Technology Acceptance by Patients: Empowerment and Stigma

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Abstract

Given the increased life expectancy and considering shortcomings in the care sector, it is a fundamental challenge how older and frail people can be empowered to stay in their private home, keeping up mobility and independency for a longer time. The maturity of information and communication technology on the one hand and of medical technology on the other basically allows technology to take over the monitoring and care. However, so far, the inclusion of human factors and technology acceptance into a successful technology design is not adequately met. In the following, we describe relevant facets of technology empowerment and stigmas and the need to rethink traditional concepts. First, the requirements of adequate use and design of information and communication technologies in the medical field are addressed. Second, as the prevailing image of age is no longer adequate to the current demographic change, the need to rethink age and aging is

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described. Finally the need of user-centered design is discussed, followed by the need of a rethinking of the technology design process and the inclusion of potential users. The chapter ends with a discussion focused on requirements of patient empowerment to reflect all the aforementioned aspects from a patient's point of view.

Introduction

In the near future, new generations of technical products, services, and interfaces have to meet fundamental societal and technological challenges: first, requirements of the demographic change are to be considered, with increasingly more and older as well as frail technology users. Second, technology is increasingly more complex and needs to be handled by diversely skilled workers. Third, the seamless integrating of technology into our living spaces with the requirements of understanding the impact of invisible technology is the most important issue. As the usage of technology is increasingly less voluntary and often vital (e.g., in case of life-saving medical technology), technology acceptance, the willingness of persons to rely and trust technology, and fear of violating intimacy and privacy are serious issues which have to be handled with care (Mynatt et al. 2004; Lalou 2008). For modern societies, it is a fundamental question how technology and technical interfaces will meet these challenges, especially in times of aging societies. The so-called demographic change challenges European countries like Germany, Italy, Poland, or Bulgaria, but also Asian countries, as Japan, to find adequate answers, solutions, and strategies.

It can be noted that the awareness for this challenge is given, and solutions, strategies, etc. are initiated in many fields. Especially the branch of medical technologies detected the need for progress early on. But although the necessity to react was indeed recognized within this branch as well as an awareness of the specific demands of patients' health and safety, there are several more global aspects that have to be rethought in the traditional development of technology, especially with respect to the complex challenge of meeting technology acceptance.

Central Questions and Challenges

In this chapter, the branch of medical technology was chosen as an example, because it addresses the dilemma between (older) patient empowerment and stigmatization in particular. While older people are obviously in need of extended long-term care, they also wish to maintain their independence as long as possible (Dewsbury and Edge 2001). Studies show that many older people regard their home as a sanctuary and therefore prefer to stay at home, even at an increased risk to their health and safety

(Cook and Das 2007; Ziefle et al. 2011). This wish is connected to a perceived gain in the quality of life in a familiar environment. Generally, quality of life is a quite complex concept referring to the individual perception of one's "physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features in the environment" (WHO 1994). Additionally, medical technology illustrates clearly what happens if the user is not integrated into the design and development process. Therefore, results from long-lasting research in the field of medical technology acceptance are presented and discussed critically regarding the interplay of patient empowerment and stigmatization.

Technology acceptance by patients has to be thought of as a multifactorial construct. Patients and current technologies are characterized by diversity. User or patient diversity typically consists of age, gender, personality, and level of education and, in the context of technology, of expertise with technology or self-efficacy with technology (Wilkowska and Ziefle 2011). Especially when it comes to an aging society, we have to learn that being old does not always mean the same, even in the same context, and that although the linguistic use makes us believe we have a homogenous user group, it is in fact very diverse (Arning and Ziefle 2009).

For the technological side, we have to remark that technology is, at least since the appearance of web 2.0, no longer limited to single devices or machines (O'Reilly 2007) but represents a combination of devices, data, and information independent from time and space. To face these changes, further deliberations about the following aspects are necessary:

– Novel formats of information and communication technology and technology acceptance as an integral component
– The concepts of age, aging, and images of aging
– The novel requirements of technology design
– Patient empowerment and stigmatization

Rethinking of Information and Communication Technology in the Medical Context

For a long time, the private use of information and communication technologies (ICT) has been specifically tailored to persons, healthy, young, parts of the work force and quite experienced with respect to the use of ICT. Since the early 1980s, ICT has found its way into the working context in which more and more people were confronted with this new form of technology. At least since the beginning of the last decade, this situation has changed completely and ICT became available for the mass. Reasons for that were, on one hand, the expansion of the Internet, a continuously progressing miniaturization of computers, as well as falling prices for ICT that led to a wide distribution of modern ICT among the European population. On the other hand, approaches of modern ICT were also further implemented into various other forms of technologies (e.g., cars, household technology, etc.).

