UNIVERSITY OF TWENTE

Implementation of In-home Monitoring Technology as a Remedy for Burdened Informal Caregivers of People with Dementia: Acceptance Research in light of Living Situation and Time since Diagnosis

Bachelor Thesis

by

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Abstract

Background

While dementia cases are on the rise, the general preference of those affected is to live at home as long as possible. This puts a strain on the informal caregivers (e.g. family and friends). Health technology, especially in-home monitoring technology, could facilitate the care-taking role significantly. Acceptance research aims at investigating factors that could hinder or facilitate the successful implementation of those technologies into the daily life of caregivers. Different frameworks based on user centred design principles emphasise the importance of an interdisciplinary and multifaceted approach to acceptance research. Nevertheless, most acceptance research focuses for the most part on a small circle of stakeholders or just the technology itself, missing out on the other domains and stakeholders essential for implementation. The scope of this study is to fill the gap by quantitatively investigating acceptance from different perspectives, including assessment of differences in informal caregiver's acceptance of in-home monitoring technology when they life together with their care recipients versus when they do not, as well as assessment of associations between informal caregivers acceptance towards those technologies and passed time since the diagnosis of their care recipient's dementia type.

Methods

76 informal caregivers of people with dementia were recruited who took part in a survey measuring acceptance towards unobtrusive in-home monitoring technology using different statements which could be valued. Acceptance was treated as the dependent variable that was used to answer both research questions using a self-constructed acceptance scale. Living situation of informal caregivers and time since diagnosis were the independent variables that were coded as a dummy and an ordinal variable, respectively. Due to non-normality of the data, the non-parametric Mann-Whitney-U test was used to assess differences between acceptance amongst informal caregivers that live with their care recipient versus those who do not and Spearman's rho was used to check potential association between acceptance amongst informal caregivers and passed time since diagnosis or care recipient.

Results

Although the results showed a general tendency towards acceptance (Md = 3.69), the Mann-Whitney test turned out to be insignificant (p = .599) as well as the Spearman's rho (p = .730). Therefore, none of the two research questions could be answered.

Discussion

Despite the insignificant results of this study, it still provides value. Firstly, it emphasises the importance and reminds the reader to adopt a more multifaceted approach when conducting acceptance research to optimise the implementation process. Aspects like accountability and responsibility when using systems based on artificial intelligence, barriers in the correct operation of those complex systems and the financing of potential training of informal caregivers for the successful handling of those technologies as well as corresponding ideas for future research are discussed. Secondly, practical implications for improved data gathering are given based on the limitations of this paper.

Introduction

A growing body of evidence from North America and Europe indicates that a shift in the age structure of the population, due to decreases in fertility and increases in life expectancy, will lead to large increases in dementia cases in the upcoming years (GBD Dementia Forecasting Collaborators, 2022). The probability of having some form of dementia increases with age, and after the age of 65, the incidence of dementia doubles (Rone-Adams et al., 2013). Globally, the number of people with dementia (PwD) was estimated to have increased by 117% between 1990 and 2016, largely due to population ageing (Nichols et al., 2019). In 2019, around 55 million people had dementia and the number is expected to rise to approximately 131 million by 2050 (Collins & Kishita, 2019). Dementia is currently the seventh leading cause of death among all diseases and one of the major causes of disability and dependency among older people globally (World Health Organisation, 2021)

Dementia is characterised by a progressive deterioration in cognitive function (Nagel et al., 2021). There are different variants of dementia with Alzheimer's disease (AD) being the most common form of dementia accounting for 60-70%, vascular dementia for 20 %, lewy body dementia 10-15% and frontotemporal dementia for 2% of dementia cases (Alzheimer's Society, 2020; Nagel et al., 2021). Every variant comes along with distinct profiles of cognitive deterioration. AD for example comprises cognitive decline in many cognitive domains, such as memory, language, attention, executive and visuospatial functioning. In contrast, the language variant of frontotemporal dementia and vascular dementia cause the biggest decline in attention and executive functioning, whilst the behavioural variant of frontotemporal dementia appears to have generally the fastest cognitive decline over time (Smits et al., 2014). As mild cognitive impairment (MCI), the intermediate cognitive state between normal ageing and dementia is defined, characterised by impaired memory and other cognitive decline, which however do not affect everyday life's basic activities (Van der Mussele, 2014).

AD's progression can be divided into three stages, which can vary in intensity (Scharre, 2019). In the preclinical stages of AD, the affected person may show subtle behavioural and cognitive changes like irritability and minor episodic memory loss, respectively. In the prodromal stages the person may experience anxiety and dysphoria while executive functioning involving problem solving and decision making notably decline. The prodromal stages are also often referred to as MCI. Lastly, in the dementia stages of AD, symptoms from severe episodic memory loss, expressed by asking repeated questions and

misplacing items over delusions and restless behaviours to needing help with personal care, up to near total dependence and inactivity (Scharre, 2019). The care process in the later stages of AD is multidimensional and intensive, comprising the compensation for the decreased ability to fulfil basic need by providing assistance in, inter alia, mouth care, toileting and grooming, the prevention and management of, inter alia, physical exhaustion as well as malnutrition and ensuring satisfaction of psychosocial needs like having a sense of belonging and acceptance, feeling safe and maintenance of social contacts (Edvardsson et al., 2008). The maintenance of social contacts is often difficult, as lifelong contacts often become fearful of interacting with people suffering from Alzheimer's disease (Coon & Edgerly, 1999). This can result in social consequences for the affected person like feelings of stigmatisation, worthlessness, boredom, potentially leading into a downward spiral towards total isolation (Coon & Edgerly, 1999; Werner, 2005).

About 70% of PwD are living at home supported by informal (family and friends) and formal (general practitioners, day-care centres etc.) caregivers with the general preference of the majority of PwD being to live at home as long as possible (Thoma-Lürken et al., 2018). Approximately one third of PwD that are supported by informal caregivers (ICG) and live alone or in a community dwelling without their ICG are mostly cared for by their adult children, whereas for the rest, the ICG resides in the same house or flat, usually being the spouse or partner of the care recipient (CR) (Miranda-Castillo et al., 2010).

The intensive and multidimensional effort needed to care for PwD puts a strain on both groups of caregivers, on those who cohabitate with their CR and on those who don't (Donaldson et al., 2018). ICGs that live together with their CR appear to be burdened the most as, next to household tasks, they provide the most intensive care (Friedman et al., 2015). They often report psychosocial consequences such as emotional exhaustion and feelings of depreciation as well as a diminished social life, feelings of discomfort when friends come over and a feeling of missing out in life. Also, physical consequences such as being physically tired or ill because of the caregiving role and a deterioration in health are often experienced by ICG who live together with their CR (Raccichini et al., 2015). The ICG's burden becomes stronger with more time passed (in years) since the CR's diagnosis (Caap-Ahlgren & Dehlin, 2002). ICGs that do not live together with their CR, the caregiver burden is generally lower as they have the ability to choose whether to provide care or not. However, since they often connect the care-giving role with other roles in their social life, like being a student or employee, they can still feel burdened by trying to balance their personal life with their CR.

experience similar burdens as the ICGs that live together with their CR, feelings such as guilt, pressure, anxiety and a generally higher mental burden are more prevalent (Conde-Sala et al., 2010). On a more societal level, the indirect costs through full-time informal caregiving due to productivity losses of the ICGs create a societal burden (Michalowsky et al., 2016).

