First, Cause No Harm:
Issues in Building Safe, Reliable and Trustworthy Elder Care Systems

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Abstract

Emerging smart, adaptive, integrative reasoning and interaction management technologies—which we choose to call Interaction Design Systems—hold enormous promise to solve a growing international problem: the provision of care for elderly populations. There are, however, substantial novel challenges to providing care with this type of technology to this population. Specific challenges arise from providing safe, reliable and affordable systems for a highly diverse population that is not in a position to oversee or compensate for technology's failings. These pressures should drive us toward specific IDS architectures designed for growth, expansion and tuning—both for the individual installation and over the lifespan of the technology. Furthermore, they should also, generally drive us toward initial delivery of systems that provide minimal automation capabilities, augmenting the supervisory role of human caregivers, rather than trying to replace them. Most importantly, any such system going into final use should strive to provide an accurate depiction of its capabilities and limitatons to both caregiver and elder.

Issues in Elder Care Systems

Data from the Administration on Aging shows that the number of people in the US over the age of 65 will double to 69.4 million by 2030—22% of the population (AOA 1998). Historically, 43% of people over the age of 65 enter a nursing home for at least one year, yet a Health Care Financing Administration (HCFA) survey found that 30% of the elderly would "rather die" than do so (HCFA 1998). The financial and emotional trauma of such moves affects thousands of families yearly.

Emerging home sensing and control technologies, integrated through emerging networking and information transfer protocols, and managed by intelligent, adaptive systems can be configured to transform a legacy home into something of a full-time caregiver by giving individual sensing and automation components an integrating 'mind' with enough intelligence to coordinate and direct their behaviors for the good of the client. 'Smart homes' are upon us, but whether they are smart enough remains to be seen. Companies are marketing microwaves that connect to the Internet, refrigerators with computer displays, and toilets that track vital signs and do chemical analyses. Builders have thus far largely concentrated on the devices themselves and the network protocols necessary for them to communicate. Experience in other domains (avionics, refineries, surgical theaters) shows that such innovations will merely produce a collection of distributed devices with localized intelligence which are not integrated, and which may actually conflict with each other in their installation and operation. Again, our experience shows that to consistently exhibit intelligent behavior, these networked devices will need a coordinating, situation aware, intelligence capable of integrating and controlling those devices appropriately for the needs of the client. That integrative intelligence has traditionally resided in a human, but the problem in the domain of elder care is that the elderly, especially those in need of caregiving support, are frequently the least able to provide adaptive and integrative control of a diverse set of complex technologies.

The techniques required to provide this intelligence via an automated or semi-automated system are emerging from computer science and human-centered systems design (HCSD). Of various terms used by researchers [e.g., (Wahlster 1998), (Opperman 1994)], we choose to call the underlying technology an Interaction Design System (IDS). IDSs process sensor data to understand the 'situation' and user needs, then rely on knowledge of HCSD and action automation to develop interaction plans—that is, a series of control actions designed to assist a client through information presentation or adaptive automation behaviors. Our goal is to combine home control devices with the knowledge-based awareness and intelligence to provide aid and a safety net to aging clients and their caregivers.

The payoffs for such a system are enormous. We have conservatively estimated (Miller 2001) that, if such technologies could defer nursing home admission for one year for less than 1 in 5 of elders, the U.S. would save an estimated $22 billion in 2005 alone—not to mention untold familial suffering.

But the barriers to such systems are also enormous. Technologically, we know or are developing multiple methods for fielding IDSs, but the more significant barriers are likely to be ones of user acceptance, system reliability, cost effective fielding and adaptation to the wide range of user and home characteristics that such systems must cover. And, of course, safety and quality of life should take precedence over technology for technology's sake in this domain even more than others. The unique challenges involved in developing our vision of such a system include:

- *Interpreting and handling the needs of a population with varying capabilities and constraints, acting in unconstrained, unstructured environments.* Clients will differ widely in cognitive, sensory, and mobility capabilities; moreover their capabilities can change, sometimes slowly over time, sometimes abruptly.

- *Designing interfaces and interactions that will be usable and accepted by a potentially technophobic generation with divergent capabilities*. Even though being able to live at home is a strong motivator, we cannot depend on our users to learn about and adapt to the system.

