



MASTER THESIS

**Experiences and expectations towards
unobtrusive in-home monitoring and healthcare
management platform Carezorgt from the
viewpoint of informal caregivers of people with
dementia – a mixed methods approach**

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Preface

This thesis is written to complete the master Health Psychology and Technology at the University of Twente. Together with Nedap Healthcare, the University of Twente is conducting research into the subject of this thesis: 'Experiences and expectations towards unobtrusive in-home monitoring and healthcare management platform Carezorgt from the viewpoint of informal caregivers of people with dementia – a mixed methods approach'

I would like to thank my supervisors Annemarie Braakman-Jansen and Christian Wrede of the University of Twente for their supervision during this process. Their feedback and the meetings together have guided me through the writing of this thesis. I would also like to thank Peter Leppers from Nedap Healthcare. Peter provided the opportunity to place the survey on Carezorgt, which yielded real user experiences and a large amount of participants. Finally, I would like to thank all informal caregivers who invested their time in participating in the interviews or filling in the survey. Because of those participants the results of this research can be properly used to improve the healthcare system and the unobtrusive in-home monitoring system.

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Abstract

Background: The number of people with dementia is extremely increasing. Many people with dementia live at home and when problems appear, they rely on informal caregivers. Those informal caregivers often live somewhere else and are leading their own lives. Informal caregivers are heavily burdened. Different assistive technologies are currently being developed to assist informal caregivers. One of those technologies is unobtrusive in-home monitoring, a sensing system monitoring the daily functioning as well as emotional- and behavioral state of the person suffering from dementia living alone. However, it is unknown what the opinion of informal caregivers of people with dementia is about unobtrusive in-home monitoring. Another assistive- technology system being used is the Healthcare platform Carenzorgt, of which it is unknown what the user experiences are of informal caregivers of people with dementia.

Objectives: The aim of this study is (1) to gain insight into the needs and barriers of informal caregivers of people with dementia (PwD) with regard to unobtrusive in-home monitoring, and (2) to gain insight in the usage and user experiences of the platform Carenzorgt by informal caregivers of PwD and to find strengths and weaknesses or points of improvement for the healthcare platform.

Methods: This study employed a mixed-methods design, including quantitative and qualitative data analysis. The qualitative study was performed by conducting semi-structured interviews with seven users of the healthcare platform Carenzorgt in order to identify both the needs and barriers related to unobtrusive in-home monitoring and user experiences of the healthcare platform Carenzorgt. Via a survey, 7118 participants were asked about their experiences with Carenzorgt.

Results: Results showed that this study identified different advantages of unobtrusive in-home monitoring systems: autonomy for the informal caregiver, more safety for the patient, the possibility to intervene faster, the system is a source of information and the burden of care of the informal caregiver could be reduced. Also different barriers have been mentioned: the system could cause more pressure for the informal caregiver, the system provided no added value, the patient will be downgraded into a technical objective and there will be loss of privacy for both the patient and the informal caregiver. The monitoring system has to meet different requirements: it should be personalized to individual patients and to the different phases of dementia, GPS should be added and the system should provide safety for the patient. Furthermore, results showed that participants are overall positive about the platform Carenzorgt. However, participants with low burden of care are more satisfied with the different functions of Carenzorgt than participants with higher burden of care ($p=.00$)

Conclusion: This research explored the expectations of informal caregivers of people with dementia with unobtrusive in-home monitoring systems and their experiences with the healthcare platform Carenzorgt. Privacy is the main issue for unobtrusive in-home monitoring and in further research, privacy should be taken into account. Regarding Carenzorgt, it appeared that the communication between the formal- and informal caregivers could be improved. Personas can be used to get more insight in both topics.

Keywords: dementia, Alzheimer's Disease, e-Health, monitoring systems, Connected Health, Carenzorgt, unobtrusive in-home monitoring

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Introduction

Worldwide, around 47 million people have dementia (Boomstra, Reitsma, & Hofman, 2018). This number of people is estimated to rise to 75 million in 2030 and 132 million in 2050 (Boomstra et al., 2018; Livingston et al., 2017). In the year 2016, the prevalence of dementia in the Netherlands was between 254.000 and 270.000 patients and this number is also estimated to increase (Alzheimer Nederland, 2019a; Prince et al., 2017; Boomstra et al., 2018;). Dementia typically progresses with age and there is no cure (Centraal Bureau voor de Statistiek, 2017). In the Netherlands, ten percent of all people die because of dementia. Because of this important cause of death and the relatively big loss of quality of life, the burden of the disease is high (Volksgezondheidzorg.info, 2019).

There are multiple subtypes of dementia (American Psychiatric Association, 2013). The most common type of dementia, which makes up around 70% of dementia cases, is Alzheimer's disease (Breteler, Claus, van Duijn, Launer, & Hofman, 1992; Seshadri et al., 2002). Alzheimer's disease is a degenerative brain disease (Wilson et al., 2012). Early clinical symptoms are: difficulty remembering recent information, apathy and depressions (Alzheimer's Association, 2018). Later stages of the disease include behavior change, impaired communication and disorientation and ultimately difficulty with speaking, swallowing and walking and thus affects the ability to perform daily activities. The cause of the disease is that neurons in parts of the brain that are involved in cognitive functioning are damaged. This neural damage also affects other parts of the brain, for example the ones that enable a person to carry out basic bodily functions. Therefore, patients in the final stages of Alzheimer are bedridden.

1.1 Informal care for people with dementia

Fifty-three percent of the people with dementia are cared for at home by family or friends (Alzheimer's Association, 2017; Peeters et al., 2012). In the Netherlands, there are approximately three hundred thousand people who care for someone with dementia living at home and are called informal caregivers (Alzheimer Nederland, 2019a). Informal caregivers give assistance with daily functioning and emotional support, voluntarily and unpaid, to persons from their social network who have severe psychological, physical or mental limitations (Droës, Scheltens, & Schols, 2018). Informal caregivers usually combine this caregiving with a paid job and/or the care of children. The informal care is given for at least three months and involves at least eight hours of care per week (Centraal Bureau voor de Statistiek, 2017).

The task of caring may be difficult, requiring the informal caregiver to face new situations which can be stressful (Boots, De Vugt, Van Knippenberg, Kempen, & Verhey, 2014). As a result, fifty-four percent of the informal caregivers are heavily burdened (Alzheimer Nederland, 2019b). This burden can be considered to include both subjective (personal, physical, emotional and social) and objective aspects (time and costs) of caring (Park, Sung, Kim, Kim, & Lee, 2015). Caregivers often feel the lack of time for their own daily tasks and their own health needs, in addition to financial issues and the lack of social life (Erder et al., 2012; Huang et al., 2015). Earlier studies show caregiver characteristics (e.g.

relationship to the patient and living together with the patient or not) and disease related factors (e.g. behavioral symptoms, cognitive status of the patient and functional impairment) as being associated with caregiver burden (Park et al., 2015; Conde-Sala, Turró-Garriga, Calvó-Perxas, Vilalta-Franch, Lopez-Pousa, & Garre-Olmo, 2014; Brodaty, Woodward, Boundy, Ames, & Balshaw, 2014). According to earlier research, female informal caregivers experience more caregiver burden than male informal caregivers (Etters, Goodall, & Harrison, 2008; Chan, 2010; Chiao, Wu, & Hsiao, 2015). Spouses and adult children caring for their family members experience the greatest burden (Chiao, Wu, & Hsiao, 2015). However, multiple studies have shown that support services such as care management, counseling and adult day care services are beneficial to informal caregivers (Erder et al., 2012; Huang et al., 2013; Zarit, Kim, Femia, Almeida, & Klein, 2013).

The government and municipal policies in the Netherlands are aimed at ensuring that care is provided as much as possible within the social network and that people stay at home as long as possible, because this reduces public healthcare costs and enhances a patient's quality of life (Peeters, Werkman, & Francke, 2014). In order to maintain care at home and to reduce the heavy load for the informal caregiver, good care for people with dementia (PwD) and their informal caregivers and coordination between all care providers involved are of great importance (Boer, Broese van Groenou, & Timmermans, 2009). Formal caregivers can play an important role in this caregiving process by supporting options, advising and taking decisions about care (Wolfs et al., 2012). In the Netherlands, the role of formal caregivers is often fulfilled by case managers and nurses (Alzheimer Nederland & Vilans, 2013). The total group of professional and informal caregivers caring for one patient is called the 'care network' (Vrije Universiteit Amsterdam, 2019). Currently, the different people within the care network of one patient often cannot satisfy the more specific needs of PwD and their informal caregivers, which may result in increased distress and burden for the informal caregiver (Bamford & Bruce, 2000; Nijhof, 2013).

1.2. The use of eHealth

Research shows that different forms of technology can provide useful for supporting PwD and reducing the burden of care on their informal caregivers by promoting independent living and early identification of problems (Cahill, Begley, Faulkner, & Hagen, 2007; Carswell et al., 2009). Making use of technology to support health, healthcare and well-being is called eHealth (van Gemert-Pijnen, Peters, & Ossebaard, 2013; van Gemert-Pijnen, Kelders, Kip, & Sanderman, 2018). There are a lot of different eHealth technologies, such as mobile health communication applications, online health care portals, domotics (home automation), robotics and sensor technologies (van Gemert-Pijnen, Peters, & Ossebaard, 2013). According to Nijland (2011), making use of different eHealth technologies keeps the quality of healthcare high, accessible and affordable. eHealth also makes care more accessible, since the healthcare is available at all times and places, which improves the efficiency and continuity of care (van Gemert-Pijnen et al., 2018).

eHealth is not just a tool; it can be seen as a holistic way to support healthcare via technology. Therefore, the system, its content, context and stakeholders and their interdependencies should always be taken into account when designing interventions (van

Gemert-Pijnen et al., 2011). eHealth technology can be divided into different categories: technology used by the PwD themselves or technology used by the caregivers of PwD and technology that does or does not work automatically, of which the automatic technology is also called ‘Ambient Assisted Intelligence’ (van der Leeuw, 2008; Nouws, Sanders, & Heuvelink, 2006; Nijhof, 2013; Blackman et al., 2016). Ambient Assisted Intelligence is a form of invisible intelligent technology in the homes of its users. The intelligent technology makes use of sensors and software that can interpret situations by using the signals received by the sensors (van der Leeuw, 2007; Nijhof, 2013). There are three kinds of Ambient Assisted Intelligence technologies. The first are ‘community alarm systems’, where the elderly can press an alarm when not feeling well. Next is a ‘monitoring system’ which automatically detects and reports problems, for example sensors that detect that the gas is still on. The third is ‘Ambient Assisted Living (AAL)’, which provides PwD for example with the opportunity to live independently and safely with minimal assistance (Mohammed, 2019; Oguntala et al., 2019). In AAL environments, multiple different devices and sensors are embedded in the homes to collect residents’ health data in order to extend their time at home (Mohammed, 2019). AAL can be seen as a potential solution to the challenges of the elderly, while improving high quality of care and unburdening informal caregivers (van den Broek, Cavallo, & Wehrmann, 2010; Jaschinski & Allouch, 2019).

1.3. Monitoring technologies

AAL is a form of monitoring technology, a kind of technology that could be used to reduce the burden of care for informal caregivers (Bossen, Kim, Williams, Steinhoff, & Strieker, 2015). Monitoring technology can detect activities of daily living, changes in health status or the occurrence of specific events like falls (Peetoom, Lexis, Joore, Dirksen, & De Witte, 2015). Monitoring technology consists of visible or unnoticed sensors which for example detect the movement of PwD in their homes, use of gas, electricity and water or sensors that are placed on the bed to measure the night rhythm (Nijhof, 2013; Zwierenberg et al., 2018). Another form of monitoring consists of body-worn wearables with sensors, for example an on-body approach which detects the location of the PwD using physical characteristics (Sztyley, Stuckenschmidt, & Petrich, 2017). Since it is not always possible for the informal caregiver to constantly observe his patient and, therefore, not always being aware of the patient’s needs, the data of monitoring technology can provide information from a distance (Zwierenberg et al., 2018).

