GPS-tagging devices in dementia care: new tasks, responsibilities and competencies

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Abstract. This paper addresses the use of GPS-tagging devices in dementia care in a Norwegian context. The paper is based on empirical data drawn from two sources: the "EFFORT" project and the ongoing "Safe Tracks" research project. The results show that the use of GPS-tagging has important implications for the actors involved. Both the persons with dementia and family carers report on improved safety and increased independence. These findings are in accordance with the expectations expressed in current policy documents, which opens up for increased use of GPS and other telecare technologies in a dementia care setting. The focus of this paper is on the key role of family carers in relation to the implementation of the GPS tagging device. The research findings show that in order to make the new technologies work, family carers are assigned new tasks and responsibilities. The critical issue raised in this paper is that many family carers do not have the necessary capacity, skills and competencies needed in order to take on these tasks. And in addition, not all persons suffering from dementia have someone to do the tasks for them. In this is the acknowledgement that the introduction of GPS tagging devices in dementia care is not a trivial matter, which calls for a nuanced understanding of the challenges posed by the introduction of new technologies to dementia care.

Keywords. Dementia care, GPS-tracking, new tasks/responsibilities, competence.

1. Introduction

Dementia is a progressive disorder that affects all aspects of cognitive functioning, including memory and orientation, and has profound effects on the ability to perform activities of daily living. In Norway today, most people suffering from dementia live at home during the early stages of the illness, and then, as their condition deteriorates, they move to a nursing home. The move from the home to an institution is often necessary because of concern for the person's safety and security.

A major risk-factor related to dementia is wandering. As the illness progresses, many suffer from memory-lapse or disorientation, and may have problems finding their way back home when outdoors. There are therefore a number of searches for people with dementia every year in Norway, and not all have a happy ending. Therefore, wanderers who are considered at risk of getting lost are often moved to the sheltered (locked) units of the nursing home. However, for many, this is not a wanted solution. Being outdoors, using the body and experiencing nature may be one of very few activities left for those in the middle or more advanced stages of the illness. On the

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other hand, institutional care is also very expensive, and requires a lot of personnel-resources.

Currently, the Norwegian health authorities are in the process of allowing the use of a GPS-tracking device in dementia care. A GPS-tragging device consists of a small device which the person suffering from dementia is to wear while being outdoors. The device is linked to a satellite positioning system[2], which makes it possible for persons with approved access to a digital map, to locate the whereabouts of the person wearing the device.

The GPS-tagging device is only one example of new technologies targeted at the frail elderly in Norway these days. Other examples are automatic door alarms, fall detectors and other forms of automatic monitoring that will send an alarm to a call center or family carers in the case of an emergency situation. These technologies are often referred to as 'telecare technologies', and in Norway they are introduced as a part of a State-financed plan for dealing with the consequences of the ageing of society. The overall aim of the investment in telecare technologies is to enable more cost- and labour efficient health- and care services, which, it is argued, will be necessary in order to meet the expected high increase in demands for services. In the public rhetoric about the advantages of telecare technologies, the focus is often on an expected 'win-win' outcome: not only will the new technologies provide more efficient services, but also contribute to more safety and security, and in this way result in better services.

1.1. Background and state of the art

The focus on new technology in care is a part of a broad international trend. In a number of countries public plan documents and deliberations refer to the demographic and economic challenges that western society is facing, with the increasing number of old people, expected lack of care personnel and projected higher costs of public health and welfare services. Examples are the report "Building Telecare in England" (2005), the OECD-report "Long-term Care for Older people" (2005), the ISTAG-report Report on "Strategic Orientations for Information and Communication Technologies Research in Europe" (2004) and the Norwegian Government Commission report "Innovation in care" (NOU 11: 2011). The research activity in this field has also been high and in particular over the past decade.[3] In Norway as in many other countries there are currently a number of studies involving the trial of different telecare constellations under way.[4]

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2 GPS is an abbreviation for Global Positioning System. This is a satellite navigation system which was originally developed for military purposes. Today this is a commercial product used for a variety of purposes.

