Can a Computer be a Caregiver?

Peter Whitehouse, MD
University Memory and Aging Center
and School of Medicine
Case Western Reserve University
Cleveland, Ohio 44106, USA
pjw3@po.cwru.edu

Cynthia Marling
School of Electrical Engineering
and Computer Science
Ohio University
Athens, Ohio 45701, USA
marling@ohio.edu

Richard Harvey, MD
Alzheimer's Society
Box 16, Institute of Neurology
Queen Square
London WC1N 3BG, England
rharvey@alzheimers.org.uk

Abstract

This paper critically examines the issues involved in computer-assisted and automated caregiving for patients with Alzheimer's disease and related dementias. First, the nature of the problems experienced by those who care for dementia patients is explicated. Next, a high-level overview of the ways in which computers might assist these caregivers, now and in the future, is presented. Finally, the ethical issues raised by the advent of automated caregiving are explored.

Keywords: Automated Caregiver, Technology in Elder Care, Computing Ethics, Alzheimer's Disease, AI in Medicine

Introduction

Comforting and caring for people affected by dementia is a human challenge that many more individuals will face as the world continues to age. Alzheimer's disease, the most common dementia, is estimated to affect up to 50% of those over the age of 85 (National Institute on Aging 2000). The most rapidly growing segment of the populations in western Europe and North America are those over the age of 85. The rate of aging is even greater in the less industrialized countries, such as China and India. Thus, more and more human beings around the world will face this challenge of providing care for relatives, friends and clients affected by these devastating conditions. The question we pose in this essay is whether computers can assist in the process of providing care for victims of progressive cognitive impairment. When we first asked the question, "Can a computer be a caregiver?" just a few years ago, the question seemed largely rhetorical. It seems less so now, but it is still not easy to answer, as technical innovations, social expectations and ethical considerations interplay. We will divide our comments into the nature of the caring relationship, the current and potential future use of computers, and the ethical issues that arise with this envisioned future use.

The Nature of Care

Patients affected by dementia by definition are impaired in more than one cognitive area. The impairment usually starts with memory or attention problems and progresses to involve language, skilled motor acts, and perception. Accompanying these cognitive problems are behavioral disturbances, which vary widely but are quite common. These behavioral disturbances include wandering, agitation and sleep disturbances, as well as more serious and traditional psychiatric conditions such as hallucinations, delusions and depression. Moreover, patients have varying degrees of insight into the condition that they are suffering from. Even early in the disease, they may not recognize their own cognitive difficulties.

The onset of dementia is often insidious, and it may only be in retrospect that the problem is clearly defined to have begun years before medical attention is sought. Several changes in personality, memory and difficulty focusing attention are usually unaccompanied by any significant problems with activities of daily living. As the disease progresses, however, the cognitive problems grow both in severity and breadth, and the patient becomes unable to accomplish complex activities of daily living. In the severe stage of the disease, the patient loses most communication functions, is perhaps only able to repeat simple words, and cannot even perform basic activities of daily living such as toileting and bathing.

The act of caring for a patient with dementia requires patience, creativity and fortitude. The illness often progresses over five to ten years. The needs of the patient change, and often the caregivers change as families are overwhelmed and more and more formal caregivers are introduced to help families with their informal care. At first the patient may be at home, requiring minimal supervision, but then will require increasing attention and perhaps need community services like home visitors and day care. In the later stages of the disease, patients frequently require residential care, which can take place in a variety of different organizations, including assisted living, nursing homes and special care units specifically designed for patients with progressive cognitive impairment. These special care units are being developed without a clear sense of what defines them or what the critical features are. Sometimes, there are only minor changes in existing environment and programming. However, some organizations have built entirely new buildings staffed in different ways to avoid the medical model and create a space that is friendly for patients with cognitive impairment. For

example, devices are used to help patients recognize their own rooms, such as personal mementos in display cases beside their doors. For patients who wander, facilities may be designed with indoor and outdoor circular tracks that avoid dead-ends in which patients may enter other resident's rooms.

Studies show that caregiver burden is a significant component of the caregiving experience (Ory et al. 1999). Caregiver burden can affect family members as well as professional staff in the community and institutional services. Contributing to the burden is the inability to communicate effectively with dementia patients and the frustration that this engenders. Moreover, patients may be unable to recognize their caregivers, even their spouses of 50 years, and may heap abuse upon the individuals who love them most and who are the most intimate with them. In the later stages of the disease, patients have problems with personal hygiene and become incontinent of urine and stool. Increasing physical disabilities may prevent patients from moving about independently, so that considerable physical energy can be required of caregivers, as well.

