

Proposal for Pervasive Elderly Care: A Case Study with Next of Kin

HANNA-LEENA HUTTUNEN, RAIJA HALONEN & SIMON KLAKEGG

Abstract This paper reports how interaction between family members and caregivers as perceived by family members could be improved via context-aware, imperceptible internet of things (IoT)-based solutions. The study focused on investigating experiences of the family members and the communication between caretakers in sheltered accommodation. Interviews including both open and closed questions revealed that there is high need for improving the communication, adding to the sparse earlier knowledge. The study revealed that the family members were willing to adopt an application to improve the communication that currently was experienced as too limited and vague. The results provide a fruitful base for further actions to improve communication between family members and professional caretakers.

Keywords: • Caregivers • IoT • Sheltered Accommodation • Mobile Application • Family Member •

CORRESPONDENCE ADDRESS: Hanna-Leena Huttunen, PhD Candidate, University of Oulu, Faculty of Information Technology and Electrical Engineering, Oulu, Finland, e-mail: hanna-leena.huttunen@oulu.fi. Raija Halonen, PhD, Adjunct Professor, University of Oulu, Faculty of Information Technology and Electrical Engineering, Oulu, Finland, e-mail: raija.halonen@oulu.fi. Simon Klakegg, PhD, Asker, Norway. e-mail: simon.klakegg@livo.no.

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1 Introduction

The purpose of our study was to investigate how family members of the elderly experience the potential use of assistive technology in sheltered accommodation when interacting with caretakers. The motivation for this study arose from earlier studies that revealed a lack of or slender interaction between caretakers and family members of elderly care centre residents.

The numbers of elderly are increasing globally, and the growth is expected to continue (Medjahed et al., 2011). The supportive role of family members in assisting their elderly is important and may lead to reduced costs down the line (Bolin et al., 2008). Along with ageing, the need for assistance and care increases, and the elderly are moving to accommodation that can offer more support than at private homes (Hainstock et al., 2017). However, the rising number of ageing occupants also means an increased need for care and resources from the caregivers (Alam et al., 2012).

Guiding family members is one of the duties of nurses. Family members bring meaning, continuity and importance to the lives of the elderly. It is important to encourage and support relatives to interact with the elderly and nursing staff (Andersen, 1995; Doty, 1986). The current study investigated the possibilities of state-of-the-art technology to support interaction between caretakers and visiting family members and other next of kin of the occupants. The research problem was compressed into a research question: How do next of kin of the elderly living in sheltered accommodation consider using assistive technology when communicating with personnel who take care of the elderly? To answer the research question, methods of qualitative research were applied in a home (dubbed Comfort in this paper) offering sheltered accommodation for elderly. Qualitative interviews were carried out in Comfort, and eight persons representing the next of kin participated in the study.

By identifying the family members' worries during their visit, it was hoped the bottlenecks resulting from the care work can be reduced, enabling family members to participate in different stages of the care. In addition, there already are devices that provide intelligent surveillance technology to help elderly people live in safety while providing energy efficiency, comfort and automation (Wong et al., 2017).

However, the question remains: Are family members willing to apply assistive technology to ease information sharing and reduce uncertainty related to the wellbeing of their elderly?

2 Earlier Knowledge

2.1 Elderly in Sheltered Accommodation

The proportion of aging populations is growing worldwide, and explosive growth is expected to continue (Medjahed et al., 2011). When supporting the elderly to maintain their independence and quality of life, the role of family is crucial. However, the next of kin can experience too heavy a burden in caring for their elderly and continuing their lives (Hainstock et al., 2017). Sheltered accommodation and treatment costs are rising, and illness is more prominent, requiring additional resources for nursing staff (Alam et al., 2012). Studies show that the life of the elderly is more meaningful in nursing homes than in an institutional care facility (Nikmat et al., 2015; Tuominen et al., 2016). In the nursing home, the elderly can have their own rooms and live in their own apartments surrounded by their own belongings. Nursing staff is available 24/7 (Coelho et al., 2015); however, with an increasing number of residents, so does the workload of nursing staff increase, thus weakening the premise of better care of patients, mostly due to efficiency bottlenecks (Huttunen et al., 2018). Intelligent care systems provide many opportunities to overcome such challenges, and elderly well-being, health and functional ability have been shown to improve with wearable sensors and personal area networks (PAN) (Wong et al., 2017).

