

Ambient Assistive Technology Considered Harmful

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Abstract. Ambient assistive technology (AAT) is envisioned as a powerful tool for facing the growing demands the demographic change toward an aging society puts on care. While AAT is often expected to increase the quality of life of older people, this paper holds that relevant interventions often embody values that can contradict such visions, and in some cases even be harmful to care receivers. We argue that the strong focus AAT puts on illness and risk management reflects a medical model of care, which often disregards the psychosocial challenges that impairments and disabilities associated with old age can rise. We suggest that design of AAT could benefit from using the social model of care as design inspiration and value foundation. Such an approach puts focus on the *person* rather than the *illness*. The paper ends by providing a short description of work in which the social model of care is adopted as a basis for design of AAT.

Keywords: Ambient assistive technology, Disability, Elderly care, Ethics, Human values, User-centered design, Value sensitive design.

1 Introduction

The population of the world is aging [1]. As a result, there is an expected increase in the prevalence of chronic illnesses and disability associated with old age [2]. This situation puts extra pressure on elderly care in many countries. Ambient assistive technology (AAT) is often envisioned as a powerful tool for facing the growing demands the demographic change toward an aging society puts on professional and family care. AAT is expected not only to reduce care costs and remedy the anticipated lack of adequate care providers for the elderly, but is also envisioned to support aging at home and increase quality of life among people of old age [3]. Most available AATs, however, tend to focus on risk management. Typically, such applications involve the use of sensors to detect events that may be critical to a care receiver's health or safety, and to inform caregivers of such incidents so that timely interventions may take place. Examples of such systems applied in the context of elderly care with chronic illnesses include GPS tracking systems, fall detection systems, and systems that monitor biometric data (e.g., heart rate and respiration). The strong emphasis these solutions put on management and control of symptoms echo in many ways what

is often referred to as a *medical model* of care [4]. The medical model of care has been criticized for constraining care to focusing on declines, negative issues, and physical care, rather than quality of life issues for the elderly and the psychosocial challenges that a person with a disability may face [4]. The alleged shortcomings of the medical model have given rise to what is known as the *social model* of care, or *salutogenesis* [5]. Rather than focusing on the disease, social models of care tend to put focus on the individual needs and disabling environmental barriers. In elderly care there has been a gradual shift over the last decades from a medical model to a social model of care.

With respect to the vision of increasing quality of life, the social critique of the medical model of care implicitly questions the appropriateness of the conceptual model that forms the basis of most AATs. This has motivated us to take a critical look at the extent to which AAT can be considered beneficial for elderly people in need of care, and if such interventions might even be considered harmful. The goal of this paper is to outline a position on the ethical foundation of AAT with a view to motivate work toward value-driven design of this type of technology. We also illustrate how social models of care may serve as a basis for design of AAT by describing work toward a safe walking technology for elderly people with dementia, and a system intended to promote social interaction for elderly within a local community.

2 Motivation

As computer technology is pervading more and more aspects of our lives, the implications of technology on human values are becoming an increasingly important aspect of HCI research [6]. The emergence of the Value Sensitive Design framework [7, 8] during the 1990s, and more recent attempts to alter or develop the framework further in order to address various issues (e.g., [9]), can be seen as recognition of this. Designing technology for ethically sensitive areas, such as elderly care, has raised the need for reinvention with regard to what the field looks at and the lenses that are used. In particular, we see a need for establishing a theoretical and ethical foundation that can help guide design of computer technology aiming to serve assistive purposes in care. Such a foundation (or lens) can help give designers a morally justified basis for taking design-related decisions in situations where conflicting perspectives and value trade-offs exist.

3 Background

The medical and social model of care represent in many ways two distinct value sets, which in turn have had different implications on provision of care. The different perspectives the two models have on the concept of disability are central in this context. Below, we will present a brief overview of the two models of care, and how they are shaped by different understandings of what disability constitutes.

3.1 Disability and Care within the Medical Model

The medical model of disability holds that illness or disability results from a physical condition, which is intrinsic to, or part of the individual [4]. The model holds that the illness or disability reduces a person's quality of life and is the source of disadvantages to that person. From the perspective of the medical model, managing or curing illness or disability put emphasis on identifying the illness or disability and understanding how to control or alter its trajectory.

The medical model regards disability as a problem of the person. The problem is the result of disease or other health condition, which consequently requires medical care provided by professionals. In the medical model, medical care is viewed as the central issue. Management of the disability aims to "cure" the individual or to cause behavior change in the individual that would lead to reduce the problem.

