Requirements for disseminating sensing information to caregivers of persons with dementia.

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Abstract

Sensing technology could significantly improve the current infrastructure for elderly care by enabling care at a distance. State-of-the-art sensing solutions can detect various physical, physiological and emotional behaviour of a person, which could also be applied in elderly care. To effectively implement these solutions in elderly care, challenges in implementation and technological development need to be considered. One such challenge is disseminating the information gathered by sensing systems to the caregivers according to their needs. For that, this research aims to identify the needs and values of the elderlies and (in)formal caregivers towards a communication platform disseminating information obtained by the sensing systems. An exploratory literature review followed by focus group/interviews was conducted with elderlies and (in)formal caregivers to identify these needs and values. Based on these interviews/focus groups, value proposition maps encompassing the needs, pains and gains from such a system were developed. Further, by inductive analysis, perceptions of the system and data collection were summarised, and seven system attributes were generated.

Keywords

Sensing Systems; elderly care; eHealth; informational needs; caregivers.

1.   Introduction

1.1. Ageing society

As the average life expectancy in the world continues to grow and the birth rate declines, the burden on the healthcare sector, especially for elderly care, has increased significantly [1]. The WHO states that the number of elderly is projected to rise 34% by 2030. This number will be double by 2050 [2]. The elderly population growth will increase the demand for both formal and informal caregivers [3]. On top of this, most elderly wish to stay at home for as long as possible. Especially in cases of people diagnosed with a form of dementia, extended living at home in familiar surroundings can positively impact the quality of their life [4]. However, as more elderly wish to stay at home for extended periods of time, formal caregivers receive more clients to care for, and informal caregivers become increasingly prone to emotional, mental and physical imbalance. In such situations, sensor-based home care technology has a significant potential to relieve pressure on caregivers without compromising the quality of care [5].

1.2. Sensor-based home care

Alongside the rapid development of sensor-based home care technology, a significant step is to effectively and efficiently ensure the bi-directional information flow, i.e. from sensing systems to and from (in)formal caregivers [6] [7]. At the moment, many IT solutions such as web and mobile platforms for information dissemination exist, but for elderly care, they should be tailored to the needs of stakeholders. Hence, to facilitate the implementation of sensor-based home care technology in elderly care, it is essential to outline involved stakeholders' possible needs and values towards a communication platform for effective and efficient information dissemination.

2.   Problem statement

This paper, therefore, sets out to investigate the following research questions:

RQ: What are the needs and values of elderlies and (in)formal caregivers towards a communication platform disseminating information obtained by sensing systems for facilitating the care of a person with Dementia (PwD)?

3.   Related works

The current body of literature on IT-based communication platforms is analysed to obtain a preliminary understanding of the requirements of (in)formal caregivers and the elderly. For that, research papers containing a combination of the keywords or derivatives listed in Table 1 within a period between 2000 and 2021 were used.

Table 1: List of combinations of keywords for literature review

Keywords
Coaching OR Online OR Digital
Communica* OR information
Platform OR Technolog* OR System* OR Design*
formal OR informal W/3 caregivers
Elder* OR Care OR Support

From this search, 24 papers describing IT solutions for caregivers of PwD or people with dementia were reviewed. These 24 papers were analysed to identify types of information systems, motivation towards their use and perceived benefits and concerns for the systems.

Based on trends observed in these 24 papers, three major types of systems that are or have been implemented in elderly care: Information, interaction and monitoring platforms were identified.

Information systems are referred to as systems or web platforms that provide caregivers and the elderly with valuable and up-to-date information on the trajectory of the PwD or procedures and sources of aid related to dementia/Alzheimer's disease. For example, the "elderly care information resource locator" module by Wopung & Guha et al. [8]. *Interaction systems* allow users to share experiences and discuss topics relevant to dementia/Alzheimer's disease to find support and gain new knowledge or relieve pressure. For example, the "Virtual

Healthcare Neighborhood Technology Project" allows informal caregivers to share experiences with other (in)formal caregivers [4]. *Monitoring systems* are systems capable of monitoring the well-being of the person with dementia/Alzheimer's Disease and possibly informing corresponding caregivers of that well-being. It is essential to make a distinction between two types of monitoring systems, *active (foreground) and passive (background)[4]*. Active monitoring systems require interaction with the PwD to assess well-being, usually in the form of a daily series of health, activity and emotion-related questions. Passive systems incorporate the use of various sensors and sensing technology to classify behaviour and anomalies.

