

Sensor Technology for Night Surveillance: The Experiences of Next of Kin

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Abstract

In-depth interviews were conducted to gather information. The aim was to investigate next of kin experiences when healthcare professionals used sensor technology to take care of their relatives in elderly care. Findings show that next of kin experienced better sleep for both themselves and their relatives. Those who were offered the sensor technology services were few. We need more research to conclude how it will work on a larger scale. We know that implementing Information and Communication Technology changes work flow, but we don't know the effect of how these tools will make changes when implemented on a larger scale.

Keywords

Home healthcare services, Night shift, Sensor technology, Elderly care, Welfare technology

1 INTRODUCTION

Motivated by an increasing cohort of elderly people, the Norwegian Ministry of Health, the Norwegian Directorate of eHealth, Norwegian municipalities, and healthcare providers look to technological solutions for help in managing the upcoming challenges in elderly care. They expect that "Welfare technology and assistive technology, as in smart homes and telecare, improve healthcare quality at the same time as saving resources" (NOU2011:11) and (NOU2015:13) and (White Paper no:2, 2016). This paper explores next of kin experiences when healthcare professionals use sensor technology to take care of their relatives in elderly care. The sensors were bed sensors, front door sensors, and fall sensors used in bathrooms. None of these elderly patients were offered video recording. Bed sensors triggered an alarm when a patient went to the toilet and did not return to bed within a pre-set time. The research questions were as follows:

1. What was perceived as the main reason for using sensor technology?
2. What were the next of kin's experiences of using sensor technology, regarding safety and security?

The project has followed four municipalities in Southern Norway in their challenges and efforts when implementing welfare technology over a period of two years.

2 BACKGROUND

Most people want to take care of themselves. However, if you are in need of daily support, you might need healthcare services or to stay in a nursing home.

Healthcare professionals may use technology to enable patients to stay at home longer and take care of themselves. Application of sensor technology as part of nursing care to get the most out of limited human resources, should be discussed. Findings from Missouri, USA, show that patients who are using sensor technology in controlled areas, such as an independent living facility, live longer (Ranz, et al.2015). No similar study has been conducted in Norway. However, the healthcare system in the municipalities aims to improve quality of life for its healthcare receivers by using sensor technology; and living longer is not necessarily a measurement of better quality.

The project we followed in this study mainly intended to monitor elderly or disabled people with sensor technology. The sensors operated in a network or were individually connected to a centralized alarm center. Combining the individual needs of the users and trying to manage elderly care in a cost-effective way were some of the overall goals for the project we studied. Maslow's Hierarchy of Needs, a five-stage pyramid where the lower levels cover how humans seek to satisfy basic physiological needs and the desire to feel safe and secure, is well known in healthcare. However; Thielke et al. (2012) have suggested that this model is only slightly consistent with how Assisted Technology (AT) tends to solve human problems in elderly care. According to Maslow's model, human needs on the lower levels must be solved before progressing to higher level needs; in this project, the AT tries to cover the need to feel safe and secure by using sensor technology to look after patients at night. In Norway, there has been a policy to get patients back to their homes quicker (White Paper:2008-2009 no. 47). Patients end active treatment and are discharged to their homes even if they could benefit from a day or two more in hospital. Patients who need nursing

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services at night after being discharged; are offered these services through home healthcare or nursing homes in Norway.

The AT alarm system has been developed to monitor people who cannot reach a phone or push an alarm button. It is important to feel safe and secure and to sleep undisturbed; however, healthcare professionals checking overnight may disturb sleep. Sensor systems that include AT may prevent sleep disturbances. Many patients and next of kin request services characterized as “to be looked after” at night in case of an emergency, for instance a fall. There are narratives from healthcare professionals of how night visits disturb the patient without providing any guarantee that they will not fall as soon as the Registered Nurses (RN) has left their bedroom. Patients suffering from dementia, who tend to go out walking at night and cannot find their way home again, are in the target user group.

Innovation in care is a politically wanted change, as this may help in dealing with the increasing number of elderly people who will need care in the years to come (NOU2011:11). Nurses working overnight shifts in nursing homes have found innovative ways to manage looking after patients who tend to walk around overnight. The photo below illustrates how some used a plastic cup on the door. When patients went to the door to get out, the healthcare professionals would be warned by the sound of the cup falling, and therefore be able to catch up with them before they left the building.



