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Unobtrusive In-Home Monitoring of Cognitive and Physical Health: Reactions and Perceptions of Older Adults

Katherine Wild, Ph.D.¹, Linda Boise, Ph.D.¹, Jay Lundell, Ph.D.², and Anna Foucek, MPH¹

¹ Layton Aging and Alzheimer Center, Dept. of Neurology, Oregon Health and Science University, CR-131, 3181 SW Sam Jackson Park Road, Portland, OR 97239; wildk@ohsu.edu, 503-494-6975; boisel@ohsu.edu, 503-494-6370; fouceka@ohsu.edu, 503-494-6370

² Proactive Health Group, Intel Corporation, 2111 NE 25th Ave., Hillsboro, OR 97124; jay.lundell@intel.com; 503-456-3377

Abstract

While the potential benefits of unobtrusive in-home sensing technologies for maintaining health and independence of older adults have been highlighted in recent research, little is known about their views toward such technology. The aims of this project were to identify monitoring needs and expectations of community-residing elderly and their family members. Focus groups were presented with examples of in-home monitoring devices and data output; participants were asked to consider whether the data showed information that was meaningful to them, and how and to whom they would like to have such data disseminated. Content analysis of transcripts revealed four dominant themes: maintaining independence, detecting cognitive decline, sharing of information, and the tradeoff between privacy and usefulness of monitoring. The acceptance by elderly of unobtrusive in-home monitoring was closely tied to perceived utility of data generated by such systems. Privacy concerns appeared to be less of an issue than anticipated in this sample.

Keywords

technology; focus groups; in-home monitoring; attitudes; maintaining independence

Older adults face many challenges to their independence, often related to a decline in mobility or cognition, and the personal and social impact can be great. Roughly 4.5 million Americans have Alzheimer's disease. An estimated 70% of persons with AD live at home. Incorrect use of medications among the elderly has become a major health care concern with associated physical and economic costs related to recurrent illness and hospitalization (Clepper, 1992; Gurwitz et al., 2003). Forgetfulness and confusion are major causes of unintentional medication nonadherence (DeBettengnies, Mahurin and Pirozzolo, 1990; Svarstad, Chewing, Sleath and Claesson, 1999). In addition to cognitive problems, many older adults suffer from chronic physical health conditions that compromise their ability to maintain their independence. For example, according to data from the National Safety Council, there were 12,900 deaths from falls in 2003 among those over the age of 65, with 7,500 of those occurring in homes (NSC, 2004).

Most care provided to older adults living at home is by family and friends. Loss of productivity and income, as well as stress related illnesses in primary caregivers all contribute to the impact and cost of home-based care (Prigerson, 2003). There are an estimated 44 million caregivers

who provide unpaid care. Of these, more than half (59%) have held other jobs while providing care (AARP, 2004). The application of in-home technology may have enormous potential in assuaging the burdens of caregivers, by alerting them to emerging care needs or urgent needs requiring immediate attention when they are away from home. In a national study of dual-earner couples caring both for children and aging parents, the majority of caregivers found various forms of technology (i.e., voicemail, cell phones, remote access to computer at work, internet access) to be helpful to them in managing their multiple work and caregiving responsibilities (Neal and Hammer, 2006).

Prolonging older adults' ability to remain safe and independent in their homes may yield economic and emotional benefits at a personal and societal level. Meanwhile, the total number of seniors living alone has risen, with approximately one of every three noninstitutionalized older adults now living alone (Cannuscio, Block and Kawachi, 2003). Despite these challenges, the majority of older adults desire to remain at home (Mann, Marchant, Tomita, Fraas and Stanton, 2002) and the majority do live at home.

For older adults to remain at home, methods to detect cognitive and physical decline that put them at risk must be in place. Many existing and potential technologies under development for the maintenance and/or supervision of health and independence offer promise. These range from blood pressure monitors and falls detection to "lifestyle monitoring" that detects changes in behavior patterns (Brownsell, Bradley, Bragg, Catlin and Carlier, 2000). Unobtrusive activity monitoring is one important area of exploration.

Ohta et al. (2002) describe a health monitoring system based on movement detection by infrared sensors placed in the homes of eight elderly subjects. By identifying "usual" and "unusual" patterns of activity over time, they were able to make inferences about changes in health conditions. A similar unobtrusive monitoring system was used in 22 separate homes in the UK (Sixsmith, 2000). This system generated alerts based on deviations in activity levels. These in-home monitoring strategies that have been deployed for early detection of cognitive or physical decline are predicated on the hypothesis that continuous monitoring of daily activities can provide a more sensitive measure of function than office-based, intermittent assessments that are the standard of current practice. Kaye et al (2007) suggest that frequent or continuous evaluation in the home represents a reasonable adjunct to conventional approaches for detection of cognitive decline.

