Lo-Fi Prototype of a Sensor-dependent Interaction Platform: Formative Evaluation with Informal Caregivers of Older Adults with Cognitive Impairment

Nikita Sharma, Karen Grotenhuijs, J.E.W.C. van Gemert-Pijnen, Harri Oinas-Kukkonen, L.M.A. Braakman-Jansen

Submitted to: JMIR Formative Research
on: October 05, 2023

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Abstract

Background: Unobtrusive sensing technologies developed for monitoring deviant behaviors in older adult care requires its integration with an interaction platform to facilitate the flow of information between them and concerned caregivers. However, the continuous monitoring capabilities generate a considerable amount of data that must be interpreted, filtered, and personalized before being communicated to the informal caregivers based on their specific care needs and requirements.

Objective: For the effective implementation of unobtrusive sensing solutions (USSs) in the care of older adults with cognitive impairment, this study aims to explore the expectation and pre-conditions for the implementation of USSs from the perspective of informal caregivers. Followed to that, a low-fidelity prototype of an interaction platform, incorporating persuasive system design (PSD) features based on the needs and requirements of informal caregivers, was designed and evaluated for its conceptual workflow and usability.

Methods: Six informal caregivers of older adults with cognitive impairment living alone participated in this qualitative (interview) study. The expectation and pre-conditions for implementation were explored through open questions whereas formative evaluation (usability study with thinking aloud approach) was conducted to evaluate the conceptual workflow and used PSD features in the interaction platform. Overall, a mix of inductive and thematic analysis was used to analysis the interviews.

Results: The result of this study presents both positive and negative outcome expectations regarding the implementation of a USSs, highlighting benefits such as objective decision-making and peace of mind, but also concerns about information overload and potential substitution of human contact. Strategic information communication agreements between informal and formal caregivers were deemed crucial for the successful implementation of USSs in care. Overall, informal caregivers had a positive experience with the lo-fi prototype of the interaction platform, particularly valuing the personalization feature.

Conclusions: In conclusion, to achieve successful implementation, a holistic design approach is necessary, and equal consideration should be given to the personalization-privacy paradox to balance user needs and privacy.

(JMIR Preprints 05/10/2023:53402)
DOI: https://doi.org/10.2196/preprints.53402

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Lo-Fi Prototype of a Sensor-dependent Interaction Platform: Formative Evaluation with Informal Caregivers of Older Adults with Cognitive Impairment

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Abstract

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Conclusion: In conclusion, to achieve successful implementation, a holistic design approach is necessary, and equal consideration should be given to the personalization-privacy paradox to balance user needs and privacy.

Keywords: Older adult care, Informal caregivers, Cognitive impairment, Sensing solutions, Information communication platform, Lo-Fi prototype

Introduction

The increase in the older adult population imposes significant challenges on the organization and functioning of the current healthcare infrastructure around the globe [1]. It demands the active involvement of different stakeholders including informal caregivers, formal caregivers, general practitioners, technology developers, policymakers, and government organizations to maintain continuous care [2]. Primarily, informal caregivers are perceived as responsible for organizing and ensuring on-time care for older adults, impacting their physical, financial, emotional, and social well-being [3] [4]. On top of that, with the emergence of cognitive impairment or co-morbidities, the care process becomes more complex and challenging for informal caregivers [5].

To support informal caregivers in delivering on-time care, sensor-based solutions, specifically the ones that are unobtrusive or device-free (do not demand direct involvement or attention from older adults), are being developed [6]. The studies showed that unobtrusive sensing solutions (USSs) are demanded and appear useful among informal caregivers of older adults with cognitive impairment (OwCI) due to their 24/7 monitoring capabilities, providing real-time insights into the health of care recipient [2] [6]. As described in the study by Sharma et al. [7], a USS is comprised of three main units: a sensing unit responsible for collecting data from the care recipient; a computing unit responsible for making sense of the obtained sensing data; and a communicating unit which communicates the output of computing unit to the informal caregivers to enable monitoring on a distance.

Over the past decade, there have been notable advancements and successful endeavors in facilitating the development of unobtrusive and ubiquitous sensing technology [8]. For example, Wi-Fi CSI (as a sensing unit) can be used for monitoring physical activity (falls, sitting, hand gestures, etc.), physiological activities (heart and breathing rate), and behaviors (sleeping patterns, personal hygiene, etc.) [9] [10] [11]. Moreover, significant growth in computing unit by using advanced machine learning methods (such as deep neural networks, generative adversarial networks, etc.) to improve privacy, reliability (minimizing false alarms), and computing time are evident [12] [13]. However, the efforts from the information technology domain (communication unit), particularly, in the direction of developing and designing interaction platforms adhering to the information communication (IC) needs and requirements of the informal caregivers (or other stakeholders) are lacking [14]. Designing the interaction platform according to the preferences of informal caregivers can assist in prioritizing and optimizing their care plans, thereby reducing the care (information) load [7].

Our previous study have explored the IC needs and requirements of informal caregivers of OwCI for different care scenarios (falls, nocturnal unrest, agitation, and normal daily life) [7]. The findings suggested that dynamic care needs are dependent on various factors including care scenarios (emergencies or normal daily activities), personal circumstances of caregivers or care recipients, and the emergence or progression of illness in care recipients. To cater to these dynamic care needs, user-centered design approaches, such as the Center for eHealth Research and Disease Management (CeHRes) Roadmap can be used [15]. This approach fosters progress toward context-aware sensing and computing by offering early feedback regarding users' needs and requirements to the designers and developers [16]. For instance, if informal caregivers prefer insights into emergencies only, the algorithm can be trained and optimized accordingly to provide relevant data, avoiding computing overload for the system and information overload for the caregivers. The study [7] also elicited design features including reduction, tailoring, personalization, reminders, suggestions, trustworthiness, and social learning based on the persuasive system design (PSD) model for designing such an interaction platform [17].

However, one of the limitations we identified was the lack of proper understanding of the USSs among informal caregivers [7]. It was understood that, given the technical novelty of the solution, informal caregivers viewed it as a black box thereby might have caused biases regarding their responses toward its usefulness and expectations. Therefore, in this study, first, we aim to delve deeper into the expectations (positive and negative) and explore pre-conditions for the implementation of USSs in OwCI care from the perspective of informal caregivers after showing them a video prototype of the solution. As a next step, a clickable low-fidelity (lo-fi) prototype (conceptual workflow) of a sensor-dependent interaction platform is designed by utilizing identified PSD features for three care scenarios namely falls, agitation, and normal daily life.

1.1 Research Objectives:

The objectives of this research are bifold:

1. To explore the expectations and the pre-conditions for implementation of USSs in older adults with cognitive impairment care from the perspective of informal caregivers.
2. To design and evaluate a low-fidelity prototype of a sensor-dependent interaction platform, incorporating the PSD features based on the needs and requirements of informal caregivers, for its conceptual workflow and usability among informal caregivers of older adults with cognitive impairment.

2. Methods

2.1 Study Design: Participatory development

The Ethics Committee of the Behavioral, Management, and Social Sciences at the University of Twente granted ethical approval for this study (request number: 230141). The interaction platform is expected to cater to different stakeholders including informal caregivers, formal caregivers, case managers, care recipients, etc. However, adhering to the research objective i.e., to provide support to informal caregivers, this study primarily focuses on incorporating the perspectives of only informal caregivers of OwCI.

In that regard, this study follows CeHRes roadmap to create a sensor-dependent interaction platform that can communicate the information obtained by the USSs to informal caregivers of OwCI [16]. The framework encompasses five distinct but intertwined phases: contextual inquiry, value specification, design, operationalization, and summative evaluation (see Figure 1). The description of these phases, along with their relevance to this study, is provided below:

- **Contextual Inquiry & Value Specification phase:** With the help of the contextual inquiry phase, an understanding of the prospective users (informal caregivers) and their context (OwCI care) is obtained. This study builds on the previous study where understanding of experiences, expectations, and usefulness of USSs among informal caregivers of OwCI was explored [7]. However, to further advance the findings, we dwell deeper into the expectations and pre-conditions for the implementation of informal caregivers after providing them with more concrete information regarding the functioning and potential benefits of using USSs in OwCI care. Furthermore, the value specification phase helps in identifying the needs and values that are very important for the intended stakeholders, which later can be translated into the requirements [16]. For that, we consider the IC design requirements regarding different care scenarios (fall, nocturnal unrest, agitation, and normal daily life) in a previous mixed-method study as a starting point to develop the interaction platform [7].

- **Design:** The primary focus of this study lies within the design phase which involves the agile development and testing of the interaction platform. Based on the requirements (design features) generated in accordance with PSD features in the previous study, a low-fidelity prototype of the technology was developed by using the rapid prototyping technique by the involved researchers' team [18] [19]. Subsequently, the prototype was subjected to formative evaluation with informal caregivers, with a specific emphasis on evaluating the conceptual workflow and use of PSD features. Specifically, a task-based study design in conjunction with a thinking-aloud approach was employed for this study. The task-based study design facilitated a realistic evaluation of user interactions with interfaces in various care scenarios [20] [21]. whereas the thinking-aloud approach provided direct access to users' thoughts, perceptions, expectations, and decision-making processes during their interactions with the interfaces [22]. By combining these two approaches, a comprehensive understanding of potential issues and areas for improvement was obtained, which could be incorporated into subsequent design iterations, enabling an iterative design process. This study specifically involved one iteration of the design round.