It is natural for the nursing staff to recognise the limitations of older people's ability to perform daily tasks, thus empowering them to provide high-quality care for the elderly. Guiding and providing information to family members are among the duties of a nurse, and the role of the family in service systems is also very important. Studies show that it is important to encourage and support relatives to interact with the elderly and nursing staff (Andersen, 1995; Doty, 1986).

2.2 Technology in Sheltered Accommodation

Over the last few decades, technological advances have been made in solutions for intelligent homes, providing a remote monitoring system useful for healthcare. The devices provide surveillance technology to help elderly people live in safety and provide energy efficiency, comfort and automation (Wong et al., 2017). Safe housing has been studied previously, in a case where an intelligent control environment was built in the home of elderly persons. Such technology was placed in each room of the home to monitor the movement of users in the rooms and, if necessary, an alarm can be triggered remotely (Freitas et al., 2015; Klakegg et al., 2017).

The elderly could be supervised by a remote system that collects information about health, activity and safety of the person. Automatically collected data gathers valuable information about their behaviour and potentially their needs to enable prompt decisions and plans for future actions. Devices exported to the home of the elderly should not compromise patient safety and therefore must be as discreet as possible and work under everyday living conditions (Klakegg et al., 2017; Nygård & Starkhammar, 2007).

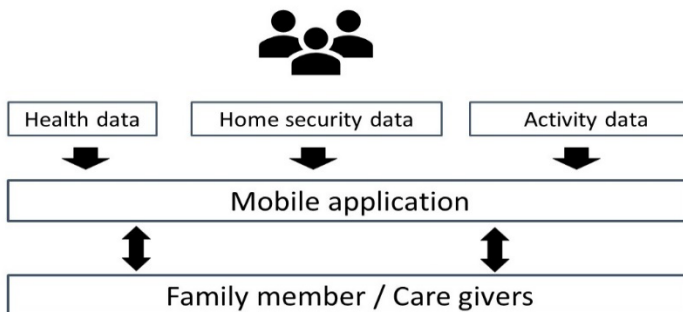


Figure 1: Data flow of mobile applications

Figure 1 illustrates how data can flow between several actors, such as care personnel in the sheltered accommodation and next of kin at their homes who are involved in the communication related to elderly persons' health-related data (Klakegg et al., 2017).

The role of digitalisation will be more visible in future in the form of unobtrusive body area networks (BAN) and PAN sensors in rooms to be applied in healthcare when the requirements of treatment grow worldwide. Sensor networks work together through a wireless network and can identify and achieve numerous opportunities to track and understand the lived phenomena of people (Krishnamachari, 2015; Atzori et al., 2010).

2.3 Healthcare Sensors in Sheltered Accommodation

Internet of things (IoT) refers to devices and items that communicate between each other and are located around us, ubiquitously (Atzori, 2010). IoT consists of sensors, net connections and information management. Sensors located in devices are energy efficient, identifiable and safe and include net technology (Gubbi et al., 2013).

Figure 2 illustrates unobtrusive BAN and PAN sensors positioned in sheltered accommodation for the elderly. Sensors attached to the body or clothing form a network in the body area (BAN). The purpose of the body sensors is to measure heart rate, daily rest, sleep quality, activity, mood and stress levels. Sensors attached to a person should be easy to use and unobtrusive so that their existence does not affect the everyday life of the patient or elderly. Movement must also be possible unobstructed (Cavallari et al., 2014). Sensors attached to the environment form a PAN where sensors are located close to the object. Sensors are placed in the home to various devices such as home appliances, bed, walls or smartphones. PAN sensors can measure, for example, movement, sound, air pressure, temperature, humidity and light. Sensors are used to gather required information about the environment of the elderly (Huttunen et al., 2017).



Figure 2: Unobtrusive BAN and PAN sensors

The use of information technology and telecommunications in healthcare provides advanced solutions for nursing staff. In addition, patients can take advantage of technology to support their own care and at the same time increase interaction between their relatives and the nursing staff. Intelligent systems are intended to enhance access to care, to develop nursing workflows and to reduce bottlenecks that occur in nursing. By first identifying nursing processes, the quality of healthcare services can be improved (Faertes, 2015; Huttunen et al., 2017).

