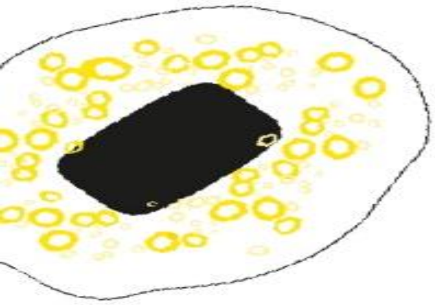
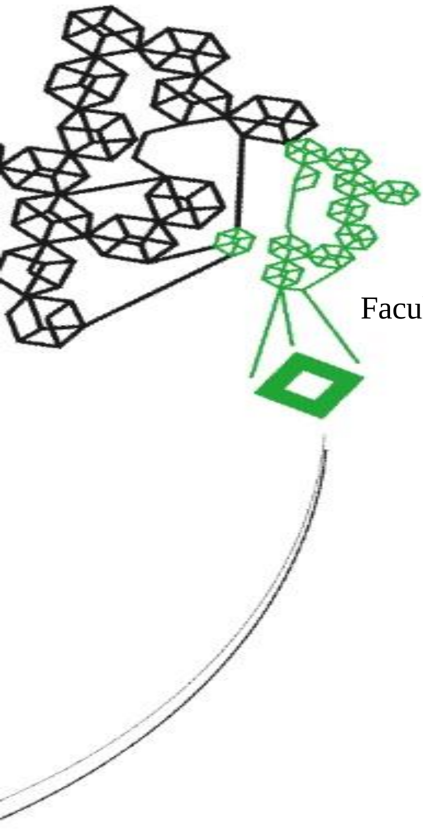


Towards digital care management and unobtrusive patient monitoring in home-based dementia care: Experiences, expectations and needs of professional caregivers.

Elles de Witte



Master Thesis
Health Sciences
Faculty: Science and technology (technische natuurwetenschappen)
University of Twente, Enschede

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Preface

This thesis is the final component of the master Health Sciences, with the specialization ‘Personalised monitoring and coaching’ at the University of Twente. The assignment is completed in collaboration with University of Twente and Nedap Healthcare. I am very happy to present to you my master thesis ‘Towards digital care management and unobtrusive patient monitoring in home-based dementia care: Experiences, expectations and needs of professional caregivers.’ While working on this Master’s assignment, I was given the chance to develop myself in the field of quantitative and qualitative research for which I am thankful. To me the subject is very interesting, which made me enjoy conducting this research and curious about the results.

First of all, I would like to thank my first supervisor Annemarie Braakman-Jansen, and second supervisor Christian Wrede of the University of Twente. I am very thankful for them investing their time in providing feedback and the interesting discussions that we had about the subject. I would also like to thank Peter Leppers of Nedap, who gave us a tour around the Nedap Healthcare department and explained the ins and outs about Carenzorgt. Thank you for answering all my questions and your feedback on applied materials. Secondly, I would like to thank every healthcare professional who invested his or her time while participating in this research. Without their participation and input, this study could not have been successfully conducted. Thirdly, I would like to thank Jan-Willem ten Beitel for providing critical feedback on my English writing and spelling. Lastly, I would like to thank my family and friends for their unconditional support and belief in me throughout the entire process.

I hope the results of this research will contribute to further development of Carenzorgt and provide a relevant basis for further research and development of unobtrusive monitoring systems within the project ‘Track, Trace & Trigger’.

I hope you will enjoy reading this thesis.

Elles de Witte

November 2019, Enschede

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Abstract

Introduction

Because of the increasing number of patients with dementia in The Netherlands, a major increase of dementia-care related healthcare costs is expected in the near future. Healthcare must be provided with less healthcare professionals to more patients with dementia, which is why it is important to invest in technological innovations. Carenzorgt is a communication platform which facilitates communication between informal and formal caregivers and enables informal caregivers to read along with reports. Knowledge about its added value from the viewpoint of its users is still incomplete. Also, remote monitoring of patients with dementia can enable more efficient care, but knowledge about the contexts in where it might be advantageous, lacks. The aim of this study lies in collecting user experiences of healthcare professionals with Carenzorgt in home care to patients with dementia, and their needs and expectations towards unobtrusive monitoring systems. The first research question is; 'What are the user experiences of healthcare professionals of different care teams that deliver home-based care to patients with dementia, with the care management platform Carenzorgt functionalities in ONS?' The second research question is; 'What are the expectations, needs and barriers of formal caregivers towards unobtrusive monitoring of persons with dementia in the home situation?'

Methods

A mixed method approach was applied, where a questionnaire and semi-structured interview was used. Positively formulated statements were introduced to respondents via an online questionnaire, where they could score the statements on a scale from 1 to 5. Differences in scores between groups are explored. The questionnaire statements were also integrated in the interview scheme.

Results

Healthcare professionals have positive experiences with Carenzorgt when it comes to usability, workflow and quality of care. Carenzorgt does not decrease the burden of care in general. The main advantages of Carenzorgt were the easy communication and improved participation of and cooperation with informal caregivers. Because informal caregivers can read along with reports, miscommunication sometimes occurs. New messages are sometimes missed due to the lack of a notification, and the agenda appeared to be less user-friendly which is why it is barely used. Respondents from smaller teams agreed more to all statements than respondents from larger teams, and significantly more to burden of care statements. The barriers that were expected towards unobtrusive monitoring systems were mainly privacy, suspicion or distress of the patient and an increased workload. Permission of patient and family is very important. Unobtrusive monitoring systems could enable more care provision from a distance, give an increased insight in the patient's functioning, help healthcare professionals with taking proactive measures and improve tailoring and quality of care. Healthcare professionals would like to have an easy-to-use, integrated system, where data is displayed in a way that is insightful and useful in practice.

Discussion

Healthcare professionals might not report certain findings in Carenzorgt to avoid miscommunication, so adding an option to hide certain reports could be a solution. Other recommendations are good training and support for informal caregivers, a notification in case of new messages or agenda appointments and better insight in the agenda. The lower scores on questionnaire statements of respondents from larger teams could be explained by possible poorer team processes that are often found in larger teams. In further research, experiences with different functionalities of Carenzorgt, such as the agenda, could be further explored to gain better insight. While redesigning functionalities, it is very useful to closely involve relevant end users. Privacy is often found as main barrier in studies where expectations of monitoring technologies are explored. Since permission of patient and family is important, shared decision making should be well-facilitated. Also, while in the contextual inquiry, it is important to explore the expectations and needs of patients with dementia. The same goes for development, but involving them can be challenging. Persona-based design would be very useful in the early development phase, and can be used for multiple purposes. The results of this research show that UCD and holistic eHealth development and design remains important during early and later developments of eHealth.

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1. Introduction

1.1 Dementia in The Netherlands

The number of patients with dementia increases due to the ageing population in The Netherlands. There are over 270.000 patients with dementia in The Netherlands (Alzheimer Nederland, 2018). In 2016, the incidence was estimated to be 24.300 (Volksgezondheidenzorg, 2019). The disease is most common among persons that are 80 years or older, around 20 percent of this group has moderate to severe dementia (Mandemaker & Leeuw, 2007). The major increase of people with dementia, that is expected in the near future, causes an increase of dementia-related healthcare costs of 85% in 2030. This could make it the most expensive disease of our society (Alzheimer's Disease International, 2010).

Dementia is a progressive chronic disease, in which the cortical function is decreased, which results in the impairment of several cognitive skills. These impaired cognitive skills are mostly language and innumeracy, logical thinking and judgement, ability to learn new information and motor coordination. Also, loss of memory occurs which is often progressive, leading to long-term as well as short-term memory loss. Furthermore, behavioural and personality changes are common symptoms (Gould & Dyer, 2011). In the early stage of dementia, the patient might need help with medication management, organisation, money management, remembering and keeping appointments, and developing coping strategies to maintain independence. As the condition of patient deteriorates, and activities of daily living are becoming increasingly difficult, the patient's control over his or her life will decrease and he or she will become increasingly dependent on help of others (Alzheimer Nederland, n.d.-a). The patient will also need more advanced (professional) care. This advanced care includes assistance with activities of daily living, such as dressing and feeding oneself. They will also need reminders and a structured schedule for the day. In the late middle stage and late stage, living at home is often not possible anymore, since the patient will then require intensive care for 24 hours a day (Dementia Care Central, 2018).

Even though individuals with dementia are less likely to live at home, doing so results in lower health care costs than when these individuals live in a nursing home (Hurd, Martorell, Delavande, Mullen & Langa, 2013). In addition to reduced costs, living in the community may improve the care that is received and increase independence and quality of life among older adults with Alzheimer's or dementia (Wilson & Bachman, 2015; Gitlin, Winter, Dennis, Hodgson & Hauck, 2010). Living at home offers a familiar environment and structure of daily living. Patients with dementia often retain the ability to deal with these matters for a long time. Moving to a new, unknown environment can cause disorientation, confusion and insecurity (Mandemaker & Leeuw, 2007).

1.2 Home care for patients with dementia

In 2018 around 70% of the people with dementia lived at home, where they are being taken care of by for example their spouse, family, neighbours or other acquaintances. They are called informal caregivers. More than half of the informal caregivers (54%) are heavily burdened due to the care process (Alzheimer Nederland, 2018). Next to the informal caregivers, there are often other caregivers involved as well, such as home care professionals and volunteers that all perform different (supporting) tasks. The total group of caregivers is called the 'care network' of the person (Vrije Universiteit Amsterdam, 2019). Around 53% of all patients with dementia receive home care in The Netherlands, with an average time of 6.6 hours per week (Peeters, Werkman & Francke, 2012).

Home care in the Netherlands encompasses medical treatment and nursing services, such as dressing wounds and giving injections, as well as personal care such as help with taking a shower or guidance on coping with daily activities (Ćirković, 2018). When a patient with dementia requires professional care and assistance with activities of daily living, such as the intake of medication, bathing and getting dressed, this can be arranged with a home care organisation (Alzheimer Nederland, n.d.-c). District nurses are responsible for arranging this care, by assessing the required care and drawing up a plan together with the patient (Government of The Netherlands, n.d.)

In the Netherlands of the mid-2000s, the care sector was characterised by a lack of continuity of care and was faced with declining quality, rising costs, and a disillusioned nursing workforce (Ćirković, 2018). Out of frustration with the existing system of care delivery where 'organisations grew bigger and involved more and expensive management', former nurse Jos de Blok set up home care organisation Buurtzorg together with 3 other former nurses. Buurtzorg is a patient-centred alternative, where all forms of central management is avoided. According to De Blok there are a lot of other home care organisations that change their models into more self-steering teams, with a big impact on the national policy (Ćirković, 2018; Wouw, 2018).

While it is becoming more and more difficult to find qualified staff in healthcare, there is an increasing demand for home care (Huisman, 2017). The growing staff shortage is partly caused by the increasing demand for care and next to this, almost a quarter of all healthcare professionals is 55 years or older and will retire in a few years (Pieters, 2018). Home care has suffered acute shortages of district nurses the last few years, which makes it difficult to allow patients to live longer at home in a responsible manner (Luque, 2018). As healthcare must be provided with less healthcare professionals to more patients with dementia, a change in the provision of healthcare is required. Because of the low rates applied by health insurance companies, healthcare professionals have to do more within the time available for their patients. This causes an increase of the experienced workload (Hogendorp, 2017). Because of these developments, it is becoming crucially important to invest in technological innovations according to the Actiz Benchmark report (2016). Technological innovations can play an important role to deal with this problem in a proper way, and can support both the patient and healthcare professional. Since healthcare professionals are not always able to visit and observe patients every day, and may not always be aware of the rapidly changing needs of the individual, data of monitoring technology could provide information in a way that early interventions are possible (Nijhof, 2013). Research also indicates that technology can be a useful tool in dementia care, and can promote independent living, enable earlier identification of problems and improved self-monitoring (Cahill, Begley, Faulkner & Hagen, 2007; Lauriks et al., 2007; Topo, 2009; Duff & Dolphin, 2007; Cahill, Macijauskiene, Nygard, Faulkner & Hagen, 2007; Nijhof, Gemert-Pijnen, Dohmen & Seydel, 2009).

1.3 Use of eHealth in health- and home care for patients with dementia

eHealth means the use of technology to support health, well-being and healthcare (Gemert-Pijnen, Kelders, Kip & Sanderman, 2018). eHealth can offer interesting possibilities to improve the quality of care, quality of life, efficiency and continuity of care. For example, it can improve information exchange between healthcare professionals and between healthcare professionals and patients (Gemert-Pijnen et al., 2018). Technology can also support fragile elderly in living independently, for example with the help of sensors, digital key lockers and GPS-trackers (Wouters et al., 2017). These technologies can also be used in care for people with dementia, while living in their own home.

Technology can be used by the patient him- or herself or by involved caregivers. The technology that can be used by the patient are aimed at assisting them with their daily activities. For example an electronic calendar for scheduling daily activities or a picture phone where the patient can call someone by just clicking on a picture. Technology that is used by caregivers are for example telecommunication systems and monitoring technologies, including signals or alarms from 'ambient intelligence'. 'Ambient intelligence' technologies are a form of invisible, intelligent technologies that go unnoticed by the patients in their home. These technologies use software that interprets situations by using incoming signals from sensors (Nijhof, 2013).

When technologies such as magnetic locks on cupboards and drawers, plug socket protection and furnace button protectors are not sufficient anymore in guaranteeing safety when the patient is home alone, remote monitoring can be a solution (Mandemaker & Leeuw, 2007). Monitoring technology can be used to keep an eye on the state of health and personal safety of the patient. Examples are a bed sensor (detects when the person is in – or out of – bed), a window or door sensor (detects whether a window or door is open or closed) and a noise sensor (detects whether a specific noise exceeds a pre-determined level) (Nijhof, 2013).

There is a lack of scientific evidence in the field of eHealth for people with dementia (Nijhof, 2013). Nijhof (2013) presents an overview of different studies that are conducted on technologies in dementia healthcare, where mostly experiences of patients with dementia and their informal caregivers are gathered. With only 4 out of the 26 included studies the experiences of healthcare professionals where gathered, so there is little evidence available. In the study of Engstrom and Ljunggren (2005) movement detectors and fall detectors were placed in the residential homes of patients with dementia. It appeared that job satisfaction, perceived quality of care, personal development and internal motivation increased in the intervention group. The workload and work-related stress increased as well because there was a lot more to deal with during working hours. In the second study that included experiences of healthcare professionals, the technology consisted of living circles that indicated where people with dementia where allowed to be, and support for caregivers through notifications about the patient for example getting up, falling, sending a request for help or leaving the room. There was no significant effect on work satisfaction and work pressure (Nouws, Sanders & Hevelink, 2008). In another study of Nouws, Sanders and Hevelink (2004), different monitoring sensors were used, such as automatic lightning, inactivity measurement, active alarm, acoustic monitoring. User satisfaction of personnel was positive, and would rather work with domotics than without them. In the study of Vilans (2006) it appeared that, due to the different monitoring sensors, nightly rounds no longer had to be carried out by the caregivers anymore. This was viewed as a positive outcome, and it was expected that it would save a lot of walking time. There was no information on what sorts of sensor data healthcare professionals would like to retrieve. Overall, very little research has been carried out in the area of opinions and user experiences of healthcare professionals with these types of technologies.

There are increasingly more technologies that facilitate cooperation and communication between informal caregivers and family. Most digital platforms enable different people, that are involved in a care process, to place messages and to keep up with the agenda (Zorg voor beter, 2017-a). Carenzorgt is a communication platform for people that receive or provide care. It enables online organisation of care, sharing of information, and planning of tasks. When the person also receives care from a healthcare organisation, the electronic patient file can be linked to Carenzorgt. With use of the platform, informal caregivers have insight in the patient’s agenda, healthcare professionals reports about the patient, they can make appointments and divide tasks. Healthcare professionals can use Carenzorgt when their healthcare organisation uses the system ONS, through which Carenzorgt can be connected (Zorg voor beter, 2019-b). Carenzorgt is developed by Nedap Healthcare and was launched in 2010. There are 500 healthcare organisations in The Netherlands that use the platform. The goals of Carenzorgt include giving insight in the care process, to facilitate safe sharing of information between healthcare professionals and informal caregivers and providing a way to keep each other up-to-date (Carenzorgt.nl, 2019).

1.4 eHealth design and development, Connected health

Systems and applications are often designed with a focus on business goals, fancy features and the technological capabilities of hardware and software, while the end-user is the most important part of the process (Saskatchewan, n.d.). It is also mentioned by Gemert-Pijnen, Kelders, Kip & Sanderman (2018), that due to a faulty development process, where there has not been enough attention for the interrelationships between the people, context and technology, the technology often does not fit the specific culture, processes and demands in health-related contexts in practice. An holistic approach is needed to ensure that eHealth is actually used by the intended target group and that its outcome is effective (Nijhof, 2013).

User-centred design (UCD) is the mindset of placing the user at the centre of the design process, where designers think from the users’ perspective (Saskachewan, n.d.). In UCD, the focus lies on the users’ needs through every phase of the design process. Each iteration of the UCD approach exists of 4 phases, namely the context, requirements, design and evaluation phase. Users are involved throughout the design process via a variety of research and design techniques, to create highly usable and accessible products for them (Interaction design foundation, n.d.). The lack of user-centred design can cost time and effort and can also determine the success or failure of a project (Saskachewan, n.d.). According to Gemert-Pijnen, Nijland, Ossebaard, Limburg, Kelders, Eysenbach & Seydel (2011), eHealth should be viewed in a holistic way. The interdependencies between system, content, context and stakeholders should always be taken into account. This also comes forward in the Cehres roadmap, which suggests a holistic view on the use of eHealth.