In this chapter, we have chosen to take medical technology as an example as it illustrates special facets of technology acceptance and its sensitive sides depending on user diversity factors particularly well. Additionally, medical technology combined with modern ICT plays an important role for the coping of the demographic change. An increasing number of people that will need more medical care made the branch of medical technology boom in the last decade (Leonhardt 2006). This led to an enormous progress in the field of medical technology for the professional use (e.g., robotic surgery) but also in the development of medical technological devices for the private use. In this context, especially the combination of traditional medical technologies with modern ICT was groundbreaking. The combination of modern ICT and medical technological devices and the medical usage of ICT are creating unprecedented opportunities for both present and future; no longer limited to single devices, interactive, intelligent, and ambient concepts offer ubiquitous support for customers on both sides of the spectrum: patients as well as care givers and relatives.

One huge field is the integration of medical devices within smartphones or other ICT (Leijdekkers and Gay 2006) to help monitor (chronical) diseases like diabetes via smartphone applications (Calero Valdez et al. 2011; Klasnja and Pratt 2012; Scherr et al. 2006; Röcker and Ziefle 2011). Another approach based on the new technological conditions was ambient assistive living (AAL) (Nehmer et al. 2006). AAL is focused on the situational and discreet support of (frail) people within their home environment. One example for that approach is the future care lab (http://www. comm.rwth-aachen.de) which was developed at RWTH Aachen University (Klack et al. 2011; Kasugai et al. 2010). The future care lab is a research space in which older and frail users can experience the character of products developed within a home environment and contribute to understanding of age requirements. Also the sensitive trade-offs between safety and security on the one hand, but also privacy and intimacy requirements on the other hand, are explored (Wilkowska and Ziefle 2012). In addition, the specific information and communication needs of integrated ICT can be examined in context, e.g., when room components (walls, floor) are used as intelligent objects (Beul et al. 2011; Leusmann et al. 2011; Brauner et al. 2013; Fig. 1).
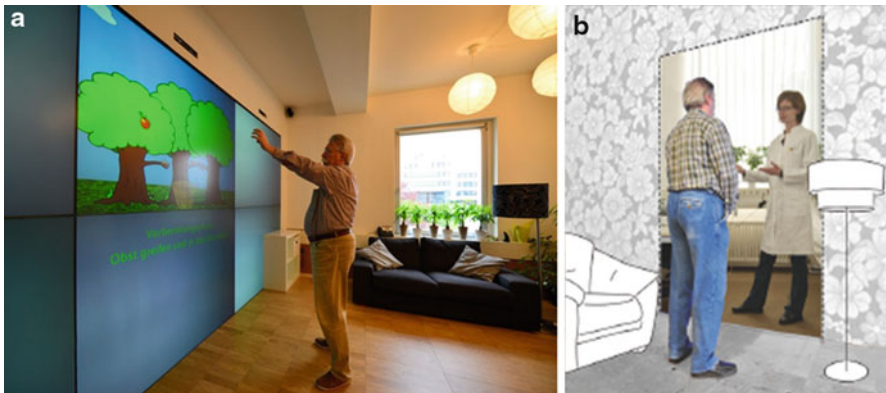

Fig. 1 Examples for applications for the future care lab (**a**) © Brauner; (**b**) © Kasugai)

AAL concepts such as the future care lab are new forms of technology integrated into the living environment that offer a wide variety of possible uses but also different degrees of acceptance based on the respective application.

Beyond the exclusive focus on the potential and feasibility of the technological potential of pervasive health care, the focus on human values, the usage context of a technology, and the requirements of user diversity are key demands of a successful development of medical technologies.

As a summary, a general rethink of ICT and its fundamental innovations is necessary, especially when it comes to fields like medical technology. The rethink is overdue in regard to the following aspects:

– ICT is no longer a niche for small user groups.
– ICT has left the specificity of the job-related context and is a ubiquitous phenomenon today.
– The combination and integration within contexts like medical technology trigger new application scenarios.

Rethinking of Age and Aging in Graying Societies

A central task is to understand the impact of age and aging. It includes a sensible understanding of the societal and individual pictures of age and aging.