3 Telecare has, for example, been a targeted research area within the European Union since the early 1990's (Thygesen, 2009).

4 There is no complete overview of all ongoing projects in this area. In Norway for example, research on the implementation or testing of telecare technologies is a target area for funding by the Norwegian Research Council and Regional research funds. This is also the case in the other Scandinavian countries. In Denmark a large GPS trial involving five municipalities and 180 persons with dementia was done in the period 2009 until 2011 (for evaluation report see www.trygfecall.dk/mediafiles/safelink/PDFfiler/Slutevaluering-GPS-til-demente.pdf). In the UK there are a number of different studies in this field, such as the KITE-project (Keeping In Touch Everyday), where technology and dementia care issues are addressed, including the use of tracking devices. The project is hosted by the Centre of Excellence for Life Sciences in North East England. Another example of a research project that addresses, in more general terms, the ethical implications of implementation of telecare technologies, is the EU financed EFFORT-project (Ethical Frameworks for Telecare Technologies for Older People at Home). The project was completed in 2011 (see www.lancs.ac.uk/effort for more information). Other research projects specifically addressing the issue of GPS-tracking in dementia care is Pot et al's pilot study (Pot et al, 2011).

1.2. The empirical basis of this paper

The paper is based on empirical data from two projects: the EU-funded EFFORT project[5], where the use of GPS in dementia care was one of several case studies, and the current "Safe Tracks" project[6] which involves the collaboration between five Norwegian municipalities and the independent research organization SINTEF. This project is funded by Norwegian Regional Research Funds.

For the EFFORT-project case study family carers who had experience with GPS tagging devices were interviewed. In the "Safe Tracks" study GPS tagging devices has been implemented as a part of formal care provision in the five municipalities in 2012. In this period a total of fifty-five persons with dementia and their family carers have been involved in the study.

2. Methods

The research has been based on a qualitative design in order to gain the necessary in-depth knowledge. Thus semi-structured interviews, focus group interviews and questionnaires were used for systematic data collection. The interviews were both targeted at the person suffering from dementia (when possible) and on family- and formal carers. Focus group interviews were used to supplement individual interviews, and for purposes of discussing and exchanging information between the actors involved. All interviews were audiotaped, given an informed consent from the participants.

3. Results

> *My husband got his [dementia diagnosis] nearly five years ago. He has always been going for long walks. The problems came after a while. There were some episodes when he got lost, and once he nearly froze to death. (...) After a while he started to wander also at night, and for a period I was out looking for him almost every night. It was a nightmare for both him and for me. (...) This was when I got this GPS, and I have to say that it was like getting a new life for us both. All the suddenly I could join the choir again and start going to the gym. And my husband started to go to the dances regularly, which he had not done in many years.*[7]

This quote, which is taken from one of the interviews with a family carer, shows the impact of the use of the GPS device on her and her husband's lives. Clearly, through the use of the GPS device a new way of life is made possible, as both of them can resume leisure activities. For the family carer, using the GPS device means that she

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5 EFFORT is an abbreviation for "Ethical Framework for Telecare Technologies", and where the target group was old people living at home. the project was a collaboration of researchers from the Netherlands, Spain, the UK and Norway and was completed in 2011.

6 "Trygge Spor." See www.sintef.no/Projectweb/Velferdsteknologi/Trygge-spor/ for more information

7 All personal details of the interview has been changed in accordance with research-ethical guidelines.

does not have to be present, together with her husband at all times, as the GPS device makes it possible for her to locate his whereabouts at any time. Increased independence and possibility of living a more active lifestyle are effects reported by many people with dementia and their family carers participating in the "Safe Tracks" study.