The term ‘Connected Health’ has been increasingly used in recent years to describe a new technology enabled model of healthcare delivery (Caulfield & Donnelly, 2013). Connected Health refers to a conceptual model for health management where devices, services or interventions are designed around the patient’s needs. It’s approach can make care more proactive and efficient, and empower different stakeholders, such as patient, informal and formal caregivers. When looking at the Connected Health cycle, the driving element is the acquisition of health related data from the patient, which in this case could be continuous monitoring and sensor data from using body worn or ambient sensor networks. Based on the aggregation and presentation of data, involved caregivers can decide which interventions are appropriate for the patient in a proactive way. Information about the patient’s overall condition, gathered through ambient sensors, could assist healthcare professionals in providing high quality care to patients with dementia that live at home. However, there is an overall consensus that there is a lack of understanding in how to use all the acquired data and transform it into accurate information about the patient’s rate of progress or deterioration and need for interventions. Also, knowledge about the contexts and care pathways, within which remote monitoring might be advantageous, lacks (Caulfield & Donnelly, 2013). In the field of remote monitoring in patients with dementia this becomes apparent. Especially in the early stage, patients with dementia often face emotional disturbances like anxiety, apathy or depression. In moderate stages agitation and sleep disorders are common behavioural problems (Cerejeira, Lagarto & Mukaetova-Ladinska, 2012). There is a need to provide solutions for monitoring of and caring for these behavioural symptoms and the emotional wellbeing of elderly with dementia.

The University of Twente and Nedap Healthcare are currently working together on a project called ‘Track, Trace & Trigger’, which is about unobtrusive sensing technologies to monitor and coach elderly with dementia. It centres around the development of a new, unobtrusive Wi-Fi disturbance-and acoustic based sensing system designed to automatically report behaviour and emotion of elderly with dementia, connected to a persuasive care platform for caregivers to provide valuable information regarding daily functioning and behavioural and emotional state. The project is currently in the contextual inquiry phase, where information is gathered about needs and expectations of unobtrusive sensing technology (Wrede, Braakman-Jansen, Havinga, Croockewit & Gemert-Pijnen, 2019).

1.5 Study focus

The focus of this study lies in collecting user experiences of healthcare professionals, who use Carenzorgt functionalities through the software programme ONS, in delivering home-based professional care for patients with dementia. Carenzorgt has become one of the largest care platforms in the Netherlands, but knowledge about its added value from the viewpoint of its informal and formal users is still incomplete. There are no studies published where user experiences of healthcare professionals with Carenzorgt are collected. The goal of this study is to gather insight in the user experiences of healthcare professionals with the connection ONS – Carenzorgt, and to find strengths and points of improvement of the platform. It is also aimed at gaining insight in how these users experience usability, burden of care, workflow and quality of care with the use of the connection ONS - Carenzorgt.

There is a lack of scientific evidence of what sort of sensor data healthcare professionals, that work in home care, would like to receive and in what manner. Next to this, it has become apparent that there is a need for monitoring specific behavioural symptoms of patients with dementia, and that the technology that is currently used in the remote monitoring of patients with dementia is often obtrusive and can make patients feel uncomfortable. This study is therefore also aimed at collecting needs and expectations of healthcare professionals on unobtrusive monitoring systems and sensor data. This is in order to gain insight into what could make unobtrusive monitoring systems and incoming sensor data valuable for healthcare professionals, specifically in care for patients with dementia.

1.6 Research questions

RQ 1: What are the user experiences of health care professionals of different care teams (with or without team manager, size of team, amount of patients), that deliver home-based care to patients with dementia, with the care management platform Carenzorgt functionalities in ONS?

1.1 What is the overall experience of healthcare professionals of different care teams with Carenzorgt functionalities in home based dementia care?

1.2 How do healthcare professionals of different care teams experience the usability of Carenzorgt functionalities in home based dementia care?

1.3 How do healthcare professionals of different care teams experience the burden of care with the use of Carenzorgt functionalities in home based dementia care?

1.4 How do healthcare professionals of different care teams experience workflow with the use of Carenzorgt functionalities in home based dementia care?

1.5 How do healthcare professionals of different care teams experience quality of care with the use of Carenzorgt functionalities in home based dementia care?

For research question 1, there are 4 separate sub questions formulated. The first sub question aims at collecting the overall experience of healthcare professionals with Carenzorgt, including strengths and points of improvement. The subsequent 4 sub questions are aimed at retrieving insight in the experienced usability, burden of care, workflow and quality of care with use of Carenzorgt. It is also aimed at finding out whether there are any relevant differences or trends to be seen in ratings between different teams (with or without team manager, small or large teams, with little or many patients).

RQ 2: What are the expectations, needs and barriers of formal caregivers towards unobtrusive monitoring of persons with dementia in the home situation?

Research question 2 is aimed at gaining a deeper insight into the perceptions and needs of healthcare professionals towards a conceptual unobtrusive monitoring system, where patients with dementia would be monitored. Needs include monitoring needs, which are factors that they would or would not like to have monitored, but also requirements about the way the system should monitor different factors, how it should communicate with the healthcare professionals and how it should display the acquired information.

2. Method

2.1 Study design

To collect information about the healthcare professionals' experiences with and opinions of the platform Carenzorgt, a mixed method approach was applied. A quantitative and qualitative approach (questionnaire and interviews) was used to answer the first research question. A questionnaire was used to gain insight in the users' demographics (age, function and gender), their work environment (team set-up, team size and number of patients), usage of Carenzorgt (number of times per shift and duration of usage) and experiences with Carenzorgt on usability, burden of care, workflow and quality of care. The team set-up stands for whether a team is managed by a manager or if it is self-managing. The team size is the number of healthcare professionals that work in the team of the respondent, and the number of patients stands for the number of patients that receive professional care from the team of the respondent. The online survey software Qualtrics was used as a tool for the questionnaire, which was online from 28th of May 2019 until the 1st of July 2019.

The mixed method approach is applied in a parallel manner. In the questionnaire different statements were introduced to the respondent, which were integrated in the interview scheme as well in the form of open questions. In this way, different data from both methods can be integrated and complemented. In the result section research question 1.1 is answered with qualitative results only. Research questions 1.2, 1.3, 1.4 and 1.5 are answered with both quantitative and qualitative results. The answer to research question 2.1 is based on solely qualitative data.

2.2 Participants

The healthcare professionals that were asked to participate, worked in home care, provided care to patients that are diagnosed with dementia and used Carenzorgt. Inclusion criteria for participation were; ≥ 18 years; professional caregiver in home care (care professional level 3 (verzorgende IG), nurse level 4 (verpleegkundige niveau 4) or nurse level 5 (bachelor of nursing, verpleegkundige niveau 5); providing care for patients that live at home, including patients with dementia; Dutch speaking; use of ONS – Carenzorgt.

2.3 Procedure

Participants were recruited via email for both the survey and the interview, in the form of voluntary response sampling. It was aimed to recruit at least 50 respondents for the questionnaire and at least 5 respondents for the interviews. An invitation letter (appendix III) was send to different healthcare organisations that used the software programme ONS and could be connected to Carenzorgt. The list of these healthcare organisations was retrieved from the website of Carenzorgt. Through the invitation, the recipient was asked to forward the invitation within the organisation to healthcare professionals that worked in home care. The healthcare professional could decide to not participate at all, to only do the questionnaire or interview, or to do both. Healthcare professionals were able to fill in the questionnaire through the link in the invitation letter. When healthcare professionals decided to participate in the interview, the informed consent (appendix IV), monitoring needs schedule (appendix V), explanation of unobtrusive monitoring systems and sensor data (appendix VI), including the Powerpoint sheets with visualisations (appendix VII), was sent subsequently. Before the interview started, the participant was asked to read and sign the informed consent. The setting where the interview took place was arranged with the respondent, for example the office where the respondent worked. From the 5 interviews that were conducted, 2 took place through the telephone. The interviews took around 60 minutes to conduct, excluding introduction and closing time. In total it took around 70 to 80 minutes. The interviews were recorded using 2 different mobile devices.

2.4 Materials

Questionnaire

The questionnaire contained 11 general questions about the background of the respondent. Background questions were asked about the respondent's function (5 categories, verzorgende niv.2, verzorgende niv.3, verzorgende niv.3 IG, nurse level 4 or nurse level 5), age (continuous), gender, team set-up (with manager or self-managing), size of team (number of healthcare professionals in team), number of patients (that receive home care from the respondent's team), experience with Carenzorgt (in years), usage Carenzorgt (number of times Carenzorgt is used per shift on average) and duration of usage (duration in minutes).

The respondents' experiences with Carenzorgt functionalities were measured with 16 statements using a 5 point Likert scale (1 means 'totally agree', 5 means 'totally disagree'). All statements were positively formulated. For burden of care a scale was constructed including 7 items. An example item was "De zorgzwaarte is minder geworden door het gebruik van de koppeling ONS - Carenzorgt" and "De organisatie van zorgtaken is makkelijker met het gebruik van de koppeling ONS – Carenzorgt". The mean inter-item correlation of these items was 0.345 and the Cronbach's Alpha was 0.79. The other themes were usability (2 statements, for example "De koppeling ONS – Carenzorgt is makkelijk in gebruik"), workflow (2 statements, for example "De werkwijze met de koppeling ONS – Carenzorgt sluit goed aan op mijn dagelijkse taken.") and quality of care (3 statements, for example "De kwaliteit van zorg is toegenomen door het gebruik van de koppeling ONS – Carenzorgt.").

All statements, except the statements related to the burden of care, are treated as single item measures. The statements are based on the goals and functionalities of Carenzorgt. It was estimated that it would take the respondent around 5 to 10 minutes to fill in the questionnaire. The results of the questionnaire were processed anonymously.

Interview

The interview consisted of 3 parts, and was semi structured (see appendix II for the interview scheme). The first part consisted of general questions, covering social demographic characteristics and Carenzorgt usage. The second part consisted of questions about Carenzorgt, where the participant was asked about his or her experiences and opinions with the platform. The Carenzorgt part consisted of questions that were classified under the 4 themes usability, burden of care, workflow and quality of care. The third part consisted of questions about unobtrusive sensor technology and monitoring of patients with dementia. where the participants were first introduced to 3 Powerpoint sheets (appendix VII) that showed a non-existent unobtrusive monitoring concept with sensors in a fictional home of a person with dementia, and different examples of data display. A written explanation was used in addition (see appendix VI), and was explained together with the Powerpoint slides (respondents also received this explanation by mail prior to the interview). The explanation described that the monitoring system gives information about the daily living patterns, behaviour and mood of a resident by a motion and sound sensor in a central location in the room. These track and classify the resident's activities, behaviour and mood automatically, and are visualised on a digital platform. The monitoring system works in the background in a non-obtrusive way, residents do not need to wear a wearable.

After the explanation, respondents were asked about their opinions and perceptions about these systems. Respondents were asked to fill in the monitoring needs schedule during the interview which included factors such as nocturnal restlessness, range of action, social contacts, emotions and cognitive deterioration (see appendix V for complete schedule). The respondent was also asked if he or she had any additions to the monitoring needs schedule. Furthermore, respondents were asked to explain why he or she would or would not like to know certain information about the patient through unobtrusive monitoring. If the respondent wanted information about that particular aspect, it was asked in what way this information should be communicated and presented towards the respondent.

2.5 Data analysis

Questionnaire

When the dataset was retrieved from Qualtrics in SPSS (IBM SPSS Statistics 23), cases with missing values in the statement section were excluded from analysis. These missing values in the statement section meant either that the respondent did not finish filling in the questionnaire, or that the respondent did not meet the inclusion criteria (the respondent is directed to the end of the questionnaire when the answer does not meet the requirements). Demographic information of respondents such as age, gender and function were explored and described using descriptive statistics, together with information about the care team set-up, team size, number of patients and experience with Carenzorgt. Tests of normality (Shapiro-Wilk and Kolmogorov-Smirnov) showed that data of the continuous variables age, team size, number of patients, experience with Carenzorgt, usage of Carenzorgt and duration of usage were not normally distributed. A split median was used for categorizing the teams. This was performed for the variables: 1) Age; 2) Team size; 3) Number of patients; 4) Experience with Carenzorgt; 5) Usage Carenzorgt and 6) Duration of usage Carenzorgt.

The Shapiro-Wilk- and Kolmogorov-Smirnov tests were conducted to test for normality of data of the statement outcomes. These tests showed that the mean score of the scale Burden of care was not normally distributed, neither were the scores of the other (single) items. The mean scores of these statements, including the median and inter quartile range was noted. These scores give an idea of the extent healthcare professionals agree with the statements and give insight in how healthcare professionals experience usability, burden of care, workflow and quality of care in general. The statement outcomes were also analysed in relation to different teams, based on team set-up, team size and number of patients. The Mann-Whitney U test is performed for the variables team set-up (2 categories), team size (2 categories) and number of patients (2 categories). A significance level of 5% is applied for all analyses.

Interview

The data of interviews was processed by transcribing all recorded audio files verbatim. Subsequently, the text was coded using Atlas.Ti. An inductive approach was used for the coding scheme (table 1), where a method constant comparison is applied. Codes were also used for the monitoring needs schedule. The different codes were applied on different units, such as groups of words or full sentences. In some cases, codes overlapped and multiple codes were applied on the same quote. Saturation was not fully reached, since new codes were applied while coding the last transcript. The quotes that were selected in the result section, show the variability in different meanings within 1 specific subject or aspect. The selected quotes also showed a clear description of the respondents experience, opinion or perception on a particular subject or aspect.

Table 1: *Code groups and applied codes*

Code groups	Codes
Sample group	Age, gender, team set-up, team size, number of patients, experience with Carenzorgt, usage of Carenzorgt and duration of usage Carenzorgt.
	Carenzorgt
Carenzorgt positive experiences	Easy and pleasant communication, communication whenever suits the user, less miscommunication/misunderstandings, more participation of informal caregivers in the care process, improvement of cooperation
Carenzorgt negative experiences	More miscommunication/ misunderstandings, usage Carenzorgt difficult for informal caregivers, new messages are not always noticed due to the lack of notification or pop-up, hidden reports not possible, unrest due to time indication Carenzorgt, interdisciplinary link with Carenzorgt as point of improvement
Carenzorgt agenda negative experiences	Planning is via message function instead of agenda, new agenda appointments are not noticed due to the absence of a notification or pop-up, difficult to retrieve an overview of the agenda, Carenzorgt agenda is not used because there already is another agenda, appointments in the agenda are not visible for healthcare professionals agenda is not linked, healthcare professionals do not look into the agenda because it is not used by informal caregivers, appointments of the agenda are not shown in the ONS handover overview
Carenzorgt agenda recommendations	Notification or pop-up in case of (new) appointments, easy insight in the agenda, link with Carenzorgt agenda, agenda in ONS handover overview

Monitoring system	
Opinions and expectations privacy	Privacy patient is a prerequisite, protection of privacy healthcare professionals is a prerequisite, privacy patient in danger, how to deal with privacy sensitive information needs to be discussed, privacy patient as reason to not use a monitoring system, trade-off between safety and privacy of patient, trade-off between safety and privacy of patient: safety is more important
Opinions about permission and competence of patient	Permission of the patient, permission of the family, patient should be competent, unsure to what extent the patient has a say in the matter
Opinions and expectations of care provision from a distance	More care provision from a distance possible, decrease in burden of care because of care provision from a distance, less social contact as disadvantage of care provision from a distance, care provision from a distance not easier
Possible advantages of monitoring systems	Improved insight due to monitoring system, proactive measures/prevention, more safety patient, increase tailoring of care due to monitoring system, increase quality of care due to monitoring system, expectation decrease in burden of care, increase or maintenance of autonomy and independence of patient, living longer at home due to monitoring system, decrease costs of care due to monitoring system
Possible disadvantages of monitoring systems	Increase costs of care due to monitoring system, suspicion caused by sensors, expectation increase burden of care
Monitoring needs	Walking, going out, personal hygiene, eating patterns, action radius (inside the home), social interaction, use of telephone, day- and night rhythm/sleeping pattern, falling, action radius (outside the home), cognitive deterioration, physical deterioration, agitation, apathy, negative mood, positive mood, nocturnal unrest
Situations	Patients in a further stadium of dementia, early stage of dementia, when in doubt of the patient’s daily functioning/ADL, when the patient gets lost regularly, when the patient forgets to take his or her medication regularly, weight reduction, agitation, danger of falling, inactivity, when patients look tired, nocturnal unrest
Requirements monitoring system	Easy to use, Everything in one system/linked to patient files, Valuable/useful data, Good agreements on how to deal with acquired information, Acquired information in reports, Acquired information via email, Only deviating data, Notification in case of new (deviating) data, In case of urgent cases, alarm via a phone call, Being able to decide what information to see or acquire

3. Results

3.1 Demographics and characteristics

Questionnaire

A total of 99 responses were recorded when the dataset was retrieved from Qualtrics (Qualtrics.com). Cases with missing values in the statement section were excluded, which resulted in a total of 66 responses that were eligible for analysis. The number of cases that left certain demographical questions unanswered, varied. The variable about the age of respondents was left unanswered by 1 respondent, size of team was left unanswered 5 times, amount of patients was left unanswered 4 times and the question on experience with Carenzorgt was left unanswered 16 times. The results of the questions about demographics, team, patients and usage are described in table 2.