- **Operationalization & Summative Evaluation:** These phases activate when the technology is launched into the market. The results obtained from this study can serve as valuable inputs for these phases, ensuring that the final product meets the needs and requirements of informal caregivers of OwCI.

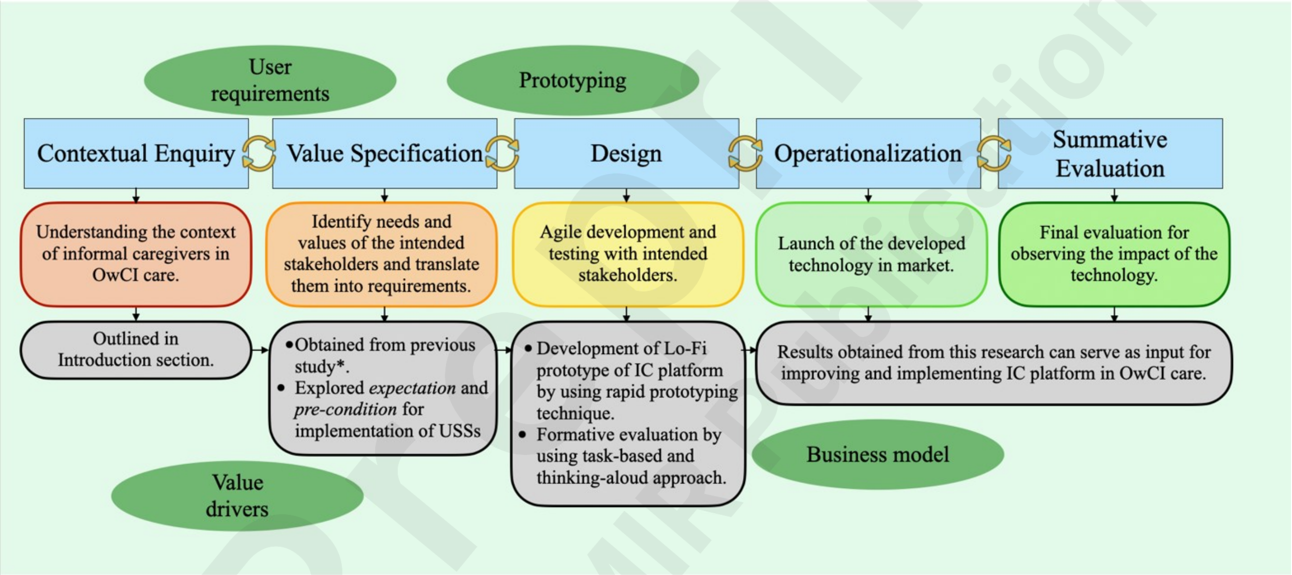


Figure 1: CeHRes Framework (*[7])

2.2 Participants

Participants were recruited from an already existing pool of candidates, who have previously been involved in similar research [7]. While it was not a prerequisite for informal caregivers to have prior experience with digital care technology, all of them were users of the Caren Platform (a digital care platform), which means they had experience with digital care technology by default (Caren, NEDAP) [23]. Informal caregivers were approached for participation in this study by email. The participants were invited to participate and received an information letter that detailed the study's purposes and procedures, along with the contact information of the researcher. When an informal caregiver was willing to participate, they were filtered on the following inclusion criteria: 1) providing unpaid care to a person with cognitive impairment, who is a relative, friend, or someone else within their personal circle, 2) the person with cognitive impairment is 65 years or older and 3) the person with cognitive impairment lives alone at home. Thereafter, an appointment for the evaluation session was planned with the researcher.

2.3 Materials: Designing Lo-Fi prototype of Interaction Platform

2.3.1 Video prototype

Given the novelty of USSs, a lack of awareness among informal caregivers about their working and implementation was observed. Therefore, to educate informal caregivers, a video prototype demonstrating the working, system architecture, and benefits of USSs in OwCI care was created. While the video was largely inspired by the previous research using Wi-Fi CSI as a technology in USSs for older adult activity recognitions [11] some brainstorming sessions with the research team (composed of eHealth researchers, experts, technology developers, and designers) were also took place to align it to the use case of OwCI care.

Overall, the video depicting three units of the USSs namely sensing, computing, and communicating unit was prototyped. The 'sensing unit' of the solution showed the working (how) and the way of data collection (what) through Wi-Fi CSI (as an unobtrusive sensing technology). The 'computing unit' of the solution presented the use of artificial intelligence algorithms for analyzing the collected data. In the 'communicating unit' of the solution communication channel for communicating the computed information to the caregivers was presented. The video provides examples of three different care scenarios namely fall incident, agitated behavior, nocturnal unrest, and normal daily life (drinking activity).

To make it realistic, the video footage was recorded in the eHealth house at the University of Twente, the Netherlands (eHealth house, UT) [25]. The video had a Dutch voice-over with English subtitles, given that the majority of informal caregivers were comfortable in Dutch. The video has a total duration of 3.5 minutes. The video was presented to the participants at the start of the interview sessions to ensure that they had the necessary information to answer the questions posed in the interview, thereby promoting more informed responses. Figure 2, shows a simplified overview of the system architecture (as conveyed in the video) of the intended USSs.

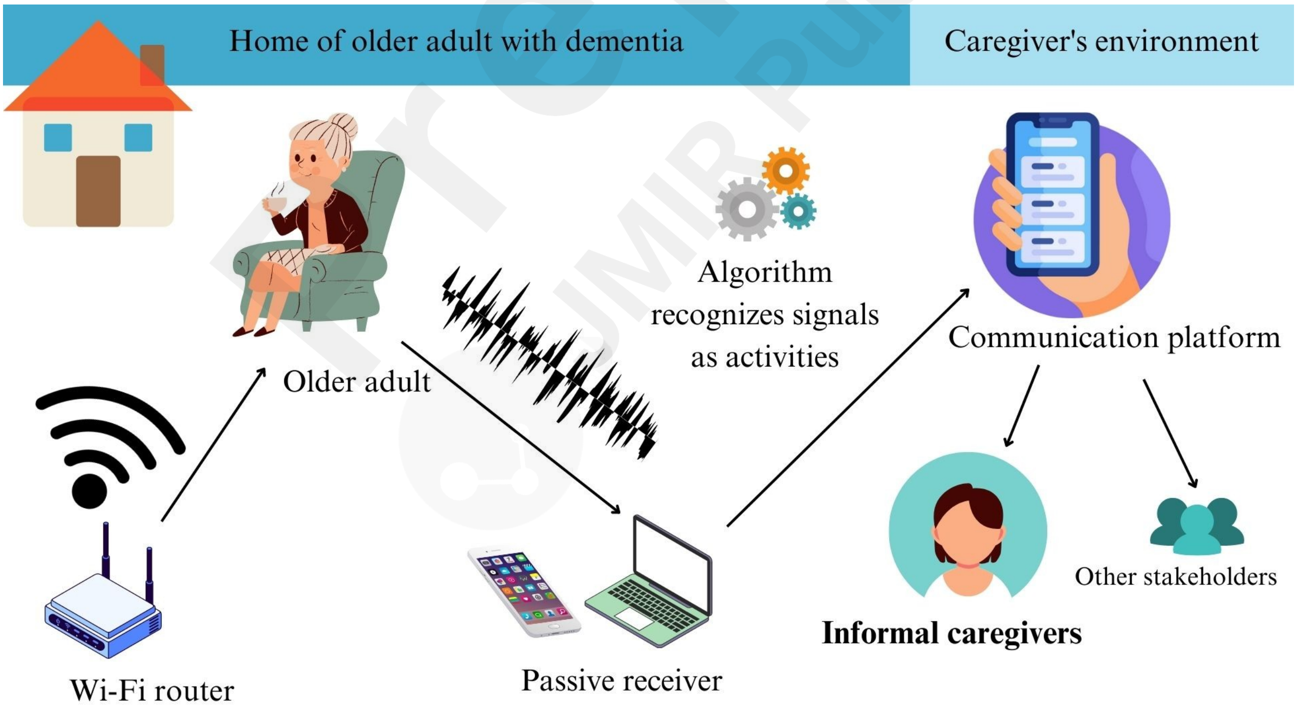


Figure 2: Simplified overview of system architecture of Unobtrusive sensing solutions

2.3.2 Lo-Fi prototype

The lo-fi prototype of the interaction platform was designed by the involved researcher's team by using Figma software [25]. Since the Wi-Fi CSI system is in the early development phase (TRL 2/4) [7] [26], a lo-fi prototype was chosen to gain initial insights from informal caregivers about the communication unit, showcasing the conceptual workflow and main functionalities of the interaction platform. Note that, this interaction platform does not intend to change the behavior of the informal caregivers but requires persuasion to form (F) or alter (A) the behavior of informal caregivers for complying with the information communicated (F- and A-Outcome, C-Change) [27].

To design the lo-fi prototype of interaction platform the findings from previous works [2] [7] [28] were utilized. Wrede et al.'s studies [2] [28] demonstrates the value of USSs in continuous and objective monitoring, leading to timely interventions. Particularly, informal caregivers found USSs helpful in clearly classifying care scenarios as urgent, non-urgent, and future risk. Further exploration in a mixed-method study by Sharma et al. [7] (comprising survey (N =464) and interviews (N=10)) revealed divergent IC needs in different care scenarios (fall, nocturnal unrest, agitation, and normal daily), including the mode, content, timing, intended users, feedback to the system for self-learning, and dialogue support. Furthermore, the study also identified seven PSD features: three from primary task support (reduction, tailoring, and personalization), two from dialogue support (reminders and suggestions), one from system credibility (trustworthiness), and one from social support (social learning) for designing the interaction platform. Based on these findings, the conceptual workflow of the interaction platform and user interfaces for three care scenarios namely fall incident, agitated behavior, and normal daily life activities were designed. In addition to these features, a system verifiability feature was added to assess its necessity or impact on the interaction platform [17]. Table 1 presents the used PSD features, their interpreted meaning, and their application in the lo-fi prototype. The below paragraphs provide details concerning the design of conceptual workflow and user interfaces.

