Needs and barriers of formal and informal caregivers of patients with dementia in lifestyle monitoring

A research that investigate the needs and barriers of formal and informal caregivers are concerning lifestyle monitoring by dementia patients who live alone.

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Abstract

Study aim- Dementia is a progressive disease caused by the appearance of physical changes in the brain which results in declined memory, language, problem-solving and other cognitive skills. The expectation is that the number of patients with dementia will increase as it is unlikely that a dementia cure will be found in the near future. The increase in the number of patients with dementia and the current shortage of professional healthcare givers can become a bottleneck in combination with the governmental focus to let these patients stay at home as long as possible. Technologies, like lifestyle monitoring can play an important role in optimizing the life of patients with dementia by allowing them to live longer at home. The purpose of this study is to gain insights in the needs and barriers of informal and formal caregivers concerning lifestyle monitoring for patients with dementia living at home.

Methods- Semi-structured interviews with seven informal and ten formal caregivers taking care of patients with dementia, were conducted. The average (SD) number of self- reported years they have worked as informal caregiver was 4,7 (2,4) and the average self- reported number of hours per week invested as informal caregiver was 13.9. The formal caregivers had an on average (SD) 3,6 (2,9) years of work experience in the field of dementia care). The interviews consisted of the following categories of questions: current experience as a caregiver, client safety, client privacy, needs and barriers, functional and non-functional values of lifestyle monitoring. The data was coded inductively until no new codes could be identified. The categories and themes were discussed with the supervisor and second coder until consensus was reached. After the data of the interviews was analysed, a map with the requirements of lifestyle monitoring was developed. These requirements are the technical translation of attributes/needs of the caregivers and are interpreted by the researcher**.**

Results- Informal caregivers believe that lifestyle monitoring could add value when it reassures them about the well-being of their relatives. For formal caregivers lifestyle monitoring should provide more high quality information about the patient with dementia, like the daily structure and activities. Next to this informal- and formal caregivers emphasize that lifestyle monitoring could add value to dementia care when the system monitors, detects and reports deviations in activities of the patients. At the same time formal caregivers indicated that an increase of their workload will be a barrier. Therefore the information needs to be tailored. This means that the system needs to provide relevant information and alerts. When the system provides these needs it could help formal caregivers to work more efficient and these caregivers believe that it could positively affect professional healthcare quality. They also expect that it will have a positive effect on the quality of life of the patient with Dementia. Next to this, the technology needs to be unobtrusive and the privacy of the patient with dementia needs to be guaranteed. Otherwise, the willingness to use lifestyle monitoring will decrease.

Conclusion **–**Further research needs to focus on verifying the requirements map with additional stakeholders. When lifestyle monitoring will be developed from a user centered point of view instead of a technical point of view it can support the caregivers in dementia care when the retrenchment in the health care sector and staff shortage continues. Additionally, it is important that the maximum budget will be increased to make sure that necessary health care can be delivered at home for everyone. With these adjustments it is possible to overcome the current challenge in dementia care: the increasing number of patients with dementia and the current shortage of professional healthcare givers in combination with the governmental focus to let these patients stay at home as long as possible.

Preface

In the period of September 2017 till April 2018 I worked on this master thesis ‘Needs and barriers of formal and informal caregivers of patients with dementia in lifestyle monitoring’.
In this thesis I will address the user requirements of informal and formal caregivers concerning lifestyle monitoring of dementia patients who are living at home. This thesis has been executed at the company FocusCura B.V. FocusCura wants to help people to stay independent for a longer period of time. In order to contribute to this, the company has developed health care innovations in two mean areas: 'home care at a distance' and 'the hospital at home'. With innovative products and services they ensure to that everyone can continue to receive the care they need.

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1. Introduction

Today over 270.000 people in the Netherlands are suffering from dementia and the expectation is that the number of people with dementia will increase enormously in the future(Alzheimer Nederland, 2017). The intensity and the duration of required care will increase (Peeters & Francke, 2014) as it is unlikely that this disease can be cured in the near future (Boots, Vugt, Knippenbergen, Kempen& Verhey, 2013). Dementia causes large changes in people's life. This disease does not only impact the patients with dementia but also their informal caregivers (D' Onofrio et al., 2014). The increase in the number of patients with dementia and the current shortage of professional healthcare givers can become a bottleneck in combination with the governmental focus to let these patients stay at home as long as possible. Technology can provide support and increases the safety and privacy of a patient with dementia (Nap, Lukkien, Cornelisse, 2016). Further, technology can reduce the workload of (in)formal caregivers and this results in a more efficient use of the available manpower. In this way healthcare stays affordable for everyone (de Veer & Francke, 2009) .

Dementia is a progressive disease which influences the cognitive and functional abilities of patients with dementia (Hugo& Gunguli, 2014) Through the progression of this disease people require more and more help from others (Alzheimer Nederland& Vilans, 2013).

Nowadays about 70% of the patients with dementia are living at home and often close relatives take care of them (Alzheimer Nederland, 2016; Huijsman, 2013; RIVM, 2007). Informal caregivers are often close relatives and together with professional caregivers they play an important role in the lives of people with dementia (Runneboom, 2010). In order to make it possible for patients with dementia to life at home as long as possible, not only formal care but also informal care is required.

It is known that being an informal caregiver is a heavy task. Trusted role patterns, resilience and equivalence in the relationship changes to a more patient- caregiver relation instead of the known family bond (Alzheimer Nederland& Vilans, 2013).Informal caregivers experience a much higher workload over dementia patients in comparison to other diseases. One of the reasons behind this is that informal caregivers do not see options to share the workload as dementia patients need complex help (Peeters ,Werkman& Francke, 2012). More than half of all informal caregivers in the Netherlands have a high burden of care and this number has increased significantly in recent years (Alzheimer Nederland, 2016; Huijsman, 2013; Lamain, Hooimijer, Visser, Bennekom& Expertisecentrum mantelzorg, 2011).