Passive monitoring can be both obtrusive through on-body or wearable sensing devices [9] or unobtrusive through the inclusion of sensors in the environment and hence more desirable. Lastly, it is worth noting that systems may also not belong to one category exclusively. For example, within a system, various modules of interaction, information modules and monitoring can be combined if desired by the system's users (e.g. caregivers or elderly) [10].

3.1. Motivation and benefits of communication systems

Starting with the formal caregivers of PwD, the main identifiable benefits coincide with a recent shift from task-oriented care to relationship-oriented care [11].

Nevertheless, formal caregivers' added workload and routine tasks today reduce the time available for establishing relations. Interaction or monitoring platforms that monitor or assess the emotional state of the elderlies thus play an essential role. A system that can assist formal caregivers by providing them with brief overviews of the needs of the PwD enables the caregivers in providing efficient, personalised and effective care [12].

Perhaps the most significant benefits can be identified among informal caregivers of PwD. Often, their primary motivation for the sensing systems originates from the desire for reassurance on the well-being of PwD while staying at a distance from their loved ones [13]. In such scenarios, effective communication systems disseminating information of sensing systems could help informal caregivers attain the feeling of reassurance and alert them when required.

State-of-the-art sensing systems can monitor the extent of the cognitive decline, which can help determine the onset of dementia. Research highlights the need for technologies that can predict and communicate a possible future state of the PwD [14]. Another valued service for current communication platforms is the opportunity for informal caregivers to easily access verified information and ask advice from professionals and other users[8] [15]. It is also observed that informal caregivers use interaction systems to find support among people in the same situation or exchange experiences or emotions [4].

Finally, for the person with Alzheimer's Disease, there are three considerable benefits for implementing eHealth technologies, specifically for sensing systems. The systems enables a PwD to continue living in familiar surroundings for an extended period without limiting the safety of the PwD and burdening the caregivers. In addition to this, assisted living systems and monitoring systems combined with caregiver supervision and a

fitting way of providing feedback can help them function better in daily life tasks (e.g. keeping up to date with calendars and lists). [13].

3.2. Concerns towards communication systems

The most prominent concerns for IT-based systems are ethical, privacy-related and economic. Generally, caregivers could experience information overload if the information dissemination is not appropriately structured according to their needs. For digitally lagging caregivers, training, usability and motivation barriers often hinder the use of sensing systems [16].

Another concerning aspect is that the obtained information can also be used by management staff and informal caregivers to monitor the actions of the formal caregivers [13]. Whereas sensing technologies and other eHealth solutions might be reassuring to most informal caregivers, these technologies create cyber dependencies for both caregivers and the elderly. When the systems become outdated or replaced by different ones, the cyber dependency might cause significant problems for the PwD and caregivers [17].

In addition to this, the rising prices of assisted living technologies (such as the Alzheimer clock) create resistance among some informal caregivers as they feel that the added functionality does not justify the additional price increase [13].

Finally, for PwDs, there are a few concerns that should be taken into account. Inclusions of unobtrusive sensing systems in elderly care could lead to de-humanisation of the provided care as well as that it might impede the privacy and autonomy of the PwD (due to security breaches) [18]. For interaction systems, older adults have generally expressed their difficulty operating and engaging with the system, causing additional strain on successful implementation of the systems [19].

4. Methods

A qualitative research approach was taken from the first phase of the double diamond approach (figure 1), aimed to discover the informational needs of the various stakeholders and explore the impact of current information disseminating systems in elderly care [20]. The double diamond approach is a frequently used method for exploring issues both widely and deeply. This method was then combined with the CeHRes roadmap to structure the process of developing information disseminating requirements from contextual inquiries [21].

