Exploring expectations and experiences of informal and professional caregivers towards a smart monitoring and communication system for home-dwelling older adults with cognitive impairment: a formative evaluation

Master Thesis
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Abstract

Introduction: In the future, the number of people with cognitive impairment will increase, while people will live at home longer and the shortage in caregivers rises as well. Smart monitoring technologies have the ability to provide support to both professional and informal caregivers of home-dwelling older adults with cognitive impairment by providing insight into the situation of the individual. Additionally, these technologies can overcome the limitations commonly associated with other sensor technologies. A communication platform should be connected to the monitoring technology to inform caregivers about the situation of the care recipient. This study aims to explore the expectations of professional and informal caregivers towards implementation of a smart monitoring and communication system for home-dwelling older adults with cognitive impairment and to evaluate a low-fidelity prototype of such a system with informal caregivers.

Methods: Six informal caregivers and seven professional caregivers of older adults with cognitive impairment who were living alone, participated in this study. The participants were recruited via email and informed consent was obtained prior to participation. This formative evaluation consisted of two parts: a low-fidelity (lo-fi) video prototype in which the functionalities of the smart monitoring system as a concept was explained and 2) a lo-fi clickable prototype of the user-interface of the communication platform. Individual semi-structured interviews were performed with informal caregivers. This included an usability test of the user-interface prototype considering different care scenarios. Furthermore, two focus groups with professional caregivers were performed. The interviews and focus groups were audio-recorded and transcribed verbatim. The data was analyzed using a thematic analysis approach.

Results: Informal and professional caregivers had various positive outcome expectations towards implementation of a smart monitoring system such as objective decision making and peace of mind. Also, some negative outcome expectations were mentioned, for example information overload and substitution of human contact. Good communication and agreements between informal and professional caregivers was considered to be important to successfully implement a smart monitoring system. This might require extra time and effort from professional caregivers. The user-interface prototype of the communication platform was experienced quite positive by informal caregivers for various care scenarios. Especially the personalization of the prototype was considered valuable. However, there were also improvements suggested regarding the visual design and conceptual workflow of the prototype.

Conclusion: In order to successfully implement a smart monitoring and communication system for home-dwelling older adults with cognitive impairments a holistic approach in the design and implementation process is required. The outcomes of this study should be considered in this process. Future research could focus on evaluating a higher-fidelity prototype with relevant stakeholders in a real-life setting.

1. Introduction

1.1 Background

Dementia is a major public health concern to countries all over the world, with more than 55 million people suffering from the disease in 2022 according to the World Health Organization (1, 2). In the Netherlands, the number of people living with dementia is currently estimated to be around 290.000, and this number is expected to increase to 520.000 by 2040 (3, 4). By that time, dementia is expected to have the highest burden of disease as expressed in Disability Adjusted Life Years (DALYs) (5, 6). However, it often takes a long time before dementia is diagnosed and some dementia patients never receive an official diagnosis (4). Therefore, instead of focusing only on dementia, this study focuses on cognitive impairment. Cognitive impairment, just as dementia, has considerable impact on the lives of patients and their relatives since it influences cognitive and functional abilities, leading to problems in performing daily activities and a decreased quality of life (7). This deterioration in functioning is often associated with an increase in the need for care (4, 7).

Most of the people with cognitive impairment continue to live at home for as long as possible (8). In the Netherlands almost 80% of all people with a dementia diagnosis are living at home (4). The Netherlands, as well as many other countries, implemented policies that stimulate older adults to live at their own homes for as long as possible (9, 10). Governments apply these policies as many older individuals prefer to age in their own place, while budgetary considerations play a role as well since institutionalization is more costly than homecare (11). Older adults are expected to rely more on their social network and informal caregivers for assistance instead of moving to a nursing home (9, 10). In the case of cognitive impairment, compliance with this policy might entail challenges for both the person with cognitive impairment and their caregivers since the demand for care increases as the disease progresses (8, 12). For example, the latter stages of dementia often associated with total dependence and inactivity (1, 4). Also, behavioral changes may arise such as wandering or aggression, which might complicate care provision (1, 4). Informal caregivers are put under great pressure and report experiencing physical, emotional and financial burdens in taking care of their loved ones (12, 13). Next to support from informal caregivers, people with cognitive impairment commonly receive care from professional caregivers such as district nurses who for instance help with performing activities of daily living and medical care (10).

However, due to the ageing of the population, a shortage of professional and informal caregivers is expected in the future (6). The increasing life expectancy and decreasing birth rates leads to the population existing of a larger proportion of elderly individuals, resulting in relatively less employable individuals available to provide care (6). According to Hallberg and colleagues, provision of professional care for people with cognitive impairment is one of the main challenges for healthcare systems in the future (14). In the Netherlands, the shortage healthcare professionals in nursing and home care is expected to grow (15, 16). Furthermore, the increase in chronic diseases and multi-morbidity leads to a higher and more specialized demand for care, which will further increase the pressure on professional and informal caregivers (6). This situation will not be sustainable in the future and thus calls for an alternative approach.

1.2 Unobtrusive monitoring technologies

The use of eHealth technology is commonly proposed as solution for healthcare challenges, since it has the potential to improve access to care, patient empowerment and quality of care (17, 18). In the case of cognitive impairment, the use of sensors seems promising in enabling persons with cognitive impairment to live independently at home for a longer period of time (19). Different types of activities can be measured with separate sensors. In the case of cognitive impairment certain types of behavior might be an indication of deterioration of the person's condition, possibly causing health and safety risks such as; more falls, sleep disturbances, malnutrition, or higher risks of infections (1, 20). The use of motion and bed sensors can provide information regarding how often a person is leaving the bed, which might be an indication for wandering or sleep disorders (19, 21). Door and fridge sensors can provide insight in how often a bathroom door or fridge has been opened. However, it does not indicate if someone has actually eaten, or entered the bathroom (19). Therefore, the data provided by separate sensors is limited and it does not provide information regarding dynamic behavior. Furthermore, wearable devices have been utilized to monitor physical parameters such as heart rate and activity levels, which might provide information regarding physical state of the person with cognitive impairment or behavioral symptoms as agitation (21, 22). However, these devices have issues regarding the acceptability of elderly persons with cognitive impairment due to stigmatization and inconvenience (23). Besides, use of wearables by persons with cognitive impairment possibly include validity or feasibility issues due to the older adult incorrectly wearing or forgetting to wear the device (23, 24).

Consequently, to overcome these issues, the emphasis has shifted to unobtrusive monitoring of home-dwelling persons with cognitive impairment (23-25). Unobtrusive monitoring technologies typically do not draw attention from and require no involvement of the user (23-25). These technologies are placed in the non-line-of-sight, thus blending in with the environment (23, 25). Unobtrusive monitoring systems include in-home contactless sensors and make use of, for example, radio waves, infra-red sensors or Wi-Fi sensing techniques to monitor behavior (23-25). Potentially, these systems are able to observe meaningful changes in dynamic behavior and provide caregivers with real-time information about the status of the person with cognitive impairment, due to the involvement of Artificial Intelligence (AI) (23-25). Unobtrusive monitoring technologies possibly respect the privacy and dignity of a person with cognitive impairment better than other monitoring technologies (23-25). Compared to camera based monitoring for instance, an unobtrusive monitoring system using AI translates raw data that is difficult to interpret, into useful information for caregivers without actually observing every activity the person with cognitive impairment performs (23). Also, monitoring from a distance probably reduces the number of physical visits needed, implying less interruptions by a caregiver for the care recipient (24). An unobtrusive monitoring system potentially has the ability to predict and detect behavior changes (e.g. wandering, agitation or dietary changes) based on previous data (24, 26). This allows for early identification of health risks and quick intervention, thus supporting caregivers and possibly causing a shift from reactive to more proactive care (24).

1.3 eHealth development

When developing an eHealth technology it is important to consider that many eHealth initiatives lack solid implementation in practice, resulting in a technology not being used and a waste of resources (18). Development and implementation of eHealth technologies is a complex process since eHealth should be considered not solely a technology, but a broader concept which also influences its context, the people and already existing structures (17). Therefore, it is important to apply a holistic approach considering the interrelations and interdependencies between people, technology and context altogether (17). The CeHRes Roadmap developed by van Gemert-Pijnen and colleagues provides a framework for holistic development, implementation and evaluation of eHealth technologies (17). It consists of several phases: the contextual inquiry, value specification, design, operationalization and summative evaluation (17). The Roadmap emphasizes the eHealth development process to be an iterative process, in which it might be necessary to go back and forth between the different phases. Formative evaluations which take place throughout the different phases of the Roadmap are of great importance to ensure that performed actions are in line with the outcomes of previous phases (17).

Important approaches incorporated in the CeHRes Roadmap are user centered design and persuasive design. The involvement of the user centered design approach in the CeHRes Roadmap implies that during all phases of the eHealth development process the human perspective should be considered (17). This can be done by involving end-users and other stakeholders throughout the different phases of the development process by including them in for example formulation of requirements, codesign sessions and evaluations (17). Focusing on the users' perspective in the entire development process should lead to an end-product which is appealing and fully aligns with the wishes, expectations and needs of the end-users, resulting in a higher chance of successful implementation (17). Next to that, persuasive design is another important approach in the CeHRes Roadmap. Persuasive technologies are aimed at changing the behaviors and attitudes of people towards certain behaviors or towards the technology itself (17, 27). The Persuasive Systems Design (PSD) model as developed by Oinas-Kukkonen and Harjumaa identifies four categories of software features for persuasive systems which can be applied to make a system more persuasive (17, 27). First of all, primary task support which supports the user in performing the intended activities (e.g. reduction, tailoring) (27). Secondly, dialogue support, which facilitates interaction between the user and the system (e.g. reminder, suggestion) (27). Thirdly, credibility support which is about the trustworthiness of the system (e.g. authority, real world feel) (27). Lastly, social support which refers to the leveraging of social influence in the system (e.g. social comparison, recognition) (27). Persuasive technology can positively influence the extent to which the technology is being used as intended and can possibly overcome usability issues (17).

1.4 Development of communication platform

In order for an unobtrusive monitoring system for home-dwelling elderly with cognitive impairment to be of value, the obtained data should be translated into understandable information by the AI algorithm. This information should then be presented to the informal or professional caregivers in such way that they get insight in the situation of the care recipient, which allows them to act accordingly when necessary. Therefore, a communication platform should be connected to the unobtrusive monitoring system, presenting relevant information to the caregivers in a comprehensible way. Previous research mainly focused on the technological side of unobtrusive monitoring systems for home-dwelling older adults with cognitive impairment. Also, research has identified initial requirements of such a system as defined by professional and informal caregivers (24). Furthermore, previous research identified what information informal caregivers would like to receive in various care situations and which PSD principles would possibly enhance information provision (28). Situations which caregivers considered important and where an unobtrusive monitoring system could play a role are fall incidents, agitation and normal daily life, with activities as medication intake or dietary behavior (28). Little is known about what the expectations of professional caregivers are towards implementation of such an unobtrusive monitoring system and what it would mean for their work and routines. Furthermore, to create a communication platform for a real-time monitoring system for home-dwelling persons with cognitive impairment that aligns with the wishes of the end users, it is important to perform formative evaluations throughout the development process. One way to do this is by performing an usability test. This allows the researcher to test whether the prototype of such a communication platform complies with the predefined requirements and fulfills the expectations and capabilities of end users (17).

1.5 Study aims

The aims of this study are: 1) to perform a formative evaluation of the user interface of a low-fidelity prototype of a communication platform designed for a smart monitoring system for home-dwelling older adults with cognitive impairment, from the perspective of informal caregivers, and 2) to explore the expectations of both informal and professional caregivers regarding the implementation of such a system. Therefore, the following research questions will be addressed in this study:

- What are the expectations of informal caregivers towards the implementation of a smart monitoring and communication system in the care for home-dwelling older adults with cognitive impairment?
- What are preconditions and requirements for implementation according to informal caregivers of older adults with cognitive impairment?
- How do informal caregivers of older adults with cognitive impairment experience the conceptual flow and use of PSD features in a low-fidelity prototype of a communication platform for a smart monitoring and communication system in fall, agitation and normal daily life care situations?
- What are work-related expectations of professional caregivers towards the implementation of a smart monitoring and communication system in the care for home-dwelling older adults with cognitive impairment?

