

Guiding People with Early Dementia Home with the TalkMeHome Service

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Abstract—People suffering from mild dementia may get lost during a walk, which can be dangerous for them and adds to the anxiety felt by their informal caregivers. TalkMeHome is a new service that allows these people to get home safely in such situations using their mobile phone. They can call a remote care professional who will guide the lost person home. To accomplish this, the professional caregiver is able to follow the person's GPS-location on a map and in Google Streetview. This paper reports on four experiments with TalkMeHome to assess the effectiveness and user experience of the service. In all four cases the participants were guided home satisfactorily, even under suboptimal conditions. The experiments further revealed that talking people home is demanding for the care professional and that they need adequate ICT support. The contribution of our work is that we evaluated this new service with real patients and real professional care givers in a semi-controlled environment.

Keywords—*dementia; location-based services; global positioning system (GPS); remote care; lost person; care professional; user test.*

I. INTRODUCTION

It has been estimated that in 2010 there were 35.6 million people living with dementia worldwide. Expectations are that this number will increase to 65.7 million by 2030 and 115.4 million by 2050 [1]. For people suffering from dementia, out-of-door mobility is an essential element of their quality of life [2]. However, these people are at considerable risk of getting lost during a walk, which can lead to hazardous situations [3, 4]. Moreover, the thought that their loved ones could be involved in an accident as a result of their disease adds to the burden felt by informal caregivers. To protect people suffering from dementia and to relieve the anxiety experienced by their informal caregivers, a number of interventions can be performed, such as locking doors to prevent a person with dementia (PwD) from leaving the house [5]. Such measures are however very disruptive and reduce the quality of life of people with dementia.

It has been recognized that the use of the Global Positioning System (GPS) may help to solve the problems experienced by caregivers and people with early dementia in a less disruptive manner [6]. Using this type of technology,

the PwD typically carries a GPS tracking device. At home, an informal caregiver may then log into a secure environment (a website) to determine the location of the carrier of the GPS device [7, 8]. Some of the available trackers can be switched to two-way voice communications, which are commonly activated using the alarm button on the device. In case somebody suffering from dementia is unable to find the way home, an informal caregiver may, after obtaining the location of the PwD, go outside and bring the loved one home.

Despite the obvious benefits of the application of tracking devices (increased mobility for PwDs, fewer worries for informal caregivers), this technology has several shortcomings. For example, in many cases the main caregiver is an elderly person, often a spouse [1], who may not be able to physically get the PwD and take him home. Moreover, other informal caregivers such as adult children may not always be available because they live too far away or because they are bound by other obligations. Finally, not all caregivers may feel comfortable using new technology, such as a secure website.

TalkMeHome [9] is a new mobile service that overcomes these problems through a healthcare professional (see Figure 1). This person works from a care center and is specialized in remote care for people with dementia. PwDs can call the professional from their mobile phone when they are lost, which results in an “alarm” on the computer system that the professional uses. The professional accepts the call and talks someone home by providing instructions on how to walk (“turn left here”, “turn right at next intersection”). To accomplish this, the professional's computer system provides a special dashboard that shows the PwD's location in real-time on a map and in Google Streetview. TalkMeHome works on a wide variety of mobile phones, as long as they have a GPS receiver and a UMTS data connection to stream the PwD's coordinates to the care professional. The service is primarily intended for people with early-stage dementia who live at home. TalkMeHome is a commercial service that PwDs will pay for. TalkMeHome also allows informal caregivers to follow the location of a PwD, but this part of the service out of scope for our work.

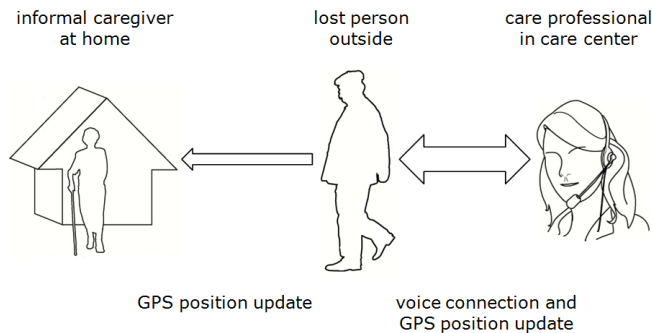


Figure 1. Main actors in the TalkMeHome service.