The Societal Images of Aging: Although "aging" or "being old" is used in the common parlance as standardized term, aging is a highly complex and individual process that is characterized by a high degree of variability. It should be noted that the process of aging starts at different points in life for each individual and with various effects in regard to decreasing cognitive, sensory, or motor skills. The same holds true for the psychological perception of being old. The functional component of aging is defined via biological and physical developments (Sterns and Doverspike 1989). In contrast, the psychological age is defined by the overall mental or cognitive status, including the ability to react to fast changing situations, make decisions in critical situations, or adapt to multitasking demands. Furthermore, individual perceptions of age and being old are characterized by one's self-concept of being old. Both these concepts undergo a certain progress: whereas the physiological age is particularly influenced by medical treatment, nutrition, life quality, and strain on the human body (through work, pollution, and other environmental stressors), the psychological age is highly correlated to a person's biography, education and upbringing, critical life events, and coping as well as social and societal parameters (e.g., the family support or the social integration in a peer network).

Societal or public parameters also influence the point at which others perceive a person as old. This can be demonstrated when looking into history. Throughout history, the aging picture changed according to the established standards of the respective time period. Before the industrialization, people were perceived as old when they were no longer physically and mentally able to do their work. At that time, the perception of being old was defined by a calendric component as well as the

decrease of physical factors. After the industrialization, this perception changed and was influenced by the time of a person's retirement, a more or less fictive point in time, set by public authorities. This led to a more social and political definition of being old. In Germany, but also in other European countries, there was a profound change in the way of the aging concept over time. Starting with the economic miracle, after World War II, the standards of living and wealth increased rapidly, which influenced, on the one hand, the physiological well-being and, on the other one, financial opportunities that allowed new lifestyles, particularly for the time after persons' retirement. Never before had the time after the active working life implied so much space for individual development. Interestingly, although the so-called third age, the baby-boomer age, and health changed so much after World War II, it can be proven that the perception of "being old" did not change to the same degree (Covey 1992). Usually, age is treated in many studies by forming four categories (Shanan and Kedar 1979): the early adulthood (age 20–30), the adulthood (age 30–40), the middle age (age 40–60), and the higher adulthood that is subdivided into a 60+ and an 80+ section. It is a basic question, though, in how far these more or less arbitrary categories hold for future age cohorts, as aging depends also on generation and time.

Another social phenomenon that is highly correlated to aging is *ageism*. The term ageism was introduced in 1969 (Butler 1969) and is defined as social discrimination based on a person's age. Whereas at first ageism included the discrimination of both young and old persons, the focus was quickly set on a negative view of older persons and a stigmatization of aging. In our current situation with an aging society and demographic change, ageism plays an important role regarding the handling of these issues. Even though it is evident that today's societies are factually graying, attitudes towards frail and old people needing technology are still negative. Reflecting this deeply ingrained habit, all ages show this negative attitude towards aging, and it can be seen in many parts of daily life: fashion, social values, advertising, sexuality at older age, earnings, job chances, and, finally, a far-reaching youthism.

A constructive handling of the ageism problem is therefore a serious issue (Palmore 2001; Nelson 2004). Beyond the negative and stigmatizing attitudes towards older persons prevailing in public perceptions by societies, work, and family environments (Iweins et al. 2013), the feeling of older persons being dependent on technology and the loss of autonomy and control are highly negatively connoted for the persons concerned. In contrast, seniors' higher experience in many parts of daily life, their wisdom and life experience, and their ability to play an active part of the workforce are not acknowledged if not ignored.

The situation necessitates a profound *reframing of age and aging* (Allen 1987; John 2013; Sharma and Thomas 2010). We have to deal with outdated but pertinacious mental models of age and aging as well as certain forms of discrimination against older people. These facts make it essential today to rethink aging concepts from a societal and an individual perspective, including the occurrence of ageism, if we want to overcome the challenges of the demographic change in an adequate, respectful, and fair way. Therefore, the following aspects should be considered in research and policy:

- Aging is an individual process.
- Ageism is deeply anchored in society (current vernacular, commercials, films, working context).
- Aging images must be adapted to reality.
- The label "old" is no carrier for specific (negative) characteristics.
- The positive aspects of age should be reflected according to their positive value for an (aging) society.
- Culture, gender, individual background, upbringing, and economic status do have a considerable impact on the self-image as well as on the public image of age and aging.
- Differentiate age and generation.

Rethinking Technology Design: User-Centered Design, Hedonic and Affective Design

The maturity of information and communication technology on the one hand and of medical technology on the other basically allows technology to take over monitoring and care. Today, some solutions are already common practice, e.g., the emergency button, but a future goal would be the combination of different applications that lead to a sophisticated AAL concept (overview in Klack et al. 2011). In order to minimize daily life health risks for old and frail people and to increase the independency and mobility of an aging society, new concepts for unobtrusive health monitoring within home environments are needed. Implementation and integration of medical technology in living spaces requires a new conceptualization of medical device design. Mostly, design aspects of interactive environments have been experimentally tried in controlled conditions, usually as an "artistic" installation. Still too little research efforts address the cognizant effectiveness of interactive environments.