The Current and Future Use of Computers

At first glance, caring for a patient with dementia appears to be a uniquely human experience. Past personal relationships with the patient enables family caregivers to be sensitive to the patient's moods and needs. However, researchers are already building systems that can understand and emulate human emotions (Picard 1997). It may not be long before practical caregiving systems are enhanced with this capability. Of course, computers already play a significant role in providing health care for patients. They may be most evident in tracking medical records and the financial aspects of health care. They are also routinely used for medical imaging, analyzing samples of blood and urine, providing access to the medical literature, and a host of other useful functions (van Bemmel and Musen 1997). What we wish to explore here, between the routine and the dream, are the imminent near-term possibilities for computers to provide "hands on," direct care to patients, assisting in day-to-day activities.

We do not believe that computers should fully replace human beings, but rather provide assistance in a variety of ways. We have long been using computers to provide educational information, advice and moral support to caregivers. At the University Memory and Aging Center (UMAC), there has been an online virtual caregiver support group for fifteen years. This system was developed by Dr. Kathleen Smyth, of the UMAC, in concert with the Cleveland chapter of the Alzheimer's Association (Smyth and Harris 1993; Smyth, Feinstein, and Kacerek 1997). It began as part of the Cleveland Free-Net, one of the world's first city-wide free public access computer networks. As such, it was a text-based bulletin board, accessed by caregivers from terminals in their homes. This in itself was significant, as caregivers are frequently unable to leave patients unsupervised to attend meetings and participate in support group activities. Early system users labeled themselves the "computer family." This system has since been updated to run over the World Wide Web.

More recently, we developed a CD-ROM at the UMAC for counseling caregivers and other family members of Alzheimer's disease patients about their own genetic risk of getting Alzheimer's disease. A simulated interview between a professional and a caregiver is employed. Caregivers can select frequently asked questions to get answers about Alzheimer's disease, genetics, genetic counseling and ethical concerns.

At the National Hospital for Neurology and Neurosurgery in London, we have developed CANDID, the Counselling ANd Diagnosis In Dementia Service. CANDID is an information, advice and clinical management service for younger people with dementia that began operation in 1995 (Harvey et al. 1998). CANDID hosts a Web site at http://candid.ion.ucl.ac.uk/candid/ that provides information for caregivers. There is also a team of trained nurses and counsellors who answer questions over the internet or by telephone. For patients who have registered at our hospital, we aim to provide sound clinical management advice, as well as general information.

While these early efforts are educational and advisory, we are moving toward systems that can provide more direct care. One computer capacity we can take advantage of is memory, which is one of the difficulties dementia patients have. Computer memory can be used to supplement and improve the memories of patients with dementia. For example, the patient who is having difficulty remembering people's names could have images of significant people and their names stored in a memory-enhancing program. Training programs tailored to each individual patient could be developed.

In early stages of the disease, small digital recorders and/or personal digital assists (PDAs) may provide memory aid to individuals (even those with normal age-related memory impairment like the authors). One such device, primarily suited for those with frontal lobe brain injuries, is already marketed for this purpose (Attention Control Systems, Inc. 2001; Levinson 1997). At the UMAC, we are exploring the further use of PDAs. Much of the attention in the area of dementia is now on preventing age-related cognitive deterioration by identifying individuals at risk for progressive dementia like Alzheimer's disease. The label Mild Cognitive Impairment (MCI) is applied to individuals who have some degree of cognitive difficulty but not enough to be labeled as demented. Individuals with MCI are at increased risk of developing progressive dementia. PDAs have technical capabilities that may provide useful assistance to people with MCI. Screen resolutions, static and video image capabilities and sound allow the creation of psychologically salient sources of information for individuals with MCI. These can include not only the standard PDA functions to help track contacts and schedule, but also visual reminders, like photographs of relatives and other family related information. Removable media such as Smart Media Cards or Sony Memory Sticks can store integrated programs of information to help an individual deal with particular circumstances. For example, a removable memory device could provide information about specific locations, like a relative's house, the

individual's own house or any other location frequented by the individual. Location specific information could include, for example, the names and photographs of particular people and maps.

Devices that have been used by the individual throughout life and that do not have to be learned anew are likely to be most successful. In the years to come, many patients with dementia will in fact have had PDAs and home computers with which they are familiar. Computer displays that are personalized and display identically wherever the patient is would also help. Just as computer interaction has been made easier for children, so too could interface mechanisms be modified to permit easier access for patients with dementia, even those who are relatively unfamiliar with computers.