The Ethics Committee of the University of Twente (Behavioural, Management, and Social Sciences) provided ethical approval for this study. All participants signed the consent form before participating in the study.

Figure 1: Double Diamond methods
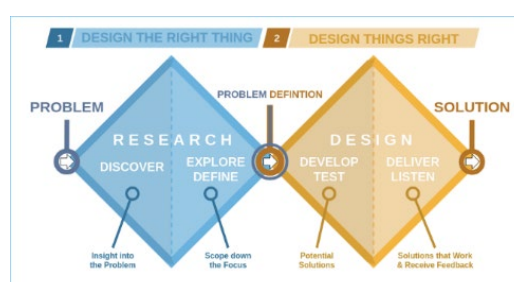
4.1. Participants
4.1.1. Informal caregivers

Informal caregivers were approached for the focus group if they are or were providing unpaid care to a relative, friend or partner diagnosed with a type of dementia.

An initial information mail was sent to a wide range of eligible participants (n=58) retrieved from an earlier study on Information Systems and persons with Alzheimer's Disease. In case the participants were interested, they were asked to provide their contact details. In addition, the informal caregivers were sent a more detailed description of the study, a consent form, and a date selection tool. In total, two informal caregivers of ages between 40 and 60 participated.

4.1.2. Formal caregivers

The formal caregivers were included in the research if they provide paid services, management or care to a group of clients, including people with forms of dementia. Formal caregivers were contacted through various elderly care organisations situated in the east of the Netherlands and provided a brief explanation of the focus group. From several organisations, three formal caregivers had indicated their interest in participation. The group was provided with additional information on the research along with a consent form for participation. In total, three formal caregivers between the age of 30 to 50 have participated in the second focus group.

4.1.3. Elderly

Given the COVID-19 situation, approaching eligible elderly participants was challenging. Hence, the inclusion criteria for the elderly were expanded. As a result, multiple categories of elderly participants can be defined:

- Elderly without any impairment (n=2)
- Elderly with dementia (n=1)
- Elderly acting as formal caregivers to a PwD (n=2)

The elderly with an affiliation to the interviewer were approached and indicated to be open for participation. They were provided with an initial explanation of the research contents, after which they were asked to fill in a consent form. In the end, five participants between the age of 70 and 85 participated.

4.2. Interview design
4.2.1. Focus groups

The focus groups aimed to identify the values and needs followed by determining the information communication needs of the interviewed stakeholders. Both formal and informal caregivers were asked similar open-ended questions to minimise framing and maximise information gain. Participants in each focus group were first asked about their current problems in the care that they provide. Afterwards, the participants were introduced to unobtrusive sensing systems through a couple of graphics. In the second section, the participants were asked about their ideas for successful communication, their current information acquisition methods, and their ideal form of interaction with the communication system (e.g. types of notifications, frequency of communication and message structure).

4.2.2. Elderly interviews

To extract the perspective of elderlies towards unobtrusive sensing and communication systems, the participants were informed about the workings of the system through infographics and black-box representations. Through a complementary card game, types of sensing information were discussed, and in doing so, a complete picture of the needs and requirements of elderlies towards sensing systems was aimed to be gathered.

4.3. Data analysis

The audio recordings from all sessions were transcribed, after which every session was individually analysed through content analysis. The transcripts were first characterised into sections relating to (1) perceived benefits of unobtrusive sensing, (2) perceived concerns towards unobtrusive sensing, (3) monitoring applications for unobtrusive sensing or (4) informational disseminating requirements for unobtrusive sensing systems. Themes and groups of recurring characteristics were identified, grouped and coded. After coding comparison, a value proposition map was created for each stakeholder. The sessions were then compared and contrasted with each other based on a summary of the key points of each session. To avoid reader bias, the transcripts were all individually coded by the researcher and supervisor independently and afterwards discussed and compared to reach a consensus on the key points of each session.

The key points and findings from related works were then used to create a structured framework for information disseminating requirements of unobtrusive monitoring systems.