Invisibility and unobtrusiveness of technical components combined with high technical reliability have to be major aspects to be respected within the guidelines for the design of future health monitoring devices. In addition to technical features, technology at home also needs to be architectonically integrated in the personal living space and should not change the character of a comfortable and cozy home, respecting individual requirements for intimacy and privacy.

For a successful scenario in which both patients and health-care institutions profit from home care solutions, the technology has to be unobtrusive, affordable, and reliable. Patients have to be and feel as safe as in a hospital combined with the comfort and the privacy of their normal home environment. A long time ergonomics and human factors have been discussed from a dominantly functional perspective. According to this, mainly pragmatic aspects of technology (usability) are focused upon effectiveness, efficiency, and satisfaction (how satisfied are users when interacting with the interface). However, facing an increasing diversity of users, using contexts, and technology types, the concentration on pragmatic aspects falls short. Traditional approaches usually do not reflect the importance of positive

emotions (Wright et al. 2005). In this perspective, the quality of "good interfaces" relies also on affective and hedonic aspects as well as on social values, on attributes emphasizing individuals' well-being, pleasure, and fun when interacting with technology.

To this end, the relationship of users and technological products is of importance, as is a consequent inclusion of potential users, their requirements, acceptance barriers, and wishes. The making sense of user experience is highly needed, facing that information and communication technology moves out of the office and into everyday life.

The requirements for novel and successful technology device development are:

– Development should focus not only on technical aspects but also on design, mental model of age, etc..
– The perspective of users, their wishes, and barriers must be integrated in early technical development.
– Usability is an important component of medical devices. However, the cognitive and emotional passion of elderly with respect to the design should not be underestimated.
– User diversity and diversity of using contexts of medical technology represent critical framing conditions.
– The different faces of technology acceptances and their impact on the design process of assistive technology.

Empowerment and Stigma: Two Sides of One Coin

In conclusion, there are a number of essential requirements, which need to be considered for a user-centered technology development and design in the medical sector. With a focus on an aging society, one of the most striking challenges for (medical) engineers and technical designers is to develop medical support devices for the needs of the elderly, and especially for chronically diseased people in their home environments.

Holistic and Interdisciplinary Technology Development

There is an urgent need to develop novel, integrative models for the design of user-centered health-care systems. This demand includes new concepts of electronic monitoring systems within ambient living environments, which are suited to support persons individually (according to user profiles), adaptively (according to the course of disease), and sensitively (according to living conditions). Thus, the development of medical technology must be a common duty of different disciplines such as medicine, medical technology, engineering, architecture, communication science, ethics, psychology, and sociology. Only if the different perspectives are combined into technology development, humane and human technology designs may result. In those cases, higher acceptance can be achieved by a device design, which includes

usability aspects and hedonic components from the very beginning. In that way a medical device can turn into something that patients are proud to wear or to possess, just like a watch or a mobile phone, which are also assistive devices in a person's daily life.

Inclusion of Potential Users

The most important modification in the traditional development approaches in the field of medical engineering is to include those users actively in the design process, for whom the technology is designed. A coherent user-centered design of medical devices will result in a medical technology, which is not only functional in an engineering way of thinking but also addresses fundamental user needs in terms of appearance, ease of use, and privacy. Especially in case of integrating technology in living spaces, this is of great importance. First, there is no other place, which is more intimate and confiding than "the own four walls." Yet, accommodation is extremely important in a human's life for reasons of perceived safety, and it belongs to the basic human needs to feel protected, stable, and secure. Second, health is the greatest wealth and therefore a very sensitive and delicate topic – there is no higher good than this and everyone tries to protect it as long as somehow possible. Thus, putting these two relevant aspects of human life together, it is all the more understandable that the involvement of end users, their perspectives, whishes, and needs into every step of the development process play a great role for a successful rollout.

Age and Frailness as a Dictum to Technology Design

Given the increasing graying of societies and the overall aim to keep older persons as valuable part of modern societies, a profound rethinking is necessary. Technical design must be specifically tailored to the needs of the most frequent user group, the seniors. This includes a reframing of social and societal attitudes and a novel definition of age as a value in and for the whole society. Positive aspects of age and aging – life experience, domain knowledge, skills and expertise, wisdom, lifelong learning, and keeper of values and culture – should be deeply anchored in the public's mind. This seems to be not only a timely duty in nowadays societies; it also secures social and societal traditions, and medical technology development is part of it. If future medical technology adheres to an open-minded age perception, empowerment of the seniors is enabled.

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