Ethical consideration of home monitoring technology: A qualitative focus group study

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J. Leikas, M. Kulju. Ethical consideration of home monitoring technology: A qualitative focus group study. Gerontechonology 2018;17(1):38-47; https://doi.org/10.4017/gt.2018.17.1.004.00 Ubiquitous monitoring and data collection technology makes it possible to monitor older people's activities and to detect human performance. However, unobtrusive intelligent technology to be used in older people's homes raises many ethical issues. This paper illustrates the results of a study which examines the most pressing ethical concerns of both older people and care professionals regarding ubiquitous home monitoring. The study was divided into two parts: (I) Studied monitoring technology as experienced by older people and (II) Examined the technology in home care in the context of ethical principles. The method was a human-centred focus group discussion, based on a semi-structured group interview technique. Talking about technology in relation to one's personal life and work opened an important path: discussing the meaningfulness of monitoring technology and gerontechnology in general. Designers and care workers should be encouraged to discuss and reflect on ethical issues related to emerging technologies. Further research should be carried out, and awareness should be increased regarding the range of value issues.

Keywords: ethics, home monitoring, older adults, meaningfulness

Ubiquitous and unobtrusive technologies create new visions and business potential for systems design and development in the area of senior citizens' well-being and health. They make it possible to monitor people's homes and activities and to detect human performance 24/7[1-5]. A promising application in this field is the detection and monitoring of senior citizens' functional and cognitive performance. Unobtrusive intelligent technologies allow the early detection of various disabilities, chronic illnesses and memory disorders, for example, and can enable more accurate treatment. This is a great benefit for the public home and health care sector, which strives to reduce costs by helping older people live in their own homes for as long as possible.

The development of ubiquitous monitoring and data collection technology proceeds much faster than the ethical discussion of its use. Unobtrusive intelligent technology to be used in older people's homes may raise many ethical issues[6,7]. Home monitoring has already provoked ethical discussion in areas such as the autonomy and privacy of older people, as well as data protection and the prevention of harm[8]. Such concerns motivated this study, which examines the most pressing ethical concerns of both older people and care professionals regarding ubiquitous home monitoring.

This paper describes the results of a qualitative focus group study on home monitoring technology with older people and relevant stakeholders, in an attempt to encourage designers and care workers to discuss and reflect on ethical issues related to emerging technologies.

THEORETICAL BACKGROUND

Technology ethics is a field of applied ethics that examines ethical problems that can be created, transformed or exacerbated by technology[9]. In information and communication technologies (ICT) research and development, ethical design is grounded on applied (information) ethics, which examines the actual and possible impacts of ICT on important human values such as life, health, psychological and physical well-being, happiness, abilities, peace, democracy, justice, and opportunities[10-12]. The impact of technology can be assessed against a number of ethical principles that are considered universal ethical values[13]. However, these principles must be discussed on a practical level in order to inform technology design. In the early 1920s, Edvard Westermarck introduced this idea of placing moral thinking in a social context[14]. He stressed the importance of empirically inspecting how moral rules are manifested and how people understand them. He was the first to suggest that the way people live should be inspected and assessed according

to ethical principles in order to see how ethics is practised in everyday life situations.

Following Westermarck's approach, and the idea of practical ethics[15], we discuss the ethics of monitoring technologies in the context of the everyday lives of older people. From a design thinking perspective, three design approaches support this idea: (1) Life-based design, (2) Contextualised technology, and (3) Responsible research and innovation.

In life-based design (LBD), the measure of technology is in its ability to enhance the quality of life for people[16]. The true value of technology is emphasised as a means of achieving this ultimate target. The aim of LBD is the use of vital understanding about people's life as the basis of the creation of design ideas and design concepts[17]. Ethical choices and values are reflected and resolved within the design decisions. This involves examining what is ethically acceptable, i.e., what constitutes "the good" for the end users. LBD focuses on a biological, psychological and socio-cultural form of life of target users[18]. Design ideas are thoroughly examined to consider how they would support or inhibit the realization of a good life in the given form of life.

The second theoretical framework comes from the contextualisation of technology[19,20,21], which is in line with LBD. It emphasises that the ethical issues concerning the adoption and use of technology-supported services for older people are raised and solved in a particular context, be it social, political, legal, economic or informational. They also arise in the context of use. How ethical dilemmas are resolved depends on the context, as well as the attitudes and views of the people within it. Ethical issues arise thus regarding the use of services rather than the inherent characteristics of the technology. These issues are related to introducing, adopting and using technology, and should thus always be contextualised. Further, the solutions that are developed must consider the specific contexts of different societies. This is why ethical thinking in this field can never produce universal solutions: ethical principles cannot offer clear answers to all design questions. Because of their contextual nature, ethical issues are case specific, transient and negotiable[21], and require discussion.