5. Results

A set of possible user requirements were identified for formal caregivers, informal caregivers and the elderly. Following this, the respective user pains (situations in which user requirements are not satisfied) and respective user gains (situations in which user requirements are satisfied) were listed using the value proposition map. Additionally, corresponding requirements for all stakeholders were defined. The below section further elaborates on the findings from the focus groups and interviews.

5.1. Requirements caregivers
5.1.1. Formal caregivers

Formal caregivers are predominantly concerned with providing the best possible forms of care (Table 2). Increased pressure on the elderly care sector requires them to work more efficiently and effectively. Besides that, formal caregivers are often in close contact with other stakeholders of the PwD to discuss observations and well-being. For formal caregivers, a significant amount of time is spent on other things than caring – i.e. administration, communication, and control visits, often through various communicative and administrative channels. Additionally, beyond planned visits, there is no way for formal caregivers to determine the well-being of the PwD. Hence, a communication platform should be provided that enables the formal caregiver to gain improved insights into the well-being of the PwD, along with a centralised place to store and share information with trusted users.

5.1.2. Informal caregivers

The primary role of the informal caregivers is to ensure the well-being of the PwD (outside of planned care) and by

arranging adequate care for the PwD (Table 2). Additionally, the group of informal caregivers (usually children and relatives) play a role in assessing the needs of the PwD. However, informal caregivers are often occupied with their day-to-day tasks and caring for their own family. Hence, there are limited opportunities for visits, and thus no reassurance on the well-being of moments outside the visits can be found. In addition, informal caregivers are often not familiar with the elderly care system, such that they have to spend much time comparing care plans and technologies to find the most suitable one for their situation.

Due to the limited insights into incidental and structural issues of the PwD, their ability to find suitable solutions is often even more challenging. Informal caregivers would benefit significantly from additional guidance in the elderly care system and through a means to monitor the PwD remotely. Nevertheless, the informal caregiver should also be able to balance the guidance and monitoring information to ensure a healthy work-life balance (Table 2).

5.2. Requirements elderly
5.2.1. Elderly with Dementia (PwD)
Persons with dementia constantly have to deal with their condition. Often, they tend to follow daily routines to feel useful in society. It is often crucial for them not to sit idle and stay connected to the world and their people. Additionally, the elderly with dementia often find it essential to stay in familiar surroundings for as long as possible without putting too much

strain on friends and family to look after them. Their most significant gains can hence be created in providing structure and a clear means to convey this structure in a communication platform. Additionally, a system should ensure safety and include the PwD into society (Table 3).

5.2.2. Elderly without impairment
For the elderly without impairments, it is challenging to envision a situation in which they would need a sensing system and related communication platform simply because they can still function in society by themselves. They value their privacy and feel no need for observation. To them, if a system should be implemented at all, it should be helpful to improve and support comfortable daily living (Table 3).

5.2.3. Elderly as informal caregivers
The elderly taking on the role of informal caregivers are looking after their well-being as well as the PwD's well-being (Table 3). If not careful, this group can quickly fall prone to becoming the invisible second patient. It can be challenging for them to understand the true feeling of the PwD and navigate a technology-driven care system. They rely upon remote informal caregivers and formal caregivers to keep them up to date on the most important events while ensuring that they will not feel burdened. All in all, their role in elderly care is critical. This group will likely benefit significantly from social and technological support to help them address issues more effectively, guide them in finding the proper help and inform relevant stakeholders in pleasant and preferred ways.