Pervasive healthcare is considered to be one of the solutions to support the future of high-quality care. Healthcare should be available to anyone, anywhere, anytime. The purpose of pervasive healthcare is to eliminate time and place limitations in healthcare. The definition includes short-term and long-term prevention, maintenance and patient controls. Medical equipment that monitors patients' vital functions, movements, quality of life and activity are provided to support patients' care at home or at sheltered housing (Varshney, 2005; Huttunen & Halonen, 2018).

Healthcare professionals are encouraged to use more and more handheld devices to obtain patient information. In elderly care, relatives can receive information about the client's status, reminders about treatment and medication changes or write prescriptions electronically. Healthcare staff rarely have training in intelligent applications, so patients and their relatives should be trained in

hospitals in the use of the information and communications technology (ICT)-enabled applications (Varshney, 2005). Handheld devices and personal digital assistants (PDAs) can also detect and monitor patients' vital functions and send alarm messages to hospitals, ambulances or patients' relatives for emergency services. Alarm messages can also support patients' own care, leading to early detection of symptoms and timely taking of medication (Varshney, 2005; Huttunen & Halonen, 2018).

3 Research Approach

Our study focused on understanding a limited group of people in their real environment (see Myers & Avison, 2002; Larsson & Sjöblom, 2010). In the study, qualitative theme-based and open interviews and observation were applied.

The study was carried out among visiting next of kin of people who were being cared for at Comfort. The empirical material was collected in two phases. In the first phase, the participants were asked to fill out a semi-structured questionnaire that consisted of 19 questions. The questions included three main questions and their sub-questions. The main questions were about the background information of the informants, care activities in Comfort and using smart technology that could transfer information about the health status of the occupants to their next of kin. In the second phase, a face-to-face interview was carried out, guided by the information from the semi-structured questionnaires.

The interviews, which lasted from 45 minutes to 90 minutes, were completed in two days. In total, eight family members were interviewed in March 2018. The questions in the questionnaires allowed freedom for the informants to describe their experiences about the interaction between them and the caretakers.

The interviews were transcribed, and the questionnaires were analysed with the help of content analysis (see Myers, 1997). Earlier studies were also noted in the analysis phase. The questionnaire included both open and closed questions, and they were answered by numerals, words or 'yes/no' responses. Eight people participated in both questionnaires and interviews, all of whom were appropriate for the research.

The background information was sorted based on sex, age, relationship with the occupant, distance of home, frequency and duration of stay in Comfort, length of care, frequency of change of care staff during occupancy and whether the next of kin experienced any lack of information related to the care given in Comfort.

Related to participating in the giving of care in Comfort, the resources of the family members were classified. In addition, the ways of participating in care, how personnel encourage participating in care and which tasks in care the informant would like more information about were analysed. Further, the preparedness of the family members to apply smart technology in interacting with care personnel were analysed, mirroring it with earlier research.

4 Findings

Our eight participants consisted of five men and three women. They were three sons, three daughters, one living partner and one other relative. Their age varied between 46 and 85 years, and their homes were situated at the distance from 1 to 230 km. The informants were also asked how often they visited their elderly (see Table 1).

Table 1: Family members as visitors

Frequency of visiting Comfort	Age	Kinship	Distance to home
Daily	85	Spouse	1km
A few times per week	60	Daughter	3km
A few times per week	56	Son	2km
Once a week	58	Daughter	10km
Once a week	69	Son	3km
A few times per month	64	Son	110km
A few times per month	47	Son	2km
A few times per month	46	Other relative	230km

Table 1 reveals that one of the relatives visited the elderly every day, two a few times a week and another two persons once a week. Families that visited often lived near, but the respondents who lived far away visited only a few times a month, except one son who despite the short distance visited a few times per month.

