Daily life of persons with dementia and their spouses supported by a passive positioning alarm
To my beloved Niklas and our children Sebastian and Christoffer
Daily life of persons with dementia and their spouses supported by a passive positioning alarm
© Annakarin Olsson, 2013

Title: Daily life of persons with dementia and their spouses supported by a passive positioning alarm.

Publisher: Örebro University 2013
www.publications.oru.se
trycksaker@oru.se

Print: Ineko, Källered 04/2013

ISSN 1652-1153
Abstract


The overall aim was to describe how persons with dementia (PwDs) reflect on being outdoors and to investigate the support provided by a passive positioning alarm (PPA) in making daily life safer for PwDs and their spouses.

Repeated conversations were held with 11 PwDs living in their own homes regarding their reflections on being outdoors (Study I). Interview study with 14 spouses to a person with dementia (PwD) with their reflections on different kinds of information and communication technology (ICT) devices that were used or can be used in the daily care of PwDs (Study II). An ethnographic approach with participant observations and conversations with five couples, a PwD and his/her spouse, describing and exploring their use and experiences of using a PPA, over time, in daily life (Study III). An experimental single-case ABAB-design with three cases, a PwD and his spouse, investigating the effects of using tracking technology on independent outdoor activities and psychological well-being (Study IV).

In summary, the results of the thesis show that being outdoors was described by the PwDs as a confirmation of their identity, the ‘Self’. The use of ICT in daily care of PwDs was described by the spouses as shifting between their own needs for safety and security and the perceived need for safety and security from the perspective of the PwD. The use of a PPA in daily life among PwDs living in their own homes can give a sense of freedom, support and strengthen the feeling of independence for both PwDs and their spouses as well as give a feeling of safety and security for them both. Use of the PPA may also increase PwDs’ independent outdoor activities and decrease spouses’ worries.

Keywords: Information and communication technology (ICT), person with dementia (PwD), spouses, outdoor activities, experimental single-case, interviews, participant observation, qualitative research, passive positioning alarm (PPA).

Annakarin Olsson, School of Health and Medical Sciences, Örebro University, SE-701 82 Örebro, Sweden, annakarin.olsson@hig.se
CONTENTS

ORIGINAL PAPERS ................................................................. 9

ABBREVIATION ........................................................................ 10

INTRODUCTION ........................................................................ 11

BACKGROUND ......................................................................... 12
Living with dementia .................................................................. 12
   Social Construction Theory .................................................. 13
   Dementia diseases .............................................................. 14
Being a relative to a person with dementia ................................. 15
Information and communication technology in healthcare .......... 17
   Ethical aspects of using tracking technology in dementia care .... 18

RATIONALE ............................................................................ 20

AIMS ....................................................................................... 21

METHODS .............................................................................. 22
Design .................................................................................... 22
Sample and setting .................................................................. 23
The intervention ...................................................................... 25
Data collection and procedure .................................................. 28
Data analysis .......................................................................... 32
Ethical considerations .............................................................. 34

SUMMARY OF RESULTS ...................................................... 35
   Study I .................................................................................. 35
   Study II ............................................................................. 38
   Study III ........................................................................... 41
   Study IV ............................................................................ 42

DISCUSSION ........................................................................... 45
   Summary of main findings ................................................... 45
   The value of being outdoors for persons with dementia .......... 46
   Problems and strategies related to being outdoors:
      perspective of person with dementia and spouses .............. 47
   Value and ethical aspects of the passive positioning alarm (PPA).... 49
   Development of the PPAP ...................................................... 50
Research ethics ........................................................................ 52
Methodological considerations .................................................. 53
Trustworthiness ....................................................................... 56
ORIGINAL PAPERS

This thesis is based on the following original papers, which will be referred to in the text by Roman numerals.


Reprints have been made with the permission of the publisher.
### ABBREVIATION

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD</td>
<td>Alzheimer’s Disease</td>
</tr>
<tr>
<td>GPS</td>
<td>Global Positioning System</td>
</tr>
<tr>
<td>ICT</td>
<td>Information and Communication Technology</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini Mental State Examination</td>
</tr>
<tr>
<td>PwD</td>
<td>Person with Dementia</td>
</tr>
<tr>
<td>PwDs</td>
<td>Persons with Dementia</td>
</tr>
<tr>
<td>PPA</td>
<td>Passive Positioning Alarm</td>
</tr>
<tr>
<td>PPAP</td>
<td>Passive Positioning Alarm Package</td>
</tr>
</tbody>
</table>
INTRODUCTION

The point of departure of the present thesis is a collaborative project between the University of Gävle, the municipality and a small business manufacturer. The aim of the project was to develop a passive positioning alarm (PPA) to support daily life for persons with dementia (PwDs) living in their own homes and their spouses.

For some PwDs, the value of being outdoors has been shown to lead to increased well-being and enhanced quality of life. However, for a PwD, spending time outdoors independently may demand some support, due to symptoms accompanying the disease, e.g., memory loss. Use of information and communication technology (ICT) could be a way to support both PwDs and their spouses in terms of their feelings of safety and security. The use of ICT could also enable PwDs to remain in their own homes longer. It is predominately the perspectives of relatives and health care staff that have been described in previous research on experiences of using ICT. Therefore, the PwD’s perspective has been important to include in the present thesis.

My experience, in both Sweden and Norway, of working as a nurse with older people and PwDs and my experience of working as an engineer with Geographic Information Systems are what piqued by interest in doing this research.

‘Either write something worth reading or do something worth writing.’

Benjamin Franklin 1706-1790
BACKGROUND

Living with dementia

Dementia results in some or several losses of a person’s abilities, and the inevitable progression of the disease will increase these losses. However, the progression of the disease follows a unique course for each person. Eventually it is fatal (1).

PwDs’ own experiences of living with the disease involve descriptions of being forgetful, feeling lost in a ‘strange and unfamiliar world’, less personal dignity and value, experiencing regret and sadness as a consequence of the disease (2-6) and of limited value to society (7). In an interview study by Steeman et al. (8) PwDs reported that their activities slowed down, meaning that simple everyday tasks were experienced as very demanding and as hovering between being of value and being worthless. A meta-synthesis of qualitative studies (9) revealed that memory loss as a consequence of the dementia disease threatened PwDs’ perceptions of security, autonomy and being a meaningful member of society. Memory impairments resulting from the disease were difficult to deal with and caused frustration, uncertainty and fear (9-12). Problems with memory and decline in cognitive abilities have also been shown to lead to wayfinding difficulties, such as not finding one’s way back home while outdoors (13).

Several negative aspects of living with dementia have been revealed, however factors that have a positive influence on quality of life and well-being among PwDs include, e.g., being outdoors (14,15) and having social contacts (10,16-18). Being outdoors in a natural environment has been shown to have a direct and positive impact on humans’ well-being (19-21). In their theory, Kaplan and Kaplan (22) emphasize that natural environments are particularly rich in the characteristics necessary for restorative experiences. The benefits and experiences of being outdoors for PwDs have mainly been described from the perspective of staff at residential homes for PwDs, where being outdoors was reported to be valuable in, e.g., decreasing aggression and improving socialization (20,23,24). However, some interview studies with persons living in their own homes (14,15) have revealed that being outdoors was seen as valuable for emotional well-being, interacting with other people and maintaining quality of life. In their interview study with PwDs and their spouses, Cedervall and Åberg (25) found that physical activity, e.g., walking, seemed to be an important routine in everyday life, and one driving force behind taking walks was enjoyment of nature and physical exercise. The benefit of phys-
Physical activity has also been shown to be valuable in delaying or preventing the onset of common chronic diseases, such as dementia (26-29). Research has also shown that keeping up social contacts is beneficial and that it is perceived by PwDs as valuable (16-18). Moreover, Cahill et al. (30) found that contact with other people was seen as a major source of well-being for PwDs. Despite the impact of dementia and the experiences of loss resulting in multiple “destructive” emotions (31-33), PwDs do not approach the disease passively (34), but use both emotion-oriented and problem-oriented coping strategies to deal with its challenges (5,6,31,35-37). However, loss of some abilities – e.g., difficulties in communicating and engaging in meaningful social activities (16-18) – may result in loss of independence (38) and thus affect the person’s identity.

Social Construction Theory
According to Rom Harré’s Social Construction Theory (39), a person’s selfhood can be expressed in terms of three selves: Self 1, 2 and 3. Self 1 refers to one’s experiences of psychological continuity and is manifested in the use of personal pronouns; I, Me, My and Mine. These pronouns are used to locate for others the sources of our attitudes, beliefs and experiences (cf. 40). Self 2 refers to one’s past and present attributes, beliefs and one’s beliefs about one’s attributes. These attributes might include abilities, physical and psychological characteristics that one is particular proud of, e.g., being a happy, positive person, or does not like, e.g., having a dementia disease (39). Finally, Self 3 is the public personae manifested with the help of others in our social world (40,41). Through narratives, we tell our life stories, what we believe, think and what we are (I am). In a recently published interview study by Hedman et al. (42), aimed at describing how persons with AD express their sense of self, the persons with AD described Self 1 as being intact (cf. 43), that Self 2 had undergone changes (cf. 44) and Self 3 as being supported by others, but sometimes exposed to malignant positioning (cf. 41,43,45,46). Kitwood (47) also considers that PwDs do not lose their personhood, and maintain it through their relationships with other people. Within the concept of person-centred care, the personal and social identity of a PwD is partly formed by what is said and done to them (cf. 40). Findings from MacRae (48) indicated that persons with AD revealed no concerns for the potential loss of their self. A systematic review by Cadell and Clare (44), however, showed variation in conclusions regarding whether or not PwDs had a sustained self during the progression of the disease. Qualitative interview studies with PwDs included in the review revealed that they perceived a sustained self, but this was not confirmed in some quantitative studies.
However, in their interview study with 10 persons with early-stage dementia, Caddell and Clare (49) found that the PwDs’ self was marked by a tension between a prior sense of self and perceived changes to it.

**Dementia diseases**

Dementia is not a disease itself, but an umbrella term for a group of diseases (1). At present, approximately 36 million people are suffering from different kinds of dementia diseases worldwide (50), and the most common form is Alzheimer’s disease (AD) (51,52). Dementia is a mental deterioration that affects the brain, with typical symptoms including impairment of memory, thought, perception, speech, spatial ability and reasoning, and it usually involves having more than one of these symptoms (53). Dementia diseases are progressive and chronic (54), but can be treated with medication to slow down their effects (55,56). All PwDs are not helped by pharmacological treatments, which stress the need for non-pharmacological treatments in the context of care (57-60). Memory problems are very common in all dementia diseases, but are the hallmark of AD (61), resulting in the person forgetting recent conversations, repeating themselves and/or having difficulty making decisions.

Dementia diseases do not only affect older persons, but also younger people (aged > 65 years), in which case daily life might still involve living with the family, having younger children, employment and economical responsibilities for a family (62). Thus, younger PwDs have other needs, in addition to struggling with the same challenges as older PwDs (63-65).

There are various stages of dementia, each of which can be classified as mild, moderate and severe (66). Mild dementia, sometimes mentioned as early stage dementia, usually means that the person is able to manage most of his/her daily life, with support from relatives. As the condition progresses to the moderate stage, the person will need more help in managing daily activities such as eating, washing, dressing and using the toilet (67). During the severe stage, the person becomes extremely dependent on others around them for support in managing daily life (68,69) and, during this stage, many are forced to change their living situation (70,71).

The Swedish healthcare system for the living situation of PwDs is organized in units for short-time care or in residential homes for PwDs (72). The municipalities offer daytime activities, which vary in organization and extent, for older and/or disabled people in need of stimulation and rehabilitation, regardless of their living situation (73). Older persons with disabilities living at home can, after needs assessment, receive assistance around the clock (home-help service), which means that many can remain at home their entire life (74).
Given the decreased number of places in units for short-time care and in residential homes for PwDs (73), the trend in Sweden is that most PwDs remain living in their own homes for a long time, alone and/or together with a relative. Therefore, becoming dependent on others to manage daily life is a reality for many PwDs.

**Being a relative to a person with dementia**

Living with a chronic disease like dementia can be devastating for those affected and for their relatives (75). Many PwDs wish to, and do continue to, live in their own home, which requires varying degrees of help from their relatives. Research has shown that informal carers are the largest group of people involved in the daily care of PwDs (76), and being a relative of a PwD often means becoming an informal caregiver. The majority of the PwDs living at home are provided with daily care, primarily from a spouse (cf. 75,77). In the present thesis, the concept of spouse will henceforth be used and seen as equivalent to partners (unmarried couples living together).

Daily care for a family member, especially one with dementia, exposes the caregiver to considerable risk of experiencing stress, feelings of burden, poor health, grief and lower quality of life (77-84). The burden experienced by spouses tends to increase as the dementia disease progresses (85), and their life satisfaction becomes increasingly related to the PwD’s state of mind and dependency (86). The amount of time spent on caring for one PwD has been shown to be approximately 10 hours a day for relatives (76). Relatives also tend to sacrifice their own hobbies in favour of taking care of their PwD (87,88). Keeping up with one’s own activities outside the home may also be difficult for spouses, due to, e.g., the risk that the PwD might leave the home unaccompanied. This particular difficulty is often part of the reason for relatives’ feelings of fear and insecurity (89). Being more independent from the person with dementia was shown to improve the relative’s quality of life (90).

The negative aspects of caregiving for persons with dementia (88,91,92) tend to receive most attention, but caring has also been shown to be associated with positive feelings and outcomes (75,93,94). Sanders (95) reported that between 55% and 90% of caregivers had positive experiences of caregiving, i.e., enjoying togetherness, sharing activities, feeling a reciprocal bond, spiritual and personal growth, increased faith, and feelings of accomplishments and mastery.

A quantitative study by Andrén and Elmståhl (96) revealed that a large proportion of caregivers expressed satisfaction, as caregiving provided a new purpose in their lives and they experienced pleasure from seeing that the person being cared for was happy.
As the symptoms of dementia develop, however, many relatives fear that the person they care for will get lost (10,13) and/or become distressed, vulnerable and/or exposed to danger (97-99). According to Swedish regulations (100), it is not legal to deprive PwDs living in residential homes and in units for short-time care of their liberty by using, e.g., locked doors, alarms, etc. Studies have shown, however, that different kinds of physical restraints are commonly used in the care of PwDs (101,102). For PwDs still living in their own homes, locking doors may be a necessary action for relatives to perform, due to the problem of the PwD wandering away from home and/or getting lost (13,103). Concerns that the PwDs may get lost and/or wander away from home may cause informal carers to decide that they can no longer manage to look after the person at home (104). In a study by Wimo et al. (76) relatives reported that a great deal of time is spent on supervision of their PwD, which might mean that the informal carer locks the person in the house, thus restricting his/her freedom (105). The possibility of a PwD getting lost was cited as a major reason why relatives seek residential placement (70,106). Different kinds of support are needed, and one way to meet the needs of PwDs and relatives in daily life might be to use information and communication technology (ICT).
**Information and communication technology in healthcare**

In the present thesis, some technical expressions will be used and these must be defined. Information and communication technology (ICT) is a ‘broad concept’ of technologies enabling people to communicate, gather information and interact with distant services, faster, easier and without the limit of space. ICT is also an umbrella term that includes communication devices or applications encompassing: radio, television, cellular phones, computer and network hardware and software, satellite systems and so on, as well as the various services and applications associated with them, such as videoconferencing and distance learning (107). Assistive Technology (AT) was cited by the US Assistive Technology Act of 1998 as “technology used by individuals with disabilities in order to perform functions that might otherwise be difficult or impossible” (108). The UK King’s Fund consultation meeting proposed the following definition: “Assistive Technology is any product or service designed to enable independence for disabled and older people” (109). Several million people are estimated to use AT devices for mobility, communication, and assistance with performing activities of daily living (ADL). AT is often promoted as a means of retaining autonomy and quality of life for older people (110), including PwDs (111), as AT might help them continue to be independent and live safely in their own home (112-118). ATs are diverse and could be used for supporting relatives or as a potential solution in professional care for PwDs (119-121).

Tracking and tagging technology are examples of two different kinds of AT, also subsumed under the heading ‘surveillance technology’ (114-116,122,123). Surveillance technologies commonly used in the care of PwDs are safety, bed, door and passage alarms (e.g., 124,125). Tagging technology detects when a person leaves a predefined area (122,126). Tracking technology, e.g., passive positioning alarms (PPA), on the other hand, is based on a global positioning system (GPS) and is able to show the exact position of the tracking device (and the person wearing the device) on a digital map. The difference between more typical tracking technology and the PPA is that the PPA involves a hidden zone, that is, the person is not visible until he/she leaves a predefined area. Another difference between the PPA and other kinds of tracking technology is that the PPA constantly sends a position. Furthermore, the PPA sends an alarm to a mobile phone (thus, not to a stationary receiver), which allows the receiving party to see the alarm signal regardless of where he/she is physically located (thus, not just while at home). Starting from the definition used in the present thesis in the methods, results and discussion sections, the term that will be used is passive positioning alarm (PPA).
Previously, researchers focused on tagging technology, but nowadays tracking via GPS is widely used in the care of PwDs because of the possibility of real-time navigation.

The main motivation behind the use of tracking technologies in the care of PwDs has been to create secure environments for the PwDs (127,128) and reduce the problems of relatives for those PwDs still living at home (129,130). In addition, tracking technologies might be helpful in delaying the move to a nursing home and provide relatively cheap solutions for remote monitoring of PwDs. Studies have also shown a tendency for tracking technologies to enhance feelings of safety, less fear and anxiety (116,131) and sense of independence (127) among PwDs and relatives. Studies have shown that relatives have more interest in tracking technologies and perceive them to be more useful, both for their own peace of mind and for the safety of the PwD, than do health care staff (131,132). These kinds of technologies may be used to reduce the very real risk of PwDs getting lost, thereby providing peace of mind for relatives (116,131). However, both relatives and health care staff agreed on the point that caring for PwDs with the support of tracking technologies is an internal family matter (131). Increased use of tracking technologies in daily care of PwDs may give rise to significant challenges that need to be discussed e.g., ethical and decision-making issues (126,133,134).

**Ethical aspects of using tracking technology in dementia care**

A tracking system may allow PwDs to walk more freely and reduce the need for more restrictive methods, such as locked doors or restraint (105). However, tracking technology may have the potential to decrease autonomy and restrict movement (131). The right to personal health and safety, versus the right to privacy (133,135) and dignity (126,136), also stand out as conflicting values in using tracking technologies in dementia care (115). Some see the GPS location of a person and transmission of this information to a central computer as an inherent invasion of privacy that threatens personal integrity, autonomy and liberty (126,134,137). At the same time as tracking technologies may have great potential, it appears to be important to consider who will gain by using them: is it the person being tracked (135,136), the relatives who feel more secure (137,138), or perhaps both? Using tracking technology also raises the question of who will decide whether and how it can be used, as well as whether it can be forced on people (139). Studies describing the opinions and experiences of using tracking technologies, from the perspective of healthcare staff and relatives, have revealed that both negative and positive attitudes exist. Positive attitudes expressed by both healthcare staff and relatives were...
related to an enhanced feeling of safety and security as well as reduced fear and anxiety (116,127). Healthcare staff, however, pointed out that there may be a risk that the use of tracking technologies will lead to inhuman care (132,140). The underlying assumption of many tracking technologies is that they can act as a safety precaution by allowing relatives to monitor the PwDs when they are alone outdoors (131,132). However, more awareness of the limitations of the tracking technology is needed (e.g., 123,133).
RATIONALE

The value of being outdoors for PwDs has been described (14,15) and at the same time fear has been expressed by both PwDs and spouses that the PwD might get lost and/or not find his/her way back home while alone outdoors (13,25). If the wish is to be able to live in one’s own home and maintain independent living throughout their lives, both PwDs and spouses need to be supported in the best way possible. From the perspective of PwDs and their spouses, it is therefore important to investigate whether and how tracking technologies could be supportive in daily care.

In several studies (114,123,127,132,141) and project (142-144), collective efforts have been made to develop different kinds of ICT for PwDs and their relatives living at home. The aims have been to investigate whether it is possible, with the support of ICT, to facilitate an independent life for PwDs living at home and to promote well-being, safety and security for both PwDs and relatives. Studies in which tracking technologies for PwDs have been tested and evaluated have mostly included the perspective of relatives and health care staff (127,129-131). However, some quantitative studies exist that have examined the use of tracking technologies from the perspective of PwDs living at home (128,145). A limited number of qualitative studies have also been conducted in which experiences of tracking technology have been explored and/or described from the perspective of PwDs living in their own homes (115,116,123). Other studies on the use of tracking technologies do exist. However, they have either included cognitively intact older persons (e.g., 133,146,147) or PwDs living in residential homes (e.g., 148,149).
AIMS

The overall aim was to describe how PwDs reflect on being outdoors and to investigate the support provided by a passive positioning alarm in making daily life safer for PwDs and their spouses.

Specific aims of the studies were:

I. To describe how persons with early-stage dementia reflect on being outdoors.

II. To describe relatives’ reflections on different kinds of information and communication technology (ICT) devices that are used or can be used in the daily care of PwDs.

III. To describe and explore the use and experiences of using a passive positioning alarm, over time, in the daily life of PwDs and their spouses.

IV. To investigate the effects of using tracking technology on independent outdoor activities and psychological well-being in three individual cases, i.e. PwDs and their spouses.
METHODS

The present research has used both qualitative and quantitative approaches. The research questions have guided the choice of methods. The qualitative approach has been given greater weight, as it is useful when investigating the reflections and experiences of individuals (150).

Design

In Study I and II, a descriptive design was used, and in Study III a descriptive and explorative design with an ethnographic approach was used. In Study IV an experimental single-case design was used. In experimental single-case designs, the selected outcomes are measured daily both during a non-intervention period (Phase A) and during an intervention period (Phase B) (151). An overview of the studies is shown in Table 1.

In Study I, the PwD’s reflections and experiences of being outdoors were sought, and Study II focused on the spouse’s experiences and/or perceptions of a PPA, but also other kinds of ICT to support daily care of a PwD. PwDs’ and spouses’ expressions of value and acceptance of the PPA were the foundation of Study III and IV, where the PPA was used by PwDs and their spouses and the effects of the PPA were measured.

Table 1. Overview of the study design, sample, data collection and analysis methods used in the thesis

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Data collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Descriptive</td>
<td>PwDs n=11</td>
<td>Repeated individual interviews (n=22)</td>
<td>Manifest and latent content analysis</td>
</tr>
<tr>
<td>II</td>
<td>Descriptive</td>
<td>Spouses to PwDs n=14</td>
<td>Individual interviews</td>
<td>Manifest and latent content analysis</td>
</tr>
<tr>
<td>III</td>
<td>Descriptive and explorative with an ethnographic approach</td>
<td>Couples (a PwD and his/her spouse) n=5</td>
<td>Repeated observations and interviews (n=27)</td>
<td>Manifest content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>Experimental single-subject</td>
<td>Couples (a PwD and his spouse) n=3</td>
<td>Interviews, structured instruments and diaries</td>
<td>Visual Inspection and statistical analysis</td>
</tr>
</tbody>
</table>
Sample and setting
The setting for Study I, III and IV was the participants’ own homes. For Study II, all spouses of PwDs lived in their own homes. However, some of their PwDs lived in either their own homes, units for short-time care or in residential homes for PwDs. Variation in age and sex was the goal in selecting participants for all studies. Furthermore, variation in mobility (Study I) and living situation (Study II) were aimed at. The Relative Caregivers Support Centre in a municipality in central Sweden (Study I-III) and healthcare staff at the memory unit within the county council (Study IV) helped recruit participants for the studies. Participants in all studies were able to communicate verbally in Swedish. In Study III, two couples included a PwD who had also participated in Study I. Additional characteristics of the participants are presented in Table 2.

