Cultural Bias and Personalization, Broad and Narrow

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Abstract. In this paper, we describe how ignoring 'invisible' cultural assumptions and specific individuals needs in outlaying populations can impact failure and success of a system. We will present examples from several studies and literature.

Introduction

This paper will discuss design issues that tacitly affect the process of providing supports for enabling 'aging at home'. As the call says 'holding relationships or creating new social interactions for elderly people is strongly contoured by individual and societal norms and values'. One of the authors is a North American researcher working in Germany and Spain and this issue has been brought into heightened contrast in the projects he has worked in. The notion of the cultural and societal bias in the use of computers becomes much more important as we move from computers in a context free domain to ubiquitous computational systems and embodied and ambient intelligent systems. The more permeable the boundaries between artefacts and the enclosing environment the more relevant the

brought-to-the-task biases and understandings in the sense that actions and meaning arise in specific settings, cultural, physical, and cognitive among other dimensions [Dourish, 2001]. The following examples although not CSCW applications in a narrow sense, are nevertheless at their core systems of collaboration and coordination.

This paper will discuss three example domains thru the lens of implicit, embedded cultural and individual norms. First we will look at Fidemaid, a tool to support financial decisions and to provide monitoring of financial acts by elders at risk of developing Dementia, next we will look at the results of the MAPS project, a tool to support accomplishing tasks by persons with intellectual disabilities. Finally we will look at the issues involved with assessing emotional states and quality of life self –perception in people suffering the process of becoming locked-in due to the progression of amyotrophic lateral sclerosis (ALS). In each situation there are mismatches between designer assumptions and users needs and desires. These mis-fits can lead to wasted design efforts because, while the system preforms to the specification the specification may not fit the user.

In some cases these misfits can be solved through deep personalization, for instance in the MAPS project [Carmien, 2005], a system for generation and delivery of custom multimedia scripts to support young adults with cognitive disabilities in performing tasks previously beyond their ability. In one study using MAPS the verbal prompt scripts for a teenaged girl needed to be recorded by someone not her mother. Although she was cognitively disabled she still had teenaged power issues with the same-sex parent [Carmien, 2007]. In other cases the system may need to be completely redesigned from the axiomatic assumptions up. An example of this occurred during a scientific review of the Fidemaid project which was aimed at providing financial decision making support for seniors based on their on-going bank balance and spending. At a review of the project, one scientific committee member said that this might work in Western Europe but would never be useful in his native eastern European country. When queried as to the source of his assertion he said that in order to use a system like this (i.e. using financial transactions accessible over the secure internet) most financial transactions had to be done thru e-banking (i.e. debit cards, automatic bill payment, etc.) and in his county a large percentage of financial transactions occurred on the black market.

Linking Embodiment and Tacit Knowledge

As a system gets pushed into the background of the environment more attention needs to be paid to the tacit enclosing environment. Examples of the two ends of this dimension (e.g. standalone vs. embedded in environment) could be a pocket calculator (which assumes knowledge only of button pushing and mathematical

representation) and controls on a DVD player, where the fast-forward controls '>>' is based on reel to reel technology where tape going to the right spool rapidly (i.e. the second ">") is going in the direction of forward in time. The DVD interface is an example of a metaphor coupled to a completely different physical act [Dourish, 2001]. Another dimension to look at is the level of abstraction, at one end are the interactions that literally take place in the physical, and at the other end are search engine parameters, as in Google advanced search. As the enclosing application becomes less and less abstract, certain physical assumptions can be relied on to be the same in many contexts. An example of this are the standard human metaphors for directionality (see **Figure 1** below [Woodson, 1992]) many of these are reflections of the actions of gravity.

However as applications become more abstract the representation of the controls becomes more arbitrary and it becomes trickier to make interfaces and functions that are easy to learn and use. This accounts for recommendations for reuse successful (or at least popular) interface paradigms like Microsoft windows and Apples OSX [Lewis & Rieman, 1993].

Action Desired	Control Movement
Turn on	Up, right, forward, press inward, clockwise
Turn off	Down, left, rearward, pull outward, counterclockwise
Turn or move right	Right, clockwise
Turn or move left	Left, counterclockwise
Move upward	Up, rearward
Move downward	Down, forward
Retract	Rearward, pull, counterclockwise, up
Extend	Forward, push, clockwise, down
Increase	Right, up, forward, clockwise
Decrease	Left, down, rearward, counterclockwise

Figure 1 - Control Movement Standards

The Fidemaid Project

When designing a system in a new domain, especially for a population that is unfamiliar, a useful way to get a good start is to do a series of semi-structured interviews and focus groups. Fidemaid [Carmien & Koene, 2009] was a project to design a web based financial support tool for elders that helped them manage their finances in making decisions (**Figure 2**) and knowing their fiscal status (**Figure 3**). Additionally Fidemaid provided concerned family members with diagnostic information about the elder's ability to manage their finances, and

most importantly to flag when the course of dementia becomes a threat to aging successfully in place. These goals were the basis for an ethnographic study of the end-users and caregivers.