Earlier research shows some concerns related to monitoring technologies. First, such systems could generate false and incorrect notifications because the technologies are not aware of the context of the patient (Zwierenberg et al., 2018). Next, ethical issues emerge when talking about assisted technology and monitoring data (van Gemert-Pijnen et al., 2013). In the first place, the privacy of the PwD living at home cannot be ensured through the use of monitoring technologies (Percival & Hanson, 2006). Even though the relationship between the PwD and the informal caregiver is important for daily care, the PwD might possibly not want to share personal information, which makes the sharing of data a sensitive issue (Nijhof, 2013), especially the ways in which the information is expanded, made visible to others and shared. Secondly, another ethical issue is the autonomy of the PwD living at home. For

example, home technologies could monitor if the gas is off. In case of an emergency, an alert is sent to the formal or informal caregiver. This procedure shifts the decision to call for help to someone other than the patient, which could lead to a decreased autonomy and self-care of the PwD (Bowes, Dawson, & Bell, 2012). Informal caregivers of PwD often have to find a balance between respecting the privacy of the older person and performing their caring duties (Van Bruggen et al., 2016).

1.4. Connected Health and Carenzorgt

Communication between formal- and informal caregivers caring for a PwD is very important in order to be able to offer the best possible care. Therefore, there are multiple technologies that facilitate this communication between formal- and informal caregivers and the patients. Carenzorgt is a healthcare platform made by Nedap, aimed at improving communication and coordination between healthcare professionals and informal caregivers, providing a better overview of the care process and creating a safe information network within the own care network (van Berlo, Duymelinck, Verwey, & Van Rossum, 2015; Carenzorgt.nl, 2019). Every informal caregiver who uses Carenzorgt creates a personal account with his own email address. The PwD who receives care can also create an account, but this is not obligatory. Third parties could be added, such as care providers or other relatives to whom the informal caregiver wants to give insight into their file. Agenda items, appointments and notes can be recorded and shared in a well-organized way. Additionally, the electronic patient file can be linked to Carenzorgt. In total, Carenzorgt has around 302.000 users and around 500 healthcare organizations in The Netherlands using the platform. However, there are no published studies about user experiences with Carenzorgt. Therefore, there is a lack of scientific evidence on the experiences of both formal and informal caregivers with the healthcare platform Carenzorgt and it is unclear if the platform sufficiently meets the needs of the end user, the informal caregiver.

The term ‘Connected Health’ describes a new model of healthcare based on technology (Caulfield & Donnelly, 2013). The Connected Health Model (CHM) is a model that provides the connection between all involved caregivers by sharing information regarding the patient, by using, for example, communication platforms (Caulfield & Donnelly, 2013). Caulfield and Donnelly (2013) also state that CHM uses devices and interventions which are designed around the needs of the patient, and in which health related data can be shared to the patients receiving care in the most efficient way. The driving element of the CHM is the acquisition of health-related data from the patient. In this study, this could be sensor data from ambient or body worn sensors and the continuous monitoring. Both formal- and informal caregivers could decide, based on the amount of data provided, which interventions fit the patient.

Currently, The University of Twente is working together with Nedap Healthcare on a project focusing on unobtrusive sensing monitoring technologies for PwD living alone and their caregivers. This project is called ‘Track, Trace, Trigger’. The project focusses on the development of a new, unobtrusive technology, which can automatically report emotions and behavior of PwD (Wrede, Braakman-Jansen, Havinga, Croockewit, & Gemert-Pijnen, 2019). The technology is a Wi-Fi disturbance sensing system connected to a persuasive care platform

for caregivers to provide them information regarding the daily functioning and emotional- and behavioral state of the PwD living alone. In this phase of this project more information is needed about the needs and expectations of this unobtrusive in-home monitoring system. It is therefore not clear how the technology could reduce the burden of care on caregivers and what requirements the system should meet.

1.5. Current study

The current study focuses on the needs of informal caregivers of people with dementia (PwD) regarding unobtrusive in-home monitoring and digital care management. In the first place, there is a lack of scientific evidence on how informal caregivers of PwD feel about using unobtrusive sensor data, also called unobtrusive in-home monitoring, within the home of the PwD. Therefore, one goal of this study is to gain insight into the needs and barriers of informal caregivers of PwD concerning unobtrusive in-home monitoring. Next, this study focuses on the experiences of informal caregivers of PwD regarding the healthcare platform Carenzorgt. The goal of this study is to gain insight in the usage and user experiences of the platform Carenzorgt by informal caregivers of PwD and to find strengths and weaknesses or points of improvement of the healthcare platform. This study therefore poses the following research questions:

Question 1: What are the needs and barriers of informal caregivers of dementia patients living at home towards unobtrusive in-home monitoring?

Question 2: What are the experiences of informal caregivers of dementia patients living at home with the healthcare platform Carenzorgt?

In order to answer this second research question, a number of sub-questions will be investigated:

- 1) How often do informal caregivers of PwD use Carenzorgt and how do they experience the different functions of Carenzorgt?
- 2) To what extent do caregivers of PwD intend to continue using Carenzorgt in the future?
- 3) What is the difference in the perception of Carenzorgt between informal caregivers of PwD with low and high burden of care?

Methods

2.1 Research design

The current study employed a mixed methods design. This includes qualitative and quantitative methodology from semi-structured interviews and surveys. The qualitative and quantitative methodologies followed a parallel approach; both the interviews and the surveys were conducted within the same period of time. However, the participants of the interviews differed from the participants of the survey. To answer the first research question, ‘*What are the needs and barriers of informal caregivers towards unobtrusive monitoring?*’, only the answers of the interviewed were used. To answer the second research question ‘*What are the experiences of informal caregivers with the healthcare platform Carenzorgt?*’, both the answers of the survey and the interviewed were used. The interviews gave in-depth information on the questions asked in the survey.

2.2. Survey study

2.2.1. Study sample

Eligible for the survey study were users of the healthcare platform Carenzorgt. In total, Carenzorgt has around 302.000 users (Carenzorgt.nl, 2019). The majority of those users are informal caregivers, next to patients who use the platform themselves. The participants of this study were recruited via the healthcare platform Carenzorgt itself. In June 2019 a pop-up message was made visible for three days (June 3th to June 5th) when using Carenzorgt, with a link to the survey. All users of Carenzorgt were invited to fill in the survey and convenience sampling has been used to select the participants for this study. Only participants who are over eighteen and are informal caregivers of PwD were included within this study. Participants were excluded of this study when they were under eighteen, not an informal caregiver of a PwD or when they were patients themselves. Also participants who had not finished the survey were excluded from this study. See figure 1 for an overview of the in- and excluded participants. In total, 7118 informal caregivers of PwD were included in this research.

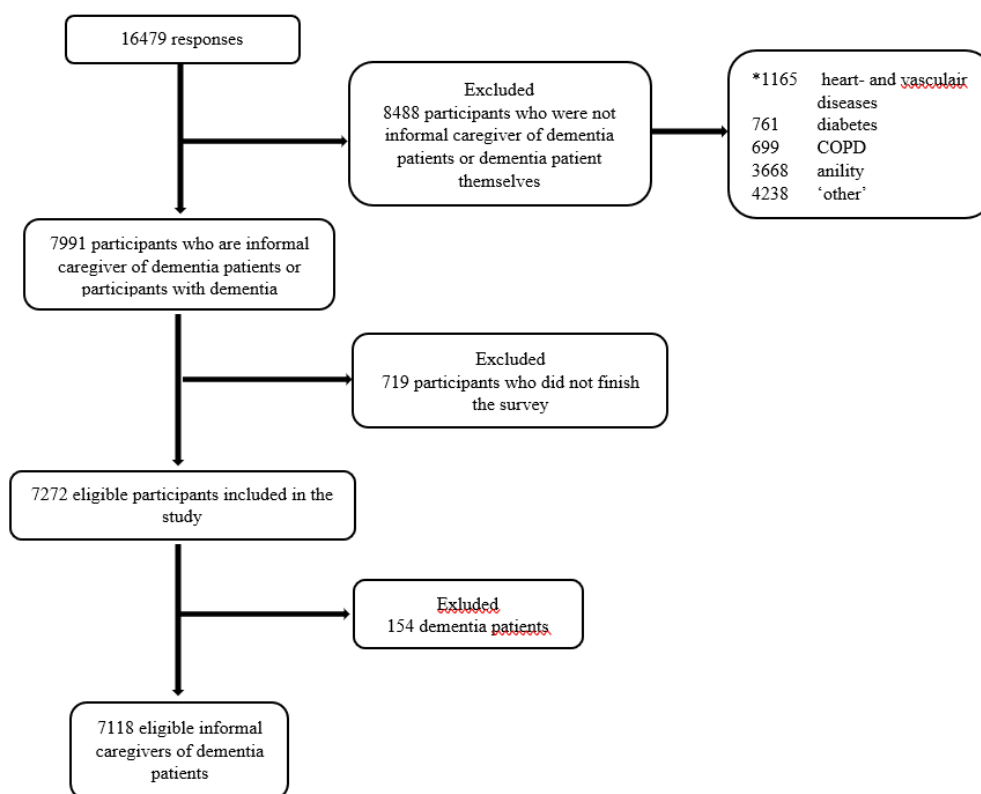


Figure 1. Eligible participants for the survey study

* There are cases of comorbidity

2.2.2. Procedure

After clicking on the pop-up message on the healthcare platform Carenzorgt, the participants were linked to the survey made in Qualtrics. First, participants were asked to agree with the informed consent. A short explanation of the survey was given and participants were asked if they were over eighteen years old, agreed with the given information and whether the participation was voluntary. After this informed consent, the survey started with eight questions about social demographic background: age, sex, reason of use of Carenzorgt, reason of care, living situation, hours of informal care per week, burden of informal care and usage of Carenzorgt. Next, in total twelve closed questions or items were asked. The items within the survey were based on the objectives and functionalities of Carenzorgt for professional context. The results of this survey are processed anonymously by anonymizing the participant details. Participant names have been anonymized by replacing them by 'participant 1', for example. The survey can be found in Appendix A.

2.2.3. Measures

Questions about components Carenzorgt

Participants were asked two different things: first, to fill in which components of Carenzorgt they use with a choice of the components: 'Kalender', 'Berichten', 'Notities' and 'Dossier'. Secondly, participants were asked to fill in whether or not they used Carenzorgt to link with other informal caregivers or professional caregivers. On a 5-point Likert scale the participants

gave their opinion about the used components: 1 (extremely satisfied), 2 (satisfied), 3 (neutral), 4 (dissatisfied), 5 (extremely dissatisfied).

Questions about use Carenzorgt

Next, the experiences of the respondents with the functionalities of Carenzorgt were measured with nine different statements. Those statements use a 5-point Likert scale to rate the opinions of the participants ranging from 1 (totally agree), 2 (agree), 3 (neutral), 4 (disagree) to 5 (totally disagree). The option *not applicable* was added to the survey because not all functions are used by all participants, which might cause unreliable answers. All statements were formulated positively.

The nine statements can be divided into five different categories or themes: usability (2 items), communication (2 items), care process (3 items), trust in the system (1 item) and intention to use (1 item). The items associated per theme can be found in Table 1.

Table 1
Items of the survey per theme

Themes	Number of items	Items
Usability	2	- Carenzorgt is easy to use - Carenzorgt is built in a logical way
Communication	2	- With Carenzorgt it is easier for me to maintain contact with other informal caregivers - With Carenzorgt it is easier for me to maintain contact with other informal caregivers with professional caregivers
Care process	3	- Carenzorgt provides a better overview of the care process - By using Carenzorgt it is easy to stay informed of the situation of my loved one - With Carenzorgt the organisation of care tasks is easier
Trust in the system	1	- I am confident that Carenzorgt will handle our data with care
Intention to use	1	- I would like to continue using Carenzorgt in the future

2.2.4. Data Analysis

Statistical analyses were conducted using IBM SPSS Statistics version 24.0. First, cases with missing values in the statement section were excluded, because this meant that the respondent did not finish the questionnaire and therefore did not meet the inclusion criteria. Descriptive statistics were used to describe the different scores of demographic information. Histograms and normality test were performed to determine the distribution of the different items. To evaluate differences in the perception of Carenzorgt between informal caregivers of PwD with low and high burden of care, the sample was split in 2 groups by using the median on the burden of care-score. Low burden of care had a score ≤ 2.5 while the high burden of care had a score > 2.5 . Subsequently the Mann-Whitney-U-test was used to test statistical differences between groups. A significance level of 5% is applied for all analyses.