Figure 1 - Photo from Østre Agder, Project: Digital Look at Patients

2.1 Prior Research

Earlier studies have shown how workflow is changed when Information and Communication Technology (ICT) is implemented (Li, 2010). The workflow in this study mainly concerns how the next of kin can change their way of interacting with their relatives when using sensor technology. Sensor technology has been introduced in smart homes as a part of AT, but the level at which it interacts with healthcare providers, with the inhabitants of the smart home, and with their relatives varies. Ding et al. (2011) argue that sensor technology seems to support independent living in smart homes; however, more evidence should be collected before widely deploying it in everyday life. Grant and Rockwood (2015) studied 14 home healthcare agencies and assisted living facilities across five states in the US by carrying out

interviews, and describing clients' satisfaction, health quality, and patient safety. They argued that clients living with telehealth services as AT would be more satisfied than those not implementing it. Chan et al. (2008) reviewed studies of smart homes. They presented challenges such as design difficulties with validating the alarm triggered, but stated that technological devices are designed to allow elderly people a more autonomous life even though they live in a secured and comfortable environment. It seems that using sensor technology in combination with services from health professionals can support fragile elderly, both in nursing homes and in their own homes. Regarding these prior studies, it is necessary to look at the use of sensor technology as a tool in the context of nursing care in the municipalities.

3 METHODS

3.1 Design

A qualitative design is well suited to catch lived experience (Polit & Beck, 2014). The findings reported in this paper are based on interviews of the patients' next of kin.

3.2 Setting and sample

The project was followed almost from the start of the planning phase to the implementation of sensor technology for monitoring of the patient during the nights. Special considerations have been made to protect individuals' anonymity in this project, as there were individuals participating from small municipalities where people know a lot about each other. Everybody included in the project was therefore invited to be interviewed and to give their opinions to the researchers. Information about this opportunity to tell about their experiences was communicated to all next of kin by the project leaders, both via oral communication individually and handing over written information and consent forms. A total of six next of kin returned signed consent forms. No additional request was made.

The interviews were planned to be conducted from the start of the project. One interview was not included in our data set because the experiences this next of kin had at the time were from only two nights of use, as the sensor had been moved to someone else who needed it more. Five individual interviews were included in this study. An open question technique was used to catch their experiences and all the interviews started with the question “Can you tell us about how and what you experienced when sensor technology was given as an opportunity to your relatives?” The interviews with next of kin gave rich information about how they regarded the use of technology and what they expected from the municipalities. The age of the patients is not recorded. The three who still lived in their own homes had all reached a point where it was a question of either installing sensor technology or applying for a full-time place in a nursing home. All the information given by the

next of kin concerning their needs is anonymized, since they all live in small municipalities. Neither the project group nor anyone else should be able to identify these persons, irrespective of whether they clearly welcomed the sensor technology or considered not implementing it. Three municipalities started implementing sensor technology in nursing homes and in-home healthcare at the same time. Both wired sensors and wireless sensors were installed. During the first stage of the project, which lasted six months, as many as 12 patients were using sensor technology during the night. By the end of the project in December 2016, a total of 75 users had been included. These users were all from three municipalities. The fourth municipality taking part in the project did not have the financial means to start implementation of the sensors, but decided to follow the process in order to be ready to install when they got funding. One of the municipalities had tried out the sensor technology in a previous pilot.

The project group contacted the researchers and participated in a discussion of design and methodology. In this paper, we present the lived experiences for patients seen from the view of the next of kin, regarding the feeling of being safe and secure overnight when sensor technology is applied in elderly care.

Both males and females were among the interviewees. Their mean age was early sixties. One of them worked full time and studied in addition. Three were retired or out of regular work in other ways. All of them also had other family members to take care of. The interviewees all decided where to conduct the interviews, these were carried out either in their homes, in the nursing home, in the researcher's office, or in an office in the public house of the municipality. There were no disturbances during the interviews; and the conversations were easy to carry out. None of the interviewees seemed embarrassed or distracted; they were all eager to share information, to express their thoughts, and to tell whether this technology was something they were able to rely on.

When there is such a close bond between the people receiving the service and the people interviewed, it is important to critically evaluate both the process and the end results. Therefore, the whole process needs to be as transparent as possible (Fog, 1994). In challenging the transparency of the research process, it is necessary to be well aware of the presuppositions of those involved. In this study, we experienced that the project group were convinced that the results were good even before we had started collecting data, and their presuppositions may have influenced some participants.