EHealth could offer great potential for informal caregivers in facilitating their duties, hence reducing the ICGs and societal burden. Generally, the term of eHealth describes "the use of information and communication technologies for health" (World Health Organisation, n.d.). Within the context of dementia care, eHealth comprises all assistive technologies that support health, healthcare and well-being (Bastoni et al., 2021). Of particular interest in this context are in-home monitoring technologies. According to Sharma et al. (2021) the most common human activity recognition (HAR) eHealth for in-home-monitoring of community dwelling elderly can be distinguished into three different systems: (1) wearable sensing systems (eg. smartwatches), (2) vision based systems (eg. surveillance cameras), (3) radiofrequency (RF) based systems (eg. radar and wireless sensors implanted in daily-use objects). Due to their technical properties, only RF-based systems are considered unobtrusive, which means that it works independently from the user, while also not drawing the user's attention by blending in with its surroundings (Sharma et al., 2021). ICGs that do not live together with their CR, but also those who do, could greatly benefit from these systems. HAR based, in-home monitoring technologies are capable of collecting health-related data such as nocturnal restlessness, eating/drinking and cooking activities, over physiological data including cognitive and physical deterioration as well as walking distance and speed, up to psychosocial data like emotional states (eg. anxiety, joy), frequency of telephone use and social interactions (Wrede et al., 2021). This data can also be useful for ICGs who live together with their CR, for example as a reassurance if they are at work (Klemets et al., 2019). Furthermore, for overstrained ICGs living together with their CR, in-home monitoring technology could provide additional assurance as they "...may be unaware of or may forget specific details about situations in which behaviours occur, leaving professionals with limited data for identification of appropriate interventions." (Williams et al., 2012).

To optimise implementation of in-home monitoring technology for daily use amongst ICGs of PwD, a user-centred design (UCD) approach, aimed at understanding the user's problems and needs, is essential (Wrede et al., 2021). The CeHRes roadmap is based on user-centred design principles, dividing the implementation process of eHealth technologies into five phases. In the first contextual inquiry phase, stakeholders (all persons affected by the eHealth technology) are identified and selected, with whom potential strong/weak points and

regulations/conditions of the current situation, as well as needs and wishes are discussed. Secondly, in the value specification phase the stakeholders express their added values they desire of the eHealth technology, which then can be implemented in the creation of the mock-ups and eventually the system. Thirdly, the created mock-ups are tested by the end users in the environment they are supposed to be implemented in. As a last step before actual implementation of the eHealth technology, in the operationalization phase all practical aspects that are important for the successful implementation are handled, such as training the ICG to understand the data provided by the in-home monitoring technology. Throughout all phases, constant evaluation regarding the match of the stakeholder's values and the technology itself is conducted, as well as a final evaluation after implementation to measure the outcomes (Gemert-Pijnen & Span, 2016).

For the successful and sustainable implementation of in-home monitoring technology among ICG of PwD, investigating the needs and problems of the ICGs through acceptance research is crucial (see first phase of the CeHRes roadmap). While there has been some acceptance research in this context, most of it is of qualitative nature. In this paper, acceptance is defined as the willingness, intention to or actual successful implementation of the respective technology (Sharma et. al., 2021; Horberry et al., 2018). In a qualitative study, Wrede et al. (2021) investigated the expected barriers, benefits, needs and requirements of caregivers of community-dwelling PwD towards unobtrusive home-monitoring technologies. Generally, the attitude towards those technologies is positive, as they "... could contribute to a shift from reactive to more preventive and proactive care." (p. 12). In another qualitative study from the Netherlands, the majority of ICGs reported that the benefits of in-home monitoring technologies outweigh the concerns. In addition to that, unlike the previous study in which less obtrusive technology was used, privacy did not seem to pose a major issue for the participants (Zwierenberg et al., 2018).

This study tries to fill the gap of the lack of quantitative acceptance research in the context of in-home monitoring technologies for ICGs of PwD, leading to the general descriptive question of "What is the acceptance towards in-home monitoring technology for community dwelling PwD from the perspective of ICGs in Germany or the Netherlands for different care situations?". As described, different situations such as ICGs living situation, and determinants, like the time since diagnosis of the CR's disease, can lead to different perceived burdens amongst the caregivers. At that time this study was made, it appears that no previous quantitative research, that considers the influence of the living situation and the time since diagnosis on the acceptance of unobtrusive in-home monitoring technology, has been

conducted. Accordingly, this study tries to answer the following research questions: (1) "What is the acceptance towards in-home monitoring technologies among ICGs of PwD or MCI who live together with their CR versus those who do not?", (2) "To what extent is the acceptance towards in-home monitoring technologies among ICGs of PwD or MCI associated with the time since the diagnosis of their CR's condition?".

Methods

Design

In order to answer both research questions, a cross-sectional study design was used.

Participants

Inclusion criteria for participation in the study required participants to provide unpaid care or support (= informal) to person(s) with dementia or MCI that live either alone, together with their caregiver or in a community-dwelling in Germany or the Netherlands. In addition, to take part in the survey, participants needed to be capable of providing informed consent and to understand German or Dutch. Informal caregivers whose CRs lived in a care-institution were excluded from further participation in the study.

A sample consisting of Dutch and German participants was collected using purposive and snowball sampling. Advertising flyers and the online survey-link were sent to dutch and german dementia-societies and self-help groups who acted as a mediator to promote the study to the informal caregivers. Furthermore, Facebook served as an additional propagation of the study. The survey was spread in several dutch and german Facebook-groups in which informal caregivers of PwD were members. Lastly, the participants themselves were motivated to forward the study to other ICGs of PwD from their social circle.

Materials

The survey items can be assigned into five sections: (1) Informal caregiver's demographics, (2) Care recipient's demographics, (3) perceived burden of care, (4) digital literacy / perceived personal innovativeness, (5) user acceptance towards in-home monitoring technology.

The sections of "(3) Perceived burden of care" and "(4) digital literacy / perceived personal innovativeness" are insignificant for this study and were only included into the survey to serve the research questions of fellow researchers.

Informal caregiver's demographics

The participant's demographics -section is composed of nine questions. Age of the ICG was measured as a continuous variable. The question of "are you an informal caregiver?" was measured as a dichotomous variable. The variables like gender, country of residence, reason of care and relation to CR, were nominal variables with more than two answer options whereas number of ICGs, travel time to CR, and ICG's education level were ordinal variables.

Living situation. The variable "travel time to care recipient" was of particular importance to answer the first research question. The research question dealt with the acceptance towards in-home monitoring technology in ICGs who live together with their CR versus ICGs who do not live together with their CR. Since the variable "travel time to care recipient" is a categorical variable with five answer possibilities (living together with CR / living between 1-5 minutes away / living between 6-15 minutes away / living between 16-30 minutes away / living between 31-60 minutes away / living more than 61 minutes away from CR) it needed to be transformed into a new dichotomous variable to fit my research question. This was done by combining the four answer options, in which the ICG needs to travel to the CR, into one new category of "Not Living Together". This resulted in a new dichotomous variable called "Living situation" with two categories: (1) with ICG and (2) without ICG.

Care recipient's demographics

The CR's demographics -section is composed of six questions. Age of the recipient was measured as a continuous variable. The question of "what describes the housing situation of your care recipient?" was measured as a dichotomous variable. The variables like type of dementia, kind of help for the CR and the question of "Where does your care recipient live?", were nominal variables with more than two answer options. The remaining variable of time since diagnosis was measured as an ordinal variable.

Time since diagnosis. The variable of "time since diagnosis" was used to answer the second research question. The research question focused on the association between the past time since the diagnosis of the CR with the acceptance of in-home monitoring technologies. The variable of "time since diagnosis of care recipient" had six answer options: (1) Less than one year, (2) 1 and 2 years, (3) 2 and 3 years, (4) 3 and 4 years, (5) 4 and 5 years, (6) more than 5 years.

User acceptance towards in-home monitoring technology

First, usage of in-home monitoring technology was explained and visually illustrated to the participants (see appendix A). Then, four different subscales measured different constructs that served the different research questions of fellow researchers. However, those subscales cannot be used to answer the research questions in this study as they strongly deviate from the adopted definition of acceptance, being the willingness, intention to or actual implementation of the respective technology. Consequently, only certain items from two of those four subscales were relevant and selected to eventually create an own scale measuring acceptance.

