

Ethical issues in the use of ICT as support for vulnerable older people to live longer in their homes – A review of literature

Summary report September 2017

Päivi Juusu and Stefan Sävenstedt

Luleå University of Technology

Introduction

The Remoage project tests and implements several services that include the use of different ICT applications and tools to support vulnerable older people. This include among other services as Remote activity support, Remote supervision, Remote consultations, Flexible support of family careers, Flexible safety systems in the home, and Multi-professional team support. In the planning and discussions that took place in the process of writing the proposal for the project ethical issues related to the implementation of the services in the different national contexts were discussed and considered very important to evaluate and learn more about. Assistive technology and ICT based services are often promoted as means of retaining autonomy and quality of life for older people, including people with dementia, and enable older people to continue to live in their own home. At the same time there are also several risks identified that could create ethical issues for the individual. Part of the process of focusing on ethical issues was to review existing research and this is a summary report describing the findings and conclusions from the review of literature.

Method

The objective of the review of literature was to provide an overview of the international literature on the most important ethical considerations in the field of using ICT applications and tools to support community-dwelling vulnerable older people. A method for systematic literature review was used to identify and analyses relevant literature. A pilot search was made in relevant scientific databases to identify proper search terms and to get an overview of this broad field. The type of ICT service or device was not specified, nor was the type of vulnerability. This was done because we wanted to give a general overview. The search terms; technology, ethics, and older people was used and literature published between 2003 and 2016 were included. After the pilot phase of the search it was decided to limit the review to include only other reviews meeting the inclusions criteria. Fourteen literature reviews were in this way included in the analysis, which together covered the content of over 250 published papers.

Findings

The findings reveal a number of aspects and themes important when using ICT applications and tools in the support services for community-dwelling vulnerable older people. Dignity and respect of the older vulnerable people in the community dwelling, was an overarching theme, which meant the right to decide on their own life and to respect their integrity always had to be present. To promote dignity included to respect older peoples' independents, integrity, participation, safety and security, the benefit of the service for the individual, and equity and justice. The findings are presented based on the areas included in the overarching theme.

Autonomy and independence

Values as autonomy and independence are important when considering ICT applications in support services for community-dwelling vulnerable older people. Research has shown that ICT applications can promote the experience of independence but also contribute to a risk of hampering the experience of safety and security and social interaction (Dahler et al., 2016). In cases where an independent living has a special focus there is a risk that vulnerable older people with disabilities can be excluded. It can also be questioned if independence should be a specific target, rather the focus should be on promoting autonomy, freedom to choose what, how and when and with whom the service should be used. This way of looking at

independence for vulnerable older people relates closely to the concept of empowerment and the possibility of ICT based services to support aging in place, social inclusion, communication and integration in the community (cf. McLean, 2011; Novitsky et al., 2015; Swijssen, et al., 2011). Studies also show that the vulnerable elderly person's own wish to continue living in their own home increase the willingness to utilize ICT services. It is important to consider that cultural values may have an effect (Peek et al., 2014), and it is therefore of importance to find out how the individual elderly person is thinking regarding independence (McLean, 2011).

The perception is that ICT services will increase independence and reduce the burden of support from family members. However, there are indications that this increased independency at the same time creates a dependency of the technology (Dahler et al., 2016; Hofman, 2013; Korhonen et al., 2015). There is a risk that remote social interaction via the technology will promote a social isolation from other community dwellers and a dependency (Novitsky et al., 2015).

In all implementation of ICT based services for vulnerable elderly people, it is important to consider the needs of each individual and the possibility for them to participate in the decision on whether they should have it or not. It is important to ask the question for whom the service is implemented, for the elderly person or to cater for the needs of the family members or health care personnel (Swijssen et al., 2011).

Informed Consent

It is important to consider how to communicate information about the ICT based support service to the vulnerable elderly person and family members. It is always difficult to understand how new things will work and what impact it will have on one's own life. The information must be communicated in a way, which takes into consideration the abilities of the individual. The individual and relevant family members must have an opportunity to test the service in a practical way to fully understand the benefit and handling of equipment (Novitsky et al., 2015; Swijssen et al., 2011). The elderly person must also have the possibility to withdraw from using the service (Novitsky et al., 2015)

