The ELDer Project: Social and Emotional Factors in the Design of Eldercare Technologies

Tad Hirsch, Jodi Forlizzi, Elaine Hyder, Jennifer Goetz, Jacey Stroback, Chris Kurtz

Carnegie Mellon University ICES/HCII Pittsburgh, PA 15213 USA +1 412 268 7890

(thirsch@andrew, forlizzi@cs, ehvder@cs, jgoetz@cs).cmu.edu

ABSTRACT

The ELDeR (Enhanced Living through Design Research) Project, comprised of a team of designers and behavioral scientists, conducted a four-month study at a seniors' community near Pittsburgh, PA. The purpose of the project was to understand the experiences of elders and their caregivers in order to: 1) study the eldercare experience from the perspective of primary stakeholders; 2) to assess the importance of psychological and social factors in the eldercare experience; and 3) to identify implications for product, interface, and interaction design and opportunities for new products and technologies. Our findings showed that social, emotional, and environmental factors play a key role in the eldercare experience and the adoption and use of new products. We argue that eldercare technologies that address all of these factors lower social and economic barriers to universal usability.

KEYWORDS

Universal usability, design ethnography, eldercare, assistive technology, social and emotional factors, aesthetics

INTRODUCTION

One of the great challenges facing universal usability research is the need to accommodate "user diversity." This includes the design of interfaces and technology products usable by people with a wide range of needs and capabilities, and developing "appropriate services" to meet these needs [20].

The ELDeR (Enhanced Living through Design Research) project is addressing this challenge by studying the needs of elders. A team of designers and behavioral scientists conducted a four-month study at a seniors' community near Pittsburgh, PA to understand the experiences of elders and their caregivers. There were three goals for this broad-based qualitative user research:

- to study the eldercare experience from the perspective of primary stakeholders – elders and the people who support them;
- 2. to assess the importance of psychological and social factors in the eldercare experience; and,

3. to identify implications for product, interface, and interaction design and opportunities for new products and technologies.

Clearly, this is not the first attempt to develop technologies that meet the needs of the aging population. The past several years have seen a number of initiatives on the part of industry and academia to meet these needs, including eldercare robots, elder-centered websites, communication devices and intelligent devices to assist with walking and eating [1, 3, 5, 9, 16, 18, 22]. For the most part, these projects have focused on developing assistive technologies that enhance elders' functional abilities, and adaptive technologies that increase access to information and communication.

Assistive and adaptive technologies have economic and psychological costs that hinder user adoption. These costs ultimately stand in the way of universal usability. Assistive and adaptive products are generally produced in small quantities for specialty markets and therefore tend to be prohibitively expensive for many users. In addition, these products highlight users' disabilities and contribute to social stigma associated with disability [14], hindering adoption of these devices.

Current research and development tends to address users' "personal competence" needs — specifically, declining motor and cognitive skills. Far less consideration is given to social, emotional, and environmental needs; factors that the "environmental press" model of aging identified as playing a significant role in the aging experience [11, 24]. This model describes behavior as a function of two variables: personal competence and environmental press. Personal competence encompasses health, sensory-perceptual capacity, motor skills, and cognitive skills. Environmental press has both social and physical dimensions, and describes the desirability of the environment to which the elder must adapt behaviorally. [11]

Failure to consider the social, emotional and environmental dimensions of the aging experience results in missed opportunities for new technologies and applications, and poses difficulties for the adoption of potentially useful products. If universal usability is to be achieved, closer

attention will have to be paid to social, emotional, and environmental factors.

METHODOLOGY

We conducted broad-based qualitative research intended to identify stakeholders' perceptions and attitudes. Our researched focused on identifying and assessing the importance of social, emotional, and environmental factors within the eldercare experience. We were particularly concerned with implications these factors have on how current products are used and on the design of assistive technologies.

