

# Persons with Dementia and Their Caregivers Using GPS

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**Abstract.** The aim of the study is to generate knowledge on the use of Global Positioning Systems (GPS) to support autonomy and independence for persons with dementia. By studying a larger cohort of persons with dementia (n=208) and their caregivers, this study provides essential knowledge for planning and implementing GPS technology as a part of public health care services. Commercially available GPS technology was provided to the cohort of 208 persons with dementia from nineteen different Norwegian municipalities. The participants used GPS when performing outdoor activities as part of their daily life during a period of time between 2012 and 2014. Their family caregivers were instructed on how to use the GPS technology for locating the participants. The study documents that using GPS for locating persons with dementia provide increased safety for the person with dementia, their family caregivers and their professional caregivers. Furthermore the results confirm that by using GPS, persons with dementia may maintain their autonomy, enjoy their freedom and continue their outdoor activities despite the progression of the disease. Preconditions for successful implementation are that health professionals are trained to assess the participant's needs, that ethical dilemmas are considered, that caregivers have adequate knowledge about using the technology and that procedures and routines for administrating the GPS and locating persons with dementia are established. Early intervention and close collaboration between persons with dementia, family caregivers and professional caregivers are important for successful implementation of GPS in public health care.

**Keywords:** Dementia, GPS, locating persons, electronic tracking

## Introduction

Dementia is a global public health challenge and is one of the major causes of disability and dependency among older people [1]. Dementia also has a significant impact on the

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lives of each person affected and might cause a profound burden of care on their families [2].

Dementia is a collective term for a number of progressive disorders that affect memory, thinking, orientation, behaviour, speech and the ability to perform everyday activities. The number of persons suffering from dementia worldwide is currently estimated to be 35.6 million, and is expected to double by 2030 and more than triple by 2050 [1].

Wandering and getting lost is common among persons with dementia during all stages of the disease, and may have fatal consequences [3]. Mobile technology and Global Positioning Systems (GPS) are commercially available, and may provide safety by locating the person being lost. Subsequently, this will mean freedom for persons with dementia to continue their outdoor activities [4,5].

In our literature review we identified two systematic reviews of wandering behaviour [6,7]. No randomised controlled trial of electronic tracking was found [8]. However, we found some intervention studies [8,9,10,11] and a recent case study [5] describing the effects tracking technology has on the daily life of persons with dementia. The majority of these studies include a limited number of participants with dementia. Additionally there is a lack of research providing knowledge on how tracking technology for persons with dementia could be implemented as part of the regular public health care services [4].

The aim of the study is to generate knowledge on the use of GPS technology to support outdoor activities and autonomy for persons with dementia. By studying a larger cohort of persons with dementia (n=208) and their caregivers, this study provides essential knowledge for planning and implementing GPS technology as a part of public health care services.

## **1. Method**

### *1.1. Research Design*

Mixed methods research designs were applied, combining elements of qualitative and quantitative research approaches for the broad purposes of breadth and depth of understanding and corroboration [12]. A combination of qualitative and quantitative viewpoints, data collection, analysis and inference techniques provide informative, complete and balanced research results [12]. Qualitative research methods were considered appropriate to study how people with dementia and their caregivers experienced using GPS when performing outdoor activities. Quantitative data from questionnaires provided demographic information describing the cohort of persons with dementia and their caregivers using GPS.

Persons with early stage dementia have been involved throughout the study. They have participated in individual interviews or focus group interviews. For participants with more severe dementia, experiences were collected from their caregivers. All participants have provided highly valuable and important personal experiences.

### *1.2. Intervention*

The target groups for the intervention have been persons with dementia or reduced cognitive function, their family caregivers and professional caregivers. During a period of 3 years, 208 persons with dementia or reduced cognitive function which affect orientation ability were identified, assessed and recruited by professional caregivers as part of the public health care services in nineteen different Norwegian municipalities. Persons with dementia living at home or at nursing homes/ residential care were both included. Those living at home were either living alone or together with their next of kin. Some of the participants living at home were receiving services from home-based care, while other did not receive any services at all. Participants living at nursing homes had access to 24-hours care.

The majority of the participants and their caregivers had no prior experience with using GPS for locating persons with dementia. Commercially available GPS technology for this purpose, from Safecall<sup>2</sup> (156), Safemate<sup>3</sup> (23), Careto<sup>4</sup> (21) and others (8) were provided to the participants depending on individual needs and the policies and priorities in the respective municipalities.