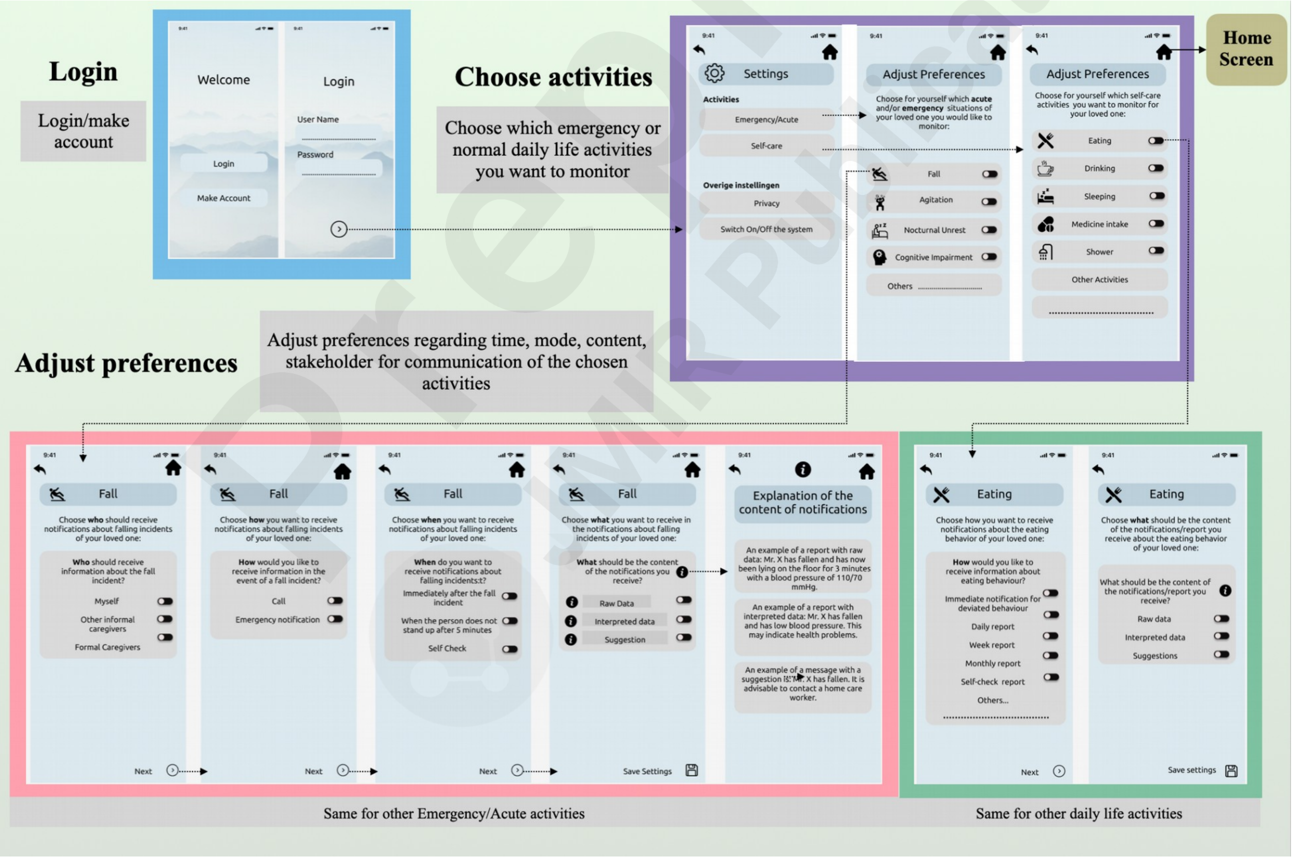
Table 1: PSD features used to design the lo-fi prototype.

PSD category	PSD feature	Meaning	Application to lo-fi prototype
Primary task support	Personalization	Providing personalized content	Option to personalized IC based on the individual needs and requirements.
	Reduction	Reducing complex tasks into smaller tasks	Immediate notifications in emergencies and real-time updates on home screen.
	Tailoring	Providing information tailored to the user’s needs	Tailored reports and notifications according to the needs of the recipient.
Dialogue support	Reminder	Reminding users of target behavior	Reminder for unresponded emergency call.
	Suggestion	Offering suggestions to facilitate behavior	Customized care suggestions for informal caregivers in different care situations.
Social support	Social learning	Learning from the experiences and	Experiences sharing page where the informal caregivers can read and

		behavior of others	react to the experiences of others.
System credibility	Trustworthiness	Providing reliable information	Reliability percentage indicator and provision to provide feedback to the system.
	Verifiability	Providing evidence to validate the accuracy	The caregiver support and communication page helps informal caregivers discuss the care plans but also provides an option to verify the system's predictions.

Design of conceptual workflow

The conceptual workflow of the interaction platform can be observed in Figure 3. This workflow reflects the logical flow of the interaction platform while personalizing the IC options. It starts from the login page followed by choosing preferred activities for monitoring, adjusting the communication preferences for the chosen activities, and the home screen where multiple functionalities of the interaction platform can be checked/adjusted. Note that, the feature of choosing activities to be monitored and adjusting the preference is attributed to the *personalization* feature of the PSD model.



Choose for yourself which **acute** and/or **emergency** situations of your loved one you would like to monitor:

Choose for yourself which self-care activities you want to monitor for your loved one:

Choose **who** should receive notifications about falling incidents of your loved one:

Who should receive information about the fall incident?

Choose **how** you want to receive notifications about falling incidents of your loved one:

How would you like to receive information in the event of a fall incident?

Choose **when** you want to receive notifications about falling incidents of your loved one:

When do you want to receive notifications about falling incidents:t?

Immediately after the fall incident

When the person does not stand up after 5 minutes

Choose **what** you want to receive in the notifications about falling incidents of your loved one:

What should be the content of the notifications you receive?

An example of a report with raw data: Mr. X has fallen and has now been lying on the floor for 3 minutes with a blood pressure of 110/70 mmHg.

An example of a report with interpreted data: Mr. X has fallen and has low blood pressure. This may indicate health problems.

An example of a message with a suggestion is: Mr. X has fallen. It is advisable to contact a home care worker.

Choose how you want to receive notifications about the eating behavior of your loved one:

How would you like to receive information about eating behaviour?

Immediate notification for deviated behaviour

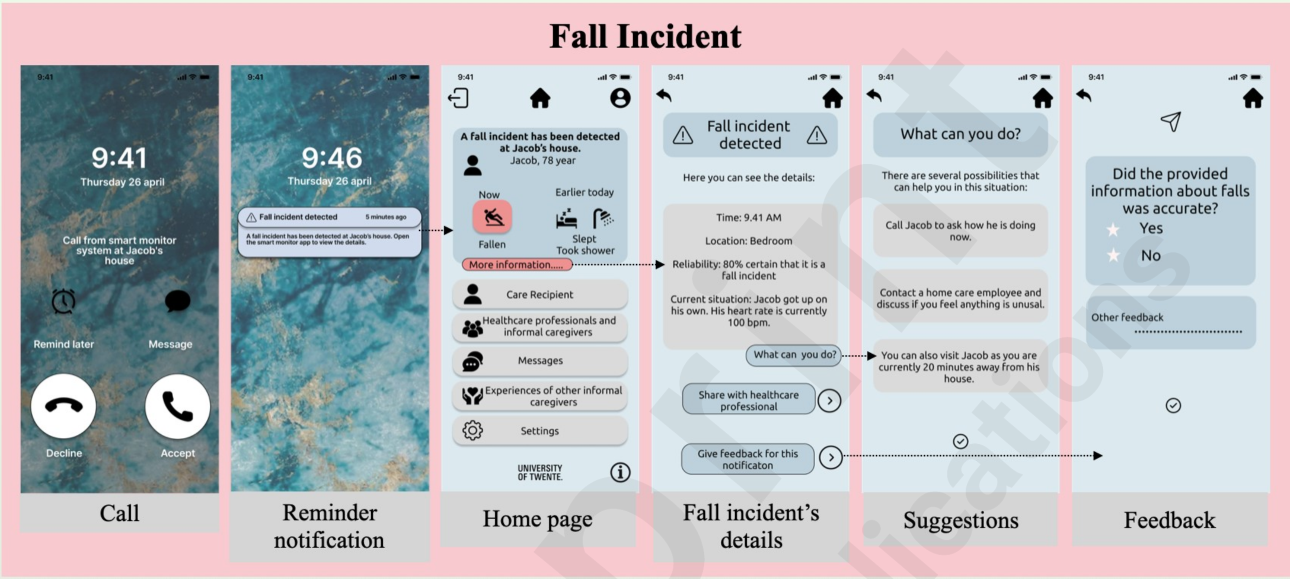
Choose **what** should be the content of the notifications/report you receive about the eating behavior of your loved one:

What should be the content of the notifications/report you receive?