Table 2: Customer segment formal and informal caregivers		
Possible Jobs	**Pains**	**Gains**
Formal caregivers		
Improving care effectiveness	Limited insights into client-specific problems	Create better long-term care plans
Improving care efficiency	Much time spent on administration and informing stakeholders	Less time spend on informing stakeholders
Improving engagement with the client	Challenging to know how the client is feeling	Insight into the emotional state of the client
Relieving own stress/workload	Either information overload or no information	Manage/prioritize/personalize information
Informing other stakeholders	Negative involvement/discussion by stakeholders in the care plan	Objective information to back up the care plan
Ensure own privacy	Monitoring of their quality of service	Clear guidelines and policy stored data on actions taken by formal caregivers
Informal caregivers		
Ensuring the well-being of the PwD	No reassurance beyond visits	Ways to monitor the person's well-being remotely
Creating a day-to-day schedule for the PwD	Hard to communicate new structures to the PwD	Way to help convey structure through technology
Provide right and on-time care for PwD	Complex care system (e.g. unclear points of contact)	Suggestions for courses of action
Identify struggles of PwD	No way to distinguish between incidents and daily (progressive) issues	Detect discrepancies in normal behaviour / Fact-checking; long term monitoring
Healthy work-life balance	Either information overload or no information	Manage/prioritize/personalize information
Assist the creation of care plans along with other stakeholders	Disagreements with other stakeholders on the course of action	A centralised platform for information and informed decision making

Table 3: Customer segment elderly		
Customer Jobs	**Pains**	**Gains**
Elderly with Dementia		
Living with Dementia	Systems not tailored to their needs	Tailoring systems to their needs
A feeling of usefulness towards society	Do not like to sit idle	Providing them with possible tasks
Maintain information privacy/security	Spread of misinformation or to other than family members	Control over the dissemination of personal information
Follow a daily schedule/routine	Dependent on caregivers for helping in designing schedule	Providing assistive technologies
Ensure healthy relationships with friends and family	Difficulty in expressing and connecting	Societal inclusion of PwD
Comfortable extended living at home	A feeling of being monitored in case technology is used	Development of unobtrusive solutions
Burden on informal caregivers	Concerns for the well-being of informal caregivers	Considering needs of informal caregivers in assistive solutionss
Elderly without impairment		
Maintaining overall well-being	Systems are observing	Companionship, providing suggestions for improvement
Elderly as informal caregivers		
Maintaining self-wellbeing	Becoming the invisible second patient	Technical and social support
Ensuring the well-being of PwD	Less/ no insight into emotional and physical needs of PwD	Awareness and understanding of needs of the person with impairment
Operating technology-based care system	Not-technology acquainted, concern about the operation of the system	Better explanations on the workings of the system; Personalised solutions
Maintain privacy/security/data-storage	Concerns about data storage	Better understanding and guidelines on the workings of the system
Communication with other involved caregivers	Challenges in providing information without burdening informal caregivers	An effective way of delivering positive/negative information
Expressing the situation to others	Situation not acknowledged or supported	Communities for informal caregivers for sharing their feelings
Effective decision making when required	Informed decision making is a challenge	Higher chance of implementation success

5.3. Value map caregivers
5.3.1. Formal caregivers

A communication platform for sensing systems creates value for formal caregivers by establishing a centralised platform where formal caregivers can instantly view incidents and problems for all clients under their watch (Table 4). Automating the data infrastructure could additionally help to reduce time spent on non-care related tasks. Additionally, client-specific insights (primarily related to emotion) will significantly help to improve the effectiveness of care and treatment. Personalisation of the information dissemination helps match individual caring styles and preferences, ensuring formal caregivers will not suffer from an overload of information (Table 4).

5.3.2. Informal caregivers

For informal caregivers, the ability to remotely observe the well-being of the PwD provides reassurance and insight. Through the system, they can support the PwD in setting reminders and notifications, but they should also determine recurring issues, which they can then address. Their information acquisition and decision-making become increasingly objective and relieve strain from other stakeholders initially providing information, though tailored to their individual information needs (Table 4).

5.4. Value map elderly
5.4.1. Elderly with Dementia (PwD)

For the elderly with dementia, a sensing and communication platform should offer control and structure (Table 5). The PwD should gain the feeling of safety through monitoring and the feeling of

usefulness through scheduling functionality. Whereas the PwD should eventually be able to decide what information to share and with whom, the diversity of monitoring applications will allow for more understanding of the PwD's situation and individual opportunities to improve due to system provided feedback.