In the first subscale, five distinct scenarios were described to the participant, in which in-home monitoring technology is used in different ways. The scenarios included (1) the use of in-home monitoring technology to monitor safety-related aspects (e.g. detection of falls and wandering), (2) risk predictions (e.g. monitoring of walking speed and patterns), (3) self-care behaviour (e.g. eating, personal hygiene etc.), (4) sleeping behaviour (e.g. nocturnal unrest and night rhythms) and (5) long-term patterns (e.g. detection of cognitive or physical deterioration). For each scenario, the same scale of ten items was repeatedly presented to the participant in each usage-scenario. For each item, the participant had to indicate the extent to which he/she agrees or disagrees to a statement using a 5-point Likert scale (1 = Strongly)disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = fully agree). Out of those ten items, only two were relevant, resulting in ten items in sum (two items for each of the five scenarios) that would be used for the computation of the acceptance score. Those two items were: (1) "I consider it acceptable to collect this type of information, using the system", measuring the ICG's acceptance of in-home monitoring technology in the respective context, and (2) "I am willing to use such a monitoring system in the (near) future", measuring the ICG's intention to eventually use the respective technology.

From the second subscale, three items out of nine were considered as appropriate and thus included in the creation of the acceptance scale. The three items consisted of statements which assessed the participant's intention to use in-home monitoring technology in the future and could be rated using a 5-point Likert scale (1 = Strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = fully agree). Those statements were: (1) "I am willing to use in-home monitoring technology for the care of the person with dementia at this moment in my life", (2) "I am willing to use in-home monitoring technology for the care of the person with dementia when cognitive or physical health of my care recipient declines" and (3) "It is a good idea to use in-home monitoring technology in the care of my care recipient".

The selected items from both subscales added up to 13 items that were appropriate for creating an acceptance scale with which the research questions could be answered. Prior to creating one acceptance scale out of the selected 13 items, the internal consistency was checked to make sure that those items can in fact reliably measure acceptance. A reliability analysis using the selected 13 items was conducted, which resulted in an excellent Cronbach's alpha of .95. For the acceptance scale, a summative scale would have resulted in a large score-range, which is why in this case a mean scale with values from 1 (=low general acceptance) to 5 (high general acceptance) was chosen. To construct that scale, the selected 13 items were computed into a new numeric variable measuring general acceptance.

Process / Procedure

Originally, the survey was phrased in English. However, since the target group consists of ICGs of PwD from Germany or the Netherlands, the survey was translated into German and Dutch (see Appendix). This was done using the translation software DeepL, followed by proofreading by the researchers as well as project leaders.

Approximately three weeks before the survey was distributed, ethical approval was requested at the ethics committee of the University of Twente. For the ethical assessment, a number of questions such as the purpose of this study, research questions and type of research had to be answered. After the ethics committee made sure that the study satisfies the characteristics and conditions for ethically responsible research, ethical approval was granted and data collection could start.

Dementia-societies were the key-distributors of the survey, as they own a pool of relevant contacts to ICGs. Before the study was sent to the dementia societies, it was pre-tested by the researchers themselves. After minor improvements to the survey, it was forwarded to all contacted societies that agreed on disseminating the study. In addition, online dementia groups, mainly on Facebook, were used to further distribute the survey.

Participation in the survey was possible by clicking on the link, which led to Qualtrics (a web-based survey tool) where one could directly start the survey. The first page of the survey consisted of an information sheet, containing the study purpose, a time estimate, information about confidentiality, the right to withdraw from the study any time, possible rewards and a declaration of consent. Then the main body of the survey (the five sections) followed. On the last page of the survey participants are thanked for their participation and asked to forward the survey to their friends, family members or acquaintances, provided they are also informal caregivers of people with dementia. Participation in the study was voluntary, however, at the end of the survey participants had the chance to leave their email so that they could have been contacted when they would have won the reward for participation in the study. The reward consisted of a ten Euro Mydays coupon for people from Germany or ten Euro Cadeaubon coupon for people from the Netherlands. At the very end of the survey participants once again could leave their email addresses, in case they were interested in being contacted about research progress and further research.

Data Analysis

For the data analysis, statistical software "SPSS" was used. The filter command in SPSS was used to remove participants from the data-set that did not finish the study (variable "finished" = 0). In the pre-test the study took approximately 20 minutes. A threshold of at least three minutes (180 seconds) of study duration was set and participants that needed less than that were removed with the filter command (variable "Duration_in_seconds" GT 179) as it was not possible to properly participate in this study in such little time. Furthermore, two exclusion questions (dementia / MCI = 0, "country of residence" = "other") did not lead automatically to the exclusion of further participation in the study. Consequently, the filter command was used to remove participants whose CR was not diagnosed with dementia or MCI and three participants were casewise removed because they chose neither Germany nor Netherlands as their country of residence. Further seven responses were casewise removed as for those cases, the care recipient lived at a care institution.

Then, descriptive statistics of the demographic variables were computed. For demographic variables that were categorical like gender, education and time since diagnosis, natural numbers (n) and percentages were computed for each category. Continuous demographic variables like age were primarily tested for normality to decide which measurement could be used to summarise the distribution. A significant Shapiro-Wilk test (p < .001) indicated non-normality for the age of ICG variable and age of CR variable. Due to non-normality, instead of the mean and standard deviation, the median and the interquartile range were used as measurements for the two continuous demographic variables.

The first research question was about the acceptance towards in-home monitoring technologies among caregivers of people with dementia or MCI who live together with their CR versus those that do not live together with their CR. ICG's acceptance towards in-home monitoring technologies is measured using the acceptance scale, which represents the dependent variable. The independent variable is the CR's living situation with two categories: (1) with ICG and (2) without ICG. To select the appropriate parametric test to answer this

research question, assumptions of normality had to be checked. To test this assumption, a Shapiro-Wilk test was used, which turned out to be significant (p = .01), thus violating the assumption of normality. Due to non-normality, the non-parametric "Mann-Whitney-U" test was used. This test compares two groups using the median, which represents skewed distributions more accurate. With the Mann-Whitney-U test, the difference in acceptance for the group of CRs that live together with their ICG is compared to the group of CRs that live alone using the median of both groups.

The second research question was about the extent to which acceptance towards in-home monitoring technology among ICGs of people with dementia or MCI is associated with the time since diagnosis of their CR's condition. Acceptance was the dependent variable that could be measured using the acceptance scale. The independent variable was time since diagnosis, which was coded ordinally. Due to non-normality of the acceptance score, a non-parametric correlation coefficient "Spearman's correlation" was used to check for an association between the passed time since the diagnosis of the CR's condition and the ICG's acceptance towards in-home monitoring technologies. Spearman's correlation can be used for ordinal, interval or ratio variables.

Results

From 250 initial responses, 94 were removed due to incompletion of the survey leaving 156 responses (dropout-rate = 37%). After removing all responses with under three minutes of survey-duration, the number of responses reduced to 118. Further removal of 30 responses of non-demented / non-MCI cases, five responses of non German or Dutch ICGs and seven responses of CRs that lived in a care institution took place, resulting in a total of 76 remaining responses after data cleaning.

Approximately three-quarters of the participants were female and german. The majority of participants were highly educated, with more than half of participants having a Bachelor / Master degree (or equivalent) or higher. The median (IQR) age in years of participants was 56.5 (8). Most ICGs were the daughters or sons of the CR (63%) while only 17% were spouses or partners. The amount of ICGs that lived together with their CR (30%) was similar to those who needed to travel between 6 and 30 minutes to reach their CR (40%) (see Table 1).