The third valuable theoretical background relates to the concept of responsible research and innovation (RRI), the importance of which current European Union policy underlines in addressing the challenge of population ageing[22-25]. Here, responsibility in research is understood as socially, ethically and environmentally acceptable actions[23]. In research and innovation, ethical questions arise from the different goals set for the R&I work, and from the way in which the research is carried out. These include ethical dilemmas concerning the research target and respective stakeholders, as well as diverse demands and conditions related to RRI by both the fundamental principles of human science and the nature of service development processes[23]. According to RRI principles, designing information systems for well-being and health must take into account a comprehensive understanding of everyday life, considering the technology user from the physical, mental and social perspectives. Design must involve an understanding of different technology needs, and take into account the requirements of individuality and community, as well as consider ethical issues and enable the participation of users and interest groups in the design process[23]. Although the focus of contemporary RRI discourse is on publicly funded research, and the term itself is not broadly known, aspects of it are already reflected in the practices of many ICT companies[26].

METHOD

The aim was to bring together a cross-section of stakeholders in Finland to informally discuss home monitoring technology in order to build a shared understanding of the ethical issues related to monitoring technology – i.e. in what forms (and on what terms) this kind of technology would be welcomed and adopted in practice. We felt it was important to involve both those who would implement the technology and those who would be affected by such decisions in this discussion. Therefore, we invited end users (older people) as well as service providers, care professionals, academics and students in the home care field to participate.

The study was divided into two parts, each of which had a slightly different focus. Part I studied monitoring technology as experienced by older people, and part II examined the technology in home care in the context of ethical principles. We noticed in part I (older people) that when discussing user experience, ethical issues were implicitly raised several times. Therefore, it was obvious that ethical principles and issues needed to be further investigated. Thus, part II focused on ethical principles and values by introducing them to participants in groups 2 and 3 before the discussion.

The methodological approach was human-centred focus group discussion. This qualitative co-design method is based on a semi-structured group interview technique that facilitates immediate interaction, which produces new insights and encourages participants to compare different views[27]. The focus group approach is in line with the RRI demand to involve end users in the design process[28]. A moderator facilitated each group to produce proactive, forward-looking ethical discussions. Along with ethical issues, possible positive ethical impacts

were sought in order to enhance design thinking about ethically sustainable technological services[29].

Participants

Part I (Group 1) consisted of older people living in their own home in a service house for seniors, and using ubiquitous technology in their home for study purposes. In part II, Group 2 consisted of professionals in the home care field. Group 3 consisted of home care personnel, project coordinators, teachers and students acting in the field of home care and health care.

A scenario for monitoring older people's activity in a home environment with the help of sensor technology (*Figure 1*) was introduced to each group.

In this scenario, sensor technology is placed in senior citizens' homes to create an intelligent ambient environment that gathers information on how well the inhabitant is performing her usual activities, and reveals possible changes in daily habits. This information enables any variations in activity level to be detected and visualised. The data complement traditional health-related information, producing an integrated understanding of the person's daily performance. The technology also reveals acute or gradual changes that may indicate a need for professional intervention. Such a service scenario generally involves formal (and often informal) care and a variety of stakeholders, which raises ethical questions of, e.g., integrity, autonomy, and privacy.

Relevant ethical principles

Relevant ethical principles and values were introduced to groups 2 and 3 (care professionals and academics) (*Figure 2*). The principles and values were selected based on the literature and the experiences gained in the SATORI (Stakeholders Acting Together on the Ethical Impact Assessment of Research and Innovation)[31] , MINAmI (Micro-Nano integrated platform for transverse Ambient Intelligence applications)[32], and RRI (Responsible Industry)[33] projects. They are:

(i) *Integrity and dignity*. Individuals should be respected, and technical solutions should not violate their dignity as human beings[34].

(ii) *Privacy*. An individual should be able to control access to her personal information and to protect her own space. Privacy is a focal ethical principle in developing technology for older peo-

ple[35-38], and has an increasingly important role in ethical discussion as ubiquitous systems increasingly collect private information.