2. Methods

2.1 Design

This study had a qualitative study design. A formative evaluation for a smart monitoring and communication system for home-dwelling older adults with cognitive impairment was performed. The evaluation existed of two parts: 1) a low-fidelity (lo-fi) video prototype in which the functionalities of the smart monitoring system as a concept was explained and 2) a lo-fi clickable prototype of the user-interface of the communication platform connected to the smart monitoring system. The evaluation was performed in two ways: 1) semi-structured individual interviews with informal caregivers along with a usability test with a think-aloud protocol and 2) focus groups with professional caregivers. The user-interface evaluation was performed only in the individual interviews with informal caregivers. Table 1 provides an overview of the different components of this study.

Table 1: Various components of the formative evaluation.

	Informal caregivers (N = 6)	**Professional caregivers (N =7)**
Video prototype evaluation	X	X
Lo-fi user interface prototype usability test	X	
Semi-structured interviews	X	
Focus group		X

This study has been approved by the Humanities and Social Sciences (HSS) Ethics Committee of the Behavioral, Management and Social Sciences faculty of University of Twente, the Netherlands. This study received the following ethical approval number: 230141.

2.2 Participants

In this study both informal and professional caregivers participated. Informal caregivers were eligible for participation if they met 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. Professional caregivers were eligible for participation if they met the following inclusion criteria: 1) providing paid homecare for persons with cognitive impairment and 2) working for one of three approached homecare organizations in Enschede, the Netherlands. It was not necessary for both informal and professional caregivers to have any experience with technological devices. Also, there were no exclusion criteria regarding the educational levels of the professional caregivers. Participants were excluded when they were not able to speak and understand the Dutch language.

Participants were recruited from an already existing pool of candidates, who have previously been involved in similar research (24). Informal caregivers were approached for participation in this study by email at the 17th of April 2023. They received an invitation to participate and an information letter as shown in appendix 1. The information letter explained the purposes and procedures of the study and provided contact details of the researcher. When an informal

caregiver was willing to participate, an appointment for the evaluation session was planned with the researcher.
Professional caregivers were recruited by email as well. This was done by sending an email to the general email address of the involved home care organization, at the 21st of April 2023. These email addresses were also already known through their involvement in previous research. The professional caregivers received an invitation to participate in a focus group and received a different information letter, since the purpose of the study for professional and informal caregivers varied. The information letter for professional caregivers is shown in appendix 2. When professional caregivers expressed interest in participating, they were asked to fill in a date picker to schedule an appointment when most caregivers were available. One week after the invitation was send, an appointment for the focus group was scheduled and the professional caregivers were informed about this by email.

2.3 Materials

Video prototype

A video of the smart monitoring system for home-dwelling elderly with cognitive impairment was created as a lo-fi video prototype. This video prototype describes the system design architecture and is based on previous research into this technology (28). The video was created based on brainstorm sessions with other researchers, during which a storyboard was developed first. The video is based on the sense-think-act loop of the system. The 'sensing' part of the system is about how and what data the system collects. The 'thinking' part of the system is about what happens with that data and how it is translated into output. In the 'acting' part of the system is about what information will be communicated on the communication platform. The video-prototype was shown to the participants at the beginning of the interview or focus group sessions to provide clear understanding of how the smart monitoring system works and its features are.

The video provides examples of different scenarios in which the smart monitoring system could engage in, which were identified as important care situations according to caregivers (28). These scenarios are a fall incident, agitated behaviour, nocturnal unrest and normal daily life, for which drinking was used as example in the video. The video footage was recorded in April 2023, in the eHealth house on University of Twente, the Netherlands. A Dutch voice-over was added providing explanation about the system and what is shown in the video, since all participants were Dutch. However, English subtitles were added to the video. The video has a total duration of 3,5 minutes. Figure 1 shows an simplified overview of the system architecture of the smart monitoring and communication system, to give an idea how it looks like.

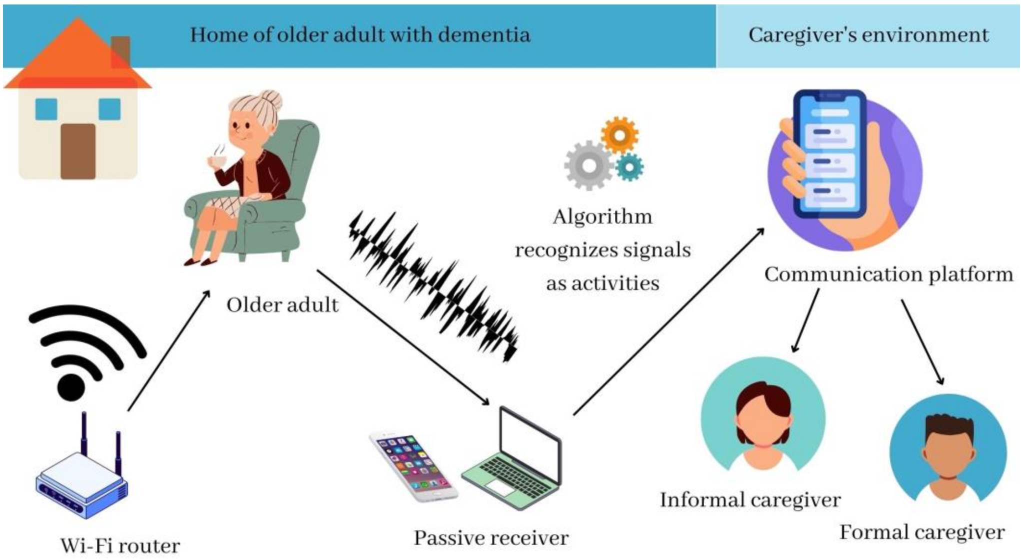


Figure 1: Simplified overview of system architecture

User interface prototype

The lo-fi prototype of the user interface for the communication platform to be used by informal caregivers was created with the software Figma. The content of the prototype for the user interface of the communication platform was based on previous research, which identified requirements regarding the content, mode and receivers of notifications, retrieved from informal caregivers for different care scenarios (28). Furthermore, previous research has also identified PSD features which could be relevant to include in such a communication platform (28). This information was used in the development of the user interface prototype.

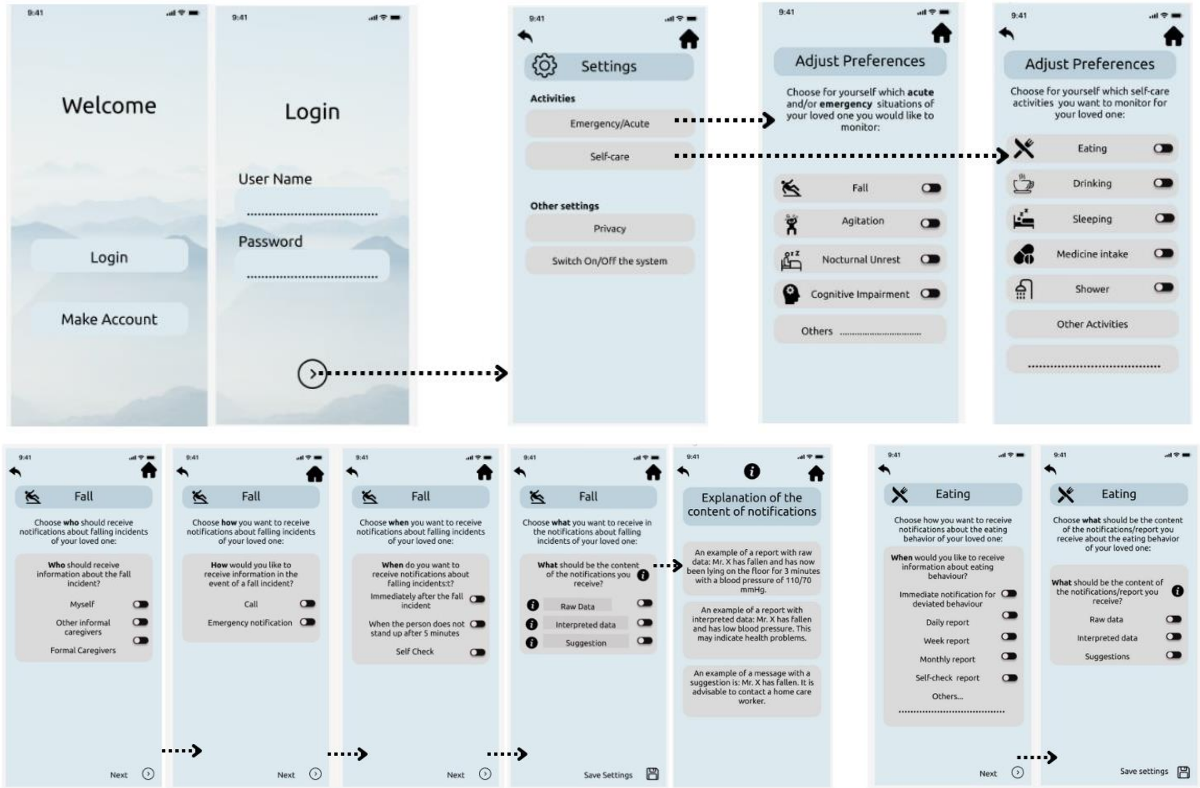
The user interface is still in its early design phase and could be considered as lo-fi prototype since it only contains the main functionalities and does not include many details (17). Also, the user-interface included only the perspective of the informal caregiver, not yet the perspective of the professional caregiver. The user interface included the care scenarios of a fall incident, agitated behavior and selfcare activities. The lo-fi user interface was made in collaboration with a second researcher. First, a flowchart was created as rough outline of what steps should be taken within the communication platform and which screens to include for the different scenarios. Also it was discussed how exactly the various PSD features could be applied. Then, the links between the different screens were made and the user interface was tested multiple times by the researchers.

In the user interface prototype several PSD features were included: personalization, reduction, tailoring, reminder, suggestion, social learning, trustworthiness and verifiability (27). Table 2 provides a short explanation of the included PSD features and how they were applied in the user interface prototype.

Table 2: PSD features (27) applied to the user-interface prototype.

PSD category	PSD feature	Meaning	Application to lo-fi user interface prototype
Primary task support	Personalization	Providing personalized content	Options to change the settings, e.g. what activities to monitor, and changing who, how, when to receive notifications.
	Reduction	Reducing complex tasks into smaller simple tasks	Directly receiving a call in an emergency situation e.g. fall situation instead of having to check for the updates yourself. Home screen directly providing information regarding the current situation.
	Tailoring	Providing information tailored to the user's needs	Tailoring reports and notifications according to the needs of the recipient of data (e.g. professional caregivers).
Dialogue support	Reminder	Reminding users of target behavior	Sending a reminder after a few minutes when the emergency call is not responded to.
	Suggestion	Offering suggestions to facilitate behavior	Suggestions for informal caregivers for possible actions to undertake in different care situations.
Social support	Social learning	Learning from the experiences and behavior of others	A page where the user can read and react to stories about experiences of other informal caregivers.
System credibility	Trustworthiness	Providing reliable information	Providing a reliability percentage in a notification and possibility to provide feedback to the system.
	Verifiability	Providing evidence to validate the accuracy	Inclusion of a page providing contact information of professional caregivers, and possibility to send messages and to connect with an electronic health record.

Figures 2 to 5 shows a few screens of the user interface prototype, for different scenarios. The scenarios are further explained below. After the first round of interviews some minor changes were made to the user interface prototype.



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?

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.