The suppliers trained the professional caregivers in using the GPS. The professional caregivers carried out the individual assessment of all participants and provided the necessary training, support and follow up to participants and their family caregivers. In one municipality, professionals from the collaborating alarm centre conducted the training and technical follow up of the family caregivers.

### *1.3. Data Collection*

Quantitative data from questionnaires and qualitative data from semi-structured interviews, focus group interviews, discussion groups and home visits were used for systematic data collection. Interview guides were developed for the different target groups on the basis of prior knowledge. Interview guides were designed for family caregivers and person with dementia. They were interviewed at baseline, before the person with dementia started using the GPS, and after they stopped using it or alternatively at the end of the study period. If possible, both the person with dementia and the family career were interviewed separately, elsewhere they were interviewed together. A separate interview guide was designed for focus group interviews of professional caregivers from seven municipalities. They also attended project meetings where discussions were held and experiences exchanged. Additional questionnaires reporting on the use of GPS were filled in by family caregivers and by professional caregivers when returning the GPS or at the end of the study period. When possible, persons with dementia also filled in the questionnaires.

Individual interviews and focus group interviews were audio-taped. Data analyses started together with the data collection, being an iterative process. The data was coded into given categories in a hierarchic structure and analysed.

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<sup>2</sup> [www.safecall.dk](http://www.safecall.dk)

<sup>3</sup> [www.safemate.no](http://www.safemate.no)

<sup>4</sup> [www.careto.no](http://www.careto.no)

#### 1.4. Ethical Considerations

Informed consent of participation in the study was obtained from the participants or by proxy from their caregivers. Ethical clearance was approved by the Regional Committees for Medical and Health Research Ethics (Reference 2010/2622-16). Participation in the study was voluntary and the participants could withdraw from the study at any time without giving any explanation. Participants were assured of confidentiality and that their participation in the study would not influence other health care services they might receive. Participants were also assured that they could continue using their GPS beyond the limits of the study, if they preferred.

## 2. Results

### 2.1. Gender and Age Distribution

The gender distribution in the study was; 53% men and 47% women. We experienced that men were more interested in outdoor activities and this could partly explain why slightly more men than women were included in the study.

The average age of the participants when they started using the GPS were 77 years; 76 years for men and 79 years for women. Figure 1 illustrates the age distribution of the participants with reference to defined age groups. The majority of participants were in their seventies or eighties. Largest was the group between 80-89 years of age representing 40% of all participants (n=208). Only 8% were over 90 years and the same percentage goes for people under 60 years of age. Current life expectancy in Norway is 84 years for women and 80 years for men [13], and this may partly explain why average age is higher for female participants than for male participants.

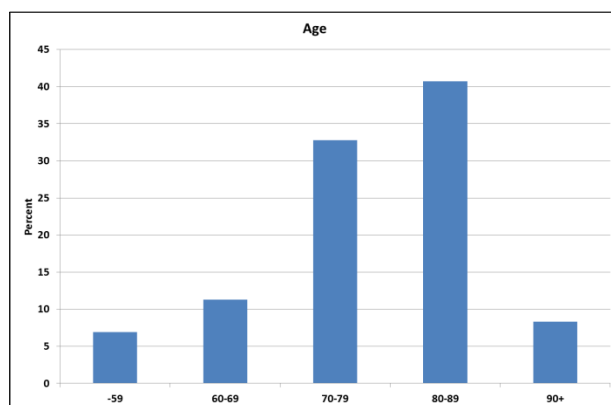


Figure 1. Age Distribution for Individuals with Dementia, n=208, 1,9 % missing.