Table 2: *Demographic characteristics and information on team and patients of included respondents* (n = 66) *(questionnaire)*

Characteristic	*Median (range)*	*Category*	*N*
Age	34 (20 – 62)		
Gender			
		Male	2 (3%)
		Female	64 (97%)
Function*			
		Secondary vocational education	28 (42%)
		Higher professional education	38 (58%)
Team set-up**			
		Self-managing	35 (53%)
		Manager	31 (47%)
Team size	12 (7 – 50)		
		0 - 12 healthcare professionals	35 (53%)
		> 12 healthcare professionals	26 (39%)
Number of patients***	50 (12 – 120)		
		0 – 50 patients	36 (55%)
		> 50 patients	26 (39%)
Experience Carenzorgt	2 (1 – 6)		
		0 – 2 years	28 (42%)
		> 2 years	22 (33%)
Usage Carenzorgt	1 (1 – 7)		
		0 - 1 time per shift	38 (58%)
		> 1 times per shift	28 (42%)
Duration of usage / per session	1 (1 – 7)		
		0 - 1 minute	52 (79%)
		> 1 minute	14 (21%)

* Secondary vocational education: care professional level 3 (verzorgende niveau 3); care professional level 3 IG (verzorgende niveau 3 IG); nurse level 4 (verpleegkundige niveau 4). Higher professional education: nurse level 5 (bachelor) (verpleegkundige niveau 5).

** Self-managing (zelfsturend of -organiserend team (zonder manager)); managed by a manager (niet zelfsturend- of organiserend (met manager)).

*** Number of patients that receive professional care from the team of the respondent.

The variable age was not normally distributed but skewed to the right. This means there were more relatively younger healthcare professionals in the sample group. The sample group consisted of mainly female respondents (97%). Respondents that had a secondary vocational education formed 42.4% of the sample group, while respondents with a higher professional education formed 57.6% of the sample group, which means the majority had a higher professional education. More than half of all respondents worked in teams with 7 to 12 healthcare professionals. The usage of Carenzorgt varied from 0 to 1 time per shift (57.6%) and more than 1 time per shift with a maximum of 7 times (42.4%). The duration of usage is in most cases no longer than 1 minute (78.8%).

Interviews

In total, 5 healthcare professionals were interviewed, table 3 shows their characteristics. From the 5 respondents, 3 respondents could be placed under age category 1 (18 to 34 years) and 3 respondents under age category 2 (> 34 years). All 5 respondents were female and nurses (level 5, except respondent 3). Usage was not always (clearly) mentioned, simply because the number of times functionalities of Carenzorgt were used vary a lot, which also strongly depends on the situation of the patient and the extent of involvement of the patient's informal caregivers.

Table 3: *Demographic characteristics and information on team and patients of included respondents (interview)*

Characteristic	*Respondent 1*	*Respondent 2*	*Respondent 3*	*Respondent 4*	*Respondent 5*
Age	Category 2	Category 2	Category 1	Category 1	Category 1
Gender	Female	Female	Female	Female	Female
Function	Nurse level 5	Nurse level 5	Nurse level 4	Nurse level 5	Nurse level 5
Team set-up	Self-managing	With manager	Self-managing	Self-managing	With manager
Team size	17	20	13	9	12
Number of patients	31	88	36	55 to 60	50
Experience with Carenzorgt	2,5 years	2 years	4 years	3.5 years	0.5 years
Usage of Carenzorgt	Not mentioned	4 to 5 times a week	1 time a week	Not mentioned	Not mentioned
Duration of usage / session	10 seconds	Max. 5 minutes	10 minutes	20 minutes	20 minutes

3.2 Overall experience

Positive experiences Carenzorgt

Interviewed healthcare professionals mentioned different experiences when asked about their opinion on working with Carenzorgt. There are several positive and negative sides of Carenzorgt usage according to them. Table 4 shows the positive experiences that interviewed healthcare professionals mentioned during the interviews.

Table 4: *Positive experiences of healthcare professionals with Carenzorgt*

Carenzorgt positive experiences	**Interview number**	**Quote**
Easy and pleasant communication	1, 2, 3, 4, 5	*Je communiceert wat makkelijker en wat sneller naar elkaar.*
Communication whenever suits the user	1, 3, 5	*... voorheen moesten we altijd gewoon mensen opbellen, maar dan waren ze aan het werk, niet bereikbaar, of ze bellen juist terug wanneer jij aan het werk bent. En nu kan je gewoon reageren wanneer je wil. Ja, en sommige mensen vinden het ook niet prettig om te bellen. Die hebben toch liever van; ik stuur even een berichtje en ik vind het goed. Zelf ben ik er heel blij mee, ja.*
Less miscommunication/ misunderstandings	5	*En wat duidelijker, ik denk dat er wat minder misverstanden komen.*

More participation of informal caregivers in the care process	1, 2, 3, 4, 5	*Ja, ja dat vind ik wel van Carenzorgt. Je communiceert wat makkelijker en wat sneller naar elkaar. (...) En iemand blijft up-to-date met hoe het gaat, normaal had je die evaluaties eens in het half jaar, die hebben wij sowieso nog, maar doordat iemand continu wat kan bijlezen kan je ook wat sneller inspringen met iemand als er echt iets zou zijn of iets geregeld moet worden.*
Improvement of cooperation	3	*Ik ervaar het ook wel als een stukje aanvulling in de zorg, omdat je tegenwoordig heel veel disciplines nodig hebt om de zorg rondom de cliënt te continueren, maar Carenzorgt is wel een aanvulling.*

The functionalities in Carenzorgt that enable for example communication with family and other informal caregivers appear to have an added value. All respondents stated that communication with informal caregivers through Carenzorgt has increased or improved, and communication is easier as well.

Another advantage mentioned by respondents 1, 3 and 5, is that communication can take place 24/7 at whatever time suits the user. Family or informal caregivers can write a message whenever they want, and the healthcare professional can respond when he or she has the time to do so.

It also becomes clear that, because of Carenzorgt, the involvement of informal caregivers in the care process increased. Respondents mention that the increased participation of family is pleasant and improves the overall picture of the patient’s situation, there is less time required to involve informal caregivers and that it is easier for informal caregivers to have insight in the care process.

Negative experiences Carenzorgt

According to the interviewed respondents, there are also several disadvantages of Carenzorgt. In table 5 all codes are shown that include negative experiences or opinions of the interviewed healthcare professionals. In table 6 all codes are shown that describe negative experiences or opinions of healthcare professionals with the Carenzorgt agenda specifically.

Table 5: *Negative experiences of healthcare professionals with Carenzorgt*

Carenzorgt negative experiences	**Interview number**	**Quote**
More miscommunication/ misunderstandings	3, 4	*Vooral je eigen interpretatie weghalen, omdat ik weleens het gevoel heb, dat je heel snel denkt, oh die is boos op mij, of die reageert zo stug, en dat moet je wel loslaten want vaak bedoelen mensen dat helemaal niet zo, maar als je iemand aan de lijn hebt, of aan de telefoon hebt, of gewoon face-to-face, dan voelt dat heel anders. (...) Je hebt sneller miscommunicatie met Carenzorgt.*
Usage Carenzorgt difficult for informal caregivers	1, 2, 3, 5	*... die berichtjes krijgen wij dan niet en dan zeggen ze van; ja maar we hebben toen en toen een berichtje gestuurd, ja maar dat hebben wij niet gehad. En dan leg je ‘t uit en dan; ooh ja zo zit het in mekaar.*
New messages are not always noticed due to the lack of notification or pop-up	1, 2, 3	*Ja, een melding. Dat mis ik echt. Want, hoe vaak is het wel niet dat je een rapportage leest dat je denkt oh jeetje, of een overdracht leest dan denk je oh jeetje dit bericht had ik eigenlijk gisteren al moeten lezen. Wij krijgen daar geen melding van.*
Hidden reports not possible	4	*Echter vind ik het wel heel jammer dat je geen verborgen rapportages kan doen, dus alles wat je schrijft kan de familie ook letterlijk lezen. En wij werken natuurlijk niet alleen met dementerende cliënten of met gewone ouderen maar we werken ook met psychiatrische patiënten, dus mensen die een bipolaire stoornis hebben, of in een depressie zitten of*

		agressieproblemen hebben, mensen met een verstandelijke beperking, dus we werken eigenlijk wel een beetje met alle doelgroepen die je je kan bedenken, maar dat maakt het natuurlijk soms moeilijk want dan weet je gewoon dat je niet alles kan noteren wat je eigenlijk wel zou willen noteren.
Unrest due to time indication Carenzorgt	4	*Ze kunnen de tijd zien van wanneer wij bij hen zouden kunnen zijn, maar dat klopt niet altijd helemaal. Dus wat je dan creëert vaak is dat mensen onrustig of geagiteerd gaan worden. (...) En dat, dat kan ook wel vervelende situaties opleveren, geven collega's ook aan. Mensen worden onrustig, bellen, de bereikbare dienst van ons wordt daardoor een stuk drukker want je krijgt telefoontjes binnen, dus dat maakt het wel soms lastig.*
Interdisciplinary link with Carenzorgt as point of improvement	4	*Ja iets wat ik ook mis, wij werken natuurlijk heel nauw samen met huisartsen, fysiotherapeuten, ergotherapeuten (...) Daar heb je die koppeling niet mee dus die kunnen niet in de rapportages van de cliënt schrijven of kunnen er niet in lezen en dat maakt het wel heel lastig. Want dat is wel iets waar veel extra tijd in gaat zitten waarvan ik denk, als je dat allemaal met elkaar zou koppelen, zou dat ook allemaal minder tijd kosten. Dan zou je ook makkelijker en sneller met elkaar kunnen communiceren.*

Respondents 3 and 4 mentioned a higher chance of miscommunication in Carenzorgt. Respondent 3 stated that the interpretation of information is different when communicating through Carenzorgt and that there is a higher chance of miscommunication. She stated that it is very important to write down information in a clear way, to make sure everyone interprets it right. Respondent 4 mentioned that she sometimes decides to not report what she intended to report, because she feels like there is a chance the patient or informal caregivers might misinterpret the information.

Respondent 3 also mentioned that usage of Carenzorgt can be difficult for informal caregivers, which for example causes miscommunication. Respondents 1, 2 and 5 also mentioned this difficulty in usage by some informal caregivers. According to respondents 1, 3, 4 and 5, (correct) usage of Carenzorgt by the informal caregivers is a prerequisite for the platform to have additional value in the care process. Also, as stated by respondents 1, 3 and 5, informal caregivers should be stimulated and educated more to make sure Carenzorgt is used correctly.

Respondent 1 explained that in the current situation, she has to open the files of every single patient separately and look through the reports of the last 24 hours to see whether an informal caregiver has sent a message or not. Also respondents 2 and 3 mentioned that messages of Carenzorgt are often missed because there is no notification in case of a new message. According to these respondents it would be very convenient to receive a notification in case of a new message.
Melding of notificatie bij nieuw bericht als verbeterpunt – R3: *"Ja hoe dat er precies uit moet zien weet ik niet, maar ik denk dat je daar rechts bovenin, hoe ik dat dan voor me zie, zo'n hoofdje krijgt van familie, net zoals je dat in de rapportage, daar heb je ook zo'n hoofdje familie."*

Respondent 4 specifically mentioned the need for reports to be shielded from the patient and informal caregivers. She explained that she works with patients with dementia, but also with patients with psychiatric problems. She stated that with these type of patients, it is not always possible to report on the patient's situation in the way that the healthcare professional might want to report it. She stated it would be very convenient to have an additional button to create 'shielded' reports, which would make sure only involved healthcare professionals could read these reports. She added that more of her colleagues struggle with this. Furthermore, she stated that healthcare professionals should get more protection for their own privacy in Carenzorgt. Their names can be seen in the reports, and while healthcare professionals pay much attention to the new privacy law in the Netherlands, she feels Carenzorgt comes short when it comes to protecting the privacy of healthcare professionals themselves.

Respondent 4 mentioned that the time indication of the healthcare professional's visit, which is given in Carenzorgt, can cause unrest and inconvenience with the patient. She explained that patients see a certain point of time that stands for the time the healthcare professional is planned to visit the patient. This time is not always the exact time healthcare professionals visit, and because of this patients can become agitated or restless. She stated that it might be better to give a broader time indication, instead of just one particular time.
Andere tijdsindicatieweergave als verbeterpunt – R4: *"Ja nu zien ze één tijd. Ik denk dat ze beter een uur speling daar in zou kunnen pakken. Half uur ervoor half uur erna, van wat iemand er eigenlijk oorspronkelijk in staat."*

Negative experiences Carenzorgt agenda and recommendations
A prominent functionality of Carenzorgt, the agenda, does not seem to be fully used or not used at all which is stated by respondents 2, 3, 4, and 5. Respondent 1 explained that the agenda is used, but she personally only uses the message function of Carenzorgt for planning. Respondent 3 also stated that instead of the agenda, the message functionality is used for planning and scheduling appointments. Table 6 shows different negative experiences that came forward during the interviews. Table 7 shows different recommendations that were named by the respondents subsequently.

Table 6: *Negative experiences of the Carenzorgt agenda according to healthcare professionals*

Carenzorgt agenda negative experiences	**Interview number**	**Quote**
Planning is via message function instead of agenda	1, 3	*Nu gaat het eigenlijk allemaal via blaadjes of familie stuurt een berichtje via ONS. Zij sturen dat dan gewoon naar ONS, dan komt het dus in de overdracht, en dan staat er; over 2 weken moet moeder naar het ziekenhuis dan en dan is geen zorg nodig, sturen wij het weer door.*
New agenda appointments are not noticed due to the absence of a notification or pop-up	2, 3	*Ja. En als het in de agenda komt te staan, als ze het alleen daarin zouden zetten dan zien wij dat niet. Nu zien wij dat niet.*
Difficult to retrieve an overview of the agenda	3, 5	*Maar, op zich vind ik het wel een mooi systeem, alleen bij de cliëntagenda, wat ik dan minder vond, is dat je een apart document moet openen.*
Carenzorgt agenda is not used because there already is another agenda	5	*Omdat, wij zitten, ehm, nu hebben we de Outlook agenda, en als we dan ook de cliëntagenda er naast hebben staan, dan moeten we in 2 agenda's gaan kijken. En de Outlook agenda kan niet weg, omdat we daar als team weer op staan, dus, dus dat is een beetje jammer.*
Appointments in the agenda are not visible for healthcare professionals, agenda is not linked	4	*Ja. Wij kunnen die afspraken niet zien in de planning of wat dan ook. Het is voor ons geen meerwaarde.(…) Nee dat is dan niet gekoppeld, nee.*
Healthcare professionals do not look into the agenda because it is not used by informal caregivers	2, 3	*Ja. Ook omdat niemand het gebruikt natuurlijk.*
Appointments of the agenda are not shown in the ONS handover overview	3	*Want, als je vergeet in de agenda te kijken dan vergeet je ook om haar bloedsuiker te prikken. Terwijl als het in de ONS overdracht rapportage staat, dat lees je altijd.*

There are different reasons why the agenda is not (fully) used. Healthcare professionals are not always able to see appointments or events, which are placed in the agenda by informal caregivers, on time. According to respondents 2 and 3, this is caused by the absence of a notification or pop-up. Respondents 2, 3 and 4 named a notification, in case of a new appointment, as point of improvement. Respondents 3 and 5 stated that it is not possible to retrieve an overview of the agenda in an easy and accessible way. Respondent 5 explained that an easily accessible overview of appointments of all patients would improve the agenda.

By respondent 4 it was mentioned that they cannot see the appointments or events, placed in the agenda by informal caregivers, at all. This was because the agenda of informal caregivers was not linked to the agenda and system used by healthcare professionals of that particular organisation. This respondent stated that she would in fact like to have this link and insight in the Carenzorgt agenda.

Respondent 3 also explained that agenda appointments do not show up in the ONS handover overview, which healthcare professionals use to gain quick insight in the latest reports and overall situation of patients. Respondents 3 and 5 stated that if these appointments would be shown in that overview, it would improve the usefulness of the agenda.

Table 7: *Recommendations for the Carenzorgt agenda*

Carenzorgt agenda recommendations	**Interview number**	**Quote**
Notification or pop-up in case of (new) appointments	2, 3, 4	*Ja eigenlijk ook die afspraken dan, dat wij dat zouden kunnen inzien, en dat je daar een melding van kan krijgen of wat dan ook, dat zou heel handig zijn voor de mensen die plannen en roosteren.*
Easy insight in the agenda	5	*Ja dat is het enige punt wat ik me tot nu toe kan bedenken inderdaad. Is dat het niet een apart document wordt, dat je gewoon mooi overzichtelijk, direct kan zien van dit is de agenda van jouw locatie.*
Link with Carenzorgt agenda	4	*Ja, ik ben ook planner en roosteraar dus het zou ook fijn zijn als je daar inzicht in zou kunnen hebben want soms krijg je zo veel mails binnen over zorgtijden die veranderen om wat voor reden dan ook, dat je zelf ook altijd even niet meer weet, was diegene morgen nou naar het ziekenhuis of was dat nou niet zo. Want soms kan je het ook nergens terug vinden en dat maakt het dan wel lastig. Dan zou zoiets heel handig zijn, want dan zou je er in kunnen kijken en dan denk je ohja klopt, ziekenhuisafspraak.*
Agenda in ONS handover overview	3, 5	*Het is handiger om dat in de overdracht te zetten, en rapportage, ook omdat we dat natuurlijk gewoon gewend zijn. Want, als je vergeet in de agenda te kijken dan vergeet je ook om haar bloedsuiker te prikken. Terwijl als het in de ONS overdracht rapportage staat, dat lees je altijd.*

3.3 Usability

The scores on statement 1 and 2 indicated that on average, respondents find Carenzorgt easy to use (table 8).