5.4.2. Elderly without impairments

Whereas the system might not be necessary in their situation, early gradual implementation could provide additional benefits. Especially the feedback and insights modules might be of value to this group as it helps them understand their structural issues and perhaps helps them discover the information they did not know before (Table 5).

5.4.3. Elderly as informal caregivers

The information dissemination system supports the elderly in their various roles. Personalisation should allow this user to identify key monitoring areas, and information should be provided wholly and comprehensively in a central overview/dashboard. To alleviate privacy concerns, the system

should allow for privacy and data storage settings to be configured. Concrete suggestions based on historical data should further help increase insight into the situation of the PwD and helps to make more informed decisions.

Finally, the system should allow the user to define what information to share and with whom to increase the feeling of safety and limit obtrusiveness (Table 5).

Table 4: Value map formal and informal caregivers		
Products and services	**Pain relievers**	**Gain creators**
Formal caregivers		
Client problem identification	Provides information on a per-client basis	Helps with determining effective care solutions
Automated data infrastructure	Automates administration and information	Relieves workload from formal caregivers
Emotion recognition module	Enables for deeper understanding of clients emotional state	Provides insight into the emotional state
Information management	Enables adjustment of notification frequency	Customises information delivery
Centralised platform	Limits possibilities for misinformation	Supports decision making
Informal caregivers		
Unobtrusive monitoring	Enables remote access to monitoring data	Provides insight into well-being beyond visits
Set reminders and notifications	Familiarises interfacing between system and PwD	Reminds PwD when necessary
Suggestions for action	Integrates with other caring systems	Simplifies the process of getting help
Self-learning / Discrepancy observation	Allows for the informal caregiver to tackle recurring issues	Enables cross-checking of information
Information management	Enables adjustment of notification frequency	Customises information delivery
Centralised platform	Limits possibilities for misinformation	Supports decision making

	Table 5: value map for elderly	
Products and services	**Pain relievers**	**Gain creators**
Elderly with dementia		
Personalised monitoring goals and information	Tailors to individual situations	Increases implementation effectiveness
Task scheduling	Creates todos and reminders for events and tasks	Provides a person with meaningful tasks
Adjust privacy settings	Shares objective information with user-defined stakeholders	Tailors information design to privacy desires
Emotion recognition module	Enables observation and communication of emotional state	empathy for PwD
Monitoring technology	Provides the possibility to be turned off by the user	Safekeeping of PwD's privacy
Control of information provisioning to stakeholders	Shares information the PwD is comfortable with	Allows informal caregiver to personalise notifications
Elderly without impairment		
Feedback / Insights module	Monitors actively on user-specified domains	Provides insights for improvement.
Elderly as informal caregivers		
Personalised message frequency and content	Allows users to specify the desired way to gather information	Provides personalised reassurance
Information dashboard	Identifies discrepancies in physical and emotional behaviour	Provides means to prevent future issues
Suggestions for actions	Simplifies interaction between informal caregiver and system	Shares algorithm logic for transparency
Configurable data storage	Provides insight into where specific data is stored and how it is processed	Complies with GDPR
Centralised information	Ensures relevant stakeholders are adequately informed	Allows adjustment of message content/style
Historical overview	Provides context to the state of decline and current situation	Suggests possible opportunities for inclusion
Self-learning (suggestions)	Provides context to the state of decline and current situation	Provides suggestions based on previous observations

6. Discussion

This research work has identified the possible requirements for the major stakeholders in elderly care, i.e. (in)formal caregivers and elderlies. Among these groups, added safety for the elderly and insight and reassurance for (in)formal caregivers were mentioned as the most considerable benefits. Privacy and security concerns were identified and mostly related to sharing personal and emotional data (not physical).

The three themes: sense of privacy, data collection, and communication, are more elaborately discussed below.

6.1. Stakeholder perspectives about the system, data collection, and communication.

More perspectives can be identified on the actual contents and data types that information systems should be allowed to control. In all cases, all participants agreed that information should be acquired in its least invasive form, meaning that direct video and audio processing was not deemed a feasible solution.

