



**Computer-Based Technology and Caregiving of Older Adults:
Exploring the Range of Possibilities and Beyond**

An Annotated Background Paper

The field of technology for the caregiving of older adults is clearly in a rapid state of development and change. This technology has the potential to alter the ways in which patients, their caregivers, and health providers interact. While its use will not be a panacea for caregivers, it could provide older adults and their families with new alternatives for services and more convenient, less stressful, choices. It can also promote an older adult's independence, provide peace of mind to caregiving relatives, and reduce the older adult's reliance upon human help for some of the activities that support daily living and independence.

The increasing availability of high-speed communications networks (broadband), coupled with computers that continue to become more powerful and less costly, will greatly enhance the potential for technology to support caregivers. These networks will make it possible to deliver a much wider range of high-quality health services to older adults at home or elsewhere by adding two-way video to voice and text communications, providing instant access to rich multimedia content, and supporting (through broadband's "always on" feature) an extensive range of continuous, unobtrusive monitoring services (Adler, 2002)

Implementation [Applications of technology for caregiving]

E-mail and online communities. In its most basic form, technology for older adult caregiving includes interactive e-mail messages with family and friends, which helps provide psychological

connectivity and group support to the older person's community. Moreover, the formation of wider online communities is capable of mitigating social isolation and loneliness in a way that no other medium can match (Furlong 1997).

World Wide Web Health Information Sites. The World Wide Web provides individuals and their caregivers with a resource for health information and education, as well as access to support groups. For example, the AlzOnline Web site (www.AlzOnline.net) at the University of Florida provides caregivers of elders with Alzheimer's and other progressive dementias with a place where they can participate in caregiver education and support classes and find the most current information on caregiving. Each month, about 3000 new persons use the site and approximately 10,000 pages are accessed. The site also hosts regularly scheduled expert forums and has a very active message board with over 3000 visits each month (Loomis, 2002).

The vast quantity of health information now available on the Web creates issues as well as opportunities for older adults and their caregivers. The ability to identify Web sites with reliable information and to search effectively on a topic has become necessary skills (SPRY Foundation, 2001). The increased use of health web sites by older adults and their caregivers has also been an impetus for web site developers to make their sites more "senior-friendly" (SPRY Foundation, 1999).

Telemedicine. Telemedicine and telehealth technologies allow the exchange of information between health professionals, patients, and caregivers with technology. This exchange can facilitate informed decision-making, promote healthy behaviors, encourage peer information sharing and emotional support, promote self-care, and manage the demand for health services (Science Panel on Interactive Communication and Health, 1999).

New monitoring devices provide unique oversight, nearly in real time, of an older person's vital signs so that the individual, the doctor, and selected family members can be aware of the person's health status from home, without the difficulties of travel to hospitals or other medical centers (Lehmann, 2002). Technology for point of care testing allows medical tests to be done in a home setting with results transmitted to physicians so that emerging problems can be detected early. Vital sign technology and point of care testing can significantly decrease health care costs for older adults by reducing their emergency room visits and hospitalizations (Lehmann, 2002).

Pharmacy Use of Communications Technology. Pharmacies and pharmaceutical distributors are providing on-line service for ordering prescriptions and home delivery of medications for people who have to stay in their homes. Large online prescription services such as Express Scripts exemplify this trend. There are also on-line services for managing vaccine distribution and for reminding patients at home to take their medications.

"Smart" Technology. Homes are now being designed with floor sensors linked to personal computers that help family members determine if the walking patterns of an older adult are normal, or if the person may have fallen or encountered some other difficulty (Abowd, Bobick, Essa, Mynatt, & Rogers, 2002; Gerontological Society of America, 2001; Honeywell Laboratories, 2000). Smart-cards allow individuals to carry data that can be accessed via computers during regular physician visit or in an emergency situation. Such technology is commonly used in both France and Germany, particularly for health insurance information (Shaefer, 1995).