3.2 Disability and Care within the Social Model

The social model of disability explicitly distinguishes between *impairment* and *disability*. Impairment refers to some bodily defect and usually corresponds to a medically classified condition. Impairment, however, does not constitute a disability in itself. Within the social model, disability is understood as a function of the interaction between the person and the environment [4]. As such the social model considers disability to be external rather than being a part of the person. The extent to which a person experiences disability is intimately dependent on the degree of which the person lives in a supportive physical and social environment. As such, a disability is understood as contextually dependent variable, i.e., a result of the gap between the capabilities of an individual and the demands of the environment.

Setting out from this principle, disability studies have typically put emphasis on external barriers that contribute to disable a person. Within the social model, disability is often considered a socially created problem. Hence, management of the problem requires social action. An example of this type of action could be to make required environmental modifications in order to promote full participation of people with disabilities in all areas of social life.

One variant of the social model of care, which over the last two decades have been particularly influential in professional dementia care, but also in elderly care in general, is the person-centered care model that emerged from the work of the English social psychologist Thomas Kitwood [10]. Kitwood re-conceptualized dementia and raised attention toward human values in care. From a medical model which considered dementia strictly as a biomedical phenomenon (and implied a strong focus on management of disease symptoms), Kitwood [10] encouraged a shift toward recognizing the psychosocial aspects of the dementia and the need to preserve *personhood*, or "the self", in dementia patients by means of positive interaction techniques. According to Kitwood, personhood is the standing or status bestowed upon one human being, by other in the context of relationship and social being. Accordingly, to maintain personhood in the wake of cognitive deterioration (or other impairments) a person depends

on those around him. Identity, attachment, inclusions, occupation and comfort are basic psychological needs, which are essential for maintaining personhood status.

3.3 A Conceptual Comparison of the Medical and the Social Model of Care

Table 1 summarizes the conceptual differences between the medical and the social model of care with respect to key aspects.

Table 1. The medical versus the social model of care

	Medical model of care	Social model of care
Objective	Eliminate impairment and disability.	Challenge social exclusion.
Focus	Diagnosis through medical insight.	The person; not the disability.
Cause of disability	Physical or mental impairment is the cause of disability.	Focus on environmental and social barriers that exclude people with a disability from mainstream society.
Authority	Health care providers.	People with disabilities.

4 Understanding Ambient Assistive Technology as Value-Laden

As elderly care is gradually turning toward AAT to address the challenges that arise as a consequence of demographic changes, the question of which care values the technology promotes increasingly becomes central. To understand how AAT can be considered to “reflect” a medical model of care requires that we first account for the non-neutral perspective of technology in relation to ethical and social issues.

The principles about the non-neutrality technology of where developed by 20th-century media theorists, such as Ellul [11], Mowshowitz [12], and Postman [13]. A central idea in the non-neutral perspective on technology is that that technology harbor values, which come into play regardless of the intentions of the user [14]. This can include values held by technology designers or values held by society. Technology, again, shapes individual behavior and social systems [15].

The non-neutral perspective on technology claims that when we use technology, the technology to some degree “uses” (or influences) us. The way a specific technology is designed sets premises for use. A revolver has been designed to fire bullets. While one might also use a revolver to hammer nails into an object, it has not been designed for such purposes and its usability with respect to this activity will accordingly be limited. In this sense, technology “insists” on being applied in certain ways. From the non-neutral perspective, then, technology acts as an autonomous force on users.

Applying the principle of the non-neutrality of technology in ethical and social issues, technology used for provision of elderly care is not merely instrumental – to a certain extent the technology also carries with it its own effects. Technology usage can give positive and negative consequences no matter how the technology is used.

Social models of care have had increasing influence on elderly care over the last decades [16]. It has helped and promoted a more holistic approach to care, which put

focus on individual needs as experienced by care receiver. In spite of this development, we find that digital assistive technology targeting elderly care often contain value biases that arguably align with the old care culture. Similar to the medical model of care, most AATs put emphasis on risk management and disease symptoms and a person a care receiver’s “weaknesses”. In this sense, there is a potential tension between newer care culture and the care ideology harbored in AAT. The non-neutral perspective on technology reminds us that identifying value-biases can be challenging as biases may be imbedded in design details [17]. Identifying the value-biases of technology targeting elderly care is nevertheless important in order to take measures that may prevent harmful side effects of use.