(iii) *Autonomy*. Autonomy is the perceived ability to control, cope with and make personal decisions about how she/he lives on a day-to-day basis, according to her own rules and preferences[38,39]. It is strongly related to coping in life. An individual has the right to decide how (and for what purposes) she is using technology. The principle of (respect for) autonomy requires respecting the autonomy of an old person.

(iv) *Reliability*. Technical solutions should be sufficiently reliable for the purposes for which they are being used[40]. Technology should not threaten a user's physical or mental health. Users of monitoring systems need to be confident that the collected data is reliable, and that the system does not forward the data to anyone who should not have it. Furthermore, it should be guaranteed that no unauthorized persons can access the data from the internet.

(v) *Justification and E-inclusion*. Services should be accessible to all user groups despite any physical or mental deficiencies. This principle of (social) justice goes hand in hand with the principle of beneficence (active intervention to positively benefit another)[41] and requires looking after individuals' interests and well-being[8]. E-inclusion is based on equality. Its goal is to prevent the arbitrary treatment of individuals. Rauhala-Hayes suggests interpreting the principle of equality as a requirement to treat individuals as equals (rather than to treat them equally)[42]. Then it would be possible to consider the unique needs of older people and justify appropriate policies for allocating technological resources. Moreover, Tinker talks about intergenerational justice and argues that the current generation of older people, especially in the UK, have benefitted from many benefits which are increasingly not available to the new generations of older people[43].

(vi) *Role of technology in society*. Society should use technology in a way that increases the quality of life and does not cause harm to anyone. Depending on what type of theory of justice a society is committed to, it may allocate resources for home care technology very differently. It may stress the principle of social justice (equality

Table 1. Study participants

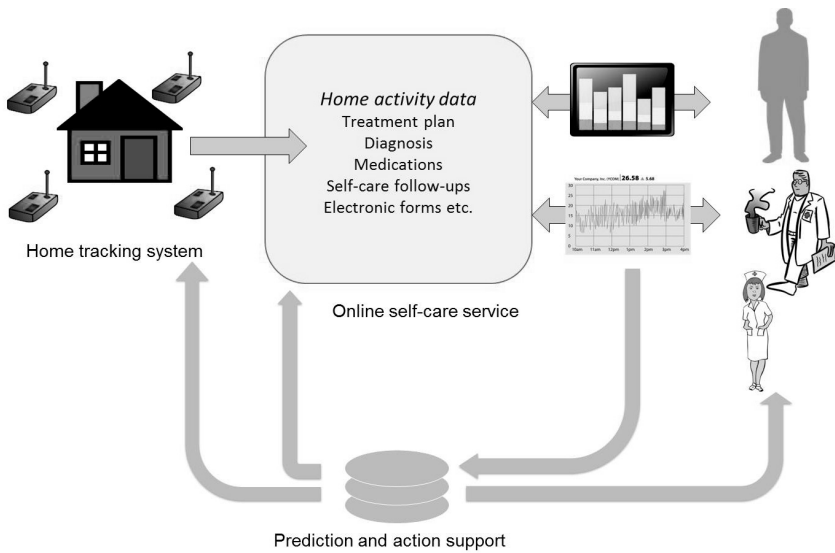| Group	Participants
Group 1	8 older people (aged 70–85) living alone in an apartment where monitoring technology (movement sensors) was installed for the study purposes.1 male, 7 females.
Group 2	6 experienced home care planning officers.1 male, 5 females.
Group 3	12 persons: academics, students and home care personnel in the field of health care. 2 males, 10 females.

Figure 1. Home monitoring scenario (Source: BeWell project30)

the meaning of the technology, and to understand the implications of her or his decision[44].

(viii) *A value of meaningfulness*. In our study, this list of principles was based on experiences in BeWell project[30,46] to indicate the role of technology in the life of an individual (the basic approach in LBD). Meaningfulness does not only refer to the usefulness of technology, but the experienced or perceived impact of technology on quality of life on an individual level, i.e. meaningful added value for the individual.

and solidarity), or the principle of autonomy (and values of individual freedom and choice). Rauhala-Heyes inspects the problem from the point of view of needs and points out that technological intervention in an older person's daily life is justified if this solution helps fulfil a basic need (to which everyone is entitled)[42].

(vii) *Informed consent*. This principle is a prerequisite for any implementation of technology and is especially significant for vulnerable older people. It means that people have the right to consent to technological intervention (adoption and usage of technology). Informed consent requires that information is provided to the person about her options and the consequences of each option, that consent is voluntary and not coerced, and that the person has the competence to decide from among the options[44]. In order to give consent, a person should have the necessary information, be able to understand

RESULTS
Part I. We found that ethical issues are relevant for older people when considering monitoring technology. However, this was explicitly expressed only when discussing the meaning of technology in life. "Sensors make independent living possible, so that nobody patronizes too much" (participant in Group 1). Universal ethical principles were also tacitly represented. "Does the world change so that one will be totally taken care by technology, only, and loses human contacts?" (Group 1 participant).