The expectation is that informal caregivers receive support from their social environment, but this is not always the case (Doekhie, de Veer, Rademakers, Schellevis & Franke, 2014). Informal caregivers indicate that they need more support and better communication with the formal caregivers. For patients with dementia informal caregivers hope to get more supervision, personal attention and guidance. One of the reasons for this is the long term-care and high actual burden (Jansen, Werkman& Francke, 2016). Further it is caused by the mandatory home care, informal caregivers are playing an increasingly important role in the care of people with dementia (Oudijk, de Boer, Woittiez, Timmermans & de Klerk, 2010). More care is moved to the home situation (de Witte,2008) , this comes down to approximately 30% of the total care(Nederlandse Zorgautoriteit, 2012). This is a result of changes in care legislation in 2014. The intention of this legislation is that people life longer independently with the necessary care and help from their own social network (Zorgwijzer, 2014). This means that people are only eligible to stay in a nursing home or in an institution when it is really

necessary. This change is resulting in an increased burden of informal and formal caregivers (Schuurman, 2011; Vilans, 2015). More commitment and support is asked of the informal caregivers (Zorgwijzer, 2014) and the formal caregivers have to meet a larger and increasing demand for care with less financial and personnel resources (Scholten, 2014).

Informal caregivers can get support from district nursing to reduce the burden. The expectation is that, in the near future, it will no longer be possible to meet the care needs of the dementia patients (Nijhof, 2013; van der Windt, Smeets & Arnold, 2008). One of the reasons for this is the expected shortage of health personnel (Hamel, 2017) and a high increase of patients with dementia (Hugo& Gunguli, 2014). Up to 2025, there is an expected shortage of 125,000 formal caregivers. Formal caregivers experience a shortage of colleagues on a daily basis, this affects the work pressure, quality and patient safety negative. The private life of formal caregivers is significantly affected by this. It generate stress, feelings of guilt towards patients, family and colleagues. A higher absenteeism and increasing outflow of formal caregivers is signalized (V&VN, 2017).

So it is important to support caregivers effectively to ensure the wellbeing of the caregivers, to reduce their burden and to extend the period that patients with dementia are able to life at home (Nijhof, 2013).To reduce those expectations, other solutions are required as the need is increasing (Doekhie et al., 2014). Possibilities for technological applications in the healthcare are increasing. Developments in this area are continuing and with the increasing shortage of staff and the rising costs of healthcare, technologies become more interesting. By making work processes smarter and increasing efficiency, the staff shortage hopefully reduces (de Veer & Francke, 2009). Unfortunately technological applications are not much used yet. Technology can help to let patients with dementia life longer and safer at home (Jansen et al., 2016), so this could be a solution to keep people live longer and safer at home (de Witte, 2008). With this, wishes of patients with dementia- to stay as long as possible at home- can be met (Niemeijer, Depla, Frederiks& Hortogh, 2012).

Technology supports informal and formal caregivers by organizing care efficiently and effectively (Nap et al., 2017). In the last decade, (ambient) technology is further developed. Ambient technology can be integrated in the everyday living context which can support safety and the quality of life of people with dementia(Nijhof, 2013; Nap& Cornelisse, 2015). One example of this is the use of sensors at home to register activities of the resident, so that deviations of the normal pattern can be detected, also called lifestyle monitoring. The aim of this technology is to support safety (Nap& Cornelisse, 2015; Nap et al., 2016; van der Heide, Spreewenberg & Willems, 2011), independency and self-reliance of the resident (Peeters, Wiegers, de Brie& Friele, 2013). Through this technological device the patient with dementia needs less support form a formal or informal caregiver, this makes patients more independent. Further the device ensures that there are less infringements in the lives of people with dementia (Nap, van der Weeg, Cornelisse, Lukkien, van der Leeuw, 2015). Unfortunately these kind of technology is still not used enough according to informal caregivers (Doekhie et al., 2014).

Some technology is not well accepted by the end- user as it is non-user centered design. As a result, adherence is often low (van Gemert-Pijnen, Peters& Ossebaard, 2013). Technologies have a bigger success rate when end-users work together with the developers in the development of technology (van Gemert-Pijnen, Peters& Ossebaard, 2013). It is important to know the problems and bottlenecks of end- users who are facing a problem, this can ensure a more successful technology

application (van Gemert- Pijnenet et al., 2013; de Witte, 2008). Co-creation, in which both developers and end-users are involved in the development phase, can help to increase the success rate of new technological applications(van Gemert- Pijnen et al., 2013). User centered design (UCD) is suitable for this, it ensures that end- users can influence the design process (Abras, Maloney-Krichmar& Preece, 2004). It is important to take the needs and values of different stakeholders into account, this can be translated in important functionalities (van Gemert- Pijnen et al., 2013). When the end users are involved in an early stage the acceptance of the technology will be higher and there will be more willingness to use the newly developed solution as their needs, barriers and expectations are taken into account (Willems, 2017). To ensure that technology will be accessible, applicable, manageable, enjoyable and feasible a holistic approach like the CeHres Roadmap (van Gemert- Pijnen et al., 2013) can be used. It is important to gain insight into the needs, barriers and expectations of stakeholders to make sure lifestyle monitoring solutions solve the actual problems in caregivers face. Prior studies showed different outcomes on the effectiveness of lifestyle monitoring technology (Nap et al, 2017). Therefore, more research about the needs and barriers of (informal) caregivers of lifestyle monitoring, with respect to the care of patients with dementia living alone, is required. So the purpose of this study is to gain insights in the needs and barriers of informal and formal caregivers concerning lifestyle monitoring for patients with dementia who are living at home.