In their comprehensive review of existing health monitoring systems, Stefanov et al. (2004) conclude that the future success of "smart houses" will depend in large part on the human-machine interface, where the individual's needs and expectations will be adequately addressed. Yet the attitudes and preferences of technology end-users, that is, older adults, family members and others, have only recently begun to be explored. At the end of the three-month trial conducted by Sixsmith (2000), 80% of the clients expressed satisfaction with the system, largely due to the increased sense of safety and security it provided. Others have found similar results, in that perceived usefulness of a monitoring system in daily life is routinely cited as an important factor in receptivity among older adults (Adams, Stubbs and Woods, 2005; Cutler, Hendricks and Guyer, 2003; Magnusson and Hanson, 2003). Melenhorst and Bouwhuis (2004) found that expectation of benefits outweighs perceived barriers for most elderly technology users.

The belief that older people are technophobes has been consistently refuted (Brownsell et al., 2000; Demiris et al., 2004; Zimmer and Chappell, 1999). According to a national survey of computer use, 40% of adults age 65 and older have a home computer (U.S. Census Bureau, 2005). Mann et al. (2002) reported strong acceptance of home health monitoring among community-residing frail elderly who were presented with pictures of devices such as

medication compliance and blood pressure monitors. One caveat of their findings, however, was the authors' subjective sense that participants were responding positively to monitoring for hypothetical others as opposed to themselves. In a survey of 100 community-residing older adults, Cohen-Mansfield et al. found that the majority had positive attitudes toward the use of electronic memory aids (2005), at least in theory.

Much of the previous research on technology applications for the elderly has focused on specific implementations, demonstrated either with existing or hypothetical products. More recently, there has been interest in the ethical implications of in-home monitoring of the elderly. Mahoney et al. (2007) note the responsibility of researchers and technology developers to consider the needs and limitations of older adults with regard to their interface with technology. The intent of the present study was to obtain feedback from older adults and their network members on home monitoring independent of specific applications or products. In focusing on unobtrusive monitoring, we were describing sensor systems and technologies that provide the capacity to continuously track and interpret motor and cognitive activity in the home. The goal of this project was to explore themes and to assess positive and negative responses to unobtrusive in-home monitoring from the perspectives of both the elderly and their family members or friends, as potential users. Further, the intent was to identify attitudes towards and concerns about specific perceived needs.

Qualitative data collection methods are an effective approach for gaining in-depth insights about research questions, and are especially valuable when there has been limited prior research. Focus groups in particular have been useful when investigating topics about which little is known (Edmunds, 1999; Lakshman, Charles, Biswas, Sinha and Arora, 2000; Morgan, 1988). They provide a relatively efficient means for exploring attitudes and for gaining understanding of issues from the point of view of the subjects. They are particularly effective in revealing similarities and differences in attitudes through directed discussions among target populations. Finally, they provide useful content areas and verbiage for survey instruments and structured interviews. As recommended by others in the field, we developed a concise set of concepts and ideas to be explored with additional probe questions designed to generate discussion.

Method

Participants

Focus groups were held for two sets of participants. Subjects in the older adults groups were men and women who were at least 65 years of age, in stable health and showing no signs of dementia. The family member/friend groups consisted of those persons identified by the elderly participants as the "person most involved or most likely to be involved in dealing with my health and medical care."

Participants were selected from a group of subjects being followed in the Community Brain Donor Program (CBDP) of the OHSU Layton Aging & Alzheimer's Disease Center. Those who met the research criteria were sent a letter in the mail, introducing the purpose of the study and requesting that they call the CBDP coordinator if they did not wish to be contacted about the study. Each individual who agreed to participate was asked to bring a spouse, other adult family member, or friend to participate in a concurrent (Family member/Friend) focus group. Twenty-three older adults and 16 family member/friends agreed to participate. The average age of the participants was 80.6 (range 66–91); family member/friends' mean age was 71.5 (range 42–86).

Data on computer use were available on focus group participants who were subjects in the Community Brain Donor Program from a technology survey administered in that project. Of

the 23 older adults participating in this study, all reported that they used a computer; most (n=17) reported daily use. Fourteen subjects reported daily use of email; 17 reported familiarity with the Internet.

Focus groups were conducted at an independent market research facility that had appropriate recording devices and rooms for focus groups. In total there were six focus groups, three with older adults and three with family members/friends, conducted over two days. The older adult groups were run concurrently with the family member/friend groups in separate rooms. The sessions were facilitated by one of the three study co-investigators and followed a protocol approved by OHSU IRB. Each group was also assisted by a co-investigator or the study project coordinator. The focus group interviews were audio-taped and transcribed to facilitate analysis.

Procedure

The procedures and questions were essentially the same for both groups of participants, except that the questions were modified to reflect the different perspectives of the groups. Specifically, the older adults were asked to think about the topic for their own current and future needs, whereas, the family member/friend groups were asked to consider the needs of others, particularly the older adult with whom they came to the focus groups. Each session was divided into four sections: 1. Introduction and consent, 2. Presentation and discussion of health monitoring, 3. Types of information displayed, and 4. Wrap up and final comments.

