

A Remote Home Monitoring System to Support Informal Caregivers of People with Dementia

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Abstract: Informal caregivers of people with dementia have a high risk of becoming overburdened. Health informatics for aging in place can provide them support by deploying unobtrusive remote home monitoring systems to assess real-time events and monitor changes in the behavior of the person with dementia (PwD). In this paper, we describe the concept, development, and evaluation of an intelligent remote Home Monitoring System (HMS) that provides support to informal caregivers by giving key information related to the health and independent living of the PwD. The HMS consists of a Sensor System that monitors low-level behaviors of the PwD, a Decision Support System that translates this into high-level behaviors, and a connected Smartphone Application that allows the caregiver to receive notifications, review behavioral information at a glance, and facilitates the collaborative care process between informal caregivers. The final HMS prototype was evaluated and scored high in terms of usability and quality of the Smartphone Application. The Sensor System showed no significant flaws during testing, and the Decision Support System is considered a viable proof of concept. The next step is to evaluate the HMS in a real-life setting in terms of offering peace of mind and reducing the burden of care.

1 INTRODUCTION

The world population is aging, resulting in an increasing number of people suffering from dementia. In the Netherlands, 1 in 5 people develop dementia (VUmc Alzheimercentrum et al. 2012). In its early stages, people are able to remain at home with the support of informal caregivers who provide the majority of care, and who have a key role in determining the person's wellbeing (Ministry of Health Welfare and Sport et al. 2009). The dependency on informal caregivers in society is increasing, many of whom face difficulties in their caregiving tasks and are (at high risk of becoming) overburdened (Ministry of Health Welfare and Sport et al. 2009; VUmc Alzheimercentrum et al. 2012). Providing them with sufficient support is therefore of great importance, but also to ensure that those with dementia can continue to live at home longer.

Technological innovations that promote aging in place, such as Ambient Assisted Living (AAL), could

provide a solution by implementing unobtrusive remote home monitoring systems that employ a network of sensors to assess real-time events and monitor changes in the behavior of a person. AAL has the potential to promote the quality of life and safety for people with dementia, give peace of mind to the informal caregivers, and promote independence and autonomy for both target groups (Alzheimer's Society 2017). This fits well with informal caregivers' need for reassurance in terms of (Instrumental) Activities of Daily Living ((I)ADL) and safety in the home of the person with dementia (Kirsi et al. 2004; Pollitt et al. 1991; Bank et al. 2006; Nolan et al. 2002).

However, the majority of AAL and related systems found in systematic reviews do not report on informal caregivers as end-users (Ienca et al. 2017; Liu et al. 2016; Carswell et al. 2009). This is also reflected in studies on caregiver burden (Peeters, Werkman and A Francke 2014; Peeters, Werkman and AL Francke 2014; Zwaanswijk et al. 2013; Miranda-Castillo et al. 2013; Peeters et al. 2010),

where informal caregivers are rarely surveyed about using AAL to support them in care tasks. Clearly, we can observe that support for informal caregivers of people with dementia is needed.

As part of the H2020 project IN LIFE (<http://www.inlife-project.eu>), we developed and implemented a Health Monitoring Application, called *HELMA*. This monitoring tool aims to inform informal caregivers about the health and wellbeing of the person with dementia over the long-term by means of short frequent online questionnaires. To improve the support for informal caregivers, and to make the system more discreet and time-efficient, we aim to improve *HELMA* with objective monitoring.

Motion and door sensors are proven to be useful to quantify (changes in) ADL (Yang and Hsu 2012) (Urwyler et al. 2017), are readily accepted in society (Pol et al. 2016), appear to be almost unnoticed by residents after installation in their homes (Nijhof et al. 2013), and are relatively simple and not too expensive (Peetoom et al. 2015). In addition, simple estimation methods can be used to quantify daily rhythms (Yang & Hsu 2012), and measuring baselines are useful to find changes in behavior (Glascock and Kutzik 2000).

As such, we have developed a Health Monitoring System (HMS): a remote home monitoring system to support informal caregivers of people with dementia in their caregiving tasks. In this paper, we describe the concept, development, and evaluation of this remote home monitoring system.