1.1 Dementia

Dementia is a collective name for several diseases. It is a syndrome that is caused by the appearance of physical changes in the brain. Those physical changes lead to a situation in which it is no longer possible for the brain to process the information in the correct way, this causes difficulties with memory, language, problem-solving and other cognitive skills. These cognitive changes negatively affect the ability of performing everyday activities. In short, dementia is a disease whereby a person suffers from a serious loss of cognitive ability apart from the normal expected aging process. (Alzheimer's association, 2017;Meiland et al., 2012; Wimo & Prince, 2010)

The change to get dementia is one out of five, where women have a higher risk than men to get the disease. There are several risk factors for dementia, but the biggest risk factor is age. The older a person gets, the larger the risk. Most dementia patients are 65 years or older, but there is also a small group of people who suffers from dementia at a younger age (Alzheimer Nederland, 2017). There are four main types of dementia, these types are vascular dementia, frontotemporal dementia, Lewy-Body- dementia and Alzheimer. Vascular dementia is characterized by damaged blood vessels in the brain. Many people with vascular dementia have a history with cardiovascular disease. The brain damages cause different symptoms by vascular dementia as different parts of the brain can be affected by this disease. The symptoms depend on the area’s in the brain that are damaged, some examples of possible symptoms are memory problems, speech problems, swallowing problems or paralysis. (Dirkse& Petit, 2016).

Frontotemporal dementia is characterized by affected nerve cells in the frontal lobe. The core characteristics of this disease are impulsive and compulsive behavior. When the disease progresses other changes can occur, such as passivity, emotional indifference, impairment of language skills, problems with speech and memory problems (Dirkse& Petit, 2016).

Lewy- Body- dementia is characterized by an abnormal buildup of proteins into deposits. This disease usually begins with attention and concentration disorders. Periods of normal functioning alternate with periods of memory disorders.

Alzheimer is characterized by nerve cells in the brain which do not function properly anymore. This is the most common form of dementia, this accounts for 60 to 80 percent of all cases (Alzheimer Nederland, 2017). The progression of the disease and the pattern of deterioration differs from person to person. Periods of fast and slow cognitive decline alternate unpredictably (Gezondheidsraad, 2002). The process of Alzheimer can be explained on basis of the three phases of Alzheimer. This will provide insight in the process of the disease and the impact on the person self and their caregivers. The first phase is "early dementia", in this phase small changes in the behavior are observable, also called Mild Cognitive Impairment (MCI). People in this stage have problems with their cognitions, this is due to the fact that the quality of the short-memory is reduced. In this phase those people are often able to compensate their inability of cognitive decline. They often start using a notebook or agenda for example. Many people who are developing dementia are realizing that their memory starts letting them down. These people are not diagnosed yet with dementia, but they are concerned about those cognitive changes (Alzheimer Nederland& Vilans, 2013). The awareness can already occur before the diagnose dementia is established. People react in their own personal way when they realize it, some of them make jokes about it and others will deny it. When the person or his/her environment notices the first subtle changes, they often inclined it to a “normal” aging process. Only when it takes someone a lot of effort to perform daily activities or when they forget recent events and conversations, the realization, usually through bystanders, arises that it could be more than only “normal” aging process. Often people realize this when they have difficulties with speaking, understanding new ideas and making decisions. They also lose their interest in other people and activities (Alzheimer Nederland, 2017). In this phase the person with dementia experiences sadness and fear because they notice the impact of the disease, they have to learn how to life with the disease (Alzheimer Nederland, 2013). People who are suffering from dementia experience a strong loss of the quality of life, on average 71 percent. These people are suffering from personality changes and they are losing their self- reliance (Alzheimer Nederland& Vilans, 2013). But despite these changes, the personal hygiene and the judgment of the patient is still sufficient to life independently at home (Alzheimer Nederland, 2017).

In the second phase, "advanced dementia", the impact gets more obvious. This is caused by the fact that the long term memory is affected in this stage, the memory becomes every time a little less. The self- reliance reduces. Table 1 shows an overview of this stadium with the symptoms and effects through the progression.

Table 1

Overview of the second phase of Alzheimer: ”Advanced dementia” (Alzheimer Nederland, 2017)

Stadium	Symptoms	Effects/ consequences
Advanced Alzheimer	Disoriented in own environment. Difficulties with recognizing people. Deterioration of repeating and forgetfulness. Aggressive, suspicious unusual behavior or mood swings (earlier	More help with the daily activities for the person, like eating and washing. Through this deterioration it is sometimes risky to life independently, so (limited) supervision is needed (Alzheimer Nederland, 2017).

	upset)
	Disrupted sleep and wake pattern

In this phase there is often a suspicion of dementia, therefore diagnostic research will be carried out. The diagnostic research includes complete disease- and care diagnostics. This is necessary due to the nature, progression of the disease and the impact on daily life. Diagnostics provide the desired clarity for the patient with dementia and at the same time it forms the input and it ensures required treatment and care are updated if needed. Often case management starts at the same time as the diagnostic process (Alzheimer Nederland& Vilans, 2013). Case managers are nurses who have a lot of knowledge about dementia. They need to function as a central professional who guides the patient with dementia and the informal caregiver in the different phases of the disease. In many healthcare organizations, a specific nurse has been hired in this role. Exceptionally nurses perform this task next to their regular tasks. The aim of the deployment of case management is to allow the patient with dementia to live in his own environment as long as possible. Case management needs to make sure that there is more cohesion, alignment and continuity in the regional dementia care. The case managers are crucial in the care chain. The case manager needs to assist with problems and concerns of the person with dementia and their caregivers. Such things as ambiguity about the possibilities of care and guidance, uncertainties about the progression of the diseases, the overload of caregivers and miscommunication between different involved people (Leidraad Ketenzorg Dementie, 2009; Peeters, et al., 2012). The aim of the diagnostic process is to minimize the period of uncertainty so that a forecast can be drawn up and treatment, guidance and support can start. This is important as many people with dementia get the diagnosis and receive the necessary help at a late stage.