To bring the elder closer into the design process we used ethnographic research methods adapted from anthropology [7] and the social sciences [4]. Although ethnography is often equated simply with fieldwork, recent examples have also provided accounts for how participants understand and organize their day-to-day activities [2]. Using ethnographic methods, researchers observe and participate in activities of everyday life in order to better understand and communicate about the culture they are studying. Our research focused on the behaviors, attitudes, and routines of elders, and more importantly, the tools and artifacts they use, and how they think about them. This ethnographic research is focused on understanding how social interactions contribute to the engineering and design of new products, artifacts, and services [2, 19].

The set of research techniques we used included the following:

A literature review to understand how others viewed these issues and had designed products to address these issues. We reviewed relevant psychology, sociology, engineering, and design literature to achieve a better understanding of how US culture defines the elderly; what sociological issues surround elders and elder care; and what product and technology developments relate to the domain of eldercare.

Lifestyle interviews to ground our knowledge within the context of the elder's lifestyle and residence. We conducted in-depth interviews with elders and caregivers to gain an understanding of the lifestyle of the elder/caregiver. We focused on the elder's individual and collaborative routines, changes in routines, attitudes, and perceptions that occur as aging takes place. These conversational interviews took place in the context of the elder's home or community, and were accompanied by photographic documentation of these spaces.

Self-documentations to provide an unrestricted view of what is important to elders and of how they conduct their lives. By asking elders to document their day with a disposable camera and log book, elders showed researchers what is important, desirable, and improvable in their lives, as well as what products and services they rely on daily. In this way, researchers are able to learn about elders' perceptions, behavior patterns, and product use. The use of these kinds of exercises, although new, has been valuable in identifying new product opportunity areas. [6, 12]

Observations provide the opportunity to track the flow of people and events and capture behavior of people and their

interactions in context. We spent twenty hours within a seniors community in the greater Pittsburgh Metropolitan Area, observing the flow of people and events during a typical day; capturing behavior in context, interactions with people and products, communication and community-building. These sessions were accompanied by short intercept interviews, note-taking, sketching, photographing, and frequent team debriefs.

Subjects

We recruited five elders for interviews (two males and three females) and ten elders for self-documentation (three males and seven females), ranging in age from 75 to 92. Included were married, single, and widowed participants who lived in a variety of settings within a retirement community, including single-family houses, and one- and two-bedroom apartments. Length of time in the community varied from several months to many years. For self-documentation all participants took photographs. Nine of the ten participants used logbooks to complete their documentations; one used an audio recorder because she is blind and cannot write.

We recruited five caregivers for interviews, all female, ranging in age from 40 to 53. Caregivers ranged in experience from several months to several decades, and included two administrators, two registered nurses, one professional companion, and one family member. All but one caregiver worked at the retirement community where the elder subjects lived. One caregiver was taking care of her mother at her mother's house.

All participants were pre-screened prior to data collection through a short telephone interview to explain procedures, construct preliminary profiles, and to prepare the datagathering team.

OBSERVATIONS

We developed a rich description of the eldercare experience from the perspective of primary stakeholders - elders and their caregivers. We studied the physical, cognitive and emotional issues that people face as they age, and witnessed how elders relate to others in their community, from family members to service people. This process enabled us to identify user needs and perceptions that will form the basis for new research and development opportunities.

Through our research, it has become clear to us that social, emotional, and environmental factors play a significant role in the eldercare experience. Three key themes have emerged from this work.

- 1. Expanded definition of care: "Care" in the context of aging refers not only to improving physical condition. Both elders and caregivers viewed eldercare as concerned with maintaining an individual's "quality of life", a complex interaction between a host of physical, social, and psychological factors.
- 2. Eldercare as a social interaction: People who contribute to caregiving for an elder are not limited to medical personnel. Due to the expanded definition of care and the importance of quality of life in this

definition, family, friends, acquaintances, and service people all play a significant role in eldercare. An elder's quality of life is dependant on a rich set of social relationships among a variety of individuals.

3. Shifting perceptions of ability – psychological factors and assistive technology: User perceptions of their own abilities are often out of step with their actual capabilities. This incongruity has significant implications for an elder's experience. This can include an elder operating at a level below her capacities, causing her to be fearful of attempting relatively safe tasks. Conversely, the elder may overestimate her own ability, causing her to undertake risky tasks. Among the factors contributing to disparity between perceived and actual capabilities, the designs of assistive technologies are significant.