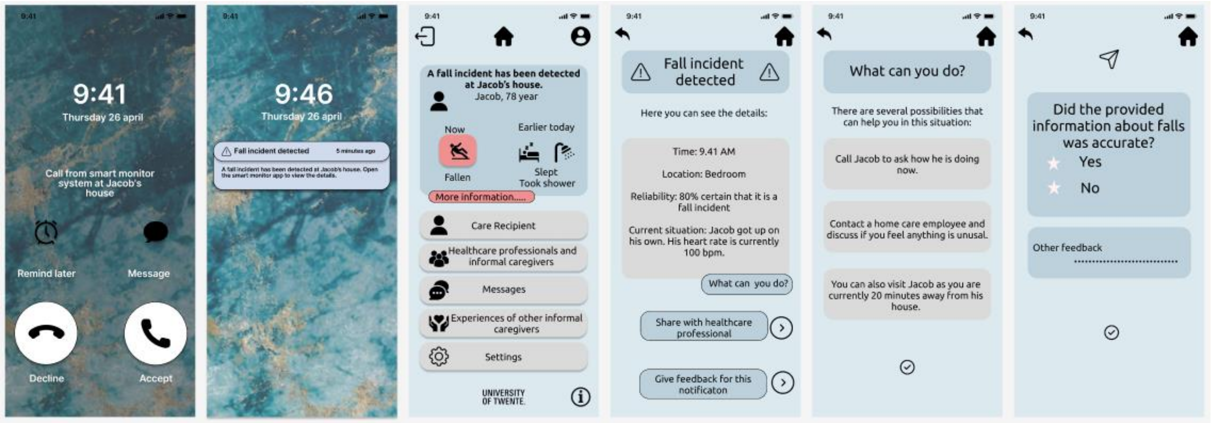
Choose how you want to receive notifications about the eating behavior of your loved one:

When would you like to receive information about eating 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 2: Changing the preferences



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:

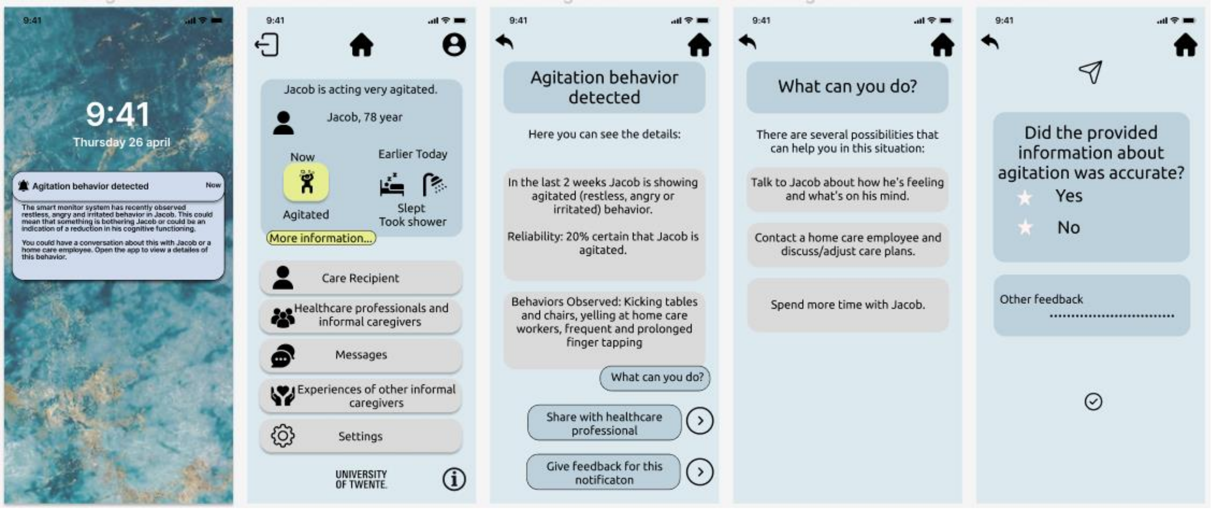
Call Jacob to ask how he is doing now.

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 3: Fall incident scenario



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.

Jacob, 78 year

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.

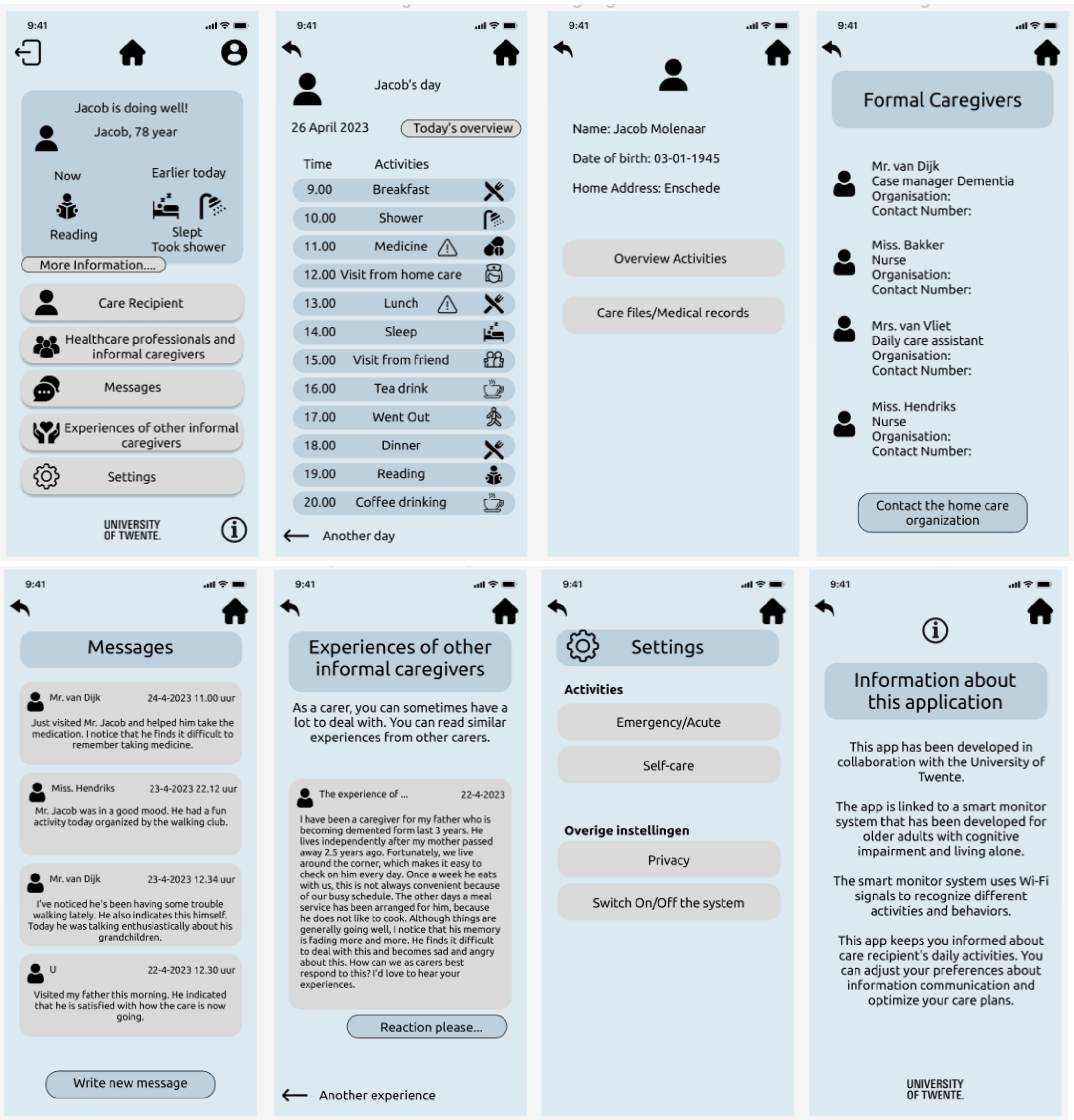
Did the provided information about agitation was accurate?

☆ Yes

☆ No

Other feedback ....

Figure 4: Agitated behavior scenario


Jacob is doing well!

Jacob, 78 year

Jacob's day

26 April 2023

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

Formal Caregivers

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:

Messages

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.

Experiences of other informal caregivers

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.

Information about this application

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.

Figure 5: Home page with different functionalities/pages

Usability test

The usability test was performed with informal caregivers. During the usability test the participant could click through the clickable user interface prototype of the communication platform for different scenarios. The participant received five tasks to perform by clicking through the user interface, each of them targeting one or multiple PSD features, as shown in Table 3.

Table 3: Usability test tasks and the targeted PSD features.

Scenario		**Task**	**PSD features**
1	Emergency situation preferences	Changing preferences regarding notifications for emergency situations	Personalization
2	Self-care activities preferences	Changing preferences regarding receiving reports/notifications for self-care activities	Personalization
3	Fall incident	Retrieving information about the fall incident situation	Reduction, tailoring, reminder, suggestion, trustworthiness
4	Agitated behavior	Retrieving an overview on the agitated behavior of the loved one	Reduction, tailoring, suggestion, trustworthiness
5	General system features	Exploring the different functions and pages of the prototype	Social learning, verifiability

During the usability test, the participant was asked to think aloud, to give insight in their thoughts. The think-aloud method allows for gathering in-depth information about the expectations and feelings of the participant regarding the system (17). The researcher explained the scenarios and what the participant was trying to achieve within the user interface, but did not guide the participant step-by-step through the system. The researcher mainly observed where difficulties emerged within the user interface and asked about his opinion. When the participant was lost the researcher helped them out, so that the process could be continued.

2.4 Interviews informal caregivers

The semi-structured interviews with informal caregivers were performed using an interview guide. The interview guide consisted of the following sections: 1) introduction, goals and procedures, informed consent, 2) background information from participant, 3) video prototype and general impression, 4) refining the user profile, 5) usability test, 6) user-interface experience and 7) closing remarks. The section 'refining the user profile' was based on previous research in which a user profile and value map was made for informal caregivers (25). This information needed to be validated and was therefore included in the current study. During the individual interviews the focus was on expectations, needs, preferences and preconditions of the intended end-users regarding the smart monitoring and communication system. The interview guide for the individual interviews is shown appendix 3. Also, a PowerPoint presentation including the different sections of the interview guide was used during the interviews to provide structure and guide both the researchers and participants through the session.

The individual semi-structured interviews with informal caregivers took place either online via Teams or in a room at the University of Twente, depending on the preference of the participant. Two of the six interviews were held online. During the interviews, there were three researchers present, two of them performing the interview and the third person was present for technical support. The individual interviews took place in the first two weeks of May 2023 and had a duration of around 1,5 hours. Before participants were allowed to enter the study, informed consent was required. The informed consent form for informal caregivers is attached in appendix 4. For online interviews the participants were verbally asked to provide informed consent, for in person interviews written informed consent was obtained. By providing informed consent, the participants indicated being aware of the aim and procedures of this study. The individual interview sessions were recorded with a recording device, or via Microsoft Teams in case of online interviews. Afterwards, the recordings were stored on a shared drive.

2.5 Focus groups professional caregivers

The interview guide for the focus groups consisted of the following sections: 1) introduction, goals and procedures, informed consent, 2) video prototype and general impression, 3) refining the user profile, 4) implementation, 5) toolkit and 6) closing remarks. Again, the section ‘refining the user profile’ was based on previous research in which a user profile and value map was made for professional caregivers (25), with some additional questions added. Besides, the section ‘toolkit’ lies outside the scope of the current study, but was included in the interview guide to retrieve useful information for another researcher. During the focus groups the focus was on expectations towards implementation of a smart monitoring and communication system relating to their work. The complete interview guide for the focus groups with professional caregivers is shown in appendix 5. A PowerPoint presentation was used during focus groups as well, guiding the researchers and participants through.

The focus group participants were divided over two sessions and took place in a room at the University of Twente. During the focus groups two researchers were present, one of them performed the interview while the other person again was present for technical support. The focus groups had a duration of around 1,5 hours as well and took place in the second week of May 2023. Before the start of the focus group, participants were asked to sign an informed consent form (appendix 6) and to fill in a background questionnaire (appendix 7). The focus group sessions voice recorded with a recording device.

2.6 Data analysis

The recordings of the individual interviews and focus groups were stored on a shared drive. The recordings were transcribed verbatim by using the description software Amberscript. Qualitative analysis was performed by using the program Atlas.ti. A thematic analysis was performed, based on the six step 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 (29). For the individual interviews, the transcripts were coded using a mixed inductive and deductive approach. For exploring the expectations and preconditions a more inductive approach was used, while for the experiences with PSD features a more deductive approach was used. For the focus groups, the transcripts were coded using an inductive approach. The text fragments which were relevant for answering the research questions were given a code. These codes were, after all the transcripts were coded, grouped into larger codes which eventually led to the formation of themes (open, selective and axial coding). For the data analysis of the interview scripts with informal caregivers 50% of the interview scripts were coded by two researchers independently, after which discussion took place until consensus on the codes was reached. The other interview scripts of informal caregivers and the focus group data of professional caregivers was coded by one researcher. The data analysis process identified a number of themes which were elaborated on in the results section.

3. Results

The results section is divided into two parts. First, the results regarding the informal caregivers are presented, including the evaluation of PSD principles, then the results of the professional caregivers are presented.

3.1 Characteristics of informal caregivers

Table 4 provides the characteristics of the informal caregivers. Six informal caregivers participated in the study, two males and four females. 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 halve 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.

Table 4: Social-demographic characteristics of informal caregivers.