The results revealed that in-depth investigation of ethical issues was needed where ethical themes can be explicitly discussed.

Part II. The participants were motivated to discuss the subject, as they were mostly care providers in the home care sector, where the exploitation of monitoring technology is a hot topic. This part of the study elicited several comments about monitoring technologies in general.

The results of the three focus groups are summarized below, categorized by the ethical values and principles analysed in the study. (The term "user" refers to older people as a target group for monitoring technology, although in the scenario they are not exactly "using" the unobtrusive system by themselves.)

Dignity
The participants emphasised that old people must be considered valued individuals whose
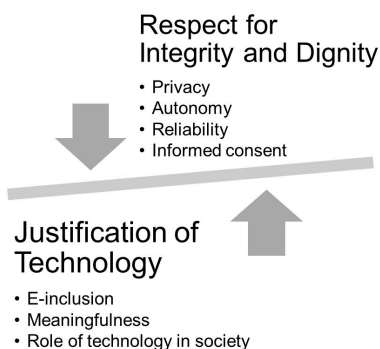

Figure 2. Ethical principles and values for discussion

opinions and decisions should be taken into account. A participant in Group 2 pointed out that "An old person is an aged adult who is allowed to make decisions concerning her own life, even though they seem to be not so rationale." Sometimes, however, it is difficult to respect the will and choices of a person when care personnel think these are inconsistent with what they believe is in the person's best interests. Especially in the case of people suffering from memory loss, the nearest ones or care persons may act on their behalf if they feel they know what is best for her.

The participants also discussed how technology could change power relationships between the customer and home caregiver in the sense that the carer is considered to be the expert in technology, which thus transfers power away from the client to the caring person.

Privacy
The participants agreed that an old person should have the right to decide how her personal data are used and should be advised on how to protect her intimacy. In the case of information systems, this is challenging, as in many cases not even care personnel know how to do this. Ubiquitous technology makes this question even more complicated. There are no regulations of privacy for this technology in a home care context. Care personnel involved in the study thus found training in privacy matters necessary.

Focal questions include: who has access to the collected data, and why? What kind of data should be classified as private, and what kind of non-private? Is it possible for an old person to verify the information, to get a summary of the data analysis? In what form? Is it possible to manipulate and misuse the data?

Although the collection of individual data in different everyday contexts, such as regular customer data, was familiar to participants, care personnel, in particular, were hesitant about privacy issues. It was discussed that some persons have even stopped using their regular customer cards, as they do not want to reveal to strangers what kind of goods they buy. Further, it was seen as difficult to weigh privacy concerns with safety considerations. Privacy should be respected, but safety can be easily neglected when weighting is placed heavily on privacy. Older participants, in particular, stressed that, especially in the case of memory ill people living alone, one has to choose safety over privacy. Every person has a right to privacy, but when a person has an impaired memory it might be difficult for her to perceive what is best for her. This is a good example of ethical thinking, where following only one principle is impossible.

Privacy was also discussed with respect to intimacy. Some participants thought it might be easier for an old person in some situations to receive help from technology rather than feel shy of accepting help from a human carer.

Autonomy
An old person has the right to decide how (and for what purposes) technology is used in her home. In order to be able to make this decision, the person has to be aware of, and understand, the meaning of the technology. Intervention using monitoring technology can be justified only if the old person has been presented with meaningful choices and sufficient information concerning her options and their consequences. This principle would not allow any devices to be installed against the person's will.

Control versus independence was the main issue that came up in the discussion with older participants. The older participants (Group 1) highlighted that monitoring technology makes it possible to live independently so that no one is making a fuss over them or worries in vain. While these participants were worried that technology would control everyday life too much, they reported that they had gradually gotten used to the technology and did not pay attention to it or even notice it anymore.

It is interesting that in the service home, the pilot system (of Group 1) evoked quite a lot of suspicion amongst some neighbours who did not have the system installed. These people commented about the "watchful eye" that is monitoring all the time. By contrast, the users of the system felt that they had control over the system. However, some users felt that it was a good thing that one did not need to "use" the system, as some were worried that they would mess it up by accident.