2 METHODS

The work described in this paper is based on an iterative, user-centered design approach as shown in Figure 1. By involving potential end-users in the design process, we aim to increase the usability and usefulness of the developed system. The HMS consists of three main components: (1) Smartphone Application; (2) Sensor System; and (3) Server.

First, we performed a state-of-the-art study by searching in among others scientific databases (e.g., Scopus, PubMed, and ScienceDirect) on the topics of dementia, informal caregivers, remote home monitoring, user interface design, and state-of-the-art of remote home monitoring systems. Based on our findings we developed a scenario following the approaches of PACT (People; Activities; Context; and Technology) (Huis in 't Veld et al. 2010) and FICS (Function and events; Interactions and usability issues; Content and structure; and Style and aesthetics) (Benyon and Macaulay 2002). Starting from the scenario, potential end-users were involved to collect, elaborate, and refine the HMS requirements. The end-users were contacted via local healthcare organizations, and consisted of small groups based on the assumption that the best results in terms of usability testing come from no more than 5 end-users and performing as many small tests as possible (Nielsen and Landauer 1993). During the evaluations, which were divided into three phases, the Smartphone Application was central.

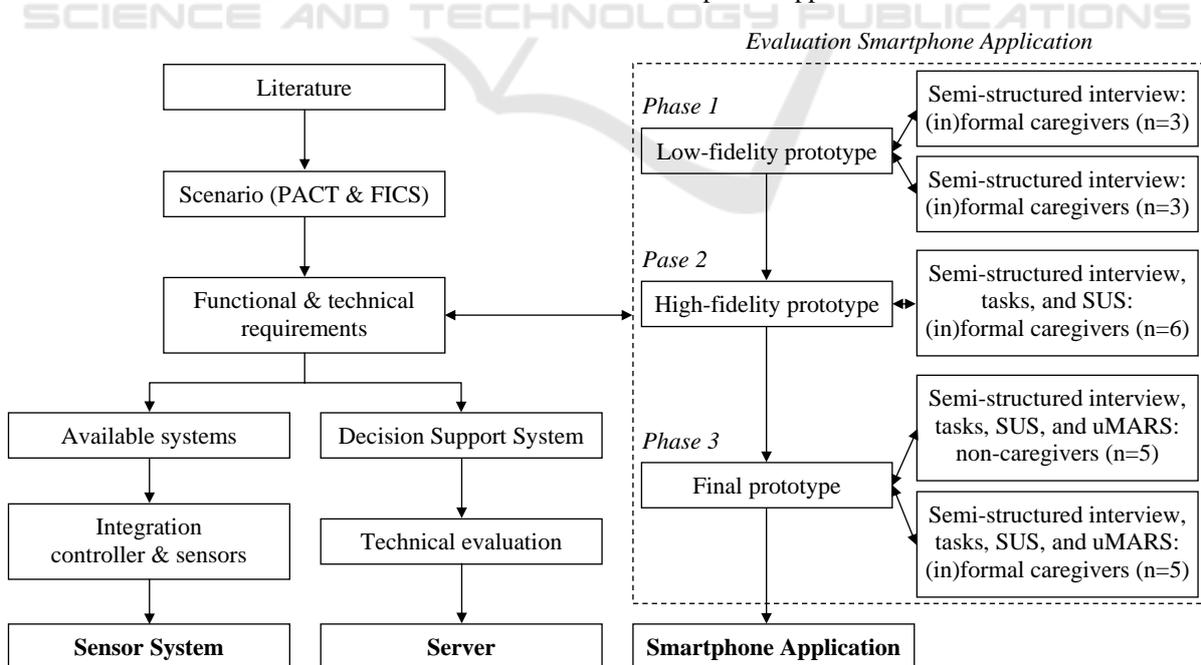


Figure 1: General iterative design process of the HMS.