Table 1

	n	Percent (%)	Median (Md)	Interquartile range (IQR)
Age (in years)			56,5	8
Gender				
Female	57	75		
Male	19	25		
Other	0	0		
Nationality				
Germany	59	78		
Netherlands	17	22		
Reason of care				
Dementia or MCI (inclusion criteria)	76	100		
Ageing	33	43		
Somatic impairment	12	16		
Mental illness	5	7		
Other	3	4		
Relation with care recipient				
Spouse / partner	13	17		
Daughter / son	48	63		
Daughter / son in law	7	9		
Sister / brother	0	0		
Grandchild	6	8		
Neighbour / friend	1	1.5		
Other	1	1.5		
Are there more people that provide care for your CR?				
No, I am the only person	22	29		
Yes, one other person	30	39		
Yes, two other persons	12	16		
Yes, three other persons	6	8		
Yes, four other persons	6	8		
Travel time to care recipient				
I live in the same house	23	30		
I live 1-5 minutes away	7	9		
I live 6-15 minutes away	18	24		
I live 16-30 minutes away	12	16		
I live 31-1 hour away	7	9		
I live more than 1 hour away	9	12		
Highest completed education?				
Primary or lower education	12	16		
Secondary education or equivalent	16	21		
Secondary vocational education	6	8		
Bachelor / master degree or equivalent	39	51		
Doctoral degree	3	4		
Other	0	0		

Demographic Characteristics of the Informal Caregivers (n = 76)

When it comes to the CRs themselves, the median (IQR) age in years was 84 (8.75). The majority of CRs live with others in their own rental house or flat. Alzheimer is the most prevalent type of dementia among the care recipients and for most CRs, dementia has been diagnosed in not more than 2 years since their ICGs participation in the study (29 %) (see Table 2).

Table 2

	n	Percent (%)	Median (Md)	Interquartile range (IQR)
Age (in years)			84	8.75
Type of Dementia / MCI				
Alzheimer	31	41		
Lewy body dementia	2	3		
Vascular dementia	7	9		
Mild cognitive impairment	11	14.5		
Other / I do not know	14	18		
There is no diagnosis (yet)	11	14.5		
Time since diagnosis				
Less than 1 year	4	5		
1 to 2 years	18	24		
2 to 3 years	14	18		
3 to 4 years	13	17		
4 to 5 years	11	15		
Over 5 years	16	21		
Housing situation				
Living alone	34	45		
Living with others	42	55		
Where does your care recipient live?				
In an own (rental) house or flat	55	72		
In a family member's house or flat	15	20		
In a assisted living home or flat	6	8		
In a nursing home (exclusion criteria)	0	0		
Other	0	0		
Type of professional care				
Home care by a (district) nurse or caregiver	26	34		
Dementia case manager	17	22		
Daycare / respite care	22	29		
Household assistance	31	41		
Meals on wheels	16	21		
None of the above	15	20		

Demographic Characteristics of the Care Recipients (n = 76)

This study investigated the degree of acceptance of in-home monitoring technology among ICGs of people with dementia or MCI in two different contexts. Acceptance was measured using the acceptance scale, which turned out to be non-normally distributed (W = insignificant). That means that the median (Md) had to be used instead of the mean (M) when specifying the score. The median (Md) score of participants was 3.69 with a score of 3 representing a neutral attitude towards in-home monitoring technology. Therefore, a median of 3.69 indicates a general tendency towards acceptance of this kind of technology (see Table 3).

To answer the first research question, acceptance in both groups, (1) CRs who live together with their ICG and (2) CRs who live alone, needed to be compared using the median (see Table 3). A non-parametric test that uses the median of both groups instead of the mean for comparison, was chosen. The non-parametric Mann-Whitney-U test turned out to be insignificant (p = .599), indicating no difference in acceptance between ICGs who live together with their CR versus those who do not.

The second research question was: "To what extent is the acceptance towards in-home monitoring technologies among informal caregivers of people with dementia or mild cognitive impairment associated with the time since the diagnosis of their care recipient's condition?". Spearman's-Rho was chosen due to the non-normality of the dependent variable of acceptance and the ordinal coding of the independent variable of time since diagnosis (see Table 3). The Spearman-Rho test turned out to be insignificant (p = .730), indicating no association between acceptance and time since diagnosis of the CR's condition.

Table 3

	Median (Md)	Interquartile range (IRQ)
Acceptance	3.69	1.04
Acceptance for each living situation Informal caregivers that live together with their care recipient Informal caregivers that not live together with their care recipient	4 3.69	1.77 0.92
Acceptance for each time since diagnosis		
Less than 1 year	4.23	1.17
1 to 2 years	3.42	1.13
2 to 3 years	3.89	1
3 to 4 years	3.85	1.35
4 to 5 years	4.08	1.46
Over 5 years	3.27	0.89

Acceptance for each group of the independent variables (n = 76)

Discussion

This study found a general tendency towards acceptance of in-home monitoring technology amongst participating ICGs, which corresponds with qualitative acceptance studies like those from Wrede, Braakman-Jansen, & Van Gemert-Pijnen (2021) and from Zwierenberg et al. (2018). However, when it comes to answering the research questions, the results of this study did not indicate significant differences in ICG's acceptance towards in-home monitoring technology and their CR's living situation (alone versus together with ICG). Nor did the results show a significant association between ICG's acceptance and the time passed since the diagnosis of the CR's type of dementia, leaving both research questions unanswered.

When reflecting upon the results of this study while being cognizant of the importance of user-centred design principles, it becomes clear that pure acceptance research among a narrow circle of stakeholders, such as the users themselves (ICGs) or the technology itself, is just one part out of many for successful long-term implementation of eHealth (Greenhalgh et. al., 2017). The concept of user-centred design by means of the CeHRes roadmap emphasised the importance of taking into account all stakeholders that will be eventually affected by the respective technology, which next to the end-users would also include the broader group of stakeholders such as the people who are being monitored (CRs), but also care organisations. As Greenhalgh et. al. (2017) state, it is especially the dynamic interaction between all those

stakeholders that needs to be considered when trying to implement a new complex technology. The majority of research on adoption of new technology comes too short of taking into consideration the bigger picture, which is why Greenhalgh et. al. (2017) created an interdisciplinary framework aimed at predicting and evaluating the success of eHealth and social care programs. The NASSS framework tries not only to address adoption (and its challenges) of eHealth and social care programs, but also non-adoption and abandonment as well as the transition from a niche product to the mainstream (Scale-up), the spread of the technology or program to new settings and businesses (spread) and its long term implementation (sustainability) (Greenhalgh et. al., 2017). Using the NASS framework, challenges that by far exceed the mere acceptance of eHealth by the end-users become apparent. For example, the implementation process of new technologies in care organisations has been barely studied, although answering questions like "What is the organisation's capacity to innovate?" or "What changes will be needed in team interactions and routines?" is essential for successful implementation. In the context of the use of in-home monitoring technologies in those organisations it is important to keep in mind that formal caregivers would probably need to restructure their care-routine, as they will constantly receive health information upon which they have to react flexibly.

In this study, the concept of unobtrusiveness in eHeath was touched upon. As an example, RT-based systems were given, which work independently from the user, while also not drawing the user's attention by blending in with its surroundings. Those RT-based systems manage to do that by analysing the human body's reflection of radio waves using deep learning and artificial intelligence (AI) while data is gathered through Wi-Fi, radar and wireless sensors implanted in daily-use objects (Sharma, Klein Brinke, Van Gemert-Pijnen, & Braakman-Jansen, 2021). Murphy et. al. (2021) investigated potential ethical concerns regarding AI. When using AI, there is no way around dealing with accountability. Questions like "who is responsible for AI errors in patient diagnosis?" have to be discussed and solved before such systems can reach the mainstream. Vourganas et al. (2022) propose that in case of unpredicted outcomes that lead to an unwanted event, the end-user or the designer would probably be considered as responsible. They add that in order to properly address those questions and deal with the accountability issue, clear classifications based on level of sensitivity for health technologies using AI should be made, which requires further research (Vourganas et al., 2022). When it comes to trust in AI based systems, one has to settle to security of confidential data. As mentioned in the NASSS framework, to overcome these challenges, those ethical issues cannot be solved in isolation, but have to be viewed in relation

to each other by for example providing inclusive development processes (Murphy et. al., 2021). When it comes to RT-based systems, privacy is less of a matter when compared to other HAR-based eHealth like wearables, as the raw data in RT-based systems is not easily interpretable by humans since it requires complex data processing (Sharma, Klein Brinke, Van Gemert-Pijnen, & Braakman-Jansen, 2021). However, this encryption of data raises new questions, as it is not clear how and by whom end-users will be taught to appropriately use those systems and correctly read its health data. Stiges-Maciá et al. (2021) present some media that could be used to properly train ICG's in the use of complex eHealth technologies. Through e-learning platforms, which include texts and videos, ICGs could not only be trained to operate those devices, but those platforms could also be used to teach ICGs new caring skills which they could incorporate into their daily routine, although their systematic review indicated no significant improvements in caring skills through those platforms. Also, it is not clear who pays for the provision of such platforms. This in turn raises new uncertainties about the financing of the training and resources most likely needed in order to properly operate those complex devices. For example, if the care organisations themselves had to pay for the training of their formal caregivers, this could constitute too big of a barrier which eventually could lead to a failed implementation of that technology. For the training of informal caregivers a similar problem arises, as for example the government would probably need to fund it, which could create a societal burden, especially if the respective technology is implemented on a larger scale. This then would add up to the already existing societal burden through productivity (and in respect thereof economic) losses caused by intensive care processes from informal caregivers (Michalowsky et al., 2016). These examples and questions illustrate the need for more research making use of a holistic approach on the implementation of new eHealth.