5 Ambient Assistive Technology Considered Harmful

Above we explained the theoretical background for how technology can be considered value-laden tools, and how most AATs can be considered to harbor a care ideology that aligns with the medical model of care. In the following, we discuss three aspects relevant for understanding in what way AAT can be considered to have potentially harmful or negative effects on the wellbeing of people in need of care. The aspects that we will discuss include (1) negative effects on the interaction between caregiver and care receiver); (2) loss of agency on the part of care receivers; and (3) obtrusive effects on care receivers’ everyday life.

5.1 Effects on Interaction between Caregiver and Care Receiver

According to the non-neutral perspective on technology, information and communication technologies do not simply convey information; they also present their specific perspective on the world. They are in other words metaphors through which we can understand reality. One of the potential dangers of AAT and particularly remote monitoring applications in the context of care, then, is linked the “image” they convey of the care receivers. There is a risk that caregivers understanding of a care receiver becomes biased when the person in need of care is primarily seen through the “lens” of monitoring technology [18]. By putting emphasis on disease or symptoms of the disease, there is a chance that caregivers learn to know care receivers by their disease rather than what characterizes them as persons, and understanding their subjectively defined experiences and needs. For example, literature which questions the application of GPS to track persons with dementia who shows wandering behavior argue that the technology can create blindness to the underlying reasons for why a person with dementia might show such behavior [18]. Understanding a care receivers subjectively defined experiences and needs is essential in a holistic approach to care.

5.2 Loss of Agency

The second danger of AAT applied in elderly care we will address is related to the potential loss of agency, and what can be considered the under-utilized possibility to build on the retained strengths and abilities of the care receiver. Implicit in many

AATs is the conceptualization of the care receiver as a passive stakeholder. Often AATs offer none or very limited interactive possibilities to the care receiver. The conceptual model on which many AATs are based do not appear to acknowledge care receivers as potential active user of technology. Conventional tracking technology applied in dementia care, for example, offer no means for the persons carrying a position tag to try and help themselves. Instead, caregivers appear as the intended user group of most AATs, and functionalities typically reflect their work needs.

For example, a system that monitors aspects of physical activity without providing feedback to the elderly person in a manner that makes sense to the users can also be considered to prevent care receivers from taking a more active part in their own well-being. Such a system can be viewed to increase elderly peoples' dependency on caregivers. In this sense, AAT may also be considered to disempower the care receiver.

5.3 Effects on Care Receivers' Everyday Life

The third concern we will raise with respect to AAT applied in elderly care, relates to the potential obtrusive effects such interventions may have on a person's life and living environment. Many interventions arguably require the person in need of care to adapt to the technology in some way. This may include adapting new routines in order to allow the technology to work according to its purpose (e.g., remembering to put on a sensor device), asserting that the technology is operative (e.g., that a device has been recharged), and reorganizing one living environment (and thereby changing ones relationship to it [19]). While the need for adapting oneself or ones environment to AAT might be considered "justifiable" from a strict safety perspective, and that acquiring an illness requires one to adapt ones way of living in any case, technology can also be a source of excess disability. Excess disability refers to deficits that arise from factors that do not relate to a disorder or illness, as such. Examples of such factors can be a person's physical and the social environment. As AAT increasingly is becoming a part of these environments, interventions can also form a contributing factor to excess disability. With respect to design, then, the concept excess disability calls attention to the importance of developing technology that seamlessly integrate with care receivers lives and routines.

6 Using the Social Model of Care as Design Inspiration

In this section we will describe work towards two AAT solutions that take their motivation from the social model of care.

6.1 Designing Safe Walking Technology with and for Elderly People with Dementia

People with dementia form a vulnerable group, as symptoms associated with the condition (e.g., memory loss and communication problems), make it difficult for them to stand up for their rights [20]. The group is often subject to excess disability as a result

of prejudice and social stigma associated with the condition (ibid.). Technological interventions that target dementia care stand a particular risk of causing excess disability for the group. One reason for this is that very few technologies available have been particularly designed for people with dementia, but rather appropriated from other domains [18].

Taking inspiration from Kitwood's person-centered care philosophy [10], and particularly the fundamental ethical principle that people with dementia have a right to participate in decisions that can influence their lives, we have worked closely with people with mild dementia and their families on designing technology supporting safe walking for the group. The activity has been part of the Norwegian research project *Trygge spor* ("Safe tracks").