During section 1, the facilitator introduced the purpose of the study and reviewed the consent form. Each participant signed the consent form and was provided a copy to take home. Participants were asked to introduce themselves, and, as an “ice breaker”, to state what their favorite technology was and why. This section lasted approximately 15 minutes.

In section 2, participants viewed a series of slides describing various aspects of monitoring in the home. Examples of these illustrations are presented in Figures 1 and 2. As seen in Figure 1, technologies promoting personal health and wellness were displayed with links between monitors in the home and potential recipients of the information, to demonstrate the general configuration of an in-home system. Other slides that were presented as examples of potential technology applications displayed methods of tracking motion through the household, monitoring of computer -based activities such as email and game-playing, and data derived from sleep sensors placed in beds. The slides were meant to generate discussion of these and other possible uses of in-home monitoring.

Figure 2 replicates a graph demonstrating how data collection from monitoring can provide a more accurate picture of health status than data gathered less frequently through traditional methods. This slide was particularly useful in conveying the concept of continuous monitoring to our participants. As demonstrated in this graph, assessments at three-month intervals can fail to capture meaningful changes or stability. Each slide was explained by the facilitators and clarification questions were fielded as needed.

Participants’ reactions to each slide and opinions about monitoring were elicited by facilitators. The following discussion questions guided this section of the interview: (a) How, if at all, would you use monitoring systems such as those presented?; and (b) What kinds of activity would you like to have monitored (e.g. behavioral, physiological)? All questions were open-ended to allow for greater depth of response. Participants were encouraged to offer positive and negative reactions to monitoring.

Toward the end of this section, participants performed a card sort task. In this task, each participant received 14 cards. Upon each card was printed a different possible target of monitoring, such as memory, falls, medication, meals, etc. (see Table 1). Participants were

asked to mark each card with either a plus sign (+), negative sign (-), or a question mark (?), where “+” means this would be a measure that would be a desirable target for monitoring, a “-“ means this would not be desirable, and “?” indicates uncertainty.

In section three, the format of outgoing monitoring information and potential recipients of the information were explored. Figure 3 presents one of the examples that was shown to stimulate discussion. In this graph, summaries of activities that could be monitored are displayed in various formats. For example, the “walking activity” graph compares the distances walked by two hypothetical residents over time.

Again, reactions to and opinions on each slide were solicited by facilitators from participants, and centered on the following discussion questions: (a) Do the data show information that is meaningful to you?; and (b) How, if at all, would you like to have such data about yourself disseminated and to whom (e.g. family members, physician, others)?

Finally, in section four, participants were encouraged to discuss any topics that were not covered in the previous sections, and to provide any advice to the researchers regarding the development of monitoring systems. Participants were thanked and paid \$25 for their participation.

Coding and Data Analysis

The audio tapes were transcribed verbatim and a content analysis using the software package QSR NVivo (ref) was performed. Each transcript was reviewed independently by two members of the research team, to identify common themes, and to define labels and codes. The research team then met to discuss impressions, themes, and to identify topics for coding. Differences among the three co-investigators in coding were reconciled at team meetings and codes were then changed to reflect consensus agreement on appropriate codes.

Coding schemes were developed to address three main areas: general themes; the perceived value, positive or negative, of monitoring; and specific targets of monitoring. The transcripts were read several times in their entirety to capture the “gestalt” of participants’ concerns and perspectives and to aid in the identification of themes. Clear, well-articulated statements that elucidated these themes were specially marked. Within the positive and negative coding, a subset of comments was coded as conditional positive and conditional negative. These comments typically took the form of a positive or negative statement with a clear qualifier. For example, “I wouldn’t mind being monitored *if* the doctor would actually use the data collected” or “(Monitoring) would be a good thing *if* someone has a worry about falls.” Finally, specific monitoring targets that were identified by participants as important to monitor were coded, such as falls, and specific medical measures such as blood pressure.

Results

Overall, participants were very engaged with the topic, the discussion was lively, and participants did not seem to be hesitant to state contrary or negative opinions. Qualitatively, there appeared to be no difference in the level of interest in the topic between the older adult groups and the family member/friend groups.

Themes

The content analysis of the interview transcripts identified a number of recurring themes. These themes centered on how participants viewed their own current and projected needs and the needs of other older adults. In considering these concerns, the participants often referred to situations of persons they knew to provide concrete examples.

Maintaining independence in the home—An overarching theme in much of the discussion was the desire for older people to remain in their own homes. As focus group participants discussed this desire, safety was the chief concern: “... I could see the real benefit if it would allow the person to stay (in the home) because just simply having an alarm around your neck which you can take off doesn’t do the job...”