Expanded Definitions of Care

According to several of our interviews, the goals of healthcare change as patients age. For young people, healthcare tends to focus on "getting better." Most ailments, such as broken limbs or mild diseases, are considered temporary setbacks that will be overcome with no long-term effects on functional ability. Older patients, however, tend to have a different outlook. Injuries and diseases are often long-term, and may in fact greatly affect functional ability for the remainder of life. Eldercare, then, tends not to focus solely on getting better, but rather on maintaining or improving "quality of life" as one's functional capacities change.

Quality of Life

Although none of our subjects was able to provide a concise definition of quality of life, several themes emerged. We understand quality of life to be a measure of an individual's physical, mental, and emotional well-being, as compared with their needs and capabilities. Quality of life is highly individualized, and changes from day to day as a person's capabilities change. Two main factors affecting quality of life are independence and engagement. (Figure 1.)

Independence Engagement Quality of Life

Figure 1. Elders and their caregivers need to balance independence and engagement to maintain dignity and enhance quality of life.

Independence is based on one's ability to exercise control over one's life - the capacity to care for oneself and to make one's own decisions. Independence is determined in relation to one's level of ability. For some people, independence can mean being able to perform as simple a task as putting on socks. For others independence can mean the ability to participate in a master's swimming race at age 70. (Figure 2.)



Figure 2. Mrs. P, aged 70, with four medals she won at an international swimming competition last year.

Engagement is connectedness to the world and to other people – the ability to share experiences and friendship, to communicate, and to share resources. Engagements can range from sharing a newspaper with one's neighbor to helping a blind friend on a daily basis.

The balance between independence and engagement determines an individual's quality of life. A person who is very independent, but not very engaged may feel isolated and alone. Someone who is very engaged but has little independence may feel infantilized.

Care as a social interaction

As functional ability decreases, connections to other people become exceedingly important in determining the individual's quality of life [8, 24]. Expanding the definition of eldercare to focus on maintenance and enhancement of quality of life requires an expanded definition of caregivers. Many researchers assume an exclusively medical definition of "care," and focus on nurses and doctors as the primary caregivers for elders. In the context of eldercare, however, it is important to include all the people who contribute to an elder's quality of life.

In our research, we found an overlapping of worlds and roles: friends, family, and even service people all participate in caregiving. In many cases, primary caregivers are not doctors and nurses, but rather family, friends, or service providers – the people elders interact with on a daily basis.

We can visualize the strength of connections between an elder and people who contribute to quality of life as a series of concentric rings. Strongest connections, determined by such factors as frequency of contact, geographic distance, and emotional attachment, occur between elders and the innermost rings. While interactions with people on the outer rings may be important, they tend to hold less significance on a daily basis.

The way these rings are populated differs greatly from elder to elder, depending on such factors as disposition, personal history, socio-economic status, and physical location. Figure 3 illustrates a composite set of relationships based on several interview participants. Mrs. S's inner ring is comprised of her son, a paid companion, and a longtime friend who also resides in her retirement community. Her secondary ring is comprised of her daughter (with whom she has a more distant relationship than her son), her primary care physician, a visiting nurse she sees weekly, an old friend from her previous home in Virginia, and two employees of the retirement community with whom she has become close. Mrs. S's outer ring includes a neighbor she recognizes but doesn't know well, her cardiologist, a bus driver who helps her take long trips outside of her community, and her grandson with whom she speaks infrequently.

Clearly, these connections are fluid and change depending on varying circumstances of the elder. For example, while an elder is healthy, her daughter may live several hours away and maintain a moderately strong connection over a physical distance. However, the connection may become stronger after a traumatic event (such a stroke) motivates the elder to relocate to a retirement community closer to the daughter; or compels a child to live with a parent.

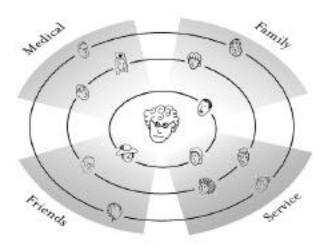


Figure 3. Contributors to a composite participant's (Mrs. S) quality of life.