2.3. Interview study

2.3.1. Study population

Eligible for the study were people who provide informal care to a person with dementia who lives alone. The participants of this study were recruited through snowball sampling (Biernacki & Waldorf, 1981).

2.3.2. Procedure

Before taking part in the research, participants received an e-mail with a short explanation of the study (appendix B) and an informed consent form (Appendix C). The informed consent guaranteed anonymity and confidentiality. After the informed consent form was signed and returned, an appointment for the interview was made. At the start of the interview, participants were instructed about the structure of the interview. The interview consisted of three different parts. First, eleven background questions were asked about demographic variables such as age, children, different variables about the informal care and the usage of a health care system. The second part of the interview was about Carenzorgt. In case participants did not make use of Carenzorgt, a few screenshots of the platform were shown. After participants had seen these screenshots, they were interviewed about Carenzorgt. During the third part of the interview, the participants were given a short explanation about a non-existing unobtrusive in-home monitoring concept. Appendix D shows the interview scheme where this explanation can be found. The participants were also shown a short PowerPoint presentation about the unobtrusive in-home monitoring. During this PowerPoint the participants were informed about the purpose, the functions, the target groups and the method of this still non-existing but being in development monitoring system. The participants also learned how the data can be analyzed and were given some examples. See Appendix E for the sheets of this PowerPoint presentation.

The setting of the interview depended on the preferences of the participant. The interview took a maximum of one hour, with an average time of fifty-two minutes. The semi-structured interviews were conducted by one researcher and were audio recorded for means of analysis. The interview scheme can be found in Appendix D.

2.3.3. Data collection

Interview Carenzorgt part

The second part of the interview was about Carenzorgt and consisted of two different versions. One version for participants who use the system Carenzorgt (13 questions), and one for participants who do not use the system Carenzorgt (14 questions). The difference between the two versions was only one question. The participants who do not use Carenzorgt were first shown some screenshots on Carenzorgt and, to begin with, were asked to answer the question ‘What is your first impression about Carenzorgt?’. Participants who already use the program were not asked this question because their first impression had been longer ago. See Appendix D for the interview scheme. The questions of the Carenzorgt part were divided into the themes *user experiences or usability* (6/7), *communication* (2), *care process* (2) and *trust in the system* (3).

Interview unobtrusive in-home monitoring part

The third part of the interview was about unobtrusive in-home monitoring and consisted of first an explanation about the in-home monitoring system with examples, after which in total thirteen questions with sub questions were asked. The questions were divided into the subjects *usability, care process, barriers of the system and privacy*.

At the end of the interview the participants were asked to fill out a short table with the different possible monitoring targets. This table can be found at the end of Appendix D (the interview scheme). Participants had to answer whether they thought a specific monitoring target could be useful to measure, not considered interesting or if it was not applicable for their situation. The monitoring targets were divided into three different categories: daily activities, safety of the patient and dementia-specific.

2.3.4. Data Analysis

To answer the first research question about unobtrusive in-home monitoring, only the answers of the interviews were used. To answer the second research question about Carenzorgt, both the answers of the survey and the interviews were used. The interview was used to elaborate on the answers of the survey.

The recorded interviews were transcribed verbatim and themes and categories were coded via inductive coding using scientific software Atlas.ti Version 8. The interview transcripts were analyzed by the researcher (A.S.) First, all transcripts were integrally read to formulate an understanding of the viewpoint of the participants. A bottom-up approach was chosen to stay close to the words of the participants. The focus at first was on exploring the data to capture every relevant data piece within a code by using open coding (Boeije, 2014). After that, thematic analysis was conducted (Braun & Clarke, 2006). The codes were linked to different themes or categories through axial coding (Boeije, 2014). These themes or categories were developed by inductive reasoning after reading all of the transcripts (Boeije, 2014). Based on themes and categories the data were labelled until no new codes were found (Baarda et al., 2013; Boeije, 2010). For both the Carenzorgt and the unobtrusive in-home monitoring part, saturation has not been reached within the seven interviews. This first version of different themes and categories was discussed with another student, until consensus was reached. The final version of the coding scheme can be found in Appendix F. To maintain confidentiality, participant details were anonymized.

Results

3.1. Background characteristics of participants interviews

In total, seven informal caregivers of PwD have been interviewed by the researcher. See for the results Table 2. All participants were female and the mean (SD) age was 61.4 (.11) years. Only one of the participants lived together with the PwD she is caring for.

Table 2

Characteristics of the interviews with informal caregivers of PwD

Participant number	Gender	Age	Gender patient	Living situation	Hours of care per week	Usage of Carenzorgt
1	Female	77	Male	Living elsewhere	<8	No
2	Female	80	Male	Living together	24-40	No
3	Female	56	Male	Living elsewhere	8-24	Yes
4	Female	58	Female	Living elsewhere	8-24	Yes
5	Female	57	Female	Living elsewhere	8-24	Yes
6	Female	50	Male	Living elsewhere	8-24	No
7	Female	52	Male	Living elsewhere	8-24	No

3.2. Opinions towards unobtrusive in-home monitoring technology

Expectations about advantages of unobtrusive in-home monitoring technology

Expectations of the advantages of unobtrusive in-home monitoring by the informal caregiver of independently living PwD have been reported. In total, eight expected advantages were revealed, see Table 3.

Table 3

Expected advantages of unobtrusive in-home monitoring system

Advantages	Participant number	Quotation
Daily activities		
Autonomy for informal caregiver	5	<i>'Het is eigenlijk ook autonomie (...) want hiermee krijg je waarschijnlijk ook meer vrijheid.'</i>
Safety		
Safety	2, 4, 5	<i>'Je hebt hiermee een zekere mate van veiligheid.'</i>
Care specific		
Intervene faster	1, 3	<i>'Ik zag bij mijn ouders dat ik niks in de gaten had als ik langskwam, als we dit hadden kunnen volgen hadden we sneller kunnen ingrijpen.'</i>
Source of information	1, 3, 6	<i>'Dus daar komt (...) een soort dossier uit met hoe het gaat. (...) het is voor de mantelzorger dus ook een soort informatiebron.'</i>
Reduction of burden of care	1, 3, 6, 7	<i>'Het zou de zorg voor mensen daaromheen verminderen als je zou weten van goh hij wordt goed in de gaten gehouden en dat als er wat is je wordt gealarmeerd en er iemand zou komen.'</i>

First of all, one of the biggest advantages of the monitoring system, mentioned by three participants, is the large amount of information, which gives a more general picture of the wellbeing of the patient. The patient is measured all day long, which gives insight into the daily pattern of the patient, in terms of not only the physical situation but also the mental state. Because of this amount of information, things such as medication can be adapted better to the needs of the patient. This also makes it easier for the informal caregiver to manage the patient and his or her situation and the caregiver can intervene faster when necessary. Because of the knowledge the patient is always being monitored and in case of emergency an alert will be sent, the burden of care for the informal caregiver would also be reduced and there is a larger feeling of safety because of the system.

Barriers of unobtrusive in-home monitoring technology

Next to the advantages, the participants also mentioned diverse possible barriers of unobtrusive in-home monitoring systems which is shown in Table 4.

Table 4

Barriers of unobtrusive in-home monitoring system

Barriers	Participant number	Quotation
Pressure for the informal caregiver	4	<i>'Ik ben ook bang dat je als mantelzorger geneigd bent om er veel eerder heen te gaan omdat alles gemeten wordt en je de gegevens kunt zien.'</i>
No added value	2	<i>'Ik zie niet zo veel toegevoegde waarde ten opzichte van het systeem dat we nu hebben eigenlijk. Als er nu iets gebeurd word ik ook als eerste gebeld als ik niet thuis ben.'</i>
Patient downgraded into technical objective	1	<i>'De patiënt wordt op alle gebieden een soort meting (...) het nadeel hiervan is dat het wel heel erg technisch gaat worden en dat de patiënt een soort grafiek wordt.'</i>
Loss of privacy	1, 2, 3, 4, 5, 6, 7	<i>'Ik kan me voorstellen dat het voor de dementerende een inbreuk op hun privacy is omdat, hoe onzichtbaar dan ook, alles van ze gemeten wordt.'</i>

First of all, the system could cause more pressure on the informal caregiver. One informal caregiver explained that getting a lot of reports also could cause more stress, because it is not possible to go to the patient every time a report has been sent. A lot of information is given by the system, but it is not clear whether this always makes the situation of the caregiver any easier. For example: suppose it becomes clear that the patient needs to exercise more, it does not mean it is also possible for the caregiver to react in the most appropriate way. This could cause more anxiety for the informal caregiver because when an alarm was not heard or was heard too late, something could go wrong. Escalations are unavoidable and it is not possible to be on location faster than possible. Therefore, participants want to have a choice as to the subjects to be measured.

Finally, the large amount of information could be an advantage, as well as a barrier. It could be seen as an infringement of privacy for both patient and caregiver, because everything will be monitored. The informal caregiver for instance, would know when the patient is on the

toilet, which is not always desirable according to the informal caregivers. Other participants did not have a problem with privacy, because they feel safety is more important than privacy. Also, there is a choice to be made with whom information will be shared. Most participants wanted to share information with people involved.

In conclusion, privacy is a big issue when talking about unobtrusive in-home monitoring, albeit most participants put safety above privacy.

User requirements of unobtrusive in-home monitoring technology

The informal caregivers of PwD have mentioned a number of needs that has to be taken into account when building the system, see Table 5.

Table 5

Requirements regarding the unobtrusive in-home monitoring system

Requirements	Participant number	Quotation
Personalize to patient	1, 3, 5, 6, 7	<i>'Dit verschilt ook per persoon, want voor sommige mensen is het heel fijn dat ze de hele tijd in de gaten gehouden worden en dat voelt veilig, terwijl je het voor een ander juist onzichtbaar moet maken.'</i>
Personalize to phase of dementia	4, 6	<i>'Ik denk dat het ook afhangt van het stadium en de fase van de dementie wat nodig is.'</i>
Add GPS	4, 5	<i>'Zo'n GPS is wel heel handig. Dan weet je ook waar ze is, en dan kun je dus ook zien of ze heel lang op dezelfde plek is.'</i>
Safety	2, 4, 5	<i>'Veiligheid is gewoon het aller belangrijkste (...) Als dit de veiligheid verbetert, vind ik dat belangrijker dan de privacy.'</i>

First of all, the system has to be adapted to the patient and the informal caregiver, because every patient has different needs. For example the need for monitoring falling, hygiene or time in bed differs per person. According to different participants, what the system should measure depends on the topics the caregiver is concerned about, next to the amount of time the caregiver spends with the patients. When someone is always near the patient, some topics are not necessary to measure. One solution proposed by a participant is that a system should be focused on one specific person and that two or three components have to be measured over a certain period instead of continuous measuring. Another suggestion was to adjust the system not only to the specific patient, but also to the phase and the degree of the dementia the patient is in.

Monitoring targets

The interviewed informal caregivers have different opinions on which targets they would like to monitor. The number of different given answers can be found in Table 6.

Table 6
Opinions of participants about monitoring targets

Monitoring target	+ (Yes)	- (No)	? (Not sure)
Daily activities			
Walking	2 (29%)	4 (57%)	1 (14%)
Excursions	2 (29%)	3 (43%)	2 (29%)
Personal hygiene	5 (71%)		2 (29%)
Food	5 (71%)	2 (29%)	
Social interaction with others		4 (57%)	3 (43%)
Use of phone	2 (29%)	2 (29%)	3 (43%)
Day- and night rhythm/sleeping pattern	6 (86%)	1 (14%)	
Safety			
Falling	7 (100%)		
Dementia-specific			
Cognitive decline	2 (29%)	5 (71%)	
Physical decline	2 (29%)	5 (71%)	
Agitation	4 (57%)	2 (29%)	1 (14%)
Apathy	3 (43%)	4 (57%)	
Negative mood (fear, depression)	3 (43%)	4 (57%)	
Positive mood (happiness, relaxation)	2 (29%)	4 (57%)	1 (14%)
Nocturnal unrest	5 (71%)	1 (14%)	1 (14%)

Table 6 shows that informal caregivers of PwD see monitoring falling as valuable. Participant one and two mentioned their loved one with dementia has an alarm around their necks, but when falling they are possibly not able to press that button. Therefore, automatic detection of falling would be interesting for the informal caregivers of PwD. Personal hygiene is also often seen as convenient, especially when it is doubtful if the patient uses the bathroom on time. Nocturnal unrest and the day- and night rhythm of the patient are also seen as valuable to measure, because this rhythm is often more disturbed. Informal caregivers do not always have the possibility to be present with the patient, so they are not always aware of the day- and night rhythm of the patient. Monitoring this would therefore be useful. Participants are less interested in monitoring cognitive- and physical decline. Some participants mentioned they can monitor this decline themselves, because they know their loved ones well. Measuring those declines do therefore have no added value.