Smartphone Application: In phase 1, we drafted the first requirements of the HMS and created a low-fidelity prototype of the application based on the scenario. The prototype was evaluated in two successive sessions using semi-structured interviews on demographics, HMS functionalities, and the designed prototype. Each session included two informal caregivers of people with dementia and one dementia case manager (total n=6).

In phase 2, a high-fidelity prototype was created for Android-based smartphones. The prototype was evaluated using a mixed-methods approach, including a semi-structured demographics interview, task-based think-aloud protocol, controlled observation, System Usability Score (SUS) (Brooke 1996), and a semi-structured interview in terms of usefulness. The evaluation included the four informal caregivers and two case managers from phase 1.

In phase 3, a final prototype was created corresponding to the approach in phase 2. In addition, the evaluation included two successive sessions and the User Version of the Mobile Application Rating Scale (uMARS) (Stoyanov et al. 2016) (using multiple-forward translation). The first session included five non-caregivers, and the second session included three informal caregivers of people with dementia and two dementia case managers.

The resulting functional requirements of the HMS were prioritized by the first author (SL).

Sensor System: Based on the requirements, we searched for a suitable Sensor System based on current systems in literature and commercially available systems. The Sensor System should have a suitable controller with open API, bi-directional communication, support for motion and door sensors, and should be commercially available in the Netherlands. The necessary motion and door sensors should be simple, small, compatible with the chosen controller, and commercially available in the Netherlands.

Server: The Server consists of the Decision Support System (DSS), which interprets the data collected by the Sensor System, and the Database Server. For the DSS, the requirements were used as a guiding principle to determine *how* and *what* should be monitored.

The technical evaluation of the DSS, and indirect of the Sensor System, was conducted in a 5-day in-home test where the first author (SL) annotated all in-home activities (see Section 7), while being monitored by the Sensor System (see Figure 5). The outcome of the annotations was compared to the data of the DSS to explore the reliability of the system.

Table 1: Functional requirements of the HMS; showing five high-priority examples.

#	Functional requirement – HMS
	The HMS should:
F1	... support multiple users
F2	... show information about events and behavioral changes
F3	... differentiate between normal, abnormal, and alarming situations
F4	... include a shared calendar
F5	... include a chat function

3 HMS CONCEPT

The HMS concept can be described as follows:

The Health Monitoring System includes multiple wireless sensors that can be easily placed in the home of the person with dementia (i.e., the resident). All these sensors together unobtrusively monitor the activities and behavioral changes of this person. The informal caregivers will be remotely informed via a smartphone application about the home situation, and receive notifications upon meaningful events and behavioral changes regarding the person they care for.

Table 1 shows a selection of five high-priority functional requirements of the HMS (as determined by the first author (SL), based on functionality, desirability, and feasibility). The original functional requirements varied in terms of specificity, ranging from for example “*should support multiple users*” to “*should only display the latest event or notification in the home screen*”. The functional requirements with respect to the parameters to be monitored by the HMS were divided into *Detections* (basic activities and actions) and *Patterns* (slow changes and unusual behavior). The Detections are shown in Table 2. The Patterns are defined as deviations on the Detections, based on the person’s standard behavior. An example is: “*The HMS should monitor deviations in the time of going to bed*”.

The Smartphone Application should primarily provide key information (i.e., on location, activity, sleeping, and eating) related to the health and independent living of the person with dementia. It is also important to support and improve communication between informal caregivers, for example by including a shared calendar and chat function.

The Sensor System should include multiple wireless sensors that can be easily placed in the home of the person with dementia. All these sensors together should unobtrusively monitor the activities

and behavioral changes of this person. The sensors should be simple, small, and largely respect privacy.

Finally, the Server should be a secure environment for the collected data. In addition, the DSS should be reliable and complete in terms of the activities and behaviors to be measured.

Table 2: Functional requirements of the HMS Detections.