Participant number	Gender	Age	Age care recipient	Years of providing informal care	Hours per week spending 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

3.2 Expectations and preconditions from informal caregivers' perspective

An overview of the themes relating to the first two research questions regarding the expectations and preconditions from the perspective of informal caregivers is provided in table 5. The following themes are discussed: 1) positive outcome expectations, 2) negative outcome expectations and 3) preconditions for implementation.

Table 5: Themes relating to expectations and preconditions for implementation of a smart monitoring system 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 of the person with cognitive impairment

		Providing peace of mind to informal caregivers	Monitoring information could contribute to peace of mind for the informal caregiver
		Stimulating meaningful conversations	By using the system for the care related information there will be more room for the relational aspect
2	Negative outcome expectations	Information overload	Monitoring activities of their loved one 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 less human contact for the person with cognitive impairment
3	Preconditions for implementation	Shared decision making (& communication strategy)	Agreements should be made about the settings and communication strategy together with professional caregivers
		Smart monitoring system as supportive system	The system should support care decisions instead of taking over the analysis

Positive outcome expectations

Objective decision making

The informal caregivers indicated that the smart monitoring system could contribute towards making objective decisions regarding the care of their loved one. 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 objective 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. These conversations aim to foster a shared understanding and consensus on the provision of care. The information can be used to make better decisions to coordinate care and to better respond to the situation.

"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 that 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 smart monitoring system to contribute to the feeling of safety of their loved one, since they know the system will notice when a safety risk might occur. Also, it was mentioned the system could give insight in whether or not it is safe for the older adult 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 smart monitoring system to contribute to their peace of mind and probably to the peace of mind of their loved ones 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.

"That's a bit of the soft side, so to speak. 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…" [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

It was indicated by a few informal caregivers they expected the use of a smart monitoring system to lead to more meaningful conversations with their loved one, instead of spending the time together only on care related issues. Due to the monitoring information provided by the system, there would be more room for talking about non-care related things and have a more personal conversation.

"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]

"More the 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]

Negative outcome expectations

Information overload

A few informal caregivers mentioned they expected information overload to be a risk for them. They indicated wanting to know everything about the situation of their loved one, when it is possible to get this information. This information might be experienced as confronting, since it provides insight into the actual situation. Also, it was mentioned that receiving a notification might cause stress and concerns for the informal caregiver, especially when they are not able to act immediately, because then they are aware that something happened to their loved one.

"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 system. Even though, sometimes it is simply not possible to take action right away due to physical distance or other factors. Although not all participants expected this would be an issue for themselves since they 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 loved one, some indicated they definitely saw this as a risk of the smart monitoring system. They see this as a due to staff shortages in health care or not finding it necessary to physically check upon the older adult since the information is already provided by the system.

"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]

Preconditions for implementation

Shared decision making

According to informal caregivers it is required to discuss and come to agreements together with professional caregivers about what activities to monitor and what communication strategy is used, so; who receives what information and who responds to which notifications. This would be necessary to prevent unclarities, unfulfilled expectations and notifications which are not followed-up, probably negatively impacting the care provision.

"You can benefit a lot from it (smart monitoring system) 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]

Smart monitoring system as supportive tool

The informal caregivers indicated it is important to use the smart monitoring as a supportive tool instead of it replacing the human component of care. The system should facilitate the conversation and interpretation of the situation instead of completely replacing it. Furthermore, it was mentioned that 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.

"They (persons with dementia) 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]

"So it's a supportive system and it shouldn't take over the analysis of the situation. It may give the numbers, but if based on that is said: 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 are going in the wrong direction, but basically it (monitoring data) can provide a better conversation." [P2]

3.3 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 6 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. Some features were discussed more elaborately than others. One of the informal caregivers could not perform all tasks, one of them was skipped, due to time constraints.

Table 6: Themes on informal caregivers' experiences with the user interface prototype.

	Main themes	Sub-themes	Description
1	Positive experiences with user interface prototype	Options to customize settings	Personalizing the settings of the system was valuable
		Directly being informed about the situation	Receiving a direct call and easily finding the desired information
		Insight in reliability of information provided in the system	Reliability numbers increased the transparency of the system
2	Mixed experiences with user interface prototype	Receiving an reminder in case of a missed emergency call	Reminders were found useful or not suitable based on the personal situation
		Reading other informal caregiver's experiences	Experiences of other informal caregivers were found either helpful or not necessary
		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 mostly text

Positive experiences

Options to customize settings

The informal caregivers positively experienced the options to change the settings according to their personal preferences. They indicated this was valuable as it contributes to a better fit with their personal circumstances and the situation of their loved one. The informal caregivers indicated various preferences for different emergency and self-care activities. Furthermore, the possibility to continuously being able to change the preferences was perceived positively, as their or their loved one's situation might change and then the preferred settings would also change.

"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]

"Well, in that case, if that happens, then I will just activate both options. We'll do everything first, and then I'll figure it out, or change it later. It would be nice if 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 inform whether or not someone is available. And the professional caregivers should also receive that notification. So I would like

to have this screen (settings), to have it variable, so that you can set it individually, per day or per time" [P5]

The tailoring of notifications and reports based on the intended recipient was also experienced positively as informal caregivers noted that a professional caregiver may require different information compared to an informal caregiver.

"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]

Directly being informed about the situation

The informal caregivers found the direct phone call in case of an emergency situation valuable as this optimizes the information flow and timely intervention. Besides, the home screen which provided a direct overview of the situation of their loved one was reported to be useful. They indicated that this provided them with a quick update about the situation of their loved one when they want one.

"Yes, in this case (fall scenario) I would like the home care being alerted first so that they can provide necessary care and support, but I also want to immediately receive a call so that I can arrange to come home from work." [P4]

"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]

"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]

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]

Insight in reliability of information provided in the system

The informal caregivers indicated being positive about the system providing a reliability number of the notification and information as they mentioned it provides transparency about the system and its fallibility. Some participants mentioned that it would not matter for them what the reliability of the notification was as an notification on itself indicates an deviation is noticed. Others mentioned that the reliability might be especially valuable to professional caregivers, as this could have implications in terms of in which order they are going to visit their clients. Informal caregivers were also willing to provide feedback to the system, as they acknowledged this would further improve the reliability of notifications.

"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]

"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]

Mixed experiences

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 professional 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]

Receiving suggestions on what actions to take

Some informal caregivers experienced receiving suggestions on what actions to take in a certain care situation as helpful as this provided them with some guidance in stressful situations. Yet, the usefulness of suggestions varied per situation.

"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 as they already have the knowledge and experience to handle various care situations, or they preferred not to rely on the system's extensive interpretation of data. Also, suggestions could be experienced as irritating as they were too obvious.

"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]

Although it differs per person whether or not someone would want to receive a suggestion, it would be valuable to have an option to do so.

"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]

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 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 mentioned such a function would not be needed for them, since they indicate having enough contacts who support them and are familiar with the care environment and possibilities to connect with other informal caregivers. Yet, they can imagine it would be valuable for informal caregivers who are providing care on their own and do not have a network to rely on.

"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]

Suggestions for improving the user interface prototype

Improvements in conceptual flow

Some informal caregivers mentioned some choices regarding the notification settings were double or unnecessary, which caused unclarities.

"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 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 are not thinking about that and are 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. So that it's indicated on the home page like: hey, take a look at this…" [P5]

3.4 Expectations from the professional caregivers' perspective

Table 7 provides the characteristics of professional caregivers. Seven professional caregivers participated in the study, one male and six females. They were divided over two focus groups, depending on their availability. The first focus group had three participants, the second one had four participants. The professional caregivers had different functions in home care organizations, some also had multiple functions: six were dementia case managers, four were nurses, one was a personal healthcare assistant and one had an additional function of network coordinator. The professional caregivers were working at three different home care organizations.

Table 7: Social-demographic characteristics of professional caregivers.

	N (%)	Mean (SD)
Gender		
Male	1 (14)	
Female	6 (86)	
Age		43,0 (11,9)
Experience in current function (years)		11,4 (8,5)
Hours per week providing care for clients with cognitive impairment		26,3 (8,0)

SD: Standard deviation; N:Sample size

An overview of the themes concerning the work-related expectations of implementing a smart monitoring system as identified by professional caregivers is provided in table 8. The following themes are discussed: 1) positive outcome expectations, 2) negative outcome expectations, 3) effort expectations and 4) preconditions for implementation.

Table 8: Themes relating to work-related expectations and preconditions for implementation of a smart monitoring system from the professional caregivers' perspective.

	Main themes	**Sub-themes**	**Description**
1	Positive outcome expectations	Data-driven care decisions	Use of data to get insight in behavior and make decision which better fit the situation of client.
		Facilitate indication assessment	Using objective information to facilitate indication assessment on when to upscale care provision or admission to a care facility.
2	Negative outcome expectations	Information overload	Receiving information regarding behavior of all different clients might lead to information overload.
3	Effort expectations	Interpretation of data	The interpretation of data requires attention from professional caregivers.
		Making agreements with informal caregivers	Professional caregivers should decide with informal caregivers on what to monitor and when to intervene.
4	Preconditions for implementation	Involvement in clinical reasoning	The clinical and human perspective of professional caregivers should always be incorporated when using such a system.
		Possibility to filter information	The information should be filtered according to what the professional needs.
		Properly organized follow-up	There should be an organized follow-up system.
		Getting familiar with the technology	The professionals should get an chance to get used to working with a smart monitoring system before actual use.

Positive outcome expectations

Data-driven care decisions

The professional caregivers indicated they expect the use of a smart monitoring system to support them in their clinical decision making process. It was suggested making care decisions based on data rather than assumptions would lead to taking actions that better fit the situation of the client, as certain patterns and behavior are now visible to professional caregivers.

"It really creates a clear picture of someone (client). Where before you were speculating and making assumptions, now you have evidence, and as a result, you can perhaps take more targeted actions." [FG1]

"I think you can better understand underlying causes and maybe anticipate on certain situations. For example, if someone starts changing their behavior pattern, you may suspect

something is wrong. If you're able to predict such changes, this can support you in making the right care choices."[FG2]

Facilitate indication assessment

According to the professional caregivers, the smart monitoring system could facilitate the process of indication assessment. They expected the system provides valuable insight in lifestyle habits and self-care activities, as well as fall incidents and wander behavior, which are factors assessed when it comes to deciding on whether someone can maintain independent living or upscaling of care is required. Additional monitoring of safety issues like door sensors or fire and gas detectors is expected to further support the assessment process as safety is an important criterium. They indicated it might be also the case that clients can take better care of themselves as what professional caregivers initially thought.

"For instance for fall and wander detection, that are also criteria upon which decisions are made regarding the admission of a person (to a nursing home), when someone is wandering around and poses danger to themselves or others in their environment."[FG1]

"Also, it is about lifestyle, everyday things. In the case of people with dementia living at home, they often struggle with simple tasks like making a sandwich or a cup of coffee. They are no longer able to take care of themselves in those basic aspects, and that's where we focus on. [FG1]

Negative outcome expectations

Information overload

It was expected by professional caregivers that a smart monitoring system might cause information overload for both professional and informal caregivers. They indicated that professional caregivers can distinguish between relevant and irrelevant information but are concerned that informal caregivers would want to know everything and which might cause unnecessary burden or stress. Furthermore, they mentioned that receiving emergency notifications can also lead to a stress reaction for the informal caregiver. This is expected to require extra time and attention from the professional caregiver.

"*The main challenge is dealing with information overload. If I can´t filter it all, no matter how good the system is, it won´t work. It´s not just for us as professionals who have to oversee care, but also for informal caregivers, especially considering the emotional burden they already carry. It would simply be too much." [FG1]*

"We have to pay attention to informal caregivers, as this is also part of case management. So if something happens then we get a call from their mother. Then you have to slow people down from getting too involved in the situation. But it depends per person how they handle it. You have to tell them: 'you may know about everything but you don't always have to do anything with it'." [FG2]

Effort expectations

Interpretation of data

According to professional caregivers, they expected some issues with the interpretation of data, as they would not want the system to interpret everything, while manually reviewing all data themselves would be too time consuming. The professional caregivers suggested that interpretation of data by the system would be desirable, to a limited extent. This process might be different than what they are used to. To prevent any uncertainty regarding the data interpretation, it was suggested to have guidelines on how this process would work.