Table 8: *Overview of average scores on usability statements*

Statement	*N*	*Median*	*Range* *	*Mean*	*SD*
Usability	-		-	-	-
1. De koppeling ONS – Carenzorgt is makkelijk in gebruik.	66	1	1 - 5	1.85	1.11
2. Het gebruik van de koppeling ONS – Carenzorgt is voor mij logisch.	66	1	1 - 5	1.68	1.00

* The range of the statement score is from 1 to 5, excluding option 6, which stands for 'not applicable'. 1 stands for totally agree, 2 for agree, 3 for neutral, 4 for disagree and 5 for totally disagree.

All interviewed respondents also mentioned that, in general, Carenzorgt is easy to use for them. Respondents 2, 3, 4 and 5 noted that the agenda functionality is not very user-friendly though.
Gebruik Carenzorgt ervaring - R3: *"Eh, ja. Ik vind het wel makkelijk in gebruik, vooral omdat je ehm, het zeg maar in de overdracht wel ziet staan. En ehm, de agenda is wat minder overzichtelijk omdat je het echt moet aanklikken."*

3.4 Burden of care

Table 9 shows that on average, respondents did not think the burden of care became any less due to use of Carenzorgt (statement 3). Statement 6 had an average rating of 1.67, which indicates that most respondents think Carenzorgt makes communication with informal caregivers easier to maintain. With an average score of 3.20 on statement 7, most respondents do not think there is more time to do other things due to Carenzorgt usage. Most respondents do agree that it is easier to stay up-to-date with the patient's situation with an average score of 1.98 (statement 8). Also, most respondents find it slightly easier to arrange care together with colleagues with the use of Carenzorgt (statement 9).

Table 9: *Overview of average scores on burden of care statements*

Statement	*N*	*Median*	*Range*	*Mean*	*SD*
Burden of care (as scale)	66	2.29	1.29 – 4.14	2.36	0.08
3. De zorgzwaarte is minder geworden door het gebruik van de koppeling ONS – Carenzorgt.	64	3	1 - 5	3.08	1.06
4. De organisatie van zorgtaken is makkelijker met het gebruik van de koppeling ONS – Carenzorgt.	66	2	1 - 5	2.30	0.99
5. Door de koppeling ONS – Carenzorgt is het makkelijker om het zorgnetwerk te onderhouden.	65	2	1 - 4	1.95	0.84
6. Met de koppeling ONS – Carenzorgt is het voor mij makkelijker om contact met mantelzorgers en familieleden te onderhouden omtrent de zorg voor de cliënt.	66	1.5	1 - 5	1.67	0.87
7. Door de koppeling ONS – Carenzorgt heb ik meer tijd over voor andere dingen.	64	3	1 - 5	3.20	1.06
8. Door het gebruik van de koppeling ONS – Carenzorgt is het makkelijk om op de hoogte te blijven van de situatie van de cliënt.	66	2	1 - 5	1.98	0.95
9. Met de koppeling ONS – Carenzorgt is het voor mij makkelijker om (samen met collega's) de zorg voor de cliënt goed te regelen.	66	2	1 - 5	2.35	1.12

The interviewed respondents have different opinions on the way Carenzorgt influences the burden of care. Respondents 1, 4 and 5 mentioned that the patient's burden of care did not change, but remained the same. Respondent 4 added that, because family is able to read along with the reports, there is more attention required when writing these. Respondents 2 and 3 stated that the burden of care is less due to faster and easier communication. Furthermore, respondent 3 described that there is less time required to involve informal caregivers in the care process.
Zorgzwaarte blijft gelijk - R1: *"De zorgzwaarte aan zich van de cliënt verandert natuurlijk niet. (...) Ik denk dat de zorgzwaarte gelijk is als ik van meet af aan, van het begin af aan goeie afspraken met familie heb gemaakt. En als iedereen goed weet wat je moet doen. Dan vraagt Carenzorgt voor mij niet meer tijd."*

Interviewed respondents answered differently when asked the question about staying up-to-date on the situation of the patient with Carenzorgt. Respondents 1, 2, 3 and 5 explained that it was easier to stay up-to-date, because of the increased participation of informal caregivers. Respondent 4 stated that it remained the same because other disciplines, such as the general practitioner, are not able to report in the same system. She stated that if that would be the case, faster communication can take place. According to her, unless the family is very actively involved, Carenzorgt does not really contribute to staying updated on the patient's situation.

Makkelijker om op de hoogte te blijven door Carenzorgt - R2: *"Ja. Want ik denk dat voor familie is het laagdrempeliger misschien om een berichtje in Carenzorgt te zetten dan te bellen. (...) Ja het zijn vooral vaak kleine dingen die worden doorgegeven, maar ook als de familie denkt van jullie kunnen bepaalde dingen beter anders doen of willen jullie de zorg anders doen, dan is dat wel heel makkelijk."*

Opinions on whether organisation of care became easier with Carenzorgt differed among the interviewed respondents. Respondent 1 did not explicitly say anything about whether the organisation of care became easier with Carenzorgt or not. Respondent 2 stated that she thinks organising care with Carenzorgt is less easy, because messages in Carenzorgt are often noticed later (due to the lack of a notification) than when someone would call. Respondents 3, 4 and 5 stated that organising care did not become easier with Carenzorgt. Carenzorgt does not have that much influence on the organisation of care tasks itself according to them. It is more for small, practical matters.

3.5 Workflow

Table 10 shows that the average rating of statement 10 was 2.21, which indicates most respondents think that Carenzorgt fits relatively well with their tasks. Statement 11 was rated with a 1.64 on average, which indicates most respondents agree that Carenzorgt has added value in the care process.

Table 10: *Overview of average scores on workflow statements*

Statement	*N*	*Median*	*Range*	*Mean*	*SD*
Workflow	-		-	-	-
10. De werkwijze met de koppeling ONS – Carenzorgt sluit goed aan op mijn dagelijkse taken.	66	2	1 - 5	2.21	0.95
11. De koppeling ONS – Carenzorgt is van toegevoegde waarde in het zorgproces.	66	1	1 - 4	1.64	0.76

Interviewed respondents 1, 2, 3 and 5 stated the same. Respondent 4 stated that Carenzorgt does fit to her tasks, but she actually does not really work that much with Carenzorgt. The only Carenzorgt functionalities that are 'used' is that reports can be viewed by informal caregivers and communication with informal caregivers, but she added that this does not really belong to her daily tasks as healthcare professional.
Aansluiting Carenzorgt op taken zorgverlener – R4: *"Hmm…. Ja verder doen wij d'r eigenlijk niet zo veel mee. (...) Het is echt dat rapporteren wat wij vooral kunnen en waarmee wij mee kunnen communiceren, maar verder hoort het niet bij mijn dagelijkse taken als zichtbare schakel."*

According to all interviewed respondents, the added value of Carenzorgt is mainly because of the improved communication between healthcare professionals and informal caregivers, and the (often increased level of) participation of informal caregivers in the care process.
Participatie mantelzorgers in zorgproces - R1: *"Nou, ik vind het gewoon heel prettig dat de familie mee kan participeren en ook, nou, dingen kunnen, kwijt kunnen in dossiers wat een totaalbeeld geeft van hoe het met iemand gaat."*

3.6 Quality of care

Table 11 shows that most respondents agree that quality of care has increased due to Carenzorgt (2.23). On average, they also think that with the use of Carenzorgt, the tailoring of care to the needs of the patient improved (statement 14, average score 2.05). Statement 15 had an average rating of 2.14, which indicates that most respondents think Carenzorgt improves the overview of the care process of the patient.

Table 11: *Overview of average scores on quality of care statements*

Statement	*N*	*Median*	*Range*	*Mean*	*SD*
Quality of care	-		-	-	-
12. De kwaliteit van zorg is toegenomen door het gebruik van de koppeling ONS – Carenzorgt.	64	2	1 - 5	2.23	0.79
14. Door het gebruik van de koppeling ONS – Carenzorgt kan de zorg beter afgestemd worden op de behoeften van de cliënt.	66	2	1 – 5	2.05	0.75
15. De koppeling ONS – Carenzorgt zorgt voor een verbeterd overzicht in het zorgproces van de cliënt.	66	2	1 - 4	2.14	0.84

Respondents 1, 2, 3 and 5 stated that Carenzorgt contributes to an increase of quality of care due to the increased involvement of informal caregivers and improved communication. Informal caregivers can help healthcare professionals with monitoring the patient's situation, which can assist healthcare professionals with providing suitable care. Respondent 4 stated that quality of care remained the same, because they do not have that many extra options in Carenzorgt, except the funcionality where informal caregivers have insight in the reports of healthcare professionals.
Toename kwaliteit van zorg door Carenzorgt - R1: *"Ik vind dat het beter bijdraagt aan kwaliteitsverbetering, Carenzorgt, omdat familie ook kan aangeven van goh, moeder was incontinent, en als het vaker voorkomt dan kun je dus zien van he, elke middag om 2 uur komt Marietje bij moeder koffie drinken en altijd is ze incontinent, dan ga ik daar een zorgmoment inzetten."*

Respondents 1, 2 and 5 stated that there is more tailoring of care, while respondents 3 and 4 stated that this remained the same and that Carenzorgt does not contribute to any tailoring of the care process. Respondent 1 mentioned that there are shorter lines in communication (if informal caregivers actively use Carenzorgt), but that Carenzorgt is not indispensable in order to tailor and organise care. Respondents 2 and 5 mention that Carenzorgt enables more tailoring of care, because informal caregivers communicate quicker in case there are certain needs of the patient that need to be addressed.
Toename afstemming van zorg door Carenzorgt - R2: *"Ja ik denk het wel.. (...) Omdat cliënten en vooral mantelzorgers toch, als er andere behoeftes zouden zijn, zij dat sneller doorgeven."*

All respondents stated during the interviews that Carenzorgt improved the overview in the care process of the patient. This is because family is more involved and communicates more often about the patient's condition, though this depends on their level of involvement.
Verbeterd overzicht/inzicht in situatie cliënt door Carenzorgt - R1: *"Sinds dat ik bij *Zorginstelling A* werk, maak ik gebruik van ONS en Carenzorgt, daarvoor heb ik bij *Zorginstelling B* in de thuiszorg gewerkt waar ze het niet hadden, en ontbrak het mij weleens aan het gegeven dat ik dacht van; gaat iemand nu naar de dagzorg vandaag of niet, of? Dat is nu dus heel duidelijk en ik weet precies wanneer iemand waar is."*

3.7 Trust in and future use of Carenzorgt

As table 12 shows, statement 13 (trust that Carenzorgt treats information of the patient carefully) had an average rating of 1.38, which means respondents trust Carenzorgt to treat the patient's information in a careful manner. The average rating of statement 16 (future use of Carenzorgt) was 1.55, which indicates respondents would like to continue the use of Carenzorgt.

Table 12: *Overview of average scores on trust in the system and future use statements*

Statement	*N*	*Median*	*Range*	*Mean*	*SD*
13. Ik heb er vertrouwen in dat Carenzorgt zorgvuldig met de gegevens van de cliënt omgaat.	66	1	1 - 4	1.38	0.63
16. Ik zou Carenzorgt in de toekomst willen blijven gebruiken.	66	1	1 - 4	1.55	0.71

All interviewed respondents stated that they had trust in the system of Carenzorgt.
Vertrouwen Carenzorgt - R3: "*Ja zeker. Ik heb het gevoel dat het gewoon heel erg dichtgetimmerd is, en je krijgt ook echt een persoonlijke code, en die printen wij ook uit, die gaat ook echt naar de cliënt, daar gaan wij wel heel zorgvuldig mee om in een afgesloten envelop.*"

All interviewed respondents stated that they would like to continue the use of Carenzorgt in the future.
Gebruik Carenzorgt toekomst - R5: "*Ja. En ik hoop ook wel meer.*"

3.8 Statement score differences between teams

Teams that are managed by a manager and smaller teams (in both number of healthcare professionals and number of patients) agree more to almost all statements related to usability, burden of care, workflow and quality of care than self-managing teams and larger teams (table 13).

Table 13 also shows that healthcare professionals from teams with a team manager and self-managing teams rated the burden of care statements equally with an average of 2.36. Respondents from teams with 50 or less patients agree significantly more with the burden of care statements than respondents from teams with more than 50 patients ($p = 0.045$).

There is a significant difference ($p = 0.012$) in average ratings of statement 12 between respondents from teams with 50 or less patients and respondents from teams with more than 50 patients. Respondents from teams with 50 or less patients agree significantly more with the statement that quality of care has increased with Carenzorgt in comparison to respondents from teams with more than 50 patients.

There is a significant difference in average rating of statement 16 ($p = 0.008$) between respondents from teams with a manager (1.32) and respondents from self-managing teams (1.74). It appears respondents from managed teams are more eager to use Carenzorgt in the future than self-managing teams.

Table 13: *Mean scores of respondents from different care teams on usability, burden of care, workflow, quality of care, trust and future use, results Mann-Whitney U tests.*

Statements	***Team set-up***				***Team size***				***Number of patients***			
	Total	*Manager*	*Self-managing*		*Total*	*<13 hcp* [a]	*> 12 hcp*		*Total*	*<51 patients*	*>50 patients*	
N	66	31	35		61	35	26		62	36	26	
Usability	*Mean*			*p-value*	*Mean*			*p-value*	*Mean*			*p-value*
1. De koppeling ONS – Carenzorgt is makkelijk in gebruik.	1.85	1.65	2.03	0.162	1.87	1.71	2.08	0.393	1.85	1.69	2.08	0.203
2. Het gebruik van de koppeling ONS – Carenzorgt is voor mij logisch.	1.68	1.45	1.89	0.168	1.69	1.66	1.73	0.635	1.71	1.56	1.92	0.161
Burden of care (as scale)[b]	2.36	2.36	2.36	0.704	2.37	2.30	2.78	0.276	2.39	2.25	2.58	0.045*
Workflow	-	-	-	-	-	-	-	-	-	-	-	-
10. De werkwijze met de koppeling ONS – Carenzorgt sluit goed aan op mijn dagelijkse taken.	2.21	2.16	2.26	0.581	2.26	2.23	2.31	0.794	2.23	2.11	2.38	0.224
11. De koppeling ONS – Carenzorgt is van toegevoegde waarde in het zorgproces.	1.64	1.48	1.77	0.087	1.62	1.54	1.73	0.383	1.65	1.56	1.77	0.299
Quality of care	-	-	-	-	-	-	-	-	-	-	-	-
12. De kwaliteit van zorg is toegenomen door het gebruik van de koppeling ONS – Carenzorgt.	2.23	2.17	2.29	0.526	2.25	2.12	2.42	0.107	2.27	2.06	2.56	0.012*
14. Door het gebruik van de koppeling ONS – Carenzorgt kan de zorg beter afgestemd worden op de behoeften van de cliënt.	2.05	1.90	2.17	0.215	2.07	1.97	2.19	0.458	2.05	1.92	2.23	0.191
15. De koppeling ONS - Carenzorgt zorgt voor een verbeterd overzicht in het zorgproces van de cliënt.	2.14	2.00	2.26	0.264	2.16	2.00	2.38	0.116	2.18	2.06	2.35	0.190
13. Ik heb er vertrouwen in dat Carenzorgt zorgvuldig met de gegevens van de cliënt omgaat.	1.38	1.45	1.31	0.740	1.41	1.40	1.42	0.993	1.35	1.42	1.27	0.511
16. Ik zou Carenzorgt in de toekomst willen blijven gebruiken.	1.55	1.32	1.74	0.008*	1.56	1.46	1.69	0.098	1.55	1.42	1.73	0.190

[a] Healthcare professionals

[b] Cells with value ‘6’ (not applicable) are excluded from analysis, this is the case for statement 3 (2 cells), 5 (1 cell), 7 (2 cells) and 12 (2 cells)

3.9 Expectations, needs and barriers towards unobtrusive monitoring

Privacy of patient and healthcare professional

Privacy of the patient appeared to be a very important factor that all healthcare professionals mentioned during the interviews. In the first reactions of healthcare professionals, when introduced to the idea of an unobtrusive monitoring system, privacy was often mentioned (table 14). The invasion of privacy could be a major disadvantage according to them. Not only the privacy of the patient, but also the privacy of the healthcare professional is sometimes seen as a barrier. According to respondents 1, 2 and 3 the system should not invade the privacy of the patient. Respondent 1 stated that the privacy of the healthcare professional should be protected as well. By all respondents it was mentioned that, with a monitoring system, privacy of the patient is endangered. Respondents 3, 4 and 5 found it difficult to decide whether privacy or safety would be more important. Respondent 1 clearly mentioned that she found safety more important, respondents 4 and 5 shared the same opinion.

Table 14: *Opinions and expectations of healthcare professionals regarding privacy*

Opinions and expectations privacy	**Interview number**	**Quote**
Privacy patient is a prerequisite	1, 2, 3	*Het moet in ieder geval aan de privacy eisen voldoen, de wet en regelgeving.*
Protection of privacy healthcare professionals is a prerequisite	1	*En stel dat het allemaal groen is, groen licht wordt gegeven, dan wil ik wel als voorwaarde dat de medewerkers het wel kunnen uitzetten op het moment dat de zorg geboden gaat worden, als er fysiek contact is.*
Privacy patient in danger	1, 2, 3, 4, 5	*Mijn eerste reactie is dat de privacy van de cliënt, echt, echt geschaad wordt.*
How to deal with privacy sensitive information needs to be discussed	3	*Sowieso duidelijke afspraken met familie, privacy gevoelige informatie bespreken en ook dat vastleggen hoe gaan we daarmee om.*
Privacy patient as reason to not use a monitoring system	3, 5	*Ja eigenlijk weer een beetje het privacy punt, dat is het enige waar ik tegen zit.*
Trade-off between safety and privacy of patient	3, 4, 5	*Ik vind het beide wel heel belangrijk. Kan niet zeggen dat ik de veiligheid belangrijker vind dan de privacy.*
Trade-off between safety and privacy of patient: safety is more important	1, 4, 5	*Ik denk als iemand zo ver in zijn of haar dementiewereld en ze geen, en diegene zelf het gevaar niet meer inziet, dan vind ik het gevoel van veiligheid belangrijker dan privacy.*

Permission and competence patient

Table 15 shows different opinions of healthcare professionals about the permission and competence of the patient. Respondents 1, 2, 4 and 5 stated that the patient must give permission for monitoring, but respondent 3 questioned the extent to which the patient has a say in this matter. Respondents 2 and 4 stated that the patient should have the competence to give this permission. Respondents 1, 3, 4 and 5 stated that family should also give permission to monitor the patient.