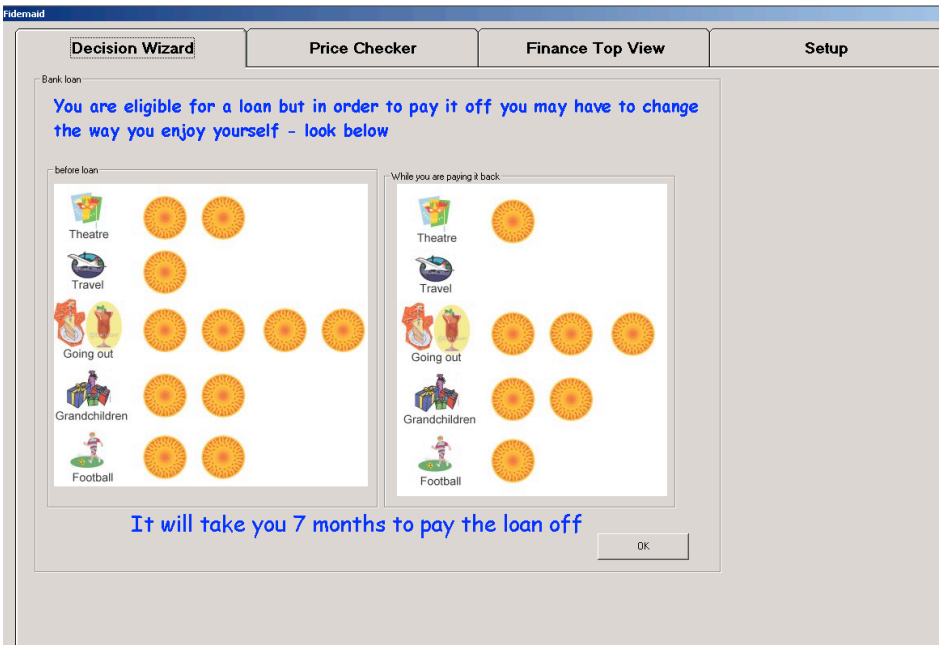

Figure 2 - Fidemaid Finacial Decision Support

When setting up the semi-structured interviews and focus groups of sets of elders (in the age range where dementia may start) and caregivers, the initial request to the senior research group that collaborated on the project [Ingema, 2009] for 'elders' and 'caregivers' was confusing for them. Where in the US the phase 'caregiver' meant anyone in the position of caring for an elder, sick person, disabled person, etc. In Spain there was a distinct difference between caregivers 'cuidadores' who were more like government professionals and not typically intimately involved in the day-to-day support of the elder in early stages of dementia and 'familiars', who were typically family members in the position of primary responsibility for the elder. This familial connection was echoed throughout the study, in high contrast to the situation in North America where family members are often separated by hundreds of miles. In fact, in Spain a high number of interviewees lived in the same house, or in a house in the neighbourhood of their extended family. This is more than an interesting life-style difference; applications and systems need to be designed to accommodate and support that familial closeness and social cohesion, in the same way the many systems for supporting elders in North America emphasise independence and self-reliance. An example of the specification for supporting family and neighbourhood was the statement of one interviewee that "*He considers the e-banking really useful and convenient, but he's afraid that digitalizing all the*