#	Functional requirement – HMS Detection
The HMS should inform about <i>location</i> by monitoring:	
D1	... leaving the house
D2	... outdoor location
The HMS should inform about <i>sleeping</i> by monitoring:	
D3	... time of going to bed
D4	... time of getting out of bed
D5	... sleep duration
D6	... number of times and time out of bed
D7	... restlessness
The HMS should inform about <i>activity</i> by monitoring:	
D8	... wandering
D9	... toilet usage
D10	... physical activity
D11	... social activity
The HMS should inform about <i>eating</i> by monitoring:	
D12	... meals (breakfast, lunch, and dinner)
D13	... drinking
The HMS should inform about ... by monitoring:	
D14	... medication intake
D15	... personal hygiene
D16	... body weight
D17	... falling
D18	... appliances
D19	... fire alarm
D20	... in-home temperature
D21	... (unwanted) visitors

4 ARCHITECTURE

The architecture of the HMS consists of: (1) Sensor System; (2) Server; and (3) Smartphone Application (see Figure 2).

The Sensor System consists of a controller and several door/motion sensors. It monitors the home of the person with dementia (i.e., the resident) and sends all sensor detections to the DSS.

The DSS receives and stores the sensor detections received from the Sensor System. Algorithms then analyze and process the data, and generate events. The DSS can generate events on multiple levels (see Section 7), which are written to the Database Server.

The Database Server consists of a MySQL backend and secure API that both communicate with the DSS and the Smartphone Application. It contains the data of all residents, and informal caregivers, based on the DSS and Smartphone Application. The DSS generates sensor events, whereas the Smartphone Application generates chat messages and shared calendar items. Every data record is linked to a resident ID that determines the access control. Informal caregivers can only access data from their own resident.

The Smartphone Application consists of the Local Database, which is automatically synchronized with the Database Server, and the User Interface, consisting of all the necessary components for the user interface interaction. The Local Database is a replication of part of the Database Server and only contains relevant data for its user. The Local Database allows the user to use the Smartphone Application offline and improves the user experience.

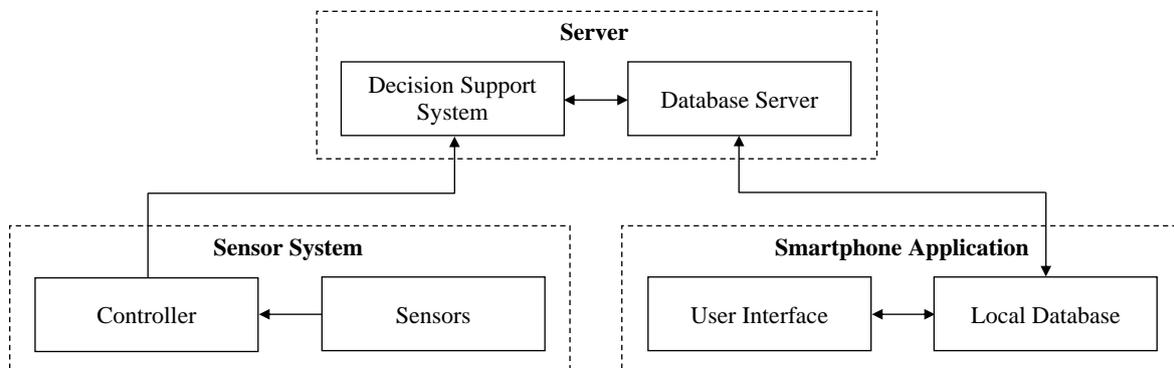


Figure 2: Architecture of the HMS.

5 SMARTPHONE APPLICATION

The Smartphone Application consists of three main components: (1) Home; (2) Calendar; and (3) Chat (see Figure 3).

The Home screen displays clear information regarding the person with dementia (i.e., the resident). There are three states for displaying information: (1) normal; (2) abnormal; and (3) alarming (see Figure 4). In the normal state, general information is displayed about the resident (e.g., “*The resident went to bed.*”). In the abnormal state, information is displayed which does not require immediate attention, but must be kept an eye on (e.g., “*The resident was 2 hours out of bed last night.*”). And in the alarming state, immediate action is required (e.g., “*The resident left the house at night!*”). An overview of all notifications is shown in Table 3.