In Study IV, the PwDs needed help/support with Instrumental Activities of Daily living (IADL) and Activities of Daily living (ADL). The spouses estimated that they carried out a few hours of daily supervision of their PwD. The PwDs’ neuropsychiatric symptoms were scored by the spouses. The spouses also felt they were somewhat burdened.
Table 2. Characteristics of the PwDs and spouses (Study I-IV)

<table>
<thead>
<tr>
<th></th>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PwD (total n)</strong></td>
<td>11</td>
<td>5</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td><strong>Male</strong></td>
<td>6</td>
<td>8</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>5</td>
<td>6</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Age (range)</strong></td>
<td>52-81</td>
<td>62-90</td>
<td>55-73</td>
<td>72-76</td>
</tr>
<tr>
<td>- ≤ 65 years</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>- 66-70 years</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>- 71-75 years</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>- 76-80 years</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>- 81+ years</td>
<td>1</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Alzheimer’s disease</td>
<td>11</td>
<td>11</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>- Vascular dementia</td>
<td></td>
<td></td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>*<em>MMSE</em> (range)**</td>
<td>21-28</td>
<td>19-28**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mild dementia [≥20]</td>
<td>11</td>
<td>4**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Moderate dementia [19-10]</td>
<td>1**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Severe dementia [≤9]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Without help</td>
<td>7</td>
<td>5</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>- Cain</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Walker</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Daytime activity program</strong></td>
<td>2</td>
<td>3</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Living condition</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Own home, together with spouse</td>
<td>9</td>
<td>10</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>- Own home, alone</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Unit for short-time care</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Residential home for PwD</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Spouses (total n)</strong></td>
<td>14</td>
<td>5</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Male</strong></td>
<td>5</td>
<td>6</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>6</td>
<td>8</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td><strong>Age (range)</strong></td>
<td>61-80</td>
<td>62-89</td>
<td>62-68</td>
<td>72-74</td>
</tr>
<tr>
<td>- ≤ 65 years</td>
<td>3</td>
<td>4</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>- 66-70 years</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>- 71-75 years</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>- 76-80 years</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- 81+ years</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PwD and/or spouses</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Housing area</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Urban area</td>
<td>2</td>
<td>7</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>- Rural area</td>
<td>9</td>
<td>7</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td><strong>Type of housing</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- terrace house</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>- detached house</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>- apartment</td>
<td>4</td>
<td>9</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>- access to summer cottage</td>
<td>5</td>
<td>2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*(n) if nothing else is reported
MMSE, Mini Mental State Examination (max value 30 points).* (152)
**Values received from spouse
The intervention

The intervention comprised a “package” with a passive positioning alarm (PPA) (transmitter and a receiver/cell phone), manuals for the PPA and cell phone and a support person involved in the project (Figure 1 - PPAP). The support person was a healthcare professional from the municipality with experience of working with PwDs and their relatives. The support person visited the participants (in some cases twice) in their own home, delivered the PPA, cell phone and manuals and provided a two-hour verbal instruction session. The support person was responsible for providing technical support throughout the study periods (III and IV). In Study I and II, the researcher showed and talked about the PPAP during the interviews/conversations. The PPA is based on a global positioning system (GPS). The transmitter, about 10 cm in height, 5 cm in width, 3 cm in thickness and about 150 g in weight, was worn by the PwD when he/she was alone outdoors. The transmitter could be worn on a belt, in a pocket or purse, etc. The receiver (a cell phone) was used and carried by the spouse, regardless of whether he/she was at home or somewhere else. Before the PwD left the home (or other place), the transmitter was activated by the spouse by pushing the big red button marked with a cross; this created a virtual fence with a radius of 500 meters (a predefined area). The virtual fence was changeable and could be individually adjusted. The PwD could also get into contact with the spouse with one push of a button after programming in the spouse’s phone number. The transmitter also has a loudspeaker function. The spouse can get into direct contact with the PwD, who does not need to push any button to hear and talk to the spouse.

Figure 1. PPAP
A passive alarm means that as long as the PwD stays inside the predefined area, no alarm is sent. The minute the PwD leaves the area, an alarm, in the form of a Short Message Service (SMS) containing a map, is sent to the spouse’s cell phone. Red dots representing the position of the transmitter are visible on the cell phone screen. The position of the transmitter is monitored every minute and sent to the receiver. If the PwD leaves the predefined area and then returns to it, the red dots remain visible on the screen, even inside the circle. Furthermore, an arrow is also seen on the cell phone screen, pointing out the direction of the transmitter, in case the spouse needs to find the PwD outdoors. The system also has built-in safety features, so that when the transmitter battery is low, an SMS “Low Battery” is sent. The battery power was tested in the project group and was calculated to last about 36 hours. The location of a transmitter was monitored online through a service provided by the device manufacturer. Figure 2 presents a description of the system.

Figure 2. System description
The research project started in 2007 as collaborative effort of the municipality (the initiator), the University of Gävle and a business manufacturer. In the project group were the developers of the hard- and software, persons representing dementia care in the municipality and researchers from the University. Regular meetings were held approximately once every third month in the project group during the evaluation periods and less often between periods. The PPAP has undergone changes during the study period, and the changes proposed by the PwDs and spouses were used to improve and develop the PPAP. All the changes have been tested by the members in the project group and by healthy elderly couples without dementia; see Figure 3. The healthy elderly without dementia were recruited from a local district of the National Pensioners’ Organisation (PRO). PRO was contacted for volunteers that were willing to use and evaluate the PPAP. The healthy couples tested the PPAP after each improvement to the system, weekly notes were made and questionnaires were filled in (unpublished data). Afterwards, group discussions were held (tape-recorded) to evaluate the changes, and finally the PPAP was introduced to and used by the PwDs and their spouses.

Figure 3. Test periods of the PPAP
Data collection and procedure

In Study I, repeated interviews were held twice with the PwDs in their own homes. The interviews were carried out in the form of a conversation (150). To get a picture of the outdoor environment in the informants’ neighbourhood in terms of its nature elements and to get a sense of the context in order to better understand when the PwDs described their reflections on and experiences of being outdoors, the researcher walked around each informant’s neighbourhood prior to the conversations. To support the PwDs’ memory, conversations were performed partly or totally outdoors or near a window with a view of the outdoor area. All conversations were tape-recorded and transcribed verbatim. Field notes were made by the researcher during and immediately after each conversation (150). The first conversation was conducted between June and October 2009 and the second between two weeks and three months later.

In Study II, data were collected through individual interviews with spouses, using open-ended questions (153,154). An interview guide was used (154) and questions were asked about: what kind of ICT devices the spouses used or had heard of, whether they could describe the devices’ functionality, what they thought about the ICT, how they had received information about ICT, their perception and experience of using ICT, decisions concerning use of ICT, and reflections on integrity and self-determination when using ICT in the care of PwDs. A computer presentation with still pictures of and commentaries on the most common types of ICT used for older persons (i.e., door alarm, safety alarm, passage sensor and bed alarm) were shown during the interviews. The presentation was intended to create a common understanding of what ICT could look like and be used for. The PPA was also shown and supplemented with verbal information about other tracking technologies used in the care of PwDs. Data were collected during October 2007 – March 2008.

In Study III, data were collected through repeated participant observations and informal conversations (150) with the PwDs and the spouses, at five to seven occasions per couple. The main focus of the observations and conversations was on how the PwDs and spouses experienced using the PPAP. A co-observer participated in 17 of the 27 data collection occasions, the aim being to allow one observer to accompany and observe the PwD on his/her outdoor walk, while the other observer observed and had an informal conversation with the spouse. Two weeks before the start of data collection, the participating couples received their transmitter, manuals for the transmitter and cell phone along with a two-hour verbal instruction session provide by the support person involved in the project.
During the instruction session, the couples were able to test the PPA, ask questions and read the manuals.

The first two data collections (test observation, also included in the analysis) were carried out with the same couple, where two researchers were present and independently made notes. The notes were transcribed and compared. Data collection was then carried out according to the following plan: together with the PwD and the spouse, appropriate observation times were identified – times when the PwD usually wants to go or went out on his/her own. When the PwD left the home for the independent outdoor walk, the co-observer or the researcher followed along (data collected but not analysed). All subsequent data collection occasions followed a specific pattern. First a joint informal conversation with the PwD and his/her spouse took place, where the couple summarized what had happen in their daily life, in relation to use of the PPAP, since the previous data collection occasion. Then the PwD went for an outdoor walk, during which time an informal conversation was conducted with the spouse in the home. The outdoor observation focused on how the PwD behaved in the physical environment, and a conversation was also held with him/her during the walk. Finally, when the PwD returned home, a joint informal conversation was held with the PwD and his/her spouse, focusing on the former’s experiences of the outdoor walk, in relation to use of the PPAP. The researcher made continuous notes after the data collection occasions. The observations and conversations were tape-recorded and transcribed verbatim. Data collection was done during October 2010 – March 2011.

In Study IV, data were collected during May 2011 – October 2011 using an experimental single-case A1B1A2B2 design (151) involving daily measures of three couples. Phases A1 and A2 were the non-intervention phases, and B1 and B2 were the intervention phases (Table 3).

Table 3. Description of length of phases in Study IV

<table>
<thead>
<tr>
<th>Couple (C)</th>
<th>A1 (weeks)</th>
<th>B1 (weeks)</th>
<th>A2 (weeks)</th>
<th>B2 (weeks)</th>
</tr>
</thead>
<tbody>
<tr>
<td>C 1</td>
<td>3</td>
<td>7</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>C 2</td>
<td>3</td>
<td>7</td>
<td>5</td>
<td>4*</td>
</tr>
<tr>
<td>C 3</td>
<td>2</td>
<td>5</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

*Phase B2 was four weeks and 2 days long.
Primary outcome variables were independent outdoor activities for the PwD (frequency and duration), individual specific outcome (proxy) irritability (PwD 1) and depressive mood (PwD 2 and 3) as well as spouse worry concerning PwD independent outdoor activities (Spouse 1 and 3) and spouse worry that her husband will get lost while engaging in independent outdoor activities (Spouse 2).

Secondary outcomes measured were PwD well-being, PwD well-being (proxy) and spouse well-being, PwD worry about getting lost when doing outdoor activities on his own (PwD 3), accompanied outdoor activities (frequency and duration), time for independent and accompanied outdoor activities and the number of generated alarms when PwDs were alone outdoors.

The ratings were scored on numerical rating scales (0-10) with end-point alternatives ‘no well-being at all’ to ‘extremely good’, ‘not worried at all’ to ‘extremely worried’, ‘no irritability at all’ to ‘extremely irritable’, and ‘no depressive mood at all’ to ‘extremely depressed mood’, respectively.

Furthermore, descriptive measures were collected and used for describing the couples: the Caregiver Burden Scale (CB scale) (155,156), the Resource of Utilization in Dementia (RUD) (157), and the Neuropsychiatric Inventory (NPI) (158,159).

The CB scale is a tool for assessment of informal caregiver burden; it reflects the feelings experienced by the informal carer in relation to the PwD. The spouses rate statements as to how true they were for them as a caregiver. There are 22 items scored from 1 to 4 (not at all, seldom, sometimes and often). The total burden index comprised the mean of all 22 items and was divided into three groups: low burden (1.00–1.99), medium burden (2.00–2.99) and high burden (3.00–4.00) (160). The higher the score are, the greater the burden. A study has shown good inter-rater reliability. The validity and internal consistency were tested showing good agreement with Cronbach alpha values of about 0.70–0.87. The CB Scale has been used for several patient groups, e.g., PwDs, stroke and Parkinson’s disease as well as in different kinds of settings, e.g., living at home, sheltered housing and day-time care (155).

The RUD scale is completed by caregivers and compiles data on the use of social services, frequency and duration of hospitalizations, unscheduled contacts with health care professionals, amount of time they spend caring and missing work, and the medication used by the PwD. The instrument is divided into three different categories: Instrumental Activities of Daily Living (IADL), Activities of Daily Living (ADL) and Supervision. The spouses were asked whether the PwD needed help in the respective categories. If they did provide help, the interviewer first asked how many days...
during the last four weeks they provided assistance for each category. Second, the spouses were asked to state how many hours they assisted the PwD on these days on average for each of the three categories. High test-retest reliability for the RUD questions was found, with intra-class correlation coefficients larger than 0.9 in each of the three categories (157).

The NPI scale is a validated informant-based interview that is widely used in clinical research studies. The NPI evaluates the frequency and severity of 12 neuropsychiatric disturbances that occur frequently in dementia: agitation, irritability, anxiety, dysphoria, hallucinations, delusions, apathy, euphoria, disinhibition, aberrant motor behaviour, appetite and eating disorders and sleep. Each item on the NPI is scored on a 4-point frequency scale (1= Sometimes, 2= Often, 3=Frequently, 4=Very frequently) and on a 3-point severity scale (1= Mild, 2= Moderate, 3=Severe). The severity score is then multiplied by the frequency score. The total score varies between 0-144. Content validity, concurrent validity, inter-rater reliability, and test-retest reliability of the NPI are established (161).

An initial interview with each couple was performed to identify individual main outcome variables for both the PwD and the spouse and to identify perceived problems concerning the PwD’s independent outdoor activities. During the interview, detailed information was given describing the study procedure, including the daily rating of the PwD and the spouse, and showing an example diary. The week prior to the baseline period (A1), the author collected descriptive measures and left diaries covering the first 2 weeks of the period. At the end of Phase A1, the couples received the PPA, cell phone and an instruction session, provided by the support person. During the session, the couples were able to test the PPA and cell phone, ask questions and together with the support person read the manuals. The predicted time for the spouses to learn to use the alarm was estimated to be 2 weeks. The couples were instructed to use the PPA as frequently as possible. At the end of Phase B1, the support person fetched the PPA and returned it at the end of Phase A2. The researcher had weekly telephone contact with the spouses during all phases. These contacts were made to remind them to complete the diaries daily and to allow the researcher to answer potential questions from the couples. The diaries were returned by mail weekly. New diaries and stamped reply envelopes were sent by mail every second week to the couples. The graphs for one phase, for each couple, were visually inspected by three authors, and the criterion for entering the next phase was stability in the data.
Data analysis

The transcribed data in Study I, II and III were analysed using manifest (III) and latent (I, II) content analyses, (150,162,163). The analysis process began with listening to and reading through all interviews repeatedly to gain an overview and general impression. In Study I, the data were divided into content areas, covering the outdoors and the PPA. Content areas are seen as “parts of a text dealing with a specific issue” (164). The analysis was continued by identifying meaning units related to the study aim. Each meaning unit was then condensed and labelled with a code. The different codes were grouped into subcategories. Subcategories expressing related meanings were then sorted into categories. Analysis in which the data are sorted into categories is regarded as manifest, and as answering the question “What?”. The underlying meaning of the findings resulted in sub-themes (Study II) and themes (Study I, II). These themes vary in depth and level of abstraction, and reflect the interpretation of the data. A latent analysis helps in answering the question “How?”. The field notes made in Study I and III were analysed along with the transcribed conversations and observations. The field notes were also used in the interpretation and presentation of the data in Study I. The analysis was carried out using a dynamic process of alternating between the whole and the parts. Collected data concerning the PPA in Study I were not analysed, however the PwDs’ reflections and experiences concerning the PPA were summarized and presented in the project group, and this informed the development of the PPAP. The findings will be presented elsewhere.

In Study IV, daily scores of primary and secondary outcomes were displayed graphically for visual inspection, and median values for primary and secondary outcomes were calculated for every week. Furthermore, level, trend, latency and celeration lines were drawn and non-overlapping values were calculated (151,165).

A change in level is seen when a sudden rise or fall in the subject’s performance across two or more phases results in changes in the ‘magnitude’ of the values between phases on the y-axis (0-10 on the rating scales). Changes in trend occur when there are differences in the direction in which the data pattern is moving. A slope change is reflected by the steepness of a data path across phases (165). Latency of change refers to the period between the onset of one condition (intervention, B phase) and changes in performance (151). Latency of change can be rapid, happening quickly after onset of the intervention (B phase) or returning to baseline (A phase), or delayed. A rapid change signals a clearer effect of the intervention. Non-overlapping data are datapoint values during baseline (A1A2) that do not approach any of the datapoint values during the inter-
vention phase (B₁B₂) (151,166). Calculations (percentages) were made of the non-overlapping scores between phases B₁ and A₁ and B₂ and A₂. The celeration line is used to demonstrate a subject’s performance pattern. The line drawn for the baseline data (A phase) is extrapolated into the intervention phase (B phase) to ‘predict’ the subject’s performance (165).
Ethical considerations

The Advisory Board at the local university granted permission for Study II (52-507/07) and the Regional Ethical Review Board in Uppsala granted permission for Study I, III-IV (2009/078). Written permission to perform the studies was also received from the head of the Relative Caregiver Support Centre in the municipality, the county council division of medicine/geriatrics and primary care. In Study I, III-IV, both the PwDs and the spouses received verbal and written information. The spouses received verbal and written information in Study II. The PwDs and spouses were informed that their participation was voluntary and of their right to end their participation for any reason and that invoking this right would be respected and have no consequences for them. The information was repeated at all interview and/or observation occasions. The collected data were treated confidentially, which means that all recorded data were kept locked in.
SUMMARY OF RESULTS

Study I
The aim of Study I was to describe how persons with early-stage dementia reflect on being outdoors. Being outdoors was described by the PwDs as a confirmation of the self. Confirmation of their ability to maintain desired activities, despite the dementia disease, was important to the PwDs. However, some confirmations were not positive; the realization that one could no longer perform certain activities could be devastating. Two subthemes emerged: Shifting between “still being part of it all” and a sense of grief and loss and Striving to keep on despite perceived barriers. Past but no longer possible outdoor activities were greatly missed, and the PwDs longed to be able to perform these activities again. To resolve possible difficulties associated with being outdoors, the PwDs used various adaptation strategies. Despite the described barriers, being outdoors was of great value to them. Figure 4 presents an overview of categories, subthemes and theme.
Figure 4. Overview of categories, subthemes and theme revealed in the analysis
In the subtheme shifting between “still being part of it all” and a sense of grief and loss, the PwDs reflected on the outdoors and shifted between being a person “of consequence” and being a person suffering from different kinds of losses. The subtheme was based on the categories sensory experiences, social interaction, freedom and independence and self-confidence. “Being part of it all” was related to external input (sensory stimulation in the form of smells, sounds, etc.), internal feelings (a sense of freedom and independence) and relations to others (social interactions). The social interaction involved in being outdoors was described by the PwDs as, e.g., meeting and talking to people passing by or just sharing something with others. Reflections on social interactions did not necessarily involve interaction with other people: just seeing, hearing and being with others were described as valuable as well. The PwDs associated being outdoors with a sense of freedom and independence they got from just being able to go out. The outdoor environment was also described by the PwDs as a contrast to the indoor environment. Freedom was described by the PwDs as, e.g., the need for a garden to go to. The PwDs described the outdoors as undemanding – as just being. Maintenance of self-confidence meant, e.g., being able to do what they had done before, and this was a confirmation of the self. Having an opportunity to perform outdoor activities they longed for meant a great deal to them, and they reflected on it as a source of confidence in oneself and one’s own abilities. Being restricted from going outdoors was described `as a loss of self-confidence and dignity’. Not being able to perform activities was described by several PwDs with a sense of grief, loss and resulted in poor self-confidence.

In the subtheme striving to keep on despite perceived barriers, the PwDs described different kinds of perceived barriers and how they dealt with them. Barriers were mentioned in relation to their own abilities (now and in the future), but also in relation to the environment. Primarily physical impairment was described, and the PwDs varied in their descriptions of having no, some or several impairments. The PwDs described concrete physical impacts as limitations on maintaining past and current activities. The PwDs said that they had problems with orientation in time and space. They also described the “mental aspects of living with dementia”. This was unlike their descriptions of physical impairment and problems with orientation, descriptions of what it is like to live with a dementia disease and how it affects their possibilities to be outdoors.

To maintain daily and desired activities, the PwDs used different kinds of adaptation strategies, mostly taking an active approach. Active approaches were described in terms of problem-solving and preventive strategies. Problem-solving strategies used by the PwDs to handle an insecure
situation were e.g., to stop and think for a while, asking someone and/or use different kinds of landmarks. Being able to reconnect to these objects made it easier to navigate and find their way back home. Preventive strategies, e.g., future orientation problems, were more carefully planned by the PwDs.

Study II
The aim of Study II was to describe relatives’ reflections on information and communication technology devices that are used or can be used in the daily care of PwDs. The findings revealed a theme ‘Shifting between different perspectives: my, your and our needs of safety and security’, interpreted as shifting between the spouse’s own needs for safety and security and those of the PwD. The theme was based on three categories, ‘ICT - a support in daily life’, ‘ICT - internal and external conditions’ and ‘ICT – the decision to use or not use’. Figure 5 presents an overview of subcategories, categories and theme.
Figure 5. Overview of subcategories, categories and theme
The category ICT - a support in daily life contained the subcategories maintaining independence, getting help in an emergency, preventing harm and finding the PwD. In the subcategories, the spouses shifted between their own perspectives and the perceived perspective of the PwD. The spouses described using different kinds of ICTs to, e.g., remind the PwD about activities, and supported the PwD in maintaining contact with family and friends. Spouses, both those with and without experiences of using tracking technologies, said that it gave the PwD an opportunity to remain physically active, despite the progressive disease, and to maintain freedom of movement and thereby experience better quality of life. They referred to the ICT as a support when they needed help in varyingly urgent situations, both for themselves and for the PwD. The most commonly mentioned situation associated with a need or desire for ICT in order to prevent harm was when the PwD made attempts to leave the home unaccompanied, during daytime or at night. The spouses also reported being constantly worried that the PwD would get lost when and if he/she were left home alone, and they feared that he/she would be found too late or never. The spouses that previously had used a tracking technology had positive experiences, saying that it gave them a feeling of security and a perceived feeling of security for the PwD. Non-users of tracking technologies had heard from others that they worked well, and were interested in testing such technology.

In the category ICT - internal and external conditions the spouses reported that the PwDs and themselves had varying levels of knowledge, skills, abilities and interest in relation to using ICT, which affected use of the ICT. Female spouses expressed that the husband (the PwD) had previously taken care of the ICT. Financial aspects were also highlighted, e.g., the possibility of being offered a less expensive alternative ICT. The spouses also said that the sex and age, and the severity of the disease of the PwD, influenced what kind of ICT they could use.

ICT – the decision to use or not use was described by the spouses as shifting between describing their own perspective and the perceived perspective of the PwD, ethical concerns and conditions for including the PwD in the decision about whether or not to use the ICT. The spouses meant that having lived a long life together made it difficult to make decisions for the PwD, despite the dementia disease. Despite difficulties in communicating with the PwD, the spouses reported that they found it important to involve the PwD in decisions about what ICT to use in daily life.
Study III
The aim of Study III was to describe and explore the use and experiences of using a passive positioning alarm, over time, in the daily life of the PwDs and their spouses. The main findings show a change over time, in which testing and checking the PPA successively led to trust in the alarm and in one’s own ability to use and handle it. These conditions along with prerequisites for and barriers to a usable PPA were required for the couples to perceive the alarm as valuable. Figure 6 presents an overview of subcategories and categories.

Figure 6. Overview of subcategories and categories revealed in the analysis
The PwDs appreciated the PPA as a daily support in compensating for potential physical limitations, e.g., fear of falling while alone outdoors, but indicated that they could not see the PPA as providing support for their dementia disease today. Some PwDs described perceptual impairment as a consequence of disease progression, while others reported having no or little effect and/or limitations related to the dementia. The PwDs were aware that they would one day, due to the progression of the disease, be much worse and in greater need of the PPA, not just for their own safety and security but also for their spouse’s feelings of safety and security. The value of the PPA was also confirmed by the fact that all couples wished to keep it after the study was completed. The couples also said that the PPA would be an important safety and security aid for them both when spending time in unfamiliar environments. The PwDs and the spouses expressed the value of being locatable and saw no problem with the PwDs being monitored; they had not even considered that aspect. Concerning possible feelings of being monitored, both the PwDs and the spouses said that being seen outweighs the risk of having their privacy violated. However, the PwDs and the spouses, independent of one another, mentioned prerequisites for and barriers to the PPAP’s usability. The person’s own abilities, knowledge and skills and suggested changes to the physical and functional design of the PPAP were mentioned, i.e. maps lacks details [cell phone] – too few objects (e.g., roads) to let you orient yourself, a possibility to communicate with each other [transmitter – cell phone], reduce the number of steps in the manuals and step-wise instructions [cell phone].

Study IV
The aim here was to investigate the effects of using tracking technology on independent outdoor activities and psychological well-being in three individual cases, i.e. PwDs and their spouses. Using tracking technology consistently increased the independent outdoor activities of two persons with dementia; for one person with dementia these activities increased only during B2. One spouse consistently reported decreased worry during B phases, another’s worry decreased only in B2 and the third showed little variability in worrying across all phases. The results of primary and secondary outcomes are presented in Table 4.
Couple 1. For PwD 1, the days with independent outdoor activities decreased from 52% in Phase A1 to 24% in Phase B1, remained stable during Phase A2 (25%) and increased during Phase B2 (49%). For Spouse 1, the celeration line indicated a decrease in worries from A1 to B1. All data-points in Phase B1 fell below the celeration line, indicating either an intervention effect or the fact that the PwD had fewer independent outdoor activities. The median for Spouse 1’s worries increased from the first intervention phase (B1) to the second baseline (A2), and then decreased during the last intervention phase (B2). PwD 1’s irritability (proxy rating) showed little variability during all phases but increased during Phase B1.

Couple 2. From A1 to B1, PwD 2’s independent outdoor activities increased from 0% to 55%. During Phase A2 the couple used a cell phone to locate the PwD, which made the independent outdoor frequency stable (54%), and then in Phase B2 it increased to 70%. During Phase A1, Spouse 2 reported no worries at all when the PwD performed no independent outdoor activities. In Phase B1 PwD 2 started engaging in independent outdoor activities in the third week and at the same time the spouse’s worry that her husband would get lost while alone outdoors increased. When PwD 2’s independent outdoor activities were monitored by cell phone in Phase A2, the spouse’s worries increased further, and then decreased in Phase B2 when 70% of days contained independent outdoor activities for the PwD. Seen over the whole study period, PwD 2’s depressive mood (proxy) decreased. From Phase A1 to Phase B1 the celeration line indicates a decreasing trend of depressive mood for the PwD (proxy). Variability in depressive mood during Phase A1 was shown for the PwD, however no changes in median were observed.

Couple 3. PwD 3 increased his independent outdoor activities during Phase B1 from 43% to 88%. The decreased days with independent outdoor activities in Phase A2 (54%) demonstrated an effect when the intervention was withdrawn. Independent outdoor activities then increased to 77% during Phase B2. During the whole study period, little variability was shown in spouse worry. Variability of the PwD’s depressive mood (proxy) was shown during the whole study period but there were no observable changes in median. PwD 3’s own ratings of well-being, depression, irritability and worry showed very little variability.

