Balancing autonomy and security over geotracking patients with Alzheimer’s using a personalized geotracking system with social support network

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Abstract

Systems for geotracking Alzheimer’s Disease patients with dementia are reported to raise ethical issues and concerns. Studies stated possible loss of freedom and autonomy for patients, along with violations of their privacy, which may lead to loss of prestige/dignity. In this study, a personalized geotracking system that aims to balance patient security and need for privacy and autonomy is proposed. In addition, the system tries to form and organize a social support network among family caregivers to help each other locating patients during wandering episodes. The system introduces a personalized, four-level temporal geofence based tracking, warning and notification protocol that incorporates a safety check mechanism operating over Global System for Mobile Communications network. It is under development using Java and will be evaluated by using both qualitative and quantitative methods. In this paper, personalization, system architecture and social support network operation principles are presented.

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1. Introduction

Wandering is classified as a potentially life-threatening behavioral disorder and state of mind, which may occur in Alzheimer’s Disease (AD) or related neurodegenerative diseases with possible development of dementia and cognitive impairment [1]. In wandering state, patients may pose sudden urges to go out or

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are prone to straying outdoors that may lead to getting lost, physical harm and death, with varying risk exposures [2]. When gone lost, safety of patients may be seriously jeopardized if they cannot be located within the “golden 24 hours” [3]. Furthermore, wandering constitutes a threat, not only to patients but also to caregivers. Studies reported high correlation between wandering and caregiver burden [4-5] and showed that wandering is a major source of carer distress [6]. Thus, wandering has considerable impact on quality of life for both patients and families and should be managed. Different methods and approaches, both pharmacological and non-pharmacological, were developed and employed for the management of wandering. In the last decade, an alternative non-pharmacological intervention called Electronic Geo-Tracking (EGT) have emerged and been implemented. EGT is a visionary approach that focuses on safe wandering/walking by minimizing risks. It enables carers to gather high resolution spatial and temporal data regarding patients’ whereabouts with high sensitivity, enhancing patient safety.

A number of studies assessed the acceptability and usability of EGT [1, 7-18]. They addressed issues, limitations and concerns, mostly related to ethics, patient compliance, cost, and technical and practical difficulties. Ethical arguments included capacity to consent, autonomy, privacy violations, and loss of liberty and dignity [1, 16]. Some studies examined views of stakeholders, concentrating mostly on family caregivers’ opinions. Only one study presented patients’ views, which also reported patients’ loss of interest following a short period of use [7]. Two review studies, classified electronic tracking as “acceptable with considerable discussion of ethical issues” [16, 17]. Recently, a qualitative study presented conflicting views of family caregivers regarding the use of advanced technology to track patients [1]. Although family caregivers had conflicting opinions, the study concluded that they were in favour of the use of EGT [1]. In some studies, carers pointed out that EGT often gave peace of mind [8-9], whereas another study showed that use of EGT “increased demand on carers’ time” [18].

Although carers stated that use of EGT often gave peace of mind, obviously, caregiving associated distress should not be expected to come to an end with the use of such systems. On the contrary, tracking a patient with possible development of wandering episode while she/he is out of home may easily become a source of anxiety and stress. Most of the time, caregivers face and deal with such caregiving related psychosocial dynamics/outcomes individually. However, there are social support interventions that focus on caregiver well-being and improving caregiver mental health outcomes [19-21]. Social support can be explained as the act enclosing any kind of emotional support, guidance, material aid and services that can be obtained through social relationships. Studies showed that social ties are critical to health status and lack of them with others is an important risk factor in psychological well-being and illness. Therefore, a social network, which is a structure comprised of social contacts and relationships, can be a significant source of social support. Of particular importance to AD patients and their caregivers, considering EGT systems, are the types of social networks to which they can turn for help in reaching and securing wandering patients. Although advances in geotracking and mobile technology have made locating patients instantly possible, reaching them while in wandering state may take time. However, a social network among patients and carers may help shorten the time that it takes to reach and secure an AD patient.