Artificial intelligence and robotics are already in the prototype phase. Robotic models are already being tested that will be able to provide in-home support services, including direct voice and visual contact with the patient, and real time monitoring of their vital signs. In a workshop

entitled “Automation as Caregiver: The Role of Intelligent Technology in Elder Care”, the American Association for Artificial Intelligence (2002) recently highlighted some of the advanced technological solutions being proposed to aid in monitoring, diagnosis, situation awareness, decision aiding and the direct automation of tasks for either the elderly themselves or for their caregivers (Haigh, 2002). Other indications of the potential importance of robotics are suggested by a study of neurologic recovery with robotic aids (Hogan 1999-2003), the Nursebot project aimed at developing mobile robotic assistants for the elderly (Pollack, 2002), development of “care bear” robots that watch over older adults in a retirement home in Japan (Lytle, 2002), and use of mobile robots to perform routine delivery tasks in hospitals (Okie, 2002). The Medical Automation Research Center at the University of Virginia is working on perfecting a “smart walker” that will help older adults with vision and mobility to get from one place to another. (Ragaza, 2002).

Policy and Planning

Given the rapid development of technologies that can support caregiving of older adults, there is a need to understand the range of these new technologies better, develop policies that address the many issues that surround their use, and design a national public education initiative in the U.S. to integrate their acceptance in society. Of special interest will be the need to link the application of technologies in home care settings to the formal health care system. There is also the need to assess the patient rights issues that these new technology approaches present.

More research will be needed on basic issues in communications and aging, including barriers to communication and design challenges for computer users; changes in cognition that come with age, cultural differences in cognition, influences of these factors on communication, and the

impact of hearing loss; and human factors design, training, and compensation issues for communication by older adults (Charness, Parks, & Sabel, 2001).

Ensuring that technologies are accessible to older adults requires development of standards. Guidelines for Web site accessibility such as those prepared by the World Wide Web Consortium's Web Accessibility Initiative (WAI) is an example. In 1998, Congress amended the Rehabilitation Act to require Federal agencies to make their electronic and information technology accessible to people with disabilities. The law, referred to as Section 508, applies to all Federal agencies when they develop, procure, maintain, or use electronic and information technology. What section 508 adds to the WAI guidelines is a clear, concise, and codified set of standards and a commitment by the federal government not only to comply with these standards but require that vendors do so as well.

The views of family caregivers and older people of information technology will have to be given careful consideration to ensure that products and services are designed to match users' needs and capabilities. (Andersson, Hansen, & Magnusson, 2002) Although studies have shown that older adults are willing to use technology if it is easy to learn, use, and understand, these principles must guide development of new technologies and support services. Furthermore, little is yet known about how interested caregivers are in using the newer types of support services such as those provided by computer-based technologies (Colantonio, Cohen, & Pan, 2001).

Telemedicine raises policy issues involving privacy and confidentiality of medical information, oversight and regulation, liability, accreditation and certification, public investment in development and research, payment and reimbursement for services, and integration of interactive health communications with clinical practice, public health, and the workplace (Science Panel on Interactive Communication and Health, 1999). Policies will have to be

developed by health professional organizations, government, and relevant groups in the private/corporate sector to address these areas.

A comprehensive review of guidelines and standards for telemedicine (Loane and Wootton, 2002) concluded that many telemedicine reports cite the need to develop guidelines, but few actually exist in practice, particularly at an international level. Furthermore, the report states, “the formulation of such guidelines does not necessarily guarantee improved patient outcomes, and continual monitoring of the effect of guidelines will be required.” The American Nurses Association has endorsed core principles on telehealth developed by an Interdisciplinary Telehealth Standards Working Group, and states in its report, “The ...core principles suggest a research agenda and the need for policy development that should be undertaken by government agencies and professions in the area of telehealth” (American Nurses Association, 1999).

One of the issues limiting the advance of telemedicine has been lack of reimbursement to health professionals for these services. However, in 2001 First Health became the first national managed care company to arrange payment for Internet consultations between patients and their network physicians through a structured model for “internet visits” (Smith, 2002). Once reimbursement issues are worked out on a broader scale, telemedicine is likely to advance rapidly. Confidentiality and security present serious policy and ethical issues. As online information grows, how to guide trust and confidence in an information and services system that has the potential to misuse the personal information made accessible through computers – and how to ensure that such trust and confidence are justified – will become paramount (Lefton, 1997).

Evaluation

Because the use of computer-based technologies in caregiving for older adults is so new, little is known at this time about its outcomes (Schulz, 2002). Some studies have begun to address relevant questions. For example, Payton, Brennan, and Silvers (1995) examined the benefits of the ComputerLink, a specialized computer network for caregivers of persons with Alzheimer's Disease. Their results indicated that community health networks do return economic and social benefits to their users. Cost benefits on the individual level occur when traditional services such as institutionalization are delayed by the technology intervention.