During the first baseline phase (A1), none of the three PwDs engaged in independent outdoor activities more than once a day. However, the PwDs in Couple 2 and 3 increased this behaviour during the first intervention phase (B1) to include two or even three independent outdoor activities a day.
Table 4. Results of primary and secondary outcomes Study IV

<table>
<thead>
<tr>
<th>Phase</th>
<th>A1</th>
<th>B1</th>
<th>A2</th>
<th>B2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Couple 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD independent outdoor activities (%)</td>
<td>11*/21 (52)</td>
<td>12*/49 (24)</td>
<td>7*/28 (25)</td>
<td>17*/35 (49)</td>
</tr>
<tr>
<td>- Spouse worry (Md, quartile)</td>
<td>5, 4.5-5.5</td>
<td>5, 3.5-5</td>
<td>7, 6-7</td>
<td>5, 5-5</td>
</tr>
<tr>
<td>- PwD irritability (Md, quartile)</td>
<td>4, 3.5-5</td>
<td>5, 4-5</td>
<td>5, 4.5-6</td>
<td>5, 5-6</td>
</tr>
<tr>
<td>Secondary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD well-being (proxy) (Md, quartile)</td>
<td>5, 5-6</td>
<td>5, 5-5</td>
<td>5, 5-5</td>
<td>5, 5-5</td>
</tr>
<tr>
<td>- PwD well-being (Md, quartile)</td>
<td>5, 4-6</td>
<td>5, 5-5</td>
<td>5, 4-5</td>
<td>5, 4-5</td>
</tr>
<tr>
<td>- Spouse well-being (Md, quartile)</td>
<td>5, 5-6</td>
<td>4, 4-5</td>
<td>5, 4-5</td>
<td>4, 4-5</td>
</tr>
<tr>
<td><strong>Couple 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD independent outdoor activities (%)</td>
<td>0*/21 (0)</td>
<td>27*/49 (55)</td>
<td>19*/35 (54)</td>
<td>21*/30** (70)</td>
</tr>
<tr>
<td>- Spouse worry (Md, quartile)</td>
<td>0, 0-0</td>
<td>1, 0-0</td>
<td>0, 0-1</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>- PwD depressed mood (Md, quartile)</td>
<td>0, 0-2.5</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>Secondary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD well-being (proxy) (Md, quartile)</td>
<td>10, 8-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
</tr>
<tr>
<td>- PwD well-being (Md, quartile)</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
</tr>
<tr>
<td>- Spouse well-being (Md, quartile)</td>
<td>8, 6-10</td>
<td>10, 8-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
</tr>
<tr>
<td><strong>Couple 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD independent outdoor activities (%)</td>
<td>6*/14 (43)</td>
<td>31*/35 (88)</td>
<td>15*/28 (54)</td>
<td>27*/35 (77)</td>
</tr>
<tr>
<td>- Spouse worry (Md, quartile)</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>- PwD depressed mood (Md, quartile)</td>
<td>0, 0-1.5</td>
<td>0, 0-0.5</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>Secondary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD well-being (proxy) (Md, quartile)</td>
<td>10, 9-10</td>
<td>9, 8.5-9</td>
<td>8, 8-9</td>
<td>9, 9-9</td>
</tr>
<tr>
<td>- PwD well-being (Md, quartile)</td>
<td>10, 10-10</td>
<td>9, 8-9</td>
<td>8, 8-9</td>
<td>9, 9-9</td>
</tr>
<tr>
<td>- PwD own worry (Md, quartile)</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>- Spouse well-being (Md, quartile)</td>
<td>9.5, 9-10</td>
<td>9, 9-9</td>
<td>9, 8-9</td>
<td>9, 9-9</td>
</tr>
</tbody>
</table>

* Refers to the proportion of days with independent outdoor activities of the number of days on which estimations were made in the diary.
** The phase were 4 weeks and 2 days long.
DISCUSSION

Summary of main findings
The overall aim was to describe how PwDs reflect on being outdoors and to investigate the support provided by a passive positioning alarm (PPA) in making daily life safer and more secure for PwDs and their spouses. The main findings showed that being outdoors was described by the PwDs as a confirmation of their identity, the ‘Self’. Confirmation of their ability to maintain desired activities, despite the dementia disease, was important to the PwDs. However, some confirmations were not positive; the realization that one could no longer perform certain activities could be painful.

The use of ICT in daily care of PwDs was described by the spouses as shifting between their own needs for safety and security and the perceived need for safety and security from the perspective of the PwD. ICTs were described by the spouses as a support in daily life for both themselves and their PwDs, however internal (knowledge, skills and abilities) and external (financial aspects) conditions affected choice of an appropriate ICT. Furthermore, the spouses expressed the need to include the PwD in the decision to use or not use an ICT in their daily life. Both the PwDs and their spouses expressed, at different points in time, the value of the PPA in their life. Testing and checking the PPA successively led to trust in the PPA and one’s own ability to use it. Those conditions along with prerequisites for and barriers to a usable PPA were a prerequisite for the couples to perceive the PPA as valuable. Using the PPA consistently increased the independent outdoor activities for two PwDs, for one PwD the independent outdoor activities increased only during B2. For the spouses, one consistently reported decreased worry during B phases, one spouse’s worries decreased only in B2 and one spouse showed little variability in worry across all phases.

In summary, the results of the thesis show that use of a PPA in daily life among PwDs living in their own homes can give a sense of freedom, support and strengthen the feeling of independence for both PwDs and their spouses as well as give a feeling of safety and security for them both. Use of the PPA may also increase PwDs’ independent outdoor activities and decrease spouses’ worries.
The value of being outdoors for persons with dementia

Result from our studies showed that the PwDs kept on and wanted to be alone outdoors (Study I, III, IV), which was interpreted as a confirmation of the Self (39) (Study I). This confirmation, however, was described as both positive and negative, depending on whether or not they still could perform desired activities (Study I). Through their outdoor activities the PwDs also described who they had been, and many times, still were (Study I). This is in line with Harré’s descriptions of Self 2 (personal attributes) as presented in social construction theory (39).

Being alone outdoors seemed to have contributed to the PwDs’ well-being (Study I, III-IV), and our results support an earlier interview study by Duggan et al. (15), where PwDs described the importance of being outdoors as promoting emotional well-being. Being outdoors has also been shown to positively affect PwDs’ self/identity (167,168). Engaging in outdoor activities was described by the PwDs as a sense of freedom (Study I). However, freedom did not necessarily have to involve particular activity, e.g., running, walking, skiing etc. Just being able to go out and stay outdoors was described as resulting in a sense of freedom (Study I). Furthermore, a possibility to spend time outdoors was described in the present thesis by the PwDs as an opportunity to ‘see a future despite living with a dementia disease’ (cf. 34). Being outdoors was not just a preference (Study I, III) but also a necessity if the PwDs were not to become irritable or experience a depressive mood (Study IV).

The PwDs described how being outdoors involved social interaction, which was perceived as important (Study I). In a study by Duggan et al. (15) being outdoors and interacting with familiar people was a source of social inclusion and identity. According to Harrés, Self 3 (the public personae) is manifested by the people around us, but also threatened by them (5,18,169). Studies have revealed that there is a risk that Self 2 attributes, which the PwD is proud of, might be marginalized when interacting with others (41,46) thus turning the person into “the demented”. While outdoors, the PwDs (Study I) reflected on sensory experiences, sights, smells and sounds, as a medicine and a reminder that there is still a lot of life left to be lived. Being outdoors, where one can experience and share these sensorium without having to remember details (i.e. names, places, things), may be a way of supporting the PwD’s Self 3, as being outdoors is a non-demanding way to meet, interact and having a social relations with others, despite living with a dementia disease (Study I). In accordance with the inclusion criteria for the present work, all PwDs in the studies wanted and/or needed to be outdoors (Study I, III, IV). We cannot assume, however, that all PwDs want to be alone outdoors or outdoors at all. One
might be a person who rarely or never engaged in outdoor activities earlier in life, and/or who prefers accompanied outdoor activities (together with spouse or others) as a form of social interaction (Study I). The outdoor activities were also described by the PwDs as an opportunity to remain physically active (Study I, III). Whether or not you have been active earlier in life, research has shown that physical activity among older persons might delay and/or prevent dementia diseases (26-28). Physical activity does not necessary need to be performed outdoors. However, being outdoors in a “restorative” environment, as described by Kaplan and Kaplan (22), has been shown to be beneficial for humans’ well-being (19), something also highlighted by the PwDs in the present work (Study I). Furthermore, positive effects of being outdoors have also been shown in PwDs with behavioural and psychological symptoms of dementia (23,24,170).

Problems and strategies related to being outdoors: perspective of person with dementia and spouses

Both PwDs and spouses in the present thesis had identified problems in daily life for PwDs associated with being alone outdoors (Study I, III), e.g., getting lost or not finding one’s way back home (cf. 13). Some problems were also described by the PwDs as physical impairments, not necessarily associated with living with dementia.

Despite negative experienced and expressed consequences of the dementia disease, the PwDs strived to deal with these challenges (cf. 35,37). The PwDs who were still able, and allowed, to be alone outdoors (Study I, III) and their spouses (Study IV) used different kinds of strategies to enhance independent outdoor activities. The PwDs in the present work mostly used an active approach, taking responsibility for their own actions, e.g., by walking in areas known to them (cf. 10,37), seeking walkways that naturally (by forming a loop) lead them back to the starting point and by using a cell phone (cf. 25,171). Cell phones were also used by the spouses in the present work (Study III, IV) to call the PwD when he/she was alone outdoors. Some PwDs used a passive approach, thereby relaying on others in their surroundings to take care of them (cf. 5,16). These results are in line with findings from other qualitative studies (e.g., (18,37,171) aimed at describing how PwDs adjust to and cope with the losses following a dementia disease. The strategies used by the PwDs might also be seen as attributes of Self 2 (cf. 42).

The PwDs reflected on the identified difficulties as things that have been, are today and/or will or might be a problem in the future (Study I, III) (cf. 16). Some PwDs felt they had no problems with orientation today,
only physical impairments (Study I, III), thus the spouses experienced that it was wayfinding problems that made them very worried (Study III, IV) (cf. 9,172). Studies have shown that there may be discrepancies between the PwDs’ and their spouses’ experiences of the PwDs’ ability to manage certain tasks of daily life, i.e. being alone outdoors (cf. 15,172). This was described by the spouses in the present work as, e.g., the fear of the PwD getting lost while alone outdoors or of leaving the home unattended (Study II-IV) (cf. 13,25).

The results from Study IV showed that the spouses’ worries increased when the PwD was alone outdoors (without the intervention). Spouses also reported that they reduced the PwDs’ ability to leave the home unattended by locking the exterior door (Study II, IV) or using other devices, i.e. bells, chairs propped up against the door, etc. (Study II). According to Swedish regulations, locking PwDs in, or using other restrictions to prevent them from leaving units for short-time care and residential homes, is not acceptable (100). For PwDs living in their own homes, these dilemmas must be handled by the co-habiting spouses. Being compelled to restrict the PwD from going outdoors was seen by the spouses as a measure that has negative consequences (Study II, IV). This might constitute a conflicting situation for the spouses, on the one hand, restricting the PwD’s freedom of movement and, on the other, preventing him/her from getting hurt. The locked door, which results in restricted freedom, might also affect the PwD’s Self (Study I), in that valuable outdoor activities, e.g., social interaction (Study I), become difficult. Studies have shown that the use of physical restrictions in geriatric long-term care is common (101,102) and related to decreased mobility and decreased psychological well-being among older persons and PwDs (173,174). The spouses in the present work justified the locked exterior door as a method to prevent the PwDs from getting harmed (Study II, IV). However, spouses shifted between their own perspective of safety and security and the perceived perspective of the PwD (Study II).

PwDs might also choose to deliberately stay indoors, which they should be able to. However, this may have consequences for their spouses. One possible consequence is that the spouses too will be confined to the home, in some respects, as leaving the PwD at home alone might entail a risk that he/she will leave the home unattended (13,98). Harris and Keady’s (63) interview study with younger carers of younger PwDs revealed that caring was seen a form of social isolation (Study IV). Therefore, helping PwDs spend time alone outdoors with the use of a PPA may lead to increased freedom for spouses to engage in their own activities, resulting in a win-win situation.
Value and ethical aspects of the passive positioning alarm (PPA)

In the present thesis, a passive positioning alarm was used by the PwDs and spouses when the PwDs were alone outdoors. The PwDs and spouses testing and checking of the PPAP led to trust in it and in their own abilities to use it, and successively over time they found the PPAP valuable (Study III). According to Rogers’ Diffusion of Innovation theory (DOI) (175), the value of the PPAP expressed by the PwDs and spouses might be seen as reflecting its relative advantage. By this, Rogers means that there should be some form of benefit for using the technology. Rogers (175) also considers that there is a need for users to identify ‘observable results’ to perceive the value of new technology. The PwDs (Study III) and spouses (Study II, III, IV) described the PPAP as providing valuable support for safety and security in their daily life. This is in line with studies in which tracking technologies have been used for PwDs living at home (e.g., 116,127,128,130). The PwDs who felt they had no need for the PPA today, as a support for the dementia disease, reported that it might be used in case they fell while alone outdoors or for some other reason needed to come into contact with their spouses (Study III). However, use of the PPA was primarily a support in case the PwD got lost or did not find his/her way back home while alone outdoors.

The value of the PPAP for the PwD might be seen in terms of increased independence, i.e. being able to spend time outdoors independently with the support of the PPA (Study III, IV). This was also found in a study by Pot et al. (128), where PwDs reported being outside alone more when using tracking technology. An interview study with family carers of PwDs (127) also revealed that using tracking technology enhanced the sense of independence for both themselves and their PwD. For the spouses, their own feelings of safety and security as well as the perceived feeling of safety and security for their PwD may be the main reason for using the PPA (Study III, IV) and may also make it possible for spouses to engage in their own activities (Study IV).

Several studies have stressed the importance of discussing and considering ethical aspects, i.e. decreased autonomy, restricted movement, privacy and dignity (115,126,133,135,136), when using tracking technologies in the care of PwDs. However, in Study II and III, both the PwDs and the spouses expressed that the opportunity to create a safe and secure environment, for both of them, overshadowed potential ethical problems. The tracking technology used in the present thesis, as previously mentioned, was passive, meaning that the position of the transmitter carried by the PwD when he/she was alone outdoors was only visible to the spouse after the initial alarm (Study III, IV). This approach is different from that of the
tracking technology used in studies by, e.g., Pot et al. (128) and Werner et al. (176) where the spouse could constantly follow the PwD’s positioning via a website. However, findings from Study III revealed that neither the PwDs nor their spouses wanted the function that allowed the PwD to “be invisible inside the circle”. Of primary concern to both the PwD and spouse was that the PwD be found immediately if and when he/she got lost while alone outdoors. Without marginalizing any ethical aspects, let us think beyond views that see the PPA as something that violates individual integrity, and instead see use of the PPA as an expression of the spouses’ care for their PwD. For couples that have lived together for a long time and know each other very well, use of the PPA can be seen as the spouses’ way of protecting their PwD, instead of violating them in some way (cf. (177). Use of the PPA can also be seen as the spouses’ way of helping the PwD avoid feelings of anxiety while alone outdoors. This too is an example of ethical reasoning and action. According to Lögstrup (178), responding to another person’s needs is an ethical requirement. The use of a PPA may also involve people other than a spouse, e.g., relatives and/or healthcare staff. The primary concern here is that the PwD’s autonomy be respected as well as his/her wishes concerning who should be able to “see” him/her on the device.

Something highlighted by the PwDs in Study III and the spouses in Study II as an advantage of the PPA was its flexibility, that the technique is not tied to a single geographic location. In contrast to the tracking technologies used in other studies (128,131,132,176) where the receiver was a computer, in the present work the receiver of the alarm was the spouse’s cell phone (Study III, IV). Thanks to the portable alarm receiver, it was possible to use it at, e.g., the summer cottage or when visiting friends/family (Study III, IV). This was perceived by the PwDs as increasing their freedom to, e.g., take a walk and pick berries and mushrooms in places where memory problems related to the dementia disease might make such activities difficult (Study III). The spouse, on the other hand, might see the PPA’s flexibility as increasing his/her own freedom to do things outside the home. In Study II, the spouses who had not used a PPA had heard from others that it functioned well and they were interested in using it too. According to Rogers (175), the visible effects an innovation has for others are described using the concept of compatibility.

**Development of the PPAP**

The value of the PPA was discussed by both the PwDs and spouses independently, as was the need for changes of the physical and functional design to make the PPA more useful (Study III). According to Rogers
this might be seen as related to compatibility, meaning that the innovation should fit the user’s life and practices. Some functional design elements of the PPA, e.g., the “hidden zone”, were intended to give the PwD privacy while alone outdoors, but neither the PwDs nor the spouses appreciated these features (Study III). The possibility to get help directly was considered more valuable than being able to walk around “unseen”. The PwDs’ and the spouses’ testing and checking also revealed prerequisites for and barriers to the PPA’s usability (Study III). Rogers (175) relates this to the concept of trialability, i.e., the opportunity for a potential user to test the innovation. Difficulties in using the PPA were also described by the spouses in connection with their abilities, knowledge and skills (Study III), and this might support the importance of running usability tests before implementing a PPA. As described by Scandurra (179), the design of the system (i.e. PPA) affects usability, meaning “it depends on who will be using the system, in which environment, and for what kind of work”. Usability tests could be used as the basis for creating an individual-specific “service” to support users (Study III, IV). Studies by Alexander (180) and Alexander and Wakefield (181) have also shown that continuous evaluation is central to improving the design and efficiency of clinical information systems in nursing homes (Study I-IV). According to the Technology Acceptance Model (TAM) (182), perceived usefulness and ease of use will lead to actual use of the technology (183).

Notable was that the males (both PwDs and spouses) showed more “interest” in the PPA (Study III). The male spouses were also somewhat quicker to learn to use the PPA, while the female spouses expressed and needed more support, e.g., more hands-on instruction by the support person (Study III). The complexity of the innovation (175) refers to the inherent difficulty of using the technology. It might also have been that the husband (now the PwD) was the one who had use and handled all the technologies in that home (Study II), and now the spouse had to learn to use them (Study II-IV). In their interview study with a single couple, Faucounau et al. (123) found that the spouse perceived difficulties in using the tracking, which meant that the device was not suited to her needs. Changes in roles within the couple might also occur due to progression of the dementia disease, entailing that the spouse now has to take over the roles previously fulfilled by the PwD (cf. 88,184).
Research ethics

Including PwDs in the research is important and necessary, but has to be discussed in relation to the ethical issues raised (185,186). There may be some doubt as to whether the PwDs always are aware of what they have consented to, and this can never be guaranteed (186,187). The researcher who performed the observations and/or conversations was experienced in talking with PwDs and used this knowledge to approach the individuals in as sensitive and respectful a manner as possible, so as to avoid making the PwD feel exposed (cf. 188,189). The observations and/or conversations might also have been emotionally stressful and raised feelings of discomfort among both the PwDs and spouses. It was therefore important for the researcher to have a sensitive approach and look for signs of distress, and to end the session if such signs appeared. During two interviews in Study I the informants showed signs of discomfort and began crying. However, they strongly expressed that they did not want to stop the interviews, just to take a short break. With the exception of these incidents, no signs of discomfort were observed in either the PwDs or the spouses in any of the studies. Despite the emotional upheaval of describing and reflecting on their current situation, all of the participants (both the PwDs and their spouses) expressed being delighted to have an opportunity to talk to someone who showed an interest in hearing their stories. The interviewer also set aside plenty of time for meeting informants’ potential needs for reflection and discussion in connection with the observations and interviews/conversations.

In Study IV, ethical concerns might be raised in connection with withdrawing the PPA during the second baseline phase (A2). Kazdin (151) means that the “return-to-baseline condition is unacceptable if this means making the client worse”. During all phases, the researcher made weekly contact with all couples and had the couples’ best interest in mind at all times.

All couples in Study IV and one couple in Study III kept the PPA after the study was concluded.
Methodological considerations

In the present thesis, there are strengths as well as limitations that might have influenced the results and the conclusions that can be drawn. The quality of the research must be addressed. Regarding the qualitative studies (I, II, III) issues of trustworthiness (163, 190) are discussed and for the quantitative study (IV) threats to validity are considered (151).

This thesis is based on four small-sample studies. However, the variations in design, different kinds of data collection methods and analysis methods have hopefully increased the quality of the thesis.

Study I and II, included in the thesis, had descriptive designs and this choice seemed appropriate given the aim to capture the PwDs’ reflections on and experiences of being outdoors and the spouses’ experiences of the ICT. In Study III, a descriptive and explorative design with an ethnographical approach was used to capture experiences of PwDs and spouses using the PPAP. In Study IV, an experimental single-case design was used to investigate the effect of the PPA on the PwDs’ independent outdoor activities and spouses’ worries when the PwDs were alone outdoors. We found the experimental single-case design suitable because it offers a carefully controlled investigation on a small scale for investigating the effects of the PPA. Using an $A_1B_1A_2B_2$ design further strengthens the study, because the intervention is withdrawn in $A_2$ (return to baseline condition) and reintroduced in $B_2$.

Purposive sampling (150, 191) was used for all four studies. According to Patton (150), “the purpose of purposeful sampling is to select information-rich cases whose study will illuminate the questions under study”. To capture variation in the PwDs’ reflections on being outdoors, variation in age, gender (cf. 163) and mobility were aimed at in Study I. The last two PwDs were recruited because we wished to include younger females in Study I. In Study II, we aimed to achieve variation in the spouses’ age, sex and the living situation for their PwD. In Study II, the finale three spouses were recruited based on the need to include PwDs living in units for short-time care and residential homes for PwDs. Variation in living situation also reflected how far the PwD had come in the progression of the dementia disease and thereby the variation in the experience of various needs. Variation in age and gender were also aimed at in Study III. Recruitment of PwDs and spouses for the studies was performed with the help of healthcare staff at the memory unit within the county council and the Relative Caregivers Support Centre. Selection bias might have occurred and a potential risk could be that only persons in favour of using the PPAP were included, which could have resulted in less nuanced find-
ings. The sample size in the studies was determined based on the potentially detailed data that can be generated from each participant. Patton (150) also states that the sample size should be determined in context and on the basis of the study purpose and rationale. No informant declined to participate in Study I-III. In Study IV, one couple declined participation after the initial interview and one couple was excluded due to a relative’s (son) inability to perform daily measures of the PwD. Schneider et al. (192) suggest that the common range in number of participants in qualitative research is usually between eight and fifteen, but this may vary. For Study I-III, the intended variation, described above, guided the sample size and was carefully considered. In Study IV, the recruitment of additional couples was discussed, however because these “new” couples would have other prerequisites, i.e. the study would have to continue through the winter when it might be more difficult for the PwDs to be outside, we decided to limit the study to three couples. All of the couples in Study IV had male PwDs, which might have had an effect on the results.

A variety of data collection methods has been used in the thesis. In Study I repeated interviews were held twice with the PwDs, though the purpose was not to study changes in PwDs over time. To achieve depth in the PwDs’ description of being outdoors, the repeated interviews enabled the interviewer to develop, deepen, and clarify any questions from the first interview and to build a valuable relationship. A warm, empathic and sensitive attitude towards both the PwD and his/her spouse is needed to generate rich data and to establish a trustful relationship between the interviewer/researcher and the informant (2,186). To enable the researcher to better understand the PwD’s descriptions of and reflections on being outdoors, the researcher took a 10-minute walk around the informant’s neighbourhood prior to each interview in Study I, to get a picture of the area. The interviews were performed near a window with a view of the outdoor area or partly or totally outdoors to support the PwDs’ memory, owing to problems that accompany the disease (189). During some of the first interviews, the spouse was present at the same time. This might have limited the PwD’s ability to speak freely, therefore at the repeated interviews the spouses were asked to not be present (if still in the house to be in another room) (cf. 2). On the other hand, Pesonen et al. (193) have highlighted the value of having a significant other present during interviews as a way to provide a safe atmosphere (cf. (186). All interviews with the PwDs (Study I, III) were carried out as conversations, which we believed would make it easier for and encourage them to express their reflections and experiences (cf. 185,188). Study III was an intervention study in which repeated participant observations and informal conversational in-
Interviews (150) were used to describe and explore the couples’ experiences and to describe how they used the PPA. The use of observations and interviews was valuable for capturing both visual and verbal information. Hubbard et al. (188) highlighted the value of using both methods in research with PwDs, as remembering or recalling events might be difficult. Given the researcher’s knowledge of the PPA and membership of the project group, several aspects need to be considered. There is a risk that this might have affected the findings, and the researcher was therefore extra cautious during data collection. The use of a support person (a healthcare professional with long experience of working with PwDs and spouses) for teaching the couples about the intervention (Study III, IV) was important in that it established the role of the researcher as being just “a researcher”. However, the researcher’s knowledge might also have been valuable during the participant observations to identify and understand the expressed and observed difficulties when using the PPA. Furthermore, in Study III a co-observer was present during approximately 2/3 of the data collection occasions. The reason for having two observers present was to be able to accompany the PwD in his/her independent outdoor activities and study the interaction between the PwD and the outdoor environment (data not analysed). It would also have been preferable if the co-observer could have been present during all data collection occasions; however this was not practicable. In all of the studies, the researcher made field notes (150), during or immediately after the data collection. These field notes detailed, e.g., the facial expressions and body language of the PwDs and spouses, where the interview and/or observation took place, etc. The notes have been valuable in recalling and supporting the researcher’s memory during data analysis and in interpretation of the data.