In this study, we specifically focus on ethical issues of out-of-home mobility of AD patients. The objective of this study is to design and develop an acceptable, EGT-based, patient-centred and personalized/individualized out-of-home tracking prototype technology embodying a protocol that

- Tries to maintain patients’ independence while assuring they are secure by using a tradeoff approach,
- Alleviates tracking associated burden and distress on carers and does not increase, on the contrary, reduces demand on carers’ time by using a safety check mechanism called call based supervision,
- Tries to constitute and organize a social support network among AD patients’ family caregivers to help locate and secure AD patients during wandering episodes.

In this paper, we present our system design and application architecture. In the next chapter, the proposed system architecture and operation will be explained. In the discussion, we will present some pros and cons together with future work and describe what is crucial to smooth operation of the system.
2. Material and Methods

2.1. Proposed EGT System Architecture

The first generation EGT (FEGT) systems [7-10] developed for out-of-home mobility carry out a number of tasks using an architecture with five elements (tracking device, cellular phone, GSM modem, application server & tracking database and a client to be used by caregiver) operating over six communication services and protocols. Table 1 introduces these services and protocols.

Table 1. Networks, services and protocols used in geotracking systems

<table>
<thead>
<tr>
<th>Element</th>
<th>Communication System/Service</th>
<th>Network</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tracking device</td>
<td>GPS (NMEA)</td>
<td>Satellite Network</td>
</tr>
<tr>
<td></td>
<td>Assisted-GPS</td>
<td>Satellite Network &amp; GSM Network</td>
</tr>
<tr>
<td>Mobile/Cellular phone</td>
<td>GPRS / SMS</td>
<td>GSM Network</td>
</tr>
<tr>
<td>GSM modem</td>
<td>GPRS / SMS</td>
<td>GSM Network</td>
</tr>
<tr>
<td>Application server &amp; tracking database</td>
<td>HTTP / SOAP</td>
<td>Internet</td>
</tr>
<tr>
<td>Client</td>
<td>HTTP</td>
<td>Internet</td>
</tr>
</tbody>
</table>

From a technological point of view, EGT systems currently in use, act as simple data transmission units with basic carer notification and data storage/access services. They are not designed to avoid or cope/help with issues such as privacy protection and heavy data traffic, which causes an increased demand on carers’ time.

The proposed architecture mainly consists of eight elements operating over the same networks and services that current systems do. In addition to elements of the current systems’ architecture, it incorporates three more units; (i) a tracking protocol that is implemented as a middleware, (ii) a database that stores patient’s out-of-home activities, geofences and other activity related data, and (iii) Google Maps™ server. Next, we describe these additional elements and other requirements necessary for smooth operation of the system. A basic schema of the proposed architecture is introduced in Figure 1.

2.1.1. Tracking device

The tracking device to be used in the proposed architecture should hold some technical requirements. The device should carry a High Sensitivity GPS receiver that can provide positioning in indoor locations. The device should also have a GSM modem having installed a GSM line, through the use of which the device should be able to access GSM network and use Assisted-GPS system that improves time-to-first-fix and enables positioning in cases of poor signal conditions. Aside from these, it must be capable of making and receiving calls, therefore, be able to ring but not necessarily enable voice communication (allow making and receiving calls) and have at least three programmable buttons (other than SOS button) that can make call to assigned GSM numbers when pressed. Assuming the device to be used owns three programmable buttons, the proposed system requires them to be set to call two GSM numbers managed by the system itself, and patient’s carer mobile phone number. By means of programmability, the device may also be set to receive calls only from preset numbers.

2.1.2. Personalization: patient activity & geofence database
Personalization of the system requires every patient and caregiver to go through a registration process. This is achieved via a procedure that involves conducting a private one-to-one semi-structured interview, for which an interview guide has been prepared. During this interview, each patient is asked to name her/his out-of-home activities (considering seasonal changes). In the end, a list of patient’s out-of-home activities is transcribed. Each activity in the list is described by a number of properties including (but not limited to) simple activity description, activity address, regularity (on daily, every other day and weekly basis)/irregularity, and accompanying third person(s) (e.g. friends, acquaintance), permission/consent to notify carer about the activity. The same private one-to-one semi-structured interview should be conducted with each patient’s carer to obtain a carer version of patient’s out-of-home activities list. Following the interviews, the next step is dedicated to obtain a refined list and detailed data to save in the database. For this purpose, four operations should be performed using both patient and carer versions of the list. First, a set union operation will be performed to uncover all possible out-of-home activities of patient. Next, each activity from the patient version should be checked and marked as either “known by carer” if the activity is in both versions of list or “unknown by carer” if it is only in patient version. Subsequently, the exact (latitude, longitude) pair for corners of each activity address/area should be obtained. In the last operation, using the coordinate pairs, patient’s geofences are calculated and proper geofence geometry is determined. Finally, collected data are recorded into the database in the last step.