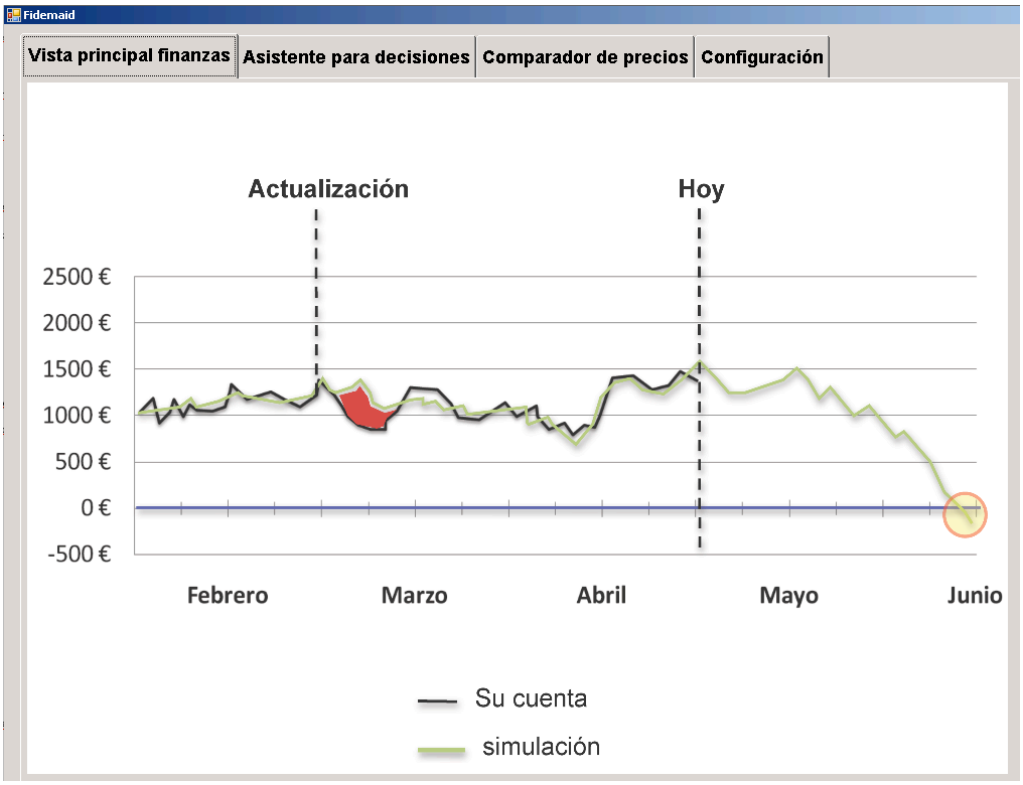

Figure 3 -Fidemaid Finantial Status Page

services could prevent people from moving and interacting with and meeting other people[1]."

Elders- Homogeneity and Heterogeneity

One surprising result from the interviews was discovering the wide variation of experience and comfort in using computers in the set of elders. They ranged from fear to high levels competency (in one case approaching creating web 2.0 mashups without formal training). In the case of e-banking the responses ranged from "*doesn't trust electronic bank account*" to "*has 6 accounts…. 4 personal and manages 2 for brothers that have Alzheimer's*". Extrapolating from an admittedly small sample (16 elders, 15 caregivers) the distribution of computer skills/comfort, while following typical Gaussian pattern, had a 'curve' was rather flattish with a relatively large SD. So just assuming that all elders are like our own parents may not be such a good predictor of application fitness. Another unexpected situation, one that exposed the researchers cultural bias, was the small age spread between the elders and the familiars, which makes sense when looking at the demographics of the mid 20th century when families tended to have children in their twenties.

Social Structures and Neighbourhoods

Along with the emphasis on social cohesion was the physical situatedness of the elder. The systems of support needed to less visible because of the proximity of

[1] Quoted text from focus groups and interviews

the elder to her life-long neighbours '*the most problematic thing was to inform the people living around about her disorder'*

Another consequence of the close family ties is the fact that e-banking was not widely used because of a lack of trust in the new system and a desire to retain personal contact. This desire for continuity of relationship is again the obverse of the North American model, and reflects the requirement for all such applications in a Spanish context to encourage connexion rather than independence per-se.

Examples Of Cultural And Individual Motifs

Some practices that affect the design of assistive technology to support ageing in place are unique to regions, some are unique to types of populations. Here are two examples of such differences.

Rotation

One interesting cultural practice that exists widely only in Spain and Italy is the practice of 'rotation' [Rivera et al., 2009]. Rotation provides a familiar buffer between elders living alone in their own homes and moving into assisted living. The idea is that when the elder becomes (potentially) incompetent to live alone the immediate family shares responsibility for helping the elder live outside assisted living for as long as possible. There are two forms that this takes: *internal rotation* is the practice of having the elder stay in her home and families take shifts moving in and out of the home, typically for a couple of weeks a shift, the other, more prevalent form is *external rotation*, where the elder moves from home to home in the same shift fashion.

This practice provides many places where computational support could make things easier, like providing continuity support for the elder's care and schedule. Because the end-users of this system are themselves typically close to the elder in age the interface and functionality need to be carefully designed to accommodate wide variation in computer abilities and the common diminution of sensory and fine-motoric ability that aging brings. The day-to-day support that the rotation system needs is like but not identical to the medical records that are kept in assisted living environments. They need also to reflect the unique mix of personal, diagnostic, and treatment information that needs to be passed between familiar caregivers, including appointments and day-to-day scheduling.

Misunderstanding by Projection

A common problem with novice assistive technology designers is to assume that the population they are designing for is very much like themselves with 'parts'

missing or much lessened in ability. Unfortunately, there is no substitute for genuine experience with the users of a system, and obtaining experience spanning time and contexts. One common error is to focus on the diagnosis of the person with disabilities rather than the inventory of skills and needs that each individual brings to the problem space. This requires a functionality-based perspective to assessing needs for design purposes. This prevents getting mired in the many dimensionality of physical and cognitive disabilities that often results in a '*universe of one*' [Erikson, 1958].