Table 15: *Opinions and expectations of healthcare professionals regarding permission and competence of patient*

Opinions about permission and competence of patient	**Interview number**	**Quote**
Permission of the patient	1, 2, 4, 5	*Daar moet de cliënt toestemming voor geven, en akkoord mee zijn.*
Permission of the family	1, 3, 4, 5	*Hmm. Ja als familie het er niet mee eens is, dan zou ik het sowieso al niet gebruiken, ja eigenlijk als je, als je met familie overlegt, en die zegt van ja, sorry maar zoiets zou*

		echt niet bij pap of mam he, gehoord hebben, ja dan zou ik zoiets al sowieso niet gaan inzetten.
Patient should be competent	2, 4	*Ik denk zelf dat het zelfs heel belangrijk zou zijn als iemand nog niet dementerend is en zoiets is al ontwikkeld dat je t daar van tevoren al over zou hebben.*
Unsure to what extent the patient has a say in the matter	3	*Ik woon hier, jullie hoeven geen sensoren te plaatsen. Dus in hoeverre heeft de cliënt daar nog zeggenschap over.*

Providing care from a distance

As can be seen in table 16, respondents 1, 2 and 5 stated that a monitoring system might enable more care provision from a distance. Respondents 1 and 2 added that this might result in less visits, which causes the patient to have less moments of having social interaction, which is seen as a disadvantage. Respondent 3 was not sure on whether such a system would make it easier to provide care from a distance, but it would make certain matters more insightful. Respondent 4 said that this would not make providing care from a distance easier. This is because, especially with patients with dementia, you need to visit patients at their home to provide appropriate care.

Table 16: *Opinions and expectations of healthcare professionals regarding permission and competence of patient*

Opinions and expectations of care provision from a distance	**Interview number**	**Quote**
More care provision from a distance possible	1, 2, 5	*Als het mij zou helpen om te zien dat iemand wel om 5 uur z'n brood heeft gepakt, hoef ik daar niet nog een keer extra naartoe. Dat zou mij wel werk uit handen nemen, want ik kan het monitoren op het systeem.*
Decrease in burden of care because of care provision from a distance	1, 5	*Ja precies, dat we gewoon op kantoor zitten, van oh, nou daar hoeven we dus niet naartoe. Dat scheelt ons ook weer heel veel tijd. Kunnen we een beetje op afstand dingen regelen.*
Less social contact as disadvantage of care provision from a distance	1, 2	*Het is dan alleen de vraag of je daarmee de patiënt van dienst bent, want die mist wel weer sociale contacten, ja.*
Care provision from a distance not easier	3, 4	*Nee, dat denk ik dan weer niet. Nee want als je echt, even over die dementerenden sector praat, daar zal je toch naartoe moeten gaan.*

Possible advantages monitoring systems

Table 17 shows possible advantages of monitoring systems mentioned by interviewed healthcare professionals. Patients with dementia can forget whether they have or have not done certain things. They also tend to withhold information from healthcare professionals, as described by all of the interviewed healthcare professionals. This makes it difficult to get an idea of the patient's abilities and – more importantly - disabilities.

Achterhouden informatie/niet meer weten – R4: *"Ja, precies, we hebben inderdaad, in 1 situatie die man, een hele intelligente meneer is dat maar, hij verbergt dat ie dementie heeft, hij zegt dat er niks met hem aan de hand is, hij wordt ook vrij kwaad als je daarover begint en dat maakt het zorg leveren dan natuurlijk wel heel lastig want, onder welk mom kom je hem dan controleren of ie wel schone kleren aan heeft, of ie wel gegeten heeft, dat maakt het wel heel erg lastig."*

What could be a major advantage of the system, which is also mentioned by all interviewed respondents, is that it can help them retrieve an objective overview of a patient's daily functioning and give more insight.

Table 17: *Possible advantages of monitoring systems*

Possible advantages of monitoring systems	**Interview number**	**Quote**
Improved insight due to monitoring system	1, 2, 3, 4, 5	*Ik denk dat het een hele boel informatie zal geven en veel meer dan dat we nu zouden weten. (...) Ja. Een totaalbeeld en misschien ook wel een heel ander beeld dan dat ik voor ogen had.*
Proactive measures/prevention	1, 2, 3, 4, 5	*Goh, diegene slaapt de afgelopen 2 weken heel slecht, misschien moeten we toch eens samen gaan kijken wat we daar aan kunnen veranderen. Is er misschien rustgevende muziek nodig, helpt dat, of als je van alles hebt uitgeprobeerd kan je zelfs nog naar een dokter gaan overleggen over medicatie of wat dan ook.*
More safety patient	2, 3, 5	*Het geeft ook wel weer een stukje geborgenheid, want, stel dat je valt, en je ligt bijvoorbeeld in de woonkamer en die sensor ziet, die weet dat jij daar bent maar het is al heel lang stil, dan krijgt misschien familie daar een berichtje over ofzo.*
Increase tailoring of care due to monitoring system	3, 4, 5	*Ja met zoiets zou je het wel mogelijk maken om misschien de zorgtijd ook anders in te zetten. Als iemand misschien een stukje rustiger is, of misschien merk je wel dat iemand heel graag wil uitslapen, dat je dan toch wat later moet komen, en dan moet overwegen die steunkousen wat later aan te trekken dan de originele afspraken. Ik denk dat het daar wel heel erg bij zou helpen om de zorg op een andere manier af te kunnen stellen.*
Increase quality of care due to monitoring system	1, 3, 5	*Je hoopt natuurlijk in te kunnen zetten op kwaliteit van zorg, he als iemand 10 keer naar de wc gaat 's nachts dat je toch maar eens de volgende dag urine gaat opvangen.*
Expectation decrease in burden of care	2, 4, 5	*Ik denk dat je minder vaak bij iemand langs hoeft te gaan, want wij komen regelmatig bij mensen eigenlijk alleen ter controle zeg maar.*
Increase or maintenance of autonomy and independence of patient	2, 3, 4, 5	*Dat denk ik wel. Want misschien als wij er op attenderen van goh, mevrouw eh, wij krijgen mee dat u toch niet zo, dat u weinig maaltijden ofzo bereidt, dat ze dat misschien kunnen motiveren dat ze het wel doen. Want misschien raakt ze dan ondervoed en wordt ze opgenomen.*
Living longer at home due to monitoring system	2, 3, 4, 5	*Ja, dat ze toch, dat wij door, dingen te monitoren, dat het toch eh, ze meer hulp kunnen bieden dat ze thuis nog kunnen blijven wonen.*
Decrease costs of care due to monitoring system	2	*Misschien dat de zorg ook wel goedkoper zou worden.*

All interviewed respondents think that, with help of the system, proactive working could increase and create more possibilities to undertake preventive actions. Respondents named for example falling, malnutrition and incontinence as potential risks for the patient's health, which could be prevented with help of a monitoring system.

Respondents 2, 4 and 5 expected that the burden of care would decrease due to the use of a monitoring system. Respondent 1 expected that, due to the increase of available information about the patient, the burden of care will increase instead of decrease.

Respondents 2 and 3 stated that with help of the monitoring system, the patient's independency can be maintained and might enable the patient to live longer at their own home. Respondents 4 and 5 stated that autonomy and independency of the patient could increase with use of a monitoring system. Respondent 1 did not think a monitoring system could have an effect on the autonomy and independency of the patient. She stated that, if you want to guide the patient through the process and provide care, you will need to visit the patient. Monitoring on a distance will not help with this, it can only help in creating more insight of the patient's situation.

Respondents 2, 3 and 5 stated that patients might be able to live at home longer with help of a monitoring system. Respondent 4 mentioned that it could have a contribution for patients to live longer at home, but only if the patient has a sufficient social network. Respondent 1 was not sure, because even though there would be a monitoring system, the disease would still progress and continue to worsen the patient's condition. According to her, it would depend on the individual and the particular context.

Possible disadvantages monitoring systems

Next to privacy as major disadvantage, the use of monitoring systems could have several other disadvantages according to healthcare professionals. Table 18 shows different possible disadvantages according to the interviewed healthcare professionals.

Table 18: *Possible disadvantages of monitoring systems*

Possible disadvantages of monitoring systems	**Interview number**	**Quote**
Increase costs of care due to monitoring system	2, 5	*Ja ik weet dan ook… zit dan met de kosten, ook voor de cliënten. Want stel je hebt een fantastisch systeem maar de cliënt, ik noem maar wat, die moet bijbetalen, ja daar wordt de cliënt natuurlijk ook niet vrolijk van. Dus dan kunnen wij het wel willen… dus dat is ook een puntje.*
Suspicion caused by sensors	1, 2, 3, 4, 5	*Maar ik denk dat ook heel veel achterdocht hierdoor komt. Dat mensen het gevoel hebben dat ze in de gaten gehouden worden.*
Expectation increase burden of care	1, 3	*Want zet je het bij de wijkverpleegkundige neer, als je dat van alle dementerenden moet gaan bijhouden, ja, daar heb je een dagtaak aan. Dat kan haast niet.*

Respondents 2 and 5 named an increase in costs might be a disadvantage. Respondent 2 mentioned that the system might reduce healthcare costs on the other hand, because patients would be living longer at home.

According to all respondents, the system would become undesirable when the patient becomes suspicious or uncomfortable due to the system. If the patient would become suspicious, for example when the system would be visible for the patient, it would be a reason to not place the system into the patient's home. Respondent 4 mentioned that when a patient becomes suspicious, you would go towards a negative direction in providing care. She explained that at the moment of the interview, there were 2 patients in care that were rebellious towards healthcare professionals. She stated that, if such a system would be placed in their homes and these patients would notice, it would cause a lot of resistance and perhaps even stimulate aggression.

Monitoring needs

There are several differences in opinions of interviewed healthcare professionals on which factors they would like to monitor and which not, with different reasons. Monitoring needs preferences of the respondents are shown in table 19.

Table 19: *Monitoring needs that respondents would or would not like to monitor*

Monitoring need	*+ (Yes)*	*- (No)*	*? (Not sure)*
Daily activities			
Walking (amount/speed)	4 (80%)	1 (20%)	-
Going out	1 (20%)	4 (80%)	-
Personal hygiene (washing/dressing/use of bathroom)	4 (80%)	1 (20%)	-
Eating patterns (for example preparing a meal)	5 (100%)	-	-
Action radius (inside the home)	1 (20%)	4 (80%)	-
Social interaction	1 (20%)	4 (80%)	-
Use of telephone (number of times)	-	3 (60%)	2 (40%)
Day- and night rhythm/sleeping pattern	4 (80%)	1 (20%)	-
Safety			
Falling	5 (100%)	-	-
Action radius (outside of the home)	4 (80%)	1 (20%)	-
Dementia-specific			
Cognitive deterioration	5 (100%)	-	-
Physical deterioration	3 (60%)	2 (40%)	-
Agitation (nervous unrest or restless movements)	3 (60%)	2 (40%)	-
Apathy (listlessness / loss of motivation and interest)	4 (80%)	1 (20%)	-
Negative mood	3 (60%)	2 (40%)	-
Positive mood	2 (40%)	3 (60%)	-
Nocturnal unrest	5 (100%)	-	-
Own additions	Bowel movement and medication intake		

Walking (amount/speed)

Respondents 1, 2, 3 and 4 would like to monitor walking, to see how active a patient is in his or her home. It might also give an idea of the patient's risk of falling. Respondent 5 stated that it might be useful to know whether the patient still moves or not at all, but information about the amount of walking and speed is unnecessary information according to her.

Going out

Most of interviewed respondents did not want to monitor if the patient went out. Reasons why were mainly privacy and that it would not have any added value in the care process. Respondent 4 said she would like to have it monitored. She thinks it is important, especially for people with dementia, to keep doing fun activities.

Personal hygiene

Respondents 1 and 4 stated that, when a patient is at an advanced dementia stage, healthcare professionals are already involved with the personal hygiene of the patient which would make monitoring unnecessary. But, especially when a patient is at an early stage, it might be useful to check up on the patient's hygiene. Respondents 2 and 3 also stated that it would be useful, especially when it is doubted whether the patient takes good care of his or her hygiene or whether he or she uses the bathroom on time. Respondent 5 stated that monitoring personal hygiene might be convenient, but has no added value for her at this moment.

Eating pattern

Respondents 1, 3, 4 and 5 would like to monitor the patient's eating pattern, to check whether the patient can prepare meals independently and whether assistance is required. Respondent 2 stated that it depends whether the patient already receives care or not. When a patient receives care, he or she will be weighed every week, which would be sufficient according to respondent 2. If a patient does not receive care, it might be useful to monitor the patient's eating pattern.

Action radius (inside the home)
Respondents 1 and 2 would like to monitor action radius, to, for example, see whether a patient has any risk to fall down and to guarantee safety. Respondent 2 stated that monitoring the action radius would not have an added value since walking would already be monitored. Respondents 4 and 5 did not want to monitor the action radius either.

Social interaction
Social interaction is seen as a private matter by most healthcare professionals. None of the respondents, except respondent 1, would like to monitor social interaction.

Use of telephone
Use of telephone is also seen as a private matter by respondents 2 and 4 and the patient's privacy would be harmed if it would be monitored. Respondent 1 stated that it is not important since most people do not use it. Respondents 3 and 5 stated that they do not need to know whether the patient uses the phone or not.

Day- and night rhythm/sleeping pattern
Monitoring day- and night rhythm is seen as useful, so is nocturnal unrest. Respondent 1 explained that the day- and night rhythm of patients with dementia is often more disturbed, which is why it could be useful to monitor this. Respondents 2, 3 and 4 also think a good day- and night rhythm and sleeping pattern is important, which is why it could be useful to monitor. Respondent 5 stated that she would not like to monitor the day- and night rhythm or sleeping pattern, she would rather receive a notification or alarm if a patient has not moved for a longer period of time.

Falling
Automatic fall detection is seen as very valuable, especially for patients with dementia. This is because patients with dementia often have a personal alarm with an emergency button around their wrist (bracelet) or neck (necklace), but may not be able or forget to press the button in case of an emergency. Personenalarmering bij dementie – R4: *"Nee want, ja goed we zouden het liefste sowieso iets hebben wat ontwikkeld was zodat je kan zien als iemand gevallen is, omdat je ook gewoon dementerende cliënten inderdaad hebt die niet meer weet of niet meer snappen hoe zo'n alarmering werkt."*

Respondents 1 and 3 said they would like to know it when a patient fell down, and also the reason why and location where this patient fell down. Respondents 2, 4 and 5 also stated that they would like to monitor it, and receive an alarm in case the patient fell down. Respondent 4 explained that if it is measured that a patient falls down more often, it enables healthcare professionals to look into what tools the patient might need to prevent the patient from falling again.

Action radius (outside of the home)
Respondents 1, 2, 4 and 5 would like to monitor the action radius of certain patients when they are outside their home. Respondents 2, 4 and 5 named patients that sometimes wander around outside, who are not always able to find their way back home, or that they tend to walk away from their home, as examples where it might be useful to monitor the patient's action radius. Respondent 5 added that it would also become easier for healthcare professionals to undertake action in case of a dangerous situation. Respondent 3 would not like to monitor the action radius of patients.

Cognitive deterioration
Respondent 1 stated that cognitive deterioration would be a very interesting thing to monitor and might be useful when a patient needs to be admitted to an intramural care facility. To acquire the right indication, objective information about the patient's cognitive state of functioning is required. Currently this is done with multiple tests, but the acquired monitoring data could make this substantiation more

complete. Respondent 4 also stated that this monitoring data could be useful in acquiring the right indication for patients. Respondents 2 and 5 would also like to monitor cognitive deterioration. Respondent 3 described that cognitive deterioration is already monitored by for example family, healthcare professionals and the geriatrician, which is why she does not see the added value of measuring cognitive deterioration with a monitoring system.

Physical deterioration

Physical deterioration might also be interesting to monitor according to respondents 1, 2 and 4. Respondent 3 stated that she would not want to monitor physical deterioration, since physical deterioration is already measured with the other factors (of the monitoring needs list). Respondent 5 explained that she can monitor the patient's physical deterioration herself, so there is no need for a monitoring system to keep track of this.

Moods patient

Respondent 1 stated it would be interesting to monitor agitation, apathy and other moods. Information about agitation could be useful to determine what caused it and how it can be prevented. Also, information about what makes a patient happy could be used for the patient's benefit, which is also mentioned by respondent 3. Respondents 2 and 3 would also like to monitor apathy, agitation and other negative moods. According to respondent 3 agitation or aggression are important factors to objectively monitor, since this data could be used to show that for example medication needs to be adjusted. Apathy might be useful to monitor in case someone does not receive care yet.

Respondents 4 and 5 stated that moods and behaviour should not be monitored. Respondent 4 stated that patients with dementia often show mood swings, which can be part of their personality at that moment. Respondent 5 also stated that monitoring these factors might be more suitable in a nursing home than in home care. She added that there is no need for an expensive monitoring system to measure this, because healthcare professionals are able to monitor it themselves.

Nocturnal unrest

All respondents would like to monitor nocturnal unrest. Respondent 4 explained that the information could help healthcare professionals understand why someone is agitated or looks tired and could also support them in finding a solution to improve the patient's night's rest.