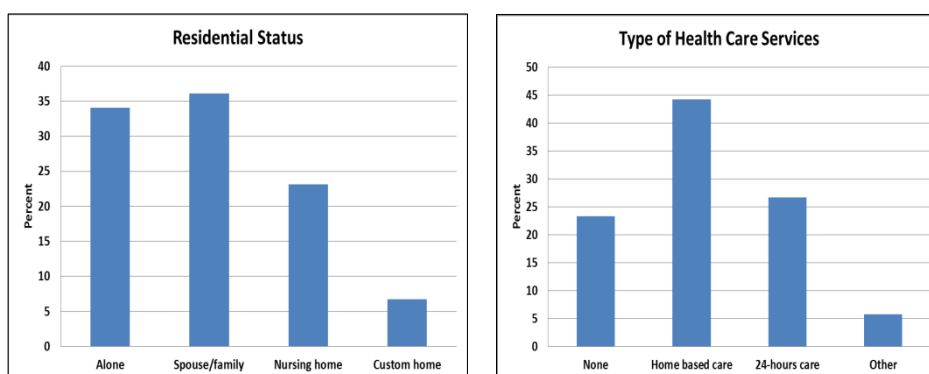
### 2.2. Residential Status and Type of Health Care Services Provided

Norwegian statistics reveal that as many as 80% of residents living in nursing homes are suffering from dementia, but only 50% have been diagnosed [2]. Furthermore, 50%

of all persons suffering from dementia are living in their own home, either alone or with their next of kin [2]. In our study, 68% of the participants had been diagnosed with dementia, mostly Alzheimer's disease. 16% were undiagnosed, but experienced problems with orientation and memory, while 16% had other diagnosis like stroke, Parkinson's disease, brain injury, severe anxiety or memory loss, all of which affect orientation ability.

Figure 2a illustrates the residential status and 70% of participants lived in their own homes, either with or without their next of kin. For the majority of participants their spouse/partner was their next of kin, while some stayed together with their children or other relatives. 34% of the participants lived alone in their home. Many of those received home based services and had family members in their neighborhood. 30% of the participants lived at an institution, either a nursing home or at a custom home like residential care facility.

Figure 2b illustrates what type of health care services participants were receiving from their local municipalities. 23% of the participants were living at home without any assistance or services from professional caregivers. They were either managing on their own or being cared for by their next of kin, often being the spouse. About 44% of the participants received home based care by professional caregivers. 26 % of the participants had 24-hour care available. 26 % of the participants had 24-hour care available.



**Figure 2.** (a) Residential Status; Participants living at home alone or at home with spouse or family, at institutional care like nursing home or at custom home like residential care. (b) Type of Health Care Services and assistance provided to the participants. n=208, 1% missing.

### 2.3. Administrating the Use of GPS

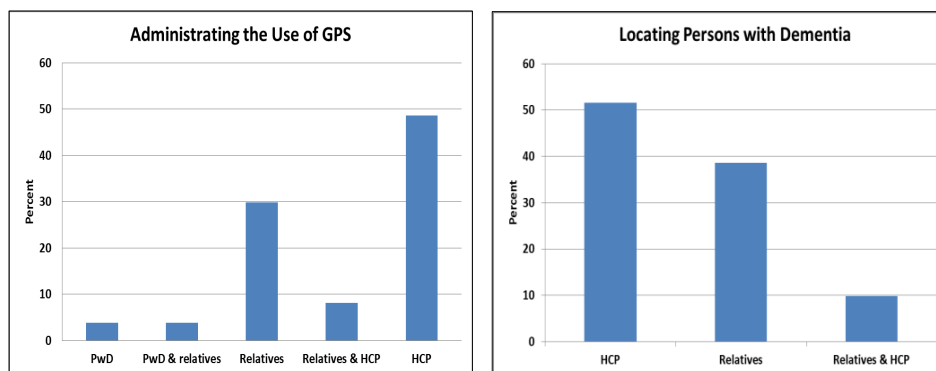
The GPS needs to be charged regularly, depending on the setup and the individual user. As a routine we recommended to charge the GPS every day. It was necessary to establish individual routines for switching on the GPS and ensuring that the person with dementia would bring the GPS along for their outdoor activities. Individual routines and procedures for locating the participants were made in collaboration with the participants and their next of kin. It was important to determine who could locate the person with dementia, who would receive alarms, when to locate the participant and what kind of actions that should be initiated in case it was necessary to search for the

participant or in an emergency situation. Ethical dilemmas and considerations were also discussed in order to ensure the participants privacy.