- *Designing an affordable system.* Previous IDS developments have relied on industry or military funding. Home-based, elder support systems may have to rely on individual homeowners or caregivers. To realize their full social and economic benefits, such systems must leverage existing structures and appliances of older, possibly antiquated homes. This challenge requires developing unique reasoning components that can analyze situations based on the inputs of a variety of low cost, off-the-shelf sensors—not expensive, specialized hardware. Furthermore, the developed system must enable an inexpensive, easy, and quick installation of hardware, software and knowledge-based components, and also must include methods for ongoing adaptation of those components to the changing needs and situations of the client.

These problems will be explored below in the context of achieving two critical attributes for IDS systems. We will present thoughts about how IDS approaches, and IDS implementation programs, can overcome them. In most cases, this trio of challenges listed above demands a solution, at least in the near term, which is not at the highest end of IDS technological feasibility, but rather uses a small amount of IDS technology to create or increase safety, accuracy and usability in a reliable and cost effective system.

Addressing the Issues

Accuracy in Situation-Response Reasoning

Traditional automation (especially home automation) operates using very simple situation-response patterns. If the temperature in the house is above a setpoint, the thermostat turns off the furnace. This simplicity proves effective because it is reliable, and because it makes use of human oversight to ensure that what the automation does is appropriate in context—e.g., to determine whether the setpoint is correct and the furnace is functioning.

A caregiving IDS provides benefit to the elderly by taking on (or sharing) much of the responsibility for reasoning about what is appropriate in context. To fully and accurately take on this responsibility means that (1) the system must have vastly more, and more complicated, situation-response patterns than traditional automation, (2) those patterns must take much more into account, and (3) responses need to be coordinated over many possible devices.

A critical risk for a care giving IDS is that it will be inaccurate or imprecise in detecting situations of interest, because of faulty or insufficient sensor data, bad links between sensor data and situations, and/or an incomplete or erroneous set of defined situations. The problem of accurate situation assessment has plagued prior IDSs. For example, most users of Microsoft Word™ 95 or 97 have had the experience of the Office Assistant offering help with drafting a letter when what they wanted to do was something completely different.

The risk of inaccurate situation assessment is exacerbated by several factors: first, a 'situation of interest' will differ from client to client and household to household. Second, available sensors will also likely differ in each home. Third, the number of options available to a person moving about his/her home is likely far greater (and thus, predictability will be far lower) than a pilot following a mission plan. If, due to any of these barriers, the system cannot deliver accurate and reliable assessment of a sufficient number of critical situations, then all of its ability to customize interaction responses will be in vain.

Similarly, the risk of inaccurate response generation is also present though, perhaps, under more control by the designer. Factors that exacerbate this problem include the sheer diversity of the user population combined with the fact that many elderly users will be less able—physically, cognitively and perhaps even emotionally—to adjust to sub-optimal system responses than the general population might be. Similarly, at least some elders will find it difficult to control or modify a complicated computer-based system—or to go through lengthy set up procedures.

But note that there is a tradeoff between the amount and sophistication of automated aiding which is provided (in terms of the complexity of system reasoning), the degree of 'coverage' of situationally appropriate reasoning, integration and responding which the system must perform and the role of humans in ensuring correct behavior in context. To the degree that humans can be put in the role of providing oversight and ensuring that lower level system reasoning and behaviors are appropriate for the contexts in which they occur, the burden on the system to provide this is diminished. The thermostat described above is an extreme form of choosing substantial human responsibility and low levels of system automation and integration. At the other end of the spectrum are some visions of smart (one might even say 'brilliant') homes that know virtually everything about their clients and how to adapt to meet their needs. Intermediate positions are possible, and will likely make more sense for elder support systems in the near term.

For example, instead of trying to create a system that knows when to call emergency services for an elderly client who has had a heart attack, it may make more sense to create a system that knows to alert a formal or informal caregiver about a lack of client mobility. Here, we've traded a portion of system autonomy and incurred more human workload, but we have reduced the requirements for system accuracy and reliability. If the goal is to reduce the load on a caregiver, rather than to replace him or her, the latter approach may be both thoroughly acceptable and, in fact, more nearly feasible with existing technology.

