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## Crossing the digital divide: family caregivers' acceptance of technology

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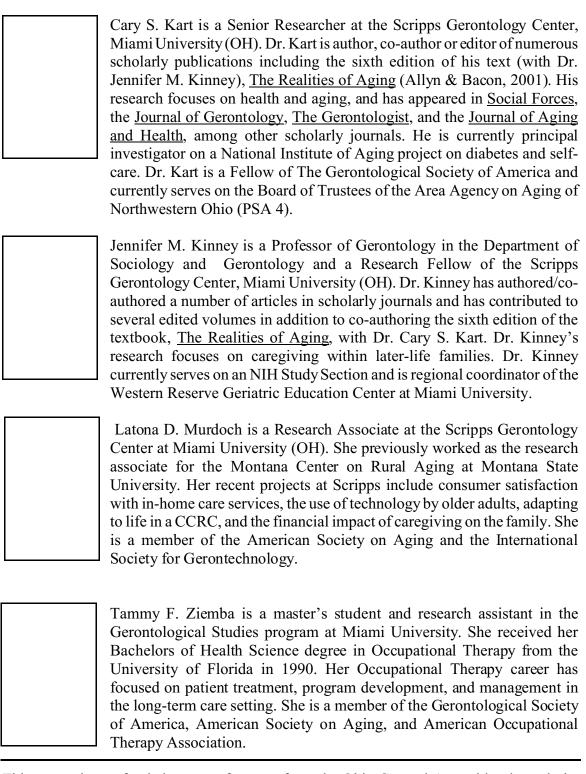
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# CROSSING THE DIGITAL DIVIDE: FAMILY CAREGIVERS' ACCEPTANCE OF TECHNOLOGY

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# CROSSING THE DIGITAL DIVIDE: FAMILY CAREGIVERS' ACCEPTANCE OF TECHNOLOGY

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#### **EXECUTIVE SUMMARY**

Recognition of the reality that most individuals with dementia reside in noninstitutional housing in the community and are cared for by family members is moving to the forefront of national and state policy-making. The purpose of this pilot project was to collect preliminary data on how electronic technology might be used to assist family members who are caring for a relative with dementia at home. The pilot project was conducted in three phases.

In Phase 1, we conducted five focus groups with caregivers of relatives with dementia to: 1) document the specific challenges faced by caregivers; 2) assess caregivers' access to, and familiarity with, electronic technology; and 3) assess caregivers' knowledge about, and willingness to explore, the extent to which electronic technology can be used to decrease caregiving burden. Findings from Phase 1 indicate that caregivers and the relatives for whom they provide care are in an evolving, increasingly challenging struggle to maintain continuity of roles, relationships, and lifestyles. Key challenges include the safety of the individual with dementia and keeping geographically distant family members aware of their relative's condition. Caregivers reported using a range of technologies in their day-to-day lives, and some caregivers directly applied existing "low-tech" solutions to challenges in caregiving. Caregivers felt strongly that technological solutions were neither appropriate nor useful across all situations, and were cognizant of the inherent trade-off between safety on the one hand and dignity, respect, privacy, and desires for independence and autonomy on the other hand. Ultimately, caregivers do not aspire to become "technology whizzes"; rather, they are interested in easily obtained, affordable, easy to use solutions to some of the challenges they face.

In Phase 2, to overcome the major challenges identified by the caregivers in Phase 1 of the project, consultants identified a technology-based solution – the Xanboo Smart House Management System. The System is easy to install and use, requires no complicated rewiring, simply plugs into an existing personal computer, and is driven through access to the Xanboo website. The System allows monitoring of a residence through placement and control of video cameras and other enabled devices, including sensors that detect motion, power interruptions, changes in temperature, the presence of water, a window or door opening, or noise (e.g., the ringing of a telephone). These sensors may be set to provide a caregiver or other interested party with immediate notification by

e-mail, pager, text messaging cell phone, or personal digital assistant (PDA). For purposes of Phase 3 of the project, a household located in a suburb of Cincinnati was outfitted with The System.

In Phase 3, we conducted two focus groups comprised of caregivers to relatives with dementia to evaluate the utility of The System identified in Phase 2. The System was demonstrated in the first group and described in the second group. Participants from both focus groups had many comments and questions; regardless, attitudes were generally quite positive. When prompted to identify barriers to using The System, participants identified the need for a computer and Internet access, and cost (although participants considered the cost quite reasonable). The report concludes with an extended and annotated bibliography on

technology and aging with special focus on scholarly articles, reports, monographs, and websites related to caring for a relative with dementia.

Taken together, the results from this pilot project suggest that there are affordable technologies that can assist family members in their efforts to care for relatives with dementia at home, and that these caregivers are amenable to the use of these technologies. Future efforts should evaluate the installation, use, and impact of The System in the homes of family caregivers to relatives with dementia.

#### **ACKNOWLEDGMENTS**

A number of people provided valuable assistance with this project. The Ohio District 5 Area Agency on Aging TOPS group (Theresa Cook, Brian Hamilton, Jerry Kithcart, Steve Nemeth, Diane Ramey, Bev Tatro, and Betty Thompson) introduced us to this exciting line of inquiry. Melissa Hall was our liaison in Mansfield, and helped us overcome logistic challenges resulting from our location in southwest Ohio. The Mansfield Alzheimer's Association allowed us to attend support groups to recruit participants in the project. We appreciate the comments of two reviewers of this report: Salli Bollin, Executive Director of the Alzheimer's Association, Northwest Ohio Chapter and Dr. Phyllis Braudy Harris, Professor of Sociology and Director of the Aging Studies Program, John Carroll University. Finally, this project would not have been possible without the participation of the caregivers who shared very important pieces of their lives with us.

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# **Background & Significance**

Recognition of the role that families assume in providing long term care is moving to the forefront of national and state policy making (Cox, 1997; National Alliance for Caregiving (AARP, 1997). Most individuals with dementia reside in noninstitutional housing in the community and are cared for by family members, mostly spouses and daughters/daughters-in-law. In a 1997 survey, approximately 72% of informal caregivers to a relative or friend, who was 50 years of age or over, were women and 52% were providing care to a parent or parent-in-law (Wagner, 1997). The typical "caregiver" is a married woman in her mid-forties who works fulltime, is a high school graduate, and has an annual household income of \$35,000 (National Alliance for Caregiving/AARP, 1997). Although caregivers generally strive to assure the physical and emotional safety of the family members for whom they care (Cheston & Bender, 1999), most caregivers do so under some constraint. For example, many communities, and especially rural communities, lack a comprehensive range of support services for caregivers (e.g., adult day centers, respite care). Even in communities

In this report, "caregiver" refers to a family member who provides care to a relative with dementia.

where such services are available, older caregivers are often reluctant to use such services, and/or logistic barriers (e.g., lack of transportation) may prevent their use. Further complicating the situation, most private health care insurance policies do not cover the costs associated with caregiving and/or respite for caregivers. Analyzing data from two National Long-Term Care Surveys, Liu, Manton and Aragon (2000) report that older people or their kin paid, in whole or in part, for approximately 50% to 60% of long-term care services used. Home health agencies have had difficulty recruiting staff during the economic expansion of the 1990's, making it difficult to obtain paid help even if funding is available.

in technology Advances redefined our social fabric, including the fields in which we live, work, and play. Advances in nutrition, medicine, and health care have contributed to significant gains in life expectancy in the U.S. population during the 20<sup>th</sup> century. Ironically, gains in life expectancy from birth, as well as in agespecific life expectancy in old age, have been accompanied by increases in many age-related chronic conditions and disabilities such as Alzheimer's Disease (AD). According to the web site of the Alzheimer's Association, a person 85 years of age or older today has nearly a 50% chance of developing AD. Estimates of AD alone (excluding other dementias) indicate that up to 4.0 million Americans are directly affected with the disease, and that 19 million Americans have a family member with AD. In Ohio, according to statewide chapters of the Alzheimer's Association, as many as 208,000 individuals may be affected with dementia (personal communication, Alzheimer's Association of Northwest Ohio, July, 2002).

As researchers in the public and private sectors continue biotechnology research efforts to identify a cure or a preventive intervention for AD, social scientists and practitioners have begun to explore the use of technology to support family caregivers. For example, Arguelles and von Simson (1999) examined the effect of a family-based, computer telephone integration system on the ability of caregivers to a relative with dementia to engage in leisure They concluded that the activities. intervention helped caregivers to overcome some of the barriers to accessing and engaging in leisure activities.

Brennan, Moore, and Smyth (1991) installed Internet-access computers in the homes of caregivers to a relative with dementia to determine whether this medium might be a realistic method for information/referral and support. During a one-week period, 68% of caregivers accessed the system. Caregivers used the forum to discuss issues related to information about the disease, available community resources, behavior management, and caregiver coping skills. Caregivers also frequently posted messages offering encouragement and support to other list members.

In a longitudinal effort, Mahoney (1998) conducted a content analysis of the messages posted on an electronic network by family caregivers to a relative with dementia for a 12 month period. Data from over 500 postings were categorized into topics that varied as a function of duration of the caregiving role. New caregivers sought information about verifying the diagnosis and anticipatory planning; middle stage caregivers sought assistance about specific challenges in caregiving; and later stage caregivers

struggled with decisions surrounding the context in which future care should take place. These findings support claims by Smyth and Harris (1993) that the accessibility of Internet-based information and support systems are a viable complement to existing services for caregivers.

These results support the timeliness of an evaluation of the extent to which currently available electronic technologies can be used to decrease the burden experienced by individuals who provide in-home care for a family member with dementia. In this regard, Planning and Service Area 5 in Mansfield, Ohio (PSA 5) has been specifically interested in the extent to which technology (e.g., computers, motion detectors, web cams) can provide support and extend the caregiving role of isolated rural-dwelling caregivers. Among others, The American Society on Aging has recognized the desirability of local Area Agencies on Aging to assess and support services for caregivers in the community (Cavanaugh & Emerman, n.d.), and design interventions to meet the needs of in-home caregivers and the individuals for whom they care.

Electronic technologies (including computers, web cams, and wireless devices) have the potential to provide solutions for a number of challenges faced by caregivers.

Electronic technologies (including computers, web cams, and wireless devices) have the potential to provide solutions for a number of challenges faced by caregivers. Whereas many caregivers have made physical modifications to make the home safer (e.g.,

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hand rails, bathroom modifications), more sophisticated technology is relatively underutilized among in-home caregivers. Nonetheless, there is mounting empirical evidence that environmental modifications/interventions, including technological interventions, have the potential to reduce caregiver burden and distress, and promote more adaptive behavior among individuals with dementia (e.g., Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Marshall, 1999; Schulz, Maddox, & Lawton, 1999).

Electronic technologies will likely be critical components of caregiving in the 21st century. These technologies have enormous potential for helping caregivers to meet their numerous responsibilities. More importantly, these technologies have the capacity to provide and support an integrated infrastructure for caregiving in the home of persons with dementia. Over the past two decades, gerontological researchers have documented the desire of older adults in the U.S. to "age in place," living at home as long as possible, if not until death. Research documents that the onset of a dementia does not lessen this desire for either the individual with the disease or the family member who provides care. We assert that technology has the power to allow for "caregiving in place," and perhaps more importantly, "care receiving in place," either in the home of the caregiver and/or the individual with dementia.

#### THE PILOT PROJECT

#### **OVERVIEW**

The purpose of this pilot project was to collect preliminary data on how electronic technology might be used to assist those who

are caring at home for a family member with dementia. The pilot project was conducted in three phases. In Phase 1, we conducted five focus groups with caregivers to: 1) document the specific challenges faced by caregivers; 2) assess caregivers' access to, and familiarity with, electronic technology (e.g., home computers, wireless telephones, assistive technology devices); and 3) assess caregivers' knowledge about, and willingness to explore, the extent to which electronic technology can be used to decrease caregiving burden. In Phase 2, we used the results from Phase 1 to work with technology consultants to develop technological interventions that overcome the major challenges identified by in-home caregivers. In Phase 3, we conducted two focus groups comprised of caregivers to relatives with dementia to evaluate the utility of technological interventions identified in Phase 2. This report summarizes the process and results for each phase of the project. The report concludes with an extended and annotated bibliography on technology and aging with special focus on scholarly articles, reports, monographs, and websites related to caring for a relative with dementia.

Phase 1: Document the Challenges Faced by Caregivers; Assess Caregivers' Access to, and Familiarity with, Electronic Technology; and Assess Caregivers' Knowledge About, and Willingness to Explore the Use of Technology in Caregiving

Phase 1 of the project consisted of five focus groups, comprised of 26 individuals, conducted during the summer of 2001. Participants were recruited primarily through presentations made by members of the research team to caregiver support groups sponsored by the Mansfield (OH) Area Alzheimer's Association. Additional

participants were identified through the Area Agency on Aging, Inc. in Mansfield. Three focus groups were conducted at the Ohio District 5 Area Agency on Aging in Mansfield, and one focus group each in a long-term care facility in Fostoria, Ohio and a hospital in Marion, Ohio.