Of particular interest was monitoring that would identify and respond to immediate needs, such as falls. Call buttons, alarms, and responding to falls were uppermost in the minds of a number of participants. As one elderly participant noted, “I’m doing 150 steps a day because of the condo and I’m up and down and up and down and even in my own mind I’m saying ‘what happens if I fall.’ And that’s the device that I think is the key.”

Living alone was also recognized as a situation where monitoring could be very valuable. A female participant noted “... if I had been alone what would I have done? I was having a sandwich in my friend’s dining room and this (choking) started happening and she looked at me with shock and then she said so calmly ... get your purse I’ll drive you to emergency.”

Although there was an overriding interest in the potential for monitoring to enable older adults to stay in their home longer, some participants discussed the concern that there comes a time when remaining in the home is not the best option. Thus, while independence was an important theme in all groups, it was specifically acknowledged by some participants that people sometimes remain in a home setting longer than is appropriate. They felt that monitoring could enable family members to gain a more accurate understanding of problems the elder was experiencing in their day-to-day activities. “I’ve seen lots of families where parents were in their home too long...” commented one family member.

Undetected cognitive decline—Many participants discussed the value of monitoring to detect gradual decline over time that might be otherwise difficult to detect. Often, this was mentioned in the context of cognitive decline. The participants were especially attentive to the potential benefits of monitoring for addressing issues of dementia. A number described personal experience with dementia in relatives or friends and were aware of the kinds of situations where monitoring would be beneficial. For example, one family member noted: “I looked after a friend who had vascular dementia and I think it would have been very helpful especially in the early stages helping her see that maybe she did need more help than she thought she did.” An older adult participant commented, “I think if you were drifting toward Alzheimer’s you’d like to know that situation is coming on.” Another added, “I would be interested in knowing if I was mentally getting out of touch.”

Subjects also suggested that people often try to hide changes and that monitoring would help provide accurate assessment:

She is one of these people like most of us she puts on a good face for the doctor and he has no idea how dysfunctional she had become. And I think something like this would have been a Godsend for anyone who is trying to monitor her.

Even people who are not trying to hide changes may not be able to accurately report problems to a family member. As one daughter related:

I think for the individual they are not always accurate reporters they can’t judge. You say “Hi Mom, how did your day go today? Did you have lunch?” “No, nobody fed me.” I mean did she take the plate out of the refrigerator that you sat there the day before? -- those kinds of things. So the caregiver or the absent person trying to be a caregiver isn’t getting accurate information and so I think (monitoring) would be very helpful.

Dementia, however, also raised special concerns with respect to setting up and implementing a home monitoring system. Several participants expressed concerns related to the cognitively impaired person's acceptance of monitoring, as succinctly noted by one older woman, "Most people who really need it don't want it and wouldn't accept it."

It was difficult for many of the focus group participants to see themselves as persons with deteriorating cognitive function and the consequent need for monitoring of their activities. While they could discuss persons they had known who had developed Alzheimer's disease, when asked about the possibility of such monitoring for themselves, their responses were frequently negative. Said one older adult, "I think it's a touchy personal thing because my memory has slipped...and I don't like to think that's the case, so I think when it becomes a grave problem there is probably even less willingness to acknowledge it." Another acknowledged, "It (monitoring) seems creepy to me. I don't think I would like it for myself..."

Sharing of information—In general, both sets of groups agreed that legitimately useful monitoring was quite acceptable. There were no expressed concerns about sharing data from monitoring with one's physician. The general sentiment was that if it was useful for the doctor, then there would be no objection to collecting the information. In offering advice to monitoring technology researchers, one older male participant recommended: "Ask my doctor if he'll use it. If he felt like he needed to monitor me I would be receptive to it."

The question of whether information should be shared with family members received a more mixed response. In general there was recognition of how useful monitoring data could be for family members, especially for those living at a distance. Offered one older adult, "I could see where it would be a great comfort to my family... if they wanted to know how I was getting along."

However, there was also reluctance expressed by the some older adults to provide such data to specific children or other relatives or friends: "I would want it communicated to my care provider there rather than my children. Because they are all far away and they can't really do a whole lot about it." Added another, "I think I'd probably hedge a little – don't want them (children) to be concerned."

Nonetheless, some participants suggested that monitoring by family members was more important than self monitoring or monitoring within the household. The following comment was from an elder subject:

Well really if you're going to do this (monitoring) except for sharing it with yourself that's what it's for isn't it really? ... people that love you and are responsible for you want to know how you're doing and so it just makes sense that if you're going to do this that's who it would be for.

Tradeoff between privacy versus usefulness—While focus group participants were aware of the potential for misuse of the data, most of the discussion suggested that privacy was not a major concern as long as there were proper controls in place. In general, privacy was a secondary issue if the monitoring was deemed useful with respect to safety, maintaining independence, and health. A number of focus group participants weighed the tradeoff of potential privacy concerns or intrusiveness against the benefit of monitoring, as seen in the following comments: "If there was somebody that could read it and make some use of it – it would be okay," and "I guess I'm not complaining about the big brother aspect of it...but what is it really going to do?"