Given the aims of Study I-III, qualitative content analysis (QCA) was found to be a useful method, because it focuses to a great extent on the subject and the context. Unlike some other qualitative methods, in QCA the researcher keeps sight of the context during the whole process (data collection, analysis and presentation). The “units of analysis” (163) in the present study constituted and were interpreted in relation to the whole interview. Due to the nature of the research question, we found other qualitative methods - e.g., phenomenology, which aims to seek the essence of a phenomenon – less suitable. In Study III, an ethnographic inspired approach was used (185). However, our study differs from ethnography in that the data were not collected and analysed in parallel (150,194). Reflections from the observations and the interviews were summarized after each data collection occasion and discussed by the first and last authors, and constituted the point of departure for the next data collection occasion.
Finally, using the Mini Mental Score Examination (MMSE) (152) was discussed, but decided against for Study IV due to the perceived risk of violating the PwD’s integrity and creating a negative “interview atmosphere” (cf. 186,193,195).

Trustworthiness
In the present research, the concepts credibility, dependability and transferability have been used (cf. 163,190). Quotations from the interviews and informal conversations in Study I, II and III helped strengthen the credibility of the studies. Increased credibility in the studies has also been ensured by having discussions throughout the analysis process in both the research team and at research seminars. All authors read the condensed material and discussed the abstraction to categories, sub-themes and theme to reduce the possibility of a researcher biased interpretation of the data. Credibility was also achieved by choosing participants of varying age and sex and by prolonged engagement (190) across two different time points (Study I). According to Patton (150), the credibility of the researcher is also important, as he/she is the major “instrument” of data collection and analysis. The researcher’s detailed knowledge of the passive positioning alarm might have initiated questions during the interviews and conversations, thereby enriching the data. Triangulation, with the use of interviews and observations in Study III, also helped strengthen the credibility (150). To address dependability, careful and thick descriptions have been made of the selection process, sample and setting, data collection procedure and analysis process, all in an attempt to enable future replication of the studies. To further strengthen the dependability, an interview guide was used in Study II. By providing sufficient contextual information, the transferability of the findings to other contexts has hopefully been enhanced. However, this must be judged by the reader, based on his/her experience, and determined through further research (150,163,190).
**Internal and external validity**

Threats to validity in the present work might be seen in terms of internal, construct and external validity (151). Threats to construct validity might include increased attention from and contact with the support person during intervention phases (B1B2). The design of the study using structured daily measures of variables during baseline phases (A1A2) and treatment phases (B1B2) mean that threats to internal validity are minimized.

Another methodological consideration concerns the fact that the study was based on three single cases, thus the data need to be interpreted with caution (165). However, the experimental single-case design does not claim to generate generalizable findings, but instead it is admitted that this is a limitation of the design. Nevertheless, the findings may serve as the scientific basis for designing a clinical randomized controlled trial or be used to conduct a replication study.

The Inter-rater reliability of the data was also estimated by letting the authors (not those included in the primary decision as to when to enter the next phase) visually inspect the data.
**Implication for practice**

The PwDs’ and their spouses’ needs and the benefit of a passive positioning alarm in their daily life should guide if and when the PPA is introduced. Providing early information, in the dementia disease trajectory, about the PPA to PwDs and their spouses could facilitate joint decision-making regarding the use of such a device later on. Testing and using the PPA early on in the course of the disease might also facilitate future use when the PwD’s cognitive impairments might be more severe (cf. 196). The barriers and facilitators expressed by PwDs and spouses as necessary to address to ensure successful use need to be discussed and considered before implementing the PPA in their daily life. The value and importance of letting PwDs express their experiences and reflections on using the PPA must be given greater priority in clinical practice. Cooperation between the nurses, district nurses, occupational therapists, physicians, etc., involved in supporting PwDs and relatives in managing daily life is important to meeting and being aware of the different needs addressed and being able to adapt the support to individual prerequisites. Such support must include detailed instructions, both verbal and written, as well as hands-on demonstration and a 24-hour service support package.

**Future research**

The findings from the present studies contribute to our understanding of reflections on and experiences and effects of using a passive positioning alarm in daily life for PwDs and their spouses, but also give rise to new questions that need to be investigated. A randomized controlled trial comparing use and non-use of the PPA would be valuable and important to further see the effects of using a PPA. Of interest would also be to measure cost effectiveness taking into account the costs of searching for PwDs who have gone missing outdoors. Further, there is a need for studies investigating at which stage of dementia the PPA is most appropriate to introduce, can be used and would be optimal to use. Longitudinal studies are also needed to reveal the effects of PPA, changes over time and into the later stages of the disease.
CONCLUSIONS
The present thesis describes how PwDs reflected on being outdoors and to investigate the support provided by a PPA in making daily life safer for PwDs and their spouses. The main conclusions of the thesis are:

- Helping PwDs spend time alone outdoors, based on their own pre-requisites, through use of a PPA may help them maintain an independent life for a longer period of time.
- Helping PwDs spend time alone outdoors, where they might have opportunities to strengthen their Self, may have a positive impact on their quality of life.
- Being outdoors supports the PwDs’ Self 1 by helping them tell their life stories through outdoor activities, Self 2 by helping them describe their strategies and Self 3 by providing a non-demanding way to interact with others.
- Mutual acceptance, on the part of both PwDs and spouses, of using a PPA in daily life is needed.
- Use of a PPA in daily life could increase the sense of freedom and independence for both PwDs and spouses.
- A PPA for PwDs and their spouses needs to be packaged as a “service” with flexibility for each user and based on their needs, knowledge, skills and abilities.
SAMMANFATTNING PÅ SVENSKA

2007 startades ett samarbetsprojekt mellan kommunen (initiativtagare), Högskolan i Gävle och näringslivet med syftet att utveckla ett tekniskt stöd för personer med demens och deras närstående i det dagliga livet. Personer med demens är i större utsträckning idag än tidigare, kvarboende i det egna hemmet och vårdad av närstående, vanligtvis en make/maka, vilket kräver stöd i olika utformning och omfattning. Ett sätt att stödja och stärka både personer med demens och närstående som bor i det egna hemmet kan vara att använda informations- och kommunikations teknologiska (IKT) stöd.

Det övergripande syftet med föreliggande avhandling var att beskriva hur personer med demens reflekterar kring utevistelse och att undersöka om ett passivt positioneringslarm kan stödja personer med demens och deras närstående i det dagliga livet.


Delstudie III var en interventionsstudie som syftade till att, över tid, beskriva och utforska användningen och erfarenheten av att använda ett passivt positioneringslarm i det dagliga livet för personer med demens och deras make/maka. Med en etnografiskt inspirerad ansats observerades och
intervjuades fem par, en person med demens och dennes make/maka, i det egna hemmet vid fem till sju tillfällen/par. En medobservatör deltog vid ca 2/3 av datainsamlingsstillfällena för att möjliggöra insamling av data vid person med demens självständiga utevistelser (insamlad data ej analyserad). Resultatet visade att paren över tid testade det passiva positioneringslarmet och successivt utvecklade en tillit till larmet och den egna förmågan att använda det, detta var en förutsättning för att paren skulle uppleva ett värde av larmet. Vidare uttryckte både person med demens och närstående, oberoende av varandra, förslag till förändringar i den fysiska och funktionella designen av larmet, ex. detaljrikare kartbild i mobiltelefonen, möjlighet att ringa till sändaren, lättare sändare och färre "steg" i instruktionsmanualerna.


Sammanfattning av avhandlingen resultat visar att användningen av ett passivt positioneringslarm i det dagliga livet för personer med demens boende i det egna hemmet kan ge en frihet, stödja och stärka känslan av oberoende hos person med demens och deras närstående samt ge en känsla av trygghet och säkerhet för dem båda. Användningen av larmet kan öka de självständiga utevistelserna för personer med demens samt minska oron hos närstående.

Slutsatsen är att personer med demens och deras närstående som önskar använda ett passivt positioneringslarm i det dagliga livet bör få ett 24-timmarsstöd utifrån ett individanpassat ”paket”. Individernas förutsättningar, oberoende på behov, kunskap, färdigheter och förmåga, att använda och hantera larmet bör vara vägledande i när stödet utformas. Det skall inkludera så väl muntliga som skriftliga stöd och instruktioner.
ACKNOWLEDGEMENT

First and foremost I would like to thank all of the wonderful people I have met during this work, for sharing your lives so openly and letting me into your homes and your lives. Without your help there would not have been any thesis.

Without three people this work had been impossible to do. First, Associate Professor Claudia Lampic, my main supervisor. I am deeply grateful for being able to share your great scientific knowledge and experience, English translations (like a dictionary) and for all “time schedules” you have made (what would I have done without them).

Associate Professor Maria Engström, my co-supervisor, you are the “main reason” that I am were I am today. I am ever so grateful for your enthusiastic way of introducing me to doing research – especially today!

Professor Kirsti Skovdahl, my other co-supervisor, for being my safe haven and “anchor” at Örebro University, for your knowledge in the field of dementia care and always valuable comments on my work.

I also would like to thank Professor Marianne Carlsson, Professor Inger Holmström, Professor Mona Kihlgren, Associate Professor Annica Kihlgren, Marja-Leena Kristofferzon, Magnus Lindberg, Maja Lindberg, Anna-Greta Mamhidir, Bernice Skytt, and Maria Hedman for your critical readings and valuable comments on my final work.

I would also like to thank all my colleagues at the University of Gävle for good and instructive discussions we’ve had during seminars.

The “ISAK” project group with Birgitta Svensk, Lena Furubacke, Tomas Castor and Martin Snygg.

My “assistants” Marie Bengtsson and Elisabeth Hörne at the Relative Caregiver Support Centre.

Thanks to the healthcare staff at the memory unit within the county council and the Relative Caregivers Support Centre with the help of recruitments of participants to the studies.

Nina Nilsson, the administrative “rock” at the School of Health and Medical Sciences, Örebro University.

My dear friends, Annica Ernesäter, Heidi Hagerman and Ann-Sofi Östlund, for being their when I “ventilate”.

A special thanks to the Faculty of Health and Occupational Studies, University of Gävle, for supporting me financially during my years as a doctoral student.

Suzanne Röhstö for all her “diversion tactics”, walks, coffee, book discussions or just cheering me up.
My mother Mailis Olsson and my late father Hans Olsson for teaching me that hard work pays off.

My brother, Per-Erik (Pelle) Olsson and his family, Annica, Olivia and Alva.

My mother-in-law, Kerstin Ulin and late father-in-law, Rolf Ulin for taking care of our children and help us with all sorts of “boring” housework.

Last but not least, I am most grateful to my family, Niklas, Sebastian and Christoffer (Bille), for having put up with me during these years. I love you all so very much ∞.

The studies in the present thesis were supported by grants from the Faculty of Health and Occupational Studies, University of Gävle, the Anna-Lisa Detlow Bergs Foundation, The Dementia Association, Örebro University, the Swedish Society of Nursing and the Knowledge Foundation.

Dear Past, thank you for all the lessons.

Dear Future, I’m now ready…
REFERENCES


(16) Clare L. We’ll fight it as long as we can: coping with the onset of Alzheimer’s disease. Aging Ment Health 2002 May;6(2):139-148.


(20) Rappe E, Topo P. Contact with outdoor greenery can support competence among people with dementia. J Hous Elderly 2007;21(3):229-248.


(49) Caddell LS, Clare L. I’m still the same person: the impact of early-stage dementia on identity. Dementia 2011;10(3):379-398.


Available from:
http://www.socialstyrelsen.se/fragorochsvar/foreskrifteromtvang ochskydds


(137) Cahill S. Electronic tagging of people with dementia. Technologies may be enabling. BMJ 2003 Feb 1;326:281.

(138) Bail KD. Electronic tagging of people with dementia. Devices may be preferable to locked doors. BMJ 2003 Feb 1;326:281.


(180) Alexander GL. A descriptive analysis of a nursing home clinical information system with decision support. Perspect Health Inf Manag 2008 Sep 2;5:12.


(194) Munhall PL. Nursing Research: A Qualitative Perspective. 5th ed. USA: Malloy Inc; 2012.


“Persons with early-stage dementia reflect on being outdoors: a repeated interview study”

Annakarin Olsson, RN, PhD student. 1, 2), Claudia Lampic, PhD, Associate professor 3), Kirsti Skovdahl, RN, PhD 2), Maria Engström, RN, PhD, Associate professor 1,4)
1) Faculty of Health and Occupational Studies, University of Gävle, Sweden.
2) School of Health and Medical Sciences, Örebro University, Sweden.
3) Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Sweden.
4) Department of Public Health and Caring Sciences, Uppsala University, Sweden

Correspondence to:
Annakarin Olsson
Faculty of Health and Occupational Studies,
University of Gävle
80176 Gävle
Sweden
Tel: +46 26 64 88 12
Fax: +46 26 64 82 35
E-mail: annakarin.olsson@hig.se
Persons with early-stage dementia reflect on being outdoors: a repeated interview study

Abstract

Objectives: The aim of this study was to describe how persons with early-stage dementia reflect on being outdoors.

Methods: Data were collected through repeated interviews with a purposive sample of 11 persons with early-stage dementia in Sweden during the period 2009-2010 and were analysed using qualitative content analysis.

Results: Informants described being outdoors as a confirmation of the self. Confirmation of their ability to maintain desired activities, despite the dementia disease, was important to the informants. However, some confirmations were not positive; the realization that one could no longer perform certain activities could be devastating. Two sub-themes emerged: Shifting between “still being part of it all” and a sense of grief and loss and Striving to keep on despite perceived barriers. Past but no longer possible outdoor activities were greatly missed, and the informants longed to be able to perform these activities once again. To resolve possible difficulties associated with being outdoors, the informants used various adaptation strategies. Despite the described barriers, being outdoors was of great value to them.

Conclusion: Independent outdoor activities seem to contribute to well-being and feelings of self-worth among persons with early-stage dementia who want to be and are able to be outdoors. If a person with dementia, despite cognitive limitations, wants and is able to engage in outdoor activities, it is important for relatives and healthcare staff to encourage and facilitate this, e.g., by discussing adaptation strategies to deal with orientation problems.

Keywords: Activities, early-stage dementia, nursing, outdoors, social construction theory
Introduction

Being outdoors in a natural environment is thought to be restorative and relaxing. The built environment, consisting of e.g., buildings and roads, requires direct attention. For persons with dementia, understanding a built environment may be problematic and lead to frustration, whereas nature can be restorative (Kaplan & Kaplan, 1989). Opportunities to enjoy outdoor activities are not always a reality for individuals affected by dementia. As the dementia progresses, problems with orientation in time and space may lead to troublesome situations, such as not finding one’s way home (McShane et al., 1998). These problems may create barriers to involvement in outdoor activities (Brawley, 2007). Yet persons with dementia can remain physically able for quite a long time while gradually losing their memory and cognitive ability (SBU, 2008). Outdoor activities may be enjoyable, important and positively affect their wellbeing (Duggan et al., 2008; Gibson et al., 2007) and identity/self (Cohen-Mansfield et al., 2000; Edvardsson et al., 2010). However, most of the research on outdoor activities has focused on persons with dementia living in residential homes, exploring their ability to engage in outdoor activities (e.g., Hernandez, 2007; Rappe & Topo, 2007), and on the effects of access to outdoor areas (Bossen, 2010; Detweiler et al., 2008; Mather et al., 1997; Namazi & Johnson, 1992). Few studies have investigated the outdoor activities of persons with dementia who are still living at home (Cedervall & Åberg, 2010; Duggan et al., 2008; Gibson et al., 2007). In research by Gibson et al. (2007), persons with dementia described how outdoor activities, e.g., walking and/or sitting in a garden, improved their well-being. Duggan et al. (2008) conducted interviews with persons with dementia and found that the outdoor environment enhanced their quality of life and that not being able to go out brought on feelings of depression. The persons with dementia valued various aspects of being
outdoors: the fresh air, opportunity for exercise and opportunities to meet and interact with friends and neighbours.

Previous research on persons with dementia has shown that social relationships play a significant role in their life and their self-perception (Surr et al., 2006). However, due to the memory problems accompanying the disease, social relationships and participating in social activities may be difficult. Difficulties may be manifested as a tension between how persons with dementia wish to be positioned in society, the family and the social network and how others perceive their current position (Pearce et al., 2002, Langdon et al., 2007). Such differences in perspective may result in a sense of exclusion, stigmatization and even betrayal (Harman & Clare, 2006) as well as a sense of loss of the social self in one’s social circles (Pearce et al., 2002). According to “social construction theory” (Sabat & Collins, 1999; Sabat & Harré, 1992), three types of self exists within every person. Through Self 1, indexical I or Me, we take responsibility for our actions, describe for others our experiences and feelings and tell stories about ourselves. Self 2 describes present and past attributes attached to us. As the disease progresses, the attentions of others are shifted to attributes perceived as shameful and embarrassing, as opposed to attributes of which they can be proud (Sabat, 2006). Sabat and Harré (1992) illustrated how persons with dementia struggle to maintain their social selves, but their attempted constructions of self were not always confirmed by others. Self 3 is manifested in interaction with the people around us (Sabat, 2005). Being in “undemanding nature” (as described by Kaplan & Kaplan, 1995) has been shown to be beneficial to humans. Cohen-Mansfield et al. (2000) showed that, in persons with dementia, outdoors activities were most likely to support the self.
In recent years, several aspects of the experience of living with dementia, from the perspective of persons with dementia, have been reported, e.g., living alone, receiving a diagnosis, and using medication (Langdon et al., 2007; Moyle et al., 2011). Other studies have explored the self (Sabat, 2005; Cadell & Clare, 2011). Studies have also been conducted to describe strategies persons with dementia use to maintain and adjust to daily life (Clare, 2002, 2003; Pearce, 2002). Studies of outdoor activities have mostly involved persons with dementia living in residential homes, despite that the majority still live at home. In addition, how persons with dementia experience being outdoors has often been assessed by staff (e.g., Bengtsson & Carlsson, 2006; Hernandez, 2007), and not by the persons with dementia themselves. Instead of focusing problems associated with the disease, it may be beneficial to support the personal attributes (Self 2) of persons with dementia who have enjoyed being outdoors. Also, the undemanding nature and social contacts experienced outdoors may promote a sense of self-worth and social standing, i.e. support Self 3 (Langdon et al., 2007).

The aim of the present study was to describe how persons with early-stage dementia reflect on being outdoors.

Method

Given the aim of the study, using interviews and qualitative content analysis (Graneheim & Lundman, 2004; Krippendorff, 2004) was considered an appropriate approach. Content analysis focuses on the subject and context and has been described as particularly relevant for understanding individual’s experiences and reflections. To understand how persons with dementia reflect on being outdoors, we used an interview technique that allowed them to tell their own stories. The present study is part of a project on information and communication technology in the daily life of persons with dementia. The study concerned two topics: 1) how
persons with dementia reflect on being outdoors (presented here) and 2) their opinions about a passive positioning alarm demonstrated during the second part of the interview.

Participants

A purposive sample of persons with dementia, varying in age, gender and mobility, was recruited. The inclusion criteria were having early-stage dementia, having a need and desire to be alone outdoors, being able to speak Swedish and give informed consent. Eleven persons, between 52-81 years of age, in the early stage of dementia (MMSE= 21–28) and living in their own homes participated (Table 1). After the informants had given their consent, their diagnosis was obtained from relatives (for those who were cohabiting) or from the memory unit (for those living alone).

Context

All interviews were performed in the informant’s home, mostly indoors but also outdoors. During the first data collection session, seven relatives were present to some extent. Before the second session, the researcher asked the relative if it would be possible to conduct the interview alone, to ensure that the informant would be affected as little as possible by the relative’s presence. At the second session, the relatives were present only for some minutes and then went outdoors (n=6), to another room (n=2) or were not at home at all (n=3).

Data collection

Individual interviews were conducted twice with each informant, in the form of a conversation. Prior to each interview, the researcher first took a 10-minute walk around the informant’s neighbourhood to get a picture of the area. This enabled the researcher to better
understand the informants’ descriptions of and reflections on being outdoors (Moore & Hollett, 2003). Owing to the memory problems that accompany the disease, the interviews were performed near a window with view of the outdoor area; some interviews were even performed partly or totally outdoors to support the informant’s memory. The interviewer started by pointing out of the window and/or in the garden and asking: ‘I see you live in a house/apartment, do you usually go outdoors, e.g., in the garden?’ Later, the informants were encouraged to describe their experiences of being outdoors, what they did while outdoors, either together with relatives or independently, etc. The first interview lasted between 35 and 87 minutes and the second between 36 and 94 minutes. The first interview was conducted June to October 2009 and the second between two weeks and three months later. The variation in time was due to some informants taking holidays. All interviews were tape-recorded and transcribed verbatim. Repeated interviews were performed to achieve depth in the informants’ descriptions and to enable the interviewer to develop, deepen and clarify any questions from the first interviews. Furthermore, repeated interviews were considered valuable for building a relationship.

During and immediately after each interview, field notes were made about informants’ non-verbal behaviours (facial expressions, e.g., joy, sadness, etc., and body language, e.g., whether they used their hands to clarify their descriptions) (Patton, 2002), where the interview took place (indoors and/or outdoors, which room) and where the relative was. These notes were used to augment the data collection and as a support in interpretation of the data.
Ethical considerations

The Regional Ethical Review Board granted permission for the study. Staff at a memory unit and Relative Caregivers Support Centre, who met both persons with dementia and their relatives, identified eligible informants. The researcher (AO) provided a more detailed description of the study aim, procedure and ethical considerations during the initial phone contact (either speaking with the person with dementia or the relative, based on the wishes of the person with dementia). Informed consent, written and verbal, was obtained from all persons with dementia. The information was repeated at each interview session. Participation was voluntary and the informants were informed that they could end participation at any point. None declined to participate in the study. Plenty of time was set aside for reflection and discussion in connection with the interviews (Hellström et al., 2007), and the researcher used a sensitive approach so as to earn the informant’s trust (cf. Sabat, 2005).

Data analysis

The data were inductively analysed using qualitative content analysis (Graneheim & Lundman, 2004). Qualitative content analysis deals with the manifest content, by describing the categories clearly visible in the interview text, and the latent content, by interpreting the underlying meaning, themes, and answering the “how” questions. The interviews were transcribed verbatim and thereafter listened to and read through repeatedly to get an overview of the data. In this process, the field notes were used to support and elucidate the first naïve reading of the texts. Next, the text concerning the topic of being outdoors was extracted and brought together into a single text (approximately two-thirds of the data). Meaning units related to the aim were identified, condensed and labeled with codes. The whole interview was the unit of analysis and the findings were interpreted accordingly. The different codes were compared and grouped into categories based on similarities and differences, thus
describing what the informants talked about. Finally, sub-themes and a main theme were identified, describing the underlying meaning.

*Trustworthiness*

To achieve trustworthiness, we used the concepts credibility, dependability and transferability (Lincoln & Guba, 1985; Graneheim & Lundman, 2004; Krippendorff, 2004). To strengthen credibility, the first and last author engaged in a critical discussion of each step in the process of analysing five interviews. All authors read the condensed material and discussed the abstraction to categories, sub-themes and theme to reduce the possibility of a researcher biased interpretation of the data. Furthermore, prolonged engagement (Lincoln & Guba, 1985) across two different time-points and quotations from the interviews were used to establish credibility. Dependability refers to, e.g., the risk of inconsistency during data collection and analysis. The informants were all asked the same main questions, and data collection and the analysis process were continually discussed in the research team. All informants had early-stage Alzheimer’s disease, thus our findings should not be generalized to all dementia types and stages. The transferability of the findings to other contexts must be judged by the reader, and determined through further research (Graneheim & Lundman, 2004).

**Results**

Analysis of the data revealed one main theme: ‘*Outdoor activities as a confirmation of self through being and doing*’. The informants described being outdoors as a confirmation of the self. Confirmation of the fact that one was able to maintain desired activities, despite the disease, was essential. A confirmation of the self was not always positive, e.g. when discovering that some activities were no longer possible to perform. Because the informants
reflected on the fact that they could no longer perform certain activities, the opportunity to be outdoors and perform activities they had been engaged in earlier in life was highly valued: ‘I need to know (confirmation) that I can do the things I did before (the dementia disease)’ (informant 8:1 [interview 1], male) and ‘as long as I can be outside and do things (activities) I’ll have an identity’ (informant 9:1, female). Thus, the informants described being outdoors as something positive, but also as something that reminded them of their losses: both were a sort of confirmation. Themes and categories are presented in Table 2.