#### RECRUITMENT PROCEDURES

During visits to caregiver support group meetings, two members of the research team explained the purpose of the research, outlined the requirements for participation (including the voluntary nature of participation), and answered any questions that potential participants had. Interested potential participants provided their names and contact information via a sign-up sheet. In addition to these recruitment procedures, information about the research was available at the Area Agency on Aging. Clients who expressed an interest in participating in the research provided contact information to a case manager, who then forwarded this information to the research team. Individuals interested in participating were contacted by a member of the research team who reviewed the requirements for participation, and scheduled the dates and times for focus group meetings. Participants were told to expect the focus groups to last approximately 90 minutes.

#### FORMAT OF FOCUS GROUPS

The same two members of the research team conducted the five focus groups. One team member (Dr. Kart) facilitated the focus group while the second team member (Dr. Kinney) served as co-facilitator. The co-facilitator took notes that were used during the group to summarize main points and guide

subsequent discussion. In addition, each group was audio-taped and tapes were transcribed for subsequent analysis. The format for each focus group was as follows: as participants arrived, they were provided with printed informed consent information which they were asked to read and sign prior to the start of the group. Participants then completed a brief information sheet that recorded demographic information and characteristics of their caregiving activities. The focus group began with introduction of participants and an overview of the procedures that would be followed.

A series of focus group prompts were employed to explore two over-arching themes: 1) challenges in caregiving and 2) creative solutions

A series of focus group prompts were employed to explore two over-arching themes: 1) challenges in caregiving and 2) creative solutions (with special emphasis on gizmos, gadgets, and technology). The prompts used to elicit discussion about each of these two themes are presented below.

#### 1. Challenges in Caregiving

- Tell us who you are caring for, and how long you have been providing care.
- Tell us the about the last time you and/or your relative had a particularly good day at home.
- For every good day as a caregiver, you have probably had a not-so-good day.
   Tell us about a day at home that was particularly challenging for you and/or your relative.

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• If you think about caregiving, is there one recent day that stands out? It can either stand out because it was a particularly good day, or a particularly not so-good day. Either way, please tell us about a recent day in caregiving that really stands out to you. This discussion was summarized by the cofacilitator before turning to the second over-arching theme of the discussion.

# 2. Creative Solutions (gizmos, gadgets, and technology)

- Think about all of the aspects of caregiving that we have been talking about. Are you using any gizmos/gadgets/technology to help you care for your relative?
- Are there any gizmos/ gadgets/technologies that would make your life as a caregiver easier?
- If you could invent one gizmo/gadget or type of technology to make it easier to care for your relative, what would it be/do?

Each focus group concluded by asking participants whether there were any issues that the facilitator and co-facilitator had overlooked or any other issues that were important to discuss before the group ended the discussion.

#### **RESULTS FROM PHASE 1**

**Description of Focus Group Participants.** The characteristics of the 26 individuals who participated in the five focus groups are summarized in Table 1. As can be seen in the table, the average age of caregivers

was approximately 63 years, and the majority of caregivers were female. On average, caregivers had spent six years in the role. Focus group participants included both current and former caregivers, and represented a range of kinship relationships with the individual for whom they provided care. At the time of the focus groups, 54% of the caregivers and care recipients resided together; 19% of the caregivers resided in the community, but separately from the individual for whom they were providing care. For the remaining caregivers, the family member with dementia resided in assisted living or a nursing home (19%), or was deceased (8%).

Caregivers who participated in the focus groups were compared with a subsample of caregivers to individuals with Alzheimer's or mental confusion from a recent national survey (National Alliance for Caregiving/AARP, 1997). This comparison revealed that the two groups were similar in terms of gender (77% v. 76%) and education (62% v. 55% completing at least some college). Focus group participants were older (average of 63 v. 49 years), more likely to be White (96% v. 81%), and had a longer duration of caregiving (6 v. 4 years). With respect to kinship tie, focus group participants were evenly divided among those caring for a spouse (42%) and those caring for a parent (43%). These results differ from the national survey, where 52% of caregivers were caring for a parent, and only 9% were caregiving to a spouse.

Findings from Focus Groups. It is well documented that older adults prefer to age in place, and this preference is not lessened by the onset of dementia. However, aging in place does not assure a high quality of life. Continuity of place is not always

Table 1: Demographic Characteristics of Phase 1 Focus Group Participants (N=26)

Characteristic	Frequency (Percent)	Mean	Standard Deviation	Range
Gender				
Female	20 (76.9)			
Male	6 (23.1)			
Age		63.19	11.83	32 - 79
Ethnic Background				
Caucasian	25 (96.16)			
Black	1 (3.84)			
Caregiver's level of education				
Not a high school graduate	2 (7.7)			
High school graduate	8 (30.8)			
Some college	10 (38.5)			
College graduate	5 (19.2)			
Graduate/professional training	1 (3.8)			
Length of caregiving (in years)		5.54	4.68	.20 - 20.00
Hours per day spent caregiving		12.86	9.04	1.5 - 24.00
Caregiving status				
Current caregiver	17 (65.39)			
Former caregiver	9 (24.61)			
Caregiver's relationship to care-				
recipient				
Care-recipient is spouse	11 (42.31)			
Care-recipient is parent	8 (30.7)			
Care-recipient is parent-in-law	3 (11.54)			
Care-recipient is step-relative	2 (7.7)			
Care-recipient is grandparent	1 (3.9)			
Care-recipient is child	1 (3.9)			
Caregiver's self-rated health (0 = very poor; 10 = excellent)		8	1.47	4.0 - 10.0

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accompanied by continuity in roles, relationships, and lifestyles, especially in the face of dementia.

Caregivers in the focus groups told us that they, and the relatives for whom they provide care, are in an evolving, increasingly challenging struggle to maintain continuity of roles, relationships, and lifestyles.

Caregivers in the focus groups told us that they, and the relatives for whom they provide care, are in an evolving, increasingly challenging struggle to maintain continuity of roles, relationships, and lifestyles. When "home" becomes a restrictive environment because of the demands of dementia, it can become the very source of discontinuity. It changes roles and relationships. As Kevin shared:<sup>2</sup>

"I had a bad day one day when I was busy outside trying to get something done....I had been in two or three times and I came in and I got a little short with [mom] and I said... 'Well, you have to watch where you put stuff; always put it at the same spot.' I guess I came off a little too strong and I went back outside and said, 'I'll be in after a while to help you look for it.' Well, when I came back in she had been sitting there crying, which doesn't make you feel good."

Caregivers and the family members for whom they care attempt to maintain their

"...she has a tendency to fall asleep, leave her front door open...my nephew went by a few weeks ago and there were two men on her front porch drinking. And she's sleeping in the chair, by herself, with that front door wide open..."

For a number of the caregivers, their family members' use of the kitchen was increasingly problematic. Bob had begun to worry about his mother's efforts to prepare meals:

"She is still quite confident as far as using the coffee maker to make coffee and using the microwave oven to heat things up, but as far as cooking on the burners of the stove, I'm just getting to the point where I'm not particularly comfortable with that."

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roles, relationships, and lifestyles in homes that symbolize this continuity. However, because of the dementia, these very homes present a number of affronts to the continuity of their pre-dementia lives. Discontinuities create moments of frustration. tension, stress, and conflict, and frequently emerge around issues of safety both beyond the home, as in the case of wandering, and within the home. For example, Amanda described her mother's hiding from her in a small barn at their family farm as "a game that she played...that was hard...but it was funny...she thought it was cute." However, the "game" ceased to be amusing when her mother actually began to wander farther away from home; Amanda revealed that on one such occasion her mother wandered seven miles from the family home before she was found. Fran's concerns about her mother-inlaw's safety were closer to home:

<sup>&</sup>lt;sup>2</sup> Pseudonyms are used for focus group participants.

More dangerous was the situation that Mary's husband created:

"He got up in the middle of the night, he would pace the kitchen....and he was a smoker and we have a gas stove and when I got up in the morning after a little nap, the stove was on."

Mary's statement, "safety in the home is a big thing. In order for somebody else or the caregiver to get some rest you have to come up with something," was met with nods of agreement from other focus group participants.

As part of the process of providing care at home, wives become guards, husbands become prisoners, and mothers who have fed their families for decades are no longer permitted to be in the kitchen without supervision.

As part of the process of providing care at home, wives become guards, husbands become prisoners, and mothers who have fed their families for decades are no longer permitted to be in the kitchen without supervision. Discussing the shifts that had occurred in his relationship with his mother who has dementia, Bob revealed:

"Supper time...we regularly have some stress between us because she feels that her playing the role of mother...is her duty and there's no reason why her son, her boy, should have to cook for his mother. So we constantly do a little dance in the kitchen trying to work around each other and who's doing the cooking and who's helping and that sort of thing".

Aging in place almost becomes secondary to caregivers' and their relatives' desires to seek continuity. If attempts at continuity are compromised by restrictive management of behaviors, another place, even a nursing home, might provide more continuity. Mary praised the situation at the long-term care facility where her mother had been placed:

"She's doing really well. She has that whole long hallway to wander in. She wanders in that whole large dining area. There's this wonderful game room with toys and dolls and books. But mostly she pushes the sweeper and she dusts because that's what her life was: gardening, being a mother, a wife, a homemaker....And so she's content to do that now."

However, for many of the caregivers, keeping their relative with dementia at home, where they could age in place represents consistency, order, familiarity, sentiment, comfort, all of which are viewed as important to a high quality of life. As summarized by Jane, "Keeping her out of a nursing home is what we're trying to do." Fran had a similar goal for her mother, "I was determined I was going to keep her home. I was not going to put her in a nursing home until we had to...," which occurred after three and a half years of in-home caregiving.

For caregivers, the best of all possible worlds would be to have their relative with dementia age in place in the least restrictive environment. One strategy for accomplishing

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this scenario is to develop technology-based strategies to enhance continuity (and minimize discontinuity) so that home can contribute to, rather than threaten and limit, a high quality of life for both caregivers and their relatives.

Introducing technology into the homes of families with dementia requires sensitivity. However, none of the homes in which focus group participants resided were without any technology whatsoever. In fact, caregivers reported using a range of technologies in their day-to-day lives, including computers for Internet access and e-mail, and some families directly applied existing "low-tech" solutions (e.g., intercoms, alarms) to be able to monitor, communicate with, and maintain the safety of their relative with dementia.

A number of caregivers put locks and/or alarms on the exterior doors of their homes. Cindy cared for her mother, who did not sleep through the night: "I was lucky enough to find a person who would design a mechanism for each of the doors so that when the door was opened the alarm would go off where I slept."

Tim, who described himself as a "technically oriented person," installed a wireless doorbell so that his wife, who is frequently confined to bed, can communicate with him when he is in other areas of their home: "So, when she has a problem...I'll hear the doorbell... 'Ding,' and I come running. If it's a case of 'I want you to come here but it's not urgent', she'll ring it twice." Tim and his wife also communicate via intercom when they are in different areas of their home, and Tim has tried to think of a way to adapt an intercom or a baby monitor so that his wife can communicate from her bed with visitors

who come to the front door, but he has not yet solved that particular challenge. For those times when Tim must be away from home, Tim's wife wears a pendant health care monitor, and he considers the cellular phones that he purchased as the two-way "umbilical cord" that connects him to his wife and her to him.

With some encouragement, caregivers were able to visualize creative technological solutions to some of the demands in caregiving.

With some encouragement, caregivers were able to visualize creative technological solutions to some of the demands in Some of the proposed caregiving. technological solutions to increase safety were quite ambitious (even futuristic); participants in two groups proposed, and were quite excited about, the prospect of a "nursing care robot" that would follow behind the individual with dementia, providing physical support to decrease the probability of falls and assisting with transfers from bed to chair and with toileting. Kathleen claimed: "We want a mechanical robot to help them walk and we want a mechanical device to get them on and off the toilet easier."

Participants in two of the groups expressed excitement about a "little necklace type thing that had a little camera in it" that the individual with dementia would wear at all times. This would permit the caregiver to view what is happening from their relative's perspective, and, should the individual wander away from home, the camera would transmit an image (ostensibly, to be viewed remotely at a computer monitor) to the caregiver, who

would then be able to see where the individual with dementia was wandering.

Caregivers were receptive to the use of technology to provide continuity for the relatives for whom they care. Kathleen commented:

"If we could come up with something where they could stay in their familiar surroundings, either in their own home or in the home of a family member, it would be really wonderful. Things that would monitor their wandering. Things that would monitor when they are in a dangerous situation like if they are trying to cook or something."

Even when considering these most creative technological solutions, caregivers were cognizant of the inherent trade-off between safety on the one hand and dignity, respect, privacy, and desires for independence and autonomy on the other hand. For example, when discussing the nursing care robot, Tim suggested that, when assisting in the bathroom, "actually, and with it being a robot, it could just stay in the bathroom. You know, maybe turn its back..." Similarly, when discussing the necklace monitor, Jane and Kevin had the following exchange:

Jane: "This way they'd still have their freedom of being outside."

Kevin: "That's right. They need to roam."

Jane: "But this way if they got out of the way, you'd know where they are."

Kevin: "They need, they want, their independence."

As illustrated above, caregivers' concerns for their relative's safety were paramount, as reflected in their discussion of strategies to combat (unsafe) wandering, "safety proof" their home, and monitor their relative's activity. Bob stated that, "Being able to monitor activities would be a huge asset," and Clyde agreed: "Now, my mother-in-law would like a monitor. She could see what he [her husband] is doing in the room." Tim found the idea of a visual monitoring system an improvement over the intercom system that he and his wife currently use:

"I never know if she's asleep or awake and if she's asleep, I don't want to wake her up. If I could peek in and see, then I wouldn't bother her."

