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Ethically Inspired Care Information Technology Can Enable Freedom of Choice of Older Users

Narciso González-Vega[a], Anna Kämäräinen[a], Outi Kalla[a]

Abstract

The goal of this paper is to present the ethical issues that are relevant at the concept development stage and inspiring its development during the CONFIDENCE (Ubiquitous Care System to Support Independent Living) project. We propose that the technology must support principles such as human rights, privacy, safety, and dignity. The voluntary contribution of people as participants in research must undergo the scrutiny of research plans by ethical review boards. Informed consent processes and procedures must be observed in this realm. Ethical issues arising in heterogeneous fields involving technology, end-users, service providers, and formal and informal caregivers pose important challenges. Attempting to maximize the ethical compliance of the results of this ICT (information and communication technology) project, we explore and suggest preventive measures for possible scenarios of misuse of this or related technology. Concluding, the observation of ethical principles throughout the development process can empower users to make informed decisions on the acceptance of ICT systems and services when these reach the market.

Keywords

Care information technology, ethics, informed consent, older people, CONFIDENCE

The population is growing older globally, and the dependency ratio is increasing in parallel (Department of Economic and Social Affairs of the United Nations 2010). This demographic phenomenon imposes socioeconomic burdens on the older people, their caregivers, and the health and social care systems (World Health Organization 2007). Information and communication technology (ICT) developments can contribute to reduce these multilevel burdens (Fozard et al. 2000).

The project Ubiquitous Care System to Support Independent Living (CONFIDENCE), aims at enabling older people to live in their preferred environment, i.e., their own home, as long as possible with the support of ICT technologies. The system will be able to identify harmful situations, such as falls, and anomalous conditions such as reduced functional ability in the performance of activities of daily living (ADL). Wearable radio frequency (RF) sensors and communication channels are the technologies that support these functions. A more detailed description of the system can be found on the CONFIDENCE Webpage (CONFIDENCE 2010).

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[a] University of Jyväskylä, Finland

Correspondent Author:
Narciso González-Vega, Ph.D., AGORA Human Technology Center, University of Jyväskylä, Mattilanniemi 2, FI-40014 Jyväskylä, Finland
E-mail: narciso.gonzalez-vega@jyu.fi

The successful development of this system cannot be conceived without the involvement of older people and relevant stakeholders. This technology involves motor behavior monitoring and the transmission of information to emergency services or other designated alarm receivers. Personal identification and the condition of the user, e.g., the person has fallen down, are provided to the alarm receiver when the system detects an alarm situation. Adherence to ethical principles is of utmost importance in these circumstances.

This paper reports the ethical issues that appear relevant at different stages of this multidisciplinary research and development (R&D) project and inspire its development. One ethical aspect is directly associated with the technology under development and how this can affect the potential users. Another ethical aspect within the project is the voluntary contribution of older people and care experts. Some scenarios in which this type of technology could be misused are also presented.

Other R&D projects tackling the same or analogous technologies, as well as commercial applications could find these aspects relevant for their developments and operations. In particular, researchers in the areas of ambient assisted living (AAL), ICT and aging, e-inclusion, and e-health could benefit from the results of this research.

Additionally, an adequate consideration of the potential ethical issues that can emerge when an ICT system or service is taken into use may contribute to improve user acceptance of the technologies and services. Consequently, a business advantage for such systems could be expected.

OBJECTIVES

This paper aims at presenting the ethical issues that appeared relevant at the concept development stage, as well as those which arose during the project, and at raising awareness of the potential scenarios in which the technology adopted to implement the CONFIDENCE system might be misused.

METHODOLOGY

At the concept development stage, we reviewed literature on ethics and research papers related to care information technology and functions analogous to the CONFIDENCE system. These included radio frequency identification (RFID), care systems, personal emergency response systems, and social alarm systems. Data were also collected from voluntary participants through semi-structured interviews with older people living independently and focus groups of care service experts. Similar research activities were carried out in Italy and Sweden. In this paper only the results obtained in Finland are reported. Twenty-three and ten older people participated respectively in two needs and requirements elicitation studies. Semi-structured individual interviews were used to collect information from end-users. Care experts participated in focus groups also in two research occasions (ten and five experts respectively) with similar requirement elicitation purposes. Both end-users and experts provided their opinions on the compliance of the system with ethical principles in addition to the questions directly addressing the requirements for the system.