Reliability
It is important that users are aware of the technology and see that it works. Older participants felt reassured by a small blinking light in the sensor, which indicated that the system was working and the inhabitant is safe. However, when a person has a memory illness, she does not necessarily understand the meaning of the light, which can them become frightening.

Reliability was seen as important in case of a fall: one has to be able to trust that the need for immediate help is truly communicated so that it can be received quickly. The user must trust that the data are collected for a reason. Reliability was also discussed in relation to location information: If the system lets outsiders know that the old person is not at home, this information could be misused to break into the apartment.

E-inclusion and the role of technology in society
All groups pointed out the worry of losing human contact if technology replaces human interaction. If the old person can be assessed remotely, they may be left alone more frequently due to fewer in-person visits.

Group 1 was worried about the high price of the monitoring system and emphasised that everybody should be able to afford it. They felt that people would be put in unequal positions if the price of the system were very high.

Meaningfulness
The concept of meaningfulness is concerned with the true value – i.e., the worth – of technology for an individual. This concept was found to be ethically significant in many respects in the context of gerontechnology.

Groups 2 and 3 both found it highly beneficial to be able to know early enough if an old person is in need of help, and further, what kind of help she is willing to accept. Often a person forgets to eat, for example, and tells the care personnel that everything is all right. And then suddenly the person is in such bad condition that she has to be taken to the hospital.

Group 3 in particular pointed out that it is necessary to understand what is "a normal functioning" of the person to be able to compare it to the collected data. This requires the collection of long-term data, maybe even before the person is in need of any help at home. Whose interest would it be in then, to adopt and install the system? The nearest ones were seen as the most valuable source of information, supported with the experience of home care personnel when outlining the person's daily routines.

Measuring physical activity and vigour were found to be important. An older participant pointed out that when her daughter visits her, she checks every time if the mother has cleaned the apartment and taken care of her hygiene. For many older people, neglecting tidiness can be a clear indicator of not feeling well.

Older participants (Group 1) welcomed "any technology that would enable independent life and guarantee peace of mind for the nearest ones". The support that would bring help quickly when needed was highly appreciated. Care personnel generally welcomed a tool for checking a person's activity levels and encouraging them to be active. Support for decision making was seen as valuable, not only for identifying problem areas but also for recommending actions to solve problems. It was understood that activity monitoring is not enough, as sensors only monitor what they're programed to do. They can signal that an unusual condition exists that deserves investigation, but not the reason for the condition. Care personnel also need to see whether the decline in a person's functioning is caused by too little activity or some other problem, such as the wrong medication or the need of medication. Groups 2 and 3 characterised a solution that would truly encourage older people to be more active and even more social as very important.

Group 1 felt that they are older people who are already interested in everything new for the benefit for their own well-being. However, technology should be created for lonely older people who do not have any nearest ones and are not interested in anything new, to make them more active and to get them to "open the door to step outside". Social life was seen as important – particularly being able to maintain one's previous lifestyle. Group 1 was interested in robotics, but worried that their use would result in less social contact.

Table 2. Main concerns about home monitoring technology

Group 1	Group 2	Group 3
How to keep living independently?	How to guarantee the positive impact of technology on everyday home care work?	How to make people live a more active life?
How to make the nearest ones worry less?	How to modify the work of care workers in accordance with the efficient use of technology?	How to properly receive informed consent?
How to guarantee that everyone can afford the technology?	How to find the best possible solution for each individual to ensure a better quality of life?	How to make people aware of the need to nominate a trustee to decide on behalf of a memory ill person?
How to guarantee safety: quick help in acute need?		How to define a trustee's qualifications? What kind of education is needed?
How to avoid loss of social contacts?		

Table 3. Stakeholders' appreciation of principles and values

Mostly put forward by **older people**	Autonomy Meaningfulness E-inclusion
Mostly put forward by **home care planning officers**	Privacy Meaningfulness Trust
Mostly put forward by **home care personnel, academics and students**	Autonomy Informed consent Role of technology in society

Informed consent

Participants in Groups 2 and 3 were worried about how to receive informed consent in an orthodox way. The right way requires that: (1) Information is provided to the person about her options and the consequences of each option, (2) Consent is voluntary and not coerced, and (3) The person is sufficiently competent to decide among the options.

Although many older people are capable of giving informed consent, this is not always straightforward, particular in the case of people with memory illness. If a direct question is not possible (e.g., the person would not understand it), it may be possible to refer to the person's life preferences and to try to find out how she would have decided in her healthy days.