A final point to be made about the above tradeoff is that the worst possible arrangement may be when the system is built (or sold) to take more of the responsibility for providing correct behavior in context than it can reliably provide. The result of such an arrangement will be a situation that needs some sort of aiding, a machine system that is failing to provide correct aiding, a caregiver who is relying on the aid and, therefore, not detecting and address the problem on his or her own, and an elder who is less than fully capable of either addressing the problem or of calling for help.

Overall System Usability

While IDS systems are currently reaching reality, system usability remains a paramount issue. The Microsoft™ Paperclip has been less that completely successful arguably because it did not use the IDS capabilities it possessed in a user acceptable fashion. User acceptance levels of our work on an IDS system for military rotorcraft were noteworthy not because they were extraordinarily high (C. Miller 2000) but precisely because they were beginning to indicate feasibility in a real world setting.

The usability challenges facing elder care systems are particularly daunting. Not only is the 'science' of determining or predicting usability for IDS systems in its infancy (Miller 2000), but the science of providing usable human-computer interactions for elderly or special-needs clients is also far from perfect. Previous experience in other domains has shown user discomfort with feeling 'out of control' or 'watched and supervised.' We have also noted the extreme visibility of a single error compared to hundreds of 'correct' actions. We expect users' acceptance issues with an elder care system will stem from concerns about reliance on technology to perform functions previously carried out by a person, a product look-and-feel that is incompatible with the users' home environment, and a human-system interaction that is perceived to be too computer-like.

These risks can be mitigated by employing a user-centered development process that devotes substantial program effort to both initial knowledge acquisition and subsequent usability testing. HCSD is a design philosophy that defines human users as integral components of any human-machine system. The goal of HCSD is to develop systems that behave in ways that match users' expectations and are sensitive to their physical, psychological, and cognitive abilities.

The application of advanced technology to the home does not inherently provide ease-of-use. It does provide increased design flexibility, which in turn creates an opportunity for optimal system performance. In a domain as diverse as elder care, it will be necessary to first establish the range of users and situations of interest. In our work, we have done this initially through review of documentation (e.g., AARP studies), consultant experts, observation, interviews and 'ride alongs' with caregivers and technical installers. Similarly, when investigating human interaction with the caregiving system, we have selected representative scenarios to inspect the range of possible situations, users, devices, etc. and have observed user interactions in naturalistic and lab settings.

The attempt to apply IDS technology to the elder care domain poses new usability and usability evaluation challenges as well. The traditional techniques used for HCSD will require innovative adaptation for IDS design. Much previous work in creating IDS systems has been more focused on achieving intelligent behaviors rather than usable ones. We must not make that mistake if the caregiving system is to be usable and reliable by its target community. It is difficult to test a highly advanced system before it is built. It is also essentially impossible to test all of the behaviors a caretaking IDS could provide. Traditional focus group and user questionnaire problems will be even more affected by the potential inability for this user group to envision the range of possible functions and interactions a caregiving IDS could provide—much less to fully understand how it would affect their daily lives. Instead, a range of part-task evaluations and Wizard of Oz (human emulation of system behavior) techniques should be given substantial weight to achieve HCSD inputs early and often. Another solution is to be sure to create the system so as to support a wide range of interaction and interface behaviors. Whether all such behavioral alternatives need to be designed concurrently, or provided to end users as tuning features, is a separate question whose answer may well be 'no'. We note that there may well be a substantial role for machine learning to tune system behaviors to the wide variety of users and user situations. Regardless of how the tuning is achieved, it must be; small differences in the 'face' that an IDS system presents to its users can make huge differences in user acceptance. Fortunately, many IDS architectures inherently support or at least facilitate the ability to tune interactions to different users and situations.

Some Design Goals

In this section, we boil down the discussion above into a few design principles or goals that we feel should be sought in the design of IDSs for elder care. These are heuristics, at best, and they will not be equally applicable to all cases and designs, nor will their manifestation be the same in all contexts, but we feel that they are generally good advice for those attempting to field an automated caregiving system that will provide benefit in this domain.

1. *Cause no harm.* Designing technology to substitute for a human caregiver in the home environment is substantially different than designing other aiding, support or entertainment systems and appliances for the home. We are likely removing traditional human support networks and, thus, we must ensure that they are fully and completely replaced by technology. The burden of proof should be on the new system to show that any modification it causes will enhance, or at least not diminish, safety for the elder. Quality of life enhancements are desirable, but they are secondary to safety considerations.