Integrity

If the ICT based service provides enough experienced benefits to the individual evaluations indicate that vulnerable elderly people often accept the risk that the service will have an impact on their integrity (Fischer et al., 2014). An example is remote supervision with a camera in the home where evaluation show that the fear of an impact of the service on the individual's privacy and integrity was limited as long as there was a balance between the benefit of being provided with supervision and the risk of losing integrity (Swijssen et al., 2011). In situations where there are many different stakeholders involved it is of special importance that issues related to integrity and confidentiality are dealt with (Hofmann, 2013; Magnuson & Hanson, 2003). The fear of not being in control of the technology is described in the literature and the individual user must therefore be able to turn on and off equipment (Mordini et al., 2009). At the same time, this possibility can create problems when the user have memory problems (cf. Novitsky et al., 2015). It can also be of importance from the

aspect of integrity and confidentiality where the technical equipment is placed in the house (Magnuson & Hanson, 2003)

Participation

It is important that vulnerable elderly people are involved already in the development and planning of ICT based service to meet their needs (Bjering et al., 2014; Novitsky et al., 2015; Piau et al., 2014; Swijsen et al., 2011; Topo, 2009). If that cannot be materialized vulnerable elderly people must be involved in the process of implementing the service (cf. Dahler et al., 2016). In this process, it is also important to involve family member (Dahler et al., 2016; Novitsky et al., 2015; Peek et al., 2014; Piau et al., 2014).

Safety and security

A key area for ICT based services is safety and security. Many of the tested services have positive evaluations and an important aspect for the acceptance of the service is how robust and reliable it is (Peek et al., 2014). There must be an established system for the service, who will respond if something happens and who will maintain the service (cf. Swijsen et al., 2011). The responsibility of each involved part must be clear and the focus of the needs of each individual elderly must be maintained (Hofmann, 2013). In that process, it is important to identify everyone's experience and knowledge of technology, to better understand what could promote acceptance and reduce worries of use (Dahler et al., 2016, Fischer et al., 2014).

Benefits

The benefit for the vulnerable elderly person of using an ICT based service must relate to the cost since the benefit of the service may not motivate the increased cost for support (cf. Novitsky, et al., 2015; Swijsen et al., 2011). There can be a benefit of the service for several stakeholders as family and the service provider, but in the end, it is important that the main benefit is experienced by the vulnerable elderly person (Novitsky et al. 2015).

Equity and justice

It is important in the planning and introduction of ICT based services for vulnerable elderly persons to consider contextual and cultural differences in experience of using technology and experiences in participatory approaches (Hofman, 2013; Korhonen et al., 2015). This include posing questions about for whom and to what purpose the service is introduced. If for example the purpose is to improve access to social and physical activities it is important to ask the elderly person if this is what they want (cf. Hofmann, 2013; Magnuson & Hanson, 2003; McLean, 2011). Accessibility to ICT based services is an important ethical issue, independent on where you live, your economic situation or your knowledge. You should have access to the service if it cater to your needs (Magnuson & Hanson, 2003, McLean, 2011). The use of the ICT base service should improve the possibility of social interaction (cf. Novitsky et al. 2015).

Conclusions

Based on the findings in the review following questions should be asked during the planning, when implementing and after implementation is ended.

Autonomy and independents

- What is the meaning of independents for each individual vulnerable elderly person?
- How important is the possibility to remain living in the private home?
- What fears do the individual user and family members have regarding the considered service?
- How motivated is the elderly person to learn more about the service?
- What alternative interventions can be offered if the elderly person withdraw from using the service?

Informed consent

- How is it insured that the seeking of informed consent is a process where the elderly person is informed in a way that he or she can understand?
- Is the possibility to test and evaluate the use of technical equipment and other aspects of the service provided?

Integrity

- To what degree is the benefit of the service compensating for possible risks?
- Are the issues related to security and access of data dealt with?
- Has the older person control over the use and functions of the equipment used in the service?
- Is the placement of the equipment considered in relation to privacy and integrity?

Participation

- How is the participation of the elderly person and family members in the planning and implementations process insured?

Safety and security

- What experience has the older person of using technology?
- Is the function of the technical equipment robust and reliable?
- Is the response of the service provider secured and well organized?

Benefit

- Will the service increase costs for the individual older person?
- Will the service cater to the needs of the older person?

Equity and justice

- Is the service developed in way that it is accessible for all in need?
- Is the service developed in a way that cultural and contextual differences are considered?