Most of the respondents felt that the information was not always delivered to the family quickly enough and that the information was not explicit enough. Some nurses provided information without asking, but most nurses responded only 'I don't know' when information was requested because they were not named as personal nurses for those elderly. Some relatives also felt that nurses gave loose answers. One of the respondents stated there was a flaw in the information flow between nurses and relatives in the service unit. One of them was very annoyed as the nurses did not note any informed observations about the elderly, who had a urinary tract infection and subsequently had to be treated in hospital.

Eight respondents stated that they didn't get enough information about the care related to their elderly. Most of them also experienced that information is not transferred quickly enough and that the information is inconsistent and changing. In general, the family members felt that the nurses give somewhat vague reports about the daily tasks of their elderly. One of the family members gave a thorough opinion about the issues related to communication between the caregivers and family members as follows:

During my visits there has never been a nurse at work who could have known about the wellbeing of my next of kin and if it has changed in a way or other during the past month. When I visit, I ask the nurse on shift how my uncle is. The nurse is not able or cannot say other but what has happened during her shift. If there had been a responsible nurse on shift, she could tell accurately because a trained nurse must be aware of all the clients and their wellbeing. For instance, the influence of medication, injections, starting new medication, results of laboratory tests and their effect on the wellbeing of the client. In addition, the nurse should be responsible for all changes in health status, medication and prescriptions and healthcare actions according to the health reports and examinations and the vital functions of the client.

Also, the family members were asked for their opinions about their resources to participate in the care in Comfort. Most of them were ready to help the elderly in Comfort as a support for the nurses. They reported that they can offer a lot of support by helping their elderly in getting dressed, going out, discussing, giving information about happenings outside of Comfort, taking care of tasks, listening, comforting, calming and cheering up the elderly and participating in the physician's visit together with the care personnel. We also asked how much the family members had been involved in planning and evaluating the care of their

relative before the client arrives in the sheltered accommodation and during the housing. Most of the respondents had been involved in the planning of their elderly person's care, but a few of them had not been able to give input on the treatment planning. 'I haven't participated due to the long distance. It could have been possible with a video call, but it was not available in the service room at that time.' One person mentioned in the interview that he was involved in a health meeting where they went through his relative's health, hobbies, interests and background information. These biographical items were written on a card where the nurses can check client information. One person also mentioned that she was involved in planning care at the beginning, but afterwards did not get enough information about her relative. *'We did a care plan with the nursing assistant when we arrived to Comfort. After that, perhaps little evaluation took place, but not collectively.'*

Eight of the informants suggested that the smart application should not automatically report about the status of the elderly, daily activities and prescriptions. Rather, the nurse should forward the information to the family member via the application and, in case of need, the family member can contact the elderly via the application. The application should also have a direct messaging functionality to inform the care personnel.

After receiving the background information, the interviewers asked if the respondent was willing to use intelligent technology for interaction between nursing staff and relatives. All eight respondents informed that they desired day-to-day communication through intelligent technology. Relatives would quickly know about changes in health and overall health. The smartphone application would replace the notebook where a family member writes while visiting his or her relative. The answer would be in real time. Family members living far away would get more information and would then be more aware of their elderly's behaviour and change in health status, and the flow of information would be facilitated. The respondents did not find it necessary to get information updates daily. However, one family member considered the smartphone application as a communication tool, defining it as *'Seeing the daily report, current medicines and doses. Despite the long distance I could experience that the distance is not that long and that I am better informed about how my uncle manages.'*

5 Discussion

This study focused on the family members of elderly living in a sheltered accommodation called Comfort and their willingness to use assistive healthcare if offered by a mobile phone application designed for caregivers.

In Comfort, each client had an individual treatment plan, which supported high-quality care in sheltered accommodation and at the same time acted as a tool for nursing staff. The treatment plans were collaborated with the care unit, occupants and relatives. The need for care of the occupant, the goal of the treatment, the implementation of the treatment and the means were recorded in the treatment plan (see Russello et al., 2008; Schenk et al., 2013).

Guiding family members was one of the nursing staff tasks, and the role of the family was very important. An active role of family members (elderly's spouse, a child or other relative) in the care of the elderly brings substance, continuity and importance to the lives of the elderly. It is important to encourage and support relatives to interact with the elderly and nursing staff (Andersen, 1995; Doty, 1986).