Own additions: medication intake and bowel movement

Respondent 1 named medication intake as a possible factor to monitor, but this would not be necessary according to her since patients already receive assistance from healthcare professionals with their medication intake. Medication intake is added by respondent 2 on the monitoring needs list, since it would be useful to monitor. Respondent 1 added bowel movement as factor she would find interesting to monitor.

Situations

Interviewed respondents were also asked in what sort of situations or with what sort of patients the use of a certain monitoring system could be useful. There were different situations named by respondents, as can be seen in table 20.

Table 20: *Situations where healthcare professionals would like to use the system*

Situations	**Interview number**	**Quote**
Patients in a further stadium of dementia	1, 4	*Ja ik denk vooral bij eh, de dementerende cliënten die we op dit moment hebben die al in een iets verder gevorderd stadium zitten. Ik denk dat daarbij zo'n sensor ook voor familie die nauw betrokken zijn, dat dat heel erg fijn zou zijn.*
Early stage of dementia	1	*Ja, maar sommige voorbeelden ook juist in een vroeg stadium. Als ik alleen maar als trajectbegeleider aanwezig ben aan zorg, en*

		verder nog niks. En de familie zegt van ja ma die slaapt 's nachts niet, ja wat gebeurt er dan 's nachts? Dan zou je dat kunnen gaan monitoren voor een tijdje.
When in doubt of the patient's daily functioning/ADL	1, 2, 3, 4, 5	*Ja bij mensen die zeggen ja, nee ik heb al gegeten, en dan zitten wij echt te kijken van ja, heb je wel echt gegeten of niet? En dan weeg je die mensen, en dan vallen ze wel af.*
When the patient gets lost regularly	2, 3, 4, 5	*Ja, dwalen en waarvan je ook weet dat ze het huis niet meer terug vinden.*
When the patient forgets to take his or her medication regularly	2	*Ja vergeetachtigheid, medicatie vergeten.*
Weight reduction	1, 3, 4, 5	*Als ik zie dat iemand bijvoorbeeld heel veel bij komt of afvalt in een korte periode, dan zou ik het wel interessant vinden om te weten, ja wat het eetpatroon dan is.*
Agitation	3	*Bij agitatie.*
Danger of falling	1, 5	*Valgevaar.*
Inactivity	3, 5	*Ja lopen zou ik wel willen weten bij iemand die ver, die wat meer vergevorderd dementerend is, en die eh, inactief wordt.*
When patients look tired	3, 4	*Eh, iemand die veel slaapt overdag, die het dag-nachtritme gaat omgooien.*
Nocturnal unrest	3	*Bij nachtelijke onrust.*

All respondents stated that they might want to use a monitoring system when it is doubted whether the patient is still able to perform the activities of daily living independently. Respondents 1, 3, 4 and 5 stated that they would like to check the patient's eating pattern if there is a reduction in weight. Respondents 2, 3 4 and 5 would like to monitor the patient when he or she regularly wanders off and possibly gets lost.

Requirements monitoring system

Healthcare professionals named several requirements which a monitoring system should meet in order to be useful for them (table 21). Respondents 1, 3 and 5 stated that the acquired measurements should be useful. Respondents 1 and 3 mentioned that the information could be very valuable, but not in every situation. It would not have any added value when the patient does not accept any help or care for a certain activity that the patient is known to neglect in daily life.

Respondents 1, 2 and 3 stated that they would like to receive the acquired data via the patient's reports, respondents 2, 4 and 5 named e-mail as another medium through which data could be received. Respondents like to receive a notification if new (deviating) data is measured, and a phone call in case of an emergency or another event that requires immediate action.

Table 21: *Requirements for monitoring systems according to healthcare professionals*

Requirements monitoring system	**Interview number**	**Quote**
Easy to use	5	*Dus niet dat je inderdaad verschillende programma's moet openen, want dan ga je het eigenlijk al niet gebruiken, het moet gewoon echt makkelijk zijn. In de zorg hebben we al niet heel veel tijd.*
Everything in one system/linked to patient files	1, 5	*Ja, dan heb ik dat in 1 systeem staan, in plaats van dat ik uit verschillende systemen informatie moet halen.*
Valuable/useful data	1, 3, 5	*Ik zou wel echt alleen informatie willen hebben waar ik iets aan heb.*
Good agreements on how to deal with acquired information	1, 3	*Ik denk dat je, voordat je zo'n systeem in gaat zetten, dit soort situaties als voorbeeld moet gaan benoemen met de familie en*

		de cliënt, van hoe gaan we dit opvolgen? En wie, en hoe gaan we daarmee om? Daar moet je van tevoren afspraken over gaan maken.
Acquired information in reports	1, 2, 3	*Het zou mij helpen als ik in het zorgplan zet dat ik wil monitoren hoe de nachtelijke rust is, dat de cijfers, of mevrouw is 10 keer uit bed geweest dat dat meteen in de rapportage komt.*
Acquired information via email	2, 4, 5	*Ja, ik zou dat ook gewoon weer via de mail allemaal, want zo kan je het ook voor jezelf een beetje bijhouden, hoe het verloop van iemand gaat.*
Only deviating data	2, 4, 5	*Als iemand prima slaapt, dan hoef ik de nachtelijke onrust niet te weten. Dan hoef ik daar geen melding van te hebben van oh die dame heeft goed geslapen, dan denk ik ja, hoef ik eigenlijk niet te weten.*
Notification in case of new (deviating) data	2, 5	*Ja dat kan ook. Maar dan moet er wel een melding over komen want wij lezen niet altijd standaard de dossiers.*
In case of urgent cases, alarm via a phone call	2, 4, 5	*Ja, het liefste telefonisch dan. Dat de bereikbare dienst gelijk een telefoontje krijgt om te gaan kijken wat er aan de hand is.*
Being able to decide what information to see or acquire	3	*Waar je wel kan clusteren, dus niet dat alles door elkaar staat.*

4. Discussion

4.1 Carenzorgt

Healthcare professionals have positive experiences with Carenzorgt when it comes to usability, workflow and quality of care. Carenzorgt appears to be user-friendly, fits well with the tasks of healthcare professionals, has an added value in the care process, and it can contribute to an increase of quality of care. Carenzorgt does not decrease the burden of care in general, but it is easier to stay up-to-date with the patient’s situation. The main advantages of Carenzorgt appeared to be the easy communication between informal and formal caregivers, where there is a 24/7-availability of the system which enables communication at whatever time suits the user. Carenzorgt can also improve participation and involvement of informal caregivers in the care process and cooperation between different parties, but correct usage of the platform by informal caregivers is a prerequisite. Respondents appeared to have trust in Carenzorgt as a system and would like to continue the use of Carenzorgt in the future.

It is sometimes seen as a disadvantage that informal caregivers can read along with the reports, mainly because it can cause miscommunication or misunderstandings with informal caregivers or the patient. In order to avoid this, it is important that healthcare professionals have sufficient skills to report in a way where the chance of wrong interpretations is minimised. If healthcare professionals decide to not report certain findings in order to avoid miscommunication or misunderstandings, it could have a negative impact on the quality of care. The lack of a notification in case of a new message in Carenzorgt is missed, which sometimes causes healthcare professionals to read messages too late. The agenda is experienced as less user-friendly and is barely used or not used at all. This is mainly caused by the lack of use by informal caregivers, the lack of a notification in case of newly entered appointments, or (new) appointments that are not visible in the ONS handover overview, where recent reports are shown. The time indication of the healthcare professional’s visit, which is given in Carenzorgt, is not always the exact time that the healthcare professional visits. This can cause unrest or agitation of the patient.

Respondents from teams with 50 or less patients agree significantly more with the burden of care statements than respondents from teams with more than 50 patients. These respondents also agree significantly more to the statement that quality of care has increased, than respondents from teams with more than 50 patients. An interesting thing is that teams that are managed by a manager and smaller teams (both in number of healthcare professionals and number of patients) agree more to all statements related to usability, burden of care, workflow and quality of care than self-managing teams and larger teams. The importance of the size of teams in determining the quality and quantity of human interactions and their outcomes for members, groups and organisations has long been recognized as an important research issue (Richter, Peiro & Schaufeli, 2007). As groups grow larger, it also changes in other ways, generally for the worse. From a theoretical perspective, smaller group size is supposed to lead to increased group cohesiveness, less specialisation of task, and better communication. However, the theoretical inquiry of Richter et al. (2007) suggests that the relationship between team size on one hand and group processes and outcomes on the other, is neither positive or negative. It seems that team climate for innovation, team performance and innovation benefits from intermediate team sizes. Aubé, Rousseau & Tremblay (2016) investigated the relationship between team size and quality of group experience and found a negative relationship. According to Aubé et al. the study shows the importance for managers to avoid creating overly large teams. Curral, Forrester, Dawson & West (2010) investigated the relationships between team inputs (task type and team size) and team processes in cross industry Portuguese teams, and found that large teams have poorer team processes. Another field-study of primary health teams (Poulton & West, 1999) also suggested that there are poorer team processes in large teams. Due to possible poorer team processes in larger teams, respondents might experience different aspects in care more negatively. This could be an explanation for the lower scores on all statements in the questionnaire.

4.2 Unobtrusive monitoring systems

The barriers that were expected towards unobtrusive monitoring systems were mainly suspicion or distress of the patient caused by the presence of sensors, the increased amount of available information which could result in an increased workload and, mostly named, the interference of the patient's privacy and also maybe that of healthcare professionals. Yusif, Soar & Hafeez-Baig (2016) reviewed the main barriers to the adoption of assistive technologies by older adults, and also found that privacy is a top critical concern to older adults. Layouni, Verslype, Sandikkaya, Decker & Vangheluwe (2009) also mentioned that one of the main obstacles facing the adoption of medical telemonitoring, is the concern among patients that their privacy may not be properly protected.

Respondents stated that permission of the patient and family to use such an unobtrusive system is very important. As stated by some healthcare professionals, the patient should have the competence to give permission for monitoring. However, discussing this matter with the patient and asking permission is not always easy, since dementia is often the reason why the patient receives care in the first place. Therefore it is very important to facilitate shared decision making, where involved parties are able to make a well-informed and considered decision together. People with dementia cannot be assumed to be incapable of making decisions on their diagnosis alone as they may have retained cognitive abilities (Lislerud Smebye, Kirkevold & Engedal, 2012). However, the patient with dementia is not always the best judge of their interests and family members might have legitimate issues needing resolution. The responsibility of healthcare professionals is to balance needs and facilitate decision making through optimal participation of the patient with dementia. Optimal involvement of patients with moderate dementia is facilitated by positioning them as capable of influencing decisions, assessing decision-specific competence, clarifying values and understanding the significance of relationships and context (Lislerud Smebye et al., 2019). Supporting tools can be used to improve the shared decision making process between healthcare professionals, patients and family. The tool *Richtlijnen en shared decision making in de praktijk* (guidelines and shared decision making in practice) describes different strategies. The healthcare professional must become aware of interventions that might be preference sensitive and needs to be provided with tools for shared decision making. An example is that alternative options, including all relevant pros and cons for the patient and family, should be discussed together. Usage of supporting materials such as a decision aid and a fact-sheet with easy-to-understand information (including relevant pros and cons) is also recommended. Communication and information should be regarded as an effective intervention in shared decision making, where for example a list with suggestions of relevant questions can be handed over to the patient, or a communication plan can be offered that is adjustable in regards to for example age, gender, comorbidity, intelligence level, culture and religion as support (IQ Healthcare, 2013).

An unobtrusive monitoring system could possibly enable (more) care provision on a distance, which could also decrease the burden of care. It could also give an increased insight in the patient's capabilities and inabilities and the extent the patient is able to perform activities of daily living. It could assist healthcare professionals in taking proactive measures and perhaps prevent further deterioration in some aspects. It could help healthcare professionals to improve the tailoring of care to the personal needs and preferences of the patient. Quality of care could improve because of these advantages. It could also improve the (feeling of) safety of the patient and maintain his or her autonomy and independency, which could also enable patients to live longer in their own home.

Healthcare professionals would like to have an easy-to-use, integrated system, where data is collected and displayed in a way that is insightful and useful in practice. The data could be shown for example through an email, or in an existing system where the acquired data is integrated in the patient's reports including notifications in case of new (deviating) data or an alarm in case of emergencies. An important thing to think about, is what added value unobtrusive monitoring could have in different situations. The data should be useful and have a positive effect on the way care is delivered. If patients do not believe the healthcare professional when he or she explains that more assistance is required, because the patient does not perform certain activities of daily living in a good way, it does not have any value.

4.3 Strengths and limitations

Respondents from the sample group were a fair representation of healthcare professionals in general. Despite the uneven distribution of the variables age, number of patients and size of team, the number of respondents were sufficient to divide them into categories and make comparisons. The internal consistency of the Burden of care statements were sufficient with a Cronbach's alpha of 0.79, and therefore treated as a scale. For the Cronbach's alpha, a coefficient of 0.7 or higher is considered acceptable in most social science research situations (UCLA Institute for Digital Research & Education, 2019).

With the mixed methods design it was possible to substantiate the quantitative results with qualitative results. The qualitative results created an increased insight of why scores of certain statements where higher or lower. However, saturation of the interviews was not entirely reached, which makes it very likely that there are more opinions among other healthcare professionals that remain unknown. Lastly, in order to guarantee the privacy of the included respondents, it was decided to not make any link between respondents that filled in the questionnaire and participated in an interview. This way it was not possible to relate any answers of the interviewed healthcare professionals to their ratings of different statements.

4.4 Future recommendations and research

Because correct use of Carenzorgt by informal caregivers is a prerequisite for Carenzorgt to have an added value, good training and appropriate support for these users is important and should be kept in mind when introducing Carenzorgt for the first time. Adding an option to create 'shielded' reports in Carenzorgt could be a solution to prevent healthcare professionals from not reporting certain findings about the patient in Carenzorgt, in case it could cause distress or miscommunication with the patient or family. Adding a notification or pop-up in the Carenzorgt display, in case of a new message or newly entered agenda appointments, could help preventing healthcare professionals from missing any new messages. Agenda appointments should appear in the ONS overview, so healthcare professionals are quickly updated in case of scheduled appointments for that day. It should also become easier to retrieve an overview of the agenda, with easy and quick access. The time indication in Carenzorgt should be broader, to prevent unrest or agitation of the client.

Mentioned by almost all healthcare professionals, an unobtrusive monitoring system could have an added value when it is unsure whether a patient is able to perform activities of daily living, if the patient gets lost often, has a high risk of falling, or loses weight in a short period of time. Other situations might be applicable too, which need to be discussed with involved parties. Privacy of patients and healthcare professionals should be guaranteed at all time. It should be thoroughly discussed what factors will be monitored and how to deal with the personal data acquired by the system. Who is responsible for what sort of information and how should it be treated? Lastly, to prevent suspicion and distress of the patient due to the monitoring system, it should be made as unobtrusive as possible to make sure patients are not disturbed by it.

In further research, it would be interesting to look deeper into the functionalities of Carenzorgt separately, such as the message function, reading along with reports and the agenda. This should result in more detailed experiences of healthcare professionals per functionality. Since the agenda functionality is not very user-friendly and often remains unused, further research is recommended to find out how this functionality could improve and increase the added value of Carenzorgt as a whole. This also brings forward the need of end-users (healthcare professionals, informal caregivers and the patient) to be closely involved when exploring their needs, wishes and requirements during (further) development of applications. eHealth should be designed and developed in a holistic way, where technology, people and context are seen as interrelated and interdependent. eHealth does not always fit in with the specific culture, processes and demands of the health-related context, which causes it to remain unused. This is because it is for example hard to understand for the user (which appeared to be the case for some informal caregivers), not user-friendly, requires too much time or effort (difficult to retrieve an overview of the patient's agenda), or simply does not fit with the user's environment (existing agendas which makes it difficult to decide what agenda to use) (Gemert-Pijnen, Kelders, Kip & Sanderman, 2018). To investigate how exactly different Carenzorgt functionalities could improve, needs and wishes from different user perspectives could be further explored by, for example, a questionnaire that allows open answers. In such a questionnaire respondents can be asked if the agenda function in Carenzorgt works properly, and if not, for what exact reason(s). Subsequently, respondents should be asked what alterations are needed in order to make the agenda a user-friendly functionality that creates added value in the care process. While redesigning functionalities, it would be very useful to involve relevant end-users for input and feedback on some choices (participatory design). They can provide developers with valuable suggestions (Gemert-Pijnen, Kelders, Kip & Sanderman, 2018).

Not only expectations and needs of healthcare professionals in the field of unobtrusive monitoring systems are interesting and important to explore, but also that of informal caregivers and - more importantly - the patient his or herself. In the end, the patient is the ‘object’ that is monitored in their own private environment, their home, with an unobtrusive monitoring system that is possibly collecting very personal data. What are their thoughts on such a system, and how would they feel about such a system being placed in their home, monitoring their activity for example? Or how do potential patients, that might be monitored in the (far) future, feel about such a system? In-depth interviews could be conducted to find out about their expectations, needs and wishes, to create a more complete image of how different stakeholders look at unobtrusive monitoring systems. People with dementia can influence the development of technology in regards to content, design, and even the initial idea, although the impact of how they experience their own involvement remains largely unknown. Suijkerbuijk, Nap, Cornelisse, IJsselsteijn, Kort & Minkman (2019), describe that few studies report on the involvement of people with dementia throughout the entire development process. People with dementia are most often only involved in the evaluative development phase, and interviews and observations are most common as method. Co-design practiced from the start of the development process can have an impact with positive, long-range consequences on the user experience of the eventual design outcome. However, because being a co-designer might require certain levels of sensory, cognitive, and motoric abilities, it is challenging for researchers and developers to actively involve people with dementia throughout the entire development process of supportive technology. According to Suijkerbuijk et al. (2019) there is a lack of specific knowledge on appropriate methods and materials for active involvement of people with dementia in supportive technology development and future research is needed to improve the desired role of people with dementia in meaningful technology development.

