Towards Supporting Caregivers to Monitor the Whereabouts of People with Dementia

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ABSTRACT

Dementia is a complex neurodegenerative syndrome that is accompanied by a progressive decline in cognitive abilities. People with dementia develop problems in coping with activities of daily living, including orientation and way-finding tasks. People with moderate to severe dementia are withdrawn and sensitive, which can make caring for and working with them challenging, especially for caregivers. Our work focusses on people with moderate to severe dementia and nursing homes. Building upon previous work in supporting way-finding for people with dementia, we propose an integrated platform to support caregivers and other stakeholders in localizing people and monitoring their whereabouts. Real-time monitoring, a history of location data and heat maps help caregivers to quickly locate people, identify critical situations and learn about preferred locations of residents. Doctors, technology and architectural designers receive valuable data on movement patterns that support diagnosis and intervention planning.

Author Keywords

Localization and navigation; indoor monitoring; dementia; integration platform; distributed technology.

ACM Classification Keywords

H.1.2. User/Machine Systems: Human factors.

INTRODUCTION

In a literature review of previous studies on technology and dementia [15], a total number of 66 studies were analyzed. Among these, 64% focused on improving the independence and well-being of people with dementia and 38% focused on supporting their caregivers. Caregivers represent an important user group. They use technology to activate residents with dementia e.g. [10], for their own education e.g. [4, 6] or to improve access to diagnoses e.g. [5, 12]. Some projects e.g. [1] provide a virtual place where caregivers can gain access to information and connect to other members of the caregiving community.

Regarding navigation and orientation support, projects mostly focus on people with mild to moderate dementia and an outdoor context [2], for instance [3, 8, 13]. There is a specific lack of studies supporting people with moderate to severe dementia in indoor environments and supporting the stakeholders (i.e. caregivers, doctors, designers) who work with them. In existing projects, people with mild to moderate dementia often use smartphones or PDAs to access the system. People with moderate to severe dementia, however, seem reluctant or unable to manipulate complex mobile devices. Rasquin and colleagues [14] observe that even a device with three buttons may be too complicated for people with moderate to severe dementia. Ly et al. [11] thus propose an intelligent and implicit assistance for navigation with a three-part framework: a monitoring system with a small size and lightweight tag, an implicit guiding system and an intelligent part that refers to context-aware computing. In the guiding system, implicit cues with light and color for people with dementia were suggested. Apart from the people with dementia themselves, other stakeholders were not involved.

In this paper, we present an extension of the system in [11] designed to support stakeholders in dementia care (i.e. caregivers, doctors, designers of assistive technology and dementia-friendly architecture) besides the people with dementia themselves. This platform provides a visualization tool including real-time monitoring of the whereabouts of patients, a history of movements, and a location heat map that could facilitate the stakeholders' work.

METHODOLOGY

We conducted several studies including ethnographic observation and interviews in two health care facilities for people with dementia (one week in facility A and six weeks in facility B, depending on the availability of the caregivers). Besides conducting studies with people with dementia, we also observed and interviewed one caregiver in facility A and two caregivers in facility B about their difficulties in interacting with people with dementia and possible solutions. The observations of both, the people with dementia and the caregivers, were naturalistic observations (i.e. unstructured), which involved studying the spontaneous behavior of participants in navigation

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settings. Naturalistic observations allowed for greater ecological validity by observing the flow of behavior in situ and greatly helped in generating design ideas. We conducted two focus group sessions with two caregivers and one manager to discuss these design ideas and prototypes. Prototypes of the stakeholder support system evolved iteratively based on caregivers' feedback and interaction. In addition, we worked with an architect who is an expert in dementia-friendly architecture. The main questions for caregivers and the architect were about their methods and tools of work and their difficulties when working with/designing for people with dementia, particularly relating to localization and navigation problems.

FINDINGS

Taking a big-picture approach, we considered the whole eco-system with people with dementia at the center and including other stakeholders e.g. caregivers, architects. We observed that people with dementia do not use technology devices or are otherwise challenged in using them, cf. [14]. Thus, implicit interaction was proposed for people with dementia [11]. In contrast, other stakeholders (e.g. caregivers, designers) in some situations needed an explicit tool displaying and visualizing localization information. Thus, we developed a platform that handles location sensors' data, turns these into meaningful information for stakeholders, and visualizes these. This platform can facilitate the work of caregivers (and designers), save time, and help in reducing their workload.