Maintaining strong connections is an essential component of caregiving. Primary caregivers assist with a variety of tasks, including medicine management, food preparation, transportation, shopping, bathing, dressing, and toileting. They fill important social roles including assistant, friend, and confidant. As trusted advisors, caregivers often play a key role in decision-making and in health maintenance. They provide insights into an elder's life to doctors, family members, and friends. Caregivers often act as intermediaries and advocates for the elder, explaining complex medical information to the elder and questioning doctors' recommendations that don't adequately address an elder's needs and capabilities. For example, one caregiver, a paid companion, convinced a client's physician that the client was capable of managing a complex medical regimen without daily visits by a registered nurse - visits the client would have found demeaning.

We believe opportunities exist for communication and technology products and applications to enhance communication between stakeholders – elders, friends and family members, doctors and nurses. Our team observed widespread use of such devices as cellphones and answering machines, and many of the elders we interviewed expressed great enthusiasm for e-mail. In fact, one interviewee noted that e-mail had greatly enhanced her relationship with her grandchildren, who apparently are much more diligent about responding to e-mail messages than to letters or telephone calls.

However, many currently existing products are not usable by elders. Cellphone buttons are frequently too small, and the letters stamped on computer keyboards are often hard to read by elders without touch-typing skills. Additionally, there is a paucity of products that meet the specific communications needs of the elder population. For example, many elders relocate to new facilities and need to initiate new relationships, which is particularly challenging for people who are homebound or otherwise have limited mobility.

Shifting Perceptions of Ability

Ability throughout life has typically been described in terms of functional abilities. The general description of this trajectory can be seen in Figure 4, which graphs functional ability over time in an average lifespan. Middle age is characterized by relatively constant, but steadily declining, level of ability. As we enter "old age," we begin a more marked period of decline, which subsequently gives way to a more rapid period of decline in the last stages of life. The transition between gradual and rapid decline is often predicated on a traumatic event, such as a fall. Every individual's figure of functional ability will look different, with individuated types and seriousness of critical events (examples include childbirth, breaking an arm or leg, appendicitis, cancer, Parkinson's) occurring at different times.

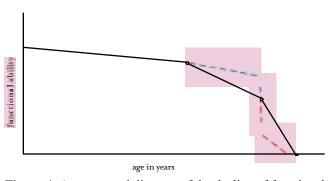


Figure 4. A conceptual diagram of the decline of functional ability over time. The solid line indicates functional ability, while the dotted lines indicate a person's perception of his/her ability. Adapted from [17].

Researchers and developers are aware of this pattern of decline, and attempt to influence it through the use of assistive technologies. In this case functional ability is equated with actual activity. However, they often fail to

consider a second dimension of decline – user *perception* of his or her capabilities. Our research indicates that an individual's perception of her own abilities is just as important as her actual (functional) abilities. Actual activity appears to be a function of both perceived ability and functional ability.

We observed many examples of disparity between actual and perceived ability. Users might exaggerate or underestimate their capabilities, as indicated by the dotted line in Figure 4. (The solid line in Figure 4 indicates the individual's actual functional abilities while the dotted lines indicate the individual's perceived abilities.) A critical event like a fall, a heart attack, or even a doctor's diagnosis can cause a re-evaluation of functional ability. Unfortunately, people often lose confidence in their abilities and become afraid to interact with the unpredictability of the world [8].

For example, one elderly woman broke her hip during a fall. After surgery to repair the hip she primarily used a wheelchair for mobility, even though she fully recovered from the hip surgery and was able to walk. Eventually she became unable to walk, as her muscles atrophied, becoming totally reliant on the wheelchair.

Functional ability often decreases in such a slow and incremental manner that it is not noticeable in everyday life. This can result in the elder's perceived ability remaining at a much higher level than her actual ability. This overconfidence in one's abilities may cause an elder to refuse to adopt devices that could be helpful. Individuals may also attempt movements and actions that were once well within the range of ability, not realizing that they now threaten health and safety.