When it comes to the phases of value specification and design, it is important that needs and wishes of all different user perspectives are taken into account. This could be further explored by, for example, using persona-based design. According to Van Velsen, Gemert-Pijnen & Nijland (2012), personas can be the linking pin in the development process of eHealth. Personas are specific, concrete representations of fictitious persons that represent the target group. It can create a thorough understanding of the future users of the technology and assist in identifying what the product should do to satisfy users’ needs (Gemert-Pijnen. Kelders, Kip & Sanderman, 2018). Van Velsen et al. (2012) describe that personas can be used for multiple purposes: to inspire the creation of requirements; as the basis for the creation of scenarios (for which interviews can also be used) and; for the design of the evaluations that will be conducted throughout the design process.

4.5 Conclusion

With this research, user experiences of healthcare professionals with the communication platform Carenzorgt and their expectations of unobtrusive monitoring systems were explored. It appeared that not all Carenzorgt functionalities worked properly, which proves UCD and holistic eHealth development and design remains important during early and later developments of eHealth. Privacy came forward as a main issue, for both Carenzorgt and unobtrusive monitoring, and should receive special attention during further research and development.

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Appendix

Appendix I: Questionnaire

Beste zorgverlener,

Hartelijk dank voor uw bereidheid om deel te nemen aan dit onderzoek naar de gebruikerservaringen van zorgprofessionals met Carenzorgt. Dit onderzoek wordt uitgevoerd door Elles de Witte, masterstudent Health Sciences aan Universiteit Twente in Enschede, in samenwerking met Nedap Healthcare.

Het invullen van deze enquête duurt minimaal 5 en maximaal 10 minuten. De enquête bestaat uit 11 algemene vragen en 16 stellingen over Carenzorgt. Deze stellingen kunnen beoordeeld worden op een 5 puntsschaal (helemaal oneens, beetje oneens, neutraal, beetje eens, helemaal eens). Uw gegevens worden geanonimiseerd en op veilige wijze verwerkt. Uw deelname is vrijwillig, wat betekent dat u op elk moment uw deelname kunt stopzetten. Alle gegevens die dan van u zijn verzameld, worden definitief verwijderd.

Indien u vragen heeft over dit onderzoek of graag meer informatie wilt ontvangen, kunt u contact opnemen met Elles de Witte, e-mail: e.r.dewitte@student.utwente.nl.

Door deze vragenlijst te starten geeft u aan dat u:
- Bovenstaande informatie heeft gelezen en hiermee akkoord gaat;
- Vrijwillig meedoet aan het onderzoek;
- 18 jaar of ouder bent
- zorgverlener bent in de thuiszorg.

Achtergrondinformatie:

1. Bent u werkzaam in de thuiszorg?
2. Verleent u zorg aan (onder andere) cliënten met dementie?
3. Wat is uw functie? verzorgende niv.2 / verzorgende niv.3 / verzorgende niv.3 IG / verpleegkundige niv.4 / verpleegkundige niv.5 / anders\
4. Wat is uw leeftijd? (in jaren)
5. Wat is uw geslacht?
6. In wat voor soort team bent u werkzaam? Zelfsturend of -organiserend team (zonder manager) / niet zelfsturend- of organiserend (met manager)
7. Wat is de grootte van uw team? (aantal collega's, inclusief uzelf)
8. Aan hoeveel cliënten verleent u zorg? (dus, het aantal cliënten dat onder uw team valt)
9. Hoelang heeft u al ervaring met de koppeling Ons-Carenzorgt? (in jaren)
10. Hoe vaak gebruikt u de koppeling Ons-Carenzorgt gemiddeld per dienst?
11. Hoe lang gebruikt u de koppeling Ons-Carenzorgt gemiddeld per dienst?

Stellingen (16 totaal):
Nu volgen de 16 stellingen over de koppeling Ons-Carenzorgt. Deze kan u beoordelen op een 5-puntsschaal, waarbij u aangeeft of u het er wel of niet mee eens bent. Ook is er een niet van toepassing (n.v.t.) optie, als de stelling volgens u niet van toepassing is.

Let op! De stellingen gaan specifiek over gebruik van de koppeling van Ons met Carenzorgt, in de zorg voor mensen met **dementie**.

Gebruiksvriendelijkheid (usability):

1. De koppeling Ons – Carenzorgt is makkelijk in gebruik.
2. Het gebruik van de koppeling Ons – Carenzorgt is voor mij logisch.

Zorgzwaarte (burden of care):
Hierbij wordt de zorgzwaarte met Carenzorgt vergeleken met de zorgzwaarte zonder Carenzorgt.

3. De zorgzwaarte is minder geworden door het gebruik van de koppeling Ons – Carenzorgt.
4. De organisatie van zorgtaken is makkelijker met het gebruik van de koppeling ‘Ons – Carenzorgt’.
5. Door de koppeling Ons – Carenzorgt is het makkelijker om het zorgnetwerk te onderhouden.
6. Met de koppeling Ons – Carenzorgt is het voor mij makkelijker om contact met mantelzorgers en familieleden te onderhouden omtrent de zorg voor de cliënt.
7. Door de koppeling Ons-Carenzorgt heb ik meer tijd op voor andere dingen.
8. Door het gebruik van de koppeling Ons – Carenzorgt is het makkelijk om op de hoogte te blijven van de situatie van de cliënt.
9. Met de koppeling Ons – Carenzorgt is het voor mij makkelijker om (samen met collega’s) de zorg voor de cliënt goed te regelen.

Workflow:

10. De werkwijze met de koppeling Ons – Carenzorgt sluit goed aan op mijn dagelijkse taken.
11. De koppeling Ons-Carenzorgt is van toegevoegde waarde in het zorgproces.

Kwaliteit van zorg (quality of care):
Hierbij wordt de kwaliteit van zorg met Carenzorgt vergeleken met de kwaliteit van zorg zonder Carenzorgt.

12. De kwaliteit van zorg is toegenomen door het gebruik van de koppeling Ons – Carenzorgt.
14. Door het gebruik van de koppeling Ons – Carenzorgt kan de zorg beter afgestemd worden op de behoeften van de cliënt.
15. Carenzorgt zorgt voor een verbeterd overzicht in het zorgproces van de cliënt.

13. Ik heb er vertrouwen in dat Carenzorgt zorgvuldig met de gegevens van de cliënt omgaat.

16. Ik zou Carenzorgt in de toekomst willen blijven gebruiken.

17. Zijn er bepaalde functionaliteiten die u mist?

18. Heb je nog toevoegingen, op- of aanmerkingen?

____
____
____
____
____
____

Appendix II: Interview scheme

Interviewschema
3 onderdelen.

Deel 1: Achtergrondinformatie

12. Bent u werkzaam in de thuiszorg?
13. Verleent u zorg aan (onder andere) cliënten met dementie?
14. Wat is uw functie? verzorgende niv.2 / verzorgende niv.3 / verzorgende niv.3 IG / verpleegkundige niv.4 / verpleegkundige niv.5 / anders
15. Wat is uw leeftijd? (in jaren)
16. Wat is uw geslacht?
17. In wat voor soort team bent u werkzaam? Zelfsturend of -organiserend team (zonder manager) / niet zelfsturend- of organiserend (met manager)
18. Wat is de grootte van uw team? (aantal collega's, inclusief uzelf)
19. Aan hoeveel cliënten verleent u zorg? (dus, het aantal cliënten dat onder uw team valt)

20. Hoelang heeft u al ervaring met de koppeling Ons-Carenzorgt? (in jaren)
21. Hoe vaak gebruikt u de koppeling Ons-Carenzorgt gemiddeld per dienst?
22. Hoe lang gebruikt u de koppeling Ons-Carenzorgt gemiddeld per dienst?

Deel 2: Carenzorgt

<u>Gebruiksvriendelijkheid</u>

1) Hoe ervaart u het gebruik van de koppeling Ons - Carenzorgt? (manier van werken, zorgverlening etc.)
   (Toespitsen op o.a. Communicatie met mantelzorgers, inzien van agenda en taakverdeling, andere onderdelen van Carenzorgt etc.)
   → waarom?
   a. Vindt u de koppeling Ons - Carenzorgt makkelijk in gebruik? (stelling 1)
      → waarom?
   b. Vindt u de koppeling Ons - Carenzorgt logisch opgebouwd/in gebruik? (stelling 2)

<u>Zorgzwaarte</u>

2) Hoe ervaart u de zorgzwaarte van de zorg voor uw cliënt met het gebruik van de koppeling Ons - Carenzorgt? Vraagt het meer/minder/evenveel van u? → waarom? (stelling 3)

3) Is de organisatie van zorgtaken makkelijker geworden met het gebruik van de koppeling Ons – Carenzorgt? (stelling 4)
   → waarom?

4) Hoe ervaart u het contact met mantelzorgers via de koppeling Ons - Carenzorgt?
   → waarom?
   a. Is het makkelijker (om het zorgnetwerk/contact met mantelzorgers te onderhouden)? (stelling 5 en 6)

5) Heeft u het gevoel dat u meer/minder/net zo veel tijd kwijt bent aan de zorg wanneer u de koppeling Ons - Carenzorgt gebruikt? Vergeleken met wanneer u de koppeling Ons - Carenzorgt niet gebruikt. → waarom? (stelling 7)

6) In hoeverre is het met de koppeling Ons – Carenzorgt makkelijker om samen met collegas de zorg voor de cliënt te regelen? (stelling 9)

7) Is het met de koppeling Ons – Carenzorgt makkelijker om op de hoogte te blijven van de situatie van de cliënt? (stelling 8)
→ waarom?

Workflow

8) Welke onderdelen van de koppeling Ons - Carenzorgt vindt u nuttig?
    a. Waarom is dit van toegevoegde waarde? (stelling 11)

9) Welke onderdelen van de koppeling Ons - Carenzorgt vindt u minder nuttig?
    b. Wat zijn nadelen/knelpunten?

10) Sluit de koppeling Ons – Carenzorgt goed aan op uw dagelijkse taken? (stelling 10)
→ waarom?

Kwaliteit van zorg

11) Hoe ervaart u de kwaliteit van zorg met het gebruik van de koppeling Ons - Carenzorgt? (stelling 12)
→ waarom?

12) Heeft u er vertrouwen in dat Carenzorgt zorgvuldig omgaat met de gegevens van de cliënt? (stelling 13) → waarom?

13) Kan de zorg beter afgestemd worden op de behoeften van de cliënt door gebruik van de koppeling Ons – Carenzorgt? (stelling 14)
→ waarom?

14) Zorgt de koppeling Ons – Carenzorgt voor een verbeterd overzicht in het zorgproces van de cliënt? (stelling 15)
→ waarom?

15) Wat mist u binnen de koppeling Ons - Carenzorgt? → waarom?

16) Zou u de koppeling Ons - Carenzorgt willen blijven gebruiken in de toekomst? (stelling 16) → waarom?

Deel 3: Unobtrusive sensor data

Eerst scenario’s laten zien met plaatjes.

Het monitoring systeem geeft informatie over het dagelijks leefpatroon, gedrag en stemming van een bewoner door een bewegings- en geluidssensor 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 potentiele ontvangers van de informatie:
1) De mantelzorgers van de dementerende oudere
2) De zorgprofessionals die betrokken zijn bij de zorg

3) De dementerende oudere zelf

Algemene doelstellingen van het systeem:

- *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.*
- *Optimaliseren van langer zelfstandig en veilig thuis wonen van dementerende oudere.*

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

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

<u>Deel 3.1:</u> percepties, verwachtingen, en behoeftes, rondom unobtrusive sensing technology

1. Wat vindt u van een dergelijk systeem als u dit hoort? / Wat is je eerste reactie?
2. Waarom zou u zo een systeem wel of niet willen inzetten bij thuiswonende cliënten met dementie?
    a. Wat zijn de voordelen volgens u?
    b. Wat zijn de nadelen volgens u?

<u>Deel 3.2</u> (deel 3 van Christian): monitoring needs (heel kort)

Wel:

1) Waarom zou u hierover geïnformeerd willen worden?
2) Wanneer zou u hierover geïnformeerd willen worden?
3) Hoe zou u hierover geïnformeerd willen worden? Hoe zou de informatie eruit moeten zien zodat u het begrijpt/overzichtelijk is? (alarm/tekst/grafiek)
    a. Hoe moet het systeem met u communiceren over de informatie die verkregen is?

Niet:

4) Waarom wilt u hier niet over geïnformeerd worden?

Twijfel:

5) Wat maakt dat u twijfelt of u hierover geïnformeerd zou willen worden?

<u>Vervolg deel 3.1:</u> percepties, verwachtingen, en behoeftes, rondom unobtrusive sensing technology

3. Welke soorten situaties zijn er waar de inzet van zo een monitoringssysteem nuttig zou kunnen zijn?
4. Hoe denkt u dat de inzet van zo een systeem de zorg rondom uw cliënten (en uw taken?) zou 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?
        i. Denkt u dat zo een systeem zorg op afstand makkelijker kan maken?
    c. waar moet zo een systeem aan voldoen om u te ondersteunen bij de zorg rondom uw cliënten en in het begeleiden van het ziekteproces?
5. De algemene doelstelling van het systeem is “Langer thuis met dementie”. Kan deze technologie dit volgens u bereiken?
    a. Waarom wel?
    b. Waarom niet?
6. Denkt u dat de inzet van dit soort systemen de autonomie en zelfstandigheid van uw cliënten kan verhogen?
    a. Waarom wel?
    b. Waarom niet?

7. Zelfs zorgprofessionals kunnen het moeilijk vinden om gedrag en emotie van dementerende cliënten te snappen (dit omdat dementerende cliënten 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 cliënten?
    b. Waar loopt u nu tegenaan als u zich een beeld wil vormen van een thuiswonende cliënt met verdachte / vroege dementie?
8. Hoe zou zo een systeem de kwaliteit van zorg volgens u beïnvloeden?
    a. In hoeverre denkt u dat de zorg m.b.v. zo een systeem beter afgestemd kan worden?
    b. In hoeverre kan zo een systeem helpen om preventieve maatregelen te nemen?

Deel 3.3 (deel 4 van Christian): Barrieres rondom unobtrusive sensing technology

1. Wat zou u weerhouden om zo een systeem bij uw cliënten in te zetten?/ Waarom zou u besluiten om geen gebruik te maken van zo een monitoring systeem? (ongeacht acceptatie cliënten)
2. Wanneer zou het systeem onwenselijk worden?
3. Welke dingen ziet u als een bedreiging voor uzelf en uw cliënt als het gaat om de inzet van zo een monitoring systeem? Vanaf wanneer zou u zeggen "Tot hier en niet verder"?
4. Stel dat u m.b.v. het systeem een problematische verandering of een incident waarneemt (bv. geïrriteerdheid of vallen):
    a. Hoe zou u hiermee willen omgaan?
    b. Welke invloed zou dit hebben op uw werkwijze?
    c. Wie zou volgens u verantwoordelijk moeten zijn om actie te ondernemen op de meting?
5. 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?)
    b. Zo nee: Wat maakt dat u dit niet zou willen? Waar bent u bang voor?
6. Vind u het gevoel van veiligheid belangrijker dan het waarborgen van privacy?
    a. Waarom wel en waarom niet?

Appendix III: Invitation letter

Beste heer/mevrouw,

In het kader van mijn afstudeeronderzoek aan de Universiteit Twente in Enschede, onderzoek ik onder andere de gebruikerservaringen van zorgprofessionals (werkzaam in de thuiszorg) met het platform Carenzorgt. Ik richt mij hierbij op gebruikers van Carenzorgt waarbij diegene zorg verleent aan thuiswonende cliënten, waaronder ook cliënten met (vermoedelijke) dementie. Daarnaast ben ik ook erg benieuwd naar de meningen van deze zorgprofessionals over het monitoren van deze cliënten, met behulp van 'unobtrusive' (niet-zichtbare of niet-'opdringerige') sensortechnologie. Het onderzoek wordt gedaan met behulp van het uitzetten van een enquête en het uitvoeren van interviews. Het invullen van de enquête duurt minimaal 5 tot maximaal 10 minuten, het interview niet langer dan 1 uur.

Achtergrondinformatie

Carenzorgt is een groot platform dat door heel Nederland wordt gebruikt door zowel mantelzorgers als professionele zorgverleners. Er is echter nog geen evaluatie of wetenschappelijk onderzoek gedaan waarbij professionele zorgverleners gevraagd worden om hun gebruikerservaringen met en meningen over het platform te delen.

Daarnaast wordt er bij de Universiteit Twente onderzoek gedaan naar de mogelijkheden van 'unobtrusive' sensortechnologieën bij de thuiswonende cliënt met dementie. Hierbij is het de vraag hoe zorgprofessionals hier tegenaan kijken, welke mogelijkheden zij, vanuit hun perspectief, in deze soort sensortechnologieën zien en wat voor hen de grenzen zijn.

Wat vraag ik van u?

Voor het uitvoeren van het onderzoek heb ik respondenten nodig. Ik wil u daarom graag uitnodigen om deel te nemen aan dit onderzoek. U kunt ervoor kiezen om deel te nemen aan een deel van het onderzoek door alleen de enquête in te vullen of alleen het interview, maar u kunt ook deelnemen aan beide onderdelen. Doordat ik met de resultaten van de enquêtes en interviews een goed beeld kan krijgen van de gebruikservaringen van Carenzorgt, kan het platform verbeterd worden en hierdoor beter aansluiten op de wensen van de eindgebruikers (waaronder uzelf). Ook door het delen van uw mening en verwachtingen wat betreft 'unobtrusive' sensortechnologieën, kunt u bijdragen aan waardevolle informatie en kennis op dit gebied.