3.3 Data analysis

In hermeneutic thinking about interpretation and analysis, the whole and parts are inextricably linked to each other (Alvesen & Sköldberg, 2009). Once we had decided to examine the feeling of safety at night, it was essential to determine how and if those involved felt safe and secure. The hermeneutic approach argues a more

phenomenological approach to their experiences in this context (Alvesen & Sköldberg, 2009; Van Manen, 2006). Several field notes were taken as a supplement to capture the "whole" from meetings and situations where the researcher was present. Capturing the whole is limited by the preunderstanding, by what the respondents can describe, and by what the analyzing process discovers. Deep interviews have been used to investigate if relatives' experiences are connected to the technological equipment, and if so, whether it influences the feeling of being safe and secure at night. The project leaders in the municipalities recruited participants for interviews, and the scientists were not permitted to directly contact any participant before they had signed and returned their declaration of consent in a closed envelope. The project has been approved by the Norwegian Centre for Research Data (NSD) and is registered with the following number: 40832.

Deep qualitative interviews were done with the patients' closest relatives. The patients could bring their relatives with them for the interviews if they wished. All the interviews, the field notes, and other texts are interpreted and analyzed through a hermeneutic-phenomenological approach. The interviews were transcribed verbatim. When they were read through again, different colors were used to separate the meaning units, and the quotes were marked. After this process, a mind map was made to identify the most important statements, and these were analyzed in a hermeneutic-phenomenological understanding as described by Hammersley & Atkinson (2007) and Kvale and Brinkmann (2009). When analyzing the data, the first focus was on the words spoken: the content. Thereafter the researcher stressed keeping preconceptions aside, because of the close bond to the project group and the fact that they wanted to tell about the success factors and how well the sensor technology worked in every meeting. We wanted to get the next of kin's descriptions without any distortions (?) and find out how they regarded the patient's and their own experiences using the AT.

4 RESULTS

All the patients who were offered sensor technology had a previous history of either wandering out alone or accidentally falling during nights. One relative said: *"We were offered help with technology after he had been staying out in the evening; it was this Spring, and it was a cold night, and he was sent to the hospital, ... I thought it was the end. It seems he didn't manage to find his way back and get inside, and I realized this could have been a very sad ending; I could no longer take the responsibility.... [I was] arguing about him with my sister, if and how he should live at home alone any longer. We decided to apply for him and try to get a place to stay and be looked after, especially at night, in a nursing home."*

The municipalities offered to let them try the sensor technology. Permission to use sensor technology is often given by next of kin who find technology useful for looking after their relatives. Another example from a next of kin shows this quite clearly. He/she said: *"After her fall in the bathroom where she lay on the floor with a hip fracture for fourteen hours, she lost her belief in being able to manage at home, but with these sensors or the technology she's confident that she will manage again."* The next of kin interviewed seemed to believe in technological solutions as something naturally to use for both helping the patients to live longer in their homes and strengthening the feeling of being safe and secure in their homes. The next of kin seem to expect technological solutions to be useful all the time and regard them as wanted by the patients because of their physiological needs. Some next of kin regard technological solutions as the rule. One said: *"I think this should be the normal standard, everybody should have it... if or when needed."*

Next of kin to patients with dementia who tend to wander around, express feeling more safe and secure that their relatives will be taken care of if needed, after the sensors were implemented. One said: *"My number one fear her worst nightmare: lying on the floor or somewhere.... not being able to alarm anyone or get up; lying there in pain for hours. You know that would be awful."*

The next of kin described the patients using sensor technology as rarely being aware of the technology. In addition, the patients were often unable to commit voluntarily to the use themselves. A relative said: *"I don't think she even knows if it is there; she never asks me about it, about the sensor, or touches it. It's just standing there. I wouldn't mind myself if I was in this condition. I would be glad someone cared for me and to be safe, even though I might not know."* Some of the next of kin clearly stated they would have given permission for the use of sensor technology both day and night, but one argued for not wanting the technical solutions to be used in the daytime because of the patient's social needs for seeing other people.

Next of kin living in multi-generation homes reported having better sleep quality when their relatives were looked after by sensor technology. One next of kin said: *"One can more easily go to sleep, as well."*

Although one next of kin did not want the sensor technology to be used in the daytime, they had decided that using it at nighttime for security was an advantage. A next of kin who had his/her relative in the nursing home living alone in an apartment argued: *"I agreed to the use of sensor technology because it was to be used at night. By day I feel she needs to see people as much as possible rather than sitting alone."*