3.3. Experiences of informal caregivers of PwD with the healthcare platform Carenzorgt

This research question will be answered using both the results of the interviews and the survey.

Participant characteristics of survey

In total, 7118 informal caregivers of PwD completed the survey about Carenzorgt. Table 7 shows an overview of the relevant characteristics. There were 1514 male (21%) and 5579 female (78%) participants with a mean (SD) of 58.7 (.9) years. The majority (97%) of the informal caregivers did not live together with the PwD they are caring for.

Table 7

Participant characteristics of informal caregivers of PwD of survey about Carenzorgt

	Survey study n= 7118	***Low burden n= 3559	***High burden n= 3559	<i>P-value</i>
Age, mean (SD)	58.7 (9.0)	58.1 (8.8)	59.3 (9.2)	
Gender (N, %)				
Male	1514 (21)	780 (22)	734 (21)	.25
Female	5579 (78)	2770 (78)	2809 (79)	.60
Unspecified	17 (1)	6 (0)	11 (0)	.22
Living situation (N, %)				
Living together	235 (3)	35 (1)	200 (6)	.00
Living elsewhere	6882 (97)	3523 (99)	3359 (94)	.05
*Hours of care (N, %)				
< 8 hours	3824 (54)	2652 (74)	1172 (33)	.00
8 – 24 hours	2799 (39)	820 (23)	1979 (56)	.00
24 – 40 hours	290 (4)	58 (2)	232 (6)	.00
> 40 hours	204 (3)	28 (1)	176 (5)	.00
**Burden of informal care, mean (SD)	2.5 (1.1)			
Usage of Carenzorgt (N, %)				
< once per week	248 (4)	145 (4)	103 (3)	.01
1 – 6 times per week	1991 (28)	1114 (31)	877 (25)	.00
> 6 times per week	4879 (68)	2300 (64)	2579 (72)	.00

* Hours of care per week, ** Burden of informal care tasks, ranges between (1) none to very small extent, (2) small extent, (3), average extent, (4), large extent and (5), very large extent, *** Low burden <2.5, high burden, >2.5.

Table 8 shows the results of the survey regarding the satisfaction of the informal caregivers of PwD with Carenzorgt. The mean score for most items varied between 1.6 and 2.0, which means that overall, participants are satisfied with Carenzorgt. The highest scores (M=1.7, SD=.7) show participants think Carenzorgt is easy to use and makes it more easy to stay informed about the person they are caring for. Participants score higher on the statement ‘*with Carenzorgt it is easier for me to maintain contact with other informal caregivers*’ compared to other statements (M=2.4, SD= 1.0). However, in general, participants intend to keep using Carenzorgt in the future.

Table 8
Overview categories survey about Carenzorgt

Category/item*	N	M (SD)	Low burden of care, M (SD)**	High burden of care, M (SD)**	P-value
Usability					
<i>Carenzorgt is easy to use</i>	7103	1.7 (.7)	1.7 (.7)	1.9 (.8)	.00
<i>Carenzorgt is built in a logical way</i>	7085	1.9 (.7)	1.9 (.7)	2.1 (.8)	.00
Communication					
<i>With Carenzorgt it is easier for me to maintain contact with other informal caregivers</i>	5391	2.4 (1.0)	2.3 (.9)	2.6 (1.1)	.00
<i>With Carenzorgt it is easier for me to maintain contact with other informal caregivers with professional caregivers</i>	6807	2.1 (1.0)	2.1 (.9)	2.3 (1.1)	.00
Care process					
<i>Carenzorgt provides a better overview of the care process</i>	7051	2.0 (.8)	1.9 (.7)	2.1 (.9)	.00
<i>By using Carenzorgt it is easy to stay informed of the situation of my loved one</i>	7083	1.7 (.7)	1.6 (.7)	1.9 (.8)	.00
<i>With Carenzorgt the organisation of care tasks is easier</i>	6704	2.2 (.8)	2.1 (.8)	2.4 (.9)	.00
Trust in the system					
<i>I am confident that Carenzorgt will handle our data with care</i>	7091	1.8 (.6)	1.8 (.6)	1.9 (.7)	.00
Intention of use					
<i>I would like to continue using Carenzorgt in the future</i>	7048	1.6 (.6)	1.6 (.6)	1.7 (.7)	.00

*All items and scales are based on a Likert score ranging from (1) totally agree, (2) agree, (3), neutral, (4), disagree, (5), totally disagree. ** Low and high burden of care are split by median at 2.5.

One remarkable result are the significant differences for almost all different statements about Carenzorgt between participants with low burden of care and high burden of care. On all statements about Carenzorgt, informal caregivers of PwD with low burden of care scored significantly lower on the different items than participants with high burden of care ($p=.00$), which means participants with low burden of care are more positive about Carenzorgt.

Table 9 shows that 63% of the users of Carenzorgt have made a connection with other informal caregivers on Carenzorgt. Also, 61% of the informal caregivers of PwD using Carenzorgt are connected with at least one healthcare provider on Carenzorgt. Overall, participants are satisfied with those connections.

Table 9
Connection to other caregivers on Carenzorgt

Component*	N (%)	M	SD
I have connected Carenzorgt with at least one informal caregiver	4457 (63)	4.0	.8
I have connected Carenzorgt with a healthcare provider	4353 (61)	4.0	.9

*All opinions are scaled on a Likert score ranging from (1) totally dissatisfied, (2) dissatisfied, (3), neutral, (4), satisfied, (5), totally satisfied.

Usage and functions of Carenzorgt

Carenzorgt was used at least once a day by the majority of participants. Table 10 shows an overview of the different functions of Carenzorgt.

Table 10
Satisfaction with different components of Carenzorgt

Component*	Users within last month N (%)	Opinion of component M (SD)
Calender	4006 (56.3)	3.9 (.9)
Messages	5145 (72.3)	3.9 (1.0)
Notes	2570 (36.1)	3.8 (1.0)
Files	6554 (92.1)	4.1 (.9)

*All opinions are scaled on a Likert score ranging from (1) totally dissatisfied, (2) dissatisfied, (3), neutral, (4), satisfied, (5), totally satisfied.

The function *files* was used most within the last month before the survey had been conducted. The function *files* was used by 92% of the participants. The mean (SD) score is 4.1 (.9), which means participants are satisfied with this function. All mean scores of the different functions of Carenzorgt are around 3.9, which means participants are satisfied with all different functions.

During the interviews, different positive comments on Carenzorgt have been made by the informal caregivers of PwD. Table 11 shows those positive points of all functions.

Table 11
Opinions about different functions of Carenzorgt

Function	Participant number	Quotation
Messages		
More involvement	2, 4, 6, 7	<i>'Het is handig als je even in het systeem een berichtje kunt sturen en dat iedereen betrokken is.'</i>
Stay informed	3, 4, 5, 6, 7	<i>'Het is handig dat (...) je een beetje een beeld hebt van hoe het gaat met hem.'</i>
Calender		
Clear function	1, 2, 5, 6	<i>'Kalender is heel duidelijk. (...) dit is voor zowel ons als mantelzorgers als voor de patiënt zelf handig.'</i>
Easy to make appointments	1, 2, 6, 7	<i>'Wij verschuiven ons werk wel eens, maar weet je van te voren dat pietjepuck van plan is om langs te komen dan kun je daar een definitieve afspraak van maken.'</i>
Better overview	1, 6, 7	<i>'Beter overzicht, qua kalender, qua afspraken. Overzicht in wie wat wanneer op bezoek gaat bijvoorbeeld.'</i>
Notes		
Documentation	2	<i>'Mijn moeder vraagt of ik mee wil naar de dokter, want dan kan ik noteren wat er gezegd wordt. Voor mijn zussen zou het heel handig zijn'</i>

Express feelings	2, 6	<i>dat ze dan kunnen lezen wat ik genoteerd heb en hoe het bij de dokter was.'</i> <i>'Het is altijd goed om een plek te hebben waar je je frustraties kunt uiten.'</i>
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First, five participants mention to stay better informed because of the function *messages* and more involved with their patients. Participants explain they like having the possibility of reading what their patient eats, does or how they feel during the day. Also the participants mention they like that they can stay informed of the situation of their loved one, while not living nearby. Next, messages can be sent at the time they prefer. The *message* function therefore also ensures involvement between different parties.

The function *calendar* is clear and it makes communication easier, because everyone connected can see this calendar. The calendar helps making appointments more smoothly, next to building a schedule of visitation. When everyone can see the appointments made for or with the patient, it is easier to schedule the visits.

One striking result is that all positive feedback of Carenzorgt about the *calendar* function was given by the participants who do not use Carenzorgt themselves. The people who do use Carenzorgt, think this function is not relevant for them. They claim they do not use the calendar, because the professional caregivers do not use it either, so it has no added value.

The results of the survey show most participants use the function *files* and were positive about this function. However, only one of the interviewed participants uses this function. Thus little can be said about *files*.

Overall, informal caregivers are very positive about the different functions of Carenzorgt.

Ease of use of Carenzorgt

All participants who were interviewed were positive about the ease of use of Carenzorgt. Table 12 shows four positive points about the ease of use.

Table 12
Ease of use of Carenzorgt

Ease of use	Participant number	Quotation
Fine pictures	7	<i>'Ik vind het hele mooie afbeeldingen. Mooi, duidelijk, leuke kleur.'</i>
Clear program	1, 2, 3, 4, 5, 6, 7	<i>'Ik vind het heel overzichtelijk. Het ziet er (...) ook voor de oudere mensen die het gebruiken ook heel toegankelijk uit.'</i>
No unnecessary information	2, 3	<i>'Er is niks dat ik niet nuttig zou vinden.'</i>

First of all, participants are pleased with the clarity of the program because the program uses a step-by-step approach to guide the user. The different options from which the user can choose are clear and there are only a few different functions, which makes the platform clear, logical to work with and easy to manage. One participant mentioned that the elderly using Carenzorgt

can also access the program. Another participant pointed out that the clarity provides some safety to the informal caregiver.

Overall, participants think Carenzorgt is easy to use, has friendly pictures and contains no unnecessary information.

Communication with Carenzorgt

Table 13

Communication with formal- and other informal caregivers with Carenzorgt

Communication with other caregivers	Participant number	Quotation
Positive		
Sharing of information	1, 2, 5, 6, 7	<i>'Je kunt gewoon even kijken naar de dagelijkse dingetjes en als er wat bijzonders is gebeurd kun je dat even berichten.'</i>
Efficiency	2, 7	<i>'Als je met meer bent, is het handig dat je snel en efficiënt kunt handelen.'</i>
Safety for the patient	1	<i>'Voor de patiënt is het belangrijk dat hij een veilig bastion om zich heen heeft. (...) de mantelzorgers moet deze veiligheid wel voor hem creëren.'</i>
Responsibility	7	<i>'Iedereen weet waar het staat dus het is gewoon kijk erin, doe er wat mee en dan is het iedereen's eigen verantwoordelijkheid om er iets mee te doen.'</i>
Stay informed	2, 3, 6	<i>'(...) je kunt toch even lezen van hoe gaat het met hem, wat is zijn gewicht (...).'</i>
Negative		
Incompleteness	3, 4, 5	<i>'Ze zetten er alleen niet alles in blijkt.'</i>
Late responses	4, 5	<i>'(...) het kan soms wel een paar dagen duren voordat iemand antwoord geeft.'</i>
Not applicable		
Does not apply	3, 4, 5, 6	<i>'Wij deden dat met een whatsapp groepje en dat was voldoende.'</i>

Table 13 shows all positive and negative comments on the communication with formal caregivers and other informal caregivers with Carenzorgt. In total, five positive points have been mentioned. Four of the interviewed participants are not interested in using Carenzorgt, because they use Whatsapp for their communication.