Bent u als zorgprofessional (verzorgende (IG), verpleegkundige niv. 4 of niv. 5) werkzaam in de thuiszorg, waarbij u zorg verleent aan onder andere cliënten met dementie? Gebruikt u daarnaast het communicatieplatform Carenzorgt (de koppeling tussen Carenzorgt en ONS)? Dan kunt u de enquête invullen via deze link: https://utwentebs.eu.qualtrics.com/jfe/form/SV_86QfBRN2l1t1XZH
Ik zou het erg fijn vinden als de enquête vóór 14 juni wordt ingevuld en opgestuurd.

Indien u zou willen meewerken aan een interview, mag u contact met mij opnemen. Vervolgens kunnen we dan een afspraak maken voor het interview en de locatie bespreken. Dit kan bijvoorbeeld bij een van de locaties van de zorgorganisatie waar u werkzaam bent of uw kantoor. Ook zou een interview via Skype of via een telefoongesprek mogelijk zijn.

Heeft u collega's die misschien deel zouden willen nemen aan dit onderzoek? Mocht dit zo zijn, wil ik u vragen contact met mij op te nemen. Ik hoor graag van u!

Met vriendelijke groeten,

Elles de Witte
E-mail: e.r.dewitte@student.utwente.nl
Telefoonnummer: +31 657918191 (best te bereiken via Whatsapp)

Begeleiders Universiteit Twente:
Annemarie Braakman-Jansen
E-mail: l.m.a.braakman-jansen@utwente.nl

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

Appendix IV: Informed consent form

INFORMED CONSENT FORMULIER

Naam van het onderzoeksproject
Healthcare management in home-based dementia care: An analysis of the care platform Carenzorgt.

Doel van het onderzoek
Dit onderzoek wordt uitgevoerd door Elles de Witte. U bent van harte uitgenodigd om deel te nemen aan dit onderzoek. Het doel van dit onderzoek is om de gebruikerservaringen van zorgprofessionals (werkzaam in de thuiszorg) met Carenzorgt te verzamelen. Daarnaast wordt ook gevraagd naar de meningen en verwachtingen van dezelfde zorgprofessionals over ‘unobtrusive’ sensortechnologieën die ingezet kunnen worden bij thuiswonende cliënten met dementie.

Gang van zaken tijdens het onderzoek
U neemt deel aan een interview waarin aan u vragen zullen worden gesteld over uw ervaringen over het communicatieplatform Carenzorgt.

U dient tenminste 16 jaar te zijn om deel te nemen aan dit onderzoek. Daarnaast bent u in de thuiszorg werkzaam, waarin u aan (onder andere) zorg verleent aan cliënten met (vermoedelijk) dementie.

Voorafgaand aan het interview zelf worden een aantal algemene vragen aan u gesteld, zoals uw leeftijd en het aantal cliënten. Van het interview zal een audio-opname worden gemaakt, zodat het gesprek later woord voor woord kan worden uitgewerkt.
Dit transcript wordt vervolgend gebruikt in het verdere onderzoek.

Potentiële risico's en ongemakken
Er zijn geen fysieke, juridische of economische risico's verbonden aan uw deelname aan deze studie. U hoeft geen vragen te beantwoorden die u niet wilt beantwoorden. Uw deelname is vrijwillig en u kunt uw deelname op elk gewenst moment stoppen.

Vergoeding
U ontvangt voor deelname aan dit onderzoek geen vergoeding . Door deel te nemen aan dit onderzoek kan er meer inzicht verkregen worden in de gebruikerservaringen van Carenzorgt-gebruikers, kan het platform eventueel verbeterd worden en hierdoor beter aansluiten op de wensen van de eindgebruikers (waaronder uzelf). Ook door het delen van uw mening en verwachtingen wat betreft ‘unobtrusive’ sensortechnologieën, kunt u bijdragen aan waardevolle informatie en kennis op dit gebied.

Vertrouwelijkheid van gegevens
Uw privacy is en blijft maximaal beschermd. Er wordt op geen enkele wijze vertrouwelijke informatie of persoonsgegevens van of over u naar buiten gebracht, waardoor iemand u zal kunnen herkennen.

Voordat onze onderzoeksgegevens naar buiten gebracht worden, worden uw gegevens **anoniem** gemaakt. Enkele eenvoudige voorbeelden hiervan:
- uw naam wordt vervangen door anonieme, op zichzelf betekenisloze combinatie van getallen.
- uw leeftijd zelf wordt niet verwerkt, maar in een categorie geplaatst. Bijvoorbeeld: leeftijd: tussen

18-25 jaar / tussen 25-35 jaar etc.

In een publicatie of presentatie zullen of anonieme gegevens of pseudoniemen worden gebruikt. De audio-opnamen, formulieren en andere documenten die in het kader van deze studie worden gemaakt of verzameld, worden opgeslagen op een beveiligde locatie bij de Universiteit Twente en op de beveiligde (versleutelde) computers van de onderzoekers.

Vrijwilligheid

Deelname aan dit onderzoek is geheel vrijwillig. Je kunt als deelnemer jouw medewerking aan het onderzoek te allen tijde stoppen, of weigeren dat jouw gegevens voor het onderzoek mogen worden gebruikt, zonder opgaaf van redenen.

Dit betekent dat als je voorafgaand aan het onderzoek besluit om af te zien van deelname aan dit onderzoek, dat dit op geen enkele wijze gevolgen voor jou zal hebben. Tevens kun je tot 5 werkdagen (bedenktijd) na het interview alsnog de toestemming intrekken die je hebt gegeven om gebruik te maken van jouw gegevens.

In deze gevallen zullen jouw gegevens uit onze bestanden worden verwijderd en vernietigd.
Als je tijdens het onderzoek, na de bedenktijd van 5 werkdagen, besluit om jouw medewerking te staken, zal dat eveneens op geen enkele wijze gevolgen voor je hebben. Echter: de gegevens die u hebt verstrekt tot aan het moment waarop uw deelname stopt, zal in het onderzoek gebruikt worden, inclusief de bescherming van uw privacy zoals hierboven beschreven. Er worden uiteraard geen nieuwe gegevens verzameld of gebruikt.

Als u besluit om te stoppen met deelname aan het onderzoek, of als u vragen of klachten heeft, of uw bezorgdheid kenbaar wilt maken, of een vorm van schade of ongemak vanwege het onderzoek, neemt u dan aub contact op met de onderzoeker: Elles de Witte, e.r.dewitte@student.utwente.nl, 06-57918191.

Toestemmings-verklaring

Met uw ondertekening van dit document geeft aan dat u minstens 16 jaar oud bent; werkzaam bent in de thuiszorg; zorg verleent aan (onder andere) cliënten met (vermoedelijk) dementie; dat u goed bent geïnformeerd over het onderzoek, de manier waarop de onderzoeksgegevens worden verzameld, gebruikt en behandeld en welke eventuele risico's u zou kunnen lopen door te participeren in dit onderzoek

Indien u vragen had, geeft u bij ondertekening aan dat u deze vragen heeft kunnen stellen en dat deze vragen helder en duidelijk zijn beantwoord. U geeft aan dat u vrijwillig akkoord gaat met uw deelname aan dit onderzoek. U ontvangt een kopie van dit ondertekende toestemmingsformulier.

Ik ga akkoord met deelname aan een onderzoeksproject geleid door Elles de Witte. Het doel van dit document is om de voorwaarden van mijn deelname aan het project vast te leggen.

1. Ik kreeg voldoende informatie over dit onderzoeksproject. Het doel van mijn deelname als een geïnterviewde in dit project is voor mij helder uitgelegd en ik weet wat dit voor mij betekent.

2. Mijn deelname als geïnterviewde in dit project is vrijwillig. Er is geen expliciete of impliciete dwang voor mij om aan dit onderzoek deel te nemen.

3. Mijn deelname houdt in dat ik word geïnterviewd, het interview zal ongeveer 60 minuten duren. Ik geef de onderzoeker toestemming om tijdens het interview opnames (geluid) te maken en

schriftelijke notities te nemen. Het is mij duidelijk dat, als ik toch bezwaar heb met een of meer punten zoals hierboven benoemd, ik op elk moment mijn deelname, zonder opgaaf van reden, kan stoppen.

4. Ik heb het recht om vragen niet te beantwoorden. Als ik me tijdens het interview ongemakkelijk voel, heb ik het recht om mijn deelname aan het interview te stoppen.

5. Ik heb van de onderzoeksleider de uitdrukkelijke garantie gekregen dat de onderzoeksleider er zorg voor draagt dat ik niet ben te identificeren in door het onderzoek naar buiten gebrachte gegevens, rapporten of artikelen. Mijn privacy is gewaarborgd als deelnemer aan dit onderzoek.

6. Ik heb de garantie gekregen dat dit onderzoeksproject is beoordeeld en goedgekeurd door de ethische commissie van de BMS Ethics Committee. Voor bezwaren met betrekking tot de opzet en of uitvoering van het onderzoek kan ik me wenden tot de Secretaris van de Ethische Commissie van de faculteit Behavioural, Management and Social Sciences op de Universiteit Twente via ethicscommittee-bms@utwente.nl.

7. Ik heb dit formulier gelezen en begrepen. Al mijn vragen zijn naar mijn tevredenheid beantwoord en ik ben vrijwillig akkoord met deelname aan dit onderzoek.

8. Ik heb een kopie ontvangen van dit toestemmingsformulier dat ook ondertekend is door de interviewer.

______________________	______________________	________
Naam deelnemer	Handtekening	Datum
______________________	______________________	________
Naam Onderzoeker	Handtekening	Datum

Appendix V: Monitoring needs schedule

Monitoring needs schema

Monitoring doelwit	+	-	?
Dagelijkse activiteiten			
Lopen (hoeveelheid/snelheid			
Uitstapjes			
Persoonlijke hygiëne (bijv. wassen, aankleden, toiletgebruik)			
Eten (bijv. bereiden van maaltijden)			
Actieradius (binnen huis)			
Sociale interactie met anderen			
Telefoongebruik (aantal keer gebruik)			
Dag- en nachtritme/slaappatroon			
Veiligheid			
Vallen			
Actieradius (buitenshuis)			
Dementie-specifiek			
Cognitieve achteruitgang			
Fysieke achteruitgang			
Agitatie (zenuwachtige onrust of onrustige beweging)			
Apathie (lusteloosheid / verlies van motivatie en interesse)			
Stemming negatief (bijv. angst, geïrriteerdheid, depressie)			
Stemming positief (bijv. blijdschap, vreugde, ontspanning)			
Nachtelijke onrust			
Zelf aanvullingen?			

Appendix VI: Explanation text unobtrusive monitoring systems and sensor data

Uitleg monitoring systeem

Het monitoring systeem geeft informatie over het dagelijks leefpatroon, gedrag en stemming van een bewoner door een bewegings- en geluidssensor 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 potentiele ontvangers van de informatie:

1) De mantelzorgers van de dementerende oudere
2) De zorgprofessionals die betrokken zijn bij de zorg
3) De dementerende oudere zelf

Algemene doelstellingen van het systeem:

- 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.
- Optimaliseren van langer zelfstandig en veilig thuis wonen van dementerende oudere.

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

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

Appendix VII : Powerpoint sheets visualisations unobtrusive sensor systems and sensor data

UNIVERSITEIT TWENTE.

PERSUASIVE HEALTH TECHNOLOGY LAB

Centre for eHealth & Wellbeing Research

PERVASIVE SYSTEMS RESEARCH GROUP

TRACK TRACE TRIGGER!

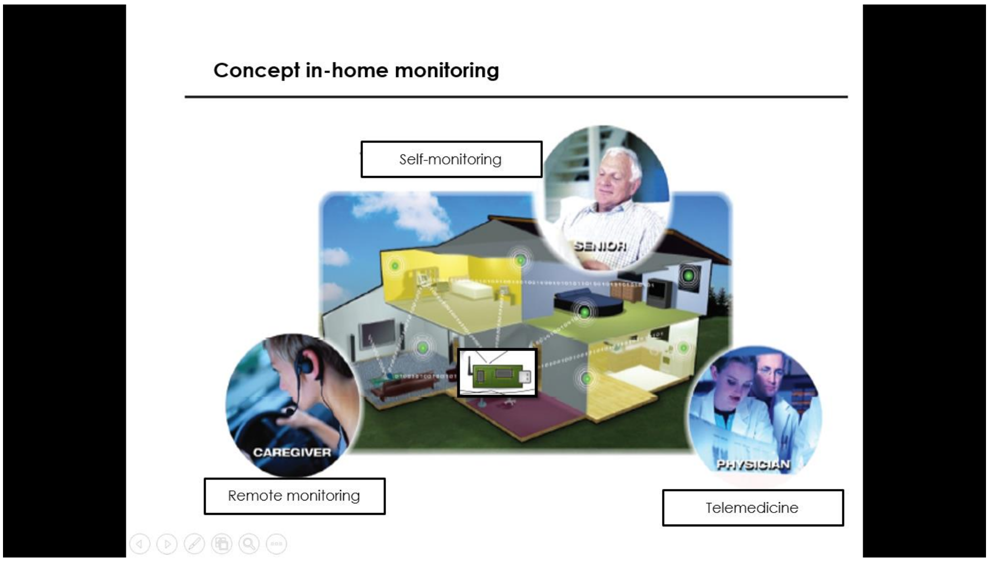
Unobstrusive sensing technologies to monitor and coach elderly with dementia

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

nedap | healthcare

dePosten

ZonMw

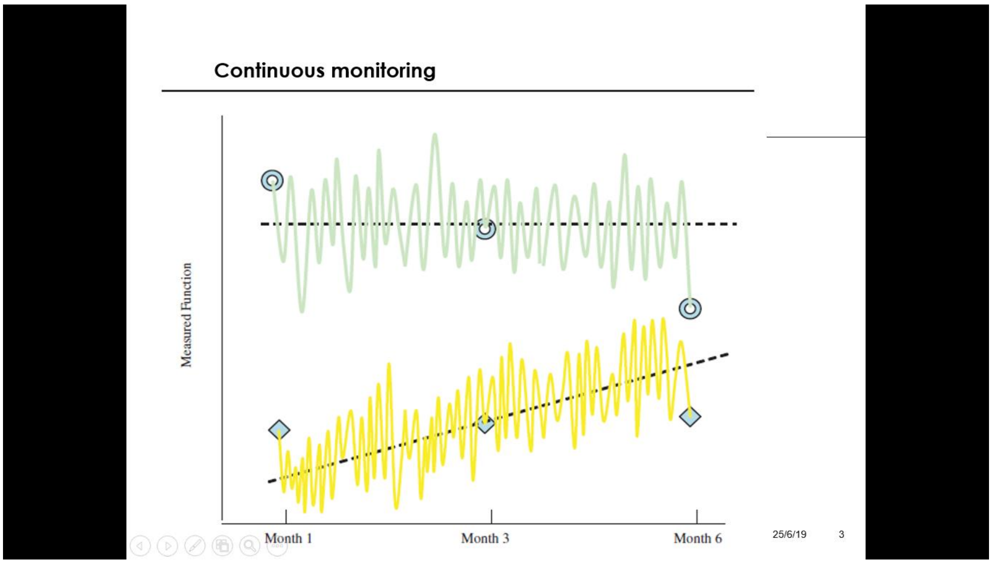


Concept in-home monitoring

Self-monitoring

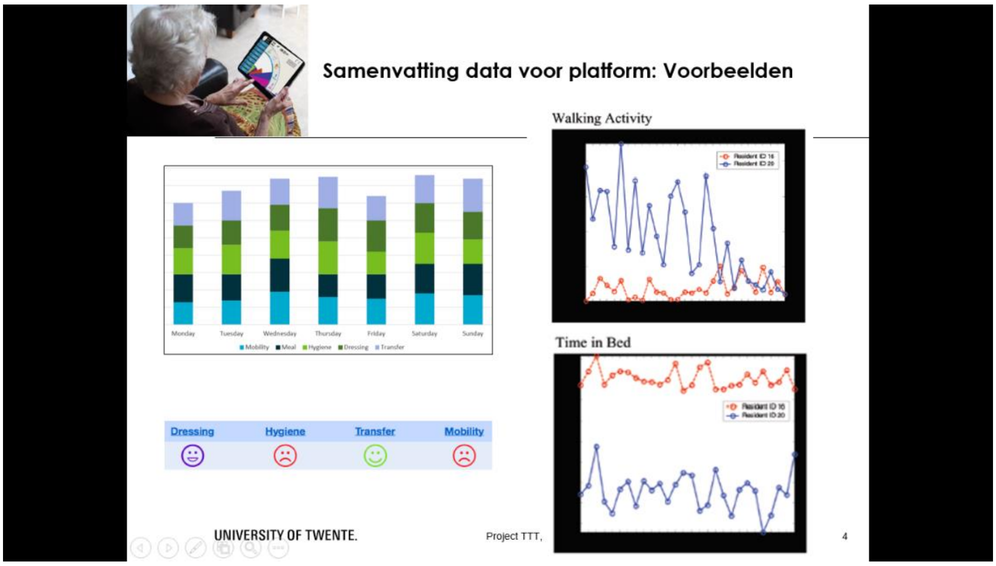
Remote monitoring

Telemedicine



Continuous monitoring

25/6/19 3



Samenvatting data voor platform: Voorbeelden

Dressing	Hygiene	Transfer	Mobility
☺	☹	☺	☹

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