An early diagnosis may reduce the need of intensive care and the risk of burden for the informal caregivers. Functional and emotional support should be given at an early stage to decrease the burden for the informal caregivers. Early diagnose often allows that people can make important decisions about financial affairs and medical care on time. Further, it gives them the opportunity to get prepared for the emotional and practical changes that will come. This is important because when the diagnose is made, a care plan will be drawn up with all the necessary treatment and care interventions. Immediately after the diagnosis dementia, a prognosis is made and a treatment initiated that can slow down the effects of dementia and help respondents with the (consequences of) dementia. This means that a conversation will take place with the case manager. A case manager will discuss with the patient who has dementia and his/ her family in which way they can get support to improve the quality of life. One example of this is that the person with dementia can get support from informal and formal caregivers by their basic care and their medication intake at home.

The disease does not only affect the life of the person with dementia, it also affects their families and friends (Nijhof et al., 2013). It effect the personal, emotional, financial and social levels negatively of those people who are involved (Alzheimer Nederland & Vilans, 2013). Especially from family members (informal caregivers) more adaptability is asked in this situation. One of the core issues is the disturbance of communication between the patient with dementia and their informal caregivers. The patient with dementia seems to life in a different world and old meanings are partially forgotten (Wimo & Prince, 2010). Informal caregivers are conducting a process of loss and mourning during the life of the patient with dementia. Step by step they lose a part of the relationship with the patient with dementia. The informal caregivers see that the patient with dementia becomes less like the

person it once was. They lose the trusted role pattern, resilience and equivalence in the relationship, mutual support, social contacts, the freedom to divide their own time and they lose their common future (Alzheimer Nederland& Vilans, 2013).

In the last phase, “severe dementia", the patients with Alzheimer requires more and more help. The memory loss is big. Table 2 shows an overview of this stadium with the symptoms and effects through the progression.

Table 2

Overview of the last stadium of Alzheimer: “Severe dementia”(Alzheimer Nederland, 2017)

Stadium	Symptoms	Effects/ consequences
Severe dementia	Not recognize objects, people and places anymore. Incontinent of urine and or defecation. Losing the ability to speak. Restless or sad. Angry or aggressive because they do not understand what people ask. No attention for the environment . Eating and drinking problems. Reaction on voices is low. (Alzheimer Nederland, 2017; de Rijdt, 2017; Meiland et al., 2012)	Gradually the person becomes completely dependent of other people

As a result of the progression of the disease, informal caregivers already distance themselves from the patient with dementia before the patient dies, this is called anticipatory mourning process. This process is accompanied by profound and confusing emotions, as the patient with dementia has not died yet. The process of saying goodbye and mourning for the informal caregivers starts long before they lose the person physically to death (Alzheimer Nederland, 2017).

The care path of the patient with dementia is generally long and intensive, from the begin of the diagnose “dementia” until death of the patient with dementia (Peeters, Francke& Pot, 2011). It is known that the overload of informal caregivers increases while the disease progresses. They have an increased risk of getting overloaded or depressed (Alzheimer Nederland& Vilans, 2013). The number of overloaded informal caregivers is big, but despites that, many informal caregivers try to do everything they can to let the patient with dementia as long as possible life in their own familiar environment. Dementia raises the feeling of impotence and deprecation by patients, relatives and formal caregivers. Often the situation confronts them with vulnerability and ultimate uncontrollability of life. Eventually the life’s of the informal caregivers will entirely be about the disease (Gezondheidsraad, 2002).

1.2 Changes in dementia care

To be able to cope with the increase of the number of patients with dementia and increasing care costs, it is important that the government is prepared for the future. They need to look at new possibilities that improves the lives of patients with dementia and their caregivers (Wimo & Prince, 2010). So to be prepared for this situation, the independence and the quality of life is one of the focus areas of the government. It is their intention to let people stay as long as possible in their own homes. In 2014 a care law was changed because of this. This law ensures that more care is moved to extramural instead of intramural care. Which means that more care has moved to the home situation (Schuurman, 2011). In practice, this change means the healthcare costs of patients who receive care but do not need 24-hours permanent supervision will be paid by municipalities (WMO) and health insurers(ZVW). But when clients need permanent supervision, the required healthcare indication needs to change. As a result the care costs will be covered by the central government (Wlz)(Nursing, 2018). Through the deployment of GP's and district nurses the government aims at a situation in which patients with dementia can stay as long as possible at their own homes. These changes manly influence the long-term care. Elderly people are less eligible for nursing homes but they need to stay home independently. To take care of this, they need some kind of support and care. This is because a significant part of this group is characterized by complex situations through multimorbidity. This groups has often a less power to decide their own direction and are highly vulnerable. Often this results in intensive care. When people get intensive care it often affects the relationship between the person and his closest, certainly when it comes to a disorder that influence the cognitive ability, like Alzheimer (Holdsworth& McCabe, 2017).

To deal with these complex issues technology can play an important role. Different organizations, like patient associations, care organizations and professionals, health insurances and the government believe that technology can improve the self-management and the safety of people (Vilans, 2015).