Tbl 2

<table>
<thead>
<tr>
<th>Shifting between “still being part of it all” and a sense of grief and loss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being outdoors was reflected on by the informants as shifting between “still being part of it all” and a sense of grief and loss. The sub-theme was based on the categories sensory experiences, social interaction, freedom and independence and self-confidence. “Being part of it all” was related to external input (sensory stimulation in the form of smells, sounds, etc.), internal feelings (a sense of freedom and independence) and relations to others (social interactions). The feelings and experiences expressed were related to different activities, e.g., biking, skiing, walking the dog, gardening or just sitting outdoors drinking coffee.</td>
</tr>
</tbody>
</table>

The sensory experiences described by the informants involved sight, smell and hearing: hearing children play in the streets, hearing the birds singing in the woods, lying on the beach and listening to the sound of the sea, seeing a green and well-maintained golf course, smelling the scents of spring and tasting the first wild strawberries or just enjoying the quietness and peacefulness of the outdoors. Just being able to sit outdoors, breathe fresh air, feel the heat of the sun, and get a tan was associated with a sense of well-being. One informant reflected on
sensory experiences of being outdoors saying ‘It’s like medicine’ (informant 2:1, male), or as another informant said ‘It (being outdoors) reminds me that there is still a lot of life left to be lived’ (informant 8:1, male), even though he experienced grief and loss in relation to other things.

The social interaction involved in being outdoors was described by informants as meeting and talking to people passing by, watching children play, walking with others, drinking coffee, or just sharing something with others. One informant said, ‘If you know that at 10 or 11 I can go to the store and buy a newspaper, then that’s something to look forward to and then I meet a bunch of people, I’m friends with almost everyone at the store and I think that’s… and I hear many people say they’ve met me at the store and exchanged thoughts. They appreciated it and I do too’ (informant 5:1, male). Many informants also said that engaging in group activities improved social contacts, and this was perceived as important. Yet reflections on social interaction did not necessarily involve interaction with other people: just seeing, hearing and being with others were described as valuable as well.

Several of the informants associated being outdoors with a sense of freedom and independence, with just being able to go out. One female informant described being restricted or not having an opportunity to go out gave her the feeling of being trapped: ‘I’d feel like a prisoner if I wasn’t able to go out… it would be horrible, it would be terrible, I don’t want to be trapped inside, never’. [The informant depicted this feeling by tracing the outline of a little box with her hands] (informant 3:1, female). She described life spent outdoors as an opportunity to move, go wherever you want to and can go. The outdoor environment was also described by informants as a contrast to the indoor environment. Freedom was described by the informants as the need for a garden to go to ‘to escape everything that has to be done at
Informants described the outdoors as undemanding – as just being (informant 8:1, male) - ’It makes you happy, it’s a relief to get out and feel that the weather is okay, or if I feel like it I can take a walk - moving around is a relief’ (informant 5:2, male). ‘Life quality is being able to move around and go where you want and where you’re allowed to go’ (informant 8:2, male). Being able to spend time outdoors was also reflected on by the informants as an opportunity to look ahead – ’to see a future despite living with a dementia disease’ (informant 2:1, male).

Maintenance of self-confidence versus poor self-confidence was discussed in relation to outdoor activities. Maintenance of self-confidence meant being able to do what they had done before and was a confirmation of the self. Having an opportunity to perform outdoor activities they longed for meant a great deal, and they reflected on it as a source of confidence in oneself and one’s own abilities, including ’what I have been doing, who I am/ have been, and what I do today’ (informant 8:1, male). They described and identified themselves through current and former activities, such as being a farmer, lumberjack or golfer ‘I mostly want to be outside, I haven’t done anything else in my life, I’m… have been a farmer …’ (informant 5:1, male). Self-confidence was thus described in terms of the importance of doing what one had done previously. In addition, self-confidence was described as being satisfied with what one can do and never giving up; ’then there are funny things that really aren’t meaningful but that I do now because I can manage them’ (informant 8:2, male). Having the opportunity to resume a former activity was seen by informants as valuable and described by one informant as ’a life elixir’ (informant 2:1, male). Furthermore, self-confidence was strengthened when the informant was trusted and allowed to, e.g., be outdoors alone, have a key to the exterior door or take care of the grandchildren outdoors. [Tears of joy and happiness and a smile on an
informant’s lips clearly revealed the value and importance of being trusted to take care of the grandchildren] (informant 11:1, female, living alone).

Being restricted from going outdoors was described by one informant ‘as a loss of self-confidence and dignity’ (informant 2:2, male), as were restrictions associated with the dementia disease, e.g., not being able to drive a car. Some male informants described this as a great loss. Not being able to perform activities was described by several informants with a sense of grief and, loss, resulting in poor self-confidence: ‘The whole disease is about insecurity, poor self-esteem and that affects your sense of direction’ (informant 8:1, male).

Striving to keep on despite perceived barriers

The sub-theme ‘striving to keep on despite perceived barriers’ was based on the categories physical impairment, problems with orientation, mental aspects of living with dementia and adaptation strategies. In the three first categories, the informants identified and described barriers at different levels concerning their physical and cognitive functions. However, though barriers were perceived, it was clear from the descriptions that they did not stop the informants from being outdoors. When reflecting on being outdoors, the informants described different kinds of barriers and how they dealt with them. Barriers were mentioned in relation to their own abilities (now and in the future), but also in relation to the environment. The value of being outdoors outweighed barriers, and the informants used different strategies to deal with these.

Primarily physical impairment was described, and the informants varied in their descriptions of having no, some or several impairments. The informants described concrete physical impacts, e.g. heart failure and eye problems, as limitations on maintaining past and current
activities. Winter was associated with a fear of falling, and the informants reported missing being able to go outdoors during this season. Some informants, however, braved the fear of falling because they did not want to be limited and forced to stay indoors. The informants also reflected on the physical capacity of their relative; sometimes the relative was not able to engage in the same activities as the informants owing to his/her own physical impairment.

Informants described having *problems with orientation* in time and space. Concrete descriptions included getting confused when the neighbourhood environment was changed. One informant described it as; ‘I can’t find it… you think you might find your way, but the fear of not being able to becomes a mental block’ (informant 8:2, male). Some informants, however, reported having no problem finding their way home in familiar environments. Others said that orientation was not a problem today, but that it might be in the future and some described a fear of such problems: ‘when that happens and I don’t know where I am, I’ll be extremely unhappy’ and ‘there’s no saying when that day will come’ (informant 9:2, female). One informant reflected on and worried about future opportunities to be outdoors: ‘the day I can’t find my way home or am incapable of doing things I enjoy, I probably won’t be able to be outside’ (informant 2:1, male).

Furthermore, when the informants reflected on the difficulties of being outdoors, they described “*mental aspects of living with dementia*”. This category included their descriptions of what it is like to live with a dementia disease and how it affects their possibilities to be outdoors. The informants described it as ‘being in another world’, ‘losing my footing’ and ‘an emptiness in my head’. [One informant described it visually by using her hands to form a “globe” around her head] (informant 3:1, female). Another informant described it saying, ‘When you go outside and you’re out there, it’s like walking in your sleep’ (informant 9:1,
female). Yet another informant described the “mental aspect of living with dementia” as involving feelings of panic and a sense of exhaustion, but despite these feelings she felt she still had rational thought; ’ that’s so fantastic that I can function rationally and be completely clear, but still I’m not really in the real world’ ( informant 3:2, female).

To maintain their daily and desired activities, the informants used different kinds of adaptation strategies, mostly taking an active approach. Active approaches were described in terms of problem-solving and preventive strategies. In order to handle problems with orientation, the informants used different kinds of landmarks, road signs, a crossroad, familiar houses etc. Being able to reconnect to these objects made it easier to navigate. An additional problem-solving strategy used to handle an insecure situation was to stop and think for a while, and then make a decision about which way to go, or ask someone for directions; ’ I usually stop, stand there and think… look around, relax… ’ ( informant 8:1, male). A further problem-solving strategy for dealing with an insecure situation was to systematically work your way through the neighbourhood, going from one house to another. One informant said: ’ I do what I want today, but maybe I have to do it differently than I did before I got this (dementia)’ ( informant 3:2, female).

Another way for informants to get help when they felt lost was to use a mobile phone. Just knowing they could call their relative gave them a sense of security. When the informants had problems finding their way, they described using several senses: ‘you use your sight, smell and hearing to locate wherever you are’ ( informant 8:1, male). The informants described listening for railways, the motor highway, etc.
Other strategies used to handle orientation problems were more carefully planned by the informants. One preventive strategy was to walk in areas that were known to the informants. One informant reported that she had trained her dog to find the way back home, the dog ensured her safety. Several informants mentioned that by walking on a path that loops through the forest, they were sure to return where they started. One informant had already searched for such forest loops to prepare her for possible future problems. The passive approach used was described as “letting someone else take care of you”. One informant said that because of her previous involvement in the condominium association, she trusted that people in her neighbourhood would recognize her, and help her home.

**Discussion**

Persons with dementia reflected on and described outdoor activities as a confirmation of the self (cf. Edvardsson et al., 2010; Cohen-Mansfield et al., 2000). Mainly positive confirmations were described, although confirmation could also be negative. A confirmation that you are no longer capable of engaging in desired activities, a change in your daily independent life, could be negative and lead to feelings of inadequacy and reduced well-being. The informants described confirmation of the self through outdoor activities as primarily a confirmation coming from themselves. The informants dealt with the difficulties they encountered (cf. Pearce et al., 2002; Clare, 2002, 2003), and while outdoors they used different kinds of adaptation strategies.

In the present study, and as described by, e.g., Clare (2002, 2003), Pearce et al. (2002) and Surr (2002), persons with dementia tried to maintain their activities and/or to adjust daily life to the difficulties associated with living with a dementia disease. “Striving to keep going”, as
described by the present informants, could be seen as shifting between maintenance and adaption, as revealed in Clare (2003), and as a continuum from self-maintaining to self-adjusting, as reported in Cadell and Clare (2011). The present findings on how persons with dementia described being outdoors as a “confirmation of self” could be discussed in relation to social construction theory (Sabat & Collins, 1999; Sabat & Harré, 1992). Informants’ descriptions of past and current outdoor activities involved attributes attached to themselves (Self 2); they saw themselves through their activities in a parallel process of seeing the person they were before and the person they still are today (cf. Pearce et al., 2002). They expressed a sense of loss and longing with regard to activities they could no longer perform (cf. Clare, 2003). Furthermore, the informants perceived values in relation to being outdoors: feelings of increased self-confidence, freedom and independence and sensory experiences. The present findings also revealed the importance for a person with dementia of continuing to be a person of value, despite the disease (Moyle et al., 2011; Steeman et al., 2006; Clare, 2002; Pearce et al., 2002). Informants’ depiction of being outdoors as something uncomplicated, undemanding – ‘just being’ – is in accordance with the “Attention Restoration Theory” (Kaplan & Kaplan, 1989). The theory is based on the notion that nature requires little energy and is thought to be unlimited and that it gives humans an opportunity to rest and recover. The uncomplicated aspect of being in nature was described by the informants in terms of sensory experiences, feelings of freedom, independence and just being with others. The fact that natural environments are non-demanding, in contrast to the built environment and indoor life, could be what allowed the informants to feel free. While in nature, they could experience being with others “in quiet” by sharing sensory impressions without verbal/ intellectual demands, which might strengthen the self.
The dementia disease itself is a Self 2 attribute, and some informants had accepted the disease, while others had not (cf. Sabat, 2006). In the present findings, physical impairments and problems with orientation were described in detail by the informants as problems and difficulties in accessing the outdoors. Several of the informants were aware they had lost certain physical and mental abilities, but also that other abilities were intact, and they worked hard to balance these two aspects of themselves (cf. Clare, 2003). The informants’ problems with walking and mobility seemed to have a greater impact on their access to outdoor activities than the dementia itself did (cf. Gibson et al., 2007). Through their portrayals of past and current activities, the informants described their identity (cf. Sabat & Collins, 1999). Having the opportunity and still being able to perform activities, even when physical and cognitive abilities are limited, could be a way to reinforce and maintain Self 2. The present findings suggest that persons with dementia struggle to maintain their identity, on the one hand, and to adjust to the changes caused by the dementia, on the other (cf. Clare, 2002, 2003). Although the disease can result in a variety of cognitive and behavioural problems and limit the person’s ability to carry out sequences of skilled actions, the condition does not seem to result in the loss of Self 1, though it does contribute indirectly to possible losses of Self 2 (Sabat & Harré, 1992). The informants expressed the importance of social contacts: talking, walking, meeting, or just being with others was perceived as socially stimulating (cf. Clare, 2002, 2003; Duggan et al., 2008; van der Röest et al., 2007). But this did not necessarily mean interacting with others; just sitting outdoors by oneself, merely observing others, was perceived as beneficial. Self 3 is also manifested by the fact that one has been affiliated with a group, e.g., that one was once a member of a hunting team. Furthermore, being trusted to take care of the grandchildren might be seen as a way of confirming the self, and as described by Clare (2003), as something that is greatly missed when one is no longer able to do it. This is
also connected to the role of others in affirming the self, in the act of permitting the person with dementia to go outside.

Our findings show that the informants used both problem-solving and preventive strategies when trying to manage potential problems in everyday outdoor life. Although most of them used such strategies, some had a more passive approach and let, e.g., relatives, friends and neighbours deal with any problems that occurred. Letting other peopleassume responsibility may be a relief (cf. Clare, 2002). The present study also reveals the creativity and imaginativeness of the informants’ strategies, traits that relatives may not have realized they had. Clare (2002, 2003) described the maintaining and adjustment that persons with dementia do to manage daily life as “holding on”, “compensating”, “fighting” and “coming to terms”. Several other studies have also described similar strategies used by persons with dementia to handle possible problems associated with the disease (Pearce et al., 2002; Clare, 2003; de Boer et al., 2007; Nygård, 2004; Øyebode et al., 2009; Preston et al., 2007; Beard et al., 2009). Previous work by Nygård and Starkhammar (2003), describing how persons with dementia use the telephone, demonstrated strategies similar to those of the present informants, e.g., seeking help from others, and repeating, stopping and reflecting to handle problems that emerged (also cf. Clare, 2002; Preston et al., 2007).

One limitation of the present study is the small sample. It is also important to bear in mind that the informants were persons with dementia who were still able to be and wanted to be outdoors. Strengths were the prolonged engagement with repeated interviews and the variation in age, gender and mobility.
In summary, the study indicates the importance of outdoor activities as a confirmation of the self for persons with early-stage dementia who want to be and are able to be outdoors. It is important that relatives and staff understand the strategies persons with dementia use to engage in outdoor activities, as such knowledge may help relatives and staff encourage and facilitate these activities. Describing their outdoor activities could also be a way for persons with dementia to explain to staff who they have been and still are.
References


Clare, L. (2002). We'll fight it as long as we can: coping with the onset of Alzheimer's disease. *Aging and Mental Health*, 6(2), 139-148.


Table 1 Demographics of the persons with dementia (n=11)

<table>
<thead>
<tr>
<th>Persons with dementia</th>
<th>All</th>
<th>Woman</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (n)</td>
<td></td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Mean age (years) (S.D.)</td>
<td>68(10)</td>
<td>62(13)</td>
<td>72(5)</td>
</tr>
<tr>
<td>Living situation (n)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- with a relative</td>
<td>9*</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>- alone</td>
<td>2*</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Alzheimer’s disease (AD) (n)</td>
<td>11</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Years since diagnosis (mean time)</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Mean MMSE (SD)</td>
<td>25 (3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Without help (n)</td>
<td>7</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>- Cane</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>- Walker</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Housing environment (n)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Terrace house</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Detached house</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Apartment</td>
<td>4</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Holliday cottage</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2 Overview of categories, subthemes and main theme revealed in the analysis

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory experiences</td>
<td>Shifting between “still being part of it all” and a sense of grief and loss</td>
<td>Social interactions</td>
</tr>
<tr>
<td>Freedom and independence</td>
<td></td>
<td>Freedom and independence</td>
</tr>
<tr>
<td>Self-confidence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems with orientation</td>
<td></td>
<td>Problems with orientation</td>
</tr>
<tr>
<td>Mental aspects of living with dementia</td>
<td></td>
<td>Mental aspects of living with dementia</td>
</tr>
<tr>
<td>Adaptation strategies</td>
<td></td>
<td>Adaptation strategies</td>
</tr>
</tbody>
</table>

MMSE= Mini Mental State Examination

*Residential neighbourhood in a small town
STUDY II
My, your and our needs for safety and security: relatives’ reflections on using information and communication technology in dementia care

Annakarin Olsson RN (Doctoral Student)1,2, Maria Engström RN, PhD (Associate Professor)1, Kirsti Skovdahl RN, PhD (Senior Lecturer)2 and Claudia Lampic PhD (Associate Professor)3
1Faculty of Health and Occupational Studies, University of Gävle, Gävle, Sweden, 2School of Health and Medical Sciences, Örebro University, Örebro, Sweden and 3Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden

Scand J Caring Sci; 2012; 26; 104–112
My, your and our needs for safety and security: relatives’ reflections on using information and communication technology in dementia care

Aim: The present paper reports on a study aimed at describing relatives’ reflections on different kinds of information and communication technology (ICT) devices that are used or can be used in the daily care of persons with dementia.

Background: Many persons with dementia continue living in their own homes, which requires the support of their relatives. One way to meet the needs of relatives and persons with dementia is to use ICT.

Methods: An interview study was conducted in Sweden (2007–2008) with a purposive sample of 14 spouses of a person with dementia. Qualitative content analysis was used to identify categories and themes in the data.

Findings: Relatives’ reflections on the use of ICT were described as ICT – a support in daily life, ICT – internal and external conditions and ICT – the decision to use or not use.

Based on these categories, a theme was revealed: shifting between different perspectives: my, your and our needs for safety and security.

Conclusion: Relatives struggle to create a situation of safety and security in daily life for themselves and the persons with dementia. ICT devices with the right functionality and used at the right time are regarded as useful in solving everyday problems. In the decision to use or not use ICT, the opportunity to create a safe and secure environment overshadows potential ethical problems. Providing early information about ICT to persons with dementia and their relatives could facilitate joint decision-making regarding use of ICT.

Keywords: burden, dementia, information and communication technology, nursing, relatives, qualitative content analysis.

Submitted 18 August 2010, Accepted 30 June 2011

Introduction

The expected increase in the proportion of elderly people with chronic diseases, such as dementia, and the associated strain on formal care services require new and innovative solutions to supporting relatives in their daily care of persons with dementia (1). One way to meet relatives’ needs for support is to use information and communication technology (ICT). According to a review by Robinson et al. (2), ICT could serve as a complement to ordinary care and to increase safety and security in the daily care of persons with dementia.

Being the relative of a person with dementia

Most persons with dementia continue living in their own homes and are cared for by relatives (3). A person with dementia gradually loses the ability to act autonomously and must therefore rely on the decisions and support of others, primarily their relatives (4, 5). A systematic review by Stoltz et al. (6) showed that many relatives of persons with dementia were actively involved in the caregiving process. One large survey study showed that relatives of persons with dementia spent 10 hours or more each day on caregiving (7), and a great deal of relatives’ caring time has been reported to concern supervision/surveillance (8).
Living with and providing care for a person with dementia has been reported to be a stressful and demanding situation for relatives (9, 10). Reviews by Torti et al. (11), Black and Almeida (12) and Machnicki et al. (13) showed that demanding behaviours such as restlessness, wandering and worry in persons with dementia were significantly associated with caregivers’ burden.

As dementia progresses, problems with orientation in time and space become more frequent and may lead to potentially dangerous situations (14), such as leaving home in the middle of the night. Unattended home exits are common among persons with dementia and are a source of anxiety for relatives. One study by Rasquin et al. (15) revealed that persons with dementia who get lost outside the home or wander away cause relatives a great deal of worry. In a study among relatives of persons with dementia exploring their perspectives on wandering (2), relatives perceived a conflict between prevention of harm to persons with dementia, on the one hand, and their right to autonomy, on the other. In such situations, some relatives have been reported to justify locking doors (16, 17). However, in a qualitative study by Duggan et al. (18), it was shown that both persons with dementia and their relatives felt the outdoor environment enhanced quality of life and that not being able to go out often brought on feelings of depression among persons with dementia.

**ICT in the care of persons with dementia**

The ICT used in the care of persons with dementia can be described as having two main functions: assistive devices for cognitive deficits and surveillance technology. Examples of assistive devices are memory aids, electronic calendars, picture phones and cooker monitors. Surveillance technologies include safety alarms, bed alarms and door alarms (19–21). Furthermore, electronic tagging devices and passive positioning systems, based on mobile telephone technology in combination with technology to determine position [Global Positioning System (GPS)], are surveillance technologies that have been developed during recent years and that are beginning to be useful in dementia care (16, 17, 22).

In managing daily life, some of the needs relatives and persons with dementia have could be met through the use of ICT devices. A review by Lauriks et al. (23) and a survey study by Rialle et al. (27) showed that using GPS technology and monitoring systems enhanced feelings of security and reduced fear and anxiety among relatives of persons with dementia. In short, previous research indicates that ICT can be used as a support for relatives in the daily care of persons with dementia.

While this previous research is helpful, it has limitations and further investigation is justified. There is a wealth of studies explaining how the consequences of dementia are experienced and managed by relatives. However, there is a shortage of studies about relatives’ reflections on using ICT when providing this care, and most existing studies have been carried out in the UK. Thus, more studies are necessary to increase our understanding of relatives and persons with dementia and their reflections on using ICT in the context of everyday life.

**Aim**

The aim of this study was to describe relatives’ reflections on different kinds of ICT devices that are used or can be used in the daily care of persons with dementia.

**Method**

This study used a descriptive design with a qualitative approach based on individual interviews.

**Participants**

The sample consisted of fourteen spouses of persons with dementia between 62 and 89 years of age. The selection method was purposive sampling (28), aiming to achieve variation in participants’ age, sex and living situation. The criteria for participating in the study were being the relative of a person with dementia, having knowledge of and/ or previously used ICT devices in the care of persons with dementia and being able to communicate in Swedish. Ten participants had experiences of using one to two different types of ICT, and four had no such experience. Additional characteristics of participants and their spouses with dementia are presented in Table 1.

**Procedure**

Personnel at the Relative Caregivers Support Centre in a municipality in central Sweden identified relatives who met the criteria for study participation and provided initial information about the study. Relatives who were interested in participating were then contacted by the first author and received detailed information about the study’s aim and procedure. Subsequently, the first author scheduled an interview at a place and time preferable to the relatives. All participants received written and oral

© 2011 The Authors
Scandinavian Journal of Caring Sciences © 2011 Nordic College of Caring Science
Table 1 Demographics of relatives and persons with dementia and their experiences of using specific ICT

<table>
<thead>
<tr>
<th></th>
<th>All</th>
<th>Woman</th>
<th>Man</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relatives</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>14</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Mean age (years) (SD)</td>
<td>73 (10)</td>
<td>75 (9)</td>
<td>71 (11)</td>
</tr>
<tr>
<td><strong>Persons with dementia</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>14</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Mean age (years) (SD)</td>
<td>76 (10)</td>
<td>70 (11)</td>
<td>80 (6)</td>
</tr>
<tr>
<td><strong>Living</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Own home</td>
<td>10</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Residential home for persons with dementia</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Unit for short-time care</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>11</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Years since diagnosis (mean time)</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td><strong>ICT</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surveillance aids</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Safety alarm</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Bed alarm</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Door alarm</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Passage sensor</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Electronic tracking device</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Assistive devices</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cooker monitors</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Talking cassette/magazine</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Picture button telephone</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Memory aid</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Special remote control</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

ICT, information and communication technology.

Data were analysed inductively (30) using both manifest and latent qualitative content analysis, as specified by Graneheim and Lundman (31). The analysis process began with the first author listening to and reading through all interviews repeatedly to gain an overview and general impression. The second author listened to three interviews and read through five interviews. The analysis was continued by the first author, who identified meaning units related to the study aim. Each meaning unit was then condensed and labelled with a code. The different codes were grouped into subcategories, and subcategories that expressed related meanings were sorted into categories. The underlying meaning of the findings resulted in a theme. The analysis was carried out using a dynamic process of alternating between the whole and the parts. To strengthen both credibility and dependability, the first author performed the analysis and all authors discussed the different steps of the analysis process to reach agreement in the coding and categorization.

Ethical considerations

The Advisory Board at the local university granted permission for the study (52-507/07). Written permission to perform the study was also received from the head of the Relative Caregivers Support Centre. Because the interview questions could give rise to feelings of discomfort among informants, the interviewer used a sensitive approach (29). This meant being sensitive to the possible need to take a break or to stop the interview, e.g., when emotionally difficult situations arose. The interviewer set aside plenty of time for meeting informants’ potential needs for reflection and discussion in connection with the interviews. The recorded data were treated confidentially and kept locked in a fire- and theft-proof safe at the university.
Results

The overall theme – *Shifting between different perspectives: my, your and our needs for safety and security* – describes how relatives shifted between their own needs for safety and security and what they perceived to be the need of the person with dementia when reflecting on the use of ICT. The findings presented in the three categories – *ICT – a support in daily life*, *ICT – internal and external conditions* and *ICT – the decision to use or not use* – together consist of six subcategories with statements about reflections on ICT in relation to time, place and/or functionality. Time was connected to a perceived need for ICT in the past, present and future, both for relatives and for persons with dementia. Place was associated with temporary and permanent changes in the living situation. The functionality of the ICT device primarily concerned design aspects. The categories included descriptions of feelings of safety and security in relation to using or not using ICT, both for relatives themselves and what they perceived to be feelings of safety and security for the person with dementia. An overview of the theme, the categories and subcategories is presented in Table 2.

**ICT – a support in daily life**

The category *ICT – a support in daily life* – consisted of four subcategories: maintaining independence, getting help in an emergency, preventing harm and finding the person with dementia. Relatives shifted between describing their fear that the person with dementia would disappear or harm him-/herself and strategies for creating safety and security, both with and without ICT.