In this paper, we discuss the evaluation of TalkMeHome. The goal of the evaluation was to assess the effectiveness and user experience of this novel service before it will be made available commercially and to investigate how PwDs and care professionals experience the service.

The novelty of our work is that we evaluated the service with real PwDs and real professional care givers in a semi-controlled environment. In recent years, a number of pilot studies on the use of GPS for dementia patients have been carried out [7, 8, 10-13], but not for a service like TalkMeHome. These studies do however endorse the potential benefits of the use of GPS technology. At the same time, they also point out that the technology used should function sufficiently reliably. Furthermore, the need for a very simple tracking device is stressed [7] plus that these devices are mainly considered suitable for patients in the early stage of their illness [10]. It has been shown that not only informal caregivers who have experience with the use of tracking devices feel positive about the application of GPS technology, but formal caregivers as well [11]. Another application of GPS technology for lost people is the use of an adapted TomTom, which they can use to find the way back home [12, 13].

The remainder of this paper is structured as follows. Section II discusses the user requirements that served as an input for the development of the service. Section III presents the technical setup for our experiments, followed by the applied method in Section IV. Section V gives an overview of the results of our evaluation, followed by a discussion in Section VI. Section VII concludes the paper.

II. USER REQUIREMENTS

Before TalkMeHome was developed, we identified what the PwD (a possibly lost person) and the care professional guiding the PwD home would require from the service. To find these requirements, desk research was conducted, including a literature study and writing scenarios. Moreover a senior care professional was consulted, an employee of “Carint Reggeland”, which is a care organization in the East of the Netherlands.

Also the researchers carried out a number of small experiments in which conventional trackers were used,

combined with an additional mobile phone to simulate the anticipated implementation as close as possible [14].

A. Persons with Dementia

The requirements of the PwDs pertained to the mobile device they would have to use. Three options for such a device were discerned:

- A conventional tracking device, which enables the localization of the PwD as well as two-way voice communication.
- The combination of a mobile phone (not necessarily equipped with GPS) and a separate tracking device which the PwD may, for instance, wear on a belt.
- A mobile phone using the 3G standard (UMTS) and GPS.

To the best of our knowledge, no conventional tracking device was available which allowed voice communication and localization updates simultaneously, a condition sine qua non for the TalkMeHome service. For that reason, the first option was rejected. The second option was regarded less desirable because in this case the informal caregiver must ensure that the PwD carries two devices, and both need to be charged as well, which was considered too cumbersome. Hence we chose the third option. An advantage of using a mobile phone is that such a device is not stigmatizing as nowadays almost everyone carries a mobile phone. Especially PwDs using a walker may want to carry the phone on a strap around the neck. For the same reason hands-free operation of the phone must be possible. It goes without saying that the mobile phone used should be as simple and as light as possible.

The second point of attention from the PwD’s point of view were the GPS location updates. The aforementioned experiments with existing trackers showed that the typical interval of one minute between two GPS location updates was too long because even with a walker, walking velocities of elderly people may range from 0.9 to 1.1 m/s [12].

B. Care Professionals

The care professional who guides a lost person home must have a map showing the position of the person. This map should be extended with images of the surroundings of the guided person, when available, so that it becomes easier to formulate adequate instructions. A trace of the path taken thus far by the PwD as well as a route planner suitable for pedestrians were seen as needed to further support the professional in guiding the PwD home. These new functions should augment the basic functions available to a care professional, such as being able to answer a call (i.e., handle an alarm) and get (medical) information on the PwD who is calling.

III. TECHNICAL SETUP

We ran the experiments with a prototype of TalkMeHome, which integrates into the Universal Alarm Receiver (UMO) from Verklizan, a company based in the Netherlands. The UMO is an existing commercial product for care centers that is widely in use across Europe, but as yet without support for guiding people home. It provides an

elaborate dashboard for care professionals to handle alarms, which we extended with TalkMeHome-specific functions. For the location updates, we used the services of FindWhere, also a Dutch company. We connected their location server to the UMO, thus making real-time location information available to care professionals.