The first positive point is the sharing of information. Participants think it is handy to share information with other formal and informal caregivers with the program because all the information is stored in one place where everyone involved can read it in their own time. Information about the patient can be shared easily, which is important when multiple people care for that person. With Carenzorgt, information can be read at any convenient time, which ensures that people can stay informed.

However, two negative points were mentioned about communication. First, the formal caregivers do not write down all the information in the system, making it incomplete. Also,

the professional caregivers often respond late to messages, which irritates the sender (the informal caregiver) of the message.

Trustworthiness of Carenzorgt

Table 14

Trustworthiness of Carenzorgt

Trustworthiness	Participant number	Quotation
Positive		
Own choice to share information	1, 6	<i>'Ik vind het heel goed dat je zelf in de hand hebt met wie de informatie gedeeld kan worden.'</i>
Trust	2, 3, 4, 5, 6, 7	<i>'Ik heb een wat naïef vertrouwen. Er kan altijd een datalek ontstaan maar ik denk dat het goed is.'</i>
Protection	1	<i>'Ik vind het goed dat er privacy zit voor bijvoorbeeld medicatie, en dat er bepaalde dingen wel beschermd worden'</i>
Negative		
Needs more clarity	3	<i>'...ik zou wat meer terugkoppeling willen. Iets meer dat ik weet wat gebeurt er nou eigenlijk mee'</i>

The participants who were interviewed revealed three positive points about the trustworthiness of Carenzorgt, in addition to one negative point, which can be seen in Table 14. First, some participants were satisfied with the possibility to choose with whom to share information, because this feels like privacy is respected. Participants trust the system, without specifically mentioning reasons linked to the system itself, but privacy-law reasons. One participant mentioned:

'Ik denk dat die privacy wet behoorlijk streng is geworden. Ik neem aan dat die regels ook hiervoor gelden.'

Another participant would like to get more feedback about what happens with the information stored in the system.

Discussion

4.1. Main findings

This study had two different goals.

Unobtrusive in-home monitoring

The first goal of this study was to identify needs, barriers and requirements of informal caregivers of PwD relating to unobtrusive in-home monitoring. This study resulted in different possible positive points or needs of the system: autonomy for the informal caregiver, more safety for the patient, the possibility to intervene faster, the system is a source of information and the burden of care of the informal caregiver could be reduced. Also, different barriers were mentioned: the system could cause more pressure for the informal caregiver, the system provided no added value, the patient will be downgraded into a technical objective and there will be loss of privacy for both the patient and the informal caregiver. According to the participants, the monitoring system has to meet different requirements: it should be personalized to individual patients and to the different phases of dementia, GPS should be added and the system should provide safety for the patient.

Interestingly, the amount of information is named both an advantage and a barrier. As an advantage, the amount of information gives a more general picture of the wellbeing of the patient and because of the all-day measurement, insight is given in the daily pattern of the patient. Since not only the patient's physical situation, but also their mental state are measured, medication can be adapted to the patient's needs. However, the large amount of information can also serve as a barrier, when it causes the informal caregiver more stress, for instance when an alarm is missed or the caregiver does not know how to respond correctly. Earlier research of Lauriks and Colleagues (2007), a systematic review for unmet needs of PwD and their informal caregivers, identified that the need for general and personalized information is a must for both PwD and their informal caregivers. However, this research only focused on general dementia characteristics instead of personal problems (Lauriks et al., 2007). More recent research shows informal caregivers feel the need for having information about the diverse symptoms of the disease of their patient, but the available information is often insufficient (Peterson, Hahn, Lee, Madison, & Atri, 2016). Information about the patient, the disease and its course can help informal caregivers improve their ability to empathize with their loved one and avoid taking the changes of their loved one due to dementia personally (Boots, Wolfs, Verhey, Kempen, & de Vugt, 2015). Information also enables informal caregivers to help their loved ones in specific situations (Kjallman Alm et al., 2014). However, in this study informal caregivers state the large amount of information can also be a barrier. Kjallman Alm and colleagues also reported this as a problem (2014). A possible explanation is the subject of the information. The information is often about the decline of the patient and can therefore be understood as negative, which may be hard to accept (Boots et al., 2015; Jahn & Brühl, 2019). Information should therefore only be relevant to help the informal caregiver assist the patient in daily care (McCabe, You, & Tatangelo, 2016).

From this research, privacy has proven to be a big issue for the in-home monitoring system. Nijhof (2013) already predicted the privacy issue by stating the ways in which information is made visible to others and shared is a sensitive issue. Yusif, Soar and Hafeez-Baig (2016) also found that privacy is a big concern of the elderly when adopting assistive technologies. Earlier research describes two different types of privacy; ‘personal privacy’, which is the right to not being monitored or the right to be left alone, and ‘data privacy’, the right to control someone owns data (Remmers, 2010; Tiwari, Warren, Day, & McDonald, 2010; Dorsten, Sifford, Bharucha, Mecca, & Wactlar, 2009). However, people with dementia become gradually less capable to make their own decisions in protecting their own sensitive data due to dementia, which might make giving permission difficult. Therefore, there is the need for standardized privacy protection (European Commission, 2012). There are official rules within in the Netherlands and the rest of the European Union regarding privacy; the ‘*Algemene Verordering Gegevensbescherming (AVG)*’ or ‘General Data Protection Regulation (GDPR)’ is applicable (Autoriteit Persoonsgegevens, 2019a). This law has strengthened and expanded privacy rights. Under this law, organizations can be obligated to carry out a Data Protection Impact Assessment (DPIA)(Autoriteit Persoonsgegevens, 2019b). This is an instrument to identify the privacy risks of data processing in advance and to be able to take measures to reduce these risks. Carrying out a DPIA is obligatory when data processing is likely to pose a high privacy risk for people whose data will be processed. One example is when a care institute uses unobtrusive camera surveillance to protect their patients: in that case the DPIA always should be carried out. Therefore, when the unobtrusive in-home monitoring system will be implemented in the future, a DPIA should be performed beforehand to reduce the privacy risks.

Carenzorgt

The objective of the second part of this research was to gain insight in the usage and user experiences of the platform Carenzorgt by informal caregivers of PwD and to find strengths and weaknesses or points of improvement of the healthcare platform. This research revealed that informal caregivers are overall positive about the healthcare platform Carenzorgt. Carenzorgt is easy to use because the program is designed as a step-by-step approach and the different functions are clear. All caregivers can stay informed thanks to the connection between all informal- and professional caregivers. Also, the participants of this research intend to use Carenzorgt in the future. Overall, Carenzorgt is positively assessed by informal caregivers of PwD.

Remarkable were the significant differences between informal caregivers who have a low burden of care and caregivers with a high burden of care on all different statements. According to earlier research, informal caregivers who live together with their loved one report the highest burden of care (Peeters et al., 2014). Because only 3% of all participants in this study lived together with their loved one, no statement can be made about the results of this study. Also according to earlier research, female informal caregivers experience more caregiver burden than male informal caregivers (Etters, Goodall, & Harrison, 2008; Chan, 2010; Chiao et al., 2015). However, in this research no significant differences in the burden of care were found between male and female caregivers. Of all participants with low burden of care, 78% were female, while almost the same percentage, 79%, of all people with high

burden of care were female. In addition to this, Chiao, Wu and Hsiao (2015) found earlier that also spouses and adult children caring for their family members experience the greatest burden. Unfortunately, in this research these characteristics have not been taken into account, therefore no conclusion can be drawn on this point. One possible explanation of the significant differences between informal caregivers with low- and high burden of care are the hours informal caregivers spend on caring for their loved one. People with high burden of care spend three times more often between 24 and 40 hours of care per week than people with low burden of care, and five times more often over 40 hours of care per week. Also, 74% of people with low burden of care spend less than eight hours of care per week, while only 33% of people with high burden of care spend this amount of time to care. This means people with high burden of care spend gradually more time per week on caring. The burden of care is one of the factors that cause the decrease of the load-taking capacity of the informal caregiver. Using an instrument like Carenzorgt could be experienced as 'more work' and thus stressful. When one experiences more burden of care, their window of tolerance is smaller and every task could be experienced as an extra load. One of the first signs of being overloaded is the caregiver's feeling of never being free of responsibilities (de Boer, Oudijk, Timmermans, & Pot, 2012). The next phase is having difficulties reconciling household, family and work and a sign of an even heavier felt burden is when experiencing conflicts at home or at work. These signs can be noticed as a result of the care tasks, specifically, and when the health of the informal caregiver deteriorates (de Boer, Plaisier, & de Klerk, 2019). In their model (see Figure 2), Van Dijk, van Dormolen, Kompier and Meijman (1990) describe the power of processing (i.e. the load-taking capacity) as dynamic. The model assumes a relation between the power of processing and burdening factors. In the case of Carenzorgt, this means informal caregivers with high burden of care experience a high number of burdening factors and show symptoms of burden, which lowers their load-taking capacity. Therefore, using Carenzorgt could be experienced as an extra factor of burden.

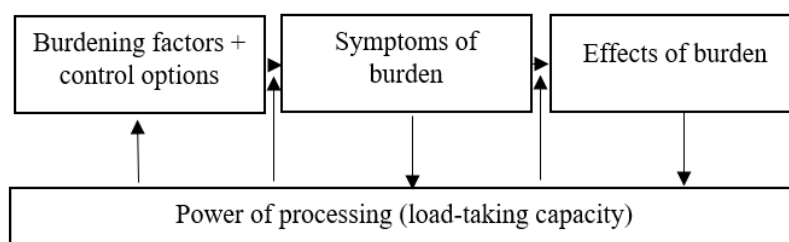


Figure 2. Burden- load-taking capacity model of Van Dijk and colleagues (1990)

Interestingly, participants were not as positive about the communication with other informal caregivers and formal caregivers via Carenzorgt compared to other functions of Carenzorgt. Participants mentioned receiving late responses from formal caregivers on the platform, besides incompleteness of information, because formal caregivers do not put all information in the program. A possible explanation for the limited use of or more negative opinion on the function of the platform, might be a mismatch between informal- and formal caregivers' needs and technological requirements of Carenzorgt (Boessen, Verwey, Duymelinck, & van Rossum, 2017). Also, according to earlier research by Krijgsman and colleagues (2016) different formal caregivers use different client registrations systems, which lack the

possibility to be integrated or connected to different applications in order to exchange patient information in the best possible way. Because of the inability of integrating the different applications information should be doubly reported, which is often more work for the formal caregiver (Krijgsman, Swinkels, van Lettow, de Jong, Out, & Friele, 2016). Carenzorgt should therefore be able to make connections with other systems of care registration to make the exchange of information more easy.

4.2. Strengths and limitations of the conducted study

Regarding this research some strengths and limitations will be mentioned. Firstly, multiple data sources were used during this research, including qualitative- and quantitative data. All data sources complemented each other, which showed a broad perspective of the opinions of the users of Carenzorgt. The interviews allowed the researcher to get more information than the survey provided and to go more indepth. Secondly, a strength of this research is the anonymity of the participants. The participants of the survey were all assigned a research number and their personal information was not visible. The results of the survey were only put on a private drive of the University of Twente, to which only the researcher and the supervisor of the project had access. The information of the participants was therefore kept private. The participants of the interview were also assigned a research number, so that their data could not be traced back to a person.

This research contains some limitations as well. In the first place, the study obtained results over a small, particular period of time. The survey was online for only three days in the beginning of June 2019. In total, Carenzorgt has around 320.000 users of which 16479 users filled in this survey during those three days. Although this seems like a high number, it means only 5% of the users of Carenzorgt have filled in this survey. It is therefore not clear if the results are generalizable to all informal caregivers of PwD using Carenzorgt. Not all users use Carenzorgt every day, so there is a possibility not all participants have seen the notification about the survey. It is also possible that the participants who are less capable of using technology did not fill in the survey, because they don't know how it works. Finally, it is possible and might be logical to suspect that a large portion of the people who finished the survey, are people who use Carenzorgt actively. Therefore the results can also not be generalized to all informal caregivers of PwD.