"Let's say you have 25 clients with dementia and you have to analyze their data, for one of them data regarding falls, the other one for showering, the other for medication, and one client for eating and drinking. Then you really won't have the time to do so. Then I would rather physically go there (to a client) as this would be much faster" [FG1]

"Maybe you would have a range of 'normal/standard values' and if the values are outside that range, or if that happens more often for example five times, that then the system provides a notification like: 'hey take a look at this'." [FG1]

Making agreements with informal caregivers

The professional caregivers expected that various issues need to be discussed together with informal caregivers. Professional and informal caregivers should make agreements about what activities to monitor, when to intervene, and who receives and acts upon which notifications. Also, this conversation might take place every once in a while, as the situation of the client changes over time.

"You should sit down together with the family, the client and nurses to see: 'those are normal behaviors what we observe, and this is what we want to avoid'. From there, you can start discussing. Then also, you can determine with when to take action. You can't provide care without having appropriate contact or involvement." [FG1]

"I think that is a good thing. We have to have that conversation and need to make a well-considered decision: 'which information is relevant to monitor'. I think in the beginning stadium of dementia it might be only eating and drinking behavior. But if you're approaching a possible admission (to a nursing home) then maybe everything becomes relevant. So we have to keep evaluating." [FG2]

Preconditions for implementation

Involvement in clinical reasoning

According to professional caregivers it is important they remain involved in the interpretation of data. It was suggested that the clinical reasoning of professional caregivers should not be completely replaced by the smart monitoring system, since there would always be a more subjective component involved.

"That gut feeling you have as a nurse with your clients, or the feeling you get during a conversation with a client is often very important. It provides more information than just the objective facts you observe. The sensor technology should not be intended to replace that intuition. Instead, it aims to make patterns visible without compromising the provision of care, it should really be a supportive system." [FG1]

Possibility to filter information

The professional caregivers indicated it is very important to have a possibility to filter the information according to what information is relevant for the care provision of the client. It was mentioned that it is important to only monitor information which is actually serving a goal.

"Because if there are more possibilities to monitor, more information to receive, then you want that all. But then you have to think about why? Why do you want to know all of that? What does that add?"[FG2]

Properly organized follow-up

Professional caregivers indicated the follow-up of the system should be organized adequately. It was mentioned that some sort of alarm system should be connected to the monitoring system in order to undertake immediate action in case of an emergency situation. However, it was acknowledged that there would be costs associated with this, which clients or informal caregivers should agree with in order to make use of such a service.

"It's important that the follow-up is properly arranged. You would need a connection with an alarm service, for urgent situations. But there would also be a payment for something like that. Because if we get a notification in the client dossier, there is a chance that we don't see it."[FG2]

Getting familiar with the technology

The professional caregivers mentioned the smart monitoring system should be easy to use and should be explained to professional caregivers in an understandable way. It was mentioned that a lot of professional caregivers are skeptical towards technological innovations as they do not have the experience or knowledge about these topics. Therefore, a trial period would be helpful as they can experience how to use the system themselves which contributes to acceptance.

"People working in healthcare are often very practical-minded, so they want to do something, try things out. If they can't feel, see or experience it, you already start with a disadvantage." [FG1]

4. Discussion

4.1 Main findings

In general, informal and professional caregivers were quite positive about a smart monitoring and communication system for home-dwelling older adults with cognitive impairment. Both informal and professional caregivers expected the system to facilitate making appropriate care decisions which fit the situation based on the information provided by the system. Informal caregivers expected the system to contribute to their peace of mind and a safer environment for their loved one. However, there were also some concerns expressed by both informal and professional caregivers, regarding possible information overload and substitution of the human aspect in care provision and the interpretation of data. Informal caregivers and professionals both acknowledged the importance of setting up the system together, to make agreements about the monitored activities and a communication and information flow. Also, they emphasized the importance of adjusting the system according to their own and the care receiver's needs. Informal caregivers experienced the user interface prototype mainly positive, as well as the use of most PSD features. However, for the PSD features reminder, suggestions & social learning the experiences were a bit mixed. Furthermore, some points of improvement were identified regarding the conceptual flow and visual design of the prototype.

4.2 Interpretation of results

The findings of this study indicate that both professional and informal caregivers recognize the value of a smart monitoring system as supportive tool in the care for home-dwelling older adults with cognitive impairment. It was suggested that the human perspective should always be incorporated in the data interpretation. Rather than relying solely on the system to interpret the monitoring data, the involvement of caregivers in data interpretation is considered crucial. Combining the strengths of technology with the insights and expertise of caregivers, a more comprehensive and effective care approach could be achieved. The interpretation of data by an algorithm and recognizing patterns and possibly predicting the behavior of the older adult with cognitive impairment has potential risks. There is always the possibility that the technology is not working sufficiently and misclassifies certain behavior patterns. As explained in an article on the progress, trends and risks of AI in healthcare, a potential concern is the overreliance of care providers on the system, which might lead to incorrect care choices (30). This would present an ethical issue regarding the accountability, since in such a situation one could question who is responsible and to what extent (30). To overcome this risk, education on how to use such a system, its capabilities and limitations would be useful. Additionally, there is a risk of bias when using AI in healthcare (30, 31). As the selection of training data impacts the learning of AI algorithms, it might be biased when predominantly representing a certain ethnicity or demographic characteristic (31). The AI algorithm may produce incorrect interpretations of data, which could lead to unfair outcomes (30, 31). This risk could be mitigated by ensuring a representative and inclusive trainings data set used for the AI algorithm, including data from a wide range of individuals with different demographic characteristics and backgrounds (31).

It is interesting that the participants were in general quite positive about the idea of using a smart monitoring system. A previous study into the concerns of patients towards the application of AI in healthcare showed that people are rather hesitant when it comes to this subject (32).

The study identified various concerns of patients regarding their safety, privacy and autonomy (32). It is remarkable that the study population of the current study was quite positive about the smart monitoring technology and its use of AI to recognize behavior patterns. This difference might be explained by the difference in study population, as the previous study focused on patients while the current study focused on caregivers. It might be that they have a different perspective as they were talking about the use of a smart monitoring system for the care recipient and it does not concern themselves. Also, this difference could possibly be explained by the involvement of the current study sample in previous research into the same topic and their experience with use of technological interventions in care provision (e.g. Caren platform). It would be assumable that they might have more interest in the topic of technology in healthcare than others. This could explain their positive and accepting nature towards the smart monitoring technology. A lot of people know little to nothing about how AI algorithms work, and consider AI as ‘black box’ (33). However, in this study, the concept of the smart monitoring system was explained using a video-prototype and providing additional explanation when necessary. The participants already had experience with technology and in general, people’s awareness about AI increases (32). Yet, there might be a difference between individuals in terms of understanding of AI. Previous research concluded that engaging and educating people about AI could contribute to their trust in AI, which is essential for successful implementation of AI technologies in healthcare (32, 33).

The results of this study show that the personal backgrounds and preferences of caregivers are of influence on the choices one would make regarding the monitoring of the care receiver. The travel distance to the care recipient could for example influence their choice on whether or not they wanted to receive an emergency call when a fall incident occurred. The participants valued the possibilities in the lo-fi user interface prototype to personalize the settings and change them to their preferences. They found it important that this could still be changed at any given moment in time. This findings emphasize the importance of an user-centered design approach, as the preferences of each individual can be very different according to their situation (17). UCD allows for increased usability as the designed application or platform better aligns with their expectations and needs (17, 34). The use of the personalization feature as included in the PSD theory, can enhance the usefulness of eHealth technologies such as the smart monitoring technology (17, 27), which is in line with the findings of this current study. Besides, this study showed the need for good collaboration, communication and consensus between different stakeholders involved on how to work with a smart monitoring system. For successful implementation of an eHealth technology it is important to consider perspectives and needs of different stakeholders involved (17). This user centered approach should be taken into account throughout the whole development and implementation process, contributing to the adoption of eHealth technologies (35). Also, the perspective of persons with cognitive impairment should be emphasized as they might have specific needs and requirements (35).

4.3 Study limitations

This study has some methodological limitations which should be considered when interpreting the results. First of all, the focus group data of the professional caregivers was analyzed by one researcher, which introduces the potential for researcher bias and subjectivity (36). For the individual interview data of informal caregivers, 50% of the data was independently coded by a second researcher, after which discussion took place and until consensus was reached. Furthermore, no data saturation was reached in this study as there was new information provided in all interviews. This indicates there might be additional themes which are not fully explored, implying the results of the study not to be exhaustive (36).

4.4 Implications for future research

For further research it would be interesting to perform a new iteration in the user centered design approach as this is an ongoing process (17). The outcomes of this research could be used as starting point to make improvements to the user interface prototype. A higher fidelity prototype of the user interface could be created and evaluated with both informal caregivers as well as professional caregivers, as this was not done in the current study. The professional caregivers might be able to provide better insight in what such a smart monitoring system would mean for them and their work once they have experienced a prototype of the communication platform. Also, this can contribute to ensuring that both sides of the communication platform, for the professional and informal caregiver, are well aligned with each other. The prototype could be tested during a trial period, in which the caregivers use and interact with the prototype. In such a study, both quantitative as well as qualitative data will be useful. Quantitative data, for instance the log-data on what functions and pages are used and in what manner, can provide insight into the flow of the prototype and the adherence of caregivers (17). Additional qualitative interview data can provide more insight into why the system is used (or not used) as intended (17). Furthermore, the creation of personas would be helpful in research, as there might be different types of desired end-users which can have different needs and requirements (17, 37). The personas could be based on characteristics such as caregiving experience, educational level, or need for cognition and can be created in a systematic way, by making use of a template (17, 37). The use of personas could provide insight into where these needs might conflict or are aligned with each other (17). 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 not only informal and professional caregivers, but also managers and policy advisors of care organizations.

4.5 Practical implications

For successful implementation of a complex eHealth intervention such as a smart monitoring and communication system for home-dwelling older adults a holistic design approach is required (e.g. CeHRes roadmap) (17). It is important to take into account different stakeholders such as informal and professional caregivers, patients, care organizations but also health insurers, governments and technology businesses. A useful approach would be business modelling as it provides insight into how value is generated and delivered to customers, which should be considered in order to bring the eHealth technology to the market (17). Implementation of a smart monitoring system would require guidelines and agreements on how to work with such a system. Caregivers should be educated on how to interact with the system, interpret and communicate the data. Attention should also be paid to rules and regulations regarding responsibility and privacy and data security (17). The European Union will introduce a new AI act, which aims to regulate the use of AI in EU countries to ensure better conditions for the development and use of AI technologies (38). Different rules will apply to different risk levels (38). The smart monitor system for older adults with cognitive impairment will probably fall under the category high risk and will be subjected to high degree of regulations (38). This is something which should be considered prior to development and implementation of this technology, and might have consequences for the extent and manner in which AI is applied.

4.6 Conclusion

Informal and professional caregivers of older adults with cognitive impairments overall had positive expectations regarding implementation of a smart monitoring and communication system. Yet, there were also some concerns identified. While they expect the use of such a system to contribute to the care decision making and to provide insight in the situation of the care recipient, information overload and loss of human aspect were perceived as risks. In order to successfully implement a smart monitoring system good communication and agreements between informal and professional caregivers and the care recipient are needed. This requires for 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 negative experiences and improvements suggested regarding the conceptual flow and visual design of the prototype. Personalization of the settings of the prototype was perceived highly valuable. The results of this study, especially the identified concerns, should be considered in the further development and implementation of a smart monitoring and communication system for home-dwelling older adults with cognitive impairments.

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Appendix 1: Information letter informal caregivers

Geachte heer/ mevrouw,

U bent misschien geïnteresseerd in deelname aan de studie "Langer thuis met dementie door innovatieve sensor technologie". In deze informatiebrief vindt u meer informatie over de studie en leggen wij uit wat deelname voor u betekent. Heeft u na het lezen van deze brief nog vragen, dan kunt u deze stellen aan de onderzoeker, mevr. Karen Grotenhuijs.
Onderaan deze brief vindt u haar contactgegevens. Wij willen u alvast hartelijk bedanken voor uw interesse.

Wat is het doel van de studie?
In samenwerking met Nederlandse ouderenzorginstellingen is de Universiteit Twente betrokken bij de ontwikkeling van technologische hulpmiddelen voor mantelzorgers van thuiswonende ouderen met dementie. De focus ligt hierbij op de ontwikkeling van innovatieve sensor technologie voor de thuisomgeving waarmee mantelzorgers ook op afstand een oogje in het zeil kunnen houden.
In 2022 heeft u meegedaan aan een vragenlijstonderzoek naar preferenties en behoeftes ten opzichte van dit soort technologie. Dit onderzoek heeft waardevolle kennis opgeleverd die wij hebben vertaald naar een eerste prototype van een monitoring platform voor mantelzorgers van thuiswonende ouderen met dementie.