Other enabling technologies for caregivers are computer vision, speech recognition, and intelligent robotics. A computer could monitor the visual and auditory world in the patient's space and learn to adjust to specific patterns. It could track and learn the patterns of activity that the patient engages in and identify changes in those patterns. For example, if the patient fell to the floor unconscious, that event could be detected by sensors with software tuned to recognize falling or the ensuing silence and lack of motion.

Ongoing research projects are currently addressing this possibility. One of these is the Aware Home Research Initiative (Georgia Institute of Technology Future Computing Environments Group 2001; Kidd et al. 1999). Here, a three-story house, or "living laboratory," has been outfitted with video cameras and a variety of sound, motion and touch sensors. While this project focuses on home computing technology for all ages, surveillance and assistance of the elderly is one important aspect.

At the Alzheimer's Society, we are working on the Safe at Home project, in cooperation with the Northampton Borough Council, the Northamptonshire County Council, and the Northampton Healthcare NHS Trust (Northampton Borough Council 2001). We have outfitted a demonstration house with a clock/calendar for patient orientation, an alarm that sounds if a patient gets out of bed at night, a gas detector and shut off device, and a doorside pressure mat that alerts caregivers if a patient leaves the house. In one study, eighteen dementia patients and their caregivers were invited to visit the house and try out these devices. Fourteen caregivers agreed to install one or more devices in their own homes for a trial. Over the next six months, the health care costs for patients in this experimental group were compared to those of patients in a control group without access to the devices. Costs for the experimental group rose by 4%, compared to 46% for the control group, primarily because more control group patients were institutionalized during this period. Two thirds of participating caregivers felt the technology they used helped to delay institutionalization.

The Nursebot project is specifically tailored to the needs of the cognitively intact elderly (Pollack et al. 2002; Nursebot Project: Robotic Assistants for the Elderly 2000). Falling is a hazard for many elderly, and detecting falls is one part of this effort. An intelligent robotic assistant is planned that could provide surveillance, daily reminders, remote doctor visits, manipulation of objects for the arthritic, and social interaction for the lonely. Our own preliminary research on a Robotic Caregiver's Assistant (RCA), at Ohio University and the UMAC, aims to extend this work by focusing on the special needs of the cognitively impaired. Making sure the patient is safe, not only from falls, but also from dangers like kitchen hazards, cigarette fires and wandering, is a primary concern. This would someday permit patients to be supervised by human beings with less intensity. The RCA is envisioned as an intelligent monitor, assisting the human caregiver by identifying events that are unusual and alerting them to the possibility of danger.

The computer might also assist in making life more pleasant for dementia patients. For patients who wish to stay in touch with current events, the computer could monitor current events that fit the interest profile of an individual patient. Moreover, the computer could present the material in a format suitable to the patient's cognitive level and reading ability. As the disease progresses and the patient's abilities to remember recent events diminishes, patients frequently exist in a past world. Many patients in long-term care facilities think that their parents are still alive and work through conflict situations in their minds with people who are long dead. The computer, with some forethought on the part of family members, could store static images, voice tracks, videos of family events, and favorite songs and movies. Thus, as the patient becomes more demented, the computer could choose to play selections that reflect the patient's tastes at that particular moment. As the patient dwells more and more in the past, it is likely that music and movies from years ago would be found more pleasant than current movies, for example. Moreover, the computer could track the patient's response to the multi-media event, for example, noting vocalizations and whether or not the patient actually watches the screen, to determine whether the selection of audio visual material is appropriate or not.

At the UMAC, we are exploring the use of individualized DVD archives for patients. Increasingly, families are maintaining archives of personal history. Frequently, these are not well organized, but computers can assist in their organization, storage and display. Previous writing projects, school records, birthday cards, home videos, photographs, and favorite music can all be digitized. Inexpensive writable DVD technology allows the creation of personal archives for use in situations where patients could obtain information, pleasure or both from reviewing significant family events.

There are many other ways in which computers could potentially help. For example, one problem dementia patients have is that of dressing appropriately. A computer could maintain an inventory of the patient's clothes and identify what the patient is wearing as well as help the patient in selecting clothes that match. It could engage the patient in speech and other forms of activity therapy to maintain communication capabilities as long as possible. It could track changes in a patient's speech as the patient becomes more demented. It could test patients' cognitive ability to monitor effects of a new drug therapy, thus allowing research to be conducted more efficiently.