Many caregivers admitted that they are always busy and often feel overwhelmed. The interview revealed that sometimes they needed to find residents quickly, for example, when they needed to see a doctor, had an appointment for a treatment, or when collecting people for lunch. In many cases, caregivers spent 20-30 minutes to find the residents. Thus, in emergency situations, too much time would be needed to find people with moderate to severe dementia. Therefore, real-time localization and monitoring emerged as necessary features of the system. Caregivers and doctors also want to see the movement history of residents (how long and how far they have walked for a certain amount of time) and some sort of 'heat map' showing how often people were in a specific location. That information along with data from biosensors and their medical history can help caregivers and doctors diagnose the physical condition of the patients. The caregivers suggested that such data should be visual and easy to use rather than being represented in tables with texts and numbers. Moreover, people with moderate to severe dementia tend to be withdrawn and sensitive, which makes it difficult for designers to work with them (another factor being their severe cognitive impairment). Thus, also technology designers and architects may benefit from a location history and heat map. These data support designers in finding potential guidance cues and understanding the behavior and patterns of movement of people with dementia. The architects otherwise are able to figure out which interior setting, floor plan topology, furniture etc. make people with dementia feel comfortable: Do they visit certain areas more frequently? Do they stay longer after an architectural intervention? Can they easily find the location?

IMPLEMENTATION

In this section, we present our platform and the current state of development.

IT Infrastructure

Our system is a web-based system using intranet of thing (IoT) features and distributed technology (Figure 1). The advantage is a high level of compatibility: users can use Android phones, iPhones, tablets, laptops, or PCs to connect to web-based services on the server anytime and from anywhere within the network.

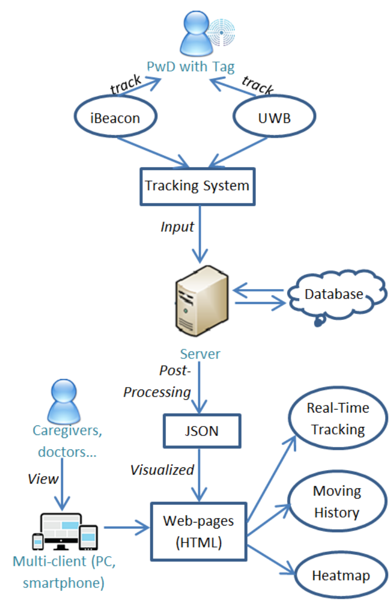

Figure 1: Infrastructure of our platform. The localization sensors send location information to the server via the internet. After post-processing, the data is stored under JSON (JavaScript Object Notation) format and visualized in a web-based interface.

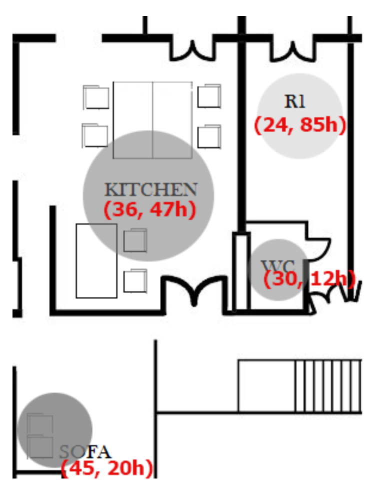

Figure 2: A part of Heat Map.

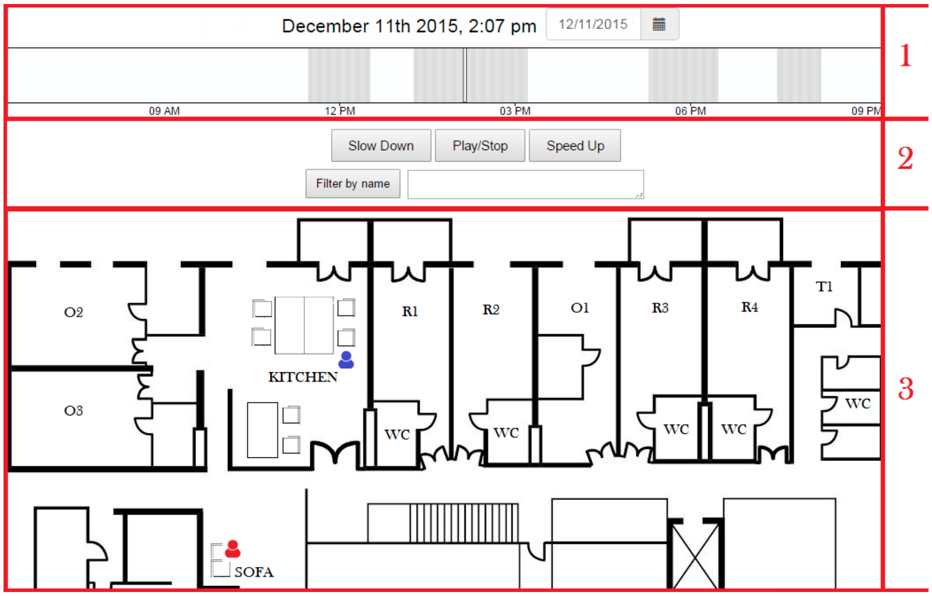

Figure 3: Moving history replay interface with three parts: 1. Date-time and time line, which shows periods with movement (gray sections) and without movement (white sections), 2. Functions: play/stop, speed up, slow down, filter by resident name (select a group by adding a semicolon between names), 3. Displaying resident localization and movement (here blue and red user-icons represent two residents).