It is not always easy to make sure that the person has understood what she has been told about. Group 3 appreciated that in those situations, all stakeholders – the old person, those closest to them, and care personnel – make the decision together. It was also a common opinion that everyone should make a will about our own care while they are still healthy, and to nominate a trustee to take care of matters if they lose the ability to make decisions.

Group 3 broadly discussed the will of people suffering from memory loss and challenged society to raise awareness of the need for a trustee (to oversee financial matters as well as to ensure "a good life" for the patient) and to discuss his or her qualifications.

Tables 2 and *3* illustrate the main concerns of each focus group and the groups emphasise slightly different issues. When older people value autonomy over privacy, home care professionals are highly concerned about the privacy of their clients and trust in technology. Meaningfulness was emphasised in groups 1 and 2. For older people, meaningfulness of monitoring technology is strongly linked with safety, a factor which they see as a prerequisite for independent living.

Group 2, planning officers who are experienced professionals in home care field, looked at the problem from their clients' point of view but also from a perspective of home care management. For this group, the problems confronting aging people seem to be well communicated despite of busy practical work. However, it is worth further investigation to study what kind of novel means of intervention could be created to help planning officers, on one hand, keep up with the needs of aging people, and on the other hand be aware of new possibilities of technology.

The third group, which also has experience in sharing the everyday lives of ageing people in daily work, comes between the first and second groups. These participants emphasise the importance of autonomy. They also pay attention to the principle of informed consent (which is intimately linked with autonomy). Interestingly, the role of technology in society was discussed in this group more than the meaningfulness of technology for older people on an individual level. This is an interesting issue that requires further research.

DISCUSSION

On a theoretical level, we have focussed on discussing Westermark's empirical ethical thinking[14]. Ethics is not only a collection of conceptual ideas and dogmas. It is a system of norms that people either follow or do not follow in their lives. To understand the contents of morals and their real values, it is essential to study how people experience and represent moral issues in their lives.

The validity of Westermark's ideas about the importance of truly represented values led him to study such issues as marriage, morality, and religion. However, ethical principles and values are also relevant for investigating modern technology in society. In this paper, we have discussed ethical issues concerning monitoring technology in home care by demonstrating the possibilities opened up by practical empirical analysis of real-life contexts.

We organised three focus groups with participants from three different contexts to discuss ubiquitous monitoring technology for older people: older people as the targets of monitoring technology; home care personnel as potential users of monitoring technology; and academics, researchers and students studying the potential

of technology in the home health care sector.

The knowledge derived from focus groups can serve innovation management processes. This method can elicit information that connects technology development to related, real-life ethical issues. In our study it offered a way to examine "the good life" of older people. What is a good life? How can an older person set and accomplish personal valuable goals?

The discussion was grounded in everyday life and everyday home care. In many cases it was difficult to find "good" and "bad" viewpoints, but easier to compare the principles and values to one's own role as a client, a service provider or a caregiver. The role of technology on a personal level – either in the daily life of an old person or in a work context – generated a lot of discussion. It is probably easier to discuss the impact of technology when it is examined from a personal viewpoint. Talking about technology in relation to one's personal life and work opened an important path: discussing the meaningfulness of monitoring technology and gerontechnology in general. This value has not been introduced in ethical discussions in the field of gerontechnology before. For the participants, the concept of meaningfulness revealed the worth of doing so – i.e., the impact of technology in the life of an old person as an individual. It is concerned with the positive outcome of technology use. Meaningfulness can only be created by examining a person's everyday life, goals and values, and how technology can help improve the quality of life and facilitate a good life. For many older participants, meaningfulness was valued more than e.g., privacy.

It was found useful to study the possibilities for ethically sound service concepts by integrating older people and relevant stakeholders into the design discussion. Both sides are needed, as they weigh ethical principles and values differently. The participation of older people in the focus group revealed that they are relevant co-designers of the meaningfulness of technology in their own lives and in society.

Despite the study's small sample size, it outlines a new way of looking at valuable problems in the design of services for older people. It calls attention to ethical problems that require further analysis and elaboration. The most important issue is perhaps the right balance between value for the customer and value for the home care work. Here it is important to understand the differences in how the three groups define value when designing technologies for home care. Second, although the three groups were committed to discuss the relevant ethical problems in home monitoring, they did not extensively explicate concrete ethical issues. Sometimes, the issues were also juridical ones. Therefore, further research should be carried out to reveal tacit ethical understanding of subjects, for example by means of focused questions. In addition, awareness should be increased regarding the range of value issues.

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