More futuristic challenges also await. Some degree of cognitive change accompanies aging in all of us. Many actu-

ally believe that Alzheimer's disease is a continuum, rather than a discrete disease, as the concept of MCI suggests. The question then becomes whether and how computers can care for people with milder memory and attention problems. As the baby boomer generation achieves elderly status, might computers be the first to recognize the subtle shifts in the cognitive abilities of their users? Will computers diagnose dementia based on a pattern of inefficiencies in their use? More importantly, will computers be able to adapt to their aging users, presenting information in ways that account for their changing cognitive abilities? More importantly still, can computers take advantage of the positive aspects of aging, like the potential for wisdom to emerge from a lifetime of experiences? Can computers help people reflect on their lives, make associations, and contribute to the personal, intellectual and even spiritual development of us all as we age?

Ethical Issues in the Use of Computers for Caregiving

From the above discussion, it seems clear that even with current capabilities and particularly with future ones, computers will be able to provide a greater role in caring for patients with dementia. After all, one only needs to recognize the ubiquity of televisions in nursing facilities, day care programs and homes. If the passive television set were replaced by an active computer with peripherals allowing it to intelligently monitor the environment, it is quite possible that the quality of lives of patients and caregivers would improve considerably. But what are the ethical issues that might be raised by such a system?

The first issue is that of invasion of privacy. A computer with a video camera that is constantly on would represent some kind of intrusion into the private space of an individual. Would this be "Big Brother" watching the demented patient for purposes of control rather than for purposes of increasing autonomy and quality of life? Finding an appropriate balance would clearly be an issue, but one that could be resolved on an individual basis, because the situation mirrors in many ways the issues involved in human supervision of patients with dementia. Individual contracts with patients and caregivers could be developed to allow a computer to monitor certain things and not others. For example, many actions occur in the bathroom, and one would have to define what level of visual supervision occurred in this space.

Maintaining the confidentiality of patient records is another major issue. There is the potential to archive vast amounts of information about individual patient behaviors. Like privacy, confidentiality is not a new ethical issue for those who employ computer technology in health care (Goodman 1998). However, it is one that has been especially significant for us with the CANDID service. Over twelve hundred people call our telephone helpline each year, and at least a thousand people access our Web site every week. People with dementia rarely call, and therefore, we are often giving advice and information to third parties. The staff must be constantly vigilant: discussing patient details with a spouse is likely to be acceptable, but discussing a patient with more distant relatives or a separated spouse presents greater ethical problems. The need for patients to receive help and support has to be balanced with our moral requirement to maintain their confidentiality.

An issue less frequently discussed is that of the interplay between technology and pharmacology (Whitehouse and Marling 2000). Most efforts to improve the quality of life of an individual with cognitive impairment focus on improving the care system and the administration of appropriate medications. A computer could be a link in the complex relationship between technology and pharmacology. A computer could track medication use and assess the patient at relevant intervals to assess the effectiveness of the therapy. Moreover, drugs may allow patients to attend more to the computer. A system that could help a patient dress appropriately, for example, would only work if the patient attended to it, but dementia patients may have attention deficits. In children with Attention Deficit Disorder, stimulant drugs like methylphenidate have been found to improve attention in classroom settings. Many clinicians believe that the current generation of drugs used to treat Alzheimer's disease, namely cholinesterase inhibitors such as donepezil, galantamine and Reminyl, act by enhancing attention. Other drugs used to treat psychosis and behavioral disturbances in dementia patients, such as the neuroleptics, may also affect attention in various ways. Thus, for the caregiving situation of the future, we need to recognize that interactions between computer-enhanced caregiving and the use of medications could occur.

New and complex ethical issues could develop around the relationship between the patient and the computer. The computer is, after all, an information processing entity just like human beings and other animals. In biomedical ethics, we consider the moral position of animals based on their own particular interests and possibilities for suffering. Clearly animals have moral status in our discussions in a variety of areas of human life. Could we ever imagine a situation in which a computer would achieve moral status? Certainly it could be viewed as a possession of an individual human being. Thus a demented patient, who became very dependent on the computer, and all of the memories and images it stored, would suffer greatly if this computer were terminated. Beyond this concern, could we imagine a situation in which the computer itself would be viewed as an individual entity with rights? It may seem far-fetched, but on the other hand, differences in capabilities between biological and physical devices for processing information may be more challenging to define than we imagine. Clearly biological creatures, from amoebae to human beings, are programmed for growth, development and death. They have interests and intents. Computer agent researchers draw from this biological basis in the popular Belief Desire Intention (BDI) model. Here, software and/or robotic agents are given human-like motivations to independently pursue their own goals (Bratman 1987; Rao and Georgeff 1995).