Another limitation of the qualitative part of this study is the fact that there has not been saturation. Therefore, the results are not complete. Because of the restricted period in which the interviews were to be conducted, it wasn't possible to interview more participants or to elaborate on the questions. Also, only three of the seven interviewed participants use the platform Carenzorgt. Big differences were found between the experiences of the users of Carenzorgt and the opinions of the non-users, for instance on the calendar-function. All three participants using Carenzorgt did not use this function, while the five participants who did not use Carenzorgt think this would be the most useful function. More time is needed to achieve saturation and more participants.

The third limitation is that the data was coded and analyzed by only one researcher. The data and the analysis are therefore vulnerable to potential bias, for which the proposed analysis must be tested to have inter-rater reliability. It would have been better to have made

use of multiple coders to increase the reliability of the study. It is for example possible that participants have given socially desirable answers. However, participants also have mentioned barriers of both systems and were critical instead of only positive. Therefore, the risk of participants only having given socially desirable answers is estimated to be low.

Finally, especially the part of this research about unobtrusive in-home monitoring was of an exploratory nature instead of focusing on testing hypotheses. Therefore, research questions remained open instead of specific at the start of the research, which is why the materials were not assembled to fit specific research questions, but to fit the overall aim of the study.

4.3. Practical implications and future research

Unobtrusive in-home monitoring

An unobtrusive in-home monitoring system should be adjusted to each different patient, where guarantee the privacy of both the patient as well as the informal caregiver is most important. It should be clear which exact factors will be monitored and how to deal with the data acquired by the system. Some possible explanations and solutions have been mentioned in this thesis, but the most valuable ones came from the participants who have been interviewed personally. However, since saturation was not reached during this study, not all opinions about privacy have been given. Developing an overview on the needs of informal caregivers of PwD about in-home monitoring systems is important for effective implementation. Therefore, it is recommended to do more research into the needs and barriers of in-home monitoring systems. In follow-up research, not only the needs and barriers of informal caregivers are important, but also those of formal caregivers or the patients themselves. Formal caregivers often have a more objective view on the patient, which could result in other outcomes, where patients are the subjects of this unobtrusive in-home monitoring system. Interviewing the formal caregivers and patients could give more information about how they feel about the system collecting personal data.

One possible addition to the interview scheme in future research could be the use of personas. Personas are concrete, specific fictional persons representing the potential target group (i.e. user archetypes) (Van Velsen, Gemert-Pijnen, Nijland, Beaujean, & Steenbergen, 2012; Fico et al., 2019). Different personas could be created, each presenting a different type of end-user (Van Velsen et al., 2018). Personas are presented as a sort biography with detailed descriptions and can be used for multiple purposes during the design process. They give insight in the different user groups of the technology, form the basis for design and can help evaluating a design (Van Velsen et al., 2012).

Carezorgt

One negative remark about Carezorgt, made by the participants of this study, is about the connection between informal- and formal caregivers: the delayed response and/or incomplete information-sharing of the professional caregivers. Informal caregivers of PwD explain that the professional caregivers either do not use this function at all or when they do, their response is often late or incomplete. As a result, the informal caregivers also use this function less than desired. Better communication between professional caregivers and informal

caregivers is desirable to be able to offer the patient the best possible care. It would thus be beneficial to adjust the function in such a way that both parties will communicate better. To achieve this, interviewing both informal- and formal caregivers using Carenzorgt about their experiences and needs from the system could be interesting and could improve the communication between both (Parveen et al., 2018). It is recommended to involve end-users (the informal- and formal caregivers) being involved during further development of their needs and requirements. eHealth can be seen as a holistic way to support healthcare via technology. This means, the system, its content, context and stakeholders and their interdependencies should always be taken into account when designing interventions (van Gemert-Pijnen et al., 2011).

Placing the user in the center of the design process is called User Centered Design (UCD)(van Gemert-Pijnen et al., 2013; van Velsen et al., 2012). In UCD, the focus is on the needs of the user, during every phase of the design process. The CeHRes Roadmap is a framework used in the design of eHealth applications which employs UCD (van Gemert-Pijnen, Peters, & Ossebaard, 2013; Kip & van Gemert-Pijnen, 2018). This framework consists of five different phases of development. First, the needs and barriers of the users are described in the contextual inquiry, after which the values are specified. The results of the first two phases are translated into functional requirements, on which the design of the technology is subsequently based. The fourth phase is the operationalization phase, in which the technology is launched. In the last phase, both formative and summative evaluations will follow. Users are involved during the whole design process via different design techniques, such as personas. Involving users in the process could possibly lead to a more concrete plan for Carenzorgt to better adjust the application to their users.

4.4. Conclusion

This research explored the expectations of informal caregivers of people with dementia with unobtrusive in-home monitoring systems and their experiences with the healthcare platform Carenzorgt. Privacy is the main issue for unobtrusive in-home monitoring and in further research, privacy should be taken into account. Regarding Carenzorgt, it appeared that the communication between the formal- and informal caregivers could be improved. Personas can be used to get more insight in both topics.

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Appendix A – Survey about Carenzorgt

Carenzorgt

Start van blok: Inleiding

Q1 Beste gebruiker van Carenzorgt,

Hartelijk dank voor uw bereidheid om deel te nemen aan dit onderzoek naar de gebruikerservaringen met Carenzorgt. Dit is een onderzoek van de Universiteit Twente in Enschede in samenwerking met Nedap Healthcare.

Deelnemen aan het onderzoek kost ongeveer 5 minuten. Gegevens worden volledig anoniem en op veilige wijze verwerkt. Deelname aan het onderzoek is vrijwillig, wat betekent dat u op elk gewenst moment kunt stoppen met het invullen van de vragenlijst.

Indien u vragen heeft over dit onderzoek of graag meer informatie wilt ontvangen, kunt u contact opnemen met Sophie van Oudheusden, email: a.s.vanoudheusden@student.utwente.nl.

Dit onderzoek wordt uitgevoerd onder leiding van Dr. Annemarie Braakman-Jansen, email:

l.m.a.braakman-jansen@utwente.nl

Door deze vragenlijst te starten geeft u aan dat u

:- Bovenstaande informatie gelezen hebt en hiermee akkoord bent

- Vrijwillig meedoet aan het onderzoek

- 18 jaar of ouder bent

Einde blok: Inleiding

Start van blok: Achtergrondinformatie

Q1 Wat is uw leeftijd?

Q2 Geslacht

- Man (1)
- Vrouw (2)
- Anders (3)
-

Q3 Ik gebruik Carenzorgt als

- Mantelzorger (1)
- Cliënt/Patiënt (2)
-

Q4 De reden van zorg is (meerdere antwoorden mogelijk)

- Dementie (1)
- Hart- en vaatziekten (2)
- Diabetes (3)
- COPD (4)
- Ouderdom (5)
- Anders (6)
-

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Mantelzorger

Q5 Welke woonsituatie is op u van toepassing?

- Ik woon in hetzelfde huis als degene voor wie ik zorg (1)
 - Degene voor wie ik zorg woont niet bij mij in huis (2)
-

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Mantelzorger

Q6 Hoeveel uren per week verleent u ongeveer mantelzorg?

- Minder dan 8 uur per week (1)
 - 8 tot 24 uur per week (2)
 - 24 tot 40 uur per week (3)
 - Meer dan 40 uur per week (4)
-

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Mantelzorger

Q7 In welke mate ervaart u belasting van uw mantelzorg taken?

- Geen tot zeer kleine mate (1)
 - In kleine mate (2)
 - In gemiddelde mate (3)
 - In grote mate (4)
 - In zeer grote mate (5)
-

Q8 Hoe vaak gebruikt u Carenzorgt gemiddeld?

- Maandelijks (1)
- Minder dan een keer per week (2)
- 1 tot 3 keer per week (3)
- 4 tot 6 keer per week (4)
- Elke dag (5)
- Meerdere keren per dag (6)

Einde blok: Achtergrondinformatie

Start van blok: Onderdelen Carenzorgt

Q9 Onderdelen Carenzorgt

Welke onderdelen van Carenzorgt hebt u binnen de afgelopen maand gebruikt?	Wat is uw mening over deze onderdelen?				
. (1)	Zeer ontevreden (1)	Ontevreden (2)	Neutraal (3)	Tevreden (4)	Zeer tevreden (5)

Kalender (25)	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Berichten (26)	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Notities (27)	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dossier (28)	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q30 Koppeling

	Welke stellingen zijn op u van toepassing?					
	(1)	Ze er ontevreden (1)	Ontevreden (2)	Neutraal (3)	Tevreden (4)	Ze er tevreden (5)
Ik ben via Carenzorgt verbonden met ten minste één andere mantelzorger (1)	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik heb Carenzorgt gekoppeld met een zorgaanbieder (2)	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Einde blok: Onderdelen Carenzorgt

Start van blok: Stellingen

Q10 Geef aan in hoeverre u het eens bent met de volgende stellingen:

Q11 Carenzorgt is gemakkelijk te gebruiken

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Q12 Carenzorgt is op een logische manier opgebouwd

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Q13 Met Carenzorgt is de organisatie van zorgtaken is makkelijker

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Cliënt/Patiënt

Q14c Met Carenzorgt is het voor mij makkelijker om contact met mantelzorgers te onderhouden omtrent mijn zorg

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Mantelzorger

Q14m Met Carenzorgt is het voor mij makkelijker om contact met andere mantelzorgers te onderhouden omtrent de zorg voor mijn dierbare

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Cliënt/Patiënt

Q15c Met Carenzorgt is het voor mij makkelijker om contact met professionele zorgverleners te onderhouden omtrent mijn zorg

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Mantelzorger

Q15m Met Carenzorgt is het voor mij makkelijker om contact met professionele zorgverleners te onderhouden omtrent de zorg voor mijn dierbare

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Q16 Carenzorgt zorgt voor een beter overzicht in het zorgproces

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Cliënt/Patiënt

Q17c Door het gebruik van Carenzorgt is het makkelijk om op de hoogte te blijven van mijn eigen situatie

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Mantelzorger

Q17m Door het gebruik van Carenzorgt is het makkelijk om op de hoogte te blijven van de situatie van mijn dierbare

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Q18 Ik heb er vertrouwen in dat Carenzorgt zorgvuldig met onze gegevens omgaat

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Q19 Ik zou Carenzorgt in de toekomst willen blijven gebruiken

- Helemaal mee eens (1)
 - Mee eens (2)
 - Noch eens noch oneens (3)
 - Niet mee eens (4)
 - Helemaal niet mee eens (5)
 - Niet van toepassing (6)
-

Q20 Laatste vraag: Heeft u nog toevoegingen?

Deze vraag weergeven:

If Ik gebruik Carenzorgt als = Mantelzorger

And De reden van zorg is (meerdere antwoorden mogelijk) = Dementie

Q31 Wij vinden het erg belangrijk om mantelzorgers te kunnen betrekken bij het ontwikkelen en verbeteren van technologie die ondersteuning kan bieden. Zouden wij u mogen benaderen voor toekomstig onderzoek? Zo ja, dan kunt u hieronder uw e-mailadres voor ons achterlaten (vrijwillig). Vergeet niet om naar de volgende scherm te gaan om de vragenlijst af te sluiten.

Einde blok: Blok 3

Appendix B – Email with explanation of study

Beste heer/mevrouw,

Ik ben Sophie van Oudheusden en ik studeer momenteel de master Health Psychology & Technology aan Universiteit Twente in Enschede. Vanuit de universiteit doe ik onderzoek naar de wensen en ervaringen van mantelzorgers van een thuiswonende dementie patiënt. Mensen met dementie wonen tegenwoordig langer thuis, wat veel voordelen biedt, maar wat voor de mantelzorger belastend kan zijn. Momenteel worden er daarom methoden ontwikkeld om het leven van mantelzorgers makkelijker te maken door bijvoorbeeld meer tijd over te houden voor eigen dingen naast de zorg.

Het onderzoek dat ik uitvoer bestaat uit twee delen.

1) De meeste mensen gebruiken tegenwoordig een online systeem om contact te onderhouden met zorgprofessionals of andere mantelzorgers. Ook kan via deze systemen informatie worden gedeeld over de zorg voor de patiënt en de patiënt zelf. Een van deze systemen is bijvoorbeeld Carezorgt. Ik ben benieuwd naar de ervaringen met deze systemen en ik hoor hierover graag de punten die als positief of negatief ervaren worden. Ook wanneer u geen gebruik maakt van een systeem kunt u deelnemen aan het onderzoek.