The Home screen is also the gateway to many other features of the application. Starting at the top, there are four buttons. In order from left to right, the Phone button allows the informal caregiver to call the resident directly, but also to temporarily block the calls from the resident. This measure is implemented because some residents call their informal caregivers extremely often, leading to frustration of the informal caregiver. When the calls are blocked, the caller (i.e., the resident) will be redirected to the voicemail. Informal caregivers are therefore advised to set a reassuring voicemail beforehand. The Mute button allows the informal caregiver to set all HMS notifications to sound and vibrate, vibrate, or mute. This does not affect other phone notifications. The Connection button allows the informal caregiver to check the connection with the HMS. And the Settings button allows the informal caregiver to view and

adjust various system settings, such as Account, Notifications, Calls, Events, and Installation. The Home screen also contains a Menu button, allowing the user to view current and historical notifications about each of the Location, Activity, Sleeping, and Eating domains (see Figure 4). The user can view all aforementioned domains in a single view in Overview. Each domain also gives the user the opportunity to view data graphically per week, month, quarter, or half year, with a view to inform about behavioral changes. The Calendar gives informal caregivers the opportunity to schedule mutual appointments. And the Chat gives informal caregivers the option to send each other messages.

The Smartphone Application follows the general design principles to clearly show its users at a glance all the necessary information.

The phase 3 evaluation with the final prototype showed a median (range) SUS score of 87.50 (15.00), and a uMARS score of 4.27 (0.73) with the following subdomains: Engagement 4.00 (1.60); Functionality 4.25 (0.75); Aesthetics 4.33 (1.00); and Information 4.50 (1.00).

In addition, the interviews highlighted improvements such as:

- The application should include the option to assign caregivers to calendar items.
- The application should include the option to add notes, photos, and contact information to calendar items.
- The application should geographically prioritize caregivers in case of alarming situations, so that geographically close caregivers are warned first. They should however be able to forward the alarm.

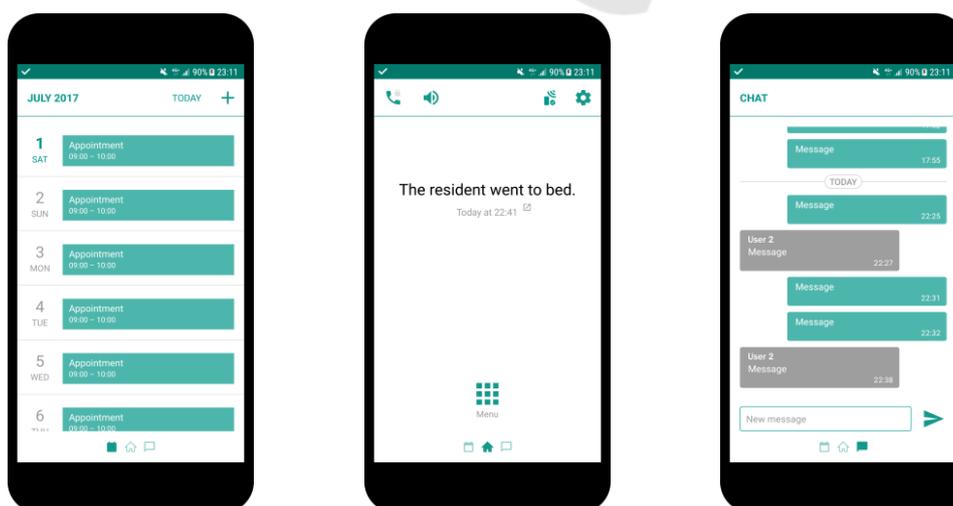


Figure 3: Smartphone Application; showing the Calendar on the left, the Home screen in the center, and the Chat on the right.