In addition, caregivers discussed technological solutions that might provide some relief from the all-consuming nature that can characterize caregiving. In Mary's words: "Everything you do is around the sick one, the one who's ill. That's where your life is." Tim quickly agreed; "You can't just decide, 'I'll go to the store now." In the absence of some type of monitoring system, caregivers find themselves limiting or forfeiting their own leisure time; quickly running errands while their relative naps and sleeping fitfully at night, if at all, when their relative is up and about.

Caregivers extended the application of some type of visual monitoring system to help bridge geographic distance between the individual with dementia and concerned family members. As Delores noted, "I think with family a lot of times the family doesn't understand it. And they are afraid of it so they stay away. And therefore you don't get any help from them." Ruthea talked about the

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difficulty she had explaining changes in their mother's condition to her sisters who lived several states away, before they came for a visit:

> "I tried to prepare my sisters before they came...And my sisters admitted afterward that I had tried to prepare them but it was really a shock to actually be there and to see it."

Mary, who had placed her husband in a longterm care facility, saw an application for a visual monitoring system to her situation:

"I was going up twice a day. And that was a lot, so that didn't last long. If there were visual communication from home to the nursing home, it would give the caregiver at home more space..."

Throughout the discussion of technologies (e.g., cameras, and interactive, web-based, communication software), caregivers were quick to point out that there were some challenges in caregiving that simply could not be addressed with technological solutions. Pointing to a series of scratches on her arm that resulted when Becky had bathed her relative, she asked, "How is technology going to stop this?" Although this is an extreme example, there was consensus that technology could not be expected to entirely replace or substitute for the efforts of family caregivers.

Caregivers identified a number of trade-offs that most likely would accompany the introduction of these technologies to meet the demands of caregiving. For example, caregivers recognized that cameras that would permit them, or another person at a remote

location, to monitor their relative could, at the same time, compromise their own privacy (if, for example, personal hygiene and bathroom behaviors were monitored). As Bob put it, "It could present some awkward situations if [the individual with dementia] would accept being monitored." Kathleen elaborated:

"My feeling is you wouldn't want a camera looking at them taking a bath or going to the toilet, but if ....you knew they were in the bathroom that wouldn't really take away from the privacy necessarily. You would know where they were but, as far as having a camera in there watching them I don't think you would want that because that would really be bad...for their dignity."

Another consideration for caregivers was if web-based technology were employed, whether access to the images could be controlled and/or limited. As pointed out by Kathleen,

"It might be a safety factor if it was just open and anybody could watch it because if somebody was aware that these people are not all together...it would be a good chance for a bad person to focus in on going there and bothering this person."

Despite this concern, caregivers were amenable to the idea of respite care at a distance, whereby someone at a remote site could monitor the activities of the individual with dementia while the caregiver performed other responsibilities. Kathleen said, "In the earlier stages it would be better than leaving them totally on their own." Sally agreed, admitting:

"There's been lots of times before she [her grandmother] got really bad that I would be nervous going to the store. Because there would be no one there. This is before she got really bad and you would be so nervous you couldn't shop or do anything. So that would be nice. That way you would feel comfortable when you left her."

When prompted, Kathleen and Sally suggested that, were such a monitoring process in place, at the first sign of trouble a page could be sent to either the caregiver or a neighbor who was on call who could quickly respond to the emerging problem. Taken together, Kathleen and Sally's comments underscore that such monitoring is not a panacea; it is not universally appropriate for all individuals with dementia at any stage in the disease process. An additional concern. not addressed by caregivers, is the extent to which individuals with dementia might attempt to tinker with and/or remove sensors and cameras. As such, careful placement of these devices is required.

In addition to these issues, caregivers advised that, to maximize utility, technological solutions to challenges in caregiving should take into account the likelihood of multiple users (i.e., both the caregiver and the individual with dementia, as well as other family members) and be sensitive to the variable and changing levels of functioning in an individual with dementia. In general, caregivers felt strongly that technological solutions were neither appropriate nor useful across all situations. and that monitoring their relatives with dementia via technology clearly was not a substitute for their presence. Ultimately, caregivers made it quite clear that they do not

aspire to become "technology whizzes;" rather, they are interested in easily obtained, affordable, easy to use solutions to some of the challenges they face.

Phase 2: Use the Results from Phase 1 to Develop Technological Interventions that Overcome the Major Challenges Identified by In-home Caregivers

## What We Know: Summary of the Existing Literature

Many studies have investigated the use of technology by older disabled persons and/or their caregivers. Appendix A presents an annotated bibliography that exemplifies the many types of technology that are available, the various ways in which these technologies are employed, and attitudes of different constituencies toward the use of technology to support caregivers and/or their relatives with dementia. Technologies can be characterized as falling into one of three broad categories: assistive devices (e.g., wheelchairs), environmental modifications (e.g., ramps or grab bars), and computerized or electronic devices (e.g., emergency medical systems or "smart houses"). Some devices modifications are considered "low-tech;" this usually means that the technology is mechanical (as opposed to electronic), considered simple and/or easy-to-use, and is commonly available (see item 4 in annotated bibliography). An example of a low-tech device is the lift-chair. "High-tech" typically refers to more complex devices that may have some electronic or computerized components and require a higher skill level for utilization (See the attached annotated bibliography for a range of available technologies).

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Researchers have examined the reasons that older adults, among others, adopt or refuse to adopt certain technologies (items 1, 21, 42, 44, 62 in the annotated bibliography). Among the many reasons identified, the level of the technology seems particularly salient. The more complex the technology, the less likely it is to be used, unless the potential user possesses a skill level to match the technology. For example, a person is much less likely to choose a computer-controlled device if they do not already possess sufficient computer skills to utilize the device. Thus, it appears that if the learning curve to use the device is steep, it is less likely to be used.

Among the high-tech devices or systems currently under development and testing are so-called "smart houses." These residential homes contain many electronic devices that monitor and/or control various aspects of the home such as climate, safety, activity, and object location. A nursing home recently constructed in Oregon is completely "wired" such that electronic identification badges can be used to monitor resident location at any time and administrative record keeping can be updated from any location in the facility. Residents can track their personal medical information and, if they choose, make it available to their families via the Internet (item 6).

The Aware Home Research Initiative at Georgia Tech University has built a two-story residence that will serve as a living laboratory with computing technologies that will "both perceive and assist its occupants" (item 81). The home includes a "smart floor" that can identify specific residents by their gait and a photo-frame interface located in a distant adult child's home that enables that

individual to monitor a parent's health and activities. These projects focus on allowing older adults to age-in-place in their own homes with assistance from computing technology.

There are several challenges to the development of smart house technology that must be overcome before it can be made widely available to consumers. Some of this technology must be "built" into a residence or building as it is constructed or major renovations would be needed to outfit a current structure. The expense of installation and maintenance of these highly complex systems is another barrier to widespread use. Technology becomes obsolete quickly and must be continually updated. Although over time these technologies may become less costly than nursing home care, they will still be expensive to install and maintain and may be unsuitable for installation in older homes. Also, it is unlikely that these technologies will replace human service providers for activities such as bathing, grooming and other activities of daily living. There are also ethical issues related to monitoring of people's behaviors and activities, particularly for individuals with cognitive disabilities who are unable to give informed consent. Security can be a concern when the Internet is used to deliver the gathered information to agencies or family members.

In spite of the aforementioned technological challenges in meeting the needs of caregivers and individuals with dementia, there are devices and services currently available that can assist caregivers and those for whom they provide care. To do so, a technological solution should meet most, if not all, of the following criteria:

- The solution should be easily adapted to a caregiver's current environmental and caregiving situation.
- The solution should be relatively low cost.
- The solution should be technologically stable so that it has a reasonable shelf life and does not require constant updating.
- The solution should take advantage of currently available technology; meaning it must be readily available and readily serviceable.
- The learning curve for using the solution should be modestly sloped and time-limited.
- Security and ethical issues should be considered and addressed.

#### The Solution

The technology-based solution selected during Phase 2 of the project is the Xanboo Smart House Management System. A team that included a computer industry consultant and an occupational therapist reviewed the findings from Phase 1, identified a range of possible product options that might be presented to caregivers for use at home, and recommended to the research group that we use the Xanboo Smart Home Management System (hereafter referred to as The System).

The System is computer based, easy to install and use, and requires an Internet connection (e.g., AOL, MSN or any other Internet Service Provider) to allow access to the Xanboo website. The System runs on a

Windows operating system (Windows 98, ME, 2000 or higher) and currently is not available to run on the Macintosh operating system. It requires an Intel Pentium CPU or its equivalent, with MMX<sup>™</sup> support, at 233Hz or faster speed, a 2X CD Rom drive, at least 64 MB of RAM, and 30MB of hard drive space is recommended. An available USB port is also required for the system controller.

The System may be purchased overthe-counter in retail outlets that sell computer equipment. The Xanboo Internet Home Management System starter kit comes with a system controller, a color video camera with built-in motion sensor and microphone, camera mounting accessories, the Xanboo software, and installation instructions (cost is \$49.99). Additional cameras (up to four at \$49.99 each) and different enabled devices may be added to the starter system (most sensors cost \$19.99 each). These include:

- Acoustic sensors, to detect sounds;
- Door/Window (contact) sensors, to detect something opening or closing, like a door, window or even a file cabinet;
- Power On/Off sensors, to detect a change in the power on or power off condition of an appliance;
- Temperature sensors, to detect changes in temperature; and
- Water sensors, to detect the presence of water, for instance, a leak in one's basement.

The System requires no complicated rewiring and plugs into a USB port on any PC. The

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cables are color-coded to minimize installation problems and the software is designed to recognize attributes of the computer being used. Step-by-step instructions for installation are provided.

The System controller provides the communication between Xanboo-enabled devices, such as the cameras and sensors, and the Xanboo software. The backbone of The System is the Internet website operated and maintained by Xanboo. Computer access to the Internet site is by subscription (\$19.95 per month) and logon requires a registered user ID and password. These features allow the user (and anyone else provided with the user ID and password) access to The System from anywhere Internet service is available. Among other features of the website, it allows the downloading of video images and video clips to a personal computer. (In the future, as new cameras and devices become available, it is conceivable that upgrades of the Xanboo software may need to be installed. At this point it is difficult to estimate the active life of the current version of the technology or of the costs associated with a system upgrade.) As currently configured, The System does not provide for two-way communication.

The Xanboo System allows for monitoring of a residence through placement and control of video cameras and sensors.

The Xanboo System allows for monitoring of a residence through placement and control of video cameras and sensors. These sensors may be set to provide a caregiver or other interested party with immediate notification by e-mail, pager, text

messaging cell phone or personal digital assistant (PDA).

A household located in a suburb of Cincinnati was outfitted with The System including two video cameras (with placement in the kitchen and the family room) and four sensors including one for sound placed near the phone, one for the bathroom door to detect opening/closing, one at a window to monitor breaking glass, and a motion sensor in the kitchen to monitor activity. (The computer that runs the system may be placed virtually anywhere in the household, including in a locked room so that access is controlled.). The Xanboo website (www.xanboo.com) may be accessed using the Internet Explorer browser (or Netscape Navigator). Successful logon takes the user directly to the XanBoard screen which provides a running status report on all cameras and sensors. The screen allows for easy identification of the date and time at which a camera or sensor was triggered. In addition, if motion occurs in a room where a camera is installed, the camera will capture a 10-12 second video clip and make it available for review on the XanBoard screen. The XanControl screen specifies whether the system is on-line and provides status information for the installed cameras and sensors. In the residence where The System was installed, one camera was placed in the kitchen and another in the family room. A simple mouse-click brings up each camera with real-time video images from the room selected.

# Phase 3: Caregivers' Assessment of the Utility of the Technological Solution Identified in Phase 2

Two focus groups comprised of 8 individuals were conducted to solicit

caregivers' assessment of the system that was developed in Phase 2 of this project.

#### Recruitment Procedures

Participants for the Phase 3 focus groups were recruited from among the group of caregivers who participated in Phase 1 of the project. Phase 1 participants were contacted by a member of the research team and invited to participate in a Phase 3 focus group to observe a demonstration and critique the technological solution that was developed in Phase 2. Again, participants were told to expect the focus group to run for approximately 90 minutes. Two focus groups were conducted, one in Mansfield and one in Fostoria

#### Format of Focus Groups

The same two members of the research team who conducted the Phase 1 focus groups also conducted the Phase 3 focus groups. One team member (Dr. Kart) facilitated the focus group while the second team member (Dr. Kinney) served as co-facilitator. The cofacilitator took notes that were used during the group to summarize main points and guide subsequent discussion. The format for each focus group mirrored the format of the Phase 1 focus groups, with the exception that participants in Phase 3 were not asked to complete the demographic sheet. These focus groups were not audio-taped. The focus group began with participants introducing themselves, and providing a brief update of how their caregiving situation compared to six months before, when they participated in Phase 1. An introduction to the demonstration and focus group was provided by the cofacilitator, who began by summarizing the purpose of Phase 1, which was to learn about

the day-to-day experiences of caregiving (i.e., what was working well and what wasn't working so well). Three over-arching concerns were identified by caregivers who participated in Phase 1: a) safety (whether at home or in the nursing home; wandering, bathroom, kitchen); b) providing normal activities and day-to-day routine (pleasurable activities; keeping relative with dementia busy) and c) how hard it is to keep family members who are not around informed about how things are going.