2) Daarnaast wordt momenteel gekeken naar het gebruik van niet-zichtbare sensortechnologieën. Dit is een systeem dat momenteel nog niet in de praktijk bestaat, maar wat ontwikkeld gaat worden. Dit zijn bijvoorbeeld sensoren die in de stoel of in het bed worden geplaatst, die bijvoorbeeld kunnen meten wanneer vaak de patiënt valt. Het systeem geeft informatie over het dagelijks leefpatroon, het gedrag en de stemming van de patiënt. Tijdens het interview zal ik meer voorbeelden geven. De algemene doelstellingen zijn:

- Het ondersteunen van mantelzorgers en zorgverleners in hun zorgverantwoordelijkheden door een betere toezicht op gedrag, welzijn en cognitieve en fysieke achteruitgang van de dementerende oudere
- Het optimaliseren van langer zelfstandig en veilig thuis wonen van dementerende oudere

Ik ben vooral geïnteresseerd in uw kijk hierop: denkt u dat het veilig is? Zou het kunnen helpen? Wat zou het systeem volgens u wel en niet moeten meten?

Het interview dat ik met u zal uitvoeren kan zowel telefonisch als op een locatie naar keuze, en zal maximaal één uur duren.

Ik wil u graag uitnodigen om deel te nemen aan dit onderzoek. Met het onderzoek wordt een beter beeld verkregen van de behoeften van mantelzorgers. Door het delen van uw mening en verwachtingen wat betreft 'niet-zichtbare' sensortechnologieën, kunt u bijdragen aan waardevolle informatie en kennis op dit gebied.

Mocht u geïnteresseerd zijn om deel te nemen aan het onderzoek of iemand kennen die geïnteresseerd is, wil u vragen contact met mij op te nemen: a.s.vanoudheusden@student.utwente.nl of 06-36495621

Dit onderzoek wordt uitgevoerd onder leiding van Dr. Annemarie Braakman-Jansen, email: l.m.a.braakman-jansen@utwente.nl

Met vriendelijke groet,
Sophie van Oudheusden

Appendix C – Informed consent

Informed Consent

Toestemmingsverklaringformulier (informed consent)

Titel van de studie: Carenzorgt en sensortechnologieën

Verantwoordelijke onderzoeker: Sophie van Oudheusden

In te vullen door de *deelnemer*:

	Ja	Nee
Ik bevestig dat ik goed ben geïnformeerd over de studie en dat ik de informatie, het doel en het verloop van de studie begrijp. Ik ben in de gelegenheid geweest om vragen te stellen. Deze vragen zijn naar mijn tevredenheid beantwoord.	<input type="checkbox"/>	<input type="checkbox"/>
Ik neem vrijwillig deel aan deze studie en ik begrijp dat ik op elk gewenst moment mijn deelname aan de studie kan beëindigen.	<input type="checkbox"/>	<input type="checkbox"/>
Ik geef toestemming voor het maken van audio opnames tijdens het interview	<input type="checkbox"/>	<input type="checkbox"/>
Ik ben me er van bewust dat mijn gegevens op een anonieme en veilige manier worden verwerkt	<input type="checkbox"/>	<input type="checkbox"/>
Ik begrijp dat de informatie die ik geef gebruikt zal worden voor het verbeteren en/of ontwikkelen van zorgsystemen en sensortechnologieën.	<input type="checkbox"/>	<input type="checkbox"/>
Ik geef toestemming voor het anoniem plaatsen van mijn quotes in het onderzoek	<input type="checkbox"/>	<input type="checkbox"/>

Naam deelnemer:

Datum:

Handtekening deelnemer:

In te vullen door de *uitvoerende onderzoeker*

Ik heb een mondelinge toelichting gegeven over de studie. Ik zal resterende vragen over de studie naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan deze studie geen nadelige gevolgen ondervinden.

Naam uitvoerend onderzoeker:

Datum:

Handtekening uitvoerend onderzoeker:

Appendix D – Interview scheme

Plaats:

Datum:

Opmerkingen:

Introductie

Allereerst wil ik u bedanken dat u deel wilt nemen aan dit onderzoek. Dit onderzoek is van de Universiteit Twente en maakt deel uit van een groter promotie onderzoek. Dit interview zal bestaan uit twee delen waarbij een aantal onderwerpen stap voor stap behandeld zullen worden. Hiervoor hebben wij ongeveer één uur de tijd.

Het eerste onderdeel gaat over het gebruik van systemen voor de zorg van uw dierbare. Een voorbeeld van een systeem dat gebruikt zou kunnen worden is het healthcare platform Carenzorgt. Ik zal tijdens dit interview vragen naar uw ervaringen hiermee en/of aan de hand van plaatjes laten zien hoe dit eruit ziet.

Het tweede onderdeel heeft te maken met het langer zelfstandig thuis wonen van mensen met dementie. Dit kan de levenskwaliteit van mensen met dementie en hun mantelzorgers namelijk verbeteren en kosten in verband met ouderenzorg verlagen. Zelfstandig en veilig wonen met dementie terwijl de levenskwaliteit van zowel patiënten als mantelzorgers wordt gewaarborgd kan echter een uitdaging vormen. Het doel van de Universiteit Twente is het om een beter inzicht te krijgen in hoe innovatieve monitoring-technologie gebruikt kan worden om het "thuis blijven wonen" te optimaliseren, de zorglast te verminderen en autonomie van mensen met dementie op een positieve manier te beïnvloeden. Hiervoor zijn wij met name benieuwd naar:

- De behoeftes en barrières rondom een mogelijke inzet van innovatieve monitoring-technologie en randvoorwaarden: In hoeverre zou zo een systeem kunnen inspelen op uw onvervulde behoeftes en waar liggen volgens u de grenzen?

Wij willen dat de technologie die wij ontwikkelen namelijk goed aansluit bij de werkelijkheid en zijn daarom heel blij dat u graag mee zou willen denken.

Het interview zal in totaal dus ongeveer één uur duren. Mocht er tijdens het interview een vraag onduidelijk voor uw zijn, kunt u dit altijd aangeven en ik zal mijn best doen om deze voor u te verduidelijken. Mocht er bovendien een vraag zijn die uw liever niet wilt beantwoorden, wil ik u vragen om dit aan te geven, wij zullen dan doorgaan met de volgende vraag.

Toestemming geluidsopname

Om geen enkele opmerking te missen zou ik graag een geluidsopname willen maken van het interview. De geluidsopname zal anoniem worden uitgeschreven. In het eindverslag zullen de gegevens zodanig worden gepresenteerd dat ze niet herleidbaar zijn tot persoon. Gaat u akkoord met het opnemen?

Informed consent

Daarnaast wil ik vragen om het toestemmingsformulier te ondertekenen. Hiermee verklaart u op de hoogte te zijn van het doel en de procedure van het interview. Tevens staan in dit formulier uw rechten gedurende het onderzoek vermeld.

Hebt u nog vragen tot zo ver? Dan ga ik nu de geluidsopname starten.

Deel 1: Achtergrond

Wij zullen beginnen met een aantal algemene vragen rondom uw situatie, uw dierbare en uw zorgtaken.

1. Wat is uw leeftijd?
2. Heeft u kinderen?
 - a. Nee
 - b. Ja, thuiswonende kinderen
 - c. Ja, uitwonende kinderen
3. Hoelang bent u al mantelzorger voor uw dierbare?
4. Hoe oud is uw dierbare?
5. Weet u welke type dementie uw dierbare heeft?
6. Hoe lang speelt de dementie al?
7. In welke relatie staat u met uw dierbare?
 - a. Familielid (partner, zoon/ dochter, enkelkind...)
 - b. Buurman-/vrouw
 - c. Vriend
8. Woont u samen met uw dierbare of bent u uitwonend?
9. Hoeveel uur gemiddeld per week zorgt u voor uw dierbare?
10. Hoe ziet de zorg/ de taken rondom uw dierbare eruit? Wie is hierbij betrokken?
11. Maakt u gebruik van een zorgsysteem? Zo ja, welke?

Deel 2: Zorgsystemen

*In dit deel zal ik u een aantal vragen stellen over het zorgsysteem dat u gebruikt/het zorgsysteem Carenzorgt.
U mag te allen tijde vragen stellen indien iets onduidelijk voor uw is.*

Optie 1: WEL gebruik makend van Carenzorgt

- 1) Wat vindt u van de overzichtelijkheid van Carenzorgt?
Wat maakt dat u dit vindt?
- 2) Welke onderdelen van Carenzorgt vindt u nuttig?
En waarom?
- 3) Welke onderdelen van Carenzorgt vindt u minder nuttig?
En waarom?
- 4) Wat mist u binnen Carenzorgt?
En waarom mist u dit?
- 5) In hoeverre is volgens u de organisatie van zorgtaken makkelijker met Carenzorgt?
- 6) In hoeverre is het met Carenzorgt makkelijker om contact te houden met andere mantelzorgers?
- 7) In hoeverre is het met Carenzorgt makkelijker om contact te houden met professionele zorgverleners?
- 8) In hoeverre is het met Carenzorgt makkelijker om op de hoogte te blijven van de situatie van uw dierbare?
- 9) Wat is volgens u de toegevoegde waarde van Carenzorgt?
Wat maakt dat u dit de toegevoegde waarde vindt?
- 10) Wat zijn volgens u de knelpunten van Carenzorgt?
- 11) Carenzorgt krijg ook informatie van u en uw dierbare binnen. Wat vindt u hiervan? Weet u wat er met deze informatie gebeurt?
- 12) Heeft u het gevoel dat Carenzorgt veilig omgaat met gegevens?
Wat maakt dat u dit gevoel hebt?
- 13) Ziet u een bedreiging voor de veiligheid van uw gegevens?

Optie 2: NIET gebruik makend van Carenzorgt

Een veelgebruikt zorgsysteem is Carenzorgt. Carenzorgt heeft als doelstellingen 1) het hebben van een veilig eigen netwerk 2) waarbinnen informatie gedeeld kan worden en men elkaar op de hoogte kan houden, 3) Het maken van afspraken en het verdelen van de taken en 4) de koppeling van Caren met de eigen zorgaanbieder. Caren kan dus gekoppeld worden aan de betrokken zorgprofessionals die hier ook een profiel hebben. Op deze manier kunt u ook met hen via Carenzorgt contact onthouden en rapportages inzien.

Ik zal een korte rondleiding door Caren geven: Wanneer wordt ingelogd op Carenzorgt is dit de beginpagina (Sheet 1)

Wanneer vervolgens gekozen wordt voor een persoon, in dit geval Beatrix van Oranje, komt u terecht op deze pagina, waarop de agenda te zien is van uw dierbare (Sheet 2). Aan de linkerkant van het scherm kunt u de rest van de opties binnen Carenzorgt zien. U kunt bijvoorbeeld berichten sturen aan andere mantelzorgers of zorgprofessionals (Sheet 3), notities maken voor uzelf en andere mantelzorgers (sheet 4) en andere mensen uitnodigen om ook deel te nemen aan de pagina en het zorgsysteem van de dierbare (sheet 5). Daarnaast kunt u ook het profiel van uw dierbare aanpassen (sheet 6).

1) Wat is uw eerste indruk van Carenzorgt nu u weet hoe het eruit ziet?

2) Wat vindt u van de overzichtelijkheid van Carenzorgt?

Wat maakt dat u dit vindt?

3) Welke onderdelen van Carenzorgt vindt u nuttig?

En waarom?

4) Welke onderdelen van Carenzorgt vindt u minder nuttig?

En waarom?

5) Wat mist u binnen Carenzorgt?

En waarom mist u dit?

6) In hoeverre is volgens u de organisatie van zorgtaken makkelijker met Carenzorgt?

7) In hoeverre lijkt het u met Carenzorgt makkelijker om contact te houden met andere mantelzorgers?

8) In hoeverre lijkt het u met Carenzorgt makkelijker om contact te houden met professionele zorgverleners?

9) In hoeverre lijkt het u met Carenzorgt makkelijker om op de hoogte te blijven van de situatie van uw dierbare?