The current study showed that family members *need support for elderly care*. They are *unsure of what's happening* in the nursing home, and they want intelligent technology to support communication. The family members would like *to know that the nurses at the sheltered accommodation can, if necessary, quickly provide topical information* through phone apps to family members.

Family members should also be *offered an opportunity to ask questions about the elderly* from the nursing staff. Intelligent systems allow information sharing between several stakeholders, such as medical staff and nursing staff (Freitas et al., 2015; Klakegg et al., 2017). Our study proposes that the means of pervasive systems are used to inform family members about the status of the elderly.

By adding technology to support nurses' workflows, it is possible to reduce bottlenecks from nursing work and to increase patient safety in sheltered accommodation. (Huttunen et al., 2018). Our study assumes that there are *family members who have resources to support care of the elderly and can thus reduce the care work* of

nursing staff. The interaction between nursing staff and family members should be enhanced by using intelligent technology to allow *prompt informing when necessary*.

Available intelligent solutions have been developed to provide remote monitoring systems for healthcare. The devices provide intelligent technology for surveillance of the elderly in housing security, comfort and automation (Wong et al., 2017). Current knowledge and technology already enable pervasive systems (Medjahed et al., 2011; Faertes, 2015; Klakegg et al., 2017). Healthcare mobile devices enable more efficient patient care, and sensors can be used to allow collecting and evaluating physiological data from the elderly (Cavallari et al., 2014).

The current study proposes that the communication between nurses and the family members should be enabled and improved via a mobile device, which could *facilitate and increase the awareness of family members about the care and status of their relatives* in sheltered accommodation. The application should inform about *facilities in use, safety of the elderly, e.g. risk of falling when standing up, duration of living in Comfort and mood of the elderly*.

6 Conclusion

To conclude, the family members strongly wanted to apply assistive technology to ease and reduce uncertainty related to the wellbeing of their elderly. Fixed and wearable sensors offer practical means to collect physical, mental and social information about the wellbeing of people. The fixed sensors collect accurate information about the location and safety of the participants. Sensor-based data can be transferred to the mobile application to be used by the care personnel, who can share information with the family members when appropriate.

By identifying the worries and troubles raised by family members when they visit sheltered accommodation, one can reduce the bottlenecks from communication between family members and nursing staff. With the help of applications, the nursing staff can include the occupants' relatives in different stages of the care to bring the nursing staff and family members closer to the elderly's everyday care during the service life. In case of unexpected issues, the family could be informed about any incidents. However, the family members also pointed out that the final decisions should be made by them, not automatically by 'the computer software'.

There are many kinds of sensors on the market that can improve people's lives. There are sensors both inside the body and wearables but also set in the environment (Klakegg et al., 2017). In Comfort, sensor information could facilitate communication between the patient and the nursing staff, as well as between relatives and caregivers.

In healthcare, the use of technical aids is seen as a key means of facilitating interaction between nursing staff, patients/clients and their relatives. Pervasive healthcare is largely based on the use of technical aids and the continuous availability of healthcare to the patient. The goal of pervasive healthcare is to turn healthcare from doctor-centred care to patient-centred care. Pervasive healthcare aims to guide patients/clients to prevent the emergence of acute illnesses and to respond more quickly to their own care (Varshney, 2005; Klakegg et al., 2017; Huttunen & Halonen, 2018). In our study, the nursing staff benefits from continuous automated data collection for a single patient, and in the current study also all family members were willing to accept new technology in caring activities for their elderly. With automation it will be possible to help and respond faster to changes in patient status.

Automation can help improve access to care (Wong et al., 2017), but the technology and security of sensors need to be improved continuously to allow patients/clients to safely use sensors to identify diseases and change lifestyles. In future, the security of tools developed for communication between nursing staff, patients and relatives to improve communication should also be investigated in order not to compromise privacy.

So far, there have been only few studies on communication between relatives and nursing staff to support elderly care. More research is needed in the future to find out how family members of the elderly experience the use of assistive technology in communication when interacting with caregivers in sheltered accommodation. The interaction should be enhanced by using intelligent technology as desired by the next of kin.

The next phase will focus on the application and communication that could extend between the relevant healthcare providers. The current study offers constructive observations and informative points to build a prototype for the mobile application.

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