References

- Baruch, J., Downs, M., Baldwin, C., & Bruce, E. (2004). A case study in the use of technology to reassure and support a person with dementia. *Dementia*, 3, 371-392.
- Bjering, H., Curry, J., Maeder, A. (2014). Gerontechnology: The importance of user participation in ICT development for older adults. *Investing in E-Health: People, Knowledge and Technology for a Healthy Future*.
- Dahler, A.M., Rasmussen, D.M., & Andersen, P.T. (2016). Meanings and experiences of assistive technologies in everyday lives of older citizens: a meta-interpretive review. *Disability and Rehabilitation*.
- De Jonge, D.M., Jones, A., Phillips, R., & Chung, M. (2012). Understanding the essence of home: Older people's experience of home in Australia. *Occupational Therapy International*, 18(1), 39-47.
- Fischer, S.H., David, D., Crotty, B.H., Dierks, M., & Safran, C. (2014). Acceptance and use of health information technology by community-dwelling elders. *International Journal of Medical Informatics*, 83, 624-635.
- Hofmann, B. (2013). Ethical challenges with welfare technology: A review of the literature. *Science and Engineering Ethics*, 19, 389-406.
- Kernisan, L. (2016). Promises and pitfalls: Technology and the future of delivering eldercare. *Journal of the American Society on Aging*, 40.
- Korhonen, E-S., Nordman, T., & Eriksson, K. (2015). Technology and its ethics in nursing and caring journals: An integrative review. *Nursing Ethics*, 22, 561-576.
- Kunskapsguiden.se (2017). Hämtad från <http://www.kunskapsguiden.se/aldre/Webb-utbildningar/Sidor/Etik-och-integritet-vid-inforande-av-valfardsteknik.aspx>
- Lauriks, S., Reinersmann, A., Van der Roest, H.G., Meiland, F.J.M., Davies, R.J., Meolaert, F., Mulvenna, M.D., Nugent, C.D., & Dröes, R.M. (2007). Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews*, 6, 223-246.
- Magnusson, L., & Hanson, E.J. (2003). Ethical issues arising from a research, technology and development project to support frail older people and their family carers at home. *Health and Social Care in the Community*, 11, 431-439.
- McLean, A. (2011). Ethical frontiers of ICT and older users: cultural, pragmatic and ethical issues. *Ethics & Information Technology*, 13, 313-326.
- Mordini, E., Wright, D., Wadhwa, K., De Hert, P., Mantovani, E., Thestrup, J., Van Steendam, G., D'Amico, A., & Vater, I. (2009). Senior citizens and the ethics of e-inclusion. *Ethics & Information Technology*, 11, 203-220.
- Myndigheten för delaktighet. (MFD). (2016). Hämtad från <http://www.mfd.se/valfardsteknologi/vad-ar-valfardsteknologi/>
- Novitzky, P., Smeaton, A.F., Chen, C., Irving, K., Jacquemard, T., O'Brolcháin, F., O'Mathúna, D., & Gordijn, B. (2015). A review of contemporary work on ethics of ambient assisted living technologies for people with dementia. *Science Engineering Ethics*, 21, 707-765.
- Piau, A., Campo, E., Rumeau, P., Vellas, B., & Nourhashemi, F. (2014). Aging society and gerontechnology: A solution for an independent living. *The Journal of Nutrition, Health & Aging*, 18, 97-112.
- Peek, S.T.M., Wouters, E.J.M., van Hoof, J., Luijckx, K.G., Boeije, H.R., & Vrihoefj, H.J.M. (2014). Factors influencing acceptance of technology for aging in place: A systematic review. *International Journal of Medical Informatics*, 83, 235-248.
- Smer rapport. (2014:2). *Robotar och övervakning i vården av äldre – etiska aspekter*. Rapport av Statens medicinsk-etiska råd. Stockholm. Hämtad från www.smer.se

Smith, V., Devane, D., Begley, C.M., & Clarke, M. (2011). Methodology in conducting a systematic review of systematic reviews of healthcare interventions. *BMC Medical Research Methodology*, 11:15.

Sveriges Kommuner och Landsting (SKL). (2017). Hämtad från <https://skl.se/naringslivarbetedigitalisering/digitalisering/nationellsamverkanstyrning/ledaforsmartarevalfard.9156.html>).

Sävenstedt, S., Sandman, P.O., & Zingmark, K. (2006). The duality in using information and communication technology in elder care. *Journal of Advanced Nursing*, 56(1), 17-25.

Topo, P. (2009). Technology studies to meet the needs of people with dementia and their caregivers. A literature review. *Journal of Applied Gerontology*, 28, 5-37.

Zwijzen, S.A., Niemeijer, A.R., & Hertogh, C.M.P.M. (2011). Ethics of using assistive technology in the care for community-dwelling elderly people: An overview of the literature. *Aging & Mental Health*, 15, 419-427.