10) Wat is volgens u de toegevoegde waarde van Carenzorgt?

Wat maakt dat u dit de toegevoegde waarde vindt?

11) Wat zijn volgens u de knelpunten van Carenzorgt?

12) Carenzorgt krijg ook informatie van u en uw dierbare binnen. Wat vindt u hiervan? Weet u wat er met deze informatie gebeurt?

13) Heeft u het gevoel dat Carenzorgt veilig omgaat met gegevens?

Wat maakt dat u dit gevoel hebt?

14) Ziet u een bedreiging voor de veiligheid van uw gegevens?

Deel 3: Percepties, verwachtingen en behoeftes rondom unobtrusive sensing technology

In het volgende zal ik uw graag een korte uitleg geven over het monitoring systeem dat wij met behulp van uw input graag zouden willen ontwikkelen. U mag weer te allen tijde vragen stellen indien iets onduidelijk voor uw is.

Uitleg unobstrusive sensing technology (Zie slides)

Slide 1

Het monitoring systeem waar wij nu over gaan praten bestaat nog niet echt, maar gaat ontwikkeld worden.

Het geeft informatie over het dagelijks leefpatroon, gedrag en stemming van een bewoner door sensoren die bijvoorbeeld beweging en geluid meten op een centrale plek in de kamer. Deze volgen en classificeren

activiteiten, gedrag en stemming van de bewoner automatisch, die op een digitaal platform worden gevisualiseerd.

Eventuele alarmering is mogelijk als een bewoner bijvoorbeeld lang geen activiteit toont. Het monitoring systeem werkt op de achtergrond op een niet hinderlijke wijze, bewoners hoeven hiervoor niets te dragen.

Binnen het zorgnetwerk zijn er (in de theorie) drie verschillende potentiële ontvangers van de informatie:

- 1) Ten eerste de mantelzorgers van de dementerende oudere*
- 2) Ten tweede de zorgprofessionals die betrokken zijn bij de zorg*
- 3) Ten derde ook de dementerende oudere zelf*

(De algemene doelstellingen van het systeem zijn:

- Het ondersteunen van mantelzorgers en zorgverleners in hun zorgverantwoordelijkheden door een beter toezicht op gedrag, welzijn en cognitieve en fysieke achteruitgang van de dementerende oudere*
- Het optimaliseren van langer zelfstandig en veilig thuis wonen van dementerende ouderen)*

Slide 2

Het systeem analyseert de data continu, waardoor ook subtiele veranderingen kunnen worden ontdekt.

Dit is mooi te zien in deze grafiek:

De bovenste grafiek toont drie meetpunten die een afname laten zien, terwijl de continue meting (blauwe lijn) juist stabiliteit suggereert.

De onderste grafiek toont drie meetpunten die stabiliteit laten zien, terwijl de continue meting (gele lijn) juist een verandering suggereert.

Slide 3

Op deze slide zijn een aantal voorbeelden afgebeeld hoe de monitoring data weergegeven zouden kunnen worden op het platform. Dit zou in de vorm van een gedetailleerde samenvatting kunnen maar ook op een heel simpele manier kunnen worden weergegeven. Echter dit zijn alleen voorbeelden.

Heeft u nog vragen voordat wij verder gaan? Graag zou ik nu een aantal vragen met u willen bespreken rondom uw verwachtingen en behoeftes rondom zo een monitoring systeem.

1. Wat vindt u van zo een systeem als u dit hoort?
2. Waarom zou u zo een systeem in willen zetten bij uw dierbare?
 - a. Wat zijn voordelen volgens u?
 - b. Welke soorten situaties zijn er waar de inzet van zo een monitoring systeem nuttig zou kunnen zijn?
3. Hoe denkt u dat de inzet van zo een systeem de zorg rondom uw dierbare zal beïnvloeden?
 - a. Wat zou de door het systeem verkregen informatie voor u betekenen?
 - b. Wat zou het voor u opleveren? Zou het u kunnen geruststellen?
 - c. Hoe denkt u zou het systeem uw taken als mantelzorger zal beïnvloeden?
 - i. In hoeverre denkt u dat zo een systeem zorg op afstand makkelijker kan maken?
 - d. Hoe sluit zo een systeem aan op de uitdagingen die u ervaart?
 - e. Waar moet zo een systeem aan voldoen om u te ondersteunen bij de zorg rondom uw dierbare?
4. De algemene doelstelling van het systeem is "Langer thuis met dementie". Kan deze technologie dit volgens u bereiken?
 - a. Waarom wel?
 - b. Waarom niet?
5. Denkt u dat de inzet van dit soort systemen de autonomie en zelfstandigheid van uw dierbare kan verhogen?
 - a. Waarom wel?
 - b. waarom niet?

6. Mantelzorgers kunnen het soms moeilijk vinden om gedrag en emotie van hun dementerende dierbare te snappen. (Dit is omdat dementerende ouderen soms dingen verbergen of niet altijd goed in staat zijn om mogelijke problemen aan te geven)
 - a. In hoeverre denkt u dat zo een systeem u kan helpen om een beter inzicht te krijgen in gedrag/gewoontes/ welzijn van uw dierbare?
 - b. In hoeverre denkt u dat de zorg m.b.v. zo een systeem beter afgestemd kan worden?

Deel 4: Barrieres rondom unobtrusive sensing technology

In het volgende deel zal ik het graag met u erover hebben wat volgens u mogelijke nadelen zijn van eerder beschreven monitoring systeem en waar u mogelijke barrieres ziet.

1. Wat zou u weerhouden om zo een systeem bij uw dierbare in te zetten?/ Waarom zou u besluiten om geen gebruik te maken van zo een monitoring systeem?
 - a. Wat zijn nadelen volgens u?
 - b. Sommige onderzoekers noemen dit systeem een babyfoon 3.0. Hoe denkt u hierover? Wat zou u liever niet willen weten?
2. Welke dingen ziet u als een bedreiging voor uzelf als het gaat om de inzet van zo een monitoring systeem?
 - a. Stel dat u tijdens gebruik van het systeem een problematische verandering of een incident waarneemt (bv. geïrriteerdheid of vallen): Hoe zou u hiermee willen omgaan? Was er dan wel (of niet) iemand die zich er zorgen over maakte? Welke invloed zou dit hebben op de zorglast die u ervaart?
3. Welke dingen ziet u als bedreiging voor uw dierbare als het gaat om de inzet van zo een monitoring systeem?
 - a. Wat zou u willen beschermen? Vanaf wanneer zou u zeggen "Tot hier en niet verder"?
4. Zou u de verkregen informatie van het systeem willen delen met anderen?
 - a. Zo ja: Welke informatie zou dat zijn? Met wie (mantelzorgers?, zorgprofessionals? huisarts?) en onder welke omstandigheden?
 - b. Zo nee: Wat maakt dat u dit niet zou willen? Waar bent u bang voor?
5. Vind u het gevoel van veiligheid belangrijker dan het waarborgen van privacy?
 - a. Waarom wel en waarom niet?

Afsluiting

We zijn aan het einde gekomen van het interview. Heeft u nog vragen of wilt u nog iets kwijt?

Graag zou ik u uitleggen hoe het nu verder gaat. Het interview zal anoniem geanalyseerd worden en in combinatie met andere interviews zal dit helpen bij het ontwikkelen van innovatieve monitoring-technologie, wat bij kan dragen aan een betere zorgondersteuning. Mocht u geïnteresseerd zijn in de uitkomsten van dit onderzoek, zou ik u hierover kunnen mailen.

Kent u hiernaast zelf nog andere mantelzorgers die zorg verlenen aan een dierbare met dementie en die mogelijk geïnteresseerd zouden kunnen zijn om aan deze studie deel te nemen?

(Indien JA): Mag ik in dit geval een e-mailadres of telefoonnummer noteren?

Dan zou ik nu graag het interview willen afsluiten. Ik wil u hartelijk danken voor uw medewerking. Dit stel ik erg op prijs!

Monitoring doel	+	-	?	N.V.T
Dagelijkse activiteiten				
Lopen (hoeveelheid/snelheid)				

Uitstapjes				
Persoonlijke hygiëne (bv. Wassen, aankleden, toilet gebruik)				
Eten				
Sociale interactie met anderen				
Telefoongebruik (aantal keer gebruik)				
Dag- en nachtritme/slaappatroon				
Veiligheid				
Vallen				
Dementie-specifiek				
Cognitieve achteruitgang				
Fysieke achteruitgang				
Agitatie (Onrustige bewegingen)				
Apathie (lusteloosheid/verlies van motivatie en interesse)				
Negatieve stemming (bv. Angst, depressie)				
Positieve stemming (bv. Blijdschap, ontspanning)				
Nachtelijke onrust				

Appendix E – Explanation sheets about unobtrusive in-home monitoring system

1.

UNIVERSITEIT TWENTE.

TRACK TRACE TRIGGER!
Unobtrusive sensing technologies to monitor and coach elderly with dementia

Annemarie Braakman-Jansen, Christian Wrede, Lisette van Gemert-Pijnen (Persuasive Health Technology Lab, UT); Paul Havinga, Jeroen Klein Brinke, Nirvana Meralnia (Pervasive Systems, UT); Jan-Hendrik Croockewit (Nedap Healthcare). In cooperation with Zoracentrum de Posten

medap healthcare dePosten ZonMw

2.

Concept in-home monitoring

Self-monitoring

Remote monitoring

Telemedicine

SENIOR

CAREGIVER

PHYSICIAN

3.

Continuous monitoring

Measured Functions

Month 1 Month 3 Month 6 2011/19 3

Dressing Hygiene Transfer Mobility

4.

Samenvatting data voor platform: Voorbeelden
and type the subtitle

Walking Activity

Time in Bed

UNIVERSITY OF TWENTE. Project TTT. 4

Appendix F – Code scheme

Code scheme unobtrusive in-home monitoring system

Coding category	Codes	Participant number	Total
Advantages	Daily activities		
	Autonomy for informal caregiver	5	1 (7.7%)
	Safety		
	Safety	2, 4, 5	3 (23.1%)
	Care specific		
	Intervene faster	1, 3	2 (15.4%)
Barriers	Source of information	1, 3, 6	3 (23.1%)
	Reduction of burden of care	1, 3, 6, 7	4 (30.7%)
	Pressure for the informal caregiver	4	1 (10%)
	No added value	2	1 (10%)
Requirements	Patient downgraded into technical objective	1	1 (10%)
	Loss of privacy	1, 2, 3, 4, 5, 6, 7	7 (70%)
	Personalize to patient	1, 3, 5, 6, 7	5 (41.8%)
	Personalize to phase of dementia	4, 6	2 (16.7%)
	Add GPS	4, 5	2 (16.7%)
	Safety	2, 4, 5	3 (25%)

Code scheme Carezorgt

Coding category	Codes	Participant number	Total
Function	Messages		
	More involvement	2, 4, 6, 7	4 (17.4%)
	Stay informed	3, 4, 5, 6, 7	5 (21.7%)
	Calendar		
	Clear function	1, 2, 5, 6	4 (17.4%)
	Easy to make appointments	1, 2, 6, 7	4 (17.4%)
	Better overview	1, 6, 7	3 (13.1%)
	Notes		
	Documentation	2	1 (4.3%)
	Express feelings	2, 6	2 (8.7%)

Ease of use	Fine pictures	7	1 (10%)
	Clear program	1, 2, 3, 4, 5, 6, 7	7 (70%)
	No unnecessary information	2, 3	2 (20%)
Communication with other caregivers	Positive		
	Sharing of information	1, 2, 5, 6, 7	5 (23.8%)
	Efficiency	2, 7	2 (9.5%)
	Safety for the patient	1	1 (4.8%)
	Responsibility	7	1 (4.8%)
	Stay informed	2, 3, 6	3 (14.3%)
	Negative		
	Incompleteness	3, 4, 5	3 (14.3%)
	Late respons	4, 5	2 (9.5%)
	Not applicable		
	Does not apply	3, 4, 5, 6	4 (19%)
Trustworthiness	Positive		
	Own choice to share information	1, 6	2 (20%)
	Trust	2, 3, 4, 5, 6, 7	6 (60%)
	Protection	1	1 (10%)
	Negative		
	Needs more clarity	3	1 (10%)