Maintaining independence. In the subcategory *maintaining independence*, relatives mainly described the perceived perspective of the person with dementia. One relative with experience of using a picture phone reported that she perceived that it helped the person with dementia maintain contact with family and friends. The relative programmed in phone numbers and put pictures on the picture phone so that the person with dementia could easily call friends and family members just by pushing a button on the phone. In this way, the picture phone helped the person with dementia maintain independence, something the relatives described as important. One relative made use of a memory aid and recorded messages to remind the person with dementia about activities, e.g. doctors’ appointments. Informants, both those with and without experiences of using an electronic tracking device, said that it gave the person with dementia an opportunity to remain physically active, despite progressive disease, and to maintain freedom of movement and thereby experience better quality of life.

The electronic tracking device allowed her to keep running and exercising for a long time. (Relative 2)

The electronic tracking device is needed so that they (persons with dementia) can move freely near their home on short walks. (Relative 10)

Getting help in an emergency. In this subcategory, mainly the perspective of relatives was described, and the safety alarm was the ICT device that all informants referred to. Relatives referred to ICT as a support when they needed help in varyingly urgent situations, both for themselves and for the person with dementia. Relatives had used the safety alarm for different purposes, e.g. when the person with dementia had fallen and they needed help.

I couldn’t get him up off the floor myself // then they came and helped me get him up // it was a great relief. (Relative 1)

Informants also used the safety alarm when they could not get the person with dementia in bed at night and when the relatives themselves suddenly became ill. Relatives who had no experience of using a safety alarm could see a possible need for one in the future.

Preventing harm. In the subcategory *preventing harm*, relatives’ statements showed a pattern of shifting between their own perspectives and what they perceived to be the perspective of the person with dementia. The most commonly mentioned situation associated with a need or desire for ICT to prevent harm was when the person with dementia made attempts to leave the home unaccompanied, during daytime or at night. One informant talked about how a door alarm allows one to catch up with the person with dementia and help him/her back into the

Table 2  Overview of subcategories, categories and theme revealed in the analysis

<table>
<thead>
<tr>
<th>Theme</th>
<th>Shifting between different perspectives: my, your and our needs for safety and security</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
<td>ICT – a support in daily life</td>
</tr>
<tr>
<td>Sub-category</td>
<td>Maintaining independence</td>
</tr>
</tbody>
</table>

ICT, information and communication technology

© 2011 The Authors

Scandinavian Journal of Caring Sciences © 2011 Nordic College of Caring Science
house, but to further increase the sense of safety and security for both of them, the informant had also supplemented the door alarm with a child-safe lock and a non-openable door handle.

The main advantage of the door alarm is that I quickly understand that something is happening and that I have time to stop her before she gets very far. (Relative 10)

To prevent persons with dementia from leaving home, some informants felt compelled to lock the exterior door. While the goal of locking the door was to increase safety both for the person with dementia and for themselves, the relatives also discussed the negative consequences of this measure.

Now I’ve locked the seven-lever lock, and that’s not good either. (Relative 3)

Relatives also mentioned movement detectors, passage sensors and bed alarms (pressure mats) as potentially useful ICT devices in the future. Relatives also invented their own nontechnical solutions to increase security for the person with dementia and for themselves. They hoped that these solutions would minimize or completely prevent the risk of the person with dementia leaving home on his/her own.

I come up with my own alarms, a stool or bench in front of the door, a bunch of bells on a band that falls to the floor when someone uses the door handle. (Relative 3)

Relatives also mentioned movement detectors, passage sensors and bed alarms (pressure mats) as potentially useful ICT devices in the future.

I think it would be good if we could get a bed alarm without paying for it // I sleep pretty deeply // I don’t wake up when she gets up // I usually sleep so deeply // I was afraid after she fell down // after that I’m more afraid it will happen again... that she’ll fall... // for me too... because she gets up anyway // she doesn’t know but it makes me feel more secure // if I woke up when she got up and could check on her... well... go with her to the toilet... and make sure everything is okay. (Relative 14)

Finding the person with dementia. In the subcategory finding the person with dementia, informants described shifting between their own perspective and the perceived perspective of the person with dementia. Relatives reported being constantly worried that the person with dementia would get lost when and if he/she were left home alone, and they feared that he/she would be found too late or never.

He was nowhere in the apartment and the front door was open // then came the cold shivers. (Relative 4)

Relatives who had used an electronic tracking device had positive experiences. They said that it gave them a feeling of security, and they also perceived that it gave a feeling of security for the person with dementia. Nonusers of electronic tracking devices had heard from others that they worked well, and some informants were interested in testing such a device.

It was terrible before we got it (the electronic tracking device)... then you just had the clock like this... and then nothing happened she was just gone... and an hour could go by... if you don’t have it (the electronic tracking device) then the anxiety is horrible... I can’t describe it, it’s so horrible. (Relative 2)

Some relatives expressed a potential need for an electronic tracking device in the future, e.g., in connection with a change in living situation (which might make finding the way home difficult for the person with dementia), when visiting family/friends or during stays at the summer cottage.

The informants emphasized that electronic tracking devices had to be designed to reduce the risk that the person with dementia would try to remove the device; they suggested that it could be sewed into his/her clothes, worn on a belt or placed in a handbag. They also said that electronic tracking devices need to be reliable and easy to use, both for the persons with dementia and for relatives, and that the design of the electronic tracking device must be tailored to the severity of dementia. One relative reported a frightening experience of using an electronic tracking device, in which administrative failure at the supplier firm resulted in problems finding the person with dementia.

ICT – internal and external conditions

The category ICT – internal and external conditions – consisted of two subcategories, ‘knowledge, skills and abilities’ and ‘financial aspects’, and describes conditions that relatives mentioned as necessary for the use of ICT.

Knowledge, skills and abilities. The informants reported that the persons with dementia and themselves had varying levels of knowledge, skills, abilities and interest in relation to ICT. They also said that relatives’ sex and age, as well as the severity of the disease of the person with dementia, influenced what kind of ICT they could use.

All informants knew about the safety alarm and its functionality. Relatives with no personal experience mentioned that safety alarms were used by friends with dementia living in units for short-time care and in residential homes. Some relatives expressed that they had very limited knowledge of ICT and also limited skills and abilities to handle it. Furthermore, relatives said that ICT manuals are difficult for old people to understand.

Female informants found it difficult to know what kind of ICT to use, and they said it was their husband (the person with dementia) who had previously taken care of technological issues. However, some female informants...
had ICT knowledge and skills based on their own interest or previous occupation. One male informant described a gender perspective in the following way:

It seems to me it might be harder in many situations... deciding what technical solutions I should come up with at home // which is usually easier for a man who uses technology more often // it’s not easy for all men either, but it is more common for us to have screwdrivers and wrenches at home. (Relative 10)

Informants described sharing their ICT knowledge and skills with other relatives of persons with dementia, e.g., at gatherings at the Relative Caregivers Support Centre. In addition, friends and the Centre for Aids and Assistive Devices were described as important sources of information about new ICT devices.

Several informants reported that, at this point, they did not think the person with dementia could deal with certain ICT devices. Especially, the safety alarm was not regarded as suitable for persons with advanced severity of dementia, because they would not remember to push the button to activate the alarm. Therefore, the severity of dementia largely determined the kind of ICT to use.

Financial aspects. Relatives said that many of the ICT devices they had come in contact with were very expensive and that they could not afford them. The informants described how they had applied for, e.g., a tracking device, but that the municipality did not supply or subsidize these technical aids. They expressed dissatisfaction with the situation.

The municipality has put up a lot of resistance to getting an electronic tracking device, because of the costs. (Relative 2)

A safety alarm was used by some informants, and despite the cost, they thought it was worth it. One relative related the following reflection about the door alarm supplied by the municipality:

I was at the Centre for Aids and Assistive Devices and they had a door alarm, but I reacted to the price... it shouldn’t have to be so expensive // at the store I found a door alarm for 1200 SEK. (Relative 10)

ICT – the decision to use or not use

In the category ICT – the decision to use or not use, relatives described ethical concerns and conditions for including the person with dementia in the decision of using or not using ICT, shifting between describing their own perspective and the perceived perspective of the person with dementia. The informants said that when two people have lived together for many years, it is difficult to make decisions for one another, even if one of them has been struck by dementia. Relatives also reported that, despite difficulties in communicating with the person with dementia, they found it important to let him/her be involved in decisions about what ICT to use in daily life.

If I didn’t make it plain to him that I intended to get ICT and he found out, then I would have messed it up somehow and not dealt with him like the person he is. (Relative 3)

One relative had let the person with dementia be active in the process of choosing and trying out different kinds of ICT, so he would not feel insulted. One ethical aspect relatives described as a problem concerned informing and explaining to the person with dementia that they had considered using ICT and doing so in a way that would not offend him/her. One relative said she explained to her husband that she would use the safety alarm for his own good and that it would minimize the time he would have to lie on the floor if he fell. The informants felt that if persons with dementia and their relatives had the opportunity to learn more about ICT before the need emerged, relatives would feel more comfortable about making decisions concerning later use of such devices.

Another ethical aspect of using a passive positioning alarm that informants described was their concern that the person with dementia would not like being supervised. Yet another aspect mentioned by relatives was that the severity of dementia affects their ability to decide on their own if, how and when to use an electronic tracking device. Despite the risk of violating the integrity of persons with dementia, informants felt that the electronic tracking device could provide independence and security for both of them. Most relatives believed that the person with dementia would accept a passive positioning alarm, but some informants expressed doubts about what attitude he/she would have towards using it.

Perhaps he would find it unpleasant to be closely watched like that. (Relative 13)

I think she’d think it was good if there was an alarm // that it would be good to have control // I don’t think it would affect her so much. (Relative 7)

Discussion

The main finding of the present study concerns how relatives shifted between describing their own needs for safety and security and the perceived perspective of the person with dementia when reflecting on the use of ICT. Relatives’ reflections on ICT were interpreted as efforts to find a balance between these perspectives, simultaneously taking time, place and functionality into consideration. The central issue from the perspective of the relative and the perceived perspective of the person with dementia is the need for safety and security, which is in line with the findings of Landau et al. (26).

While relatives’ reflections on using ICT in dementia care included reasoning about different ethical aspects, the overall impression is that the opportunity to use ICT devices to create a safe and secure environment for both the person with dementia and his/her relative...
overshadows potential ethical problems, such as violating the integrity of the person with dementia.

Beyond the perceived safety and security that ICT provided relatives, ICT reduced their constant fear and concerns that something could happen to the person with dementia. In addition, relatives perceived that ICT helped persons with dementia to maintain their independence and freedom of movement. The present findings suggest that the decision to use or not use ICT in the care of persons with dementia is not straightforward. Instead, this decision involved considering when, what type and how to use or not use ICT as well as whose needs should guide the decision. These findings illustrate the need for reciprocity between relatives and persons with dementia in the process of making decisions about use of ICT.

With regard to using ICT in dementia care, the autonomy and integrity of the person with dementia are central issues (32). In the present study, this was illustrated in relatives’ reports on the dilemmas they had experienced in relation to decisions to use or not use ICT. Relatives described taking into account their own needs as well as those of the person with dementia and striving to avoid their own needs being met at the cost of ignoring the needs of others – a finding also described by Robinson et al. (16). In a genuine caring relationship, such as that between a person with dementia and his/her relative, there is an ethical requirement to respond to the other person’s needs (33). Despite the fact that the dementia disease made it difficult for relatives in the present study to discuss with their spouse when and what kind of ICT to use, they did emphasize the importance of involving the person with dementia in the decision process and found it difficult to make decisions for him/her. Therefore, an advanced care planning process, in which both parties play a mutual and active role, would respect the autonomy of persons with dementia (34) and prevent them from feeling offended.

The present findings also indicate that, for some relatives, a gender perspective in relation to general knowledge of and interest in technology had an impact on their propensity to use ICT devices in the daily care of persons with dementia [cf. (27)]. In addition, the severity of dementia seemed to play a decisive role in relatives’ appraisal/decision regarding the use of ICT. Relatives also said that the functionality and design of the ICT device are important to take into consideration, including factors such as the size of the device [cf. (35)], its reliability and ease of use both for the relative and for the person with dementia [cf. (16, 17, 36)].

Methodological considerations

The present study includes informants with highly varying experiences and knowledge of ICT. Thus, the findings are not solely based on personal experiences of using ICT in the daily care of persons with dementia, but also on informants’ perceptions and assumptions concerning ICT. Most interviews were performed in the informants’ own homes, and the nearness of the person with dementia may have influenced these informants’ narratives. On the other hand, the interviews performed at the Relative Caregivers Support Centre may have been influenced/disturbed by relatives’ concerns about their spouses being alone at home. In the present study, individual interviews were chosen because of their suitability for collecting data on personal experiences of sensitive topics. In addition, the fact that interviews could be conducted in the informants’ homes allowed them to ‘keep an eye on’ their spouses.

To establish trustworthiness in the study, the criteria described by Graneheim and Lundman (31) have been followed, and credibility was achieved by choosing participants who varied in age, sex and living situation. After eleven interviews, we recognized the need for more variation regarding the living situation of family members with dementia and decided to include three additional relatives of persons with dementia living in residential homes or units for short-time care. Quotations for the interviews provide examples to further establish credibility. The generalizability of the study result is limited, as this is not a goal of qualitative research. With regard to transferability, the present findings may be applicable to caregiving spouses in the same situation, i.e. caring for a person with dementia or other cognitive dysfunction. Transferability of the findings to other contexts or groups, e.g. to relatives other than spouses, must be judged by the reader, based on his/her own experience, and determined through further research.

Conclusion

The present findings have implications for clinical practice and policy regarding dementia care, as well as for future research. Our study shows that the relatives of persons with dementia were most likely to have received information about various kinds of ICT devices from family, friends, the Relative Caregivers Support Centre and the Centre for Aids and Assistive Devices. The fact that most relatives had not received information about ICT devices from formal care providers may be a consequence of nursing staff’s limited knowledge of ICT. Nurses who frequently meet with persons with dementia and their relatives, e.g. district nurses, need to have up-to-date knowledge of ICT devices for use in dementia care, including functionality, design and financial issues. This can be achieved through continuous and regular information and training for nursing staff, and also by including information about ICT in nursing education.

Relatives who are willing and able to care for their family member with dementia should be offered the best possible resources, including various ICT devices, throughout the progression of the dementia disease.
Financial concerns regarding certain ICT must be acknowledged and may be addressed by offering less expensive alternatives or by policy decisions regarding subsidies. Providing early information about ICT to persons with dementia and their relatives, and involving them as mutual and active parties in the advance care planning process, could facilitate joint decision-making regarding use of ICT. Increased use of ICT may help to improve safety and security as well as quality of life for all concerned, and for some persons with dementia, the use of ICT devices may also help to delay admission to a long-term care facility.

Relatives of persons with dementia struggle to create a situation of safety and security in daily life for themselves and persons with dementia. While the present findings indicate that relatives’ decision to use or not use ICT included reasoning about ethical aspects, the opportunity to create a safe and secure environment with ICT devices overshadowed potential ethical problems. How persons with dementia experience the use of ICT, and how they perceive ethical aspects of using ICT, is largely unknown. It is important to increase knowledge about the perspective of persons with dementia, both in the clinical context when making decisions regarding use of ICT in daily care and in the research community. We believe that involving persons with dementia and their relatives in research on the use of ICT in dementia care would be useful and would promote a development towards increased use of ICT in the daily life/care of persons with dementia.

Acknowledgements

We thank the relatives who agreed to be interviewed and to Marie Bengtsson at the Relatives Support Centre in the municipality.

Author contributions

Annakarin Olsson, Maria Engström, Claudia Lampic and Kirsti Skovdahl were responsible for the study design. Annakarin Olsson drafted the manuscript and performed the data collection and data analysis. Maria Engström, Claudia Lampic and Kirsti Skovdahl participated in the data analysis and made critical revisions to the manuscript. Maria Engström, Claudia Lampic and Kirsti Skovdahl supervised the study.

Funding

This study was supported by grants from the University of Gävle, Sweden, The Swedish Dementia Association and Swedish Society of Nursing.

References

1 Magnusson L, Hanson E, Borg M. A literature review study of information and communication technology as a support for frail older people living at home and their family carers. Technol Disabil 2004; 16(4): 223–35.
9 Söderlund M. Som drabbad av en orkan. Anhöriga tillvaro när en närståendes drabbas av demens. 2004, Åbo Akademi University in Finland, Åbo.
A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use. *Health Technol Assess* 2006; 10(26).


33 Logstrup KE. *The Ethical Demand*. 1971, Fortress Press, Philadelphia, PA, USA.


STUDY III
A passive positioning alarm used by persons with dementia and their spouses – a qualitative intervention study

Annakarin Olsson, Maria Engström, Claudia Lampic and Kirsti Skovdahl

Abstract

Background: Increasingly, information and communication technology is being used to support persons with dementia living at home and their relatives. The aim of the present intervention study was to describe and explore the use and experiences of using a passive positioning alarm, over time, in daily life among persons with dementia and their spouses.

Methods: Using an ethnographically inspired approach, five couples, each including a person with Alzheimer’s disease and his/her spouse living in their own home, were repeatedly observed and interviewed regarding their experiences of using a passive positioning alarm. Interview text transcripts and field notes were analyzed using qualitative content analysis.

Results: The main findings show changes over time, where testing and checking the passive positioning alarm successively led to trust in the alarm and in one own’s ability to use it. These components were a prerequisite for the couples to perceive the value of the alarm.

Conclusions: A passive positioning alarm for persons with dementia and their spouses needs to be packaged as a “service” with flexibility for each user and based on user needs, abilities, knowledge and skills. Using a passive positioning alarm can be a valuable support that allows persons with dementia to be alone outdoors and can increase safety and security for them and their spouses. The present study contributes to our understanding of what prerequisites need to be in place and what barriers need to be dealt with before successful implementation can occur.

Keywords: Alzheimer’s disease, Information and communication technology (ICT), Interview, Participant observation, Passive positioning alarm, Spouse, Tracking

Background

Being outdoors on one’s own is considered an important activity of daily living and, for many; it is associated with the ability to maintain independence. A dementia diagnosis is distressing in its own right, but when paired with the threat of losing one’s independence, the issue of the living situation becomes problematic for both the person with dementia and his/her relatives [1]. One way to help persons with dementia be outdoors by themselves and to increase safety and security for relatives and persons with dementia may be to use different kinds of information and communication technologies (ICT) [2].

Living with a progressive disease such as dementia affects the entire life situation [3], not only for the person with dementia, but also for his/her relatives [4,5]. For persons with dementia, managing daily life often requires the help and support of relatives [6]. Several studies have shown that relatives of a person with dementia experience a feeling of being burdened [1,7-9]. The impairments accompanying the disease, e.g., memory and orientation difficulties, may lead to safety issues, such as the person with dementia getting lost [10], and may even force relatives to lock exterior doors or in other ways prevent the person with...
dementia from going outdoors [11,12]. Being outdoors is seen by healthy persons as well as persons with dementia as something valuable and important [13] and studies have revealed that being in nature environments has health benefits [14,15]. Thus, it would seem to be important to develop technologies that make it easier for persons with dementia to be outdoors on their own in a way that allows them and their relatives to feel safe and secure.

According to research in the area, use of ICT in the care of persons with dementia has increased [2,16,17]. A wide range of technologies exist that are intended to support the daily life of persons with dementia and their relatives, e.g., GPS (global positioning system) tracking technologies [18-20]. GPS provides a means of locating the user at any given moment by locating the device via satellite and sending the information via a network to a personal computer, a call center or a cell phone [21]. A review by Lauriks and colleagues [2] showed that tracking technologies promote perceived safety and security among relatives of persons with dementia in that such devices allow relatives to locate the person if he/she is lost. Recently published studies by Olsson et al. [22] and White et al. [20] have revealed that relatives of persons with dementia perceived ICT as a support in everyday life. However, earlier studies in this area have primarily taken the perspective of relatives and/or healthcare staff, and the need to investigate the perspective of persons with dementia has been emphasized [16,23-25]. Studies including the perspective of persons with dementia by interviewing them have mostly concerned ICT other than tracking technologies (e.g. [12,26]), and few of these have involved persons with dementia still living in their own homes (e.g. [19,27]). Some observational studies concerning ICT use among persons with dementia have been identified [28,29], however these studies did not focus on GPS tracking. Using tracking technologies in the care of persons with dementia has also raised ethical concerns concerning, e.g., the risk of violating the privacy and dignity of these persons [24,30-32], and critical voices have also been heard in society at large suggesting that the technology could be seen as a form of surveillance [30]. As such, it is important to further investigate users’ use and experiences of ICT in everyday life, both persons with dementia and their relatives.

Only a limited numbers of studies [18,24] have explored and/or described experiences of using GPS tracking technology from the perspective of persons with dementia. Observational studies on how involved actors use as well as relate to GPS tracking are important if we are to create need-driven and individually adapted technology. The aim of the present intervention study was to describe and explore the use and experiences of using a passive positioning alarm, over time, in daily life among persons with dementia and their spouses.

**Table 1 Demographics of the persons with dementia and spouses**

<table>
<thead>
<tr>
<th>Persons with dementia</th>
<th>All</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>5</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Age (Md years)(range)</td>
<td>68(55-73)</td>
<td>60</td>
<td>71</td>
</tr>
<tr>
<td>Years since diagnosis (Md time)</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>MMSE* (Md)(range)</td>
<td>23(19-28)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Age (Md years)</td>
<td>67 (62-68)</td>
<td>67</td>
<td>65</td>
</tr>
<tr>
<td>Living</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Terrace house</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detached house</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apartment</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summer cottage</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daytime activity program</td>
<td>Frequency (day-s/week)**</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

* MMSE= Mini Mental State Examination (valued measured < 1 year ago).
** Varied between 1-3 days/week.
The passive positioning alarm package (PPAP) intervention

The intervention comprised a “service package” containing a transmitter (based on GPS technique), a cell phone, manuals for the transmitter and the cell phone and a support person (who demonstrated the passive positioning alarm and could be reached by telephone) (Figure 1). When the persons with dementia went on their daily outdoor walks, they carried the transmitter in their pocket, glove or bag. Before the person with dementia left the home (or other place), the transmitter was activated by the spouse, who pushed a big red button marked with a cross, thereby creating a virtual fence with a radius of 500 meters. When the person with dementia left this predefined area, a Short Message Service [SMS] with a map was sent to the spouse’s cell phone, enabling the spouse to see the location of the person with dementia. Before the present study began, the passive positioning alarm package (PPAP) was tested for a period of six weeks by healthy elderly persons without known cognitive impairments.

Two weeks before the start of data collection, the couples received their transmitter, manuals for the transmitter and cell phone along with a two-hour verbal instruction session provide by the support person involved in the project. The support person was a healthcare professional from the municipality with long experience of working with persons with dementia. During the instruction session, the couples were able to test the transmitter and cell phone, ask questions and read the manuals. The support person was responsible for providing technical support throughout the study period.

Procedure

Participant observations and interviews

Inspired by an ethnographic approach [35] repeated participant observations and interviews were used to describe and explore the couples’ experiences and to describe how they used and handled the PPAP. The observations were conducted in the couples’ homes and during outdoor walks with the persons with dementia. For each couple, data collection was performed on five occasions (seven occasions for one couple). The observations focused on the couples’ handling of the transmitter and cell phone. The interviews, henceforth called informal conversations [34], focused on how the persons with dementia and their spouses experienced using the PPAP. A co-observer (another healthcare professional with long experience of working with persons with dementia, not the support person) participated in 17 of the 27 data collection occasions [34]. Use of a co-observer allowed one observer to accompany and observe the person with dementia on his/her outdoor walk, while the other observer observed and had an informal conversation with the spouse. The researcher and the co-observer alternated roles during the data collection occasions. On all data collection occasions, a summary was made (together when there were two observers present) immediately after the data collection, where field notes were written down and data were synchronized [34].

The first and last authors conducted the first two data collection occasions together, the goal being to develop ideas about how to best carry out the observations and informal conversations. Details and impressions were discussed between the researchers after the initial data collection occasions, concerning, e.g., the appropriate (physical) location from which to visually obtain the most information before and after the person with dementia took his/her outdoor walk. For all couples, the first data collection occasion occurred two weeks after they had received the PPAP. On this data collection occasion, the persons with dementia and their spouses were encouraged to describe their everyday life (focusing on the outdoor activities of persons with dementia) and to describe why they were interested in participation in the present study focusing on use of a passive positioning alarm. The first occasion also seemed to be important in creating confidence and a trusting relationship.

All subsequent data collection occasions followed a specific pattern (Figure 2). First a joint informal conversation with the person with dementia and his/her spouse took place, where the couple summarized what had happen in their daily life, in relation to use of the PPAP, since the previous data collection occasion (Part 1). Then the person with dementia went for an outdoor walk, during which he/she was encouraged and instructed to walk as he/she normally did when alone. During this walk, an informal conversation was conducted with the person with dementia.
and simultaneously, an informal conversation was conducted with the spouse in the home (Part 2). Finally, when the person with dementia returned home, a joint informal conversation was held with the person with dementia and his/her spouse, focusing on the former’s experiences of the outdoor walk, in relation to use of the PPAP (Part 3). To facilitate and stimulate recall [35,36] of the outdoor walks and to see on the map where the person with dementia had walked, the transmitter and cell phone were placed on the table during this part of the data collection. The couple’s own spontaneous experiences and reflections were then followed up on the subsequent data collection occasions. The time intervals between data collection occasions varied across couples depending on their vacations or other planned activities.