One example of this overestimation of abilities is Mr. M, who suffers from Parkinson's. Mr. M has serious difficulty with motor control, including fine hand control and speech. Despite these problems he insists on driving to church every Sunday.

In our study, we found that perception played a critical role in users' behavior. Many physical, psychological, and emotional factors influence perception including rate of decline, the user's environment, and attitudes such as pride and fear. As will be discussed in the following section, our research also identified design attributes of many devices that effect user perception and user behavior. These attributes play a key role in determining how a user interacts with an artifact, particularly with regard to adoption.

DISCUSSION

One advantage of using observation and in home interviews is the opportunity these techniques provide to interact with the subject in the subject's own environment. These techniques enabled us to see and ask about devices and objects that were in everyday use, or not used at all. Designers of assistive technologies for eldercare tend to address physical decline in isolation from other dimensions of the aging experience. Our research indicates that "eldercare," as it is experienced by primary stakeholders

(namely, elders and their caregivers), involves a complex blend of social, emotional, and environmental factors. We believe that these findings have implications for the design of assistive technologies, and for universal usability more generally.

Social and Psychological Dimensions in Design

Although 92 years of age and clearly experiencing a loss of hearing and sight, Mrs. K. resisted using devices such as her hearing aid. She only employed these assistive devices when "she knew she would need them." In many cases where she might benefit from her hearing aid, Mrs. K. often doesn't use it because her perceived need for the device is outweighed by her desire not to rely on it.

Mrs. X, a ninety-year old woman, lives alone in her own home. Because she is prone to falls, her daughter has purchased an emergency-alert necklace for her to use. This necklace is intended to be worn at all times, and offers immediate communication with emergency response personnel at the touch of a button. Although she recognizes that such a device might be useful, Mrs. X consistently fails to wear the necklace, keeping it neatly stored on her nightstand instead. When asked, she simply states that she doesn't like it.

Both of these examples illustrated to us the importance of considering user perception in the design of assistive technologies. In both cases, perception had a strong influence on adoption.

The design of technology products influences users' perception of the artifact and of themselves, and can contribute to an inaccurate assessment of one's functional ability. Devices that cause users to feel ashamed and powerless are said to posses a "stigmatizing aesthetic," [17] and may contribute to late-life depression. We found several cases of older people who resisted interaction outside their homes or limited environments because of embarrassment of their reliance on assistive devices. For example, Ms. T, a caregiver, reported that her mother has significantly decreased the amount of socializing she does because she is embarrassed by her need for a wheelchair. This is troubling because reluctance to venture outside one's home can cause people to lose ties with crucial social support, become isolated, and not engage in physical activity [11].

Failure to consider social and emotional aspects of elders' experience can also result in missed opportunities for new and innovative products. In interviews with nurses at the University of Pittsburgh, we discovered a perception within the medical community that wearable devices are not appropriate for elders, because many older people will forget to put them on (e.g., Mrs. X). We suspect that this analysis may not be entirely accurate. Our team observed many examples of elders' ability to consistently wear meaningful artifacts, such as wedding rings, earrings, and other pieces of jewelry. We believe that at least some of elders' "forgetfulness" may in fact be an expression of preference to not wear explicitly "assistive" devices. Devices that contribute positively to the user's self-image

might be more readily adopted. Elders, and others, might have less difficulty "remembering" to wear such devices.

Aesthetic Factors and Usability

Until fairly recently, the design of technology products has largely been driven by their function. Now, smaller, less expensive components are enabling great freedom in the form a device may take [13]. No longer constrained by engineering requirements, the form of the artifact must now be driven by the aesthetic requirements of intended users. This becomes increasingly important with the advent of ubiquitous or pervasive computing. Computers that reside in the home or are worn on the body become more than mere tools; they play an important role in how users perceive themselves and each other.

Aesthetic considerations such as "look and feel", size and materials, as well as product function and underlying technology are equally essential components of assistive products. This may be a difficult assertion for some. The computer-human interaction (CHI) community has long had an ambivalent relationship with aesthetics. Norman has famously posed aesthetics as the antithesis of usability [15]. With the notable exception of Laurel [10], CHI researchers have largely considered aesthetics as something to ignore or belittle [23]. Nonetheless, aesthetics play an important role in user experience of artifacts. More than simply making devices visually pleasing, aesthetic factors provide an added dimension to usability. Traditional usability factors determine whether a device can be used; aesthetic factors determine whether a device will be used (adoption), and what the emotional, psychological, and social outcomes of that use will be (perception).