Could a computer measure the quality of life of its care recipient and gain reward from this? Could the reward be distribution of its caring approaches to other information systems in "support" groups? Could systems of computers

compete for resources based on health outcomes of populations of patients under their care? When these things become possible, where do we draw the line between excluding an information processing entity from moral dialogue and allowing them in our ethical conversations? Perhaps we will have to ask the computers of the future that question.

Acknowledgments

This work was funded, in part, by the Takeyama Foundation and by the Alzheimer's Society of the UK. The authors gratefully acknowledge this support. The authors would also like to thank Jared Bendis and David Chelberg for technical contributions to this work.

References

Attention Control Systems, Inc. 2001. The planning and execution assistant and training system. World Wide Web site, http://www.brainaid.com/.

Bratman, M. E. 1987. *Intentions, Plans, and Practical Reason*. Cambridge, MA: Harvard University Press.

Georgia Institute of Technology Future Computing Environments Group. 2001. Georgia Tech's aware home research initiative. World Wide Web site, http://www.cc.gatech.edu/fce/house/house.html.

Goodman, K. W., ed. 1998. *Ethics, Computing and Medicine*. Cambridge, UK: Cambridge University Press.

Harvey, R. J.; Roques, P. K.; Fox, N. C.; and Rossor, M. N. 1998. CANDID - Counselling and diagnosis in dementia: A national telemedicine service supporting the care of younger patients with dementia. *International Journal of Geriatric Psychiatry* 3(6):381–388.

Kidd, C. D.; Orr, R. J.; Abowd, G. D.; Atkeson, C. G.; Essa, I. A.; MacIntyre, B.; Mynatt, E.; Starner, T. E.; and Newstetter, W. 1999. The aware home: A living laboratory for ubiquitous computing research. In *Proceedings of the Second International Workshop on Cooperative Buildings*.

Levinson, R. 1997. The planning and execution assistant and trainer (PEAT). *Journal of Head Trauma Rehabilitation* 12(2):85–91.

National Institute on Aging. 2000. *Progress Report on Alzheimer's Disease, 2000*. Bethesda, MD: National Institutes of Health. NIH Publication No. 00-4859, available online at http://www.alzheimers.org/pubs/prog00.htm.

Northampton Borough Council. 2001. Safe at home. World Wide Web site, http://www.northampton.gov.uk/news.archive%5Fnews/pr273.htm.

Nursebot Project: Robotic Assistants for the Elderly. 2000. World Wide Web site, http://www.cs.cmu.edu/ nursebot.

Ory, M. G.; Hoffman, R. R.; Yee, J. L.; Tennstedt, S.; and Schulz, R. 1999. Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist* 39(2):177–185.

Picard, R. W. 1997. *Affective Computing*. Boston, MA: MIT Press.

Pollack, M. E.; McCarthy, C. E.; Tsamardinos, I.; Ramakrishnan, S.; Brown, L.; Carrion, S.; Colbry, D.; Orosz, C.; and Peintner, B. 2002. Autominder: A planning, monitoring, and reminding assistive agent. In *Proceedings of the Seventh International Conference on Autonomous Intelligent Systems*. To be published in March.

Rao, A. S., and Georgeff, M. P. 1995. BDI agents: From theory to practice. In *Proceedings of the First International Conference on Multi-Agent Systems*, 312–319. Cambridge, MA: MIT Press.

Smyth, K. A., and Harris, P. B. 1993. Using telecomputing to provide information and support to caregivers of persons with dementia. *The Gerontologist* 33:123–127.

Smyth, K. A.; Feinstein, S. J.; and Kacerek, S. 1997. The Alzheimer's disease support center: Information and support for family caregivers through computer-mediated communication. In Brennan, P. F., and Schneider, S. J., eds., *Information Networks for Community Health*. New York, NY: Springer. 189–204.

van Bemmel, J. H., and Musen, M. A., eds. 1997. *Handbook of Medical Informatics*. Heidelberg, Germany: Springer-Verlag.

Whitehouse, P. J., and Marling, C. R. 2000. Human enhancement uses of biotechnology, ethics, cognitive enhancement. In Murray, T. H., and Mehlman, M. J., eds., *Encyclopedia of Ethical, Legal & Policy Issues in Biotechnology*. New York, NY: Wiley.