This study has some limitations that could be addressed in future research. A power analysis indicated that for a medium effect size (d = 0.5), 80% power and a p-value set on .05 (double sided), a sample size of at least 128 participants would have been necessary to find significant differences in acceptance between both living situations of ICGs. With a sample of just 76 participants, the effect size of this study was small, which could have decreased the probability to detect an effect, even though the effect might have been present. Time constraints, a lack of resources to recruit enough participants and the inclusion of ICGs of only two countries are altogether the primary reason for the small number of participants, which in turn are responsible for the lack of power of this study and its insignificant results. Another factor adding to the lack of recruited participants was most likely the relatively long

duration of this study (approximately 20 minutes), resulting in already highly burdened ICGs not finding the time to participate. Besides, the targeted population of ICGs was difficult to recruit, as there is presumably no openly accessible register which lists contact details of ICGs. Nevertheless, for the scope of this study the best has been done to recruit as many participants as possible, using creative ways like prizes for the participants, different sampling methods and dementia societies and organisations as distribution channels for the survey. Another strong point of this study was the survey itself, which exhibited a high internal consistency between the items to reliably measure the construct of acceptance.

As further investigation is required to address the multifaceted issues like training of ICGs, accountability and responsibility of AI based systems and financing, that come with implementation of new eHealth technologies, this study offers some practical recommendations that can facilitate this holistic research. In order to increase the power of the study, implications regarding the recruitment of participants should be acknowledged. First and foremost, if time permits, one should take its time for the data collection. Furthermore, if the research questions allows, the survey should be translated into more languages to increase the pool of potential participants. Lastly, the implementation of new creative ways to reach participants like the use of flyers or social media could prove as effective.

On the subject of future research, this paper provides valuable insight on how quantitative research in the context of acceptance towards in-home monitoring technology amongst ICG of PwD or MCI can be addressed. It also stresses the importance of an holistic or interdisciplinary approach on research concerning the implementation of eHealth. Although there is already lots of acceptance research, albeit of qualitative nature, on the adoption of eHealth by the end-users, actually many more stakeholders are involved in the successful integration of the respective technology that remain unnoticed. In this paper, user acceptance regarding different care-situations is investigated using quantitative methods, thus contributing to the aforementioned need of holistic acceptance research. The idea of assessing acceptance in different care-situations could be extended to ICGs themselves, as a study by Lin et al. (2017) shows. They investigated the use of unobtrusive HAR technology for caregivers themselves who are at risk of injuries due to patient handling. Applying unobtrusive HAR technology for ICGs themselves may at first sight appear disconnected to the context of monitoring care recipients that are probably more susceptible to injury than ICGs, however the initial aim of those technologies, that is reducing the caregiver burden, is still pursued. In a similar manner, acceptance research could consider close relatives of ICGs, who with the help of HAR technologies could support the ICGs in their caretaking process and provide additional assurance. Besides, further research could investigate the practicalities of implementing new eHealth technology with respect to the greater picture as elucidated in implementation schemes that include user centred design principles like the NASSS framework or the CeHRes roadmap. For example, research on legal issues related to the integration of monitoring technologies, questions about financing of potential training to operate more complex eHealth systems or ethical issues like privacy and trust concerning the use of AI based systems are all significant topics that require more attention.

In conclusion, despite the lack of significant results, two things can be taken from this paper. First, the reminder of conducting more quantitative acceptance research by taking into account different contexts to optimise implementation of new technologies and secondly, incorporating the practical recommendations on data gathering of hard-to-recruit target populations.

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Appendix: Dutch Survey

Acceptatie van innovatieve monitoring technologie in de zorg voor thuiswonende ouderen

Hartelijk dank voor uw bereidheid om deel te nemen aan dit onderzoek. Dit onderzoek wordt uitgevoerd door studenten Psychologie aan de Universiteit Twente als deel van hun Bachelor Scriptie.

Het doel van dit onderzoek is om meer inzicht te krijgen in factoren die een rol spelen bij de acceptatie van technologie voor het monitoren van thuiswonende ouderen. We zijn in dit onderzoek in het bijzonder geïnteresseerd in de mening van mantelzorgers van ouderen met dementie. Mantelzorgers zijn informele verzorgers die op vrijwillige basis onbetaalde zorg/hulp verlenen aan een zorgbehoevende naaste. Voorbeelden van een mantelzorger zijn een echtgenoot, zoon/dochter, een ander familielid of vriend.

De vragenlijst wordt verspreid in Nederland en Duitsland. Bij het invullen van deze vragenlijst is het geen vereiste om eerdere ervaring te hebben met monitorende technologie. Deelname aan deze vragenlijst zal ongeveer 20 minuten duren.

Uw antwoorden zullen volledig anoniem worden verwerkt waardoor de gegevens dus niet tot een persoon kunnen worden herleid. Uw gegevens zullen alleen worden gebruikt voor dit wetenschappelijk onderzoek.

Uw deelname in dit onderzoek is volledig vrijwillig, wat betekent dat u op elk gewenst moment kunt stoppen met het invullen van de vragenlijst.

Indien u vragen heeft over dit onderzoek kunt u contact opnemen met Maarten Akgül (m.t.d.akguel@student.utwente.nl), een van de onderzoekers, of Dr. L.M.A. Braakman-Jansen (I.m.a.braakman-jansen@utwente.nl), de onderzoeksleider.

Om u te bedanken voor uw deelname bieden we u aan het einde van de vragenlijst de mogelijkheid aan om een prijs te winnen! U kunt namelijk een cadeaubon ter waarde van €10 winnen.

Verklaring van goedkeuring voor deelname

Ik bevestig dat ik 18 jaar of ouder ben en dat ik bovenstaande informatie gelezen en begrepen heb. Op basis van voorstaande keur ik vrijwillig goed om deel te nemen aan dit onderzoek.

🔿 Ja

O Nee

DEMOGRAFISCHE INFORMATIE

Deel 1: Algemene vragen over uwzelf

Fijn dat u mee wilt werken aan dit onderzoek. Wij willen graag beginnen met enkele vragen over uwzelf.

Wat is uw leeftijd (in jaartallen)?

Wat	is	uw	ges	lac	ht?
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O Man

O Vrouw

O Anders

In welk land woont u?

O In Nederland

O In Duitsland

O Anders

Bent u een mantelzorger?

(Een mantelzorger is iemand die vrijwillig (onbetaald) zorg/ hulp verleent aan een naaste. Voorbeelden van een mantelzorger zijn een echtgenoot, zoon/dochter, een ander familielid of vriend)

O Ja O Nee Wat is de reden dat u mantelzorg verleent? (U kunt meerdere antwoorden kiezen)

- Dementie of lichte cognitieve beperking / geheugen klachten
- Ouderdom
- Lichamelijke beperking(en)
- Psychische stoornis
- Anders

Wat beschrijft het beste uw relatie met de persoon voor wie u zorgt?

Ik ben

- O Echtgenoot/partner
- O Dochter/Zoon
- O Schoondochter/Schoonzoon
- O Zuster/ broer
- O Kleindochter/Kleinzoon
- O Buurman/ Buurvrouw/ Vriend
- O Anders, namelijk:

Zijn er meer mantelzorgers die een aandeel in de zorg voor uw naaste hebben?