Figure 2 depicts the implementation of the TalkMeHome service in more detail. The most important components are:

- A dashboard, used by the care professional to guide PwDs home. When an alarm is received, the dashboard displays (medical) information about the PwD as well as the location of the PwD. For this purpose, Google Maps with Street View was used. The dashboard also enables the voice connection with the PwD.
- A smartphone, used by the PwD to make contact with the care professional. For the test described below a Nokia 5230 was selected because of its uncomplicated user interface and favorable pricing. FindWhere's application iFindWhere (version 6.07.05) was installed on the smartphone and the red button of the Nokia served as the alarm button to be used by the PwD in order to establish the contact.
- A location server, which keeps track of the position of each smartphone, provided that the smartphone is registered properly. In the test version of the software used to update the GPS location, the time interval between two updates was set to 18 seconds.

IV. METHOD

The goal of our evaluation was to answer two questions: (1) how effective is the TalkMeHome service in guiding PwDs home and (2) what is the user experience during the process of talking someone home, both for PwDs and for care professionals.

A. Participants

As has been noted by other researchers, getting participants (people with dementia) was not easy [10]. The customer database of Carint Reggeland was consulted, medical coworkers were invited to recommend participants and local newspapers published information about the service tested. In addition, we used a set of inclusion criteria to determine if PwDs fall in the target group of TalkMeHome (see below).

Eventually four participants took part in the evaluation, as well as the two care professionals (Figure 3, taken from [15]). All participants came from the region of Twente, in the Eastern part of the Netherlands.

The inclusion criteria we used for the participants were:

- Suffering from mild dementia.
- Lives more or less independently at home.
- Is quite able to follow instructions.
- Must be able to use the available smartphone.
- Is able to walk a longer distance.
- Signed an Informed Consent (and the informal care giver as well).

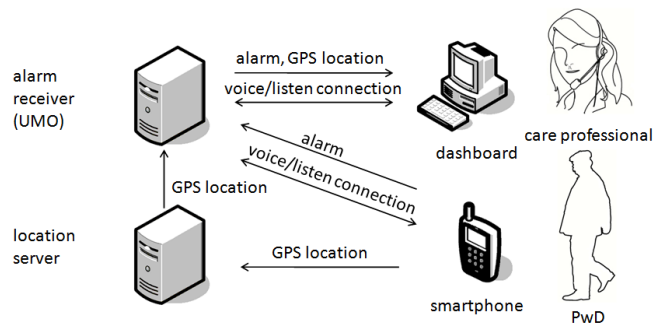


Figure 2. Organization of the TalkMeHome service.

Two experienced care professionals took part in the test. Both of them were employees of Carint Reggeland, one of whom also provided input during the user requirements phase (see Section II). It should be noted that prior to the tests the care professionals had not had an opportunity to gain experience in guiding a person with mild dementia home.

B. Talking Someone Home

For the actual evaluations, each participant was visited at home. Then it was determined first whether the participant met the inclusion criteria. If this was the case, the participant was invited to go out for a walk, accompanied by two researchers from our team. After walking a certain distance (typically 500 m.) the actual test began by pushing the alarm button, simulating the PwD being "lost". This established a connection with the care professional. After that, the care professional guided the participant back home. One of the researchers observed the participant while the main responsibility of a second researcher was to ensure the safety, for instance regarding traffic, of the participant.



Figure 3. One of the care professionals guiding someone home.

While the participants were being talked home, data was collected in a number of ways. First, the observations made were written down. Moreover, the conversation between the participant and the care professional was digitally recorded.