The observations were mostly recorded using an Mp3 player, though sometimes written observations were made. The audio-recorded observations were used to avoid the couples feeling “studied” and hearing what was recorded. The observer described verbally on the Mp3, e.g., the preparations made (spouses pushing the transmitter button, giving the transmitter to the person with dementia or putting it in his/her pocket, bag or glove) before the person with dementia went on his/her outdoor walk. To maintain complete focus during the observations, most field notes were written immediately after each data collection. The field notes consisted of reflections made during the observations and informal conversations: placement during the observation and informal conversation, physical position of the observer when the person with dementia left the house, perceived state of mind of the spouse and the person with dementia, facial expressions of the spouse and person with dementia, and the weather at the time [34].

**Data analysis**

The Mp3 files containing the recorded observations and informal conversations were transcribed verbatim. The transcripts, together with the field notes, were analyzed using qualitative content analysis as described by Graneheim and Lundman [37], Krippendorff [38] and Patton [34]. The field notes provided necessary and important information, allowing the researchers to put the data in the “right” context. First, all transcripts and field notes were read through several times to gain an overview and general impression of the data. Second, meaning units related to the study aim were identified, thereafter condensed and labeled with a code. These steps were performed by the first author and discussed with the last author. Codes that expressed related meanings were grouped together into five sub-categories and two categories. The identified codes, sub-categories and categories were discussed in the entire research team. Analysis and findings from observations and informal conversations during the outdoor walks (Part 2), concerning the persons with dementia and their strategies for and feelings about being alone outdoors, will be reported elsewhere (Figure 2).
Ethical considerations
Approval was obtained from The Regional Ethical Review Board (2009/078). The participants received oral and written information about the study and both the person with dementia and the spouse gave their written informed consent. Participation in the study was strictly voluntary and all participants were assured of confidentiality. No participant declined participation. Furthermore, methodological and ethical considerations especially relevant in research on persons with dementia were taken into account [39], such as the fact that observations and conversations might be emotionally stressful and raise feelings of discomfort among both persons with dementia and relatives. It was therefore important for the researcher to approach the situation with sensitivity, to look for signs of distress and, if necessary, to end the observation and/or conversation.

Results
The participants’ experiences of the PPAP appeared to change over the time in which the couples were observed using and becoming familiar with the PPAP. The progression toward comfortable and competent use and handling of the PPAP was individual, owing to crucial factors such as abilities, knowledge and skills in using the device. By testing and checking the PPAP and their own performance, they developed a trust in the PPAP and in their own ability to use it. In parallel with this increased trust, they also described the PPAP as valuable. The findings are presented in three categories and four sub-categories (see Figure 3); the categories “Prerequisites for and barriers to PPAP usability” and “Trust in the PPAP and one’s own ability to use it” are considered preconditions for the category “Value of the PPAP”.

Prerequisites for and barriers to PPAP usability
The couples described and showed the abilities, knowledge and skills needed to use and handle the PPAP. The design aspects of the PPAP that needed to be revised, changed and/or complemented were discussed by both the spouses and the persons with dementia.

Abilities, knowledge and skills
The spouses’ described their ICT abilities, knowledge and skills as varying from limited to more extensive. The spouses who described previously or still working with ICT reported being and were shown to be more comfortable with using the PPAP. In some couples, the person with dementia was primarily the one who had handled, or was still handling, technical devices (e.g., remote controls, DVD player, etc.) in the home, and in other couples the spouse was the more technical person. Those who felt they had and showed limited abilities, knowledge and skills reported on the first data collection occasion that they needed further verbal and hands-on instructions from a support person if they were to use the transmitter and cell phone and understand the manuals. They showed and expressed problems with, e.g., picking up an SMS with the map, reading and understanding the manuals (instructions), getting the transmitter and cell phone started or just knowing and understanding whether the transmitter and cell phone batteries were fully charged. As some spouses said: “Then it depends on how technical you are and I’m definitely not, right? How familiar you are with cell phones in general” [spouse occasion 1] and “I’m not so great at technical things so I think, can I do this?” [spouse occasion 2]. Spouses who described themselves as more skilled ICT users expressed and showed confidence in handling the technology across all the repeated data collection occasions.

Physical and functional design of the PPAP
Both the persons with dementia and their spouses discussed the need for improvements and changes in the design of the whole service package, irrespective of previous abilities, knowledge and skills in relation to different kinds of ICT. Some persons with dementia made statements about desired changes in the design of the PPAP during the first data collection occasion, while others never mentioned changes or described them later on. Among the spouses, all made statements about the need for design changes, but like the persons with dementia, these statements came at different times throughout the data collection. One spouse rewrote the manuals after having seen the transmitter and phone demonstration, “There’s too much information, reduce the number of steps” [spouse occasion 1] and “step-wise instructions would be desirable” [spouse occasion 2].
occasion 1]. Furthermore, the persons with dementia said that in situations when they felt lost outdoors, it was important to be able to contact and hear/talk to their spouses. The spouses also felt this was important, ‘the telephone button should be activated (work) . . . so we can communicate with each other’ [transmitter] [spouse and person with dementia occasion 2]. Based on their previous ICT abilities, knowledge and skills and their need for increased control, one couple manipulated the PPAP by not activating a new virtual fence when the person with dementia went alone outdoors. Thanks to this manipulation, the position of the person with dementia was constantly visible to the spouse. Other couples also expressed wanting this function, because they felt it would make them feel both safe and secure, ‘would like a non-hidden safety zone . . . [I should always be visible’ [cell phone] [person with dementia occasion 5].

Trust in the PPAP and one’s own abilities

During the entire data collection, the spouses expressed and showed a need to test and check the PPAP, and they sought verification from the researcher regarding their use and handling of the ICT. The tests and checks were made on the basis of the couple’s abilities, knowledge and skills in using the PPAP. Whether or not they felt they could depend on the PPAP was based on their trust in the PPAP and in their own ability to use and handle it.

Testing and checking the PPAP

The spouses reported frequent testing and checking of the PPAP. To do this, the couples took joint walks outdoors and constantly followed their own path on the cell phone. ‘Now we’ve gone out together the last time taking it [transmitter] with us just to see if it worked’ [spouse occasion 1]. ‘Then I took both the phone and the GPS [transmitter] with me when I walked in the woods’ [spouse occasion 3]. This approach was described by the male spouses. The spouses also checked by asking the person with dementia a question, e.g., ‘Do you know if I should always be visible’ [cell phone] [person with dementia occasion 5].

Testing and checking one’s own ability

To determine whether they were handling the PPAP “correctly,” the spouses showed the researcher what testing and checking one’s own ability could entail, e.g., the different steps in navigating and pushing buttons on the PPAP and cell phone and picking up the map (SMS) as a way of verifying that they were using the ICT in the “right way”. This approach (testing and checking one’s own ability) was observed more frequently among the female spouses than among the male spouses. As one spouse described: ‘When it says “go to” then I know exactly what I should do. But it often shows . . . sometimes it shows the stock-exchange rates. So should I push the one down here [cell phone] because then I’ll get a (signal). . . now it’s just a mess . . . I’m . . . I’m doing it wrong now? Because I’m not getting a map. Wait a minute, now I forgot . . . how can I see the map now? Now there’s a connection. Now I’m supposed to push it [transmitter] here right. Right, wasn’t that it?’ [spouse occasion 2].

The value of the PPAP

Both the persons with dementia and their spouses expressed, at different points in time, the value of the PPAP in their life. In parallel with increasing trust in the PPAP and in their own ability to use and handle it, they expressed the value of the PPAP. But the value of the alarm was also described with some caution, as one spouse said: ‘I think it’s good. As long as I make sure she has it [transmitter] with her, in her pocket when she leaves . . . I try to do this’ [remember]. ‘Then I usually put it [transmitter] on the chest of drawers there so . . . she knows she’s supposed to take it with her’ [spouse occasion 3]. The reported need for and value of the PPAP differed both between and within couples.

Safety and security

The persons with dementia appreciated the PPAP as a daily support in compensating for potential physical limitations, e.g., fear of falling while alone outdoors, but indicated that they could not see the PPAP as providing support for their dementia disease today. Some persons with dementia described perceptual impairment as a consequence of disease progression, while others expressed little or no effect of their dementia disease and limitations related to it. The persons with dementia reported being aware that they would one day be much worse and have a greater need for the PPAP, not just for their own safety and security but also for their spouse’s feelings of safety and security. Most of the spouses felt that the person with dementia had some cognitive problems and the spouses expressed a desire and/or a need for the PPAP to support daily outdoor life for the person with dementia. These needs were based on incidents in which the person with dementia could not find his/her way back home while being outdoors on his/her own or had repeatedly absconded from home. One spouse described it as follows: ‘I don’t know if she’d [person with dementia] dare. . . I don’t know, it could happen . . . /so really you need one [transmitter] that she wears. Pretty much all the time. . . /that she wears all the time, then I wouldn’t need to worry about her going out, then I’d find her’ [spouse occasion 3]. The value of the PPAP was also confirmed by the fact that all couples wished to keep it after the study was completed.
One spouse expressed it like this: ‘I would like to keep it [the passive positioning alarm] . . .// because it really provides security’ [spouse occasion 5]. The couples also said that the PPAP would be an important safety and security aid for them when spending time both in their summer cottages and in an unfamiliar environment. One person with dementia described how the PPAP could help her move in the area around her cottage, e.g. picking berries and mushrooms, without being afraid of not finding the way home, ‘I don’t dare go to places I don’t recognize, so I avoid it’ [person with dementia occasion 3].

The persons with dementia and their spouses saw the value of being locatable and saw no problem with the persons with dementia being monitored; they had not even considered that aspect. One person with dementia said: ‘I like the idea that I put it [transmitter] on and then he [spouse] knows where I am’ [person with dementia occasion 3]. In response to the researcher’s question concerning possible feelings of being monitored, both the persons with dementia and the spouses said that being visible on the map outweighs the risk of having their privacy violated, or as one person with dementia expressed it: ‘But that’s what we [persons with dementia] want, to be seen!’ [person with dementia occasion 3]. The possibility for spouses to use their cell phone to follow the person with dementia on his/her outdoor walks alone was described as creating both a feeling of safety and security for the couple and the possibility of freedom for the person with dementia. One person with dementia said: ‘Now when there’s so much talk about being locked in, dementia and all . . . then you can’t see it as a restriction, you have to turn it around and see it as a possibility’ [person with dementia occasion 5].

**Discussion**

The aim of the present intervention study was to describe and explore the use and experiences of using a passive positioning alarm, over time, in daily life among persons with dementia and their spouses. The main findings revealed changes over time in the participants use and experiences of the PPAP, such that testing and checking the PPAP successively led to trust in the PPAP and in one’s own ability to use it. The participants talked about the importance of the PPAP being easy to use, and this was expressed by the couples and observed in statements about the physical and functional design of the PPAP and about the abilities, knowledge and skills needed to be able to use the device (cf. [41]). The present results also revealed that, mostly for the spouses, trust in one’s own abilities to use and handle the ICT and trust in the ICT itself were important for actually using the device. Although some persons with dementia felt no current need for the PPAP, describing themselves as "too healthy", all reported wanting the PPAP in the future. However, at the outset of the study, all couples described occasions when the person with dementia had gotten lost while he/she was alone outdoors. In view of this, it appears important that persons with dementia and their spouses receive adequate information and be given the opportunity to discuss different types of ICT with healthcare personnel. Such discussions with the couple, relatively early in the disease process, could facilitate joint decision-making regarding both current and future use of ICT in daily life (cf. [22]). In additional it is important that the technology being developed based on the needs and experiences of the person with dementia and their relatives and that such need-based development should go hand in hand with collaboration between the research community and private enterprise.

The present study showed that the couples’ perceptions of the PPAP increasing their safety overshadowed any risk of violating personal integrity. None of the couples in the present study spontaneously raised the ethical issue of whether use of the PPAP was intrusive, and the implementation of a hidden zone was not a desired feature. On the contrary, not being seen was considered a source of insecurity. These findings are in contrast to the ethical debate concerning tracking technology, which has focused on the risk of offending and violating the integrity of persons with dementia [24,30-32]. One explanation for this discrepancy may be that the PPAP used in the present study allowed only the spouses to monitor the persons with dementia on their outdoor walks. Several studies have reported that implementation of ICT in the care of persons with dementia needs to be preceded by extensive ethical discussions [11,32,42]. Welsh and colleagues [30] reported that some ICT (e.g., tracking technology) devices used in dementia care were perceived by healthcare staff as violating human
dignity and freedom, given the use of similar technology in criminal surveillance. While this stance is understandable considering that all such devices are based on GPS, it could also be argued that it is unethical to deny persons with dementia and their relatives the opportunity to use a service, such as the PPAP, that could give them independence and security in daily life. It is also important that the tracking technology be adapted to the individual and used as an aid to living a daily life that is as fulfilling and active as possible despite the presence of a dementia disease. Finally, gender differences in testing and checking one’s own abilities as well as the PPAP were described and revealed in the present study. Further studies are needed to investigate these differences.

Methodological considerations
The main strength of the present study was the use of repeated participant observations and informal conversations, an approach that allowed us to follow the couples and the development of their use of the PPAP over time [34] and can thereby be seen as appropriate. A further strength was that the observations and conversations were performed in the couples’ own homes and that the persons with dementia participated actively as informants. Despite the emotional upheaval of describing and reflecting on their situation, all of the participants (both persons with dementia and their spouses) appreciated being given an opportunity to speak with someone who showed an interest in hearing their stories. The observers’ knowledge and experience of caring for persons with dementia and their relatives were considered a prerequisite for admission to the home, for creating a trusting environment in which to carry out the observations and conversations, and for being given the opportunity and permission to return (on the next occasion) (cf. [35]).

Credibility [37,43] was achieved by the first and last authors discussing the steps used in the process of analyzing the observation and conversation occasions. All authors were engaged in a critical discussion of the analysis at all levels, from code to category. To further strengthen the credibility, excerpts from the interviews were included in the results. To increase the dependability of the study, the data collection and analysis process were continually discussed in the research team. The findings may be transferable to groups of people with other cognitive disabilities, although decisions about transferability must be made by the readers [34,37,43]. A limitation that should be taken into account is that data collection was carried out during a time of year when outdoor activity is limited, due to snow and low temperatures. This might have influenced the frequency of the couples’ use of the PPAP. Moreover, future research is needed to explore the experiences of persons with dementia in later stages of the disease. Persons with severe dementia may experience deterioration of their verbal communication skills, which is why a longitudinal observation study should be considered.

Conclusions
The passive positioning alarm was perceived as providing valuable support for both persons with dementia and their spouses. Achieving successful implementation of the PPAP in the daily life of persons with dementia and their spouses requires a service package that provides an overall solution promoting the usability and value of the PPAP. The present study contributes to our understanding of what prerequisites need to be in place and what barriers need to be dealt with before successful implementation can occur. Due to the physical and functional design of the device, persons with dementia and their relatives must receive individual support that is based on their individual abilities, knowledge and skills. Such support and feedback at “the right level” should enable them to feel trust in themselves and in their use of the PPAP.

Abbreviations

Competing interests
The authors declare that they have no competing interests.

Authors’ contributions
All authors participated in the design and analysis of the study and the manuscript preparation. Data collection was performed by AO. All authors read and approved the final manuscript.

Acknowledgements
This study was supported by the University of Gävle, Örebro University, The Knowledge Foundation and by grants from The Dementia Association - The National Association for the Rights of the Demented.

Author details
1 Faculty of Health and Occupational Studies, University of Gävle, Gävle 80176, Sweden. 2 School of Health and Medical Sciences, Örebro University, Örebro 701 82, Sweden. 3 Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm 171 77, Sweden. 4 Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden. 5 Faculty of Health Sciences, Buskerud University College, Drammen, Norway.

Received: 7 June 2012 Accepted: 31 January 2013
Published: 5 February 2013

References
A passive positioning alarm used by a qualitative intervention

van Vliet D, de Vugt ME, Bakker C, Koopmans RT, Verhey FR:

Holst G, Edberg AK:

Stim B, Barroso J, Davis LL:

Bantry White E, Montgomery P, McShane R, McShane R:

Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence.


A systematic review of evidence for the added benefits to health of exposure to natural environments.


A pilot study on the use of tracking technology: Feasibility, acceptability, and benefits for people in early stages of dementia and their informal carers.


Electronic tracking for people with dementia: a longitudinal study of a behavioral symptom.


Balancing rights and risks: conflicting perspectives in the management of wandering in dementia.


Surveillance technology: an alternative to physical restraints? a qualitative study among professionals working in nursing homes for people with dementia.

Effects of tracking technology on daily life with dementia – three experimental single-case studies

Annakarin Olsson, RN, PhD student 1, 2), Maria Engström, RN, PhD, Associate Professor 1,3), Pernilla Åsenlöf, PT, PhD, Associate Professor 4), Kirsti Skovdahl, RN, Professor 2,5), Claudia Lampic, PhD, Associate Professor 6)

1) Faculty of Health and Occupational Studies, University of Gävle, Sweden.
2) School of Health and Medical Sciences, Örebro University, Sweden.
3) Department of Public Health and Caring Sciences, Uppsala University, Sweden
4) Department of Neuroscience, Physiotherapy, Uppsala University, Sweden
5) Faculty of Health Sciences, Buskerud University College, Drammen, Norway
6) Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Sweden

Correspondence to:
Annakarin Olsson
Faculty of Health and Occupational Studies,
University of Gävle
80176 Gävle
Sweden
Tel: +46 26 64 88 12
Fax: +46 26 64 82 35
E-mail: annakarin.olsson@hig.se
Abstract

Objectives: To investigate the effects of using tracking technology on independent outdoor activities and psychological well-being in three persons with dementia and their spouses.

Methods: Three experimental single-case studies with an A₁B₁A₂B₂ design, A representing baseline phases and B intervention phases. Continual daily measures of independent outdoor activities among persons with dementia and spouses’ worries about these activities were made during all phases.

Results: Access to a tracking technology consistently increased the independent outdoor activities of two persons with dementia; for one person with dementia these activities increased only during B₂. One spouse consistently reported decreased worry during B phases, another’s worry decreased only in B₂ and the third showed little variability in worrying across all phases.

Conclusion: Using tracking technology may serve as an aid in the daily life of persons with dementia by allowing them to be independent outdoors and may decrease spouses’ worries.

Keywords: Alzheimer’s, dementia, experimental single case study, information and communication technology (ICT), outdoors, tracking technology
1. Introduction

The value of being outdoors for persons with dementia (PwDs) has been described [1-3], including how it strengthens their sense of identity, the ‘Self’ [4, 5]. Some PwDs continue to spend time outdoors on their own despite relatives’ worries that they might get lost or hurt [6-8], while other PwDs are restricted from going outdoors by their relatives due to such worries [9]. Locked doors are commonly used in residential homes for PwDs [10, 11] and also in their own homes, although being restricted from going out has been shown to lead to decreased independence and feelings of being trapped [12]. Living with and caring for a PwD puts relatives in situations where they tend to subordinate their own activities to seeing to the PwD’s needs [13, 14]. In a recent study [15], the strongest predictors of caregiver burden were PwDs’ lower cognitive status and more time spent walking independently outdoors. In order to support PwDs and relatives in daily life, tracking technologies based on GPS technique (global position system) have been developed [11, 16-18] that have the potential to increase feelings of safety and security among both PwDs and their relatives [10, 19]. There are few experimental studies evaluating the effect of using tracking technique on independent outdoor activities among PwDs and well-being among PwDs and their relatives [20]. Results from Pot et al. [20] showed that, while using tracking technology, PwDs experienced more freedom and were less worried while outdoors on their own and that caregivers showed a trend toward being less worried.

Experimental single-case designs are suitable for evaluating the effect of an intervention on behaviors and reactions in daily life. This design allows participants to be their own controls and to be studied in their natural settings, e.g., their homes. The design has methodologically strong tools for showing effects of an intervention, due to the possibility to carry out daily measures of individual-specific outcomes during the different phases of the study. Daily
measures assessed in structured diaries have several advantages in that they, e.g., eliminate recall errors and produce consistent reporting [21]. Selected outcomes are measured daily both during a baseline period (Phase A) and a period of intervention (Phase B) [22]. Using an A₁B₁A₂B₂ design strengthens the experiment, in that the intervention is withdrawn in A₂ (return to baseline condition) and reintroduced in B₂. In contrast to randomized control trial studies, where the same outcomes are measured for all participants, experimental single-case designs allow for assessment of individual-specific outcomes, taking into account that the intervention may have an impact on different aspects in different individuals. Intervention effects are demonstrated as differences in scores between phases A and B [22]. The aim of the present study was to investigate the effects of using tracking technology on independent outdoor activities and psychological well-being in three individual cases, i.e., three persons with dementia and their spouses.

2. Methods

2.1 Design

Three experimental single-case studies using an A₁B₁A₂B₂ design were used, alternating non-intervention phases (A₁A₂) and intervention phases (B₁B₂).

2.2 Setting and participants

The study was conducted in the participants’ own homes and surroundings. Inclusion criteria were couples consisting of a person diagnosed with a dementia disease and his/her relative, living together in their own homes; the PwDs should have a desire and be physically able to be outdoors. Recruitment of participants was performed with the help of healthcare staff at the memory unit within the county council (4 couples) and the Relative Caregivers Support Centre (1 couple) in a city in central Sweden. One couple was excluded due to the relative’s
difficulties in carrying out the daily measures, and another couple declined participation after receiving detailed study information. Participating PwDs were all men with an Alzheimer’s disease, were retired and took medications intended to delay the progression of dementia. Participating spouses were all women and retired. Data collection was performed from May to October 2011. Characteristics of the participating couples were collected at study inclusion using individual interviews and self-administered instruments (cf. Procedure and Measures); participant characteristics are presented in Table 1.

Insert Table 1 about here

_Couple 1._ The couple lived in an urban area with green areas/parks and several walking and bicycling paths in their neighborhood. The PwD usually took daily outdoor activities, predominantly alone. He had no mobility problems, was physically strong and able to take long walks. On several occasions during the month preceding study inclusion, the PwD had gotten lost while outdoors alone, causing his spouse great worry. The spouse had tried to restrict the PwD from going outdoors unaccompanied by locking the exterior door, but the PwD did not accept this and responded with irritability. According to the spouse, the PwD needed to be outdoors to avoid being irritable. The spouse also perceived the PwD to show signs of apathy, irritability, and disinhibition (Table 1). The spouse reported that she was not engaged in her own regularly occurring activities. She had primary responsibility for the household and reported that the PwD needed some help with instrumental activities of daily living (IADL) (Table 1). The spouse perceived her level of burden due to her husband’s disease to be medium (Table 1).
Couple 2. The couple’s neighborhood contained green areas/parks along with several walking and bicycling paths; they lived in an urban area. The couple usually took daily outdoor walks together. The PwD had no history of getting lost, but due to the spouse’s fear he would get lost, he was not allowed to take independent outdoor activities. According to the spouse, the PwD needed to be outdoors to have a feeling of well-being, and she was sad she had to restrict him from going out. The PwD participated in daytime care organized by the county council. The PwD was alone at home several hours a day when the spouse was engaged in her own activities. Because the spouse was worried that the PwD might leave the home while she was away, she locked the exterior door with an extra lock when he was at home alone. The spouse regarded this action as insulting but necessary, and felt her husband accepted being locked in. The PwD had some mobility problems (not quite steady on his feet), but did not want to use any kind of aid. According to the spouse reported that the PwD showed signs of depression, anxiety, apathy, aberrant motor behavior changes and severe sleep and eating disorders (Table 1). The spouse had primary responsibility for household and the PwD needed a great deal of help with IADL and some help with activities of daily living (ADL). The spouse perceived her level of burden due to her husband’s disease to be low (Table 1).

Couple 3. The couple lived in a rural area, near wooded areas of various sizes where one could walk. In the neighborhood there were also several walking and bicycling paths. The PwD usually took daily independent outdoor walks and bicycle rides. He had on one occasion been lost while outdoors alone, but this did not lead to the spouse restricting him from being outdoors. He did not have any mobility problems. The spouse was engaged in several of her own activities; she was sometimes away for the night, leaving the PwD home alone. The spouse expressed a worry that the PwD might get lost while alone outdoors. The couple did
very few outdoor activities together, but during Phase B₁, they were on a weeklong trip to the mountains. The spouse was primarily responsible for the household, although the PwD participated. The PwD needed some help with ADL, and the spouse perceived her level of burden due to her husband’s disease to be medium (Table 1).

2.3 Intervention

The intervention (passive positioning alarm [PPA]) comprised a “service package” containing a transmitter (based on global positioning [GPS] technique), a cell phone, manuals for the transmitter and the cell phone and access to a support person. When the PwDs took independent outdoor walks during phases B₁ and B₂, they carried the transmitter on them. When the PwD left a predefined area with a radius of 500 meters a message (Short Message Service, SMS) with a map was sent to the spouse’s cell phone, enabling the spouse to see the location of the PwD. Further information about the PPA is reported in Olsson et al. [23].