Figure 3: Conceptual workflow of the interaction platform

Design of user interfaces

User interfaces for fall, agitation, normal daily life, and home screen were designed. Fall being an emergency, informal caregivers expect to receive a direct call *(reduction feature)*, and if they do not respond within five minutes they expect a reminder notification *(reminder feature)* in their preferred content style (raw, interpreted, or suggestions). Furthermore, the details of the fall incident such as time, location, system's confidence in prediction, and current state of the care recipient were made accessible for the informal caregivers. Additionally, to support informal caregivers options to get suggestions from the system on what to do and when to act *(suggestion feature)* as well as directly communicate with formal caregivers were also provided. Lastly, as informal caregivers desire a trustable system (with minimum false alarms), an option to provide feedback to the system for its predictions to enable self-learning was also added *(trustworthiness feature)*. Figure 4 illustrates the interfaces for the fall scenario.



Call from smart monitor system at Jacob's house

A fall incident has been detected at Jacob's house. Open the smart monitor app to view the details.

A fall incident has been detected at Jacob's house.
Jacob, 78 year

Here you can see the details:

Time: 9.41 AM

Location: Bedroom

Reliability: 80% certain that it is a fall incident

Current situation: Jacob got up on his own. His heart rate is currently 100 bpm.

There are several possibilities that can help you in this situation:

Call Jacob to ask how he is doing now.

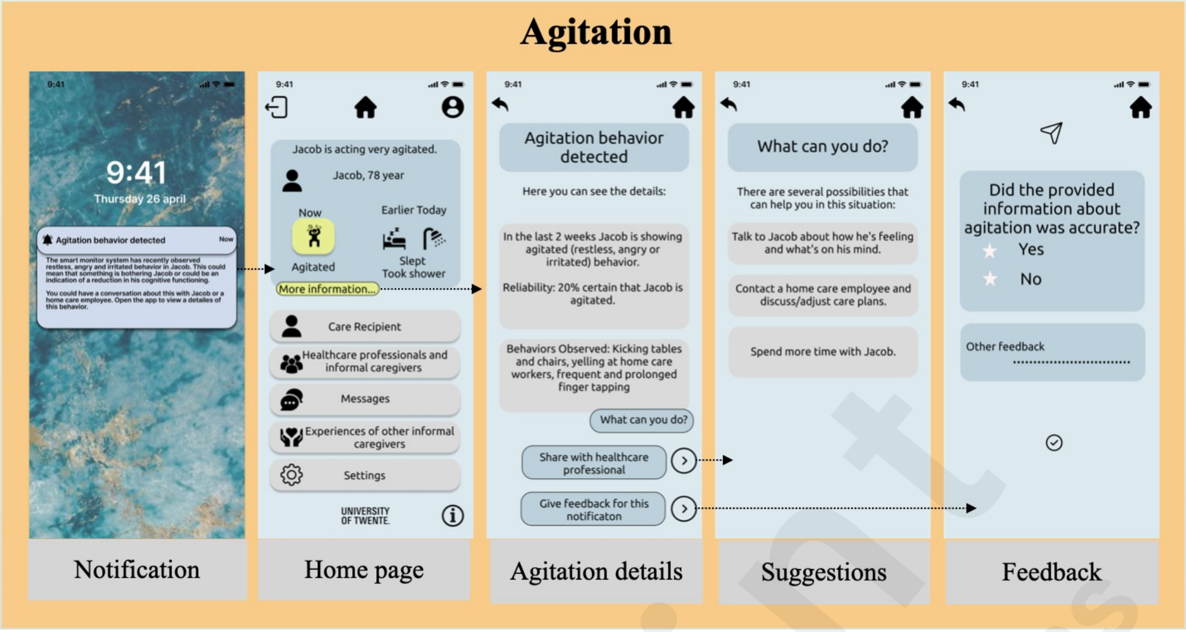
Contact a home care employee and discuss if you feel anything is unusal.

You can also visit Jacob as you are currently 20 minutes away from his house.

Did the provided information about falls was accurate?

Figure 4: Interfaces for fall scenario

On the other hand, agitation being an acute scenario, informal caregivers expect the system to monitor it for a few weeks and share a report tailored to the concerned stakeholders i.e., themselves or formal caregivers *(tailoring feature)*. Interfaces depicting notification (in preference content style), details of agitation behavior (duration, system's confidence in prediction, other observations), suggestions from the system *(suggestion feature)*, the possibility to share the report with formal caregivers, and an option to provide feedback to the system for its predictions were designed *(trustworthiness feature)*. Figure 5, illustrates the interfaces for the agitation scenario. The user interface for normal daily life (as shown in Figure 3) presented multiple self-care activities (eating, drinking, shower, etc.). The informal caregivers can adjust their preferences regarding the content, how frequently and detailed information they want to receive regarding the selected activity.



The smart monitor system has recently observed restless, angry and irritated behavior in Jacob. This could mean that something is bothering Jacob or could be an indication of a reduction in his cognitive functioning.

You could have a conversation about this with Jacob or a home care employee. Open the app to view a detailes of this behavior.

Jacob is acting very agitated.

Here you can see the details:

In the last 2 weeks Jacob is showing agitated (restless, angry or irritated) behavior.

Reliability: 20% certain that Jacob is agitated.

Behaviors Observed: Kicking tables and chairs, yelling at home care workers, frequent and prolonged finger tapping

There are several possibilities that can help you in this situation:

Talk to Jacob about how he's feeling and what's on his mind.

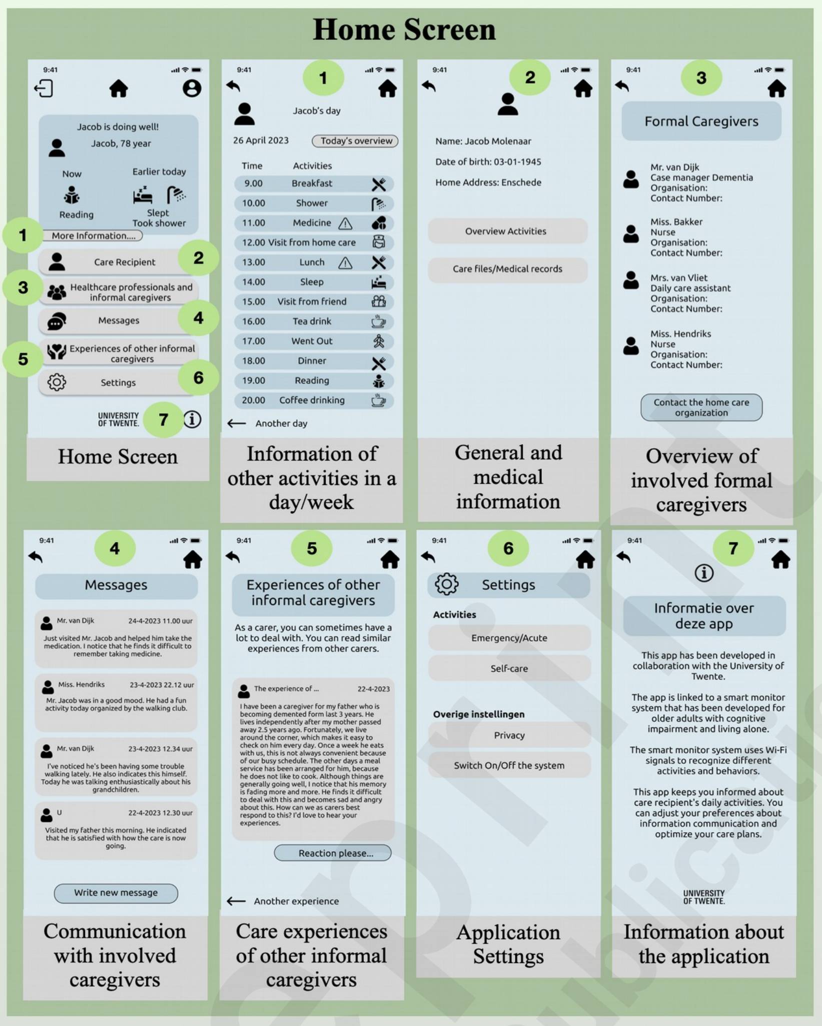
Contact a home care employee and discuss/adjust care plans.

Spend more time with Jacob.

Figure 5: Interfaces for agitation scenario

In general, informal caregivers demand a centralized care approach, i.e., the possibility to access all the relevant care information such as general, medical, and communications with other stakeholders in one platform [7]. Thus, in line with this requirement home screen contained the following functionalities: observing the present and past situation of the care recipient (*reduction*); obtaining more detailed information/reports of daily activities; the general and medical information of the care recipient (verifiability), an overview of involved formal and informal caregivers, communication option with involved formal caregivers, and system credibility (Figure 6). Additionally, an option to read care experiences shared by other caregivers as a part of the *social learning feature* from the PSD model was added. Lastly, options for application settings (adjusting preferences), and information about the organization/team developing the application to show *system credibility (real-world feel)* were also added.

Figure 6: Interfaces for home screen



Time	Activities
9.00	Breakfast
10.00	Shower
11.00	Medicine ⚠
12.00	Visit from home care
13.00	Lunch ⚠
14.00	Sleep
15.00	Visit from friend
16.00	Tea drink
17.00	Went Out
18.00	Dinner
19.00	Reading
20.00	Coffee drinking

Name: Jacob Molenaar
Date of birth: 03-01-1945
Home Address: Enschede

Mr. van Dijk
Case manager Dementia
Organisation:
Contact Number:

Miss. Bakker
Nurse
Organisation:
Contact Number:

Mrs. van Vliet
Daily care assistant
Organisation:
Contact Number:

Miss. Hendriks
Nurse
Organisation:
Contact Number:

Mr. van Dijk 24-4-2023 11.00 uur
Just visited Mr. Jacob and helped him take the medication. I notice that he finds it difficult to remember taking medicine.