Our main motivation has been to form an understanding of what people with dementia want from technology aimed to support safe walking. Through a set of participatory design workshops we have identified the following factors to influence the views of the participants with dementia on how safe walking technology can fit their needs and life situation:

- *Desire for control and self-management*: Having a technology that can offer the person with dementia direct assistance in challenging situations, via a user interface he or she can master, was central for the participants with dementia. Receiving assistance from others (e.g., family members) was considered a less favorable option, and was regarded as a back-up solution reserved for safety-critical situations.
- *The subjective experience of symptoms*: The participants gave different accounts of how they experienced disease symptoms, and to what degree they experienced that their condition affected their safety when they performed outdoor activities on their own. Personal experiences from episodes the participants had experienced as difficult or challenging tended to influence their vision of safe walking technology.
- *Routines and skills*: We found that the knowledge and skills of people with dementia can act as an inspiration source for user interface design. Providing people with dementia user interfaces that build on familiar concepts enables the group to build on such abilities as they have retained.
- *Empathy for caregivers*: From the perspective of the persons with dementia who participated, freedom of movement was not only reserved to being able to go for outdoor walks whenever and wherever they wanted. Being able to perform outdoor activities without raising concerns among close family members was also important for the group. For some participants, the concerns raised by family members was a central factor for accepting remote monitoring of outdoor activities. Technologies that supported self-management for the person with dementia was seen as a means for relieving close family members of the burden of caring, and possibly saving them from having to intervene.
- *Local environment*: The participants' familiarity with their local environment and their confidence that people living there would assist them in difficult situations also played a central role with respect to how they perceived their own safety situation. The participants' perceptions of the local environment also influenced the extent to which they considered remote monitoring technology (e.g., GPS) beneficial for their own safety.

We plan to use the needs, desires and preferences described above to inform the design of future functional prototypes, which can be tested in real-life situations.

6.2 Supporting Social Interaction among Elderly within the Local Community

Medical conditions, or lack of the same, are not the main parameter ensuring a happy senior life. Living alone and isolated is a prevailing problem among the elderly population; in particular in the western world [21, 22]. Addressing isolation and loneliness is increasingly being recognized as an important aspect of improving elderlies' living conditions. Loneliness is commonly associated with disconnections from society, lacking social relations and not being appreciated [23].

Tackling loneliness and isolation is the main concern of the ongoing Ambient Assisted Living project *Co-Living*. Encouraging elderly to participate in social activities is done through a personalized mobile social recommender system encouraging active living [24].

The co-living system is based around the idea of offering relevant activities to elderly through a recommender system. Events are currently supplied by the municipality and described along relevant dimensions, such as physical and dancing or social and café [25]. Users' interests are also modeled and the combination of events and user interests are used as the foundation of recommendations. Yet, a traditional event recommender does not necessarily satisfy the socialization issue. Thus, co-living includes three features that are specifically designed to encourage socialization. First, group recommendations in the form of, e.g., "You should attend the polka class this Monday with Mr. Johnson who also enjoys dancing", which should promote attending social events. Secondly, users can invite others to join them at activities. Finally, users have the possibility to publish their own events, which will be published and recommender just like the official events supplied by the municipality.

The system is currently being tested and evaluated in two different sites. In the Netherlands elderly in a retirement home are using the system as an integrated part of their services. The second installation is running in Norway, where elderly living at home is using the system on a daily basis. Preliminary reports suggest that the system is well received by both people living in an institution and at home. The project is currently in its final stage and more thorough results will be available during the second half of 2013.

7 Summary and Concluding Remarks

In this paper we have argued that, with respect to the envisioned benefits AAT can give elderly people in need of care, there appears to be a fallacy between equating the increased possibility for detection of health or safety critical events with empowerment of and improved life quality for elderly. Drawing on non-neutral perspective of technology in relation to ethical and social issues, we have argued that AAT tend to reflect a medical model of care. We have discussed how the emphasis this model

places on illness and risk management also can have potentially negative effects on a care receiver's quality of life. In particular, we discussed how AAT may (1) alter caregiver-care receiver interaction and reduce opportunities for face-to-face contact; (2) lead to loss of agency on part of care receivers; and (3) have an obtrusive effect on care receivers' life and possibly contribute to excess disability. We have also provided examples of how an alternative social model, which forms a more holistic approach to care, can be used as design inspiration for AAT.

This paper has highlighted that the extent to which technological interventions in elderly care are beneficial (or even harmful) to care receivers is intimately dependent on how we conceptualize disability, and how we understand the needs of people living with chronic conditions. The understanding of AAT as value-laden tools strengthens the argument that ethics and human values need to be paid explicit attention as part of their process of design.

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