After talking someone home, a short interview with each of the participants was conducted asking their opinion about the ease of use of the smartphone, their feelings regarding safety and security, and their motivation to use a smartphone. After each TalkMeHome session, the care professional also completed a questionnaire containing questions about the hardware and software used (e.g. the experienced usability), work load (e.g. whether it was possible to do other tasks while guiding somebody home), how the communication with the participant was experienced, and finally how comfortable the care professional felt when guiding a person home. After completion of all tests, the data were assembled, analysed and discussed by the researchers. In a second meeting the views held by the two participating care professionals were put forward.

V. RESULTS

In this section, we present a short summary of the results of the four TalkMeHome sessions. We discuss the effectiveness of the service and the user experience in Section VI.

A. Participant #1

The first participant was an elderly lady in her seventies. Together with her husband she lives in a small town with 7000 inhabitants. She was diagnosed with Alzheimer four years ago. Sometimes her right-left discrimination is poor.

Establishing a connection between participant and care professional took place without difficulties. But after a few minutes the transmission of GPS locations came to a halt, most likely due to insufficient UMTS coverage. However, this participant was able to describe her surroundings accurately, including street names and characteristic features such as buildings and parking lots. Based on this information, the map and corresponding satellite images, the care professional was able to satisfactorily guide the participant through her home town. Only once the participant took the wrong direction but this was corrected by the care professional after 20 meters. Right-left confusion occurred only once. The care professional knew on which wrist the participant wore her watch, which could have been helpful if necessary.

B. Participant #2

The second participant lives on her own in a larger city (130,000 inhabitants). She has been known to suffer from Alzheimer's disease for some time. She walks with a walker and for that reason the smartphone was used hands-free.

Despite this use of the smartphone, the communication between the participant and the care professional went smoothly during the test. Only once the participant took the wrong direction but again this could be corrected after 20 meters. The map used, however, turned out to be incomplete and inaccurate as the apartment of the participant was not on the map yet. But as she was familiar with the immediate vicinity of her home she still could be guided home successfully.

C. Participant #3

The third participant lives in a city of more than 70,000 inhabitants. She has suffered from dementia for some years. She already got lost once.

This test started under the trees of a small park. GPS locations got through to the care center only after a restart. The walk began with a straight road of about 100 meters with no crossroads. Because apparently no information was needed, the care professional stopped talking for a while. Then, somewhat confused, the participant stopped walking. When the conversation was resumed, the participant responded very well to instructions. Difficulties were observed at a road construction site. It took a while before the care professional understood the situation. After that, she guided the participant home taking a detour.

D. Participant #4

The fourth and final participant lives with his spouse in a village (over 7,000 inhabitants). He has been diagnosed with a mild form of Alzheimer's disease by a gerontologist.

Again, at the start of the walk, there were some difficulties establishing the connection between the care professional and the participant. Also, the participant broke the connection once unintentionally. As in the previous tests no technical problems were encountered after that. Contrary to the findings of the other three tests, this participant sometimes gave erroneous information, such as incorrect street names, which made the care professional's task harder, particularly since for this area Street View was not available. This participant interrupted the walk for a short chat with a friend.

VI. DISCUSSION

We discuss the results of our evaluation in terms of the two questions we are addressing: (1) how effective is TalkMeHome and (2) what is the user experience during the process of talking someone home. We also discuss the limitations of our results.

A. Effectiveness

In all four tests the participants were guided home satisfactorily. The start of a walk posed a specific problem: as the viewing direction of the participant was unknown, and the participant was not walking yet, the meaning of the terms left and right were not clear. In the experiments this was solved by asking the participant simply to start walking. If the direction turned out to be wrong, the participant was subsequently asked to turn around. Apart from this issue only a couple of easily corrected mistakes were observed during the tests.

The experiments showed that conditions for the TalkMeHome service are optimal if three conditions are met: a reliable map is available, GPS locations are updated frequently (preferably with interval of less than 10 seconds, as experiments showed), and PwDs are giving a good description of their surroundings during a walk. However, if only two of the three conditions are met, guiding a PwD home may still be possible. For example, the PwD's description is not really necessary as guiding a PwD home

based on a reliable map and GPS locations turned out to be possible as well. Moreover, it is still possible to guide a PwD home if the update of GPS locations should (temporarily) come to a halt, provided an initial location is available, the PwD is able to describe his or her surroundings sufficiently, and a reliable map is available. Finally, a small difference between reality and the map used is not necessarily insurmountable.

