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
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 my 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-
ical 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.
(44). 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>1</td>
<td></td>
</tr>
<tr>
<td>- 81+ years</td>
<td>1</td>
<td>5</td>
<td>1</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><em>MMSE</em> (range)</em>*</td>
<td>21-28</td>
<td>19-28**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mild dementia [≥20]</td>
<td>11</td>
<td></td>
<td>4**</td>
<td></td>
</tr>
<tr>
<td>- Moderate dementia [19-10]</td>
<td></td>
<td>1**</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>2</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>1</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></td>
<td>2</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 a 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>C1</td>
<td>3</td>
<td>7</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>C2</td>
<td>3</td>
<td>7</td>
<td>5</td>
<td>4*</td>
</tr>
<tr>
<td>C3</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 (A1,A2) 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 keep 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><strong>Primary outcomes</strong></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><strong>Secondary outcomes</strong></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><strong>Primary outcomes</strong></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><strong>Secondary outcomes</strong></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><strong>Primary outcomes</strong></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><strong>Secondary outcomes</strong></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 necessarily 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 primary 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 PPAP (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
(175) 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 A1B1A2B2 design further strengthens the study, because the intervention is withdrawn in A2 (return to baseline condition) and reintroduced in B2.

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 investigated 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 dagligalivet. 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 stärка 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 I** syftade till att beskriva hur personer med tidig demens reflekterar kring utevistelse. Elva personer med tidig demens intervjuades vid två tillfällen i det egna hemmet. Data analyserades med kvalitativ innehållsanalys. Resultatet visade att utomhusvistelse var ett sätt att bekräfta personer med demens identitet. Det upplevdes värdefullt att få en bekräftelse på förmågan att utföra önskade aktiviteter, däremot var bekräftelsen inte alltid positiv. Insikten att vissa aktiviteter inte längre var möjliga att utföra kunde vara förkrossande.


**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 datainsamlingstillfällena 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, möjligt 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.

_Slutssatsen_ 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, beroende 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/foreskrifteromtvangsomskydds


(109) FAST: Definition of the term ‘Assistive Technology’. [cited 2013 March 28]. Available from:
http://www.fastuk.org/about/definitionofat.php


(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.


* Seriens namn var tidigare (nr 1–24) ”Örebro Studies in Caring Sciences”.

---

**Publications in the series**

**Örebro Studies in Care Sciences**

**Publications in the series**

**Örebro Studies in Care Sciences**


* 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.


