the video system to keep track. Sophisticated software algorithms are being developed to ensure that tracking systems are accurate and widely applicable, so that new models need not be reinvented for each specific task that one may want to monitor (Fig. 4) [19–21].

Digital television prompting systems may be very useful for people affected by AD who tend to spend a lot of time in front of the television. This type of system may be extremely useful not only to the person living alone, but also to those living with caregivers, because this system can relieve some of the “prompting” burden from the caregiver and help reduce conflict. The prompts can range from very subtle (images of food near mealtimes) to explicit (a message to take a particular medication), but must be scheduled via an easy-to-use control interface. Requirements-gathering and system design are real challenges, calling for a range of coordinated methodologies [22].

Cell phones are relatively simple, light, and wearable devices that can be used to communicate with individuals, mainly as a reminding device [23,24]. A week’s or a month’s worth of short video messages, recorded with a computer and webcam, can be loaded into the phones and set to deliver appropriate messages at the appropriate time. The system design can also accommodate a certain degree of flexibility, so that messages can be updated or substituted on the go. This may be particularly useful for the busy caregiver who may have to delay visits or alter schedules. These systems are being designed backwards, from the end-user. Appropriate target activities will be identified and developed via interviews with people affected by AD and their caregivers. These will then be tested in the field, and appropriate adjustments will be made.

Problems and areas for future development include:

- What to prompt? Choosing the best prompt that is most likely to get the desired response is important.
- How to prompt? Prompts can be images, an engineered machine voice, a recorded human voice, or a tone. Voice prompts have the advantage of being able to deliver very specific messages. Recorded human voices may be less irritating and more comforting, especially those of a family member or primary caregiver. However, populating systems with recorded messages may take considerable time.
- How to input prompts? If systems are flexible enough that prompts can be customized, the input interface must be user-friendly.
- How to cope with ignored prompts? The systems should be flexible enough to recognize when users are ignoring prompts, and respond appropriately. Developing this capability may be challenging.
- How to handle data volume? Monitoring systems will contain a high number of variables, and the volume of
data generated for analysis will be considerable. Systems must be robust enough to cope.

6. General considerations and conclusions

Regardless of the application, some overarching considerations apply to the development and dissemination of all types of ICTs that might be used to improve the lives of those dealing with AD. Some topics worthy of future research and discussion are outlined below.

6.1. Ethical issues

We found that many Institutional Review Boards (IRBs) were ill-equipped to provide timely review of ETAC-related projects, often because they use drug trials as their model for evaluating risk, though many ICT-enabled protocols involve little to no participant risk. The development of a general strategy or white paper that describes the concepts, development, and potential benefits of technological approaches would be useful for IRBs that may be unfamiliar with the technology, and that may have ethical or privacy concerns. Given the cultural differences involved in living with AD and the varying privacy concerns, understanding differences across nations and cultures would also be useful.

6.2. Proprietary issues

System integration and the technology challenges of ETAC-type grants often require partnership with industry,
which may mean that researchers face restrictions on sharing information. The interoperability of these technology systems is key if we are to achieve the size and scale of pilots required to prove return on investment (ROI) and efficacy of ICTs for AD. A guideline for researchers and industry partners on how to navigate confidentiality and intellectual property issues would be helpful. Given the need to accelerate the pace of discovery, reduce redundancy in research, and produce larger data sets for statistical validity, we believe that open-source hardware and software platforms may help solve some of these issues.

6.3. Funding

Because the field is relatively new, members of funding panels and organizations may be unaware of the value of this type of research for AD and other age-related conditions. Many ETAC researchers, even when armed with positive, promising research results from their initial pilots, find it impossible to gain additional funding for larger studies. Often they “fall between the cracks” of technology-based funding initiatives and clinically based funding initiatives that do not support cross-disciplinary and applied investigation. We believe it is imperative to bring more visibility to assistive technology research programs, and to advocate nationally for increased funding of clinical and technological research focused on innovative uses of ICTs.

6.4. Integration and ease of use

Through ETAC, we have found that many research centers are spending significant amounts of time and money to build technologies that may already exist. Often, these researchers fail to obtain much pilot data in the field because so much of their funding is spent on technology integration or on making technologies usable by frail individuals and untrained family members. We must find ways to cooperate and prevent the simultaneous development of similar technologies, thus preserving resources while accelerating outcomes studies. Over the long term, integrating research technologies from numerous universities and research centers into shared research platforms can alleviate this problem, with the caveat that this could restrict novelty if pushed too aggressively in the early stages of the field.

6.5. Developing a community of researchers and reviewers

One of the most significant challenges facing the ETAC program has been to find reviewers with mixed-discipline expertise to evaluate research proposals. Most ETAC researchers have reportedly been rejected for follow-up grants by technical reviewers who clearly have no clinical understanding of AD, and by clinical reviewers who do not understand assistive technologies. As with any new field or nontraditional research domain, building a community of researchers and reviewers takes time, and scaling to larger research pilots will remain a challenge without creative ways to increase the research community. The ETAC initiative, in a short period of time, has played a central role in bringing visibility and momentum to this emerging field, and will look to ICTs not only to help people suffering from AD and their caregivers, but to help the researchers themselves collaborate better across borders, disciplines, and cultures.

6.6. Stigmatization of older people

Finally, perhaps the “grand challenge” of ETAC is to overcome the cultural stigma and denial about aging that has kept these topics from rising to the top of national research agendas, in spite of the imminent age wave and its inevitable economic impacts. Stigma and denial take numerous forms, from funding agencies that ignore the unique needs of aging populations to companies that refuse to have their brand associated with “old people.” The ETAC researchers have routinely found that other researchers, family members, social workers, and policymakers assume that older people and people with AD are incapable of learning and using ICTs. The portfolio of ETAC grants thus far highlights promising directions that we cannot afford to ignore. This portfolio offers demonstrable evidence that today’s older members of society—and certainly tomorrow’s, who will be even more “tech-savvy”—are eager to use and to co-invent new information and communication technologies that hold promise to improve their lives.

References