During the past years the development of new technologies to improve the independence and the quality of life of older people has grown rapidly. But for some specific groups, there are specific needs, like dementia patients(Sixsmith, 2006). To increase the independence of this group and to increase the support of caregivers, different technological solutions are tried (Runneboom, 2010). Technical applications can be subdivided in three different categories: controlling the technology by dementia patient themselves, controlling the technology by the caregiver and technology that works automatically (ambient technology). Ambient technology is invisible and intelligent technology that is not noticeable for the resident. One example of this is the use of sensors and detectors, they can interpret situations and when it is needed the sensor will send an alarm to the caregiver (Nijhof, van Gemert- Pijnen, Dohmen& Seydel, 2009).

Through the application of ambient technology the independency, safety and comfort of the dementia patient can increase (Cook, Augusto& Jakkula, 2009). But technology is often unfocused, unfounded or undeveloped in the dementia care sector (Nijhof et al., 2013). Recently a lot of progress is made on in the use of technology to support healthcare for patients with dementia. This kind of technology focused on reducing the need for care of patients with dementia by increasing their ability to cope independently and at the same time it supports the caregivers (Nijhof, 2013).

A lot of technology for patients with dementia and/or their caregivers is available. But not all kinds of technology can be applied in every phase. For example because the technology is no longer useful for the patients with dementia at a certain moment in time.

Technology can help patients with dementia with their symptoms. Often it is necessary to assist patients with dementia by their day- to- day activities and medication intake. This could be done by different kinds of technology. An electronic calendar for example can assist a dementia patient by their day- to day activities. It helps them with scheduling their daily activities, these activities can be created by caregivers (Nijhof, 2013). In certain phases, like early or mid-phase dementia, the people need assistants by their medication intake. Often those people get baxterbags. Baxterbags consist of medication that are packed in one bag per day or per medication intake moment (e.g. at 08:00 A.M.). One bag contains all the medication they need to take at one moment. But at a certain moment, at the end of the early phase or in the mid phase, this tool does not help anymore while a medical dispenser will still be useful. This is a technological device that helps the person by giving reminders on their medication intake. With this device the people get the right medication at the right time (Nijhof, 2013). But also this device loses its helpfulness at a certain moment (late phase) as the patients forgot which actions they need to execute. From this moment a district nurse needs to help the patients with their mediation intake (Domoticazorg, 2017).

There are also technologies that helps patients with dementia with social contact and companionship, like information and communication technology tools (ICT). Apps, video phones, simple mobile phones and robotic toys (which can play games) are some examples of ICT's. In general it has a positive impact on the lives of the patients with dementia and their caregivers. It reduce their limitations (such as memory loss) and it enhances the confidence of the dementia patient (Lauriks et al. 2007).

Next to this there is a wide variety of technology applications that patients with dementia can support with their health and safety. A personnel alarm for example helps patients in the first phases of dementia. A personal alarm is an alarm button in the form of a wrist strap or neck strap. With this alarm people can have direct contact from their home, when they presses the button of the strap, with an emergency center in case of an emergency. Often the personal alarm is no longer useful in the mid phase of dementia. The cognitive decline is so large that the patient is not able to use it anymore, because they forget to wear the strap or after falling the patients are not able to think about pressing the button of the strap for help. A (active) personal alarm can be replaced by sensor technology. Sensor technology help to ensure that a person with dementia can stay longer at home (Peeters et al., 2013), like lifestyle monitoring. So this could be a good solution for the current problems.

Lifestyle monitoring is a sensor technology that monitors and interprets people's activities in their homes. Often this technology consists of different sensors, like bed, window, door sensors etcetera. These sensors detect activity and inactivity (Nijfhof, 2013; Nap et al., 2016). Lifestyle monitoring is an ambient technology that can support people in the care related to dementia. It provides insights in slow changes of the daily lifestyle of patients which are living alone. For the deployment of lifestyle monitoring several sensors need to be placed at different spaces in a house and these sensors register activities of the resident over a longer period. Lifestyle monitoring can provide healthcare professionals which guide the patient with dementia and/ or other informal caregivers insights in the current situation and trends in the person's lifestyle. Without adjusting cameras, the

system offers options for extra monitoring in addition to regular visits. With the help of lifestyle monitoring, a potentially crisis situation can be identified in advance, which makes it possible to intervene in an earlier stage. For example, the system recognizes increased toilet usage due to urinary tract infections, changes in daytime rhythm and sleep disorders. So through early signaling it is possible, also at a distance, to detect crisis situations earlier. Lifestyle monitoring can help with the care of a patient with dementia, partly by providing insights into the daily activities of the patient with dementia and by increasing the potential healthcare network (Nap et al., 2016).

Research has shown that lifestyle monitoring supporting care for the person with dementia and provides an added value for the majority of informal caregivers because they receive more information, which causes for a better respond to situations. Informal caregivers hope to gain insights into what happens when they are not around (Nap et al., 2016). Furthermore, they hope to get global insights into the deterioration and they want to get a warning signal if something happens with the patient with dementia. It turned out that these needs are for a large extend provided by the use of lifestyle monitoring. Informal caregivers indicated that, through the use of lifestyle monitoring, they were able to better determine what the person with dementia says, gained more insight into what happens to the person when they are not around and gained insights into the person's day-night rhythm. Informal caregivers were better able to deal with the person's situation and they were more involved as informal caregivers at distance. The deployment of lifestyle monitoring makes caregivers feel more at ease about the situation of the dementia patient, it also showed that the overload feeling experienced by informal caregivers decreased (Nap et al., 2016). Lifestyle monitoring often provides an increased sense of safety and it reduces the fear and anxiety feelings (Lauriks et al., 2007).

However, it appears that a number of informal caregivers do not have sufficient confidence in lifestyle monitoring. For some caregivers it causes a restless feeling or stress, due to reports that the system gives. In addition, many informal caregivers have the need to be warned by the system in time if something is going on, but it appears that this is not functioning properly. Although most caregivers indicate that lifestyle monitoring contributes positively to the care of a patient with dementia, it is important to notice that a part of them does not experience it is an added value (Nap et al., 2016) . So to improve the quality and the added value of lifestyle monitoring, it is important to get more insights in the needs and barriers of caregivers.