Also, it was reported that although many of the Phase 1 participants use computers, they do not think of themselves as being particularly savvy about technology. It was explained that the findings from Phase 1 were used to guide Phase 2 of the project, and that the purpose of the Phase 3 groups was to demonstrate the technology that was identified and evaluated in Phase 2, and allow caregivers to assess the technology.

#### **Results from Phase 3**

**Description** of Focus Group Participants. The eight caregivers who participated in both Phase 1 and Phase 3 of the project did not differ significantly from caregivers who only participated in Phase 1 with respect to age, gender, education or on their subjective ratings of health. However, on average, Phase1 caregivers reported being in the caregiver role for a longer period of years than the Phase 3 caregivers (6.6 v. 3.4 yrs, p <.05).

Findings from Focus Group 1. The first Phase 3 focus group of four caregivers was held in Mansfield, OH at the offices of the Area Agency on Aging, Inc. The particular advantage of this site for

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conducting a demonstration of the technology was the availability of a network broadband connection for access to the Internet website. Although the website can be accessed through a telephone modem, the clear advantage of the network connection is in the speed of transfer of real-time video.

Although name plaques were in place, introductions were made and focus group participants provided a brief update on status changes that had occurred (to the individual they were caring for or themselves) since their last contact with the research group.

Initially, The System was presented to focus group participants as described above. With a laptop computer and a projector that projected an enlargement of the computer screen onto the wall for all focus group participants to see, we used the Internet Explorer browser to open the Xanboo website. Participants were shown the logon screen and the ease of logging in. Successful logon takes the user directly to the XanBoard screen which provides a running status report on all cameras and sensors. Participants were shown this screen and were easily able to identify the date and time at which the phone rang or an enabled device sensed motion. If motion occurs in a room in which a camera is installed, the camera will capture a 10-12 second video clip and make it available for review on the XanBoard screen. This feature was demonstrated.

The XanControl screen specifies whether the system is on-line and provides access to the installed cameras, in this case the cameras placed in the kitchen and the family room. A simple mouse-click brings up each camera with real-time video images from the room selected. For 10-15 minutes, focus

group participants observed real-time video from the residence in Cincinnati. By prearrangement, they were able to monitor a member of the household carrying out everyday tasks in the kitchen (e.g., making acup of tea) and family room (e.g., watching tv and folding laundry).

In response to the demonstration, participants had many comments and questions, although attitudes were generally quite positive.

In response to the demonstration, participants had many comments and questions, although attitudes were generally quite positive. As Julie expressed, "That's an excellent idea—I wish I had that several years ago." Delores concurred, "this is wonderful." Tim pointed out that "there could be a security camera outside the [front] door; you could access it [the camera] from anywhere—in the house or outside the house." Becky asked whether her "son in the next state would need a computer" to access the website? (Yes!)

Because expressions were so positive, participants were prompted about what possible problems there might be with the system. Responses were as follows:

- "You would have to have a computer."
- "...even though the price is quite reasonable, it does cost money."
- "I wouldn't want the pager going off every time the phone rang. I'd only want emergency things making the pager go off."

• "You'd have to be connected to Xanboo."

Subsequent discussion ranged far and wide over related issues involving the use of technology in the home. Participants were reminded that in the Phase 1 focus groups, some concerns were expressed about having cameras in the home – How did they feel about this now? Julie reflected that, "it would be ok if it was in my mother-in-law's house; it wouldn't be in my house." Others indicated that it would be acceptable if they could control the cameras. As one participant put it, "put a towel over them, if you need some down time."

Findings from Focus Group 2. A second focus group was conducted at a local long-term care facility in Fostoria, OH. Four participants were in attendance, all of whom had participated in a Phase 1 focus group held at the same site. Introductions were made and participants provided an update about themselves and/or the person for whom they give care.

Research members team (the facilitator and co-facilitator) came prepared with a laptop computer and projector to demonstrating the system using a telephone modem to connect to the Internet website. Unfortunately, the characteristics of the nursing home's internal phone system made it impossible to connect by phone to an Internet service provider. As a result, we were unable to demonstrate the technology, but did provide a detailed description of The System, including cameras and enabled devices, the website, and how the system could be used. This was not difficult, as three of the four participants were somewhat familiar with

computers and used them for e-mail and surfing the web.

Again, participant comments were generally positive. As Betty indicated,

"Yes—it is wonderful! I have a daughter in Monroe, Michigan, and she really doesn't understand what it is like...She comes down once a month, but that's really not enough; if you don't live with it...."

The implication was that with the Xanboo system, as it was described, her daughter could access the website and use the cameras to actually see what was going on. Some discussion ensued about the adaptability of this technology to other settings including assisted living and/or long-term care facilities. As Madeline offered,

"My husband is healthy, except for this disease...he could be wandering for years. Wandering is my number one problem. In a nursing home, couldn't this technology help?"

Participants were probed on a number of important issues. For example, on the costs of The System, Kevin pointed out that "compared to nursing home costs, this is really cheap! Do you think there could be a tax incentive for home caregiving or something?" The idea was introduced that an agency, perhaps an Area Agency on Aging, could offer a respite monitoring service using this technology. Ruthea agreed:

"Someone could make a lot of money, with this. I could have a home business, and give up my day job. I could work out of my home, watching

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people for others so that they could get out."

Finally, focus group participants were asked if there were "places where you and/or your relative with dementia wouldn't want cameras?" Kevin opined that, "my mother would probably be offended, but it depends on the person..." and Ruthea suggested that context could mean everything: "If you don't live with it, you just don't know. Families could use this to check in."

Because our intent was to determine whether family caregivers would be receptive to this type of technological intervention, several issues associated with implementation of the intervention were not systematically explored with focus group participants. The first issue is the tradeoff between caregivers' efforts to maintain the safety of their relatives with dementia while at the same time maximizing the autonomy of those relatives. A second related issue concerns privacy. Even careful placement of cameras and sensors may result in private behaviors becoming observable to others. This may be the case for individuals with dementia whose private behaviors become observable to the caregiver who resides with them, as well as for caregivers whose private behaviors become visible to other family members who log in to the website from 100 miles away. In addition to the two issues identified above, successful implementation of the technology to conduct a careful evaluation will require the development of clearly articulated protocols and procedures to guide responsible use of the technology described in this report.

### **Conclusion**

The results from this pilot project offer evidence that there are affordable technologies that have the potential to assist family members in their efforts to care for relatives with dementia at home. Further, and perhaps more importantly, this small group of caregivers was amenable to the prospect of using these technologies. Admittedly, some caregivers were more amenable than others, and identified applications for the technology for themselves and their families. For one caregiver, it was the potential respite such technology could provide from the constancy of near 24 hour vigilance. For another, it was the prospect that an adult child living in Michigan could "look in" and perhaps better understand the consequences of dementia for her parents.

Based on the results of this pilot project, we plan to undertake a demonstration project in which the Xanboo system or its equivalent is tested with in-home caregivers. The purpose of such a demonstration would be to evaluate the following aspects of the intervention: 1) caregivers' perceptions of the advantages and disadvantages of using the technology intervention; 2) the extent to which the intervention changes caregivers' day-to-day lives (e.g., the amount of time spent caregiving; the amount of time spent in social activities outside of the home); and 3) caregivers' quality of life (i.e., psychological

well-being). The results of such a demonstration would help us to answer such policy-related questions as:

- With appropriate training and support, will caregivers use the technology?
- What are the effects of the technology on caregivers and their relatives over time?
- Does use of the technology facilitate communication among family members at great distance from each other?

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#### References

Argueelles, S., & von Simson, A. (1999). Innovative family and technological interventions for encouraging leisure activities in caregivers of persons with Alzheimer's disease. <u>Activities</u>, <u>Adaptation and Aging</u>, 24, 83-97.

Brennan, P. F., Moore, S. M., & Smyth, K. A. (1991). ComputerLink: Electronic support for the home caregiver. <u>Advances in Nursing Science</u>, 13, 14-27.

Cavanaugh, G., & Emerman, J. (n.d.). ASA study: Aging agencies must do more on assistive technology. Retrieved on July 10, 2001 from http://www.asaging.org.

Cheston, R., & Bender, M. P. (1999). <u>Understanding dementia: The man with the worried eyes.</u> London: Jessica Kingsley.

Cox, C. (1997). Findings from a statewide program of respite care: A comparison of service users, stoppers, and non-users. <u>The</u> Gerontologist, 37, 511-517.

Gitlin, L. N., Corcoran, M., Winter, L., Boyce, A., & Hauck, W. H. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. The Gerontologist, 41, 4-14.

Liu, K., Manton, K. G., & Aragon, C. (2000). Changes in home care use by disabled elderly persons: 1982-1994. Washington, DC: AARP.

Mahoney, D. F. (1998). A content analysis of an Alzheimer family caregivers virtual focus group. <u>American Journal of Alzheimer's Disease</u>, 13, 309-316.

Marshall, M. (1999). Technology to help people with dementia remain in their own homes. Generations, 23, 85-87.

National Alliance for Caregiving/AARP. (1997). <u>Family caregiving in the U.S.:</u> <u>Findings from a national study</u>. Washington, DC: National Alliance for Caregiving/American Association of Retired Persons.

Schulz, R., Maddox, G., & Lawton, M. P. (Eds.) (1999). <u>Annual review of gerontology and geriatrics: Focus on interventions research with older adults</u>. New York: Springer.

Smyth, A., & Harris, P. B. (1993). Using telecomputing to provide information and support to caregivers of persons with dementia. The Gerontologist, 33, 123-127.

Wagner, D. L. (1997). <u>Comparative analysis of caregiver data for the caregivers to the elderly</u>, 1987 and 1997. Bethesda, MD: National Alliance for Caregiving.

# **APPENDIX**

Annotated Bibliography

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#### **Bibliography**

#### **Abstract**

1. Agree, E. M., & Freedman, V. A. (2000). Incorporating assistive devices into community-based long term care: An analysis of the potential for substitution and supplementation. *Journal of Aging and Health*, 12(3), 426-450.

Data from the Phase 2 Disability Supplements to the 1994-95 National Health Interview Surveys were used to compare the use of personal care and equipment among persons reporting difficulty with a given ADL. Substituting equipment (assistive devices) for or to supplement personal care is task-specific and depends on the characteristics of the devices and the personal care providers. In general, those using complex devices (e.g., chairlift, hospital bed) are more likely to use formal care services, whereas those using simple devices (all other devices) are less likely to use informal care services provided by friends and family.

Key Words: Assistive devices, communitybased long-term care, personal care

2. Allen, S. M., Foster, A., & Berg, K. (2001). Receiving help at home: The interplay of human and technological assistance. *Journal of Gerontology*, *56B*(6), S374-S382.

This research investigated use of mobility equipment as a substitute for human assistance and examined whether use of mobility equipment results in out-of-pocket cost savings associated with formal home care services. Data was collected from 9,230 respondents to supplements to the 1994 and 1995 National Health Interview Survey. Findings suggest that canes and crutches (not walkers and wheelchairs) are effective and efficient home care resources that can increase autonomy and facilitate self-management in older adults with disabilities and chronic conditions.

**Key Words: Mobility equipment, home care resources, autonomy, self-management** 

3. Anders, K. T. (2000). Toilet (re)training. *Contemporary Long Term Care, April*, 41-42, 46.

This article on direct patient care assesses efforts to provide better continence for dementia residents of nursing homes and assisted living facilities. Environmental adaptation (signs, color, lighting), staff training, and physical help (including use of available technologies) are discussed. One technological intervention briefly discussed is called extracorporeal magnetic innervation — a chair with a magnetic field

generator that provides stimulus to relax muscles of the pelvic floor.

# Key Words: Continence, toilet re-training, dementia, nursing home, assisted living facility

4. Assistive Technology. (n.d.). Retrieved on July 11, 2001 from: http://www.ucpnyc.org/assist.htm

Assistive technology is any device, item, piece of equipment or service that can be used to maintain or improve functional abilities. Assistive technology represents a wide range of products and services, which can be categorized as either high tech or low tech. With assistance from technology, individuals with disabilities can learn more effectively, live more independently, and meet demanding career and life goals. The primary goals of assistive technology are the enhancement of capabilities and the removal of barriers to performance. Limited information is provided on specific assistive technology options for the four following daily activities: shelter, personal care, interpersonal relationships, and home management.

# Key Words: Assistive technology, activities of daily living, disability

5. AT funding for persons with cognitive disabilities. (n.d.). *AT Messenger Newsletter*. Retrieved on July 11, 2001 from: http://www.asel.udel.edu/dati/Atmessenger/html

Several factors must be considered when determining the appropriate assistive technology funding source(s) for a given device. Typical considerations are the person's age, type and severity of disability, eligibility for state or federal government benefit programs, insurance coverage, type of equipment needed, and the intended use of the equipment. Medical necessity, generally a requirement for reimbursement, is usually met when the selected treatment can restore a physical function that has been absent or significantly diminished due to a diagnosed medical condition. The nature of the assistive device's application can be viewed in terms of the task and/or the environment in which the task is to be carried out. Reimbursement through Medicaid, public and

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private insurers, vocational rehabilitation, Social Security, and Medicaid Waiver programs is explored in this article.