Miss. Hendriks 23-4-2023 22.12 uur
Mr. Jacob was in a good mood. He had a fun activity today organized by the walking club.

Mr. van Dijk 23-4-2023 12.34 uur
I've noticed he's been having some trouble walking lately. He also indicates this himself. Today he was talking enthusiastically about his grandchildren.

U 22-4-2023 12.30 uur
Visited my father this morning. He indicated that he is satisfied with how the care is now going.

As a carer, you can sometimes have a lot to deal with. You can read similar experiences from other carers.

The experience of ... 22-4-2023
I have been a caregiver for my father who is becoming demented form last 3 years. He lives independently after my mother passed away 2.5 years ago. Fortunately, we live around the corner, which makes it easy to check on him every day. Once a week he eats with us, this is not always convenient because of our busy schedule. The other days a meal service has been arranged for him, because he does not like to cook. Although things are generally going well, I notice that his memory is fading more and more. He finds it difficult to deal with this and becomes sad and angry about this. How can we as carers best respond to this? I'd love to hear your experiences.

This app has been developed in collaboration with the University of Twente.

The app is linked to a smart monitor system that has been developed for older adults with cognitive impairment and living alone.

The smart monitor system uses Wi-Fi signals to recognize different activities and behaviors.

This app keeps you informed about care recipient's daily activities. You can adjust your preferences about information communication and optimize your care plans.

2.4 Procedure

The semi-structured interviews with informal caregivers took place either online via Teams or in person, depending on the preference of the participant. Two of the six interviews were held online. The interview guide (can be found in Appendix 3) was used and consisted of the following sections: 1) introduction, goals and procedures, informed consent, 2) background information from participant, 3) video prototype, 4) formative evaluation of user interfaces, and 5) closing remarks. Upon watching the video, participants were asked if they had any further questions regarding the systems and clarified. This video and explanation were important as due to the novelty of USS, informal caregivers are not very aware of this concept/type of sensing solution. After that, their expectation and pre-conditions for implementation were discussed in-depth.

Thereafter, a formative evaluation (by employing usability testing and thinking-aloud approach) of the designed interaction platform was conducted with the help of five tasks (Table 2). In task 1, informal caregivers were asked to choose the emergency/acute situations of their care recipient they want to monitor followed by adjusting the IC preferences for chosen activities. Similarly, in task 2, informal caregivers were asked to choose and adjust the IC preferences for the daily life (self-care) activities of the care recipient they want to monitor in the long term. Here, the use of PSD feature personalization was evaluated. Furthermore, for tasks 3 and 4, a possible sequence of actions in the fall and agitation scenario was evaluated. Specifically, the ability of the platform to immediately call/ notify informal caregivers (reduction), send reminder notifications in case they do not respond (reminder), provide suggestions to support informal caregivers (suggestion), and maintain a transparent link between the system and caregiver by providing the predication percentage (trustworthiness) were assessed.

Lastly, in task 5, informal caregivers were asked to explore the home screen to see if it satisfies their requirement of a centralized care platform, present evidence to validate the provided information (verifiability). They were encouraged to identify, suggest, and reason the functionalities which help them in improving the caregiving process. The sessions were conducted in Dutch by a native Dutch speaker and were audio-recorded to facilitate analysis. The duration of each session was approximately 60 minutes. On the basis of the feedback from the first four sessions, slight improvements in the design were made and further evaluated in the last two sessions.

Table 2: Used tasks to evaluate the conceptual workflow and PSD features used in interaction platform.

Task description	**Feature added/Evaluated**	**Value associated**
Task 1: Choose emergency activities and adjust preferences for chosen activities.	Personalization	Every care scenario is different and thus informal caregivers should be able to choose which activity they want to monitor (for both emergency and daily life). Furthermore, they should also be able to adjust the preference of IC for the chosen activities. Informal caregivers need the flexibility to select and monitor specific activities based on the care scenario. They should also have the option to customize their preferences for IC related to the chosen activities [28] [7].
Task 2: Choose self-care activities and adjust preferences for chosen activities.	Personalization	
Task 3: Suppose a fall incident occurred in the home of your care recipient.	Reduction Reminder Suggestion Trustworthiness	In emergencies, informal caregivers expect: direct calls or reminders if they are unable to answer; Trustworthy and accurate information; and suggestions to ensure timely and appropriate actions [7].
Task 4: Suppose your care recipient is experiencing agitation.	Reduction Tailoring Suggestion Trustworthiness	In acute scenarios like agitation, informal caregivers expect: Notification and long-term reports which can be shared with formal caregivers; Trustworthy and accurate information along with suggestions to support the care recipient in the right manner [7].
Task 5: Explore features of the home screen	Reduction Verifiability Social learning System credibility	Informal caregivers desire a centralized care platform, where they can find important care elements at once, for example, quick or detailed overview of the activities, access to medical records, connection with caregivers, etc. [7].

2.5 Data analysis

The recordings were transcribed verbatim by using the description software Amberscript. Qualitative analysis was performed by using the Atlas.ti [29]. A thematic analysis was performed, based on the six steps by Braun and Clarke: 1) familiarizing with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the report (Braun and Clarke, 2006). The transcripts were coded using a mixed inductive and deductive approach. For exploring the expectations and preconditions an inductive approach was used, while for the experiences with PSD features a mix of inductive-deductive approach was used. All the transcripts were read by both researchers NS and KG in English and Dutch respectively. Overall, the joint probability of agreement was 75% followed by in-depth discussion until a consensus was reached on all defined themes.

4. Results

The results section is divided into two parts. First, the results regarding the expectations and preconditions for implementation are presented. Secondly, results corresponding to the formative evaluation of the lo-fi prototype including PSD features were presented.

4.1 Demographics

A total of six informal caregivers (mean age: 58.7, SD: 2.87) of older adults (mean age: 85.7, SD: 4.18) living alone participated in the study. Among the participants, four were females and two were males. All informal caregivers were children of the care recipient and were the primary informal caregiver. All care recipients were living alone. Half of the care recipients had Alzheimer’s disease, the other half had cognitive impairment due to other causes or no official dementia diagnosis. All informal caregivers used technology before in the care provision, differing from using communication platforms (Caren platform) or medication dispensers to personal alarm and monitoring systems. They have been providing care for at least the last two years and their care hours ranged from (1.5 to 15). Table 3 provides an overview of the characteristics of the interview participants.

Table 3: Social-demographic characteristics of informal caregivers.

Participant number	Gender	Age	Age care recipient	Years of providing informal care	Hours per week spent on informal care	Travel distance to care recipient
1	Female	61	87	2	5	30 minutes
2	Female	59	88	2-3	1,5	2 hours
3	Female	60	86	3	8	Next door
4	Female	53	79	2	10-15	1,5-2 km
5	Male	60	91	20	12	45 minutes
6	Male	59	83	5	2	20 minutes

4.2 Expectations and preconditions

An overview of the themes relating to the expectations and preconditions from the perspective of informal caregivers is provided in Table 4. The following themes are presented: 1) positive outcome expectations, 2) negative outcome expectations, and 3) preconditions for implementation.

Table 4: Themes relating to expectations and preconditions for the implementation of USSs from the informal caregivers’ perspective.

Main themes	Sub-themes	Description

1	Positive outcome expectations	Objective decision making	Monitoring information could be used to make objective care decisions.
		Safer environments for independent living	The system is expected to contribute to the feeling of safety for OwCI.
		Providing peace of mind to informal caregivers	24/7 monitoring could contribute to peace of mind for the informal caregiver.
		Stimulating meaningful conversations	By using the system for care-related information there will be more room for fostering their relationship with the care recipient.
2	Negative outcome expectations	Information overload	Continuous monitoring information might lead to information overload for informal caregivers.
		Feeling obliged to undertake action	The informal caregiver might feel obliged to undertake action when they receive a notification.
		Substitution of human contact	The system might lead to a reduction in human contact for the OwCI.
3	Preconditions for implementation	Shared decision making (& communication strategy)	Agreements should be made about the settings and communication strategy together with professional caregivers or other involved stakeholders.
		USSs as support	The solution should support care decisions instead of interpreting the data by itself.

4.2.1 Positive outcome expectations

Objective decision making

The informal caregivers indicated that USSs could contribute towards making objective decisions regarding the care of their loved ones. Instead of relying solely on observations of both informal and formal caregivers or on what the care recipient mentions themselves, the system can provide involved informal and professional caregivers with more objective and in-depth monitoring information. According to informal caregivers, this information not only enables prompt diagnosis of underlying health conditions, but also facilitates objective communication between professional caregivers, the care recipient, and themselves. Thus, fostering shared care situation understanding, consensus on the provision of care, and better coordination on response to the (emergency) situations.

"It provides the facts, so what she herself isn't mentioning yet, but what is actually already

there, that could be beneficial to support her, to make better choices and to better understand what is going on." [P2]

"It provides monitoring information, for example, we are now at a stalemate with my father, he should have more help and we need to request that, but he doesn't want that because he believes he can still manage. It (the monitoring data) can prove that we are right, but it can also prove if he is right. If he is right, then we'll have some peace for a while, so it indicates such things." [P4]

Safer environments for independent living

Informal caregivers expected the USSs to contribute to the feeling of safety of their loved one, they believe that the system will notice when a safety risk might occur. Also, it was mentioned the system could give insight into whether or not it is safe for older adults to live independently at home. Multiple informal caregivers mentioned being interested in receiving information about safety matters, for instance, if the door has been opened, or if the gas is on.