The test showed the value of relevant information, such as on which hand a (wedding) ring is worn in case of a right-left confusion. It should be investigated how such information can be made available to the care professional and how it can be kept up-to-date.

B. User Experience

The contact between the PwD and the care professional was found to be good as became apparent from the completed questionnaires and the digitally recorded conversations. There were few misunderstandings between them. If possible, the participant and the care professional had a chat, for example about the weather conditions, which contributed to a relaxed atmosphere while maintaining the necessary contact.

The evaluation further revealed that guiding somebody home is a demanding task for the care professional because a great deal of information needs to be processed quickly by them. As there is always a certain time delay the care professionals should anticipate the situation ahead. A higher update frequency for the GPS locations resulting in a more fluid motion, and more precise locations would be helpful. There appeared to be little time for other tasks, such as looking up additional information about the PwD. This suggests that the user interface of the dashboard needs to be optimized for TalkMeHome.

C. Limitations

The focus of the evaluation described in this paper is the actual process of guiding people home. How the TalkMeHome service will be incorporated into everyday life of the PwD, including the question whether PwDs are able to contact the care center autonomously, was not taken into consideration. A PwD who has difficulty to contact the care center may benefit from alternative scenarios, for instance a scenario in which a worried informal caregiver contacts the care professional, who then establishes the contact with the PwD.

The PwDs who participated in the evaluation were not really lost, but accompanied by researchers who paid attention to safety issues. It is unclear how PwDs would react to the TalkMeHome service in a more stressful situation. The meeting with the care professionals revealed the professionals' concerns regarding these matters. How should they act if a PwD is unable to respond properly? How can an unsafe situation (e.g. in traffic) be avoided? Issues regarding their (legal) responsibility should be looked into.

VII. CONCLUSION AND FUTURE WORK

We discussed TalkMeHome, a novel mobile service that allows people with early-stage dementia to get home safely

when they are lost. With the single press of a button, they can call a remote care who is specialized in (remote) care for people with mild dementia. This care professional uses the TalkMeHome dashboard to follow the lost person's location on a map and to provide instructions (directions) for this person how to get home safely. The service's added value is that it increases the quality of life of people with mild dementia (increased level of mobility) as well as that of the informal care giver (fewer worries). It also allows people to live at home longer, which reduces the load on intramural care facilities.

We evaluated the service with four people with early-stage dementia. Our goal was to assess how effective TalkMeHome is and how the users (PwDs and care professionals) would experience it. The novelty of our work is that it involved real PwDs and real professional care givers in a semi-controlled environment

As for effectiveness, all four participants were guided home satisfactorily, technical imperfections set aside. Only a few easily corrected mistakes were noticed. The evaluations further showed that guiding a PwD home is possible even under suboptimal conditions (unreliable information of the PwD, missing location updates or an incomplete map). This suggests that TalkMeHome is an effective service, which increases our confidence that it can be made available as a commercial service. It also shows that a technology that is not 100% accurate can still provide an added value. Regarding the experiences of the users, both PwDs and care professionals, we conclude that the contact between both was easy but guiding somebody home is a demanding task for a care professional.

Additional research may focus on optimizing the use of the service in everyday life as well as alternative scenarios.

In terms of user experience, our work revealed the difficulty of the care professional's task. This suggests that the user interface of the dashboard needs to be optimized for TalkMeHome and that it is of paramount importance to offer proper education for care professionals, both in regular education and continuing training. With an aging population the demand for appropriate support will only increase. For this reason the research group 'ICT-Innovations in Healthcare' will take the initiative for a 'Skills Lab', a laboratory equipped with the necessary hardware and software to facilitate research and training with regard to the skills of a care professional, for instance in terms of protocols for care professionals to guide someone home. This research and training will not be limited to the actual TalkMeHome service presented in this paper. The Skills Lab will support the necessary research and training facilities.

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