2. *Accurately convey system capabilities, data, assumptions and limitations.* Forces will combine to tempt system designers (and marketers) to claim more for their systems than the systems can provide. All the traditional factors of marketing will push toward this end, but a more insidious pressure will be present as well. Users of such support systems will need and want information at a higher level than the system may be fully able to provide, and the temptation will be to give it to them. For example, a remote caregiver may want to know whether the elder has gotten up this morning. By contrast, the implemented system may only be able to report that motion was detected in the kitchen at 9:03 AM. There is a probabilistic link between the observation and the conclusion, and it may be acceptable to report this probability (though the utility of that is yet to be determined). It would, however, be unacceptable and potentially misleading and dangerous to report that the elder had gotten up on the basis of that observation alone.

3. *Avoid depending on the elderly client for active input of information either at configuration or on an ongoing basis.* This constraint can be relaxed for some applications, but in general requiring the elder to actively participate in providing information to the system should be avoided. Not only is this intrusive, it is also unreliable and may fail precisely when it is needed most—when the elder is most in need of help.

4. *Don't prohibit the elderly client from providing active input.* While active input from the elder should not be relied upon, especially for safety critical functions, the elder should be capable of adapting and configuring the system to better suite his or her needs. To prohibit this would add to the feeling of being watched and controlled by automation and would, again, lead to lack of user acceptance.

5. *Design for growth.* The consequences of many of our other principles may well be a certain conservativism in the fielding of technology to provide care to the elders. Some technologies will not yet meet the safety, reliability, and accuracy tests required to cause no harm and provide accurate information that is also useful. But these technologies will mature as time passes and there will be pressure to incorporate them into the caregiving environment. A system that is capable of incorporating new and enhanced technologies into its general environment will be superior to one that must be scrapped. This applies especially to the system interfaces which the elder experiences and to the elder's physical environment—being able to add a new system capability without requiring the elder to learn a new set of UI actions or ripping out walls to install new wiring will be an enormous advantage.

6. *Design for change.* The previous principle emphasized the growth of technology. It is also characteristic of this domain that the elder's capabilities will change. These changes will drive the need for modifying, and frequently growing, the capabilities of the system over time. This will be true both on large time scales (e.g., during the progression of Alzheimer's) and on small ones (e.g., the elder has the flu today and won't be getting up as much). System reasoning and response behaviors must be sensitive to both kinds of change.

7. *Design for variance.* The degree of variance among potential users and usage contexts for caregiving technology systems is dramatic. In other domains for which safety critical systems have been designed (e.g., aviation, military systems, industrial processing, power generation, medicine) users are frequently selected for a certain common set of skills and then trained to behave in common ways. Operational environments, such as a surgical theater or cockpit, are designed specifically for the tasks to be performed there and to have specific commonalities with all other cockpits or theaters. None of this is true for the elder care domain. Elders have a wide variety of capabilities, personalities, education, experience, etc. and their homes and their contents will vary enormously. While it will be acceptable (and maybe necessary) to select more nearly homogenous groups for the fielding of specific systems, it is quite likely that every caregiving system will need to be configured and adapted to the specific user and home it encounters. Not only must this range of adaptation be designed into the system, but methods for accomplishing it in an easy and cost effective manner will likely make the difference between a successful aid and a failure.
8. *Design to enhance quality of life*. Elders can face several emotionally and mentally stressful losses as they age—the loss of freedom, privacy and convenience associated with impersonal, inept and unhelpful technology need not be one of them. We should continually seek ways to make the impact of technology as caregiver be a positive one for the elders that must experience it. After safety and accuracy concerns are addressed, the next question that should be asked about a prospective aiding technology is "will this make life better for the elderly client?"

Conclusions

Fielding an IDS system for elder caregiving support should be regarded as a long term project which begins with simple functions for a select and restricted user community and which offload human caregivers slightly but in no way remove them from the loop. As these simple behaviors are tuned and proven to be acceptable, reliable and safe—thanks to the flexibility inherent in IDS technology—we can begin to expand system functionality and to broker the system into new user communities. To proceed in any other fashion would not only jeopardize the acceptance of IDS technology in this domain, but it would also risk the lives and health of some who are least able to fend for themselves. Caregiving technology, like caregiving itself, should first strive to do no harm.

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