In de huidige studie willen wij deze prototype graag aan u voorleggen (in de vorm van een video en plaatjes) en feedback verzamelen. Daarbij zijn wij vooral benieuwd naar vragen zoals: Wat vindt u van het prototype? Hebben wij de behoeftes van mantelzorgers adequaat vertaald naar het prototype? Wat zou u graag anders willen zien en waarom?
De resultaten zullen worden gebruikt voor de verdere ontwikkeling en verbetering van het prototype.

Wie kan mee doen?
Voor deze studie zoeken wij mantelzorgers die onbetaalde zorg/ hulp verlenen aan een naaste met dementie of geheugenklachten.

- De naaste met dementie/ geheugenklachten kan iemand zijn uit de familie, vriendenkring of buurt.
- De naaste met dementie/ geheugenklachten is 65 jaar of ouder en woont alleen thuis.

Ervaring met technologische hulpmiddelen is niet nodig.

Wie voert de studie uit?
De studie wordt uitgevoerd door de vakgroep Psychologie, Gezondheid & Technologie van de Universiteit Twente en maakt deel uit van een overkoepelend onderzoeksproject gefinancierd door de Europese Unie (ENTWINE informal care) en de Nederlandse organisatie voor gezondheidsonderzoek en zorginnovatie (ZonMw). De studie wordt geleid door dr.
Annemarie Braakman-Jansen, mevr. Nikita Sharma en dhr. Christian Wrede.

Wat houdt deelname in?
Wij zullen een gesprek met u inplannen op een moment dat u het beste uitkomt waarin wij de boven beschreven onderwerpen samen zullen bespreken. Het gesprek kan online of face- to-face plaatsvinden op Universiteit Twente, afhankelijk van uw voorkeur. Het gesprek zal ongeveer 1 uur duren en zal worden opgenomen met een audio-recorder om de analyse te vergemakkelijken.

Wat gebeurt er met mijn gegevens?
Al uw gegevens worden vertrouwelijk behandeld en alleen ten behoeve van onderzoek gebruikt. Om uw privacy te waarborgen worden uw antwoorden tijdens het gesprek apart van uw persoonlijke

gegevens bewaard. Voor wetenschappelijke rapporten zullen de gegevens nooit worden weergegeven in een vorm dat deze te herleiden zijn naar individuele personen. U blijft dus te allen tijde anoniem.

Compensatie voor deelname
Als dank zullen alle deelnemers na afloop van de studie via email een Bol.com cadeaubon ter waarde van 25 € ontvangen.

Hoe kunt u zich aanmelden?
Heeft u interesse om mee te doen? Dan kunt u zich aanmelden door een e-mail te sturen naar of te bellen met de uitvoerende onderzoeker, mevr. Karen Grotenhuijs:
e-mail: k.t.grotenhuijs@student.utwente.nl
Tel.:

Wij stellen uw medewerking zeer op prijs en hopen op uw steun.

Appendix 2: Information letter professional caregivers

Geachte heer/ mevrouw,

U bent misschien geïnteresseerd in deelname aan de focusgroep bijeenkomst “Innovatieve sensor technologie in de dementie thuiszorg”. In deze informatiebrief vindt u meer informatie over de studie en leggen wij uit wat deelname voor u betekent. Heeft u na het lezen van deze brief nog vragen, dan kunt u deze stellen aan de onderzoekers. Onderaan deze brief vindt u hun contactgegevens. Wij willen u alvast hartelijk bedanken voor uw interesse.

Wat is het doel van de focusgroep bijeenkomst?
In samenwerking met regionale ouderenzorginstellingen is de Universiteit Twente betrokken bij de ontwikkeling van technologische hulpmiddelen voor de dementie thuiszorg. De focus ligt hierbij op de ontwikkeling van niet-hinderlijke sensor technologie die cliënten met dementie a) in staat stelt om langer thuis te kunnen wonen en b) het zorgproces ondersteunt door een beter toezicht op welzijn en zelfzorg van cliënten met dementie. Wij hebben gedurende de laatste jaren onderzoek uitgevoerd onder thuiszorgprofessionals van o.a. Zorgcentrum de Posten, Liberein en Triviummeulenbeltzorg. Dit heeft belangrijke eisen opgeleverd waaraan sensor technologie moet voldoen.
Tijdens deze bijeenkomst willen wij de meest belangrijke resultaten graag aan u terugkoppelen en u van harte uitnodigen om met ons mee te denken over:

- Wat zijn randvoorwaarden voor implementatie van nieuwe sensor technologie in de dementie thuiszorg?
- Hoe kan de technologie optimaal aansluiten bij de werkwijze en zorg- en rapportage taken van thuiszorgprofessionals?
- Hoe kunnen wij mogelijke implementatie barrières overkomen?

Wie kan mee doen?
Voor deze focusgroep bijeenkomst zoeken wij zorgprofessionals (alle niveaus) die werkzaam zijn in de thuiszorg en zorg verlenen aan (onder andere) mensen met dementie. Ervaring met technologische hulpmiddelen is niet nodig.

Wie organiseert de focusgroep bijeenkomst?
De focusgroep bijeenkomst wordt georganiseerd door de vakgroep Psychologie, Gezondheid & Technologie van de Universiteit Twente en maakt deel uit van een overkoepelend onderzoeksproject gefinancierd door de Nederlandse organisatie voor gezondheidsonderzoek en zorginnovatie (ZonMw).

Wat houdt deelname in?
Wij zullen een bijeenkomst organiseren waarin wij met een kleine groep deelnemers (ca. 5- 6) de boven beschreven onderwerpen zullen bespreken. De bijeenkomst zal 1,5 uur duren en zal worden opgenomen met een audio-recorder om de analyse te vergemakkelijken. Al uw gegevens en antwoorden worden vertrouwelijk behandeld. Voor wetenschappelijke rapporten zullen de gegevens nooit worden weergegeven in een vorm dat deze te herleiden zijn naar individuele personen. U blijft dus te allen tijde anoniem.

Locatie en tijdstip van de focusgroep bijeenkomst
De bijeenkomst zal plaatsvinden op de Universiteit Twente (gebouw en kamer wordt z.s.m. bekend gemaakt). Wij zullen voor lekkere lunchbroodjes en dranken zorgen.

Compensatie voor deelname
Als dank zullen alle deelnemers na afloop van de bijeenkomst via email een Bol.com cadeaubon ter waarde van 25 € ontvangen.

Hoe kunt u zich aanmelden?
Heeft u interesse om mee te doen? Dan kunt u zich aanmelden door een email te sturen naar c.wrede@utwente.nl.
Voor vragen over de focusgroep bijeenkomst kunt u contact opnemen met:

Dhr. Christian Wrede
E-mail: c.wrede@utwente.nl
Tel.:

Mevr. Karen Grotenhuijs
E-mail: k.t.grotenhuijs@student.utwente.nl
Tel.:

Wij stellen uw medewerking zeer op prijs en hopen op uw steun.

Appendix 3: Interview guide individual interviews informal caregivers

Introductie

Ik zal beginnen met mijzelf voor te stellen: Ik ben Karen en studeer Health Sciences aan de Universiteit van Twente. Ik ben momenteel bezig met mijn scriptie onderzoek, vandaar dat u bent uitgenodigd voor dit gesprek.

Uitleg doel onderzoek en procedure

Het doel van dit onderzoek is te achterhalen hoe professionele zorgverleners en mantelzorgers denken over een smart monitor systeem om thuiswonende ouderen met dementie te monitoren. Het interview zal bestaan uit twee delen. Eerst zal ik een video laten zien waarin de smart monitor systeem wordt uitgelegd en zal ik u hier wat vragen over stellen. Het is de bedoeling dat aan dit systeem een communicatieplatform gekoppeld wordt, wat informatie over de situatie van uw naaste doorgeeft aan u als mantelzorger of een professionele zorgverlener. Daarom zal ik u vragen om een prototype voor een communicatieplatform uit te testen en heb ik ook hierbij wat vragen.

Vertrouwelijkheid en data

Alle informatie die u met mij deelt zal vertrouwelijk behandeld worden, dit betekent dat het niet terug te leiden zal zijn naar u als persoon. Gegevens worden veilig opgeslagen en zullen niet met andere partijen worden gedeeld. Gegevens zullen na afronding van het onderzoek worden verwijderd.

Audio opname

Ik zou graag een audio opname willen maken van het interview als u hiermee instemt. De audio opname wordt alleen gebruikt voor data-analyse doeleinden.

Duur van interview en vroegtijdig stoppen

De totale duur van het interview zal ongeveer 1 tot maximaal 1.5 uur zijn. Mocht u tijdens het interview een pauze willen of vroegtijdig willen stoppen dan is dit geen probleem en mag u dit gerust aangeven. Dit mag op elk moment tijdens het gesprek en u hoeft hier geen reden voor te geven.

Toestemming

Gaat u nog steeds akkoord met deelname aan het interview? Dan zou ik willen vragen dit formulier te ondertekenen.

Online interview: mondeling informed consent opgenomen door audio-recorders

In-person interview: geschreven informed consent formulier

Ondertekenen informed consent formulier
Opname apparatuur aanzetten

Achtergrond informatie

1. Geslacht: man/vrouw
2. Leeftijd van zorgvrager
3. Leeftijd mantelzorger
4. Aantal jaren mantelzorger:
5. Schatting aantal uren/week aan mantelzorgtaken
6. Welke mantelzorgtaken
7. Relatie tot zorgvrager
8. Diagnose zorgvrager
    a. Wanneer zijn de symptomen begonnen
9. Waar/hoe woont de zorgvrager
    a. Hoe ver bij mantelzorger vandaan?
10. Primaire mantelzorger?

    a. Andere mantelzorgers betrokken?
11. Aantal professionele zorgverleners betrokken
12. Gebruik van andere technologieën bij de zorgverlening?
    a. Monitor technologie
    b. Communicatie technologie (platform Caren)

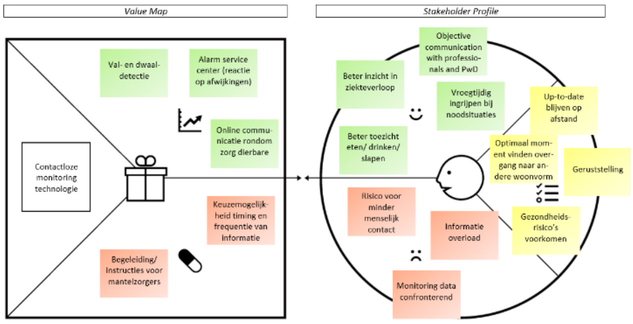
Video aanzetten en kijken

Onduidelijkheden
U heeft een video gezien waarin het smart monitor systeem wordt uitgelegd. Het systeem kan dus door gebruik te maken van Wi-Fi signalen, door de muren heen registreren welke activiteiten uw naaste uitvoert. Vervolgens kunt u en andere zorgverleners deze informatie binnenkrijgen op een app op uw telefoon. Zijn er naar aanleiding van deze video op dit moment nog vragen of onduidelijkheden over het smart monitor systeem?

Interviewvragen m.b.t. smart monitor systeem
Algemene indruk

1. Wat is uw algemene indruk van het smart monitor systeem zoals het is uitgelegd in het video prototype?
2. Hoe denkt u erover dat dit systeem op ieder moment plekken/activiteiten kan registreren?

Refining user profile (Christian)
Een eerder onderzoek onder mantelzorgers van thuiswonende ouderen met dementie heeft geresulteerd in een voorlopig gebruikersprofiel. Dit bevat een aantal voor- en nadelen t.o.v. monitoring technologie (rechts) en gewenste functionaliteiten (links). We zijn benieuwd in hoeverre u zich kan vinden in deze resultaten.



Stakeholder profile (rechts):

- In hoeverre kunt u zichzelf vinden in deze voordelen? Welke zijn het meest relevant voor u en waarom? Hebt u iets toe te voegen of wilt u iets veranderen?

Deze vragen gebruiken om door te vragen

- In hoeverre heeft dit systeem impact op uw zorgtaak als mantelzorger?
- In hoeverre beïnvloedt dit systeem uw rol binnen het netwerk van zorgverleners?
- Op welke manier zou het gebruik van het smart monitor systeem uw ervaren last/druk als mantelzorger kunnen beïnvloeden?
- Wanneer zou het systeem voor u peace of mind (gemoedsrust) met zich meebrengen?
- Op welke manier zou dit systeem volgens u het zelfstandig wonen van uw naaste kunnen beïnvloeden?