The database is modelled to store many different types of data regarding patients’ out-of-home everyday lives. We adopted the Entity-Relationship modelling principles to design our data model. The database is modelled to store; personalization data related to patient’s out-of-home mobility (acquired before the system starts to track), instant out-of-home mobility data (during tracking) and system’s tracking activities & operations (during tracking). In the data model, acquired data related to patient’s out-of-home activities are represented by three entities. The data model consists of 12 entities with 23 relationships among them.

2.1.3. Tracking protocol & middleware

The tracking protocol is the unit that defines the system’s basic operation and determines the tracking, warning and notification policies to apply throughout a patient’s out-of-home trip based on instant tracking data and data collected during registration. It introduces three important security measures and mechanisms using which the protocol administers the balance between autonomy and security.
The first mechanism provides personalized geofences. Personalization of geofences has two dimensions, where (activity location or address) and when (regularity of activity). Based on temporal pattern of patient’s activities, i.e. regularity property, the mechanism defines a “four-layered when&where” geofence structure. Therefore, it assigns four geofences to each patient; i.e. daily geofence, weekly geofence and general geofence. Each geofence is defined based on the preferred geofence geometry using a set of activity addresses (a set of coordinates of activity addresses) of those activities with the same specific regularity naming that geofence, in addition to upper geofences’ activities. The only geofence defined using addresses of all activities of a patient, including irregular ones, is general geofence.

The system adopts two different geofence geometries; circular and polygon. A polygon geofence is formed by simply connecting coordinates of activity addresses. It may be preferred to be used in rural areas such as small towns and villages. The circular geofence, however, is formed using coordinates of a patient’s home and the farthest activity address, which belongs to an activity in a set of activities of a specific regularity. A patient’s home is considered as the centre of the circle. The distance between home and farthest activity address is calculated and accepted as the radius. The radius is calculated based on the Great-circle Distance using the Haversine Formula [22]. The circular geofences may be convenient for...
use in urban areas such as a relatively big town or city with a huge transportation network. In order to measure whether a patient is out of a geofence or not, the system makes use of two different algorithms for circular and polygon geofences; Haversine Formula [22] and Crossing Number Algorithm (also known as Ray Casting Algorithm) [23], respectively.

The second mechanism that the protocol introduces is “call-based supervision”. It is a half-duplex communication to acknowledge at regular intervals that patient is mentally ok/not in wandering state. The communication primitives are calls (with no voice communication) to be made from system to a patient and from a patient to system. The system initiates the communication through a request primitive, which is basically a call called “are you fine?” and expects the patient to respond she/he is fine by placing a call called “I am fine” within a specified period of time, a priori. In order to achieve that, a patient should hear the device ringing or vibrating and recall the button programmed to call the system’s dedicated GSM number and press it. When the right button is pressed, the device places the call and response is fetched. Thus, the system assumes patient is wandering-free. As a protocol requirement, the GSM device, which is connected to the application server, should be able to handle two GSM numbers at the same time. The first one is the GSM number the system uses to make “are you fine?” call requests and to receive “i am fine” responses. The second GSM number is reserved for emergencies and used only for receiving SOS calls. Using two GSM lines instead of one GSM line is a significant protocol requirement that makes the operation of the protocol robust.

The third mechanism is called “Patient Tracking Status” (PTS). Simply, it is a structure of tracking measures to determine the actions to take in response during the interaction between system and the patient. In other words, the system uses PTS to dynamically determine the tracking, warning and notification policies to apply during patient’s trip. It consists of seven variables, patient’s speed, current geofence level, location query period, “are you fine call?” flag, “are you fine?” call period, carer notification. Table 2 summarizes patient tracking statuses.