DESCRIPTION OF THE SYSTEM

The CONFIDENCE prototype consists of wireless RF sensors/tags, a processing unit or base station, and a portable device. The portable device serves as the interface between the user and the system. The software modules localize the tags worn by the user in the three-dimensional space, and reconstruct the bodily position of the user, and interpretation algorithms discriminate among normal, emergency, and increased risk level situations. The users are able to control whether the alarms are forwarded to an alarm receiver or not. The intelligence and predictive capabilities of the system represent some of the main innovations of CONFIDENCE.

RESULTS

Ethics in the Development of ICT

Ethical issues related to research with human participants are mature. However, when technological innovations are considered, such as CONFIDENCE, there might be issues hard to foresee and arduous to handle. At the beginning of the project, we reasoned that the system ought to support principles such as basic human rights, safety, privacy, integrity, and dignity (European Parliament Council Commission 2010). It also became apparent that the European and national regulations on personal data processing were relevant to the activities of the project (European Parliament Council 1995, 2002).

Freedom is perhaps the most valuable of the human rights achieved by human kind. The technology employed in this system shall respect the freedom of choice of the user. The user will be able to decide whether to use the system or not. This might seem obvious. For instance, one has the right to switch on and off the TV. Nevertheless, in the future of interoperable health and care ICT products and services, the freedom to use a certain component of the system or not, e.g., a monitoring device which causes inconvenience to the user, might not be so clear. The end-user may be responsible for handling appropriately a number of devices in order to obtain an adequate level of care or health service. It can be assumed that the service received depended on the concurrent operation of e.g., two devices but the end-user switched off one of these. In this context, the service provider could be exempted from responsibility in the case of failing to handle an emergency occurring to the older person. We could imagine that the end-user switched off the device which was the only one providing user access key to the service—jeopardizing his or her safety. Undoubtedly, this hypothetical case should be prevented by a system which demonstrates sufficient transparency and operative robustness.

The system collects and processes information concerning the users, i.e., 3D bodily posture and motor activity acquired through (RF) tags and sensors (Cochran, Tatikonda, and Magid 2007). Initially, the mechanism implemented by CONFIDENCE to comply with data processing regulations has been to assign the role of data controller to the user. This is, the data collected and processed by the system belongs to and is managed by the user.

Privacy is also respected because the system is not intended to share data with other systems or services. However, a commercial product based on the CONFIDENCE prototype, might well involve different service providers and interoperation with other care or health systems. The mechanisms to assure respect of privacy in this context should be reanalyzed and redesigned as the original settings would not suffice. Ethics and privacy issues in the context of ambient intelligence systems can also be found in Van Hoof et al. (2007).

The information is relevant for detecting falls and other behaviors that may relate to health problems, and to summon help when there is an emergency. It can be assumed that the principles of beneficence, purpose, and proportionality are satisfied by the current state of development.

The user controls whether an alarm procedure is initiated or not, except when the person is not capable of acknowledging this situation, for example, when the person is unconscious. In the latter case, the system initiates the alarm without the explicit consent of the user at this particular moment. Information and training to the user before adopting the system should guarantee that the informed consent of the user for this situation has been declared in advance of these potential hazardous events.

Ethical Aspects in the Research With Humans

The pioneering field in which ethical guidelines appeared to safeguard the rights of the human participants in research was medicine. The World Medical Association (2008) developed the declaration of Helsinki in 1964 followed by different updates. Other disciplines such as the social and behavioral sciences and engineering have followed (American Psychological Association 2010; Association for Computing Machinery 1992). These have also provided their associates with codes of conduct and ethical guidelines. Freedom, respect for life, justice, beneficence, and privacy are the most salient human rights contemplated in ethical guides (American Psychological Association 2010; Association for Computing Machinery 1992; World Medical Association 2008).

The project consortium is multidisciplinary and multicultural. In alphabetical order, Finland, France, Germany, Italy, Slovenia, Spain, and Sweden participate in the project. An ethical manual was elaborated (González et al. 2008) in the beginning of the project. This serves as the common ethical reference for the R&D process. Several research activities within CONFIDENCE required the participation of older people, health and social care experts, and family members, or others providing care to older people.

Following a pragmatic approach, two of the partners carrying out research with human participants have established internal ethical committees for this project within their organizations. We direct ethical enquiries to the institutional ethical committee of the university. Ethical approval for two needs and requirements elicitation studies has been obtained from the respective ethical committee of each research site.