- In hoeverre kunt u zichzelf vinden in deze mogelijke nadelen? Welke zijn het meest relevant voor u en waarom? Hebt u iets toe te voegen of wilt u iets veranderen?
- Hoe denkt u dat het smart monitor systeem uw relatie met uw naaste kan beïnvloeden?

Value map (links):
Wij hebben de meest belangrijke voor- en nadelen t.o.v. monitoring technologie vertaald naar een aantal functionaliteiten (Deze benoemen):

- Zijn de functionaliteiten een goede vertaling van de meest belangrijke voor- en nadelen?

- Welke functionaliteiten zijn het meest belangrijk voor u en waarom? Hebt u iets toe te voegen of wilt u iets veranderen?
- Hoeveel euro (per maand) zou u bereid zijn om te betalen voor een dergelijk systeem?

Uitleg usability test
Dan gaan we nu verder met het testen van het prototype voor het communicatie platform. Het prototype is echt pas een eerste versie, dus echt alleen de basis van het communicatie platform. Ik heb u een link gestuurd waar u het prototype kan bekijken en door kan klikken. Het prototype bestaat uit een aantal schermpjes die u als mantelzorger in een app op uw telefoon zou kunnen ontvangen. Ik wil u straks vragen om deze schermpjes zo te behandelen alsof het een echte app zou zijn. Ik zal u een situatie voorleggen met een opdracht die u mag uitvoeren. U kunt hierbij geen fouten maken. Terwijl u dat doet, wil ik u vragen om alles wat u doet en denkt hardop te benoemen en ook eventuele suggesties te benoemen. Wij willen graag weten hoe we het systeem moeten aankleden en wat u nodig heeft in het systeem. Er is hierbij dus geen goed of fout, wij zijn enkel geïnteresseerd in uw ervaring en uw mening. U mag dus zeggen wat u wilt terwijl u de opdrachten uitvoert.

Usability test
Opdracht 1: login en voorkeuren aanpassen (tunneling and personalization)
Als eerste wil ik u vragen om in te loggen in de app en uw voorkeuren met betrekking tot het ontvangen van meldingen over acute / risicovolle situaties aan te geven.

1. Hoe denkt u over de mogelijkheden om uw voorkeuren aan te passen?
2. Wat vindt u van de manier waarop u door de schermpjes wordt geleid?

Opdracht 2: vallen (suggestion, reduction and tailoring)
Ik wil u nu graag een situatie voorleggen waarin uw naaste is gevallen. U ontvangt een telefoontje van het smart monitor systeem. U heeft het telefoontje niet beantwoord, dus het systeem stuurt u na 5 minuten een herinneringsmelding.

1. Wat is uw mening over het ontvangen van een direct telefoontje in een nood/acute situatie zoals een valincident? En wat vindt u ervan dat u daarna een melding krijgt in het geval dat u niet binnen 5 minuten reageert?
2. Denkt u dat het meerwaarde heeft/gunstig is om direct professionele zorgverleners op de hoogte te brengen?
3. Wat vindt u ervan dat het systeem u informatie geeft over de betrouwbaarheid van de gegevens en suggesties geeft voor welke acties u zou kunnen ondernemen?
4. Wat vindt u ervan om aan het systeem terug te koppelen in hoeverre de melding accuraat was (bv. valse alarm)?
5. Was er iets dat anders ging dan wat u had verwacht?

Opdracht 3: geagiteerd gedrag (reduction, suggestion, tailoring)
Ik wil u vragen om een situatie voor te stellen dat uw naaste de laatste tijd steeds vaker geïrriteerd of boos is. Ik wil u vragen om door de schermpjes te klikken en meer informatie op te vragen over dit gedrag van uw naaste.

1. Hoe denkt u over het krijgen van het gedetailleerde overzicht en de suggesties die het platform doet in deze situatie?
2. Wat vindt u van de mogelijkheid om deze informatie met een professionele zorgverlener te delen?
3. Wat had u van het systeem verwacht/willen zien in deze situatie?

Opdracht 4: zelfzorg activiteiten (personalization)

Er zijn ook bepaalde activiteiten/gedragingen die behoren tot ‘zelfzorg’. Dit kan bijvoorbeeld gaan om het onjuist innemen van medicatie, of dit compleet vergeten, of om eten, drinken en slaapgedrag. Ik wil u vragen om door de schermpjes te klikken en uw voorkeuren zo aan te passen dat u een melding krijgt van activiteiten/gedrag waar u zich zorgen om maakt als het om uw naaste gaat.

1. Wat denkt u van de mogelijkheden tot personalisatie (het aanpassen van uw voorkeuren) bij de zelfzorg activiteiten?
2. Wilt u hier nog wat aan toe voegen?

Opdracht 5: algemene systeem features – langdurig monitoren en social learning (social learning)
Zodra u de app opent komt u op het home-screen waar u een overzicht kan vinden van de huidige situatie van uw naaste en ook andere functionaliteiten van het systeem kan bekijken. Ik wil u vragen om het home-screen te bekijken en uit te proberen welke functies/pagina's het heeft.

1. Zou het voor u motiverend werken om ervaringen van andere mantelzorgers te lezen? Waarom wel/niet?
2. Wat vindt u van de mogelijkheid om over een langere periode te monitoren en hier een rapport/overzicht van te kunnen ontvangen?
3. Is er iets wat u nog wilt toevoegen?

Interview vragen m.b.t. user interface

1. Denkt u dat het makkelijk zou zijn om het systeem te gebruiken?
2. Zou u bereid zijn om een eigen bijdrage te betalen voor het gebruik van een dergelijk systeem?
3. Wat zijn volgens u goede en minder goede punten aan het prototype voor het communicatie platform?
    a. Hoe zou dit verbeterd kunnen worden?
4. Wat mist er volgens u nog aan de schermpjes van het communicatieplatform/prototype?
5. Welke pagina’s/functies vindt u overbodig of minder noodzakelijk?
6. Wat verwacht u verder nog van dit platform?
7. Zou u dit platform graag geïntegreerd zien met andere zorgplatforms zoals Caren?

Intention to use

1. Welke activiteiten moet het systeem volgens u sowieso kunnen registreren?
    a. Nood/acute situaties
    b. Zelfzorg activiteiten
    c. Waarom vindt u dit belangrijk?
2. Aan welke randvoorwaarden moet het systeem voldoen voor u om vertrouwen te hebben in het systeem?
    a. Waar moet het systeem voor u aan voldoen om veiligheid te garanderen?
    b. Waar moet het systeem aan voldoen om privacy te garanderen?

Afsluiting
Dan zijn we nu aan het einde gekomen van het interview. Zijn er nog dingen die u kwijt wil die nog niet aan bod zijn gekomen?
Zoals gezegd zullen gegevens vertrouwelijk worden behandeld en niet worden gedeeld met anderen. Ik zal nu het interview uittypen en de gegevens gaan analyseren. Deze informatie zal worden gebruikt om het systeem te verbeteren en zo in te richten zodat de eindgebruikers er wat aan hebben.
Ik wil u bedanken voor deelname aan het onderzoek. Mocht u achteraf toch nog vragen hebben dan kunt u mij altijd bereiken via de mail of telefonisch. U krijgt binnenkort een bol.com waardebon toegestuurd via de mail als bedankje voor uw deelname.

Einde formatieve evaluatie
Opname apparatuur afsluiten

Appendix 4: Informed consent form informal caregivers

Toestemmingsformulier (informed consent)

Hierbij verklaar ik dat ik duidelijk ben geïnformeerd over de studie 'Langer thuis met dementie door innovatieve sensor technologie. Ik doe op vrijwillige basis mee aan dit onderzoek. Ik heb het recht om af te zien van deelname aan het onderzoek zonder hiervoor enige reden te hoeven geven. Ik ben ervan bewust dat ik mij op elk moment mag terugtrekken uit het onderzoek. Mijn onderzoeksresultaten worden compleet anoniem gemaakt wanneer ze worden gebruikt in wetenschappelijke publicaties. Mijn persoonlijke data zal niet aan derde partijen worden verstrekt zonder mijn toestemming.

Als ik verder nog informatie wil ontvangen over het onderzoek, nu of in de toekomst, mag ik contact opnemen met de betrokken onderzoekers (Karen Grotenhuijs: k.t.grotenhuijs@student.utwente.nl, Nikita Sharma: n.sharma@utwente.nl, Christian Wrede: c.wrede@utwente.nl).

Ik geef toestemming voor deelname aan dit onderzoek:

Naam: ……………………………………

Datum: …………………………………… Handtekening: ……………………………………

Appendix 5: Interview guide focus groups professional caregivers

Welkom (slide 1)
Van harte welkom bij deze bijeenkomst en bedankt voor uw bereidheid om deel te nemen aan dit onderzoek. Ik zal beginnen met mijzelf voor te stellen: Ik ben Karen en studeer Health Sciences aan de Universiteit van Twente. Ik ben momenteel bezig met mijn scriptie onderzoek.

Ons project (slide 2)
Het centrale thema binnen dit project is: Langer thuis met dementie: Hoe kunnen wij ervoor zorgen dat mensen met dementie zo lang mogelijk zelfstandig en veilig thuis kunnen blijven wonen, terwijl de zorglast van mantelzorgers en zorgprofessionals niet ondragelijk wordt?
Dit vraagt om innovatieve oplossingen. De focus binnen ons project ligt op de ontwikkeling van niet-hinderlijke monitoring technologie voor de thuissituatie die het thuis blijven wonen kan optimaliseren en mantelzorgers en thuiszorgprofessionals ondersteuning kan bieden. Dit vooral door een beter toezicht op gedrag, welzijn en veiligheid van een bewoner met dementie.

Doel van bijeenkomst (slide 3)
Wij hebben gedurende de laatste jaren onderzoek uitgevoerd onder thuiszorgprofessionals van o.a. Zorgcentrum de Posten, Liberein en Triviummeulenbeltzorg. Dit heeft belangrijke eisen opgeleverd waaraan sensor technologie moet voldoen.
Tijdens deze bijeenkomst willen wij de meest belangrijke resultaten graag aan u terugkoppelen en u van harte uitnodigen om met ons mee te denken over:

- Wat zijn randvoorwaarden voor implementatie van nieuwe sensor technologie in de dementie thuiszorg?
- Hoe kan de technologie optimaal aansluiten bij de werkwijze en zorg- en rapportage taken van thuiszorgprofessionals?
- Hoe kunnen wij mogelijke implementatie barrières overkomen?

Uw perspectief als zorgprofessional is van belang omdat wij technologie willen ontwikkelen die aansluit bij uw wensen en behoeftes. Wij stellen het daarom zeer op prijs dat u graag met ons mee zou willen denken.

Algemene zaken (slide 4)
Tijdens deze bijeenkomst zullen wij een aantal onderwerpen stap voor stap met u willen behandelen. Wij willen hierbij graag ook een aantal zaken benadrukken:

- Er zijn geen goede of verkeerde antwoorden, wij gaan ervan uit dat we veel verschillende meningen te horen krijgen.
- Als u iemand anders wilt aanvullen, als u het ergens mee eens bent of juist niet, of als u een voorbeeld wilt geven, u bent vrij om dat te doen.
- Vanwege de tijd hebben we vandaag een strakke planning. Dit betekent dat wij soms wellicht een interessante discussie moeten afkappen, omwille van de tijd. Wij gaan natuurlijk wel ons best doen om u allemaal de kans te geven om iets te zeggen.
- Om geen enkele opmerking te missen zouden wij de discussie graag op willen nemen. Echter, er zullen geen namen worden genoteerd in de gespreksverslagen, en er zal ook geen deelnemerslijst worden weergegeven in het eindrapport, dus uw opmerkingen blijven altijd vertrouwelijk.

Informed consent + opname starten (slide 5)

- Tekenen informed consent
- Achtergrond vragenlijst invullen
- Opname starten

Voorstelronde (slide 6)

Voordat wij verder gaan, zouden wij graag eerst een snelle voorstelronde doen waarin u even aangeeft wat uw naam is en wat uw functie is.

Uitleg smart monitor systeem (slide 7)

Wij zullen beginnen met een korte toelichting over het smart monitor systeem dat momenteel in ontwikkeling is. Hiervoor hebben wij een korte video gemaakt.