### Table 2. Patient Tracking Status

<table>
<thead>
<tr>
<th>Tracking Status</th>
<th>Speed (km/h)</th>
<th>Geofence Level</th>
<th>Location Query Period</th>
<th>“Are you fine?” call period</th>
<th>“I am fine” response time</th>
<th>Carer Notification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compatible Pedestrian</td>
<td>&lt;=6</td>
<td>Day-based</td>
<td>5 min</td>
<td>45 min</td>
<td>5 min</td>
<td>45 min (SMS)</td>
</tr>
<tr>
<td>Compatible Vehicle</td>
<td>&lt;=6</td>
<td>Geofence</td>
<td>2 min</td>
<td>10 min</td>
<td>4 min</td>
<td>30 min (SMS)</td>
</tr>
<tr>
<td>Active on Foot</td>
<td>&lt;=6</td>
<td>Every Other</td>
<td>4 min</td>
<td>45 min</td>
<td>4 min</td>
<td>45 min (SMS)</td>
</tr>
<tr>
<td>Active on Vehicle</td>
<td>&gt;6</td>
<td>Day Geofence</td>
<td>2 min</td>
<td>7 min</td>
<td>20 min</td>
<td></td>
</tr>
<tr>
<td>Sightseer on Foot</td>
<td>&lt;=6</td>
<td>Week-based</td>
<td>3 min</td>
<td>30 min</td>
<td>3 min</td>
<td>30 min</td>
</tr>
<tr>
<td>Sightseer on Vehicle</td>
<td>&gt;6</td>
<td>Geofence</td>
<td>1 min</td>
<td>5 min</td>
<td>15 min</td>
<td></td>
</tr>
<tr>
<td>Explorer on Foot</td>
<td>&lt;=6</td>
<td>General</td>
<td>2 min</td>
<td>20 min</td>
<td>2 min</td>
<td>20 min</td>
</tr>
<tr>
<td>Explorer on Vehicle</td>
<td>&gt;6</td>
<td>Geofence</td>
<td>1 min</td>
<td>4 min</td>
<td>12 min</td>
<td></td>
</tr>
<tr>
<td>Potential Wanderer</td>
<td>-</td>
<td>-</td>
<td>30 sec</td>
<td>10 min</td>
<td>1 min</td>
<td>10 min (SOS)</td>
</tr>
</tbody>
</table>

Carer of this patient is notified about the current status of patient via SMS every 45 minutes while patient is out. However, in the SMS, the system provides the carer patient’s distance to home, but not patient’s exact location, together with the last “I am fine” response time. In case the system notices that
patient has reached or is around an activity location, the system checks whether the patient has given the permission to notify the carer or not, and if she/he did, informs the carer via SMS about patient’s whereabouts and the activity. The patient’s whereabouts are expressed in both address and (latitude, longitude) format. For this purpose, the system makes use of reverse geocoding service of Google Maps™. Simply, the system’s Hypertext Transfer Protocol (HTTP) client sends the (latitude, longitude) pair that system received from patient’s tracking device to Google Maps™ server through HTTP and expects the response in a lightweight data interchange format called Javascript Simple Object Notation. After a decoding operation, the address is extracted from server’s response.

The system informs the carer about the exact location of patient in following cases:

- For the first two tracking status, in case patient does not respond to two consecutive "are you fine?" calls,
- At the last two tracking status, in case patient does not respond to an "are you fine?" call, system repeats the call at the end of response waiting period, if no response is received at the end of second response waiting period, too, the system places the call for the last time and waits. If patient does not respond within the “I am fine” response time defined in her/his current PTS, the system informs carer,
- When patient is out of general geofence and does not respond to an “are you fine?” call.

Additionally, the system provides carer a service to check patient’s current location at random times. For this purpose, the carer should send a blank SMS from his phone number recorded in the database to system’s call based supervision number. After receiving that SMS, the system applies the call-based supervision to patient. The system makes the rather random “are you fine?” call, and expects patient’s response depending on the response time related to patient’s current tracking status. In case of no response in specified period, the system places the second call in five minutes at random. If no response is response is received, system informs the carer with the exact location of patient via SMS.