Key Words: Assistive technology, reimbursement

6. Berck, J. (n.d.). The wired retirement home. New York Times.Retrieved April 6, 2001, from: http://www.nytimes.com

This article describes the "smart houses" developed by a residential care complex in Portland, Oregon. The complex consists of 10 group homes, each of which has separate bedrooms for 12 residents, common public areas, and a kitchen. Among the technologies found in the units are bed sensors, infrared motion sensors, and programmable lights for the purposes of cueing residents. In addition, residents wear tracking badges that serve as electronic room keys and help buttons. Tracking information is sent via a high-bandwidth fiber optic system to a central data base for purposes of monitoring; family members and residents can also access these data via the web. Concerns associated with smart houses, such as loss of human interaction and privacy, are discussed.

**Key Words: Smart houses** 

7. Brink, S. (1997). The twin challenges of information technology and population aging. *Generations*, 21(3), 7-10.

Two important societal trends are occurring at the same time: the aging of the population and the shift to a technology-based information economy. Which trend will dominate? Information technology has the potential to redefine disability, makes possible new patterns of activities associated with the life course, requires know-how, and helps to manage consumption. Will the potential benefits of information technology be equitably distributed across the population, including older people?

**Key Words: Population aging, information technology, aging consumers** 

8. Calkins, M. P., & Namazi, K. H. (1991). Caregivers perceptions of the effectiveness of home modifications for community living adults with dementia. *Journal of Alzheimer's* 

The purpose of this study was to identify a variety of modifications made mostly by caregivers to the homes of people with Alzheimer's and related dementias (ARD), to

Care & Related Disorder Research 6(1), 25-29. Retrieved September 5, 2001, from: http://www.homemods.org/library/calkins.html

ascertain the effectiveness of each modification, and to evaluate the impact of the changes on the confused person and on the caregiver. Of primary concern were modifications made to increase the safety or autonomy of the persons with ARD. The following four categories of modification were explored: wandering, incontinence, safety and independence, and reducing havoc. Concern for safety of the person with dementia was frequently the impetus for making an environmental modification. Although more research is needed, results of this study suggest that modifying the home environment can enhance the lives of people with dementia and their caregivers.

Key Words: Alzheimer's disease, dementia, home modifications, caregiver, wandering, safety, incontinence

9. Cavanaugh, G., & Emerman, J. (n.d.). *ASA* study: Aging agencies must do more on assistive tech. Retrieved on July 10, 2001 from: http://www.asaging.org

This article reports the results of a study conducted by the American Society on Aging. Funded by a grant from the Administration on Aging, the purpose of the study was to explore whether the aging and disability networks were collaborating to promote independence and autonomy among older adults. Specifically, the study focused on state units on aging, area agencies on aging, and the 56 state programs funded under the "Tech Act" of 1988. Results indicated that Tech Act Programs evidenced the highest involvement in providing services to older adults, followed by local area agencies on aging and then state units on aging. The article concludes with a discussion of two challenges-the funding of assistive technology and home modification services, and the need to increase awareness of the importance of this funding at the local level.

**Key Words: Assistive devices, funding** 

10. Childress, C. A. (1999). Interactive e-mail journals: A model for providing psychotherapeutic interventions using the

The Internet affords psychologists unprecedented opportunity to provide psychological services to populations who might

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internet. CyberPschochology & Behavior, 2(3), 213-221.

not ordinarily turn to the mental health system but who may nevertheless benefit from psychological intervention. This article discusses a model for providing online psychological interventions based on the similarity of e-mail composition to traditional journal writing. Two different approaches to interactive online journaling, the Intensive Journal method and dream journaling are examined for their possible application to the delivery of psychological services via the web. Potential restrictions and risks associated with Internet-based psychological interventions are discussed.

**Key Words: Internet-based intervention** 

11. Constantly connected: Unique residential lab This news release describes the opening of the studies how technology interacts with and affects domestic lifestyle. (2000, April). Retrieved on September 17, 2001, from Georgia Institute of Technology, Research News Web site: http://www.gtri.gatech. edu/res-news/html

Georgia Institute of Technology Broadband Institute Residential Laboratory, a facility that is capable of knowing the whereabouts, activities, and vital medical profiles of its inhabitants. The goal of the facility which combines communications connectivity with lifestyle computing is to discover technology combinations that unobtrusively enhance lifestyle in the home of the future – for special groups of inhabitants such as older adults and infants, and for families in general.

Key Words: Technology, domestic lifestyle, computers, communications connectivity

12. Coughlin, J. F. (n.d.). Technology needs of aging boomers. Issues in Science and Technology Online. Retrieved on July 10, 2001 from: http://www.nap.edu/ issues/16.1/coughlin.htm

This article discusses the role of technology in responding to the needs of an aging society, and argues the need for policies that will develop technologies to promote well-being, facilitate independence, and support caregivers of aging baby boomers. After summarizing the demography of aging, older adults' technological needs in the areas of transportation, home, personal communication, and a productive workplace are discussed. Also discussed is the role of technology in providing support for caregivers. The article concludes with recommendations to educate the public about

demographic trends, implement tax incentives to encourage investment in this emerging market, and develop mechanisms to ensure that lowincome older adults and their families have access to new technologies.

Key Words: Assistive devices, assistive technology, gerotechnology

13. Coulson, J. S. (2000). Shhhhh: An expert system for the management of clients with vocally disruptive behaviors in dementia. *Educational Gerontology*, *26*, 401-408.

Expert systems contain expert knowledge and provide decision support when experts are not available. Expert systems are a subset of artificial intelligence and have been used for educational purposes. The expert system described in this article was developed to train caregivers new to the area of dementia care in the management of vocally disruptive behaviors. Audio and video are interfaced with the software application to provide case studies of clients, allowing the user to select the most appropriate intervention.

**Key Words: Expert systems, caregiving, dementia, vocally disruptive behavior** 

14. Cummings, D. M., Morrissey, S., Barondes, M. J., Rogers, L., & Gustke, S. (2001). Screening for diabetic retinopathy in rural areas: The potential of telemedicine. *The Journal of Rural Health*, *17*(1), 25-31.

This article reports on the feasibility of a new approach in rural areas to screening for diabetic retinopathy. According to the authors, digital imaging is a feasible screening modality in rural areas, may improve access to eye care, and may improve compliance with care guidelines for individuals with diabetes mellitus.

**Key Words: Diabetes, rural communities, telemedicine** 

15. Czaja, S. J. (n.d.). Enhancing the home safety This article summarizes the most common of the elderly: Technological and design interventions. Retrieved on September 5, 2001, from: http://www.Homemods. org/library/life-span/enhancing.html rich to consider how assistive devices can be used to help older adults live successfully at home and

This article summarizes the most common sources of accidental injury among older adults living at home, and identifies the need to consider how assistive devices can be used to help older adults live successfully at home and perform routine tasks. Necessary steps in developing strategies that enable older adults to age in place include assessment of the types of problems encountered by older adults at home and data about the capabilities and limitations of

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older adults. The challenge of disseminating assistive devices is discussed, and the importance of human performance testing is highlighted. The article concludes with a summary of the types of knowledge that are needed to enhance the functional independence of older adults and to allow them to age in place in their own homes.

**Key Words: Aging in place, assistive devices** 

16. Davitt, J. K., & Kaye, L. W. (1995). Hightech home health care: Administrative and staff perspectives. *Home Health Care Services Quarterly*, 15(4), 49-65.

This study examines staff perspectives on the delivery of high-tech home health care services to older adults. Data were collected from a national sample of 154 agency directors and 92 local agency staff. Staff appears to recognize that high-tech services enhance the quality of life of older adults, however they believe it is difficult to define and more difficult to deliver. Developing appropriate staff training and quality assurance measures are necessary components of efforts to deliver high-tech services to older adults.

**Key Words: Home health care, high-tech service delivery, staff perspectives** 

17. Deatrick, D. (1997). Senior-med: Creating a network to help manage medications. *Generations*, *21*(3), 59-60.

This is a brief introductory report on Senior-Med, a project (located at HealthCare Associates in Boston) to address the problems of over- and under-medication and non-adherence to drug interventions, and to provide older adult patients with the tools to do a better job managing their medications. The linking of patients and providers through a communication network seeks to provide patients with tailored information, social support, and access to their physician and pharmacist providers.

Key Words: Over-medication, undermedication, nonadherence to drug interventions

18. Eisenberg, A. (2001, April 5). A 'smart' home, to avoid the nursing home. *New York* 

Older people want to "age in place" – that is, stay in their homes as long as is possible. The new aid may be the home itself, what academic

*Times.* Retrieved April 6, 2001, from: http://www.nytimes.com

19. Gilbert, N. H. (2000). Technology: The

future is now. *Provider*, 26(6), 53-54.

postpone institutional care. Sensors could provide surveillance and notify family and friends living elsewhere of significant changes in pattern – weakness in gait, for example. Other systems could provide memory augmentation by documenting tasks, or reminding people to take medication, eat or drink water. Researchers from Georgia Tech, University of Rochester, and MIT are interviewed regarding their work with diverse technologies to help support older people.

and corporate researchers are describing as the "smart" home. Presumably, "smart" homes

would use the growing power of computer networks and sensors to help the elderly avoid or

**Key Words: Smart home, technology, computers, cameras, older adults** 

This article provides a general overview of how technological innovation has the potential to make virtually all interactions including interactions in the health care industry, faster, cheaper, and easier, and to achieve patient outcomes that were not considered possible as recently as a decade ago. The article specifically describes wireless application protocol (WAP)/wireless technology and virtual reality. The article concludes with a description of technologies that can be used to help people with memory impairments function more independently, and interactive health care monitoring through wearable technology.

**Key Words: Assistive devices, health and long-term care, technological interventions** 

20. Gitlin, L. N., & Corcoran, M. A. (1996). Managing dementia at home: The role of home environmental modifications. *Topics in Geriatric Rehabilitation*, *12*(2), 28-39.

Environmental modification represents a new treatment approach that enables caregivers to manage daily care and maintain individuals with dementia at home, thus influencing caregiver well-being. This article proposes that dementia-related behaviors can be managed by modifying physical objects, simplifying task requirements, introducing assistive devices, or involving home

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alterations.

**Key Words: Assistive devices, caregiver intervention, home care** 

21. Gitlin, L. N. (1995). Why older people accept or reject assistive technology. *Generations*, 19(1), 41-45. Retrieved September 5, 2001, from: http://jbr.org/articles.html

We know from research and practice that acceptance and rejection of assistive technology is a complex matter shaped by a variety of factors. These factors can be categorized in three ways: person-based, such as perceived need, functional status, and personal evaluations of disability and devices; environmental, including the demands imposed by a particular task, and the physical and social characteristics of the context in which the device is used: and devicecentered, such as its aesthetic quality, durability, ease of use, and fit with the person and environment. Social attributes related to device and cultural judgments concerning independence and dependence, having or not having a disability, seem to represent powerful influences on whether devices are accepted into a person's daily public and private routines. The independent and joint influences of these multiple factors for facilitating or hindering the use of these devices remain under-researched and little understood for different segments of

Key Words: Assistive technology, assistive devices, use and abandonment, caregiver

22. Gitlin, L. N., Corcoran, M., Winter, L., Boyce, A., & Hauck, W. W. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist*, 41(1), 4-14.

Families (N = 171) of dementia patients were used to test the short-term effects of a home environmental intervention on self-efficacy and upset in caregivers and daily function in dementia patients. The intervention involved 5 home visits by OTs who provided education and physical and social environmental modifications. The program had a modest effect on dementia patients' IADL dependence and, among certain subgroups of caregivers, improved self-efficacy while reducing upset in specific areas of caregiving.

### **Key Words: Home care, home modification, clinical trial**

23. Harvey, F. (2001). Robots offer help to the elderly of the future: Technology and old age. *Financial Times Online*. Retrieved on July 9, 2001 from: http://www.ft.com

This article provides brief descriptions of a number of efforts currently underway to use technology to improve the quality of life of older adults. Examples of the technologies described include smart houses, home networking, electronic health monitoring, and robotics, among others. The article concludes with the identification of several challenges associated with the use of technology, including maintenance of older adults' dignity, independence, and control; protection of privacy; ease of use; and costs.

**Key Words: Smart houses, robotics** 

24. Holmes, D., & Teresi, J. (1996). Using technology in behavioral approaches to Alzheimer's disease. *International Psychogeriatrics*, 8(1), 67-71.

Behavioral-based treatment and management of Alzheimer's disease (AD) often fails to take advantage of technological development in related fields. Thus, what is needed are not new behavioral approaches but rather efforts in determining how to apply discoveries in these related areas to dealing with AD. The authors lay out a set of questions that provide a basis for strategic planning regarding research design, needed resources, roadblocks to be encountered, ethical dilemmas, implementation, and dissemination. Examples of domains and specific intervention techniques are offered.