Islands of Ability

An interesting example of the *universe of one* phenomenon is the incidence of island of abilities in seas of needs and islands of needs in seas of abilities (see **Figure 4** below) [Cole, 2006] that is frequent in persons with cognitive disabilities.

In designing task support systems for persons with cognitive disabilities experience, research, and best practices revealed that, especially for people with comorbid disabilities, the ability to perform tasks was not uniform. It is not uniform across time: reporting that the participant was having a 'bad day' or a bad' week' or that 'afternoons were particularly difficult for them'. It was not uniform across tasks: one 37 year old MAPS participant who had cognitive disabilities so that he needed to live in in a group home, yet high enough intellectual capacity to have a job in the local gymnasium helping cleaning up, using public transportation and his own bank account. Although he was able to live almost independently, could not successfully fold his own clothes after washing. His parents and several professional caregivers have tried over the years to coach him through the task but it was not till the MAPS prompting system was he able to successfully accomplish the task. The caregiver at the group living home built a custom prompting sequence developed specifically for him and his environment which walked him through the steps for folding the various items of clothing. With this he succeeded [Carmien, 2007].

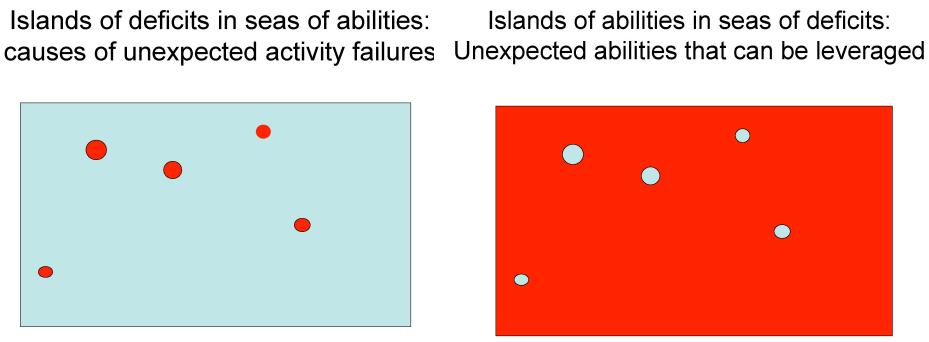

Figure 4 - Islands and Seas of Ability

Similarly, there are commonly cases where the opposite held true- that in a person of moderate to low cognitive ability instances of much higher than expected ability exist. An example of this was the 19 year old participant who learning how to sort clothes in a used clothing store with the MAPS hand held prompter system while being walked through the by a job coach. Her grandmother was quite surprised to discover that she had mastered the complex and expensive family home theatre controls such that she could teach her how to use it, when some of the family with typical cognitive abilities were confounded by its complexity.

Locked In and the State of Despair

In general, the key to successful assistive technology design is to study the problem space more thoroughly and discard assumptions about ability and experience of outlaying user groups.

A good example of how experts and the general public can have wrong assumptions about what persons want and feel, can be derived from the research on depression and quality of life of persons with amyotrophic lateral sclerosis (ALS).

ALS is a fatal motor neuron disease of unknown etiology and cure. It is a neurodegenerative disorder of large motor neurons of the cerebral cortex, brain stem, and spinal cord that results in progressive paralysis and wasting of muscles [Cudkowicz et al., 2004] . Survival is limited by respiratory insufficiency. Most patients die within 3-5 years after onset of the disease [Cudkowicz et al., 2004], unless they choose life-sustaining treatment [Hayashi & Oppenheimer, 2003]. As the disease progresses, people get more and more paralyzed until ultimately they may become locked-in (awake and conscious in a paralyzed body).

The choice (written down in a living will) to accept or decline life-sustaining treatment, such as artificial nutrition and artificial ventilation, is probably the most difficult choice a patient has to make during his disease progress. In fact, most people find it so difficult that they do not make a decision at all and decisions are made or inspired by caregivers or medical staff in case of emergency. However, herein lays the problem. Most physicians, caregivers and family members (significant others) assume that quality of life of ALS patients is poor [McDonald et al., 1994]. Empirical data on quality of life in ALS patients show instead that quality of life does not necessarily depend on the physical situation and that it can be maintained despite physical decline [Chio et al., 2004; Kübler et al., 2005; Robbins et al., 2001; Simmons et al., 2000]. A study from Kübler and colleagues even showed that artificially ventilated people have a quality of life comparable to non-ventilated people [Kübler et al., 2005]. Thus, although healthy persons may think that living with severe paralyses is a life not worth living, most persons in that state say they do not wish to die [Kübler et al.,

2006]. You can only imagine what happens if these patients take advise from healthy persons around them.

Conclusions

The broad range of examples described here have one common thread. That is that a system designer, in the domain of assistive technology and Augmentative and Alternative Communication (AAC) must take into account the tacit environment to have an application succeed in being accepted and broadly used.

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