1.3 Opportunities and challenges of technology

Technology offers new possibilities for healthcare professionals and the patients. It is generally assumed that technology can strengthen the patient’s position, more control over his/ her own life and leads to greater self-reliance (NPcF, 2009). But the most important thing is the culture change, with the healthcare provider, the coach and patient will become the co-therapist. A potential positive effect is that a more equal relationship can arise as the patient has a lot of information. So the difference in knowledge between the therapist and the patient will reduce(NPcF, 2009).

Some studies show significant improvements in the field of securities on behavior (less falling down) and the quality of life for both caregivers and patients with dementia. For caregivers technology makes life easier, it leads to time-saving, independence and less depressive feelings. Besides this the user satisfaction of the different technologies are good, they have proven to be easy in use (Nijhof et al., 2009).The application of technology would improve the quality of care, contribute to a more stable

health condition of the patient and it can prevent exacerbations. Different forms of technology can promote the independence and self- reliance of people. Hospitalization can be avoided and the demand of professional care can decrease (Peeters et al., 2013).

Despite these positive aspects of the deployment of technology, there are also risks involved with the use of technology which need to be taken in account. Privacy, or rather, "privacy violation" becomes an important ethical argument against the use of technology in health care. In addition, it makes quite a difference whether it is technology that the patient uses himself, for example, contact with a healthcare provider or to transmit data to a central database. The question is how far (professional) care may be, or must, penetrate the daily lives of patients. Continuous control can give patients a safe feeling, but it is the question of whether control is not at the expense of privacy and personal responsibility (Brandsma, 2009).

The impact on the quality of life of patients with dementia and employee disability is lower as expected (Nijhof et al., 2009). One of the reasons for this is technology is often technology- driven. This means that technology often is developed from a technical or medical point of view instead of cognitive models of the intended users and their personal or occupational contexts. So it is better that technology is user- driven. This means that the users are involved in the design process. This will improve the acceptance, enhances usage and user satisfaction. Through this approach the implementation of a technology is more successful (van Gemert- Pijnen et al., 2013). Next to this there are often ‘access’ and ‘motivational’ barriers that negatively influence the uptake of technology. To overcome these barriers, needs, motivational factors, social- cultural contexts and profiles of different population groups need to be taken into account. This can make technology a success (van Gemert-Pijnen et al., 2013). Co-creation with end users in the development can help with this. Co- creation ensures that technology will be developed with the end users instead of developing it for the end users. User centered design is suitable for this, it ensures that end- users can influence the shape of a design (Abras et al., 2004). Therefore it is important to take the needs and values of different stakeholders into account, this can be translated into important functionalities (van Gemert- Pijnen et al., 2013). When the users are involved the satisfaction will be higher and the more tend there is to use it as the needs, barriers and expectations of different stakeholders are taken into account. Therefore it is important to involve the users early in the innovation process(Willems, 2017). To ensure that technology will be accessible, applicable, manageable, enjoyable and feasible a holistic approach can be used. One holistic approach is the CeHres Roadmap, this roadmap is designed to develop new technologies, improving existing technologies and making technologies more effective (van Gemert-Pijnen et al., 2013).

One of the technologies that not yet fulfills the needs of the stakeholders is lifestyle monitoring (Nap et al., 2016). This is a technology that has more potential and options in the future (Nap et al., 2017), but the question is whether this is desirable. To make this technology a success, more research to identify the needs of the people with dementia, their informal caregivers and their formal caregivers is required.

1.4 Aim and scope of the thesis:

Get insight into the needs and barriers of informal and formal caregivers with respect to the care of home living patients with dementia. This study will focus on healthcare situations where lifestyle monitoring could be used to support safety at home and aims to increase the quality of life. The outcome of this study will be a value map to prioritize the values and requirements which fulfill the needs of informal and formal caregivers. This map can be used to determine requirements for lifestyle monitoring at home, to set conditions for technological observations and to get insight in the use of technology in relationship to a platform for informal caregivers.
The following research questions have been drawn up:

1. What are the needs and barriers of informal and formal caregivers concerning lifestyle monitoring of patients with dementia who live alone?
2. What are the requirements of informal and formal caregivers for monitoring technology by patients with dementia who live alone?

2. Methods

2.1 Design

The participatory and agile research approach CeHRes Roadmap (van Gemert- Pijnen et al, 2013) will be performed: the contextual inquiry and value specification. This are the first two cycles of the CeHRes Roadmap. Based on literature about technology that supports dementia patients at home an interview schedule will be drawn up. For this research a qualitative method was carried out, it exist of a semi- structured interview.

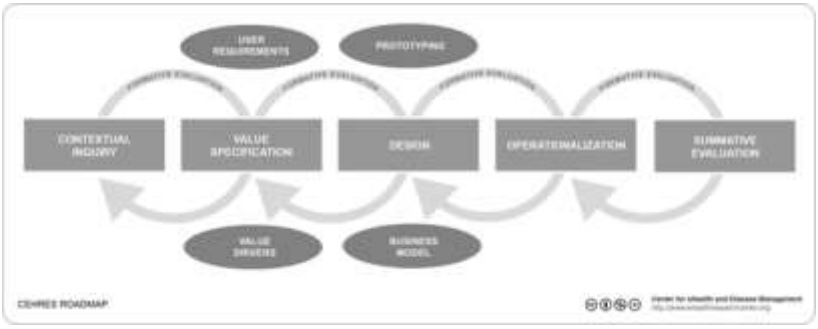

Figure 2. CeHRes Roadmap (van Gemert- Pijnen, et al,. 2011)