## Key Words: Technology, Alzheimer's disease, behavioral approach, strategic planning

25. Hyzny, J., & Hammel, J. (2000). Using the computer and the World Wide Web with older adults. *American Occupational Therapy Association: Gerontology Special Interest Section Quarterly*, 23(4), 1-4.

The computer can be a tool to enable older adults and persons with disabilities to locate valuable information and perform online activities. In addition, accessing and locating information and resources to stay in the home and participate in the community is a major focus for older adults. Older persons encounter several obstacles to their use of computer technology: lack of training, fear of new technology, and accessibility. A brief summary

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of potential physical, cognitive, and sensory limitations experienced by older adults is presented. The authors conclude by encouraging occupational therapists and technology specialists to close the "digital divide" by sharing resources for connectivity and working with older adults to lessen the barriers to using this technology within everyday routines and occupations.

Key Words: Computer, World Wide Web, web sites, occupational therapist

26. Johnson, A. M. (1996). Dementia and ethical issues surrounding the use of technology in helping people with dementia. Response of paper presented at The 1996 Graham Lecture, Ismaili Centre, London.

From a provider perspective, Johnson discusses technology: A discussion of the practical and how technology should NOT be used – to reduce staff, maximize profits, compensate for bad building design, or in any thoughtless manner. Technology should be used to compensate for failing mental and physical powers, to improve quality of life, for security, to release staff for person-centered activity, to provide diagnostic information, to reduce staff stress, and normalize resident life. Providers are offered a series of questions to address in assessing possible use of any new technology.

> Kev Words: Technology, surveillance, provider perspective, dementia

27. Jones, B. N. (1999). Telemedicine in geriatric psychiatry. Psychiatric Annals, 27(7), 416-420.

Telecommunication options developed during the past decade have important implications for the delivery of health care services. This is especially the case for underserved populations, including older adults in nursing homes who frequently do not have access to adequate mental health services. Evidence for the reliability of delivering such service through videoconferencing is discussed. Also, the validity of telemedicine assessment of geriatric depression is discussed. Further studies of patient preference and clinician acceptance will help identify the limitations of the technology and refine assessment protocols.

**Key Words: Telemedicine, geriatric** 

#### psychiatry, geriatric depression, long-term care, videoconferencing

28. Kapp, M. B. (1995). Legal and ethical issues There is a strong and growing emphasis in the developments in home care services for the elderly: Innovations in policy, program, and practice (pp. 67-94). New York: The Haworth Press, Inc.

in home-based care. In L. W. Kay (Ed.), New U.S. on providing long-term care services both formally and informally to mentally and physically disabled individuals, primarily but not exclusively the elderly, in their own home environments. Both formal and informal home caregiving for disabled persons engender a rich and inescapable array of legal and ethical considerations for the various professionals and lay persons engaged in this enterprise. This chapter outlines several of the most salient of these issues.

> Key Words: Formal caregiving, informal caregiving, regulatory framework, legal liability, restraint

29. Kaye, L. W., & Davitt, J. K. (1995). The importation of high technology services into the home. In L. W. Kay (Ed.), New developments in home care services for the elderly: Innovations in policy, program, and practice (pp. 67-94). New York: The Haworth Press, Inc.

chapter summarizes programming strategies for agencies that are interested in providing technology-enhanced home health care services. A number of administrative challenges in providing high-tech care, such as documenting need, establishing admissions criteria, reimbursement issues, program management, staff training and supervision, quality assurance, and client assessment and training are reviewed, with an emphasis on the particular needs of older and physically disabled clients. Challenges, drawbacks, and benefits of high tech services are discussed. The chapter concludes with a highlight of innovations in high-tech medical care that can be provided in home settings, such as cardiac care, infusion therapy, artificial nutrition and hydration, and personal emergency response systems.

Key Words: Technology enhanced home health care; high-tech services; communitybased long term care

30. Kaye, L. W., & Davitt, J. K. (1999). Current This edited volume addresses the benefits, practices in high-tech home care. New York, drawbacks, and challenges of importing high-

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technology medical care into home-based care. It includes both a descriptive report of researchbased observations and interpretative analyses of the major issues and policies in the delivery of technology-enhanced care. The authors examine a number of home-based care services (e.g., ventilator therapy, artificial nutrition infusion pumps), in terms of legal, ethical, and administrative issues. Topics addressed in individual chapters include the experiences of providing and receiving high-tech home care; patients' rights; the impact of high technology on agencies; and guidelines for providers.

**Key Words: High-tech home care** 

31. Kienzle, M. G. (2001). Coming up short: Telemedicine's promise in perspective. The Journal of Rural Health, 17(1), 14-15.

This brief commentary questions whether telemedicine, even if optimally conceived, would eliminate unequal access to health care services. The author concludes that important factors remain untouched by the technology. These include income and education levels, availability of health insurance and sociocultural norms; all are powerful factors in rural and underserved settings.

Key Words: Telemedicine, access to health care, assessment

Kim, K. W., Lee, D. Y., et al. (2000). A telemedicine system as a care modality for dementia patients in Korea. Alzheimer Disease and Associated Disorders, 14(2), 94-101.

32. Lee, J. H., Kim, J. H., Jhoo, J. H., Lee, K. U., The authors developed a telemedicine system for dementia patients and examined the acceptance. reliability, and clinical outcomes of the service. There have been 140 patients registered for 2 years. Patient acceptance of the system is good, and consistency of assessment between the telemedicine system and in-person assessment ranged from 76% to 89%. Almost one-half (46%) of dementia patients in nursing homes showed clinical improvement with the service. The telemedicine system will be promoted as a core of a home-based care system for dementia patients.

> Key Words: Dementia, telemedicine, care system, clinical outcomes

33. Liebig, P. S., & Sheets, D. J. (1998). Ageism, Recent advances in medicine, rehabilitation, and disability and access to environmental interventions. Technology and Disability, 8, 69-84.

public health have increased life expectancy and caused the prevalence of disability to rise. These trends have resulted in a convergence between the aging and disabled populations; consequently older adults are experiencing the onset of disability in later life, and more persons with life-long disability are living into old age. However, older adults remain underserved from both perspectives. Environmental interventions, including assistive technology and home modification, are an important strategy for maintaining independence, productivity, and community participation. This article suggests that the lingering effects of 'ageism' and 'structural lag' in aging and disability policies and programs limit the access of older adults with disability to environmental interventions. Major policies influencing this access by older adults with disability and recent trends in research, policy and practice are described. Strategies for improving the access of older adult.

#### Key Words: Assistive technology, home modifications, aging, disability, policy

Millions with Alzheimer's disease at risk: Alzheimer experts offer providers and of staff turnover and increase care quality. (2000, July 17). Retrieved on June 29, 2001 from: http://www.alz.org

34. Long term care workforce crisis is looming-- According to the Alzheimer's Association, "the U.S. is about to be blindsided by a devastating one-two punch" – potential dramatic increases in policymakers solutions to slow shocking rate older adults with Alzheimer's disease and a longterm workforce crisis. Today, approximately 4 million Americans are estimated to have Alzheimer's disease and estimates run to as high as 14 million by 2050. The critical factor in quality care – at home or in a long-term care setting – is adequate numbers of well-trained and fairly compensated direct care staff. Unfortunately, low wages, poor benefits, inadequate staffing and inadequate recognition make it difficult to recruit and retain quality staff. Care and policy experts at the World Alzheimer Congress 2000 offered solutions to the workforce crisis.

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### Key Words: Alzheimer's disease, staffing, quality of care, Medicaid

35. Mahoney, D. F. (1998). A content analysis of A content analysis of the messages posted by an Alzheimer family caregivers virtual focus family caregivers on an Alzheimer's disease group. *American Journal of Alzheimer's* electronic network over a twelve-month period was conducted. Data from 566 participant

family caregivers on an Alzheimer's disease electronic network over a twelve-month period was conducted. Data from 566 participant postings were categorized as a function of stage of caregiving. New caregivers sought information about verification of the diagnosis and anticipatory planning; middle stage caregivers sought assistance in solving specific problems; and later stage caregivers struggled with decisions surrounding whether to continue caregiving responsibilities. Based on the data, a conceptual model of caregiving transitions emerged. Key themes were normalizing, managing, surviving with "being there" and vigilance. Findings suggest that virtual focus groups offer access to geographically diverse caregivers and complement traditional support methods.

## **Key Words: Dementia, internet based interventions, online support groups, virtual communities**

36. Mahoney, D., Tennstedt, S., Friedman, R., & The reliability and validity of an automated telephone system for monitoring the functional status of community-residing elders. *The* disabled elders residing in the community. *Gerontologist*, 39(2), 229-234. Within a 72-hour period, twenty functionally

The reliability and validity of an automated telephone monitoring system was tested for assessing changes in the functional status of disabled elders residing in the community. Within a 72-hour period, twenty functionally disabled older adults enrolled in a home care program were assessed in person by home visit, by personal telephone contact, and twice by automated telephone contact. The personal telephone and automated telephone contacts yielded similar results, although neither identified as many impairments as the home assessment.

**Key Words: Telephone monitoring, medical informatics, computers, home care** 

37. Mann, W. C. (1997). Common telecommunications technology for promoting safety, independence, and social interaction for older people with disabilities. *Generations*, 21(3), 28-29.

This article describes many of the telephone features and add-on assistive devices that can assist older adults with various types of impairments. For older adults with disabilities and/or mobility limitations, the telephone can provide access to social contacts, enable completion of instrumental activities of daily living, and can be used to summon help when necessary. Nonetheless, vision and hearing impairments, mobility limitations, and cognitive impairments result in approximately 10% of frail older adults having difficulty using their telephones. Fortunately, assistive devices (e.g., answering machines, voice activated speakerphones) can overcome these difficulties. Special attention is devoted to personal response systems.

### **Key Words: Assistive devices, interventions, telephones**

38. Mann, W. C. (1992). Use of environmental control devices by elderly nursing home patients. *Assistive Technology*, *4*(2), 60-65.

This study sought to determine the impact of environmental control devices on environmental interaction, as measured by radio use, of elderly nursing home patients. Two groups of patients were given radios, and each patient in one of the two groups was given a remote device to simplify the task of turning the radio on and off. Over a period of twelve weeks, the experimental (remote control) group showed a significantly higher rate of radio use than the control (no remote control) group.

# Key Words: Assistive devices, assistive technology, environmental modifications, institutional setting

39. Mann, W. C. (1995). Rehabilitation engineering: The National Institute on Disability and Rehabilitation research focuses on assistive technology for elders. *Generations*, 19(1), 49-53.

This article summarizes the research conducted by the University of Buffalo's Rehabilitation Engineering Research Center on Aging (RERC-Aging). Funded by the National Institute on Disability and Rehabilitation Research, the RERC-Aging follows the principles and procedures of consumer-oriented research and dissemination in addressing fourteen broad

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objectives, ranging from determining the impairments and disabilities experienced by older adults that could be addressed through assistive devices and environmental interventions to providing solutions that meet the needs of all older populations. RERC-Aging projects in each of four areas--research, device development, education, and service--are summarized.

### Key Words: Assistive devices, assistive technology

40. Mann, W. C. (1997). Aging and assistive technology use. *Technology and Disability*, 6(1,2), 63-75.

Currently, older adults with disabilities are underserved by the assistive technology service delivery system. This population is expected to increase in upcoming years, and will increase demands for health care, social services, and assistive technology. This increase requires an in-depth examination of the needs and concerns of this population, and movement toward greater acceptance of and access to assistive technology for older adults. This article emphasizes the importance of the consumer perspective, reviews chronic diseases and conditions of older age, provides an overview of assistive devices for this segment of the population, and concludes with discussions of systems problems and policy options.

### **Key Words: Chronic diseases/ conditions, assistive devices**

41. Mann, W. C. (2001). Technology. In B. R. Bonder & M. B. Wagner (Eds.), *Functional performance in older adults* (pp. 429-447). Philadelphia, PA: F. A. Davis Co.

This chapter provides an overview of assistive technology for increasing or maintaining functional performance for older adults with impairments. The Disability Impact Continuum is introduced as a model for examining older adults' functional performance and determining their needs for assistive devices, and specific assistive devices for mobility/motor impairments, vision, hearing, cognitive and communicative limitations are summarized. The chapter concludes with a brief discussion of important issues related to technology and older

adults. An appendix provides resources on assistive technology for older adults.

Key Words: Assistive devices, assistive technology, Disability Impact Continuum

42. Mann, W. C., & Tomita, M. (1998). Perspectives on assistive devices among elderly persons with disabilities. *Technology and Disability*, *9*(3), 119-148.

The RERC on Aging is conducting a longitudinal study of the needs of older persons with disabilities for assistive devices and environmental interventions. This paper presents an analysis of the results of interviews with 508 home based seniors, focusing on their ownership, use, and satisfaction with assistive devices. While previous reports from this RERC-Aging study indicate a relatively high rate of satisfaction with devices, this paper primarily focuses on problems consumers are having with devices they use. This paper also reports the suggestions of study participants for new devices and modifications to existing devices.

Key Words: Assistive devices, home care, disability

43. Mann, W. C., Hurren, D., Charvat, B., & Tomita, M. (1996). The use of phones by elders with disabilities: Problems, interventions, costs. *Assistive Technology*, 8(1), 23-33.