O Nee, ik ben de enige mantelzorger voor mijn zorgbehoevende naaste

- O Ja, een andere persoon
- O Ja, twee andere personen
- O Ja, drie andere personen
- O Ja, 4 of meer andere personen

Welke van de volgende opties beschrijft het beste hoelang het gemiddeld duurt om bij de woning van uw zorgbehoevende naaste te arriveren? (Ga hierbij uit van uw meest gebruikte manier van transport).

- O Ik woon in hetzelfde huis als de persoon voor wie ik zorg
- O lk woon op 1 tot 5 minuten afstand
- O Ik woon op 6 tot 15 minuten afstand
- O Ik woon op 16 tot 30 minuten afstand
- O Ik woon op 31 minuten tot 1 uur afstand
- O Ik woon op meer dan 1 uur afstand

Deel 2: Algemene vragen over uw naaste

Nu volgen een aantal vragen over de naaste voor wie u zorgt.

Wat is de leeftijd van de naaste voor wie u zorgt (in jaartallen)?

Welk type dementie/cognitieve beperking is van toepassing op uw naaste?

O Alzheimer

O Lewy-Body dementie

- O Vasculaire dementie
- O Milde cognitieve stoornis
- O Ander type / Weet ik niet
- O Er is (nog) geen diagnose vastgesteld

Sinds wanneer vertoont uw zorgbehoevende naaste verschijnselen van dementie/ geheugenklachten (naar schatting)?

- O Minder dan 1 jaar
- O 1 tot 2 jaar
- O 2 tot 3 jaar
- O 3 tot 4 jaar
- O 4 tot 5 jaar
- O Meer dan 5 jaar

Wat is de leefsituatie van uw zorgbehoevende naaste?

- O Alleenwonend
- O Samenwonend

Waar woont uw zorgbehoevende naaste?

- O In een eigen (huur)woning
- O Inwonend bij een familielid
- O In een aanleunwoning of aanleunappartement dat hoort bij een zorginstelling
- O In een verpleeg- of verzorgingshuis
- O Anders, namelijk:

Van welke type professionele zorg/ service maakt uw zorgbehoevende naaste gebruik? (meerdere antwoorden mogelijk)

- Thuiszorg door een (wijk)verpleegkundige of verzorgende
- Casemanager dementie
- Dagopvang/ dagbesteding/ tijdelijke opvang
- Huishoudelijke hulp
- Maaltijdservice
- Geen van bovenstaande

ERVAREN ZORGLAST VOOR DE MANTELZORGER

Caregiver Burden: 4-item ZBI screening scale by Bédard et al. (2001):

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview. The Gerontologist, 41(5), 652–657. https://doi.org/10.1093/geront/41.5.652

Digital literacy: Kayser et al. (2018):

Kayser, L., Karnoe, A., Furstrand, D., Batterham, R., Christensen, K. B., Elsworth, G., & Osborne, R. H. (2018). A multidimensional tool based on the eHealth literacy framework: development and initial validity testing of the eHealth literacy questionnaire (eHLQ). *Journal of medical Internet research*, 20(2), e8371. doi: 10.2196/jmir.8371

Personal innovativeness: Agarwal and Prasad (1998):

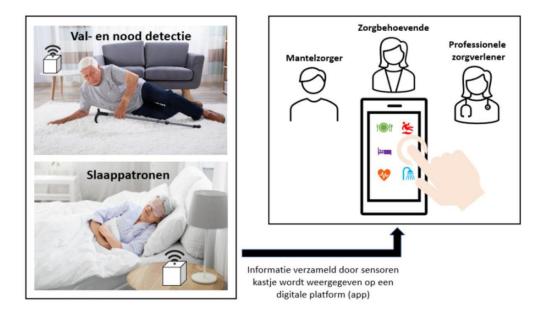
Agarwal, R., & Prasad, J. (1998). A conceptual and operational definition of personal innovativeness in the domain of information technology. *Information systems research*, *9*(2), 204-215. doi: 10.1287/isre.9.2.204

Deel 5: Contactloze monitoring technologie in de zorg voor een naaste

Bekijk a.u.b. de beschrijving en afbeelding hieronder voordat u verder gaat naar de volgende vragen.

Er worden steeds meer technologieën ontwikkeld die tot doel hebben mantelzorgers te ondersteunen en hun naasten in staat te stellen langer thuis te kunnen wonen. In dit deel van de vragenlijst richten we ons op een nieuwe vorm van ondersteunende technologie: Contactloze technologie voor het monitoren van uw zorgbehoevende naaste. Contactloze monitoring technologie is een sensor systeem voor de thuisomgeving. Het is bedoeld om de mantelzorger een beter inzicht te geven in de situatie van zijn/haar thuiswonende naaste, vooral wanneer de mantelzorger op afstand woont of het huis verlaat.

De technologie werkt contactloos, d.w.z. de naaste hoeft hierbij geen apparaten te dragen. Zoals u kunt zien in de onderstaande afbeelding kan er een klein kastje met ingebouwde sensoren in een hoek van de woning geplaatst worden. Dit slimme kastje kan met behulp van kunstmatige intelligentie het dagelijks leefpatroon van uw naaste leren herkennen en belangrijke veranderingen waarnemen, zoals minder drinken of eten of nachtelijke onrust. In geval van nood (zoals bv. een val) kan het systeem de mantelzorger alarmeren. De verzamelde informatie kan weergegeven worden op een digitaal platform dat toegankelijk is voor de mantelzorger en naaste. Indien gewenst kan de informatie ook gedeeld worden met betrokken zorgprofessionals.



Hoe duidelijk vond u de beschrijving en afbeelding over contactloze monitoring technologie

in de zorg voor een thuiswonende naaste?

O Niet duidelijk

O Een beetje duidelijk

O Duidelijk

Heeft u suggesties voor het verbeteren van de duidelijkheid van de beschrijving en afbeelding?

ACCEPTATIE VAN VERSCHILLENDE MONITORING SITUATIES

Deel 5A: Verschillende gebruiksscenario's

In dit deel van de vragenlijst zullen we u 5 verschillende scenario's presenteren. De scenario's beschrijven verschillende situaties waarin contactloze monitoring technologie toegepast kan worden en ieder scenario omvangt andere aspecten waarover het systeem zou kunnen informeren. Voor elk scenario willen wij u graag een aantal vragen stellen.

Scenario 1: Het detecteren van noodsituaties

Stelt u zich voor: Bij uw zorgbehoevende naaste thuis is contactloze monitoring technologie geïnstalleerd. Deze technologie zal voortdurend de veiligheid van uw naaste monitoren in het gehele huis. Het systeem kan bijvoorbeeld valincidenten of dwalen detecteren en u als mantelzorger (of een door u aangewezen persoon) direct informeren over deze noodsituatie.

Geeft u alstublieft aan in hoeverre u het eens of oneens bent met de volgende uitspraken over dit scenario:

Contactloze technologie voor het detecteren van noodsituaties van mijn naaste...

	Helemaal mee oneens	Mee oneens	Neutraal	Mee eens	Helemaal mee eens
Zou ik acceptabel vinden	0	0	0	0	0
Zou mijn zorgbehoevende naaste acceptabel vinden	0	0	0	0	0
Zou behulpzaam zijn voor mij	0	0	0	0	0
Zou mij ondersteunen in het verlenen of organiseren van de best mogelijke zorg	0	0	0	0	0
Zou mij in staat stellen om me gerust te voelen over de situatie van mijn naaste	0	0	0	0	0
Zou mij helpen om sneller te reageren op de zorgbehoeftes van mijn naaste	0	0	0	0	0
Zou mij helpen om mijn naaste langer thuis te laten wonen	0	0	0	0	0
Zou mij helpen om als mantelzorger langer vol te houden	0	0	0	0	0
Zou mij informatie geven die ik graag zou willen delen met de zorgprofessional(s) van mijn zorgbehoevende naaste	0	0	0	0	0

Ik zou contactloze technologie voor het detecteren van noodsituaties van mijn naaste in de (nabije) toekomst willen gebruiken.