Positive and Negative Statements

The number of positive and negative comments for the focus groups of older adults and the focus groups of family members/friends was counted. Positive and negative comment counts included both unconditional and conditional judgments about monitoring. There were more positive than negative comments for both groups, with the proportion of positive comments relative to total rated comments tending to be higher for the family member/friend groups (70%) than for the older adult groups (58%).

Positive comments were focused on the potential for informing individuals, families, and providers of changes in an elder's condition, objective updates on activities of daily living, and providing efficient emergency assistance. The following exchange illustrates a generally held view of monitoring:

Woman A: I think it is really useful.

Woman B: Yes – for the sake of the families.

Woman A: And then it allows you to feel more independent too because it doesn't feel like I'm hovering.

Woman B: None of us want to give up control but being monitored I think would be very reassuring."

Negative comments tended to revolve around two main concerns. One was whether a "high tech" method was an improvement over the tried and true informal or "low tech" approach, as voiced by this woman: "We have a system in our church we use the buddy system. There are people...it keeps people in touch." These negative comments most frequently related to doubts about the usefulness of a monitoring system. There was substantial skepticism about whether a monitoring system would be worth the effort and expense of setting it up and analyzing the data resulting from such a system, as voiced by two older male participants: "I fail to see how in this whole network of information...you've showed us, are going to accomplish anything," and "...but what is it really going to do? It seems like a big program for a little result."

A second area of negative comments centered around the difficulty that a number of participants had in identifying with a potential future situation in which they would need to be monitored. Some participants simply could not conceptualize future deterioration in functioning, especially related to cognitive deficits: "I know pretty much what my life is and what my problems are and aren't and I don't need a piece of paper to tell me what they are." One older adult concluded, "I was going to say that at this stage I'm very active and I just don't see any need."

Specific Monitoring Needs

In analyzing the comments in which specific monitoring desires were mentioned, a few topics emerged consistently. Respondents often mentioned specific medical measures such as blood pressure, heart rate, and blood sugar level in open discussion. The card sort activity described above in the methods section was used to get a better understanding of the elders' attitudes about particular targets of monitoring. The activities listed on the cards were intentionally undefined to elicit participant thoughts on monitoring that were most relevant to them. On several items listed on the cards, however, participants asked for and were provided clarification. For example, it was clarified that "phone calls" did not refer to listening in or tracking the content of telephone calls but rather to monitor the number of calls being made. Also, it was explained that "outings" was intended to refer to leaving the house, not the specific type of outing, since the topic under discussion was motion-sensing within the home. The results of the card sort activity provided more detail on the types of monitoring seen as most useful, and illustrated some of the differences between the two sets of groups. Table 1 shows

the number of older adults and family member/friends who marked each index of potential monitoring as either “positive (desirable)” or “negative (not useful)” in the card sort activity. The latter were more likely to rate individual card sort items as positive than were the older adults. For example, participants in the family member/friend groups were more likely to rate “calendar”, “outings,” and “phone” as positive and older adults were more likely to rate these items as negative. In a chi-square test for the total number of positive and negative ratings for all card sort items, the difference between groups was significant ($p = 0.005$).

In general, the non-medical measures were less important to the older adults, whereas those measures were often seen as equally as useful as more medically oriented measures by their family members/friends. For example, walking, outings, and general activity level were seen as very important by the family member/friend groups, and considerably less so by the older adults. This might be interpreted as the former’s desire to know if the latter is “doing OK” or “having a normal day” in addition to how well the older adult might be doing medically.

Discussion

A primary goal of this research was to obtain reactions to the potential for continuous in-home monitoring among those who might be monitored and those informal caregivers and loved ones who might benefit from the information that could be collected. Overall, participants were positive about the potential of in-home monitoring systems. They were able to identify major benefits and concerns with little prodding or additional explanation. Some key issues and concerns emerged from the comments and questions across all groups. These issues have been classified under four dominant themes.

First, in considering their living situations, participants were quick to describe examples from their own experiences in which this type of technology might have helped. Older adults were less enthusiastic than the family members/friends about some of the possible monitoring measures, but their reservations were expressed more as a need for pragmatic justification than as an a priori rejection of the concept. The overarching theme of maintaining independence was often invoked in this context – if the technology in question can help them to maintain independence, then it is valuable.

We are not the first to report the importance to the elderly of maintaining independence in their homes. Zimmer and Chappell (1999) interviewed over 1400 older adults in their own homes and found that threats to independence were the driving force behind receptivity to home-based technology. A monitoring system designed to provide improved safety and security for older adults was well received by the participants as a means of enhancing their ability to remain in their own homes (Sixsmith, 2000). Indeed, there is a consistent recognition in this literature that any technology will be judged by its contribution to prolonging independent functioning.