Recognizing the important role that telephones play in the lives of frail older adults, this research sought to gain a better understanding of the problems that older adults encounter when attempting to use the telephone. Results indicated that approximately 10% of frail older adults sampled experience difficulty using the telephone. Interventions with a subsample of older participants found that, at a 6-month follow-up, participants were satisfied with the intervention. Telephone usage increased by 50% for participants who were provided with an intervention. The average cost of the intervention equipment was \$70.45; costs associated with personnel time were significantly higher. The article concludes with recommendations to address telephone-related limitations experienced by frail older adults.

**Key Words: Assistive devices, interventions, telephones** 

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44. Mann, W. C., Hurren, D., Tomita, M., & Charvat, B. A. (1995). The relationship of functional independence to assistive device use of elderly persons living at home. Journal of Applied Gerontology, 14(2), 225-247.

This study explored the relationship between use of assistive devices and functional independence for non-institutionalized elderly. Predictors of functional independence were determined through correlation analysis on a sample of 364 subjects; these predictors included age, sex, education, mental status, physical disability, and visual impairment. From the sample of 364 elders, 117 pairs of subjects were matched on these predictors and compared for levels of functional independence relative to assistive device use. Two instruments were used for assessing functional independence: the Functional Independence Measure (FIM) Motor Section for Activities of Daily Living (ADLs), and the Older Americans Research and Service Center Instrument (OARs) for Instrumental Activities of Daily Living (IADLs). Given the limitations of the study design, results suggest, but do not determine, that increased use of assistive devices relates to increased functional independence.

#### Key Words: Assistive devices, functional independence

45. Mann, W. C., Hurren, M. D., Charvat, B. A., This research study of older persons with & Tomita, M. R. (1996). Changes over one year in assistive device use and home modifications by home-based older persons *Rehabilitation*, 12(2), 9-16.

Alzheimer's disease found that as their physical and mental status declined a subsequent decrease in their use of assistive devices was with Alzheimer's disease. Topics in Geriatric demonstrated. An increase in caregiver use of assistive devices and environmental modifications correlated to the care-recipient's decline.

#### Key Words: Aging, Alzheimer's disease, assistive devices, functional independence, home modifications

46. Mann, W. C., Ottenbacher, K. J., Fraas, L., Tomita, M., & Granger, C. V. (1999). Effectiveness of assistive technology and environmental interventions in maintaining independence and reducing home care costs for the frail elderly: A randomized trial.

The objective of this research was to evaluate a system of assistive technology environmental intervention service provision designed to promote independence and reduce health care costs for physically frail elderly persons. All participants underwent a Archives of Family Medicine, 8 (May/June), 210-217.

comprehensive functional assessment and evaluation of their home environment. Participants in the treatment group received intervention based on the results of the evaluation. The frail elderly persons in this trial experienced functional decline over time. Results indicate rate of decline can be slowed, and institutional and certain in-home personnel costs reduced through a systematic approach to assistive technology providing environmental interventions.

Words: Assistive technology, environmental modifications, home care, independence, assistive devices

47. Marshall, M. (1999). Technology to help people with dementia remain in their homes. Generations, Fall, 85-87.

Illustrations are provided of ways in which technology can increase safety at home, monitor and maintain health, and enhance quality of life for people with dementia. Assistive technologies are being developed by engineers to meet specific needs of people with dementia, but also to help practitioners who work with these patients. Technology should be seen as a single component in a larger care plan that includes adaptations to the home, and input of professional staff and family caregivers. Care must be taken so that use of technology does not become an end in and of itself and diminish the "personhood" of the patient with dementia.

Key Words: Technology, assistive devices, dementia, smart house

48. McShane, R., Gedling, K., Kenward, B., The feasibility of electronic tracking devices in dementia: A telephone survey and case series. International Journal of Geriatric Psychiatry, 13, 556-563.

This research documented whether individuals Kenward, R., Hope, T., & Jacoby, R. (1998). with dementia could benefit from electronic tracking devices and the practical feasibility of using such tracking devices. Telephone surveys with 99 caregivers to an older adult with dementia indicated that 20% of care-recipients were at risk of traffic accidents and 45% were at risk of getting lost when they attempted to travel independently. The practical feasibility of a tracking system was assessed in 24 older adults with dementia. Results indicated that 9 older

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adults consistently used the device. The device was successfully used in a search for two older adults. The researchers conclude that significant numbers of older adults with dementia are at risk, and electronic tracking devices might be useful in carefully selected cases.

Key Words: Dementia, electronic tracking devices, wandering

49. Meeting the needs of older women: A diverse Most older Americans are women. One in every June 29, 2001 from: http://www.aoa.dhhs. gov/factsheets/ow.html

and growing population. (n.d.). Retrieved on 10 persons in the U.S. is a woman at least 60 years of age. One of every six women is in a minority group. Eighty-three percent of centenarians are women. Because women live longer than men, the health, economic and social challenges of the elder population are more often the challenges of women. These include economic security, access to community services, and health and long-term care. This U.S. Administration on Aging report seeks to promote planners and policy makers to include the varied issues surrounding older women as they seek to address the diverse needs of an aging society.

Kev Words: older women, social policy, the Older Americans Act, National Family Caregiver Support Program, Area Agency on Aging

50. Mitka, M. (2001). Home modifications to make older lives easier. Journal American Medical Association, 286(14), 1699-1700.

Through project GEM (gerontologic environmental modification), Cornell University is acquainting physicians (and others) with issues of home safety. The Cornell Medical College has begun to train medical students, residents, and postgraduate physicians to understand age-appropriate design in homes, hospitals, and long-term care environments. Physicians are in a unique position to help reduce injuries in the home and improve lifestyle for older adults patients.

Key Words: home (or environmental) modification, home assessment, home safety

51. Mynatt, E., Essa, I., & Rogers, W. A. (November, 2000). *Increasing the opportunities for aging in place*. ACM Conference on Universal Usability, Arlington, VA.

elsewhere is supporting older adults who want to continue living independently as opposed to moving to an institutional care setting. Through the careful placement of technological support, the researchers believe older adults can continue living in their own homes longer. The intent of this research is to assess the feasibility of designing environments that aid older individuals in maintaining independence. Based on initial research, there are three key problem areas to be considered: recognizing and averting crisis, assisting daily routines, and supporting peace of mind for adult children.

Key Words: Aging in place, environmental

A growing social problem in the U.S. and

Key Words: Aging in place, environmental modifications, assistive technology, caregiver support

52. National Council on Disability. (1993, March 4). *Study on the financing of assistive technology devices and services for individuals with disabilities*. Retrieved July 11, 2001 from: http://www.ncd.gov/newsroom/publications/assistive.html

Assistive technology redefines what is possible for children and adults with disabilities. Assistive technology enables people with disabilities to be more independent, productive, and integrated into the mainstream of community life. Assistive technology includes Velcro, adaptive clothing, computers, seating systems, powered mobility, augmentative communications devices, and special switches, among thousands of other commercially available devices and adapted items. This 1993 landmark study by the National Council on Disability (NCD) documents both the benefits and the costs of different kinds of technology-related assistance.

**Key Words: Assistive technology, disability, regulation, social policy** 

53. National Council on Disability. (2000, May 31). Federal policy barriers to assistive technology. Retrieved July 11, 2001 from: http://www.ncd.gov/newsroom/publications/assisttechnology.html

Through the Assistive Technology Act of 1998 (P.L. 105-394), Congress gave recognition to the need to remove barriers and fill gaps in federal policy regarding assistive technology. The Act requires that the National Council on disability (NCD) prepare a report describing barriers in federal assistive technology policy to increasing

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availability of and access to assistive technology devices and services for individuals with disabilities. In this report, dated May 31, 2000, NCD provides recommendations to address specific policy barriers identified through research.

Key Words: Assistive technology, disability, federal policy

54. Nochajski, S., Tomita, M., & Mann, W. C. (1996). The use and satisfaction with assistive devices by older persons with cognitive impairments: A pilot intervention study. *Topics in Geriatric Rehabilitation*, 12(2), 40-53.

Frail elderly persons with cognitive impairments use fewer, and are less satisfied with, assistive devices than frail elderly persons who are not cognitively impaired. This study sought reasons for device dissatisfaction among elders with cognitive impairments, and assessed the impact of professional intervention on the use of, satisfaction with, and effectiveness of assistive devices. Twenty persons with cognitive impairments received a comprehensive assessment, individualized interventions. training, and follow-up. Results indicated that devices for physical impairments were more readily accepted and used than devices that addressed cognitive impairments. However, participants were more satisfied with cognitive devices. User satisfaction with physical devices appeared to increase with training and support. However, dissatisfaction with cognitive devices appeared to be more related to user limitations than training and support. The need for "early intervention" for persons with cognitive impairments is discussed.

Key Words: Assistive devices, cognitive impairments, training and support, frail elderly

55. Olsen, R. V., Ehrenkrantz, E., & Hutchings, B. L. (1996). Creating the movement-access continuum in home environments for dementia care. *Topics in Geriatric Rehabilitation*, 12(2), 1-8.

Since the majority of people with Alzheimer's disease receive some care at home, the environment of that home must be safe and supportive. Interviews with 90 experienced caregivers identified tactics for creating these settings through home-modification and technology. Successful modification appears to

follow a three-stage movement-access continuum that responds to the disease course – assistance, restriction with compensation, and wheelchair accessibility. The authors believe that with a sensitive and ongoing modification strategy, the home environment can become an asset rather than a liability for caregiving.

Key Words: Alzheimer's disease, caregiving, home modification, home environment, movement-access continuum

56. Ory, M. G., Yee, J. L., Tennstedt, S. L., & Schulz, R. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. In R. Schulz (Ed.), Handbook of dementia caregiving: Evidenced-based interventions for family caregivers. New York: Springer United States Administration on Aging Web site: http://www.aoa.gov/carenetwork /ory- article.html

This chapter provides an overview on the prevalence of caregiving in general, with specific attention to caring for an older adult with dementia. The effects of caregiving on caregivers' mental health, physical health, health-related behaviors, and sub-clinical changes in disease are summarized. Data from Publishing Co. Retrieved June 29, 2001 from the 1996 National Survey on Family Caregiving (National Alliance for Caregiving and American Association of Retired Persons) are used to document the prevalence of family caregiving in the United States; provide a profile of caregivers (including demographics, the amount and type of caregiving provided, and the impact of caregiving), and explore variations in the caregiving experience. The chapter concludes with a discussion of future research needs and implications for policy and practice.

Key Words: Caregiving, dementia, interventions, mental health, physical health, impact of caregiving

57. Quality dementia care is a family affair. (2000, July 16). Retrieved on June 29, 2001 from: http://www.alz.org

Caring for a family member with Alzheimer's disease is overwhelming and exhausting. Unfortunately, most caregivers are not savvy consumers of health care services. The Alzheimer's Association (AA) seeks to empower family caregivers by providing information and support. They view family caregivers as partners with health care professionals, working together to provide a high quality environment for the person with Alzheimer's disease. AA provides

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a list of 8 "tips" to help caregivers get the best possible care for their family members from home health agencies, assisted living facilities and nursing homes.

Key Words: Alzheimer's disease, family caregiving, quality care

58. REACH, conceptual framework workgroup. (n.d.) Progress report, January 2000. Retrieved July 11, 2001 from University of Pittsburgh Web site: http://www.edc. gsph.pitt.edu/reach/j2k.html

This is a report of the "Conceptual Framework Workgroup" of REACH, a project examining the effect of well-defined interventions on caregivers, care recipients, and delivery characteristics of the caregiving environment. Workgroup members will seek to identify common metrics for characterizing interventions or components of interventions at the various project sites. Domains targeted for intervention include knowledge, cognitive skills, behavior, and affect.

Key Words: Family caregivers, caregiver services, MRDD, Older Americans Act, **National Family Caregiver Support Program** 

59. Redford, L. J., & Parkins, L. G. (1997). Interactive televideo and the internet in rural case management. Technology and Rural Case Management, 6(4), 151-157.

The authors seek to inform case managers of the opportunities available with telecommunication technologies to improve access to care as well as the quality of care in rural communities. These technologies include interactive tele-video and the Internet, among others. As advocates, coordinators and facilitators, case managers are ideally positioned to help rural communities move into the "information age."

Kev Words: Case management, telecommunications, rural communities, reimbursement, confidentiality

60. Sanders, J. M. (2000, Winter). Sensing the subtleties of everyday life. Retrieved on Technology, Research Horizons Web site: http://gtresearchnews.gatech.edu

The article describes work being carried out by members of the Future Computing September 5, 2001, from Georgia Institute of Environments (FCE) group at the Georgia Institute of Technology's College of Computing. The FCE group has been investigating the increasingly ubiquitous nature of computing and are opening a residential laboratory, what they

sometimes describe as the "Aware Home" project. When opened, this living laboratory will be capable of knowing information about itself and the whereabouts and activities of its inhabitants. Through their "Aging in Place" initiative, FCE researchers attempt to show that older adults may be the most important potential users of the practical applications being proposed.

Key Words: Computers, broadband, sensing technology, cognitive support, behavioral tracking

M., Zdaniuk, B., Hirsch, C., et al. (2001). Involvement in caregiving and adjustment to death of a spouse: Findings from the caregiver health effects study. Journal American Medical Association, 285, 3123-3129.