6.1.1. System perspectives

The first reaction of nearly all the stakeholders when informed about the system related to the feeling of being watched ("big brother"). Even though the system was explained to be using non-invasive monitoring techniques, participants found it hard to shake the feeling of being watched constantly. An informal caregiver said the following for unobtrusive sensing:

"It could also become a type of big brother, resulting in PwDs not being allowed to make their own decisions anymore. The informal caregiver must not correct the behaviour of the PwD immediately; that would be troublesome. It would also be dangerous if there is nothing. In that case, the PwD would not be able to know when the system is observing him/her and when it is not."

6.1.2. Physical/vital data

All elderly groups were convinced that sharing physical and, most importantly, vital data – i.e. heart and breathing rate – is wise and not problematic. They mention that their physical attributes are of lesser importance to their privacy but significant in detecting structural issues and emergencies. Caregivers also identified that data related to the physical and vital domain is essential to assess the needs of the PwD better.

6.1.3. Emotional data

Whereas both previous literature and caregivers identified this category of data as beneficial to increasing engagement and effectiveness of care for the PwD, all elderly groups considered emotional data too private to be shared [7]. One of the elderly said:

"My children have a family and personal life, having to care for my and my husband adds additional pressure. I do not want to burden them too much. The idea that they spend much time with it [interacting with the monitoring system] is discomforting to me."

To the elderly, emotions were natural and mostly incidental and should not be monitored by a system. They would either be identified regardless during visits or expressed by the elder person himself/herself.

6.1.4. Communication in regular situations

In everyday situations, the groups of elderly addressed the fact that (in)formal caregivers should be able to determine for themselves whether they would want to receive information actively or not. Most of the caregivers agreed that passive information acquisition, e.g. through login on to a dashboard, would be most preferred in normal living situations. However, possibly an occasional (weekly) summary of past events would be beneficial as well.

6.1.5. Communication in emergencies

In emergencies, for example, in the case of a fall, all parties agreed that communication should take place as directly as possible with as much precision and detail as possible. Placing several calls in a particular order was frequently mentioned as a good idea, and details should include the location of the affected person, vital signs (e.g. consciousness and heart rate) and possibly other signs such as the level of pain, prediction on the cause and estimate of the damage.

6.2. System attributes

Furthermore, some interesting perspectives were mentioned about the general attributes the information system should possess.

6.2.1. Personalisation

By all groups, personalisation was mentioned as a critical requirement for the information platform. Not only to align with individual information needs but also to support the changing situation and needs of the PwD. For example, one of the elderly mentioned:

"There are many advantages, but they depend on what you would need the system for. With PwDs, there would perhaps be even more benefits, such as monitoring eating and drinking behaviour. Medication intake could be important but is monitored by formal caregivers as well. Possibly emotion and weariness monitoring could help, but that would only be in the situation that you are unable to express yourself in those areas."

To the elderly, another dimension of personalisation was to adjust what information should be gathered and shared by the system. Being in control over one's data was an additional top requirement for them for several reasons. About providing information to their children, one of the elderly stated:

"I have doubts about the direct forwarding of information. If not careful, I might not feel at home in my own house anymore".

About providing information to formal caregivers, the participant mentioned:

"I would like to decide myself whether to pass on recorded data; I do not want her [case manager] to immediately act on everything the system observes".

6.2.2. Autonomy & Self-monitoring

Specifically for persons with dementia but also for other elderly, the system should allow them to regain autonomy and structure. The system should act more like a friendly companion, helping them adhere to daily schedules and improve their well-being (through self-monitoring) and less like a fly-on-the-wall. One of the elderly addressed his views on fall detection in the bathroom:

"Slipping is an accident. The system wants to help me, and that would be okay for me. However, maybe I have fallen for the third time, and in that case, we should investigate whether to adjust things in the bathroom".

Caregivers acknowledged the added value of interaction with the PwD and mentioned that many of them are open to feedback, though they sometimes question the success of the human-machine interaction with PwD.