During the information consent process, the participants received the information sheet and the informed consent form. A requisite for participation in the research was to read and listen to the information provided by the researcher, confirm that the information had been understood, and sign the informed consent. The information sheet indicated that their participation was voluntary and invited them to read the explanation of the studies. This also stated the purpose of the research, the procedures involved, the potential benefits, risks, discomforts, and precautions of the research. It also described the alternative procedures available to them. In our case, it was indicated that no alternative treatments were available, as these studies did not involve treatment to the participants. The right to withdraw from the study at any time without consequences was also stressed. Confidentiality and anonymity of the information they provided were assured. Their identity would not be disclosed in scientific or other publications, or to third parties. The participants were also reminded of their rights concerning the processing of personal data.

Another section of the information sheet considered the possibility of obtaining incidental findings. These may have significance for the health or well-being of the participant. Often, incidental findings are associated to biomedical research but can appear in other fields as well. Therefore, the participants were asked whether they wanted to be informed or not. Finally, information and contact details were supplied about the persons they could contact concerning the research, i.e., the principal investigator, and the ethical committee which had approved it.

One issue raised by these ethical reviews has been the comprehensibility of the information provided to the participants describing the research. Therefore, we modified this information to ensure that the participants understood unequivocally the purpose of the research and their role. Further research such as usability studies with prototypes of CONFIDENCE will follow similar ethical reviews.

The researchers described the CONFIDENCE system in such a way that the essence of its components and operation was maintained while the participants comprehended this technology. For example, the technical references to communication protocol standards were obviated while the older people and experts understood the principles involved in the RF communications used for the localization of tags in space. Adding references to the particular standard protocols employed by the system would only cause unnecessary distraction of their attention in the research situations.

Ethical Concerns of the Participants

In the beginning of the project, 23 older people participated in individual semi-structured interviews aimed at collecting information about their needs and requirements for the design of CONFIDENCE. When the end-users were asked for the first time about integrity, 18 of the 23 participants considered that the system could violate their integrity. Answering a follow-up question, they considered that integrity was an “abstract concept”. Some manifested that the relevance of the system to the person may justify the use of this technology. Quoted from two end-users, they thought that the “system does not violate privacy, if the information collected is confidential” and “if obtaining help relies on the technology, it doesn’t violate integrity”. However, they also thought that constant monitoring could violate their privacy.

The participants had positive attitudes toward using tags at home. Twenty respondents would use tags. Similarly, 19 of 23 would accept the presence of tags in clothes.

Semi-structured interviews with end-users at a later stage of the project involved ten participants. Eight participants thought that the system would not violate their privacy or integrity. However, eight participants preferred hidden sensors and tags. It can be assumed that unnoticeable devices would help them to maintain their dignity. If these devices could not be perceived or interpreted by others as care technology the self-esteem of the user would not be affected.

The participants had doubts about who could access the information and if it could be possible to misuse it. One participant pointed out that legal aspects should be considered carefully and formulated “who is allowed to investigate the location of the user?”.

Additionally, we asked the participants to provide their opinions about the ethical issues that could arise from using CONFIDENCE. Care experts, who participated in focus groups and end-users, reported that the system, as presented to them during these research activities, seemed to respect the rights of the users in terms of privacy, autonomy, integrity, and dignity.

Possible Scenarios of Misuse

Within the consortium, researchers and developers explore, and suggest options to prevent possible scenarios of misuse of this technology. A non-exhaustive set of potential cases where this or similar technologies could be misused is presented.

One case, as pointed out by end-users, concerns the disclosure of information involving the ADL of the users. For example, family caregivers might obtain information from the care system about how the older person is doing by default or by setting this feature on the system, e.g., how long time the user is staying at home or how long time this person is going out. Under normal circumstances the users might tell these caregivers about their whereabouts by own initiative. However, in some other circumstances the user might want to keep this information private. In the latter case the user must be able to easily, i.e., not requiring advanced knowledge of the operation of the system, switch on and off the capability of the system to share this information with another person. Yet still in some other circumstances doing so might represent a hazard for the user. Imagine a user with limited cognitive ability that becomes disoriented when leaving the household and is incapable of returning back without assistance. Some ethical dilemmas can emerge even though attention had been paid to these issues in the design and development process of a given care system. By design, such a system could support the rights of self-determination, autonomy, and privacy of the user in some circumstances. On the contrary, under subtly different circumstances some or all of these user rights, including freedom, might not be guaranteed. The rights of the end-user might have been handed over to a legal custodian or representative. This could be the case when the rights of the person are in conflict with his or her personal safety. Further elaborations on the use of RF identification and its implications on privacy and freedom can be found for example in Wasieleski and Gal-Or (2008).