In the following we will however go beyond these results and focus on one aspect of GPS tagging implementation that in our experience get little attention in the public debate about the advantages of telecare technologies: the work and skills required to make these technologies work. And as stated in the introduction to this paper we will focus our attention of this paper on the role of family carers. In order to do so we will introduce more quotes taken from interviews with family carers.

3.1. New tasks

> *"It was a challenge to get him to take it [the GPS device] with him. I found a small pouch for a mobile phone with a key-ring. He still remembers to lock the door. It was a routine I knew he still had. And he takes it [the GPS device] with him 80% of the time. But then the pouch was too thin I found. Because when he had it in his pocket he pressed the button by accident, so it switched itself off. So I bought a new pouch with a key ring."*

This quote, which is taken from another interview with a family carer, shows some of the complexity related to making the GPS device work for her husband. Her situation is that she is working and away from home for parts of the day, and therefore has to find creative ways of ensuring that her husband takes the GPS with him on his long daily walks, and that the device does not accidently switch itself off. However, these are only two of several tasks involved. For the GPS device to work the batteries needs to be charged. And someone also needs to log into the computer or smart-phone in order to locate her husband's whereabouts. These are all tasks that need to be done on a regular or even daily interval, because otherwise the GPS device will not work as intended. And all of these are examples of tasks that usually are performed by family carers.

3.2. New responsibilities

> *"By using the GPS I am given more responsibilities. I am responsible for the GPS being charged, because if it is not, and he goes for his walks and the battery goes flat, it is my fault if something happens. And it is up to me to find a solution that ensures that he takes it with him. So it is not just about the GPS device itself. There are problems with pockets, zips and jackets. And this is supposed to function together with the equipment [the GPS]."*

In this quote the family carer reflects on the implications of the use of the GPS device. Clearly, if the tasks involved in making the GPS work are not met, the technology will not work, which means that it will not offer any protection or safety for the person suffering from dementia. The consequence is that new forms of responsibilities are put on family carers.

3.3. The requirement of new skills and competencies

Following on from this, it is clear that the new tasks and responsibilities require certain skills and competencies. For example, competencies are needed in handling the GPS equipment. Charging batteries, switching the device on, and logging on to internet to locate the person who wears the GPS device are tasks that require basic computer-skills. Many family carers have very limited experience in using computers, so although the technology may be simple and user friendly, it may still prove to be a barrier. And importantly, also other skills and competencies are needed that relate to the physical and mental capacity of the family carers involved. The establishments of routines for charging batteries, or ensuring that the person wears the GPS while outdoors require a good memory, the capacity to plan and the ability for creative problemsolving.

Our research shows that many family carers do not have these skills and competencies. And for many, the requirements of the new technology, such as the GPS tagging device, come on top of an already heavy care-burden.

4. Conclusions

In concluding, we will like to emphasize the positive potential of new technologies, such as GPS tagging devices in dementia care. In this paper, which is based on empirical research studying the implementation and use of GPS devices in dementia care in Norway, we have focused especially on the role of family carers in making the new technologies work as intended. Drawing on excerpts from interviews with family carers we have shown that although the use of GPS tagging devices gives both the person with dementia and family carers opportunities for more independence and increased safety, there are also certain requirements that have to be in place. Family carers play a key role in performing the tasks required in order to make the technology work. These tasks involve the establishing of routines for charging the batteries and for ensuring that the person brings the GPS device when outdoors. In the delegation of these tasks to family carers there are also new forms of responsibilities involved, because if the technology does not work, it will not offer the necessary protection and safety for the person suffering from dementia.

In practice this means that telecare solutions, such as GPS tagging devices, also have its limitations. The technology does not work on its own. Many tasks and functions cannot be delegated to the technology alone. And as we have shown, someone must therefore take on these tasks that make up the preconditions for the technology to work. Many of these tasks are left for formal carers to do. The bottom line of our argument is that many family carers do not have the skills and competencies needed in order to take on these tasks and responsibilities. And not all persons suffering from dementia have someone who can take on the tasks and responsibilities.