61. Schulz, R., Beach, S. R., Lind, B., Martire, L. The impact of losing a spouse varies as a function of the caregiving experiences that precede death. In this study, those caregivers already strained prior to the death of the spouse showed no additional strain with the death itself; these individuals do show improved health practices following the death of the spouse. Noncaregivers and caregivers reporting no strain showed increased depressive symptoms following the death of the spouse. Clinicians are encouraged to tailor interventions to the caregiving experience of the surviving spouse.

Key Words: Caregiving, spouse, strain, burden, death of care recipient, interventions

(n.d.). Retrieved on July 11, 2001 from: http://www.asel.udel.edu/dati/selecting.html

62. Selecting and obtaining assistive technology. Selecting assistive technology is usually not a simple matter. Finding the "best fit" between person, environment, and technology is a multistep process, starting with an assessment by a qualified professional. Prospective consumers and those helping them must carefully gather and evaluate information, and then make informed decisions. This article outlines the steps in selecting and obtaining assistive technology. Factors to be considered by the consumer and specific questions one should ask of a prospective vendor are provided.

> **Key Words: Assistive technology, equipment** identification, vendor

Page 48 Miami University 63. Statement of Carol O'Shaughnessy, Specialist Statement of Carol O'Shaughnessy, Specialist in in Social Legislation Congressional Social Legislation in the Congressional Research Research Service. (n.d.). Retrieved June 29, Service, who testified before Congress providing 2001 from: http://aging.senate.gov/hr70co.html an overview of long-term care for the elderly

Social Legislation in the Congressional Research Service, who testified before Congress providing an overview of long-term care for the elderly and persons with disabilities. Congress has grappled with issues of long-term care for years and has chosen an incremental approach. Policymakers must reconcile concerns about costs of various proposals (i.e., social insurance for home and community-based care and first 3 months of nursing home care) with the clear need to assist family caregivers.

Key Words: Long-term care, Medicaid, family caregivers, home care, community-based care

64. Stewart, L. M., & Kaufman, S. B. (n.d.). High-tech home care: Electronic devices with implications for the design of living environments. Retrieved on September 5, 2001, from: http://www.homemods.org/library/life-span/high/html

After reviewing the most common health conditions experienced by older adults, and those that are expected to become prevalent in upcoming decades, this article presents descriptions of electronic devices that target these common or critical conditions (e.g., ambulatory problems, incontinence, wound healing). This is followed by descriptions of electronic devices (e.g., filters, monitors, and telecommunications) that have the potential to address multiple conditions. The article concludes with a discussion of several challenges (e.g., weight and space planning, aesthetics, integration) that accompany the use of more ambitious high-tech and electronic devices.

**Key Words: High-tech home care, chronic conditions, next-generation technology** 

65. Sweeney, S. (2001, June 4). *HEALTHvision* announces first U.S. Internet Alzheimer's support network. Retrieved July 11, 2001 from: http://www.healthvision.com

This press release describes the first nationally accessible Internet-based service for families coping with Alzheimer's disease, the Alzheimer's Internet Support System (ACISS). ACISS is a comprehensive "one-stop shopping" service that supports the medical, social, and psychological needs of family caregivers. Among the services provided are on-line support

groups, tele-counseling, a reference library and message center. Developers of ACISS believe that ACISS can reduce caregiver stress, delay institutionalization of the older adult with dementia, thereby reducing financial burden, and improve the quality of life of both caregivers and individuals with dementia. The article concludes with a description of HEALTHvision, the Internet company that developed ACISS; the Alzheimer's Association, a major resource for dementia-related issues; and Wellesley Centers for Women.

### **Key Words: Alzheimer's disease, dementia, Internet-based support**

66. Tennstedt, S. (1999, March 29). Family caregiving in an aging society. Presented at the United State Administration on Aging Symposium: Longevity in the New American Century. Retrieved June 29, 2001, from: http://www.aoa.dhhs.gov/caregivers/FamCare.html

This review article begins with demographic descriptions of who needs care, who receives care, and who provides care. The types and amounts of informal care provided to older adults, and the interface of informal and formal care are discussed. Comparisons of the costs of formal versus informal community-based care, community-based versus nursing home care, and the economic value of informal care are presented. The personal, social, and health impacts of caregiving are summarized, as are resources (e.g., sense of control, coping) that might mediate or buffer the negative consequences of caregiving, and implications for designing interventions are suggested. The article concludes with implications for policy and practice.

Key Words: Caregiver demographics, care recipient demographics, informal care, cost of caregiving, impact of caregiving

67. Thomas. C. (2000). Keep an eye on dad. *New Scientist*. Retrieved March 5, 2001 from: http://www.newscientist.com

The Everyday Computing Lab at Georgia Tech has come up with a system that lets people see at a glance how an elderly relative is faring. Sensors are used to monitor the elderly person's activity. A digital family portrait with a JPEG photo of the subject in the middle is displayed on a flat screen "picture frame." Animated

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icons displayed around the frame are used to highlight different facet's of the subject's activity. How much information should leave the older person's home? Will 24-hour surveillance cause loss of psychological independence?

Key Words: Older adults, independence, sensors, surveillance

68. United State House of Representatives the needs of people with disabilities through federal technology transfer. Retrieved July 11, 2001 from: http://www.hq.nasa.gov /congress/disabled.html

This hearing before the Subcommittee on Subcommittee on Technology, Committee on Technology of the U. S. House of Science. (1997, July 15). Hearing on meeting Representatives' Committee on Science focused on technology transfers in the field of assistive technology. Expert testimony came from the public and private sectors. The shared view was that over 700 federally funded laboratories are working on developing technologies and the findings/results need to be shared with all segments of society. In particular, assistive technologies offer great potential for enhanced quality of life for those individuals with disabilities.

Key Words: Assistive technology, technology transfer, disability, Federal Laboratory Consortium (FLC)

69. United States Administration on Aging. (2001). The many faces of aging: Family caregiving. [Brochure].

Families are the primary source of long-term care for older persons in the United States. The enactment of the Older Americans Act Amendments of 2000 (Public Law 106501) established the National Family Caregiver Support Program. The program calls for all states to provide basic services for family caregivers. Priority consideration should be given to low income, minority individuals and older individuals providing care and support to persons with mental retardation and related developmental disabilities.

Key Words: Interventions, effects interventions

70. United States Department of Health and Human Services. (2001). Mortality declines for several leading causes of death in 1999.

Mortality for leading causes of death declined in 1999, according to preliminary figures from the Centers for Disease Control and Prevention

Retrieved on June 29, 2001 from: http://www. (CDC). In particular, there were declines in agecdc.gov/nchs/releases/01news/declindea. html

adjusted death rates for heart disease and cancer, continuation of a multi-year pattern. In 1998 Alzheimer's disease ranked 12th among leading causes of death but jumped to 8th in 1999, due mainly to the inclusion of a cause of death formerly classified as "presenile dementia," which accounted for substantial additional Alzheimer's deaths in 1999. The almost 45,000 deaths from Alzheimer's disease in 1999 exceeded the totals for other major causes of death, including motor vehicle accidents and breast cancer.

Key Words: Mortality, Alzheimer's disease, heart disease, cancer

71. Vastag, B. (2001). Easing the elderly online in search of health information. Journal American Medical Association, 285(12), 1563-1564.

This article explores current efforts to encourage older adults to use the Internet to access information, including health information. Although as many as three-fourths of older adults who are not already "online" express no interest in going online, it is projected that the number of older adults using the Internet will increase from 14 million in 2000 to 27 million by 2003. The article encourages designers to find creative solutions to help older adults overcome barriers to using computers that derive from age-related losses, and offers guidelines for designing "senior friendly" web sites. Additional barriers (e.g., perceptions of complexity) and concerns for their alleviation are discussed.

Key Words: Internet, health information

72. Wylde, M. A. (1995). How to size up the the older adult. Generations, 19(1), 15-19.

The author specifies a process by which current and future markets: Technologies and prospective markets for technologies designed for an aging populace can be sized up. The author advocates evaluating the concept, prototype, and product with prospective users who represent the "worst case". These include individuals who have the greatest activity limitations, thus the greatest expectations, and who are likely to voice the loudest complaints. If a new technology can satisfy the least able and

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most critical, it's potential for satisfying other users is increased.

#### Key Words: Technology, older adult market, functional limitations

73. Wylde, M. A. (1998). Consumer knowledge of home modifications. Technology and *Disability*, 8, 51-68.

Better, safer, and easier-to-use home environments are important in an aging society. Unfortunately, only small proportions of people who need more accessible living environments modify or adapt their homes. There are a number of reasons improved living environments have not 'caught on'. While there are many excellent educational programs and materials for educating consumers, the approaches have targeted the consumer as the problem. In addition, suggested modifications have often been inconsistent with consumer preferences. This article suggests that a great deal of knowledge exists about how to improve living environments; the next step is how to make these improvements part of the mainstream consumer marketplace.

#### Key Words: Home modifications, environmental modifications, accessibility, remodeling

74. Yurick, A., Burgio, L., & Paton, S. M. (1995). Assessing disruptive behaviors of nursing home residents: Use of microcomputer technology to promote Journal of Gerontological Nursing, April 1995, 29-34.

This article describes the use of computerassisted, real-time observations to study disruptive behaviors among individuals with dementia who reside in institutional objectivity in planning nursing interventions. environments. Specifically, the purpose of the research was to use computer-assisted data systems to investigate the contextual variables that affect the behaviors of disruptive nursing home residents. Computers were used to document the location of the residents within the nursing home; the frequency and duration of disruptive behaviors; environmental sound; and the presence or absence of restraints. The article discusses several aspects of this methodology, including the importance of strict adherence to the observational procedures; unique characteristics of a nursing home environment

	Key Words: Computer-assisted observation, dementia, disruptive behaviors, long-term care
Site	Description/Site Title
75. http://www.accesstoday.com	Accessibility Products provides a catalog of home health equipment and aids for daily living. <b>Key Words: Accessibility Products</b>
76. http://www.alz.org	Alzheimer's Association web site.  Key Words: Alzheimer's Association
77. http://www.beyondbarriers.com	Beyond Barriers' goal is to improve the daily living conditions for persons with disabilities and seniors who find their independence threatened, by offering a full range of products designed to allow freedom and independence.  Key Words: Beyond Barriers
78. http://www.cltcmag.com	Contemporary Long Term Care web site.  Key Words: Contemporary Long Term Care
79. http://www.asel.udel.edu/dati/	Delaware Assistive Technology Initiative focuses on improving public awareness, public access to information, funding for assistive technology devices and services, training and technical assistance, and coordination of statewide activities.  Key Words: Delaware Assistive Technology Initiative
80. http://www.enablingdevices.com	Enabling Devices provides a catalog of assistive technology devices. <b>Key Words: Enabling Devices</b>
81. http://www.gtresearchnews.gatech.edu/fce/ahri/	Georgia Institute of Technology research information web site on the Aware Home project.

nursing.

that must be considered in this type of research; and the implications of this methodology for

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#### **Key Words: Georgia Institute of Technology**

assistive technology devices and adaptive

equipment for independent living.

**Key Words: Independent Living Aids** 

disabilities and their families access life-

enhancing technology. **Key Words: Infinitec** 

84. http://www.longtermcareprovider.com Long Term Care Provider is a site with

information on adaptive equipment, long term

care resources, and catalog shopping.

**Key Words: Long Term Care Provider** 

Housing and Home Modification details information on modifying the living environment to increase use, safety, security,

and independence.

Key Words: National Resource Center on

**Supportive Housing and Home Modification** 

86. http://www.resna.org Rehabilitation Engineering and Assistive

Technology Society of North America is an interdisciplinary association of people with a common interest in technology and disability.

**Key Words: Rehabilitation Engineering and Assistive Technology Society of North** 

America

87. http://www.nap.edu/issues Online journal of Issues in Science and

Technology.

**Key Words: Science and Technology** 

88. http://www.techconnections.org Tech Connections is a one-stop resource for

information on Assistive Technology designed to accommodate people with disabilities in the

workplace and in everyday life activities.

**Key Words: Tech Connections** 

89. http://www.ataccess.org	The Alliance for Technology Access is a network of community-based resource centers, developers and vendors, affiliates, and associates dedicated to providing information and support services to children and adults with disabilities and increasing their use of standard, assistive, and information technologies.  Key Words: The Alliance for Technology Access
90. http://www.ncd.gov	The United States Council on Disability web site.  Key Words: United States Council on Disability
91. http://www.aoa.gov	The United States Department of Health and Human Services web site for the Administration on Aging.  Key Words: United States Department of Health and Human Services, Administration on Aging
92. http://aging.senate.gov	The United States Senate Special Committee on Aging web site.  Key Words: United States Senate Special Committee on Aging
93. http://cat.buffalo.edu/rerca.htm	University at Buffalo Center for Assistive Technology web site. Resources on research, education, services, and information dissemination are provided.  Key Words: University of Buffalo Center for Assistive Technology
94. http://www.edc.gsph.pitt.edu/reach	Resources for enhancing Alzheimer's caregiver health.  Key Words: University of Pittsburgh

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