Second, the need for objective in-home assessment was clear to all participants. However some older adults were resistant to the notion of detection of subtle health changes, particularly related to routine daily activities such as monitoring meals, telephone use, or keeping a calendar. This resistance appeared to be due in large part to an inability to anticipate one’s own cognitive decline. The family members/friends did not share these same concerns, possibly because they were asked to reflect on the information regarding others, not themselves. Indeed, family member/friend participants expressed much interest in detecting subtle changes, and told stories about acquaintances who deny problems in daily living and who “put on a good face” to maintain the appearance of competence. Some told stories of older adults who lived alone long past the time when they should have had assistance.

At a qualitative level, the two sets of groups did reveal different preferences for specific monitoring measures. This difference can be explained in a number of ways. Older adults felt

they were already aware of their status on some of these measures, and thus didn't think the information was needed. For example, most had no difficulty remembering if they had eaten breakfast. Similarly, telephone use and monitoring of scheduled activities on a calendar were seen as unnecessary. On the other hand, family member/friend participants seemed to feel that more measures are generally better than fewer measures, providing a more complete picture of the older adults' current status. At the same time, older adults often expressed a fear of being overwhelmed by too much information.

In a third theme, older adults in this study were unanimous in their expressed desire to maintain control of data collected from any monitoring system. Within this parameter, however, there was considerable variability in the specifics of acceptable data sharing. Some assumed that family members, for example, should have access to all information in order to be kept apprised of their health status. Others were reluctant to "worry" or "burden" their children. While most participants thought their health care providers could receive regular updates based on the monitoring information, there was a widely held perception that medical professionals had little time to devote to perusal and analysis of such data. Kassirer (2000) argues, however, that there is a growing pressure from patients in general for their providers to become more receptive to electronically transmitted information.

Finally, the participants made it clear that timely response to health emergencies was a primary benefit of monitoring. Moreover, this feature was often mentioned as one that would justify privacy concerns. Previous studies have consistently described the tendency of elders to judge technology in terms of immediate benefits. Magnusson and Hanson (2003) found that the majority of users of in-home technology were satisfied if and only if the technology was of direct benefit in their daily lives. Others have reported a willingness to trade privacy protection for enhanced safety and independence (Brownsell et al., 2000; Demiris et al., 2004; Mann et al., 2002; Melenhorst, Fisk, Mynatt and Rogers, 2004).

Limitations of the Study

The participants in this study represented people with more computer experience than a random sample of the current U.S. population of elders would show. Therefore caution in generalizing to the elderly population at large is warranted. One of the reasons for this recruiting strategy was in order to minimize the need for long, explicit, and possibly biased explanations – participants already had some idea of what computers are capable of, and also were presumably more aware of the potential limitations and privacy issues than people with little or no experience. Additionally, it is anticipated that computer users are likely to be early adopters of this technology. As an exploration of advanced applications of computer technology, this seemed a reasonable approach. This is a rapidly changing environment. Elders who may currently be considered early adopters, will likely in the near future represent a more mainstream cohort, as computer use becomes more widespread among the elderly. Indeed, census data report that 72% of 45 to 54 year-olds, and 63 % of 55 to 64 year-olds own computers (U.S. Census Bureau, 2005). It is only a matter of time before these cohorts join the ranks of the retired elderly such as those in the present study.

The sample was primarily selected from a population of current participants in an ongoing study of brain aging. The participants were self selected (as are most focus group participants) and clearly were a group of people interested in brain aging and health, and were likely to have a positive orientation to health research in general. Further research needs to be conducted with populations with less computer and research experience to discover the different perspectives and concerns of these potential users.

There was an explicit attempt to begin the focus group sessions with non-specific examples in order to elicit the key topics and themes from the participants, rather than introduce specific

topics with a possibly biased perspective. While this may have produced some initial confusion among participants regarding the possibilities of in-home monitoring, the trade-off seemed reasonable. Although one can never rule out demand characteristics in a study such as this, we believe that participants were not hesitant to bring up negative impressions or voice their concerns.

Implications for Future Research

There are many researchers working on technology to provide monitoring and support for elders in their homes (Stefanov et al., 2004). Many of these systems are still in an early stage of development, and large scale trials of these types of systems are rare. Indeed, many of these “smart homes” are essentially single home-like laboratories located on university campuses, where development and maintenance is easily supported. As progress in this area continues, this study suggests several important aspects of the technology development that should be given more attention.

Comments from study participants carried the implication that monitoring systems must be capable of real-time response and intervention. Researchers should investigate what automatic, immediate interventions are currently available or could be developed for elders living alone. Practicality was an important consideration for these participants; as a corollary, one might expect affordability of monitoring systems to be a primary variable in its adoption. This was not a focus of our study but certainly will need to be addressed by future research.