"She (mother of informal caregiver) will feel safer. Her desire is to continue living at home for as long as possible, but she has concerns about it, like: 'yes, I am alone and if something happens to me, well, what should I do then?' And this is a system that detects it (a fall) without her having to do anything. So, if she feels safer, she will also feel calmer, which has an impact on her dementia symptoms." [P1]

Providing peace of mind to informal caregivers

Some informal caregivers indicated that they expect the USSs to contribute to their peace of mind and probably to the peace of mind of their care recipient as well. They find it reassuring that the system acts as a safety net and alerts them or care professionals when there is an emergency situation. Furthermore, they indicated the system could confirm the wellbeing of their loved one, whereas without such as system there would be uncertainty and doubt about the situation, and they might be unnecessarily worried about their loved one.

"It brings peace of mind. It provides, like, you can't fully rely on the technology, but knowing that you have an additional safety net, that you are a bit more at ease, and also for the person involved it helps" [P3]

"I only see reassurance, you know, you receive, you know that everything is fine, but you receive a confirmation that it is indeed going well" [P5]

Stimulating meaningful conversations

A few informal caregivers indicated that if USSs can gather care-related information, they might be able to spend more meaningful time (personal conversations) with their loved ones. This is because the care component is important and requires lots of attention, they overlook the personal or relational aspect, thus impacting their relationship with the care recipient.

"Because it's not constantly asking 'how are you doing', there is an additional aspect behind it. Yes, you still have to keep asking, but it's more about showing interest in the person rather than focusing solely on the care component. So, I think there's more room for the human aspect rather than just the caregiving aspect." [P3]

"It can help in relational aspect, I would really appreciate that, because I miss the conversations with my mother, there is always that caregiving component that comes in-between." [P3]

4.2.2 Negative outcome expectations

Information overload

A few informal caregivers also expressed concerns about the possibility of information overload from USSs. They mentioned that the continuous availability of information about the care recipient, enabled by USSs, might lead them to constantly check and monitor every aspect of their loved one's situation. Additionally, informal caregivers highlighted that receiving notifications might trigger panic and worry, particularly if they are unable to respond immediately even after being aware of it.

"At some point, you want to know everything. Especially if you're worried, then it's nice to be able to see a lot, yet you can't do anything with it." [P2]

"If I look at myself… I think if I receive such a notification (emergency) then the first reaction is panic, okay that is a strong word, but as I already said: I work in healthcare myself, I see the most terrible things, that doesn't affect me. But when it concerns your own parents, it immediately causes stress."[P4]

Feeling obliged to undertake action

The informal caregivers also mentioned that once they are aware of what is going on with their loved one, they cannot ignore the situation and feel obliged to undertake actions according to the information provided by the USSs. Even though, sometimes it is simply not possible to take action right away due to physical distance or other factors. However, some participants indicated not having the urge to immediately act upon the data or being able to filter important information, they suggested it might be problematic for other informal caregivers.

"If I see worrying things, then I literally and figuratively have to go there, if I see it, then I have to go there: normally, you wouldn't, or quickly call, but now you see it, so you feel compelled to go there…" [P4]

"So for my situation that (information overload) won't happen so quickly. For my sister, it might be a bigger struggle, as she is less able to distance herself from the situation as it is. I think when she receives detailed information from the system, she may feel the need to intervene, whereas I have less trouble with that." [P6]

Substitution of human contact

Although not all informal caregivers expect the system to substitute the human contact of their care recipient, some of them indicated perceived this as a risk from USSs. They suggested that if USSs are capable of providing comprehensive insights into the health of the care recipient, it could potentially result in reduced or no visits from professional care staff. This is concerning, considering the already existing scarcity of professional caregivers.

"It's simply impossible to find enough staff, and apparently the situation is even worse in home care. So, if you're going to develop technology to do more, with fewer people, to be more efficient, it means there will be less human contact, and that means less home care visits for my father, while on the other hand, he's already experiencing so much loneliness" [P4]

"I find it a risk that people retrieve all their information from this system and they might start thinking they no longer need the contact moment, while it is actually so important." [P1]

4.2.3 Preconditions for Implementation

Shared decision making

According to informal caregivers, it is required to discuss and come to agreements together with professional caregivers about the IC including which activities to monitor, what communication strategy to use, who receives and responds to the information, and what should be the content of the information. This would be necessary to prevent unclarities, unfulfilled expectations, and unaddressed notifications or follow-ups, as it could otherwise potentially hinder the effectiveness of care provision.

"You can benefit a lot from it (USSs) together and I think if you don't do this together, everyone can get a lot of trouble from it. That's not what you want." [P1]

"I would never fill it (the settings of the system) in alone, I would really do that together with other professional caregivers or informal caregivers. I think you should all agree with each other about how you fill this in and what you expect and so on… this would be a nice moment to put our

heads together and make a choice together." [P1]

"… it could be that you alert three parties simultaneously and one thinks, 'hold on, I won't do anything because the other two will take care of it', and everyone assumes that of themselves. And then, nobody responds…" [P6]

USSs as a supportive tool

The informal caregivers indicated it is important to perceive USSs as a supportive tool rather than a tool to replace the human component in the care.

"They (persons with cognitive impairment) actually require people around them to be present. It's better for them, otherwise, they will completely withdraw. Human interaction, maintaining contact with others is extremely important. So that aspect should be preserved. The system should not result in less human contact, as that would further distance individuals with dementia." [P1]

However, they expected the solution to provide concrete data to facilitate the conversations and interpretation of the situation together with formal caregivers.

"Cognitive decline happens slowly and there are some things that we (informal caregivers) can't point out. Now it (wandering in the house) is starting to happen more and more. Such raw data can be important for such situations, especially if you have to go to the neurologist or something, then you can do a lot of things." [P4]

It was also mentioned that care decisions should not solely be based on the information provided by the system. Instead, it is imperative to engage in discussions with professional caregivers, before making definitive decisions.

"So it's a support system and it shouldn't take over the analysis of the situation. It may give the numbers, but if on that basis it is said of oh, she (care recipient) only needs so much more care time, or this is no longer necessary since she can still handle this task herself. Yes, then we're going the wrong way." [P2]

4.3 Informal caregivers' experiences with PSD features and user interface prototype

In general, the informal caregivers indicated being quite positive about the user interface prototype. Most of the screens were reported to be clear and understandable. However, there were also some negative experiences and suggestions for improvement. Table 5 provides an overview of the themes regarding the informal caregivers' experiences with the applied PSD features and the user interface prototype of the communication platform: 1) positive experiences, 2) mixed experiences, and 3) suggestions for improvement.

Table 5: Themes on informal caregivers' experiences with the user interface prototype.

	Main themes	**Sub-themes**	**Description**
1	Positive experiences with user interface prototype	Personalization: Options to customize settings	Personalizing the settings of the system was valuable.
		Reduction: Directly being informed about the situation	Receiving a direct call or notification and ability to easily find the desired information.
		Tailoring: Provide information based on the stakeholder	Providing information based on the intended stakeholder.
		Trustworthiness: Insight into the reliability of	Reliability numbers increased the transparency of the system.

		information provided in the system	
		Verifiability: Possibility to view EHR and connect with formal caregivers	Verifiability enhances the system’s credibility by presenting evidence to validate the provided information.
2	Mixed experiences with user interface prototype	Reminder: Receiving an reminder in case of a missed emergency call	Reminders were found useful or not suitable based on the personal situation.
		Social Learning: Reading other informal caregiver’s experiences	Experiences of other informal caregivers were found either helpful or not necessary.
		Suggestions: Receiving suggestions on what actions to take	Suggestions were found helpful in stress situations or were experienced as too obvious or irritating.
3	Suggestions for improving the user interface prototype	Improvements in conceptual flow	The sequence of screens could be improved and a feedback loop should be integrated.
		Improvements in visual design	The prototype should use more visuals instead of text.

4.3.1 Positive experiences

Personalization: Options to customize settings

All informal caregivers had a positive experience with the flexibility (not a one-time setup) of adjusting the interaction platform settings to accommodate their dynamic care needs, thereby improving the quality of life for care recipients. Specifically, they appreciated being able to personalize the settings based on their individual circumstances, the evolving condition of their care recipient, and the monitoring scenario at hand (such as emergencies or self-care activities).

“I think this is a good thing. The more you can adjust it to fit your and well in this case my father’s needs and lifestyle, the quality of care can be improved.” [P4]

“We’ll do everything first (make all the settings), and then I’ll figure it out, or change it later. It is nice that I could still make adjustments later on, so that it’s not a one-time set-up.” [P3]

“That depends; do I live next door, or close by, then it might be sufficient to be the only one being notified. But this should be available, like imagine I’m away for a weekend. The other informal caregivers will temporarily take over, then I will adjust whether or not someone is available. And the professional caregivers should also receive that notification. So, I would like to have this screen (settings) flexible, so that you can set it individually, per day or per time” [P5]

“Well, it's already quite intuitive. It is good that you can click through quickly on different options within each activity and it is indeed stored for future usage. Also, it is nice that you can always come back and adjust things later if needed” [P6]

Tailoring: Provide information according to the stakeholder

Tailoring alerts, notifications, and reports based on the intended recipients (formal or informal caregivers) were found valuable in the development of the interaction platform. Informal caregivers felt that a formal caregiver may require different information compared to an informal caregiver.