5 DISCUSSION AND IMPLICATIONS

Some next of kin expect technological solutions to be available for everyone. The technological solutions seem to give the opportunity to let next of kin fulfill the patient's wish to live in their home as long as possible. The more sensors we install, the more alarms we will have to answer. This will change the way next of kin communicate and look after their relatives. We have examples of people developing their own surveillance systems to monitor their parents or spouses when they get ill; they often argue that these systems help the monitored person to become more independent of other people or to live home longer. Use of technology might give the patients and the next of kin a higher level of self-care; as described by Barnard and Sandelowski (2001) technology can be an extender of care. Normally people are regarded as wanting to manage on their own. One can divide patients in need of nursing in two groups: those who can decide to buy and install technology to be able to live longer in their homes on their own, and those who need help to still be able to live at home or to stay independent. Nursing theory is described by Orem (2001) in different levels of self-care, with human potential and human limitations; nursing theory can regard applying technology as the patients' action to maintain a higher level of self-care and allowing them to stay at home longer. Technologies used in social media might change this situation totally. Just imagine taking part in a family Christmas dinner sitting in your own place, or in the nursing home, and having a real-time video communication; being able to see enjoying the feeling of being there. Using technology in healthcare solutions and knowing how reliable it is; is another interesting issue. Permission to install sensors is often given by relatives, who find technology useful for this purpose. When asking next of kin, the researcher needs to have a clear understanding of the technology's capabilities and rely on the information given. The next of kin seem to expect technological solutions and assume them to be useful all the time.

Implementing technology changes the workflow in more than one way. It is nearly always expected that one can work more effectively and get more done using technology, but research has also shown how ICT is reshaping organizations by simply affecting more and more tasks and thereby changing the way we work (Li, 2010). Is it in fact possible that the technology will identify more work to be done, and if so, how will the health professionals manage and deal with this extra workload? In this case, it is possible to program the sensors to alert relatives first if they live nearby or in the same house. If the alarms are activated precisely every time an acute situation occurs, everyone will be satisfied with these solutions. But if the alarm alerts the next of kin without being needed the technology will most certainly be considered useless. Ding et al. (2011) argue that sensor technology for smart homes should address actual needs. In our study, it seems that this

recommendation is taken care of, as all the next of kin described a change in the patients' health as the triggering reason to start using the sensor technology. But one must consider carefully whom this sensor will alert, and how often the relatives will be alerted at night. The situation will also differ between households; as everybody has individual needs. When family members are part of the caregiving team through being alerted, one should consider whether the situation is properly taken care of regarding all parts involved. First, is this a solution the patients would want if they could commit voluntarily? Zwijsen and Niemeijer (2011) point out that the debate regarding autonomy in ethics of using AT in elderly care seems inappropriate considering the situation of frail, elderly people. Some may regard this use of sensors as illegal surveillance. In some ways, this is quite close to our opinion, especially regarding those patients unable to commit to the use of sensors.

But we also need to discuss whether use of technology is what is needed and wanted for patients with dementia to live the way they would wish if they could decide for themselves. It ought to be possible to give an early statement regarding commitment to use before dementia develops too far.

Considering the case of relatives, often patient's closest contacts are his or her own children, friends, or neighbors living nearby. Hence, it is necessary to know the will of the patients. Who are to be involved as next of kin if a person with dementia falls on the way to the toilet and can't get up again without help? Family structure is changing fast in Norway; more and more families consist of few people. One- or two-person families are not rare. One can't expect everybody to take on the responsibility for elderly people living at home. If sensor alarms go off every night, this would be very much like having a baby to look after. Being able to sleep undisturbed through the night is crucial to most of us. Relatives in this study report sleeping better after the sensors were implemented. Relatives of patients with dementia who tend to wander around feel more safe and secure that their relatives will be taken care of if needed. This feeling also tends to improve their sleep: relatives living in multi-generation homes report having better sleep quality when they know the patients are looked after by sensor technology. In this case, the alarms tend to give better sleep quality because relatives can rest and let go of worries about whether the patients are wandering around and might fall. To this point, one can say the relatives are feeling safe and secure and get better sleep.

But do the patients with dementia feel safe and secure with the technology when they don't know they are monitored? Some of them will never feel safe and secure no matter what the technology can provide because their illness is at a stage where this is beyond their concern. In this case, the technology can help the healthcare giver to meet a patient's needs from the moment they occur and this may lead to the next of kin feeling safe and secure

that their relatives are taken care of in a proper way. But the patients themselves will hardly notice why they receive help in the moment they fall or rise to get out of bed. Another important question is whether they would want this solution if they knew of it.

So far, all technological solutions need power to work; if technological solutions don't have any backup power, they will be turned off after a storm or when someone accidentally destroys a cable. In healthcare, this needs to be paid proper attention to; one needs to know what to do when technology fails, because it will sooner or later.