While the participants in our focus groups were not unduly concerned about privacy issues, there is an ethical imperative to provide privacy protection and security capabilities. The person being monitored should have control over what type of information is collected and who has access to it. Further, participants insisted that monitoring technology must be non-intrusive and not interfere with or place demands on daily life. Some of the participants made it clear that they would be resistant to having to wear a special device, while others worried that they would have to change their routines or learn new technical skills (“*I’m not going to input data*”). Further, the system must be flexible and customizable as the needs of elders change.

It was clear that a few participants were unwilling to consider monitoring because of a perceived invasiveness that no benefits would overcome. Designers of monitoring systems should develop tools for helping people to make informed decisions about monitoring so that they can make judgments based on realistic costs, risks, and benefits.

Unobtrusive in-home monitoring is one of many technology-based methodologies under development to address the health and functional needs of older adults. Technology has great potential to sustain the independence of older adults and to offer solutions to the individual and societal challenges faced by the aging of our population. Seeking the views and perspectives of the potential users will help to ensure that these technological solutions are responsive to the needs of older adults in an ethically responsible way. As technology changes and develops, it will be imperative to keep monitoring these stakeholders’ needs and perceptions, as they too can be expected to change with time and exposure to the systems in question.

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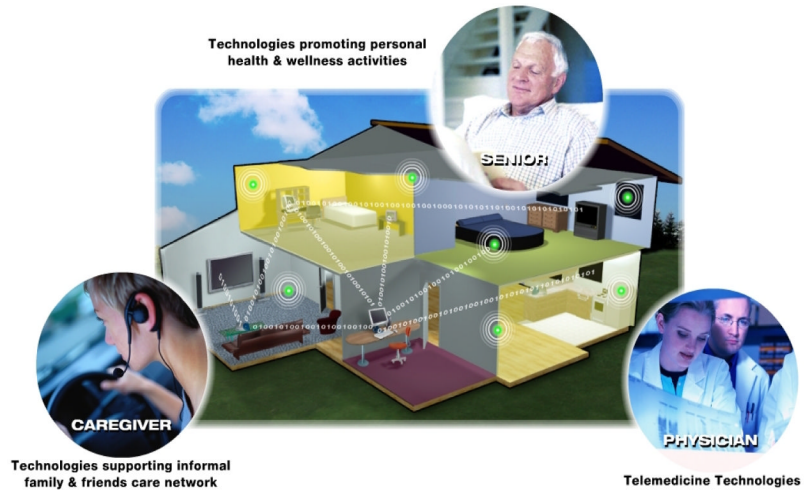


Figure 1.
Focus group slide displaying the concept of in-home monitoring.