Colantonio, Cohen, and Pan (2001) studied support needs of caregivers of persons with dementia to determine their interests in several types of support services such as telephone support, newsletter, and computer services. In the area of computer support, 58 caregivers out of a study population of 148 had access to or owned a computer, but only 42 caregivers were interested in receiving information and support via this medium. Younger caregivers had the greatest interest in using computer support. Non-spousal caregivers, non-married caregivers, and caregivers with a higher education were also significantly associated with interest in computer support.

Andersson, Hanson, and Magnusson (2002) studied the concept of usability of information technology with family caregivers and older people and emphasized the importance of working closely with participants in order to create an information and communication service that is both acceptable and of direct benefit to family members in their everyday caregiving situations.

Furlong (1997) has studied the creation of online community for older adults, looking at the role of these communities in a changing world and giving examples of what needs to be considered in creating an online community.

One survey (Harris Interactive, 2000), in which interviews were conducted online with 1000 health care consumers, followed by focus groups with both consumers and physicians, found that

consumers see the Internet as a tool they can use along with other tools and services to communicate with caregivers and to manage their healthcare. Consumers indicated that they want personalized care and information from their doctor delivered by the most effective medium: face-to-face communication, telephone, or the Internet. Doctors, on the other hand, want to make sure the Internet doesn't add to their already crowded schedules or interfere with the doctor-patient relationship. Doctors are also understandably concerned about issues of medical record privacy and possible malpractice suits.

A number of studies have focused on older adults' satisfaction in using computer-based technologies. Kubeck, Miller-Albrecht, Murphy (1999) found that although there were differences in the way younger and older adults performed on problems involving Web searches, with brief but well-designed training, novice older adults were successful in their Web searches and had very positive reactions to the Web experience. Morrell, Mayhorn, and Bennett (2000) conducted a survey to document Web use patterns in middle-aged (ages 40-59), young-old (ages 60-74), and old-old adults (ages 75-92). Among their findings were that middle-aged and older Web users are similar in their use patterns, old-old adults have the least interest in using the Web compared with the other age groups studied, and the primary content areas in learning how to use the Web are electronic mail, accessing health information, and information about traveling for pleasure. White and Whitehall (2000) investigated older adults' accounts of their use of information technology (IT) using grounded theory methodology and found participants began using computers because IT was associated with modern life, leading them to recognize the potential that IT had to offer them. Their mostly positive attitudes toward IT were strongly linked to the personal usefulness of the technology and direct experience with, and personal ownership of, information technology.

A Web-based diabetes care management support system was developed at the Center for Health Services Research, Henry Ford Health System (Detroit), in an effort to improve routine monitoring and screening among patients with diabetes (Baker, Lafata, Ward, Whitehouse, & Divine, 2001). Results of the evaluation of the system's use showed modest improvements in testing rates.

Although the above studies offer some initial insights, the research agenda for evaluating outcomes of computer-based technologies in caregiving of older adults is very broad and not yet fully defined. Far more research is needed to provide an understanding of how these technologies can be used for maximum effectiveness in caring for older adults. Research areas include those related to cost, access, privacy, ethics, standardization, links to the existing health care system, patient satisfaction, quality of care, policy, and others.

The Need for a New Dialogue

Although the above studies offer some initial insights, the research agenda for developing, testing, and evaluating outcomes of computer-based technologies in caregiving of older adults is very broad and not yet fully defined. Far more research is needed to provide an understanding of how these technologies can be used for maximum effectiveness in caring for older adults, particularly in their homes and other residential settings. In addition, there is a critical need to understand cost, access, privacy, ethics, standardization, links to the existing health care system, patient satisfaction, quality of care, and other policy-related issues.

A major goal of this conference is to highlight these key issues for research. The conference will bring experts together in the fields of computer-based technology, research, caregiving, ethics, and public policy to exchange ideas and begin to identify and initiate the process of answering

many of the most pressing questions. Such dialogue is the most powerful way to leverage existing ideas to meet the caregiving needs of today, and plant the seeds that will help to meet the caregiving needs of tomorrow.

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