2.4 Procedures

The staff at the memory unit described the study to the couples, obtained their verbal consent, and forwarded contact information to the first author (AO), who then contacted each couple and screened them for eligibility for the study. The first author (AO) conducted an in-home interview separately with the PwDs and their spouses. This interview was done to identify individual-specific outcome variables for both the PwDs and the spouses based on perceived problems related to the PwDs’ independent outdoor activities. Detailed information was given describing the study procedure, the spouse was asked to complete self-report measures, and verbal and written informed consent were obtained from both the PwD and the spouse. In the week prior to the first baseline period (A₁), the first author made a second in-home visit, during which she provided repeated information regarding study procedure, diaries covering
the first 2 weeks of the study period and stamped reply envelopes. During Phase A₁, the couples were instructed to make daily ratings in the diaries. On Friday at the end of Phase A₁, the couples participated in an instruction session regarding the PPA, provided by the support person. During the session, the couples were able to test the PPA, ask questions and read the manuals together with the support person. The predicted time it would take for the spouses to learn to use and handle the alarm was 2 weeks. The couples received the PPA and were instructed to use the device as frequently as possible during Phase B₁. At the end of Phase B₁, the support person removed the PPA from the homes. During Phase A₂, the couples received no intervention. At the end of Phase A₂, the PPA was returned to the couples for use during Phase B₂.

The researcher (AO) had weekly telephone contact with the spouses during all phases. These occasions were used to remind them to complete the diaries daily and for the researcher to answer any questions the participants might have. The participants returned their diaries by mail every week. New diaries and stamped reply envelopes were sent by mail every second week to the couples. Decisions regarding the length of each phase, for each couple, were made by three authors (AO, CL, PÅ) following visual inspection of the graphs depicting the collected data; the criterion for entering the next phase was stability in the data.
2.5 Measures

Primary and secondary outcomes were assessed using daily structured ratings.

**Primary outcomes**

**PwD independent outdoor activities (spouse rating).** The number of independent outdoor activities each day was reported by the spouses. Data are reported as the percentage of days with independent outdoor activities during each period.

**Spouse worry concerning PwD independent outdoor activities (spouse rating).** The specific items concerned “worry when the husband was outdoors alone” (Spouse 1 and 3) and “worry that the husband would get lost while outdoors alone” (Spouse 2). Ratings were scored on numerical rating scales (0-10) with end-points ‘not worried at all’ to ‘extremely worried’.

**PwD irritability and depressive mood (proxy rating by spouse).** The specific items concerned PwD irritability (proxy PwD 1) and depressive mood (proxy PwD 2 and 3). Spouses’ proxy ratings were scored on numerical rating scales (0-10) with end-points ‘no irritability at all’ to ‘extremely irritable’, and ‘no depressive mood at all’ to ‘extremely depressed mood,’ respectively.

**Secondary outcomes**

**General well-being for spouses (spouse rating) and PwDs (proxy rating by spouse; PwD rating).** Ratings were scored on numerical rating scales (0-10) with end-point alternatives ‘no well-being at all’ to ‘extremely good’.

**Worry about getting lost during independent outdoor activities (PwD 3) (PwD rating).** Ratings were scored on a numerical rating scale (0-10) with end-point alternatives ‘not worried at all’ to ‘extremely worried’.
The diaries also contained a part in which the spouses could write whatever subjective comments they wished, e.g., daily events that might have influenced use of the PPA. In addition, accompanied outdoor activities (number each day), length of independent and accompanied outdoor activities (minutes) and the number of generated alarms when the PwD was alone outdoors were assessed.

**Descriptive measures**

Participant characteristics were collected at the start of Phase A using three instruments completed by the spouse. The Caregiver Burden Scale (CB Scale) [24] includes 22 statements rated in terms of frequency (1 = not at all, 2 = seldom, 3 = sometimes and 4 = often). A total burden index based on each individual’s mean scores is formed with mean scores interpreted as low burden (1.00–1.99), medium burden (2.00–2.99) and high burden (3.00–4.00). The Resource of Utilization in Dementia (RUD) [25] consists of three different categories, assessing how many hours are spent a day assisting the PwD with Activities of Daily Life (ADL), Instrumental Activities of Daily Life (IADL) and supervision. The Neuropsychiatric Inventory (NPI) [26, 27] includes 12 items describing symptoms that are scored regarding frequency (1 = Sometimes, 2 = Often, 3 = Frequently, 4 = Very frequently) and severity (1 = Mild, 2 = Moderate, 3 = Severe); the absence of individual symptoms is assessed with a 0. Frequency scores are multiplied by severity scores, thus forming a total score that varies between 0 and 144.

**2.6 Manipulation check**

The intervention was checked by documenting any events or circumstances that may have influenced the possibility for the PwDs to perform independent outdoor activities using the
PPA; this was achieved by inviting participants to document this in the diaries and through weekly telephone contact between the researcher (AO) and the spouses.

2.7 Data analyses

Graphs for each outcome were displayed and medians for each outcome and phase were calculated. Visual inspections of the graphs were made so as to identify changes in level, trend and latency [22]. Furthermore, visual inspection and calculations (percentages) were made of the non-overlapping [22, 28] scores between phases B₁ and A₁ and between B₂ and A₂, and celeration lines [29] were drawn to “predict” the couples’ performance in later phases.

2.8 Ethical consideration

The Regional Ethical Review Board granted permission for the study (2009/078). Participation in the study was strictly voluntary, all participants were assured of confidentiality and that they could withdraw from the study at any time without giving any explanation.

3. Results

Primary outcomes: Independent outdoor activities, spouse worry and PwD irritability and depressed mood

Couple 1

The percentage of days with independent outdoor activities for PwD 1 decreased from 52% in Phase A₁ to 24% in Phase B₁, remained stable during Phase A₂ (25%) and increased during Phase B₂ (49%) (Table 2). Figure 1 shows Spouse 1 worry concerning PwD 1 independent outdoor activities together with the percentage of days with PwD 1 independent outdoor
activities during each phase. For Spouse 1, the celeration line (red line in Figure 1) indicates a decrease in worry from A$_1$ to B$_1$. All except one point data point in Phase B$_1$ fell below the celeration line, indicating either an effect of the intervention or that the PwD 1 had fewer independent outdoor activities. The median for worry for Spouse 1 increased from the first intervention phase (B$_1$) to the second baseline phase (A$_2$), and then decreased during the last intervention phase (B$_2$). PwD 1 irritability (proxy rating) showed little variability during all phases, but increased during Phase B$_1$ (Figure 2); change in level and latency from A$_1$ to B$_1$ were observed, but no trend.

Insert Figure 1 and 2 about here

**Couple 2**

For PwD 2, the percentage of days with independent outdoor activities increased from 0% in Phase A$_1$ to 55% in Phase B$_1$. This frequency remained stable (54%) during Phase A$_2$, and further increased to 70 % in Phase B$_2$ (Table 2). During Phase A$_2$, PwD 2 carried a cellphone when alone outdoors, and his walks between the home and the daycare center were monitored by telephone calls between Spouse 2 and center staff to communicate PwD’s departures and arrivals. Figure 3 shows data on Spouse 2’s worries that her husband would get lost while alone outdoors, together with the percentage of days with PwD independent outdoor activities during each phase. In Phase A$_1$, during which PwD 2 performed no independent outdoor activities, Spouse 2 reported no worry. When the intervention was introduced in Phase B$_1$, PwD 2 started performing independent outdoor activities with the support of the PPA in the third week, and Spouse 2’s worries increased. In Phase A$_2$, when PwD 2’s independent outdoor activities were supported solely by the cell phone and telephone monitoring (see above), this was accompanied by increased spouse worry. Finally, a decrease in spouse worry
was shown in Phase B₂, when 70% of days contained PwD independent outdoor activities. PwD 2’s depressive mood (proxy) decreased over the whole study period. The celeration line (red line in Figure 4) indicates a decreasing trend of depressive mood for the PwD (proxy) from Phase A₁ to Phase B₁. PwD 2 showed variability in depressive mood during Phase A₁; no changes in median, level, trend or latency were observed.

Insert Figure 3 and 4 about here

Couple 3
For PwD 3, an increased frequency of independent outdoor activities, from 43% to 88%, was shown during Phase B₁ (Table 2). An intervention effect was also demonstrated by a decreased percentage of days with independent outdoor activities when the intervention was withdrawn in Phase A₂ (54%). During Phase B₂, frequency of independent outdoor activities again increased to 77%. Figure 5 shows the data for Spouse 3’s worries concerning PwD independent outdoor activities together with the percentage of days with independent outdoor activities for each phase. Spouse 3’s worries showed little variability during the study period (Figure 5). Depressive mood for PwD 3 (proxy) showed variability during the whole study period (Figure 6), but no changes in median, level, trend or latency were observed.

Insert Figure 5 and 6 about here

Secondary outcomes: Spouse and PwD well-being, PwD self-reported outcomes and additional outdoor activity variables
None of the PwDs performed independent outdoor activities more than once a day during the first baseline phase (A₁). During the first intervention phase (B₁), both PwD 2 and PwD 3
were independently outdoors two, even three times a day (Table 2). The PwDs’ own ratings of well-being, depressed mood, irritability and worry showed very little variability. The results for the primary and secondary outcomes are summarized and presented in Table 2.

Insert Table 2 about here

4. Discussion

The present results show that access to a PPA consistently increased the independent outdoor activities of two persons with dementia. For two spouses’ access to a PPA decreased levels of worry about the PwDs’ independent outdoor activities despite increased frequency of such activities. All couples in the present study had, in one way or another, come to a situation in which PwDs being alone outdoors was experienced by the PwDs and spouses as entailing a risk [cf. 30]. The three couples differed in their attitudes toward the PwDs’ possibility to continue independent outdoor activities and the couples could be seen as illustrating how these difficulties can be approached. In Couple 1, the PwD was more active outdoors than the spouse was and refused to be restricted by his wife’s attempts to lock him indoors. Both spouses 2 and 3 had their own activities outside the home to a greater degree than did Spouse 1 and worried that the PwD would get lost while being outdoors alone. Spouse 2 therefore locked the PwD in, which he accepted, while spouse 3 refrained from restricting her husband.

In Couple 1, the interviews with the couple revealed PwD 1’s great need to be outdoors, and according to the spouse, not being allowed to go outdoors was causing him to become irritable and her to worry when the PwD was outdoors on his own. Scores on the NPI supported the Spouse 1’s perception of irritability in the PwD 1. Quinn et al. [31] revealed that caregivers’ perception of relationship quality was influenced negatively by the PwDs’
needs for help with ADL and by the severity of behavioral problems. Spouse 1’s worries decreased during the second intervention phase, and this might be related to the fact that the spouse had developed trust in the PPA as well as the knowledge, skills and ability needed to use the device [cf. 23]. Previous research has shown that the intention to use and later actual use of new technology might be preceded by a stage of perceived usability [32]. Olsson et al. [23] revealed that the value of a tracking technology, in terms of safety and security, was related to users’ possibility to test and evaluate the technology as well as to their own abilities, knowledge and skills. Increased trust in the PPA during the second intervention period may also have contributed to the finding that PwDs’ independent outdoor activities increased during B2 for all three couples [cf. 23].

Couple 2 took regular outdoor walks together, but Spouse 2 did not want him to be alone outdoors. When Spouse 2 had her own activities away from home, she felt compelled to lock PwD 2 indoors, which felt wrong but still necessary. However, PwD 2 accepted being locked in. In the present study, Spouse 1 and 2 had tried to prevent the PwD from going outdoors alone in different ways, e.g., by physically preventing him (standing in the way) and/or by locking the exterior door. Locked doors are commonly used in residential homes for PwDs to prevent them from leaving their homes [33, 34], and studies have also shown that relatives use this strategy in their own homes as a safety precaution for their own as well as for the PwD’s sake [10, 35]. Following no independent outdoor activities for PwD 2 during the first baseline period, the couple carried the PPA with them on joint outdoor activities during the first weeks of the intervention period B1, which has been described as a way to achieve trust in the PPA [23]. During the third week of Phase B1, PwD 2 engaged in his first independent outdoor activities, resulting in his wife scoring higher on worry that her husband would get lost while alone outdoors despite the PPA. During the second baseline period (A2) PwD 2
maintained the same frequency of independent outdoor activities with the support of him carrying a cell phone and telephone monitoring of his walks between the home and the daycare center. Spouse 2 reported that this gave them both a feeling of safety and security [cf. 23, 36] and made it possible for her to engage in several daily independent activities outside the home, thus maintaining her freedom. Spouse 2 also reported somewhat increased worries during Phase A2, which could be explained by the absence of the PPA. With use of the PPA, the door could be unlocked, improving the PwD’s depressed mood, and the spouse could be less worried and able to continue her own activities.

In Couple 3, the spouse engaged in several of her own activities outside the home and on these occasions, PwD 3 was left alone at home. Spouse 3 did express worry about his safety but she did not lock him in as she felt that would be wrong. While PwD 3’s independent outdoor activities increased during both intervention periods, no effect was found for spouse worry, PwD depressive mood and PwD worry about getting lost. This was a surprising finding because both PwD 3 and Spouse 3 had expressed being worried when the PwD was alone outdoors. While Spouse 3 reported very few neuropsychiatric symptoms for her husband and spent few hours a day supervising and supporting him in activities of daily living, she nevertheless reported being moderately burdened by caring for her husband. She described that she had already given up some desired activities and that her feeling of independence was limited, suggesting that her experience of care burden was related to perceived limitations in own activities. Earlier studies [13, 14, 37] have shown that taking care of a PwD tends to take precedence over the care-giving spouse’s own activities and hobbies, which are sacrificed.
4.1 Methodological considerations

The main strengths of the present study are its structured daily measures and the $A_1B_1A_2B_2$ design with two baseline and two intervention phases [22], which are believed to minimize or rule out potential threats to internal validity. The strength of the design was most obvious in Couple 3, where a decrease of PwD’s independent outdoor activities was shown in phase $A_2$ when the intervention was withdrawn. However, some limitations have been found. During some parts of the phases, the PwDs had few independent outdoor activities, thus resulting in few scores, which might have affected the results. Measures related to the spouses’ worries when the PwDs were alone outdoors are missing for the days when the PwDs were not outdoors (Couple 1 and 3). For Couple 2, the question regarding the spouse’s worries was formulated differently. The experimental single-case design is not intended to generate generalizable findings, instead this is an expressed limitation of the design. Inter-rater reliability was assessed by two of the authors (not the one who primary made the visual inspections) examining the graphs, followed by a discussion in the research group.

Assessment of the PwDs’ cognitive competence using the Mini Mental Score Examination (MMSE) was considered but rejected due to the researchers’ experienced difficulties with establishing a trustful relationship with PwDs after having examined them with MMSE [cf. 38].

5. Conclusion

The present study demonstrated that the use of a passive positioning alarm could provide support in daily life by allowing PwDs to engage in independent outdoor activities and decreasing their spouse’s worries about these activities. The present findings could serve as the scientific basis for designing a larger-scale clinical randomized controlled trial to examine the effectiveness of a passive positioning alarm for PwDs and their relatives.
Acknowledgments

This study was supported by the University of Gävle, Örebro University and by grants from The Dementia Association - The National Association for the Rights of the Demented as well as The Knowledge Foundation.
References


### Table 1. Characteristics of participating couples.

<table>
<thead>
<tr>
<th></th>
<th>Couple 1</th>
<th>Couple 2</th>
<th>Couple 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Persons with dementia</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td>72</td>
<td>76</td>
<td>72</td>
</tr>
<tr>
<td>Daytime care</td>
<td></td>
<td>x*</td>
<td></td>
</tr>
<tr>
<td><strong>Spouse</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td>72</td>
<td>74</td>
<td>72</td>
</tr>
<tr>
<td><strong>Housing environment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Villa</td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Apartment</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td><strong>Descriptive measures</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RUD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- IADL (hours/day)</td>
<td>8</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>- ADL (hours/day)</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>- Supervision (hours/day)</td>
<td>2</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>NPI (total score)</td>
<td>29</td>
<td>44</td>
<td>3</td>
</tr>
<tr>
<td>- Delusion</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>- Hallucination</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>- Agitation</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>- Depression</td>
<td>2</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>- Anxiety</td>
<td>0</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>- Euphoria</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>- Apathy</td>
<td>8</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>- Disinhibition</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>- Irritability</td>
<td>6</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>- Aberrant motor behavior</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>- Sleep</td>
<td>4</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>- Eating</td>
<td>1</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Caregiver Burden Scale (M)</td>
<td>2.09</td>
<td>1.82</td>
<td>2.27</td>
</tr>
</tbody>
</table>

RUD, Resource of Utilization in Dementia; IADL, Instrumental Activities of Daily Living; ADL, Activities of Daily Living; NPI, Neuro-Psychiatric Inventory, total score (range 0-144) and subarea score (range 0-12). For all instruments high scores indicate more perceived symptoms and burden.

*Three days/week
Table 2. Outcome results.

<table>
<thead>
<tr>
<th>Phase</th>
<th>A1</th>
<th>B1</th>
<th>A2</th>
<th>B2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Couple 1 (weeks)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD independent outdoor activities (%)</td>
<td>11*/21 (52 %)</td>
<td>12*/49 (24 %)</td>
<td>7*/28 (25 %)</td>
<td>17*/35 (49 %)</td>
</tr>
<tr>
<td>- Spouse worry (Md, quartile)</td>
<td>5, 4.5-5.5</td>
<td>5, 3.5-5</td>
<td>7, 6-7</td>
<td>5, 5.5</td>
</tr>
<tr>
<td>- PwD irritability (Md, quartile)</td>
<td>4, 3.5-5</td>
<td>5, 4-5</td>
<td>5, 4.5-6</td>
<td>5, 5-6</td>
</tr>
<tr>
<td>Secondary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD well-being (proxy) (Md, quartile)</td>
<td>5, 5-6</td>
<td>5, 5-5</td>
<td>5, 5-5</td>
<td>5, 5-5</td>
</tr>
<tr>
<td>- PwD well-being (Md, quartile)</td>
<td>5-4-6</td>
<td>5-4-5</td>
<td>5-4-5</td>
<td>4-5-5</td>
</tr>
<tr>
<td>- Spouse well-being (Md, quartile)</td>
<td>5-5-6</td>
<td>4-4-5</td>
<td>5-4-5</td>
<td>4-4-5</td>
</tr>
<tr>
<td>Additional outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Days with 2 or more independent outdoor activities</td>
<td>0/21</td>
<td>0/49</td>
<td>1/28</td>
<td>0/35</td>
</tr>
<tr>
<td>- Independent outdoor activities (min) (Md, quartile)</td>
<td>65, 62-70</td>
<td>60, 45-82</td>
<td>45, 27-107</td>
<td>60, 40-72</td>
</tr>
<tr>
<td>- Accompanied outdoor activities (n)</td>
<td>1</td>
<td>10</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>- Accompanied outdoor activities (min) (Md, quartile)</td>
<td>45, -</td>
<td>60, 39-70</td>
<td>40, 35-45</td>
<td>37, 32-41</td>
</tr>
<tr>
<td>- Generated alarms (n)</td>
<td>15</td>
<td>12</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Couple 2 (weeks)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD independent outdoor activities (%)</td>
<td>0*/21 (0 %)</td>
<td>27*/49 (55 %)</td>
<td>19*/35 (54 %)</td>
<td>21*/30** (70 %)</td>
</tr>
<tr>
<td>- Spouse worry (Md, quartile)</td>
<td>0, 0-0</td>
<td>1, 0-0</td>
<td>0, 0-1</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>- PwD depressed mood (Md, quartile)</td>
<td>0, 0-2.5</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>Secondary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD well-being (proxy) (Md, quartile)</td>
<td>10, 8-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
</tr>
<tr>
<td>- PwD well-being (Md, quartile)</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
</tr>
<tr>
<td>- Spouse well-being (Md, quartile)</td>
<td>8, 6-10</td>
<td>10, 8-10</td>
<td>10, 10-10</td>
<td>10, 10-10</td>
</tr>
<tr>
<td>Additional outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Days with 2 or more independent outdoor activities</td>
<td>0/21</td>
<td>11/49</td>
<td>12/35</td>
<td>17/30**</td>
</tr>
<tr>
<td>- Independent outdoor activities (min) (Md, quartile)</td>
<td>40, 39-49</td>
<td>40, 30-40</td>
<td>40, 40-48</td>
<td>40, 40-48</td>
</tr>
<tr>
<td>- Accompanied outdoor activities (n)</td>
<td>21</td>
<td>37</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>- Accompanied outdoor activities (min) (Md, quartile)</td>
<td>75, 70-95</td>
<td>65, 40-75</td>
<td>75, 65-102</td>
<td>62, 52-67</td>
</tr>
<tr>
<td>- Generated alarms (n)</td>
<td>59</td>
<td>30</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Couple 3 (weeks)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD independent outdoor activities (%)</td>
<td>6*/14 (43 %)</td>
<td>31*/35 (88 %)</td>
<td>15*/28 (54 %)</td>
<td>27*/35 (77 %)</td>
</tr>
<tr>
<td>- Spouse worry (Md, quartile)</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>- PwD depressed mood (Md, quartile)</td>
<td>0, 0-1.5</td>
<td>0, 0-0.5</td>
<td>0, 0-0.5</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>Secondary outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- PwD well-being (proxy) (Md, quartile)</td>
<td>10, 9-10</td>
<td>9, 8.5-9</td>
<td>8, 8-9</td>
<td>9, 9-9</td>
</tr>
<tr>
<td>- PwD well-being (Md, quartile)</td>
<td>10, 10-10</td>
<td>9, 8-9</td>
<td>8, 8-9</td>
<td>9, 9-9</td>
</tr>
<tr>
<td>- PwD own worry (Md, quartile)</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
<td>0, 0-0</td>
</tr>
<tr>
<td>- Spouse well-being (Md, quartile)</td>
<td>9.5, 9-10</td>
<td>9, 9-9</td>
<td>9, 8-9</td>
<td>9, 9-9</td>
</tr>
<tr>
<td>Additional outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Days with 2 or more independent outdoor activities</td>
<td>0/14</td>
<td>13/35</td>
<td>2/28</td>
<td>4/35</td>
</tr>
<tr>
<td>- Independent outdoor activities (min) (Md, quartile)</td>
<td>40, 30-45</td>
<td>52, 42-55</td>
<td>40, 40-42</td>
<td>40, 40-43</td>
</tr>
<tr>
<td>- ACCompanied outdoor activities (n)</td>
<td>5</td>
<td>7</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>- Accompanied outdoor activities (min) (Md, quartile)</td>
<td>60, -</td>
<td>35, 25-58</td>
<td>42, 38-100</td>
<td>65, 42-85</td>
</tr>
<tr>
<td>- Generated alarms (n)</td>
<td>31</td>
<td>24</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Refers to the proportion of days with independent outdoor activities of the number of days on which estimations were made in the diary.

** The phase was 4 weeks and 2 days long.
Figure 1. Spouse 1 worry concerning PwD independent outdoor activities (O) and PwD 1 independent outdoor activities (%)

Figure 2. PwD 1 irritability (proxy) and independent outdoor activities (%)

STUDY IV
Figure 3. Spouse 2 worry concerning PwD independent outdoor activities (%) and PwD 2 independent outdoor activities (%)

Figure 4. PwD 2 depressive mood (proxy) and independent outdoor activities (%)

26
Figure 5. Spouse 3 worry concerning PwD independent outdoor activities (O) and PwD 3 independent outdoor activities (%)

Figure 6. PwD 3 depressive mood (proxy) and independent outdoor activities (%)

STUDY IV
Publications in the series
Örebro Studies in Care Sciences*

   Doktorsavhandling/Doctoral thesis with focus on Nursing.

   Doktorsavhandling/Doctoral thesis with focus on Nursing.

   Vetenskaplig uppsats för licentiatexamen/Academic essay.

   Vetenskaplig uppsats för licentiatexamen/Academic essay.

   Vetenskaplig uppsats för licentiatexamen/Academic essay.

   Vetenskaplig uppsats för licentiatexamen/Academic essay.

   Vetenskaplig uppsats för licentiatexamen/Academic essay.

   Doktorsavhandling/Doctoral thesis with focus on Occupational Therapy.

   Vetenskaplig uppsats för licentiatexamen/Academic essay.

    Doktorsavhandling/Doctoral thesis with focus on Nursing.

* Seriens namn var tidigare (nr 1–24) ”Örebro Studies in Caring Sciences”.
Doktorsavhandling/Doctoral thesis with focus on Nursing.

Doktorsavhandling/Doctoral thesis with focus on Nursing.

Doktorsavhandling/Doctoral thesis with focus on Nursing.

Vetenskaplig uppsats för licentiatexamen/Academic essay.

Doktorsavhandling/Doctoral thesis with focus on Occupational Therapy.

Doktorsavhandling/Doctoral thesis with focus on Nursing.

Doktorsavhandling/Doctoral thesis with focus on Nursing.

Vetenskaplig uppsats för licentiatexamen/Academic essay.

Doktorsavhandling/Doctoral thesis with focus on Nursing.

20. Lidskog, Marie (2008) *Learning with, from and about each other: Interprofessional education on a training ward in municipal care for older persons.*
Doktorsavhandling/Doctoral thesis.

Doktorsavhandling/Doctoral thesis with focus on Public Health.

Doktorsavhandling/Doctoral thesis with focus on Nursing.

Doktorsavhandling/Doctoral thesis with focus on Nursing.