Another scenario that we have considered is the use of information collected by the system for purposes for which it is not intended. A case can be considered where a health insurance company has provided a system such as CONFIDENCE to the older person. The purpose of the system as informed by the insurance company would be to allow the person to obtain help when is needed whether the user is able to summon help or not. The insurance company also has information about the functional ability of the person and by means of this information decides to adjust the coverage or the premium of the insurance policy. There should not be any argument against this practice if these conditions are explicit to the user when the insurance agreement is made. In other circumstances, the ethicality or the legal validity of this practice would probably not be supported. Frequently, the terms and conditions of insurance policies are complex. Understanding these is difficult for the vast majority of the non-professional insured customers. Therefore, in general, clear and understandable terms and conditions of the insurance providing the system must be guaranteed.

Profiling the user by means of the information gathered by the system for purposes such as advertising or selling products or services must be prevented. This case also falls within the realm of using the system for unintended purposes. A hypothetical situation could materialize with relative ease if we consider the business of proximity marketing enabled for example through Bluetooth connectivity. Self-determination, autonomy, dignity and freedom could be at stake if the users are not informed and have not consented unequivocally to receive this form of advertising. There are similarities with the phenomenon of spam e-mail messages that we experience so often or the unsolicited telephone calls and direct mail marketing that was more prevalent a few years ago.

There will be situations beyond the capacity of the technology to prevent misuse if the users are not aware of the risks involved and the protective actions that they can perform. Furthermore, the users would likely find new uses for which the system was not conceived. To prevent situations like these, the only possible precaution is to ensure that the user is properly informed about the functions of the system and the possible hazards.

CONCLUSIONS

The CONFIDENCE project continuously considers ethical issues and data processing regulations from the outset. The partners in the consortium are aware of the ethical issues that may appear as a result of the technologies employed in this R&D activity, and as the users interact with the system. Ethical committees review and provide opinions on the research plans involving human participants. Their opinions have been used to improve the comprehensibility of the information presented to the participants. They cannot make free decisions when the research situation is not completely understood. These have also reassured that the research procedures would not jeopardise the rights of the participants or harm them. According to the opinions of research participants, personal data processing, privacy, and dignity do not seem to be at stake within the development of the project.

The system, as a possible commercial product, shall implement each of the available mechanisms to protect the privacy, dignity, and safety of the older people. Misuse of the system shall be prevented through design and information to the users specifying how they can contribute to maintain their privacy and safety. As a corollary, assistive ICT aimed at supporting older people's independence shall include privacy enabling mechanisms such as access keys and data encryption as minimum specifications.

The contribution of voluntary participants to this project is an invaluable resource toward the development of ethically compliant technologies, which could assist older people to maintain their independent living. The efforts dedicated to ethical issues during the project could transfer to and inspire the development of ethically compliant and acceptable commercial applications for the benefit of older people. Products and services that do not comply with ethical principles may render ICT products and services unacceptable for potential users. The reverse condition could significantly contribute to the success of the product in the market when other necessary requirements are also satisfied, e.g., utility, usability, acceptability, and affordability. This is also applicable to AAL, e-health, and other ICT systems which may impact on the freedom, privacy, and dignity of the person.

It is recommend to take a systematic ethical standpoint from the start of any ICT concept formation, e.g., AAL or e-health. Potential end-users, and other stakeholders, e.g., formal and informal caregivers, health professionals, service providers, should be involved in the research processes. The information collected should then be translated into the technical specifications and implementations. Development cycles representing changes in the original plans should be accompanied by a revision of the ethical issues through the consultation of users and stakeholders. Additionally, providing comprehensible and sufficient information to the users will be the only means to empower them to make informed decisions. Finally, this process will support their dignity, privacy, and freedom also when they consider the acquisition of AAL, e-health, or other systems and services. Taking this approach as an integral part of the R&D process could make a difference between successful and unsuccessful commercial care systems devised to support older users' independent living and participation in society.

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Bios

Narciso González-Vega, Ph.D., senior scientist, AGORA Human Technology Center; University of Jyväskylä; research fields: older people independent living, care and assistive technology, ethics, healthy ageing, quality of life, human technology interaction, indoor and outdoor mobility.

Anna Kämäräinen, researcher, AGORA Human Technology Center; University of Jyväskylä; research fields: older people independent living, social care, privacy, ethics, human computer interaction, technology acceptance.

Outi Kalla, Ph.D., researcher, AGORA Human Technology Center; University of Jyväskylä; research fields: older people independent living, social care, ethics, healthy ageing, human technology interaction, psychological intervention.