"The information to professionals should be sent as per their needs. Of course, it will be very different from what informal caregivers need." [P2]

For example, the raw data obtained from the sensors could provide more meaningful information to the formal caregivers, while they found interpreted data to be sufficient for themselves.

"The raw data is more useful for the healthcare professional than data which is already interpreted by the system. I don't want raw data because that won't help me, so then I would go for interpreted data." [P3]

Reduction: Directly being informed about the situation

The reduction feature was used in two ways: to receive direct calls/notifications in emergency situations, and second, to provide a quick overview of current and past activities throughout the day on the home screen. In emergency scenarios such as falls, informal caregivers found the system-generated alerts (via quick calls/notifications) to be valuable, as they have the potential to streamline communication and facilitate on-time care. This automated approach eliminated the need for caregivers to contemplate whom to contact and bypassed potential delays when reaching out to formal caregivers.

"It is about on-time care. I think, if something happens, what do you need to do? Whom should you call to organize care quickly? There must be logical thinking behind it and the system can do it quickly." [P3]

"What I find important is that there is an alarm service-like solution, but initially it could be directed straight to the caregiver, a direct signal from the system saying: 'here we see a deviation, this is what the system, the technology detects and intervention may be required here' or 'we see a fall, immediate intervention in necessary'." [P6]

Furthermore, all informal caregivers found the possibility to look quickly at current and past activities in the day on the home screen convenient.

"I find this (home screen) quite clear now, that you can see which activity has already been performed earlier today, but also what is happening at the moment. This is really nice, and at the top, okay so is the situation at the moment." [P1]

"Yes, I think this is fantastic, I must say. Specifically, the fact that you do indeed see an interpretation of the situation that the system has apparently determined and everything goes well." [P6]

The informal caregivers were also positive about the functionalities of sending messages, finding contact information of caregivers and connecting to an electronic client dossier as this would address the issue of having to use multiple systems.

"I think it is always desirable to have everything in one place and not having to deal with various different systems again." [P2]

Trustworthiness: Insight in the reliability of the information provided in the system

Most of the informal caregivers indicated being positive about the system providing a reliability percentage of the notification and information. According to them a reliability score increases their trustworthiness towards the system.

"It is still a technology, sometimes false alarms may occur, for example, when she has dropped something and trying to pick it up. Then, that's okay, that system indicates it is reliability percent. I actually like it. It points towards the trustworthiness of the system and also indicates that at times it can miss classify some things." [P2]

With a higher reliability percentage, they sense the urgency and seriousness of the situations and were compelled to take required actions.

"A reliability of 80 percent, yes, that did something with me… I thought that I should really take this seriously, like really seriously" [P1]

On the other hand, when the confidence percentage was low, informal caregivers might be a bit relaxed but they still wanted to ensure the safety of the care recipient. However, they felt that an indication of a lower or higher confidence percentage might help formal caregivers to organize their care better. For example, they can prioritize their visits depending on the system's relibility percentages.

"For me, it's fine to read that information, whether it is 50 percent or 80 percent, that doesn't matter. But I think for professional caregivers that it does matter, because if they receive 6 notifications and one has 30 percent reliability and the other 80 percent. Then they will first go to the one with 80 percent reliability."[P4]

Interestingly, one informal caregiver expressed that giving percentages might be a bit confusing for them to interpret thus simple terms such as 'very reliable' or 'less reliable' can be used.

"Now I can't judge 10 percent or 80 percent or 20 percent or whether that's right." [P3]

Furthermore, informal caregivers demonstrated a willingness to offer feedback to the system in order to enhance the reliability of the system's alerts. However, it was recognized that this responsibility should be shared with other caregivers, particularly formal caregivers, who are also involved in responding to alerts and thus can also provide context-aware and detailed feedback to enhance the system's learning.

"The system is self-learning, so I'm actually positive about it. I hope people understand that when they provide feedback, they need to specify what exactly went wrong, so that the system can learn from that. For example, if someone didn't fall but just lay down on the couch, then this should be adjusted. The system can become smarter by processing more data and thus increase the reliability of notifications. So, it's important to add more context in order for the system to learn from it." [P5]

Verifiability: Possibility to view EHR and connect with formal caregivers

The possibility to view electronic health records (EHR) and connect with concerned formal caregivers was found very handy and desirable. These functionalities also support the notion of an all-inclusive platform.

"For example, If I want to speak to Mrs. Baker (formal caregivers), I click on Mrs. Baker and she can guide me further." [P1]

"I think it is always desirable to have everything in one place and not have to deal with various different systems again, also considering different passwords and identification or authentication as well." [P2]

4.3.2 Mixed experiences

Reminder: Receiving a reminder in case of a missed emergency call.

Mixed experiences were reported regarding the reminder which was received in case of a missed emergency call. Some informal caregivers found it useful, others thought it would not be necessary to receive a reminder themselves, as this would be more useful for formal caregivers, depending on their personal situation. One informal caregiver experienced the reminder as confronting.

"I would like a care professional to receive such a reminder when she falls, because I am always at a distance" [P1]

"If I see this message, and realize I've missed the emergency call, then I feel like I should have been more attentive, then I would like to have the information quickly and in a concise format, without having to read through a lot of details." [P3]

Suggestions: Receiving suggestions on what actions to take

The use of suggestions along with alerts/notifications was found debatable in older adult care. On one hand, informal caregivers found suggestions valuable in situations like emergencies where they panic or are unsure of the possible actions to take in order to facilitate the right care.

“We all know what stress and panic can do, in those moments we can sometimes make stupid decisions, or forget the best order of doing things. So, having such a suggestion can serve as a helpful guide.” [P4]

“I feel that falling is different from agitated behavior. Falling means immediate danger, while agitated behavior often arises in the context of the dementia process that people experience. In such cases, it would be helpful to receive tips on what to do.” [P1]

On the other hand, some informal caregivers felt that the suggestion was unnecessary and subjective to care experiences of the informal caregivers.

“I think many people would appreciate it. You see, I’ve been working in healthcare for many years, so I’m familiar with these things. I believe there are many people who would benefit from receiving suggestions on what to do in certain situations. While I may quickly come up with solutions based on my experience, this is not the case for everyone. Thus I think many people would find it supportive.” [P1]

Moreover, informal caregivers expressed concern that if suggestions are system-generated they will be generic, which could potentially limit their thinking to the provided suggestions only. Thus, losing the personal touch in care and inducting the feeling of annoyance.

“I find this terrible, very annoying. Because I’m already stressed out, and then I get those too obvious suggestions that say ‘do this, do that’. My stress levels are already high and then I read something stupid… no thank you. Very irritating…” [P2]

Overall, while the usefulness of suggestion differs person to person, it would be valuable to have such an option for those who are willing to receive it.

Social Learning: Reading other informal caregiver’s experiences

The informal caregivers reported varying experiences regarding the page which included stories about the experiences of other informal caregivers. Some indicated this was valuable for them since reading about the experiences of others could provide them with some support, insight, and inspiration on how others handled certain situations.

“You can share your experiences, this is not strictly necessary, but it does help because then you realize you’re not the only caregiver. And when you share experiences, you get tips and tricks, you can learn from them. I think this is really great.” [P5]

Other informal caregivers who are experienced (either caring for a long time or were medical/care professionals) or have support from other informal caregivers didn’t perceive social learning as advantageous. Although they seek value in social learning for people who are providing care by themselves and do not have a social network to support them.

“I don’t need this, because I actually know the possibilities in the field quite well and I experience a lot of support from my brother and sister. We are doing well together…” [P1]

“I think that for some people who live alone and are the only informal caregivers, it would be a welcome thought. This is about how you have organized your caregiving network. That is not always easy, sometimes quite complicated. So in that sense, it could be a very helpful feature.” [P3]

4.3.3 Suggestions for improving the user interface prototype

Overall the conceptual workflow of the prototype of the interaction platform was assessed positively by the informal caregivers. They indicated that most of the screens were clear and understandable. However, some suggestions about screens or connections that were perceived as less logical or where improvements could be made were provided by the informal caregivers.

Improvements in conceptual flow

Informal caregivers highlighted that some choices regarding the notification settings were double or unnecessary, which made the flow unclear or redundant. Specifically, in Figure 3 (Fall incident) fourth screen and Figure 3 (Agitation) third screen, the option to share the respective information with the formal caregiver was given although informal caregivers already mentioned their choices to share or not share with formal caregivers during adjusting the preference (Figure 2). Keeping the process iterative, this was adjusted for the following (last two) interview sessions.

"Here, I again have the choice if I want to share with a care professional. But if that happens again, then I wonder if I have set it up correctly in the settings. So does this still appear on my screen? In the beginning, you make a choice about sharing information with a care professional, and here that comes up again, so it's kind of redundant." [P3]

"This is what I don't understand. If I let the notifications go to the home care professionals for this situation, then I should not have to fill this in (choice for the content of the notification)." [P4]

Furthermore, informal caregivers indicated that it was inconvenient to immediately receive the option to provide feedback to the system in case of an (emergency) notification as they mentioned at that moment they were not thinking about that and were probably not the right person to provide this information. It was suggested to send a reminder to provide this feedback at a later moment. Also, there should be an option to give more details about the situation.

"Provide feedback on this notification, yes that can be useful, but it has to be at a later moment. You don't do this in the notification itself, but you can add at a later moment what the issue was and whether the notification was accurate." [P2]

"For this, I would appreciate a reminder. I don't necessarily enjoy receiving a lot of notifications all the time, but specifically for this purpose, yes. It's about helping each other and helping the system learn, and thus improving the care. And I think when I'm actually there (at loved one) or when I come from there, then I might forget that. So, a reminder would be helpful, but it would be good to have a choice in the type of notification." [P3]

Informal caregivers also suggested that there should be feedback provided to them after they received a notification so that they know that someone handled the situation and what actions have been taken.