2.2 Participants

To get a more representative image of the needs and barriers of informal and formal caregivers, potential participants from six organizations were approached to participate in this research. For this research, case managers (n=4), district nurses (n=6) and informal caregivers (n=7) were approached. A case manager is someone who acts as a central trusted health care professional, with a great knowledge about dementia and the social card. They accompany people with dementia and their informal caregivers in different stages of the disease trajectory (Leidraad Ketenzorg Dementie, 2009). A district nurse is health care professional who helps and take care of sick people who live at home (Van dalen, 2018). An informal caregiver is a person who provide long-term and unpaid care of the

person with dementia. Purposive sampling was conducted, this means that participants are selected for the sample by the researcher. The purpose sampling is a non- probability method, it indicated that the respondents were consciously selected on the basis of certain characteristics (Black, 2010). For this research the network of FocusCura B.V. will be used.
The inclusion criteria were: being a (in)formal caregiver of a patient with dementia who is living alone in the Netherlands. The exclusion criteria were: do not speak or understand the Dutch language, do not take care for a patient with dementia stage one or two and when they are no informal caregiver, district nurse of a case manager.

2.3 Procedure

After the ethical committee of the University approved this study, the network of FocusCura has been used to get in touch with potential participants. This means that the client's (staff members of care organizations/ informal caregivers) of FocusCura B.V. were approached by an email with the question if they are interested to participate in this research. In this email detailed information about the research was given and the informed consent was also included. When the potential participants agreed with the informed consent, the participants were contacted by an email or by a phone call to make an appointment for the interview. Before the interview started, the participants received a short introduction about the purpose of the interview, informed consent was obtained and for recording the interview permission was asked. During the interview questions about the need and barriers of current care and the needs and barriers of lifestyle monitoring were procced. Before questions about lifestyle were asked, everyone read a short introduction about what lifestyle monitoring involves. All interviews are recorded by a voice-recorder. Interviews were conducted with formal caregivers the participating health care organization and each interviews with informal caregivers were conducted at the informal caregivers home and finished within one hour.

2.4 Materials

For this study, lifestyle monitoring has been indicated as: “Lifestyle monitoring provides insight into changes in the daily life patterns of people living alone. Lifestyle monitoring consists of sensor technology that records the resident's activities. This data can be viewed via a computer program”.
For the informal and formal caregivers different interview schedules are designed. The interview schedule of informal caregivers consisted of 27 questions and the interview schedule from formal caregivers consisted of 28 questions The interviews are both semi- structured. The questions related to the interviews can be found in Appendix 1. The interviews for the formal and informal caregivers consist the following categories current experience health care, client safety, client privacy, need and barriers, functional and non-functional needs of lifestyle monitoring. Functional needs focus on requirements related to the technology that is required for a lifestyle monitoring system and non-functional needs focus on the service around the system.

2.5 Analysis

A soon as the interviews were finished, the resulting data were transcribed. The transcribed data was subsequently coded inductively by researcher (LW). This means that interesting quotes were collected and grouped. Based on themes and categories quotes of the collected data were labelled. Inductive analysis categories and themes has been applied until no new codes were found (Baarda et al., 2013).

The categories and themes were discussed with second coder and study supervisor (A.B.) until consensus was reached. When all the data of the interview was analysed the value map with requirements was developed. This has been done based on outcomes of the interviews. User expressions were used to find all values of the caregivers. A value is an ideal or interest of the caregivers. After this all the values were summarized (also called attributes), these attributes are the basis for the lifestyle monitoring system requirements. Requirements are the technical translation of attributes/needs of the caregivers which have been developed by researcher (L.W). The requirements map is based on the requirements development approach of van Velsen, Wentzel and van Gemert-Pijnen (2013).

3. Results

3.1 Informal caregivers

Table 1 shows general information of informal caregivers. In total seven informal caregiver were interviewed. The group consisted out of five females and two male participants. All participants have the Dutch nationality. The average (SD) number of self- reported years they have worked as informal caregiver was 4,7 (2,4) and the average self- reported number of hours per week invested as informal caregiver was 13.9. The mean is calculated based on the information of five informal caregivers as the average number of hours invested was not available for two participants. One of the informal caregivers said that she takes fulltime care for her relative, in the schedule this is displayed with 16 hours. Next to this Table 3 provides an overview of the informal caregivers, the numbers of years as informal caregiver and the average care hours per week.

Table 3
General information of participating informal caregivers

Informal caregiver	Gender	Self- reported number of years working as an informal caregiver	Self-reported average number of hours per week working as an informal caregiver
1	Female	1,5	2,5
2	Female	3,5	n.a.
3	Female	4	16
4	Female	4	n.a.
5	Female	5	21
6	Male	5	21
7	Male	10	9

3.1.1 Frustrations and needs of the current dementia health care

Table 4 shows the frustrations and needs of informal caregivers concerning the current dementia health care. In general, the informal caregivers were satisfied about the professional dementia care their relatives receive. However, there were also some frustrations, like slow doctor referral and superfluous information. Informal caregivers indicated that it takes too long before they receive information or advise from a health care organisation. They often found the information by themselves before receiving an answer from the health care organisation. Other irritations are cutback of supporting services in general and cutbacks of supporting service due to an incorrect assessment of the

relative. Some informal caregivers do not feel supported, they have the feeling that they have to defend the required care, which causes frustration.

Informal caregivers indicated that they need a central contact, for example one (health care) professional who coordinates everything around the care need of their relative. One central contact point ensures them that communication and decision making become less complex. Furthermore, a need is expressed about consultation. Consultation makes it possible to share concerns about their relative and to react on it. Additionally informal caregivers say that they would like to receive reassurance of the well-being of their relatives. Next to this one informal caregiver indicated that she would like to have more freedom without always taking her relative into account. Remarkable is that another informal caregiver indicated that she would like to see an increase in the frequency of medical monitoring of her relative carried out by their general practitioner.