6.2.3. Regularisation
Formal and informal caregivers mentioned that the system must undoubtedly adhere to policies and regulation in healthcare (other than the privacy regulations of the GDPR). Elder themselves expressed the wish to remain in control over the system:

"If I have visitors, I have the feeling that they can watch over me; the system may then be turned off, assuming that I can remember turning it on after the visitors have left".

6.2.4. Tunnelling
Both groups of caregivers frequently mentioned the tunnelling characteristic of the system to reduce information overload. For example, initial notifications may be provided concisely, allowing the user to retrieve more detailed information after clicking on the notification.

For formal caregivers, the tunnelling aspect was of increased importance because they need to manage information of multiple clients within the same system.

6.2.5. Privacy awareness
All groups mentioned privacy as the uttermost concern, which is understandable given the quantity and informational value of the acquired data. The elderly groups expressed the wish to control the system, preferably even being able to turn it off when desired. Informal caregivers found it essential to ask for the consent of the monitored persons repeatedly.

In addition to this, the formal caregiver will also be monitored by the system in caring situations. Without a clear policy on the use of this information, formal caregivers are concerned that management or informal caregivers will use the system to assess the quality of care provided to the PwD and be required to justify their caring decisions more frequently. One of the formal caregivers mentioned the following on a centralised platform for observation data:

"You constantly have to justify to the family for all the care that you provide. Agreement sneed to be made on this matter as well. It is also an area in which we still have to find our style".

6.2.6. Reliability
Finally, the concept of cyber dependency found in literature was not frequently mentioned in the various stakeholder sessions. One of the elderly mentioned that it might be problematic for all stakeholders if the system would seize to function (e.g. power outage or malfunction), though none of the other stakeholders seemed to acknowledge this point. On the one hand, this might be because these stakeholders assumed that the system would always be functioning normally for the sake of simplicity. On the other hand, in case of a system breakdown, stakeholders will still be able to revert to older

methods, given that the system should not replace current structures but extend them.

7. Conclusion
Before successful implementation of monitoring systems and their information platforms can be achieved, a significant effort should first be spent on informing the user base about the monitoring techniques, computer algorithms and workings of the system to create more confidence among the users. In addition, the current perception of privacy is one of the most significant barriers to implementation. Hence a proven privacy-aware system should help to relieve some of these concerns.

Information disseminating solutions are subjected to a rapidly changing environment in elderly care and therefore must be flexible and personalised to ensure that the needs of all stakeholders can be met. For the elderly this means that they should have control over which information to share with whom. For caregivers, this means that they should have control over the frequency and style of the information they receive.

Overall, an architecture is required to ensure a baseline of requirements for functionality, personalisation and privacy that all elderly care systems should adhere to. A joint framework containing the needs of all relevant stakeholders involved. This way, the framework can help to facilitate a transition towards the inclusion of caring technologies in elderly care.

8. Limitations
There are a few limitations to the conclusions made in this research. For starters, due to the COVID-19 pandemic, it was not possible to interview older adults situated in nursing homes as visitations were only allowed for nursing staff and family. This implies that the research lacks the perspective of the elderly living in nursing homes with increased assistance and possibly monitoring. Additionally, only one of the four participants for the elderly interview was diagnosed with dementia, and none of the participants lives alone. Therefore, the findings of this research might not wholly represent the target demographic of the elderly with a form of dementia. However, their perspectives largely contribute to our overall understanding of the perspectives of various demographics towards unobtrusive sensing.

Secondly, the number of participants in each session was relatively limited and implied that the conclusions drawn in this research might not be fully representative of a larger population. In addition to this, the focus group with informal caregivers had to be conducted online using a tool the participants had never worked with before. The online environment could have impacted the discussions' richness about the various topics addressed in that focus group.

Finally, though this research has managed to address the perspectives of elderlies and caregivers towards the system, perspectives of other stakeholders such as management, insurance and possibly different age groups are still lacking. Therefore, further research should aim to identify the needs and values of these groups towards a platform for disseminating information concerning the PwD.

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