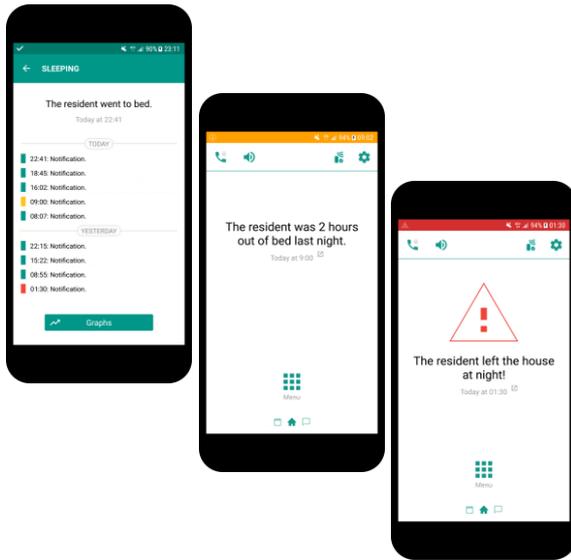


Figure 4: Smartphone Application; showing the Sleeping overview on the left, the Home screen during an abnormal event in the center, and the Home screen during an alarming event on the right.

Table 3: Overview of the notifications implemented in the Smartphone Application.

#	Smartphone Application notification
<i>Location</i> notification about:	
N1	... coming / leaving home during the day
N2	... coming / leaving home at night
N3	... leaving home for a long period of time
N4	... not coming home at night
<i>Sleeping</i> notification about:	
N5	... going to bed
N6	... getting out of bed
N7	... not going to bed
N8	... not getting out of bed
N9	... sleep duration
N10	... number of times and time out of bed
<i>Activity</i> notification about:	
N11	... physical in- or overactivity
N12	... social inactivity
N13	... remarkable toilet usage
<i>Eating</i> notification about:	
N14	... forgetting / preparing too many meals (breakfast; lunch; and dinner)
<i>Other</i> notification about:	
N15	... in-home temperature
N16	... new calendar item
N17	... new chat message

6 SENSOR SYSTEM

In our search for a controller, thirty products were found varying from complete systems to standalone controllers. Of these, the following five products fitted the requirements: (1) Insteon; (2) Fibaro; (3) Raspberry Pi + RaZberry + Domoticz; (4) Eedomus; and (5) Vera. Other systems, such as Samsung SmartThings, BeNext, Zipato, D-Link, Devolo, Wink, and others, were unsuitable due to not being available for the Netherlands, not having an open API, or other reasons. The final choice was the Vera Plus. In the search for suitable sensors, the compatibility with this controller, and the in Section 3 mentioned requirements, were taken into account. As a result, the Philotech PST02-1A sensor was chosen, based on its compatibility and suitability; small, and combining both motion and door sensor.

In our test environment (see Figure 5), the controller was placed in a location where all sensors were still in range. The sensors were placed in each room of interest, if possible at 1.60 m height, and focused on the area where movement was most likely. The sensors all monitored motion and/or opening/closing of doors (see Section 7), and were placed inside the appointed room for a more reliable outcome (e.g., the toilet sensor measures motion inside the toilet room).

Sensors

- | | | |
|---------------|--------------------|----------------|
| 1. Front door | 4. Cutlery drawer | 7. Bedroom |
| 2. Toilet | 5. Kitchen cabinet | 8. Living room |
| 3. Kitchen | 6. Fridge | 9. Back door |

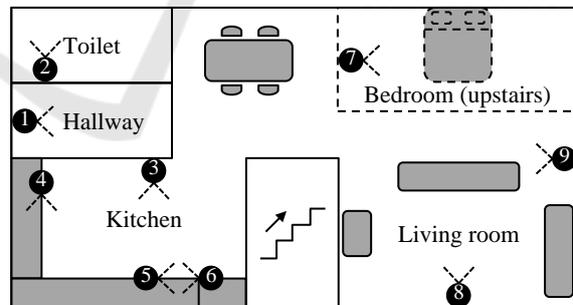


Figure 5: Sensor System; showing the sensor locations.

7 DECISION SUPPORT SYSTEM

The DSS of the Server interprets the sensor data collected from the Sensor System. Following the various abstraction levels of the monitoring requirements, the DSS subdivides information into four levels: (1) raw sensor data; (2) location/action; (3) events/alerts/statistics; and (4) trends. Information

from each level is used to generate information for the subsequent level.