0 0 0 0

Scenario 2: Het voorspellen van acute situaties

Stelt u zich voor: Bij uw zorgbehoevende naaste thuis is contactloze monitoring technologie geïnstalleerd. Deze heeft als doel om acute situaties niet alleen te detecteren maar te voorspellen. Zo kan de technologie bijv. voortdurend de loopsnelheid en looppatroon van uw naaste monitoren. Door middel van deze informatie kan het systeem het risico op vallen van uw naaste voorspellen en u (of een door u aangewezen persoon) inlichten over de situatie. Het doel hiervan is om noodsituaties zoals bijv. vallen te voorkomen.

0

Geeft u alstublieft aan in hoeverre u het eens of oneens bent met de volgende uitspraken over dit scenario:

	Helemaal mee oneens	Mee oneens	Neutraal	Mee eens	Helemaal mee eens
Zou ik acceptabel vinden	0	0	0	0	0
Zou mijn zorgbehoevende naaste acceptabel vinden	0	0	0	0	0
Zou behulpzaam zijn voor mij	0	0	0	0	0
Zou mij ondersteunen in het verlenen of organiseren van de best mogelijke zorg	0	0	0	0	0
Zou mij in staat stellen om me gerust te voelen over de situatie van mijn naaste	0	0	0	0	0
Zou mij helpen om sneller te reageren op de zorgbehoeftes van mijn naaste	0	0	0	0	0
Zou mij helpen om mijn naaste langer thuis te laten wonen	0	0	0	0	0
Zou mij helpen om als mantelzorger langer vol te houden	0	0	0	0	0
Zou mij informatie geven die ik graag zou willen delen met de zorgprofessional(s) van mijn zorgbehoevende naaste	0	0	0	0	0
Ik zou contactloze technologie voor het voorspellen van acute situaties van mijn naaste in de (nabije) toekomst willen gebruiken.	0	0	0	0	0

Scenario 3: Het monitoren van zelfzorg

Stelt u zich voor: Bij uw zorgbehoevende naaste thuis is contactloze monitoring technologie geïnstalleerd. Deze technologie zal voortdurend de zelfzorg van uw zorgbehoevende naaste monitoren zoals eten, drinken en persoonlijke hygiëne (bijv. wassen, toiletteren, aankleden). Het monitoring systeem kan belangrijke afwijkingen in de zelfzorg detecteren en u (of een door u aangewezen persoon) hierover inlichten.

Geeft u alstublieft aan in hoeverre u het eens of oneens bent met de volgende uitspraken over dit scenario:

Helemaal Mee Helemaal mee Mee Neutraal oneens oneens eens mee eens Zou ik acceptabel vinden 0 0 0 0 0 Zou mijn zorgbehoevende naaste 0 0 0 0 0 acceptabel vinden 0 0 0 0 0 Zou behulpzaam zijn voor mij Zou mij ondersteunen in het verlenen of organiseren van de 0 0 0 0 0 best mogelijke zorg Zou mij in staat stellen om me 0 0 0 gerust te voelen over de situatie 0 0 van mijn naaste Zou mij helpen om sneller te reageren op de zorgbehoeftes van 0 0 0 0 0 miin naaste Zou mij helpen om mijn naaste 0 0 0 0 0 langer thuis te laten wonen Zou mij helpen om als Ο 0 O O O mantelzorger langer vol te houden Zou mij informatie geven die ik graag zou willen delen met de 0 0 0 0 0 zorgprofessional(s) van mijn zorgbehoevende naaste Ik zou contactloze technologie 0 0 0 0 voor het monitoren van de 0 zelfzorg van mijn naaste in de (nabije) toekomst willen gebruiken.

Contactloze technologie voor het monitoren van de zelfzorg van mijn naaste...

Scenario 4: Het monitoren van welzijn gedurende de nacht

Stelt u zich voor: Bij uw zorgbehoevende naaste thuis is contactloze monitoring technologie geïnstalleerd. Deze technologie zal voortdurend het welzijn van uw zorgbehoevende naaste monitoren gedurende de nacht. Het monitoring systeem kan afwijkingen van het gewoonlijke nachtelijke patroon (zoals nachtelijke onrust, slaapproblemen of een instabiel dag- en nachtritme) detecteren en u (of een door u aangewezen persoon) hierover inlichten.

Geeft u alstublieft aan in hoeverre u het eens of oneens bent met de volgende uitspraken over dit scenario:

Contactloze technologie voor het monitoren van het welzijn van mijn naaste gedurende de nacht...

	Helemaal mee oneens	Mee oneens	Neutraal	Mee eens	Helemaal mee eens
Zou ik acceptabel vinden	0	0	0	0	0
Zou mijn zorgbehoevende naaste acceptabel vinden	0	0	0	0	0
Zou behulpzaam zijn voor mij	0	0	0	0	0
Zou mij ondersteunen in het verlenen of organiseren van de best mogelijke zorg	0	0	0	0	0
Zou mij in staat stellen om me gerust te voelen over de situatie van mijn naaste	0	0	0	0	0
Zou mij helpen om sneller te reageren op de zorgbehoeftes van mijn naaste	0	0	0	0	0
Zou mij helpen om mijn naaste langer thuis te laten wonen	0	0	0	0	0
Zou mij helpen om als mantelzorger langer vol te houden	0	0	0	0	0
Zou mij informatie geven die ik graag zou willen delen met de zorgprofessional(s) van mijn zorgbehoevende naaste	0	0	0	0	0
Ik zou contactloze technologie voor het monitoren van het welzijn van mijn naaste gedurende de nacht in de (nabije) toekomst willen gebruiken.	0	0	0	0	0

Scenario 5: Het monitoren van geleidelijke gezondheidsveranderingen

Stelt u zich voor: Bij uw zorgbehoevende naaste thuis is contactloze monitoring technologie geïnstalleerd. Deze technologie zal over een langere termijn veranderingen die geleidelijk ontwikkelen in de gezondheid van uw zorgbehoevende naaste monitoren. Het monitoring systeem kan u (of een door u aangewezen persoon) bijvoorbveeld informeren over cognitieve of fysieke veranderingen van uw naaste in een bepaalde periode.

Geeft u alstublieft aan in hoeverre u het eens of oneens bent met de volgende uitspraken over dit scenario:

Contactloze technologie voor het monitoren van geleidelijke gezondheidsveranderingen van mijn naaste...

	Helemaal mee oneens	Mee oneens	Neutraal	Mee eens	Helemaal mee eens
Zou ik acceptabel vinden	0	0	0	0	0
Zou mijn zorgbehoevende naaste acceptabel vinden	0	0	0	0	0
Zou behulpzaam zijn voor mij	0	0	0	0	0
Zou mij ondersteunen in het verlenen of organiseren van de best mogelijke zorg	0	0	0	0	0
Zou mij in staat stellen om me gerust te voelen over de situatie van mijn naaste	0	0	0	0	0
Zou mij helpen om sneller te reageren op de zorgbehoeftes van mijn naaste	0	0	0	0	0
Zou mij helpen om mijn naaste langer thuis te laten wonen	0	0	0	0	0
Zou mij helpen om als mantelzorger langer vol te houden	0	0	0	0	0
Zou mij informatie geven die ik graag zou willen delen met de zorgprofessional(s) van mijn zorgbehoevende naaste	0	0	0	0	0
Ik zou contactloze technologie voor het monitoren van geleidelijke gezondheidsveranderingen van mijn naaste in de (nabije) toekomst willen gebruiken.	0	0	0	0	0

Deel 5B: Verwachte voordelen & nadelen

In het volgende willen wij u enkele vragen stellen over de algemene voor- en nadelen m.b.t. contactloze monitoring technologie in de zorg voor uw naaste.

Geeft u alstublieft aan in hoeverre u het eens of oneens bent met de volgende uitspraken.

Ik denk dat contactloze monitoring technologie mij kan helpen om...