"I think that is a bit of a gray area, so you received or made a notification, but what happens with it? That I would expect to receive feedback on." [P5]

"Now I still have the feeling like I have to go there because I don't know if it (notification) has been received and if someone is going there." [P1]

Improvements in visual design

It was suggested by informal caregivers to include a clear visual indication when a deviation in behavior was noticed by the system, for example, a warning sign. Also, one informal caregiver mentioned it would be more useful to express reliability in words instead of percentages, as this might be easier to interpret. Lastly, informal caregivers suggested the prototype could be improved by providing information in a more visual way and including more graphs, images, and pictograms, as this could make it easier to interpret the information they were looking for.

"At a glance, I can see that everything is going well… but then (in case of deviation) could have a different color like red, and for yourself there could an exclamation mark or warning sign to indicate that this is not optional information but something that needs to be looked into because it is not as it should be." [P5]

5. Discussion

In this study, informal caregivers showed a significantly positive attitude towards using USSs driven by AI algorithms for providing care to home-dwelling OwCI. However, a prior study that explored care recipient's perspective regarding AI in healthcare revealed hesitancy, primarily driven by worries related to safety, privacy, and autonomy [31]. This divergence could be attributed to two factors: the difference in the study population, and the potential lack of knowledge about USSs (on in general technological care solutions) among the previous study's participants. The previous study by Richardson et al. [31] focused on care recipients' perspectives whereas this study involved informal caregivers who might have a different perspective as USSs will be monitoring the care recipient and it does not concern informal caregivers. Furthermore, many people have limited knowledge about AI algorithms and view AI as a 'black box' [32]. Previous research suggests that educating and engaging individuals about AI can enhance their trust in AI as well as contribute towards their successful implementation in healthcare [31] [32]. In this study, USSs were explained using a video-prototype and additional verbal explanations, which most likely increased participants' awareness of AI usage. However, individual differences in understanding AI might also influence their positive and accepting attitude towards USSs.

The USSs rely on AI algorithms to predict the behavior of OwCI, which might not function flawlessly and could misclassify certain behavior patterns. Therefore, care providers need to be cautious and should not become overly reliant on USS, as it may lead to incorrect care choices [33]. This would present an ethical issue regarding accountability, as it prompts the question of who is responsible and to what extent [33]. To overcome this risk, educating caregivers on its usage, capabilities, and limitations might benefit them. Additionally, the risk of bias when using AI in healthcare should also be accounted [33] [34]. The training data if predominantly represents a specific population (gender, age, ethnicity, etc.) might create biases [34]. This risk could be mitigated by ensuring representative and inclusive training data sets i.e., including data from a wide range of individuals with different demographic characteristics and backgrounds when training the AI algorithm [34].

Furthermore, the informal caregivers recognize the value of a USSs as a supportive tool in the care of home-dwelling OwCI [2]. Specifically, USSs can facilitate appropriate care decision-making, contributing to their peace of mind while also creating a safer environment for their care recipients. However, there were also some concerns expressed by them, regarding possible information overload, the substitution of the human aspect in care provision, and the (over) interpretation of data. To mitigate these, they acknowledged the importance of setting up (make agreements about the monitored activities and strategies regarding communication) the solution together with other stakeholders (specifically formal caregivers). This is in alignment with the CeHRes roadmap i.e., for successful implementation of an eHealth technology, it is important to consider the perspectives and needs of different stakeholders involved [15] [16]. Also, it can be said that by combining the strengths of technology with the insights and expertise of caregivers, a more comprehensive and effective care approach and implementation could be achieved.

Additionally, informal caregivers experienced the lo-fi prototype and use of most PSD features elicited in our previous study as positive [7]. Particularly, participants valued the possibility to personalize the settings and change them to their preferences at any given moment in time. The use of the personalization feature as suggested in the PSD theory has the potential to enhance the usefulness of eHealth technologies such as USSs [7]. However, before making solutions personalized, careful consideration of the personalization-privacy paradox should be given [35]. This paradox highlights the tension between providing personalized services and protecting user privacy while demanding the right balance between offering personalized experiences and safeguarding user privacy [35] [36]. It might be achieved by implementing robust privacy measures, obtaining informed consent, being transparent about data usage, and providing users with control over their data as described in ethical guidelines issued by the European Commission for trustworthy AI [37] and the European Health Data Space (EHDS) regulation [38]. Moreover, for the PSD features reminders, suggestions & social learning the experiences were a bit mixed. These findings emphasize the importance of a user-centered design approach, as the preferences of each individual can vary depending on the care situation, personal circumstances, and preferences in IC [16]. For example, the travel distance to the care recipient could influence their choice on whether or not they wanted to receive an emergency call when a fall incident occurred.

6. Implications for future research and practices

For successful implementation of a complex eHealth intervention such as USSs for home-dwelling OwCI a holistic design approach is required [16]. It is important to take into account the perspective of different key stakeholders such as informal and professional caregivers, care recipients, and care organizations but also secondary stakeholders such as health insurers, governments, and technology businesses while designing and implementing such solutions. For future research, it would be interesting to perform the next design iteration by using the results of this study as a starting point. Gradually, a high-fidelity prototype of the user interface could be created and evaluated with different stakeholders in OwCI care. Furthermore, the creation of personas would be helpful in research, as there might be different types of desired end-users having different needs and requirements [39]. The personas could be based on characteristics such as caregiving experience, educational level, or need for cognition [39]. Additionally, it would be interesting to explore the ethical implications of implementing a smart monitoring and communication system for home-dwelling elderly, which could be done by performing in-depth interviews with involved stakeholders.

Prior to the implementation stage, a business modeling approach can be used. It provides insight into how value is generated and delivered to customers, which should be considered in order to bring eHealth technology to the market [40]. Along with that, implementation of such a solution requires guidelines and agreements (on how to work with such a system) within organizations as well as at the government level. Caregivers should be educated on how to interact with the system, interpret, and communicate the data. Additionally, it is essential to consider regulations like the Medical Device Regulation (MDR) to determine if USSs will be categorized as medical devices or not. MDR offers provisions to address privacy and security concerns, especially concerning medical devices that collect and process personal health data [41]. Furthermore, since USSs utilize AI, it is crucial to take into account the new AI Act proposed by the European Union. This act aims to regulate the use of AI in EU countries, ensuring better conditions for the development and use of AI technologies (EU AI Act, 2023) [42]. In this act, different rules will apply to different risk levels, with USSs probably falling under the category of high risk, and will be subjected to a high degree of regulations [42]. This might have consequences for the extent and manner in which AI is applied.

7. Study Limitations

This study has some limitations which should be considered when interpreting the results. First, all the informal caregivers who participated in this study had prior experience with technological interventions in care provision (e.g., Caren platform) and also participated previously in related research. While it is important to acknowledge that the findings of this study may not fully generalize to participants with no prior experience in digital care technology, the overall growth in digital literacy is noteworthy and holds promise for the realization of the study's findings. Secondly, the majority of informal caregivers who participated in this study reported that their care recipient had received a formal diagnosis of cognitive impairment. However, some informal caregivers also expressed their own opinions regarding the indication of cognitive impairment in their care recipients. Given the scope of the study, which aimed to explore the perspective of informal caregivers, their opinions hold higher value in this study [43] [44] [45].

Thirdly, it is important to note that this study was conducted in the Netherlands, which may limit the generalizability of the results to international healthcare infrastructures. Different countries have diverse regulations and policies regarding older adult care, thus different expectations and pre-implementation conditions from USSs can be imagined. Lastly, it is worth mentioning that data saturation was not reached in this study, as new information was provided in all interviews. This indicates that there may be additional themes that were not fully explored, suggesting that the results of the study may not be exhaustive. However, it is important to recognize that the design process is iterative, and during the evaluation of the lo-fi prototype, the aim was to further enrich the platform, making data saturation less critical for this stage of development [46].

8. Conclusion

Informal caregivers of OwCI overall had positive expectations regarding the implementation of USSs. They expect the use of such a system to contribute to care decision-making and to provide insight into the situation of the care recipient. However, information overload and loss of human aspect were perceived as risks. In order to successfully implement a USSs good communication and agreements between informal caregivers, formal caregivers, and the care recipient are needed. Thus, necessitating a holistic approach in the development and implementation process. Informal caregivers were quite positive about the lo-fi prototype of the user interface and the application of PSD features, yet there were also mixed experiences and improvements suggested regarding the conceptual flow and visual design of the prototype. Personalization of the settings of the prototype was perceived as highly valuable. The results of this study, especially the identified concerns, should be considered in the further development and implementation of USSs for home-dwelling OwCI.

Conflicts of Interest

None.

Acknowledgements

This research was funded by the European Union’s Horizon 2020 research and innovation program under the Marie Skłodowska-Curie grant agreement number 814072 for the ITN ENTWINE informal care. The authors would like to thank Prof. Dr. Paul Havinga, Dr. Jan Hendrik, and Dr. Duc Le Viet for their valuable feedback.

Multimedia Appendix 1

Used Semi-structured interview script for qualitative data collection.

Abbreviations

USSs: Unobtrusive Sensing Solutions
IC: Information Communication
OwCI: Older adults with cognitive impairments
PSD: Persuasive System Design Model

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