Real-Time Monitoring System

The main techniques that can be employed for indoor monitoring are visual tracking, wireless localization, and dead-reckoning (DR). Kaddoura et al. [7] provide an example of visual tracking, which is normally expensive in cost and still has difficulties with identifying people. The Wi-Fi approach requires relatively expensive access points, whereas most DR systems rely on attaching motion sensors to a body's part e.g. [9, 16]. In general, a DR solution is affected by large errors, which increase over time. An RFID solution is a good option, which is used in many commercial products, for instance, Capterra, Ekahau. However, those products are also too expensive to employ in care homes. We thus developed a low-cost monitoring system combining iBeacon and ultra-wide band (UWB) technologies. Overall, these two technologies are good for our purposes due to their small tag sizes, long battery life and low cost. We first tested iBeacons (Onyx iBeacon and Android phone) and UWB (Decawave products) separately. The results showed that iBeacon technology has a short detection range (~10m without obstruction, 5-7m with walls or objects in between) and low accuracy (0.1-0.2m with a short distance and no obstruction, 3m with long distance and obstructions). However, the very low-cost iBeacon technology is a good solution in cases when it only needs to be determined whether people with dementia were passing by or entering a small zone or area (e.g. doors). The UWB solution incurs higher cost, but has a long detection range (290m without any obstruction but in a building many walls, it is up to 10-40m) and high accuracy (<0.1m with distance 1-10m). This approach with trilateration has advantages in large areas like the cafeteria, entertainment room and other cases where a precise movement detection is needed. For example, to detect a person who has been moving around a table for a while indicating the need for support, the UWB solution is better, as the iBeacon solution possibly gives inaccurate readings. After the server received the location data, the post-processing (Figure 1) synchronizes the arrival times and applies filters and K-nearest neighbor algorithms. We used the JSON (JavaScript Object Notation) format to store the location data and to visualize and display the data to the users (i.e. caregivers, doctors, designers). The real-time monitoring interface is similar to the interface used to replay movement histories (Figure 3). However, in real time monitoring, there would be no buttons to "speed up", "slow down" and movement history displayed. In addition, the map in real-time monitoring can be zoomed and displays a short history of movement e.g. the last 5-60 seconds.

Movement History

The movement history is replayed by JSON data (Figure 3). It works similar to a video player. The gray sections represent times that people were moving. The white sections indicate times without movements. Users can click on the timeline to jump to a specific time, or adjust the moving speed of the replay (the slowest speed is 0/ stop). Location and movement are shown respectively in part 3.

Heat map

Figure 2 is a part of the heat map displaying information of person 1 for one week. Names of the place, numbers of visits, and hours of staying are displayed. For example, this person visited the sofa 45 times but only stayed for 20h in total, whereas the person was in the bedroom 24 times with 85 hours. The darker a circle is, the more frequent the person visited that place.

CONCLUSION AND FUTURE WORK

Focusing on dementia care facilities, we extended a system for supporting the indoor navigation of people with dementia [11] to support other stakeholders (i.e. caregivers, but also doctors, architects, and designers). The main functions of this platform are real-time monitoring, a history of movements, and a heat map of frequent places.

We chose IoT and distributed technologies, as well as JSON as the basis of our development, since it provides online services for users with any device anytime and anyplace within the network. In addition, it supports integration of different technologies, frameworks, and programming languages.

We presented the first implementation of our platform. Overall, the first feedback from the stakeholders indicated that we seem to be on a good way. However, the platform needs further work, and a formal usability test involving the relevant stakeholders. On the technical side, we expect to optimize the combination of iBeacon and UWB technologies for the monitoring system. On the stakeholder side, we believe that adding an intelligent component that analyses the movement patterns and highlights potentially critical situations to the caregivers could be helpful. Designers and architects may profit from integrated cognitive architectures that can simulate the effects of environmental interventions on the behavior of the inhabitants. Finally, on the side of people with dementia we would like to explore the impact of making the display available to the residents. Will they be interested to see the whereabouts of their peers? What social dynamics ensues from this? How can we be ethical about the data collection and displaying the location of people to others? Can we expect people with moderate and severe dementia to decide to opt out? These will be important challenges to consider.

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