2.1.5. Social support network

System takes advantage of knowing potentially wandering patient’s current location and asks registered carers by multicasting an SMS to secure that patient if they are close to her/him and available.

Basic scenario starts with system determining that a registered AD patient may potentially be in wandering state. System locates the patient and finds current location address. Next, mobile phone numbers of those caregivers, who are voluntarily registered to social support network, are queried and acquired from the database. Meanwhile, an SMS message stating that a patient may be wandering is prepared and appended patient’s current location address. At the end of the message text, system asks the recipients to reply within a period of time, a priori, with the text “SUPPORT” if they are available and close to the address and tells to wait for an acknowledgement message. Prepared message is multicast via SMS to the carers’ phone numbers and system starts to wait for the first reply for a period of time, a priori, while tracking patient. As soon as system receives the first reply, it sends an acknowledgement message containing name of patient, current location of patient and patient’s carer phone number to that carer who replies first. It also sends another message to other carers, who had sent a reply, stating a carer has been directed to patient’s current location. Following, system sends an SMS message to patient’s carer, reporting the directed carer’s name and phone number. System keeps the directed carer and patient’s carer informed about the current location of patient until it receives a message with text “FOUND” from either of them.

In order to form such a network, each patient and carer pair should be asked, at the end of registration interview, if they would like to be a member of such a social support network. Patients should be asked whether they feel comfortable to be reached, secured and taken care of by another AD patient’s carer or not. Carers should be asked whether they volunteer and are willing to take care of an AD patient other than theirs, whenever they are available and close to potentially wandering patient’s current location. Positive final decision should be reached by a consensus of two, patient and carer. In case one of the
parties does not like to join whereas the other does, the final decision should be negative, i.e. patient and carer pair does not join the social network.

3. Discussion and Future Work

In this paper, we provided insights of an EGT system for AD patients’ out-of-home mobility, which tries to administer the balance between patient’s autonomy and security. The protocol has been kept as simple as possible for the patient side. The most complicated action that system expects a patient to do is pressing a button on her/his tracking device.

The system, tries to undertake the carer’s “active tracker” role. In fact, it almost turns a patient into a self-controller and a carer into an inspector. This effort may reduce demand on carer’s time and carer distress related to current systems’ geofence and notification policies. In order to locate its impact, we plan to use Depression Scale and Zarit-Burden Interview [24], before and after the use of system.

The Patient Tracking Status structure and in particular “are you fine?” call period, “I am fine” response time and carer notification time variables, must be tested for applicability and feasibility. At first, it should be discovered whether the structure can be assigned generalized set of values or not. For this purpose, patients and carers will be invited for repetitive interviews. If a common set of values can be set, they need to be optimized. In case there is no common ground, the patient tracking status might need to be personalized as well.

System’s smooth operation and success depends on the registration process during which data regarding patient’s out-of-home life is gathered. However, this dependence may appear to be temporary. Out-of-home mobility data acquired through the interviews allow the system to initiate tracking. However, these data might become incomplete and therefore misleading for the system in time. For this purpose, the system may use a mechanism to constantly update a patient’s out-of-home activity list by learning that patient’s patterns of movement based on collected tracking data. Herewith, the proposed system may employ geofences based on seasonal changes; e.g. different geofences every three months, for every patient. Considering a patient’s full movement cycle is a year long, the system can adapt the geofences at every seasonal change after completing a full movement cycle, i.e. after collecting tracking data for a year for that patient. However, these constant updates may also require periodical interviews with (patient, carer) pairs to acquire other necessary properties of new activities, such as permission to notify the carer about an activity.

As the world population gets older, Alzheimer’s disease prevalence increases every year. The increase will give rise to serious outcomes including cost. A significant way to deal with such outcomes might be to form social networks among patients, carers and friends of them. The technology helps to cope with AD and its complications, however, it may also help them come together and organize. EGT applications and systems may be a trigger for this purpose as well.

References