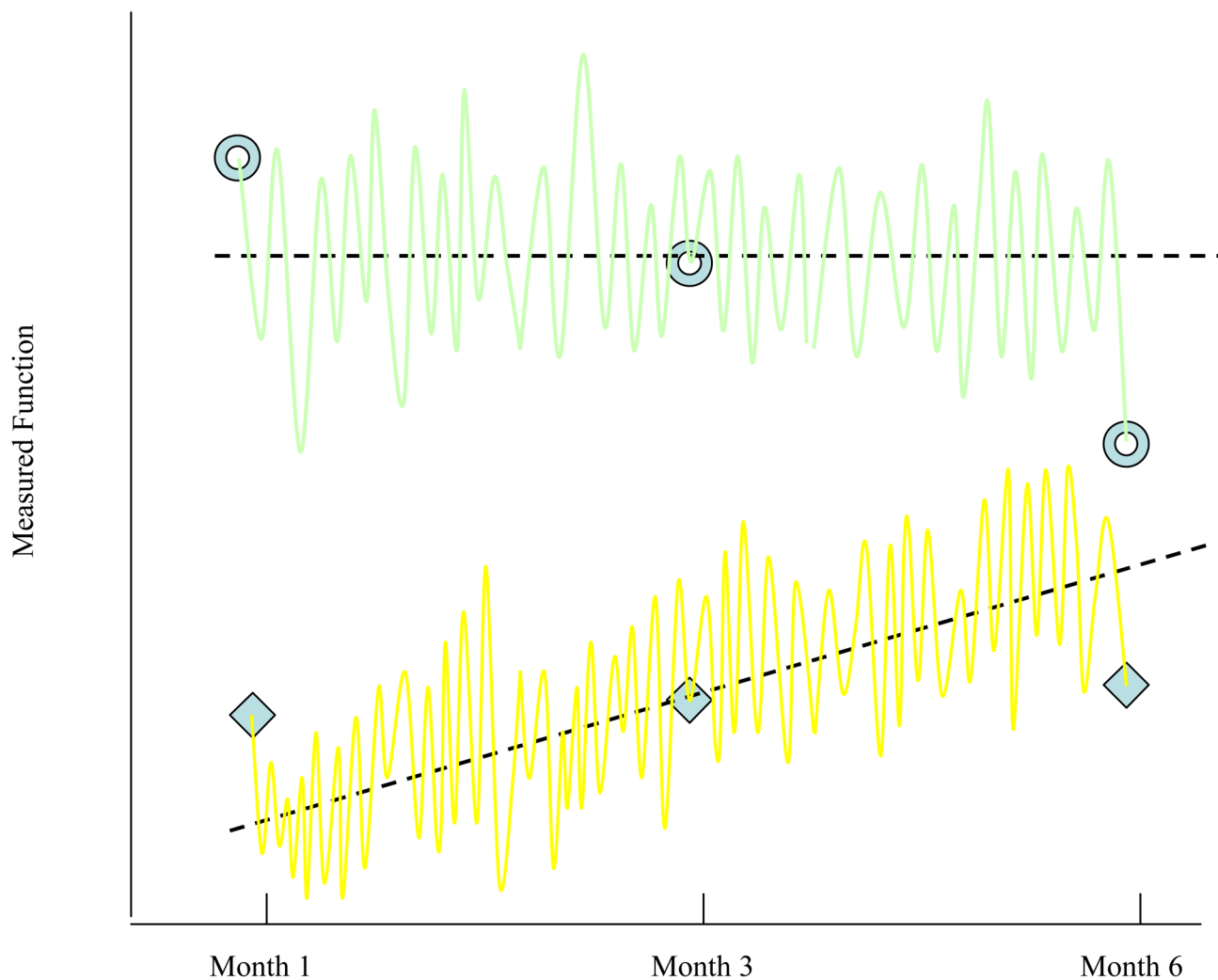


Figure 2. Focus group slide displaying advantage of continuous data monitoring. Circles represent assessments of a hypothetical subject who appears to be declining but is in fact stable over time; diamonds represent assessments that would indicate stability in a subject who is in fact improving over time.

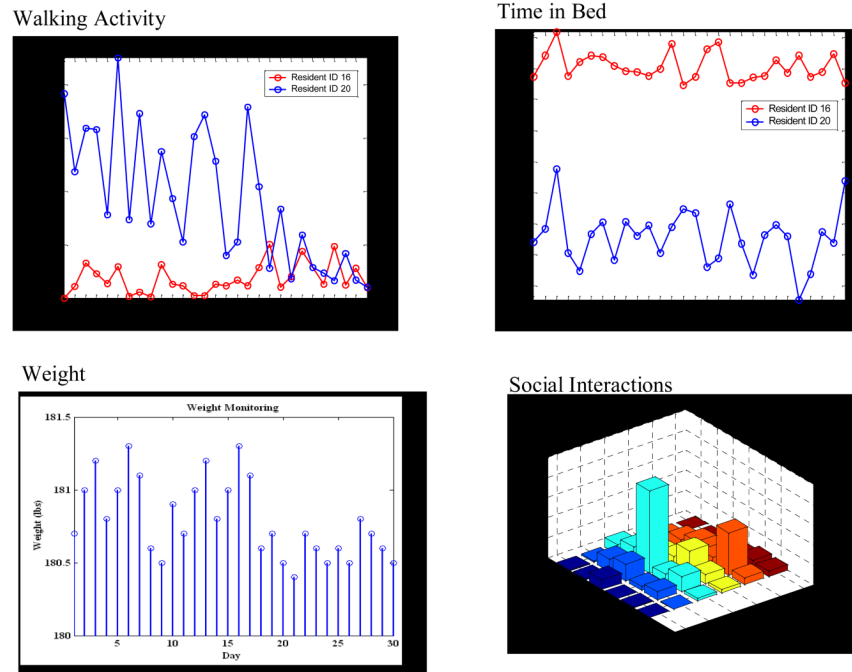


Fig. 3. Focus group slide displaying summaries of different activities.

Table 1**Specific Monitoring Needs: Results of the Card Sort Exercise^a**

Monitoring Targets	Elders (N=13) ^b		Primary Contacts (N=16)	
	+	-	+	-
Disease Specific	11	1	15	1
Memory	10	2	16	0
Falls	10	2	14	1
Weight	10	2	11	2
Medications	9	3	16	0
Confusion	7	3	14	0
Bathing	7	5	10	3
Toilet Use	6	4	7	4
Walking	5	3	11	2
Meals	4	5	10	2
Phone Use	3	8	6	3
Gen. Activities	2	6	10	3
Outings	2	9	9	2
Calendar	1	9	7	2
Total	87	62	156	25

^a Number of elders and primary contacts who found specific information valuable (+) or not valuable (-). The groups generally completed this task without difficulty; when questions arose about particular items, clarifications were offered.

^b Only two of the three elder groups participated in the card sort task.