Before jumping to the conclusion that both patient and next of kin feel more safe and secure, there is a need for a broad discussion about whether this is a solution that the patients wish for themselves and welcome for use in their own life. One must pay attention to the skepticism noticed among elderly people, who tend to respond that it might be useful for someone else but not for them Thielke et al. (2012). This might be a polite way of telling us that this is something they don't want to be used in their home. It is also important to discuss whether a longer life is necessarily a better life. Individuals seek to meet their needs differently; some want to be as healthy as possible and put safety and the feeling of being safe and secure above nearly everything else, while others tend to seek independence which implies insecure situations. The AT used in this study was introduced to frail, elderly people who had accidentally had a fall, got lost by wandering, or encountered other risky situations and this made their next of kin feel insecure on their behalf. This might present an easy argument for a decision to use sensor technology to monitor all patients so it won't happen again. We must recognize that AT can feel like a technological prison for people who usually do as they please in their own home. Thielke et al. (2012) have argued that AT in general does not yet meet what the patients seek; as it is described by elderly as not what they want for themselves, but something that may be useful to someone else. Some elderly who tend to be insecure and anxious might welcome this technology more than others who rarely get that feeling.

The same arguments can be made for people who have responsibility for someone else, whether they are healthcare providers or next of kin. Taking risk in one's own life is something one does all the time and is closely connected to the feeling of being independent as a human. The technological solutions must seek to still give this feeling of independence, even when using sensor technology. If the individual being taken care of can still manage and make real use of the technology to live more independently, that is a reasonable situation if one wants to live at home. Some elderly argue that living at home is the most important. However, being frail and old might be different from what we imagine; a lot of elderly seem to appreciate getting company, and tend to seek satisfaction of social needs by staying in nursing homes. Some even get more active because they are not alone. In Norway, these institutions are not being prioritized;

nursing homes tend to be inhabited by patients who are very sick and fragile and who often suffer from cognitive failure. This might make sensor technology useful for the healthcare providers in nursing homes.

More and more people in Norway tend to buy their own flats to manage better when growing older. This trend might open up for installing and using technologies in ways that have not yet occurred to the developers. Smartphones can take care of a lot of needs as long as you manage to program or install what you want on them. An example is controlling heat and blocking out the sun in a home; this is more common today and something many people manage on their own. Nearly everything can be regulated by sensors, and if this is how one can manage everyday life, why not use it in care when getting fragile and old? Sensor floors in flats may send a message if you stay there more than an hour and might not even feel intrusive if you install them yourself. Chan et al. (2008) stress the need to meet the individual needs of each person when installing assistive technology and they underline the need to consider the legal and ethical problems in this context. In Norway, the regulations were changed to allow use of sensor technology in elderly care. This change was made during the project period, and there is a need to follow this developing process further to be sure ethical challenges are properly solved. Digital security and the use of ICT for a simpler working day are intended to both streamline work processes and protect individuals White Paper no. 27 (2015 - 2016). We must also consider and discuss further whether loneliness is a private problem, or a healthcare problem to be taken care of. If we accept it as a healthcare problem, nursing may be able to discover if this is caused by sickness and if not, nursing might not be the right treatment.

6 CONCLUSIONS

Better sleep quality is a key reason for installing sensor technology in nursing homes and home healthcare services, according to the next of kin in this study. Sleep quality has an effect on a person's health conditions and everyday life. Our results need to be confirmed through further studies because the number of participants was low. The question of when and if a patient or next of kin is feeling safe and secure is one perspective. However, both earlier studies and this study implies that use of sensor technology lead to the next of kin's feeling of keeping their relatives safe and secure during night. Also, the importance of being able to sleep undisturbed is of utmost importance for the health of both patients and their next of kin. Regarding Maslow's pyramid these basic needs for sleep and feeling safe and secure can be met to a certain extent by using sensor technology to look after the elderly at night. This also seems to help some patients, and/or their next of kin, to maintain a higher level of self-care. The question of whether to apply digital surveillance to achieve healthcare quality and efficiency needs to be solved, especially when people who need AT

care can't commit voluntarily to its use. Technology is not the only challenge for dignity in elderly care; but if it used in a way that the patient or the next of kin finds suitable, it may actually protect dignity. In a few years, this might actually not be regarded as an ethical issue any more.

Author contributions

LIMH was responsible for the study's conception and design, performed the data collection and data analysis, and drafted the manuscript. MF and CEM participated in data analysis and made critical revisions of the paper.

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