Video laten zien (4 min)

U heeft de video gezien waarin het smart monitor systeem wordt uitgelegd. Het systeem kan dus door gebruik te maken van Wi-Fi signalen, door de muren heen registreren welke activiteiten een cliënt thuis uitvoert. Vervolgens kunnen u en andere zorgverleners of mantelzorgers deze informatie binnenkrijgen op een app op uw telefoon/tablet. Zijn er naar aanleiding van deze video op dit moment nog vragen of onduidelijkheden over het smart monitor systeem?

User profile

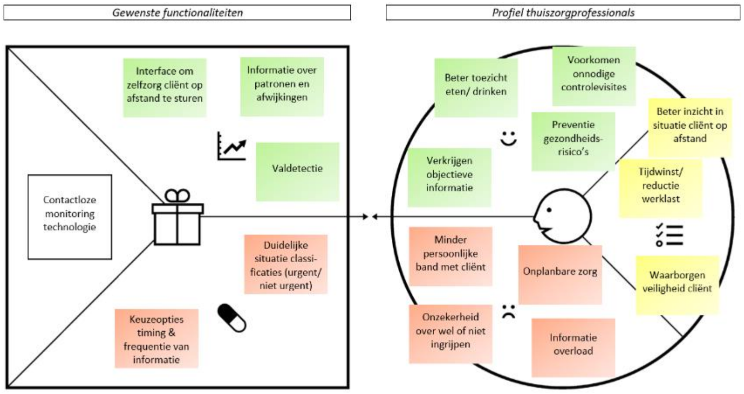
Algemene indruk (slide 8)

1. Wat is uw algemene indruk van het smart monitor systeem zoals het is uitgelegd in de video?
2. Hoe denkt u erover dat dit systeem op ieder moment plekken/activiteiten kan registreren?

Gebruikersprofiel (slide 9)

In de volgende stap willen wij graag inzoomen op het gebruikersprofiel, wat onze basis is voor ontwikkeling van nieuwe monitoring technologie. Wij hebben in 2021 onderzoek uitgevoerd onder verschillende belanghebbenden van monitoring technologie. Dit onderzoek heeft onder andere ook een voorlopig gebruikersprofiel opgeleverd voor de thuiszorgprofessional.

Dit bevat de meest belangrijke voor- en nadelen t.o.v. monitoring technologie (wat u aan de rechte kan kunt zien) en een aantal gewenste functionaliteiten (wat u aan de linke kant kunt zien). We zijn vooral benieuwd in hoeverre u zich kan vinden in deze resultaten.



Voordelen

Als wij naar de rechte kant van de figuur kijken, dan staan er in de groene vakjes een aantal verwachte voordelen of opbrengsten.

1. Ziet u een voordeel staan die u zelf het meest belangrijk vindt in uw werk als zorgprofessional? (toelichting?)
2. Ziet u ook een voordeel staan die misschien wat minder of helemaal niet belangrijk is voor u? (toelichting?)
3. Zijn er andere voordelen die het monitoring systeem voor uw zou moeten opleveren die hier nog niet tussen staan? Zo ja, welke?

Nadelen

Aan de rechte kant van de figuur ziet u ook een aantal rode vakjes waarop een aantal mogelijke nadelen of risico's staan t.o.v. monitoring technologie.

1. Ziet u een nadeel staan die u zelf het meest relevant vindt in uw werk als zorgprofessional? (toelichting?)
2. Ziet u ook een nadeel staan die misschien wat minder of helemaal niet relevant is voor u? (toelichting?)
3. Zijn er andere risico's voor u die u relevant vindt maar die hier nog niet tussen staan? Zo ja, welke?

Welk label zou u op het systeem plaatsen: wat moet het voor u opleveren in één woord?
Op welke manier zou de inzet van het smart monitor systeem een invloed hebben op uw job satisfaction?

Gewenste functionaliteiten
Wij hebben de meest belangrijke voor- en nadelen van monitoring technologie in een eerdere studie onder thuiszorgprofessionals vertaald naar een aantal functionaliteiten van het systeem. Dit ziet u aan de linker kan van de figuur.

1. Welke van deze functionaliteiten vindt u als zorgprofessional het meest en minst belangrijk en waarom?
2. Zou u graag een andere functionaliteit toevoegen die u voor uw werk belangrijk zou vinden maar die hier nog niet tussen staat? Zo ja, welke?

3. Welke informatie of activiteiten moet het systeem volgens u sowieso kunnen registreren? En waarom?
    a. Zelfzorg activiteiten
    b. Acute/risicovolle situaties
4. Welke functies moet het communicatie platform hebben volgens u?
    a. Welke informatie moet sowieso naar u worden doorgestuurd? En welke informatie juist niet?
5. Aan welke randvoorwaarden moet het systeem voldoen voor u om vertrouwen te hebben in het systeem?
    a. Waar moet het systeem voor u aan voldoen om veiligheid te garanderen?
    b. Waar moet het systeem aan voldoen om privacy te garanderen?

Implementatie (slide 10)
In het volgende gedeelte willen wij graag samen met u nadenken over wat er nodig is voor succesvolle implementatie van een smart monitor systeem in de dementie thuiszorg. Wij nemen hierbij het perspectief van de thuiszorgorganisatie welke de smart monitoring technologie wil aanbieden aan thuiswonende cliënten met dementie.

Kernactiviteiten & mensen en middelen

1. Welke activiteiten moet uw thuiszorgorganisatie uitvoeren om smart monitoring technologie succesvol te implementeren?
    a. Wat is nodig om de technologie optimaal te laten aansluiten bij de huidige werkwijze/ routines van thuiszorgprofessionals?
        i. Bv. nieuwe manier van data-gedreven werken: Van gepland naar flexiebel: Hoe haalbaar/ gewenst is dit? Hoe omgaan met meer onplanbare zorg als gevolg van real-time monitoring informatie?
        ii. Hoe omgaan met verhoogde transparantie van de zorgverlening door monitoring informatie? Bang om verantwoordelijk te worden gehouden voor foute beslissingen obv de data?
    b. Hoe kan de technologie optimaal aansluiten bij de bestaande ICT-structuur in de thuiszorg? Zijn er koppelingen nodig (bv. met bestaande rapportage systemen/ ECD)?

   c. Welke services om de technologie heen zijn eventueel nodig? (Training? Mogelijkheid om uit te proberen? Technische support/ onderhoud service?)
   d. Welke mensen en middelen (resources) zijn nodig om de technologie goed te kunnen implementeren? Denk bv. aan beschikbaar personeel of kennis over wet- en regelgeving of bepaalde vaardigheden die thuiszorgprofessionals moeten hebben.

Eindgebruikers

1. Welke cliënten zijn volgens u het meest geschikt voor een smart monitor systeem thuis? Wanneer is het juiste moment voor inzet van de technologie in het ziektetraject?
2. Wat vindt u ervan dat dit systeem nog meer informatie en details geeft over de situatie van de cliënt? Wat vindt u ervan dat de mantelzorger deze informatie ook ontvangt?
3. Hoe vind je een acceptabele balans tussen cliënt veiligheid waarborgen en mogelijke inbreuk op privacy?

Kanalen & eindgebruikers relatie

1. Via welke weg zou een smart monitor systeem het beste geïntroduceerd moeten worden? Bv. primair via de thuiszorg? Of direct verkopen aan de mantelzorger en client als een off-the-shelf device (dus ook aan clienten die geen thuiszorg ontvangen?
2. Kan een smart monitor systeem van invloed zijn op de relatie met uw cliënten? Hoe zou u de ideale relatie met een client die gebruikt maakt van een smart monitor systeem beschrijven?

Inkomsten/ bekostiging

1. Wie heeft volgens u het grootste voordeel van de inzet van een smart monitor systeem? (De client? De mantelzorger? De thuiszorg? Andere zorgsectoren?)
   a. Wie zou u mee laten betalen voor de inzet van de technologie en waarom? En in welke vorm?
2. Zou de technologie volgens u in bestaande bekostigingsstructuren (zorgverzekering, WLZ, WMO) ingebed moeten/kunnen worden? Zo ja, hoe?

Toolkit website (slide 11)

Wij hebben in ons project de laatste jaren veel onderzoek gedaan naar monitoring technologie ter ondersteuning van het langer thuis wonen van mensen met dementie. Dit heeft kennis opgeleverd over wat er nodig is van de technologie zelf maar ook wat er nodig is voor succesvolle implementatie (zie ook de figuur op de slides).

Als onderzoekers publiceren wij vooral in wetenschappelijke tijdschriften, maar wij vinden het belangrijk dat relevante kennis ook in de praktijk gebruikt kan worden. Wij willen daarom de projectresultaten graag vertalen naar concrete aanbevelingen die makkelijk te gebruiken zijn door een brede groep van ontwikkelaars, beleidsadviseurs zorgtechnologie en (indien van toepassing) ook zorgprofessionals. Wij zijn van plan om hiervoor een toolkit website (kennisproduct) te maken.

- Waar zou zo een website/kennisproduct volgens u aan moeten voldoen (qua inhoud en vorm)?
- Wat kenmerkt volgens u een goed/ bruikbaar online kennisproduct?

Vragen & bedanken(slide 12)

Dan zijn we aan het einde gekomen van deze bijeenkomst. Zijn er nog vragen of opmerkingen over wat we vandaag hebben gedaan en besproken? Wij willen u allemaal heel hartelijk bedanken voor uw medewerking! Uw antwoorden zullen anoniem geanalyseerd worden en in combinatie met andere focusgroep sessies zal ons dit helpen bij het opstellen van randvoorwaarden voor de implementatie van innovatieve monitoring technologie die bij kan dragen aan een betere zorgondersteuning. Mocht u achteraf toch nog vragen hebben dan kunt u ons altijd bereiken via de mail of telefonisch. U krijgt binnenkort een bol.com waardebon toegestuurd via de mail als bedankje voor uw deelname.

Appendix 6: Informed consent form professional caregivers

Toestemmingsformulier (informed consent)

Titel onderzoek:	Innovatieve sensor technologie in de dementie thuiszorg
Onderzoeksteam:	Christian Wrede, MSc./ Karen Grotenhuijs, BSc./ Dr. Annemarie Braakman Jansen/ Prof. dr. Lisette van Gemert-Pijnen Afdeling Psychologie, Gezondheid & Technologie Universiteit Twente, Enschede
Contact:	c.wrede@utwente.nl (Tel:...) k.t.grotenhuijs@student.utwente.nl (Tel:...)

In te vullen door de deelnemer

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode en het doel van het onderzoek. Ik weet dat mijn antwoorden tijdens het onderzoek vertrouwelijk worden behandeld en niet aan derde partijen worden verstrekt zonder mijn toestemming. Mijn antwoorden zullen uitsluitend voor analyse en/of wetenschappelijke publicaties worden gebruikt waarbij gegevens nooit te herleiden zullen zijn naar individuele personen.
Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgaaf van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam deelnemer: …………………………………………………………………………..

Datum: …………………..   Handtekening deelnemer: …..…………………………………

In te vullen door de uitvoerende onderzoeker

Ik heb een mondelinge en/of schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker: …………………………………………………………………………..

Datum: …………………..   Handtekening onderzoeker: ..……………………………………

Appendix 7: Background questionnaire professional caregivers

Vragenlijst achtergrondgegevens

(Voor)naam deelnemer: ____________________________

1. Wat is uw leeftijd (in jaren)? ________
2. Wat is uw geslacht?
    a. mannelijk
    b. vrouwelijk
    c. anders
3. Hoeveel jaren werkervaring hebt u in uw huidige baan? ________
4. Wat is uw functie?
    a. Verzorgende niv. 2
    b. Verzorgende niv. 3
    c. Verzorgende niv. 3 IG
    d. Verpleegkundige niv. 4
    e. Verpleegkundige niv. 5
    f. Casemanager dementie
5. Voor welke zorginstelling bent u werkzaam? ________________
6. Hoeveel uren gemiddeld per week verleent u zorg aan thuiswonende cliënten met dementie (zorgcontacturen)? ________

Zou u een terugkoppeling van de resultaten willen ontvangen? Zo ja, dan kunt u hieronder uw e-mailadres voor ons achterlaten:

____

Zouden wij u mogen benaderen voor mogelijk toekomstig onderzoek? Zo ja, dan kunt u hieronder uw e-mailadres voor ons achterlaten:

____