	Helemaal mee oneens	Mee oneens	Neutraal	Mee eens	Helemaal mee eens
1. Te controleren of mijn naaste voldoende voor zichzelf zorgt (bijv. Eten/drinken)	0	0	0	0	0
2. Onnodige bezoekjes ter controle van de zelfzorg van mijn naaste te voorkomen	0	0	0	0	0
3. Gerust te zijn over de veiligheid van mijn naaste	0	0	0	0	0
4. Meer vrijheid en mobiliteit voor mijzelf te verkrijgen	0	0	0	0	0
5. Factoren te identificeren en te verwijderen die de zelfstandigheid van mijn naaste mogelijk belemmeren	0	0	0	0	0
 Sneller te reageren op de zorgbehoeftes van mijn naaste om gezondheidsrisico's te voorkomen (bijv. ondervoeding, slaapproblemen, eenzaamheid) 	0	0	0	0	0
7. Anderen, inclusief professionele zorgverleners, een goed beeld van de situatie van mijn naaste te verstrekken	0	0	0	0	0
8. Het optimale moment te achterhalen waarin mijn naaste de overstap kan maken naar een andere woonvorm	0	0	0	0	0

Geeft u alstublieft aan in hoeverre u het eens of oneens bent met de volgende uitspraken.

Als ik contactloze monitoring technologie zou gebruiken, voel ik me...

	Helemaal mee oneens	Mee oneens	Neutraal	Mee eens	Helemaal mee eens
1. Bezorgd om met te veel informatie beladen te worden	0	0	0	0	0
2. Bezorgd dat de monitoring informatie mij nodeloos bezorgd zou maken	0	0	0	0	0
3. Onzeker of ik wel of niet moet reageren op informatie uit het systeem	0	0	0	0	0
4. Bezorgd dat de monitoring informatie gedeeld wordt met derde partijen zonder toestemming	0	0	0	0	0
5. Bezorgd dat de voordelen niet opwegen tegen de schending van de privacy van mijn naaste	0	0	0	0	0
6. Bezorgd dat de technologie wellicht het menselijk contact vervangt.	0	0	0	0	0

ALGEMENE ACCEPTATIE VAN CONTACTLOZE MONITORING TECHNOLOGIE

Deel 5C: Algemene acceptatie van contactloze monitoring technologie

In het volgende zijn we geïnteresseerd in uw algemene acceptatie van contactloze monitoring technologie in de zorg voor een naaste. Houd hierbij rekening met alle informatie die u nu heeft over de functie en mogelijke inzet van deze technologie.

Geeft u alstublieft aan in hoeverre u het eens of oneens bent met de volgende stellingen:

Ik denk dat contactloze monitoring technologie in de zorg voor mijn naaste behulpzaam is voor mij...

	Helemaal mee oneens	Mee oneens	Neutraal	Mee eens	Helemaal mee eens
1. Op dit moment in mijn leven	0	0	0	0	0
2. Wanneer de cognitieve of fysieke gezondheid van mijn naaste verslechterd	0	0	0	0	0

Ik zou contactloze monitoring technologie in de zorg voor mijn naaste willen gebruiken...

	Helemaal mee oneens	Mee oneens	Neutraal	Mee eens	Helemaal mee eens
1. Op dit moment in mijn leven	0	0	0	0	0
2. Wanneer de cognitieve of fysieke gezondheid van mijn naaste verslechterd	0	0	0	0	0

Geeft u alstublieft aan in hoeverre u het eens of oneens bent met de volgende stellingen:

	Helemaal mee oneens	Mee oneens	Neutraal	Mee eens	Helemaal mee eens
Het is een goed idee om contactloze monitoring technologie te gebruiken in de zorg voor mijn naaste.	0	0	0	0	0
Mijn familie en vrienden zouden het positief vinden wanneer ik contactloze monitoring technologie gebruik in de zorg voor mijn naaste.	0	0	0	0	0
De professionele zorgverleners van mijn naaste zouden het positief vinden wanneer ik contactloze monitoring technologie gebruik in de zorg voor mijn naaste.	0	0	0	0	0
Het zou voor mij gemakkelijk zijn om de aan het monitoring systeem gekoppelde informatieplatform (app) te leren bedienen.	0	0	0	0	0
Ik verwacht dat ik voldoende kennis en ondersteuning heb/ krijg om contactloze monitoring technologie in de zorg voor mijn naaste te gebruiken.	0	0	0	0	0

ACCEPTATIE VAN VERSCHILLENDE VORMEN VAN MONITORING TECHNOLOGIE

Deel 5D: Verschillende vormen van monitoring technologie

We zijn nu aangekomen in het laatste gedeelte van de vragenlijst. Monitoring technologie in het algemeen kan gebruik maken van verschillende apparaten/ sensoren om informatie in te winnen over de toestand van uw zorgbehoevende naaste. Deze variëren afhankelijk van het soort contact met het lichaam (contactloos, indirect contact, direct contact). We zijn benieuwd wat u van deze apparaten vindt.

Geeft u alstublieft voor elk van onderstaande apparaten/ sensoren aan in hoeverre u ze acceptabel vindt in de zorg voor uw thuiswonende naaste.

	Zeer onnaceptabel	Onnaceptabel	Neutraal	Acceptabel	Zeer accepta
(Direct contact) 1. Draagbare apparaten (apparaten die dicht bij het lichaam gedragen worden; zoals smartwatches, mobiele telefoons, draagbare alarm knoppen)	0	0	0	0	0
(Contactloos) 2. Visuele apparaten (zoals camera's die geanonimiseerde beelden produceren, d.w.z. beelden waarop gezichten niet herkenbaar zijn)	0	0	0	0	0
(Contactloos) 3. Apparaten gebaseerd op geluidsdetectie (zoals microfoons, smart speakers)	0	0	0	0	0
(Contactloos) 4. Apparaten gebaseerd op radiofrequenties (zoals bv. een centraal geplaatste sensor die bewegingen binnen het huis kan detecteren via radar)	0	0	0	0	0
(Indirect contact) 5. Object-gebonden apparaten (apparaten die vast zitten aan dagelijks gebruikte voorwerpen zoals bewegingssensoren aan deuren of de koelkast of druksensoren op bed matrassen)	0	0	0	0	0
EDUCATIE					

Ten slotte nog een laatste vraag over uwzelf:

Wat is uw hoogst genoten educatie (diploma behaald)?

- O Basisonderwijs of lager
- O Voortgezet onderwijs: VMBO
- O Voortgezet onderwijs: HAVO, VWO
- O Middelbaar beroepsonderwijs (MBO)
- O Bachelor/ Master of gelijkwaardig diploma (HBO of Universiteit)
- O Doctoraal diploma
- O Anders

EINDE VRAGENLIJST

Hartelijk dank voor uw deelname! U maakt nu kans om een prijs te winnen!

Wij danken u voor uw deelname en hulp bij ons onderzoek. Als u nog vrienden, familie of kennissen kent die ook mantelzorger zijn, zouden wij het zeer waarderen als u deze vragenlijst met hun zou delen.

Voor meer informatie met betrekking tot dit onderzoek kunt u terecht bij Dr. Annemarie Braakman-Jansen (I.m.a.braakman-jansen@utwente.nl), de projectleider, of bij Maarten Akgül (m.t.d.akguel@student.utwente.nl), een van de onderzoekers.

Om u nogmaals te bedanken voor uw deelname en hulp, maakt u kans op een cadeaubon ter waarde van €10,-. In totaal zullen er d.m.v. een loting willekeurig 4 winnaars bekend worden gemaakt. Indien u wilt meedoen aan de loterij kunt u hieronder uw e-mailadres achterlaten:

Wij vinden het erg belangrijk om mantelzorgers te kunnen betrekken bij het ontwikkelen van technologie die ondersteuning kan bieden. Zouden wij u mogen benaderen voor toekomstig onderzoek? Zo ja, dan kunt u hieronder uw e-mailadres voor ons achterlaten.

(De gegevens worden uitsluitend gebruikt om contact op te nemen en worden apart van uw antwoorden verwerkt.)