There are at least two considerations affecting the design of assistive technologies for eldercare: context of use and empowering users.

Context of use: Artifacts must be designed with an understanding of how and where they will be used. As elders age, they progressively contract their life-space, and the immediate environment of their homes become more important. They become more and more sensitive to small environmental changes [21]. Assistive technologies intended for use in the home must be unobtrusive and appropriately styled to match the home environment. For example, Mrs. K carefully covered any device that suggested it was assistive to blend in to the décor of her home. You can see this in Figure 5, illustrating a cover on a magnifying glass Mrs. K used for sewing.

Failure to meet these criteria will negatively affect adoption. One of our participants, Mr. M, who has Parkinson's disease, making him susceptible to falls, leans on wall-mounted towel racks for support in his bathroom. When Mr. M has a serious fall, the towel racks cannot support his weight and they are pulled out of the wall. His wife is aware of the existence of stronger grab bars that provide additional support. However, she refuses to do so because she finds them "institutional looking" — even though Mr. M's repeated falls have caused her to replace the towel racks several times.



Figure 5. The cover on Mrs. K's magnifying glass.

Empowering users: The use of assistive technologies impacts elders' sense of identity and their estimation of functional ability. While assistive devices can increase users functional capacities, they can also embarrass and stigmatize elders. In our research, mobility-enhancing devices such as wheelchairs and walkers often stigmatize users. On the other hand, we observed widespread use of motorized scooters in the retirement community (Figure 6). These provide similar functionality to wheelchairs but lack negative connotations because they are styled to be fun and sporty rather than assistive and institutional. Assistive technologies must both raise functional ability and enhance elder's perceptions of self-worth.



Figure 6. Although they perform similar function as wheelchairs, scooters avoid stigmatizing aesthetics. They are stylized to be fun and sporty.

Elders rely on assistive technologies in many of their daily activities and routines. The use of these devices has significant impact on self-esteem and emotional outlook. Considerations of usability must include the manner in which a device is be integrated into the whole of a user's life. Grab-bars so "institutional-looking" that elders refuse to install them in their homes cannot be considered "usable;" nor can wheelchairs that embarrass elders so much

they stop visiting friends. In addition to making assistive technologies easy to use for people with a wide range of cognitive and physical abilities, designers must consider aesthetic dimensions of usability.

CONCLUSIONS

Our research strongly indicates that assuming elders will use an assistive technology simply because they "need" it is misguided. We have seen many examples of elders who downplay this need, choosing to radically alter their behaviors and lifestyles. They will do this even at the expense of independence or social interaction, rather than rely on a device that makes them feel embarrassed or incapable.

We suggest approaching the design of technologies for eldercare in the same way that one approaches the design of other products. This requires the designer to recognize that users have choice, and design products that are not only useful and usable, but also desirable. Such devices are more readily adopted by elders because they simultaneously address functional, emotional, and social needs.

Experience tells us that products designed in this way also broaden user base. The OXO Good Grips kitchen tools were initially designed for the arthritic users (Figure 7). Innovations in form and materials made these products more usable for the target population, but the attention to styling made them extremely popular amongst a wider range of users.



Figure 7. A selection of OXO kitchen tools.

We believe that information technology products for elders could have similar impact. For example, a well-designed wearable device that enables instantaneous wireless communication with emergency response personnel at the touch of a button does not only benefit elders who have fallen in their homes. Such a product will find widespread adoption among such user groups as wilderness sport enthusiasts (e.g skiers and hikers) and safety-conscious urban residents.

Products with broad user bases tend to be less expensive than specialty-market devices. Widespread use also reduces social stigma often associated with assistive devices. By broadening user base, designing I.T. products to address functional, emotional, and social factors ultimately lowers social and economic barriers to adoption and furthers the cause of universal usability.

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