Figure 3a illustrates who was charging the GPS, switching it on/ off and assisting the participants bringing the GPS along for their daily activities. The health professionals administrating the GPS were caregivers from home based services, nursing homes or daycare centers. Professional caregivers were responsible of charging and switching on the GPS for about half of the participants. For 30% of the participants their family caregivers were administrating the GPS, and about 4% of the persons with dementia were charging the GPS themselves. Some family caregivers and persons with dementia (4%) were also sharing the responsibility. This indicates that almost 10% of the participants were involved in administrating their own GPS. For 8% of the participants relatives were assisted by the professional caregivers in administrating the GPS. The majority of the relatives reported that they managed to administrate the GPS relatively easy, after being trained by the professional caregivers or the suppliers. However, a few family caregivers did not manage to be in charge of administrating the GPS, as they experienced it being stressful.

Figure 3b illustrates that there were slightly more professional caregivers (50%) than family caregivers (40%) that were locating the person with dementia, and receiving alarms. The professionals caregivers were from alarm centres, home based services, nursing homes or day-care centres. In 10% of the cases both family and professional caregivers were locating the person with dementia. Health professionals at alarm centres were entitled to locate the participants and assist in emergency situations, while they were otherwise not involved in administrating the GPS.

Both family caregivers and professional caregivers highlighted the need for a close collaboration between the involved stakeholders, both during assessment and follow up.



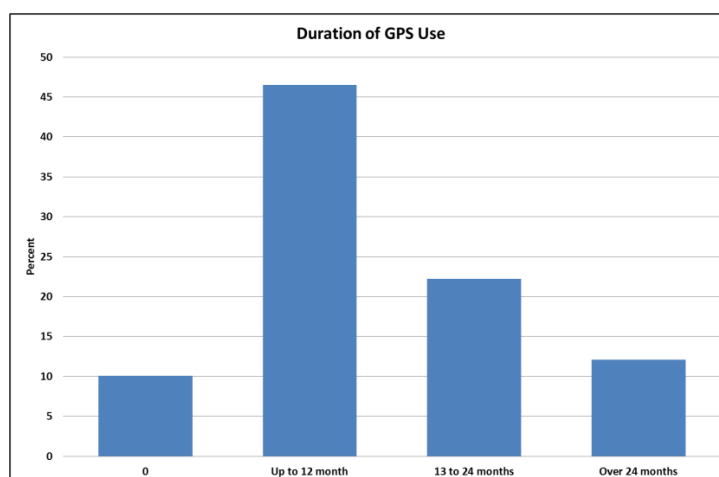
**Figure 3.** (a) Administrating the Use of GPS. (b) Locating Persons with Dementia (PWD); Relatives/ family caregivers or Health Professionals (HCP)/ professional caregivers. n=208, 5,8% missing.

#### 2.4. Duration

The participants used their GPS when performing outdoor activities during a period of time which ranged from one week up to more than two years. About half of the participants terminated using their GPS during the 3 year project period. Figure 4 illustrates that from those who stopped using their GPS, 46% used their GPS up to one

year, 23% used their GPS up to two years and 12% used their GPS for more than 2 years. The duration of time using the GPS, was depending on the physical and mental level of functioning of the participant and the level of support from their caregivers. Early intervention indicates that GPS can be used for longer period time.

The most common reason for termination of GPS use was that the participants were no longer able to perform outdoor activities. Some passed away and others moved to nursing homes that did not facilitate independent outdoor activities. 10% of the participants did not get to use the GPS at all, because their health conditions suddenly deteriorated. A few participants did not want to use the GPS after all, and a few others were not considered as "safe pedestrians" and thus could not go out independently. Being able to take care and handle the traffic when wandering alone was a prerequisite for using GPS.



**Figure 4.** Duration of time the participants used their GPS. n=99, 9% missing.

### *2.5. Impact of Locating Persons with Dementia*

Family caregivers reported that increased safety and freedom for their next of kin were the most important impact using GPS. Some reported that they would have restricted their next of kin to walk alone if they did not have the GPS. "I feel safe when I can locate her if she is not home in time after her daily walk" and "If he is lost, I can find out and meet him" are typical statement from family caregivers.

For persons with dementia, autonomy and freedom to continue outdoor activities were highly valued by most participants. It was not experienced to reduce personal contact, but rather the contrary because the participants were allowed to go out by themselves. A caregiver stated that "He just goes down to the café and meet with people before he returns back home". One participant, who stayed at a nursing home for rehabilitation, experienced that the caregivers were not trained to use his GPS and therefore restricted him to go for his daily walks outside alone. When he came home to his family he clearly stated; "I have been to prison. I was not allowed to walk outside, and I will never go back". Both he and his wife felt his autonomy and freedom were

compromised when the professional caregivers restricted him to walk outside instead of using his GPS.