At the location/action level, location refers to a room in the house. Location cannot be tracked outside the house, but the system can reliably detect when a person leaves or enters the house. Actions defined at this level are particularly cooking and sleeping.

Locations and actions are directly determined from the door/motion sensors. We decided that the DSS should consider the motion sensing as primary data, as it reliably detects the presence of a person (i.e., none of the errors were related to the motion sensor). The door sensing is used as supplemental data. A door opening and closing could mean a person is either entering or leaving a room, and sometimes doors remain open. A simple algorithm where a door opening is assumed to mean a person leaves the room, unless the room's location sensor is triggered, is used. Cooking can be determined by the fridge and on operating either the cutlery drawer or kitchen cabinet.

We tested the location/action algorithm using the annotated 5-day in-home test data. This test consisted of the following annotations: leaving the house (via front or back door); entering the house (via front or back door); bedroom (entering or leaving); sleeping (going to bed or going out of bed); cooking (start or end); and toilet (entering or leaving).

For each location, we determined: minutes seen (how many minutes being in the location were correctly detected); minutes unseen (how many minutes being in the location were not detected), times seen (how many times being in the location were correctly detected); times unseen (how many times being in the location were never detected for the duration the resident was there); and times false (how many times being in the location were falsely detected). The results are shown in Table 4.

Overall accuracy is quite high, 92%. Standing out is the relatively high unseen minutes of the toilet. Our findings are that the motion sensor picks up motion slowly with respect to the typical duration of the toilet visits (about 1-2 minutes). The number of visits is however the most relevant for toilet use, which scores well (only 12% total error rate). The same applies for cooking, where *times* are far more relevant than *minutes* (which is why minutes for cooking were not calculated). The opposite applies to Bedroom/Sleeping, Indoors (other), and Outdoors, where number of times seen are not relevant for the alerts we generate. For these, the number of false positives seem quite high. This can be explained by the system registering opening a door as leaving that room. When residents do not actually leave the room, it takes only about 30 seconds before the motion sensor corrects that, but it

does clock up the number of false positives. This is a trade-off between measuring minutes (necessary for Bedroom/Sleeping, Indoors (other), and Outdoors) and times (necessary for Toilet and Cooking).

Table 4: DSS location detection results;

Minutes seen is defined as the number of correctly detected minutes in the location. Minutes unseen is defined as the number of undetected minutes in the location. Times seen is defined as the number of correctly detected times in the location. Times unseen is defined as the number of undetected times in the location. And times false is defined as the number of falsely detected times in the location. TOTAL is the sum of all above described parameters. The corresponding percentage is calculated as follows: minutes seen and minutes unseen are the result of dividing each by the sum of minutes seen and minutes unseen; times seen, times unseen, and times false are the result of dividing each by the sum of times seen, times unseen, and times false.

Location/ action	Minutes seen	Minutes unseen	Times seen	Times unseen	Times false
Toilet	12	26	38	3	2
Bedroom/ Sleeping	2637/ 2271	354	23	2	20
Indoors (other)	3123	140	118	5	42
Outdoors	2021	149	42	1	27
Cooking	-	-	14	1	5
TOTAL	7793 (0.92)	669 (0.08)	235 (0.69)	12 (0.03)	96 (0.28)

For the events/alerts/statistics level, the DSS relies on the location to generate events. Most events could be specified with the help of two types of triggers: a time interval trigger (the resident visits a specific location in a specific time interval); and a timeout trigger (the resident remains in, or never reaches, a specific location for a given duration). For example, the resident leaving the house at night is specified as a time trigger between 11.00 pm and 6.00 am, and the resident staying away for a long period is specified as a timeout trigger on staying outdoors for 5 hours. In addition, the system must reliably model the sleep/wake cycle in order to generate statistics like sleep duration. The sleep/wake cycle progresses when the resident goes to sleep or gets out of bed for at least 45 minutes on particular times of the day.

Finally, the trends level uses the non-parametric Mann-Kendall test (Kendall 1975), which enables any trends to be detected in time-series data. The Mann-Kendall test detects statistical significance and direction of a trend. The test is conducted periodically on statistics data, so the alpha value was lowered each time using Bonferroni correction (Dunn 1961). We did not have data to test the effectiveness of the

algorithm, but we created simulated data to assess it. We generated noisy data with a linear trend, with daily values over a year, and we looked at the point at which the algorithm could detect the trend in spite of the noise. We used either normal or Poisson distribution, depending on the statistics. For example, wake-up time is normally distributed, and number of toilet visits per day is a Poisson distribution. We found that the algorithm could detect small trends at low alpha levels even in cases where the trend was not visually apparent. For example, a 30-minute shift in wake-up time over a year with a standard deviation of 1 hour was detected with $\alpha < 0.001$. As such, we consider the algorithm a viable proof of concept.

8 DISCUSSION & CONCLUSION

In our effort to improve HELMA with objective monitoring, we conceptualized, developed, and evaluated the Health Monitoring System (HMS). The majority of identified requirements have been implemented, and the HMS scored high in terms of usability and quality of the Smartphone Application. The Sensor System showed no significant flaws during our tests, and the DSS is considered a viable proof of concept.

The user-centered design resulted in a set of requirements with emphasis on the provision of relevant information in terms of the health and independent living of the person with dementia by monitoring their activities and behavioral changes, and on the communication between informal caregivers. In this way, the concept of the HMS distinguishes itself from other systems (e.g., systems found in systematic reviews (Ienca et al. 2017; Liu et al. 2016; Carswell et al. 2009)) by focusing on informal caregivers of people with dementia as primary end-user. Moreover, the HMS aims to be a versatile, unobtrusive, and privacy-friendly system.

The current HMS implements most of the identified requirements. The requirements that have not yet been addressed in this work are: outdoor location; restlessness at night; wandering; drinking; medication intake; personal hygiene; body weight; falling; appliances; fire alarm; and (unwanted) visitors. These requirements should be incrementally added to the system to enrich the information provision on health and independent living, and to add the element of safety (indoors and outdoors). Priority should be given to: outdoor location (e.g., by using a GPS wristband); medication intake (e.g., by using a medicine dispenser); falling (e.g., by using a wristband or unobtrusive fall detection sensor);

appliances (e.g., by using a sensor on the stove); fire alarm (e.g., by using a smoke detector); and (unwanted) visitors (e.g., by registering the presence of the visitor's smartphone). The discussed recommendations from participants should be incrementally added to the Smartphone Application to improve its functionalities and user-friendliness. This provides particularly more overview on who takes care of which task or alarming situation.

The Smartphone Application shows with a median (range) SUS score of 87.50 (15.00) and uMARS score of 4.27 (0.73) excellent usability and good quality, suggesting that the application is most likely well implementable in practice. The high outcome is most likely due to our chosen design process; involving potential end-users throughout the design. The current drawback is the lack of testing in a real-life setting, which could have determined whether the provided information is sufficient, the Calendar and Chat come to their full right, and functionalities such as blocking calls are being used.

The Sensor System seems to work well, and the DSS shows a high accuracy score of 92%. This is most likely due to using relatively simple sensors and algorithms. On the downside, the technical evaluation was short and in a controlled environment. Future evaluations should pursue carrying out longer (real-life) trials, allowing to find unnoticed problems, and to test the Sensor System on properties such as durability and battery life. In addition, the DSS should be brought to a higher level, using for example machine learning to map behavior of the resident to better identify activities and behavior, making the system more reliable and thus more user-friendly.

The next step for the HMS would be to evaluate the system in a real-life setting, and to search for possibilities to merge the HMS with HELMA. We do expect that, over time, much of the HELMA data can be replaced with more accurate objective measurements, making the HELMA questionnaires more time-efficient and more focused on purely subjective information.

In conclusion: the HMS seems to be a promising proof of concept in providing effective support to informal caregivers of people with dementia. The system gives key information related to the health and independent living of the person with dementia, and aims therewith to promote the quality of life of the informal caregivers by offering peace of mind and reducing the burden of care.

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