The majority of participants and caregivers reported that they did not experience the person with dementia being monitored or under surveillance. Caregivers explained that locating a participant was only done when necessary and one stated that "I feel like an intruder if I locate without a reason". The persons with dementia expressed orally or by body language that they accepted to bring the GPS along, and many appreciated that their caregivers could meet them if necessary. One participant explained that "Now, safety is more important than privacy". Only a few participants refused to use the GPS and they were not granted a GPS, as illustrated in Figure 4. Some participants reported that they did not need the GPS themselves, but they accepted to bring the GPS in case their next of kin wanted to locate them for their safety.

Administrating the use of the GPS was sometimes experienced to be a challenge, especially for persons with dementia living alone in their private homes, while it was much easier for participants living with their next of kin. It was experienced that technical training of all caregivers was crucial and close collaboration between persons with dementia, family caregivers and professional caregivers were important for successful implementation of services for locating persons with dementia.

Technical challenges occurred from time to time, and despite these challenges the family caregivers made it very clear that "using GPS has made our life easier even though the system is not perfect". Some caregivers indicated that it might enable persons with dementia to remain at home and postpone transfer to institutional care.

### **3. Discussion**

The study includes a larger cohort of persons with dementia or cognitive reduced functioning (n=208) during a longer period of time than previously identified from the literature review.

Caregivers stated that using GPS for locating persons with dementia provided increased safety, and persons with dementia could enjoy their freedom, maintain their autonomy and continue their outdoor activities despite the progression of the disease. Persons with dementia expressed that they appreciated their freedom, and using GPS was considered less intrusive than physical or chemical restraint. A participant considered using GPS as a "safety issue" rather than an "infringement of privacy". These findings confirmed the results from recent studies [4,5], while another study viewed the use of tracking technology as a way of restraining and controlling people with dementia [14]. Our study also documents that using GPS might decrease anxiety and the burden of care of family caregivers, as described in recent case study [5].

In order to obtain safety and freedom for persons with dementia we experienced that there are some preconditions to be fulfilled. Professional assessment of users' needs followed by thorough discussions about ethical dilemmas and how to identify the least intrusive intervention were reported to be important for successful implementation. This should be an integrated part of the services, as indicated by the pilot study [4]. Questions about informed consent were frequently asked by professional caregivers, and there is a need for formalising procedures and guidelines that comply with legislations and regulations and the legal rights of person with dementia.

Furthermore ensuring that family and professional caregivers possess sufficient knowledge and information about the use of GPS technology for locating persons with



dementia is pivotal. Access to technical support and knowledge were also echoed from previous pilot study [4], and reported to be key factors for implementing sound and safe technologies and services. Close collaboration between family- and professional caregivers were experienced to be of mutual interest and facilitated administration of the GPS and follow up of the participant. Professional caregivers could assist the relatives and relief their situation, while relatives could be an important resource supporting the person with dementia.

The emphasis on inclusion, independence and empowerment of individuals with dementia [15] and their families are reflected throughout the study.

#### **4. Conclusions**

The data obtained from the study provides demographic information and highly valuable knowledge for planning and implementation of technology for locating persons with dementia as integrated health care services.

The study confirms that using GPS for locating persons with dementia provided increased safety for persons with dementia and their family- and professional caregivers. Furthermore it confirms that by using GPS technology persons with dementia can maintain their autonomy and continue their outdoor activities despite the progression of the disease. This means that they can thereby enjoy their individual freedom and independence. Both family- and professional caregivers experienced that being able to locate persons with dementia made daily life easier; they were less anxious, more secure and felt they could better cope with the situation, and it was not experienced to reduce personal contact. Using GPS for localisation might enable persons with dementia to remain at home and postpone transfer to institutional care.

Preconditions for successful implementation are that health professionals are sufficiently trained to assess the participant's needs, that ethical dilemmas are considered, that caregivers have adequate knowledge about using the technology and that procedures and routines for administrating the GPS and locating persons with dementia are established. It is further experienced that early intervention and close collaboration between persons with dementia, family caregivers and professional caregivers are key factors for success.

More research is needed in order to document possible long term effects and consequences of implementing technology for locating persons with dementia as integrated health care services.

#### **5. Acknowledgment**

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