Table 4

Frustrations and needs of informal caregivers concerning current c care

Frustrations of current care	**Quote**
Slow doctor referral	*"Een geriateronderzoek, dat je moet kijken hoe iemand is, dat je daar ik weet niet hoelang op moet wachten en vervolgens dat er dan een advies, dan ben je weer drie maand verder en het duurt allemaal en het duurt allemaal" (respondent 6).*
Superfluous information	*"Ja soms denk je wel van moet ik dat nou weten. Soms bijvoorbeeld dat de wc soms iets vast loopt maar als je na de tijd twee keer spoelt dan is het klaar. Kijk dat hoef ik dan niet te weten."* *(Respondent 7)*
Cutbacks of support services	*"Ik heb nog geen bejaarde gezien die vooruit gaan in zo'n situatie. En dan denk ik van doe een keer zo'n test en kijk wat ze nodig heeft en probeer er niet nog weer een uurtje of een half uurtje eraf te krijgen. En helemaal niet in die doelgroep." (Respondent 6)*
Cutbacks of supporting service due to incorrect image of relative	*"Dan komt iemand van de gemeente en mijn moeder voelt zich eigenlijk nog best trots van dit kan ik allemaal nog en daar wordt ze gelijk op afgerekend. Mijn moeder gaat staan met de rollator en met veel pijn en moeite gaat ze naar de keuken om een koekje bij de koffie te pakken voor diegene van de gemeente en die zegt ow maar dat kunt u nog wel, een half uur eraf. Als iemand zo'n onderzoek heeft gehad, dat iemand daar op getest moet worden vind ik prima maar dat hoeft niet elke jaar. Iemand gaat achteruit."(Respondent 6)*
Needs current care	**Quote**
A central contact point regarding professional care	*Een centraal aanspreekpunt voor alle overkoepelende dingen die je hebt….één persoon alles coördineert (Respondent)*
Consultation formal caregivers	*"Dan ben je wel alleen maar dan heb je wel een sparringpartner in het geheel… Ik merkte wel met de buurtzorg dan is het gewoon fijn dat je met elkaar dingen kunt delen en dan heb je toch niet het gevoel dat je er alleen voor staat en dat is wel heel fijn". (Respondent 2)*
More frequent medical monitoring by general practitioner (GP)	*"De huisarts kan wel wat vaker komen, die zie ik nooit. Hij moet het zien dat ze achteruit gaat maar hij vraagt er verder niet naar." (Respondent 1)*
Reassurance well-being relative	*"Als je 's avonds een keer een blik zou kunnen werpen bij moeder om te zien hoe het gaat… Soms zit je met de gedachten thuis van verdorie ze was niks te best te pas en dat je dan denkt van zal ik even gaan kijken.. maar dan maak ik haar misschien wel weer wakker en dat wil je dan ook weer niet". (respondent 7)*
Freedom of informal caregivers time	*"Als ik weg wil moet ik regelen dat iemand bij mijn man blijft .. Ik zou het wel heel graag een keer willen dat ik niet gebonden aan tijd ben en dat ik zelf kan bepalen tot hoe laat ik weg blijf". (Respondent 3)*

3.1.2 Important insights of relative(s)

Table 5 shows important insights of relatives according to informal caregivers. Informal caregivers indicated that they like to know the well-being status of their relative. Important insights for them are mental health, physical health, eating behaviour and safety. The mental and physical health condition is important information as informal caregivers react differently to their relative when they know about the disease. Safety and eating behaviour where indicated as important insights because sometimes informal caregivers had no idea what is going on by their relative(s).

Table 5

Important insights on relatives according to informal caregivers

Important insights on relative(s)	Quote
Mental health condition	*"Ik vind het belangrijk om te weten hoe hij zich voelt. " (Respondent 3)*
Physical health condition	*"Nu je weet dat ze een diagnose heeft dan weet je ook dat je anders moet reageren en dat is wel heel erg belangrijk… Nu je weet dat ze dement is denk je ja wat heeft dat voor een zin om daar wat van te zeggen. Want daar worden ze alleen maar onrustig van dus dan ga je daar anders mee om en dat is wel belangrijk om te weten." (Respondent2)*
Eating behaviour	*"Of ze haar eten wel netjes op eet en dat soort dingen."(Respondent 7)*
Safety	*"Haar veiligheid dat ik inzichtelijk krijg maar wat ik zo zelf kan bekijken thuis gebeuren er geen rare dingen maar ik weet natuurlijk niet of ze s avonds gaat dwalen."(Respondent 1)*

Most of them only Furthermore, an informal caregiver indicated that clear agreements must be made about possible follow ups based on the outcomes of the system. It is notable that there is no unambiguous opinion about the follow up of the system output. Some informal caregivers indicated that they would do the follow up themselves when there would be an alarm. Others indicated that a health care organisation should do this, one reason for this is that it will not be possible for the informal caregiver to do the follow up themselves at all times. Next to this the informal caregivers indicated that the system needs to be unobtrusive and it needs to support relatives instead of controlling them. Furthermore, there must be restricted access to the monitoring results in relation to the privacy of the relatives. It is particularly important that the system reassures the informal caregivers about their relatives wellbeing and that the system provides tailored information.

3.1.4 Functional and non-functional requirements concerning lifestyle monitoring

Table 6 shows a requirements map of informal caregivers concerning lifestyle monitoring. Informal caregivers indicated that equipment that will be placed at the homes of patients with dementia needs to be unobtrusive because the patients should not get restless due to it. Informal caregivers also indicated that they would like to have a reassurance of the safety and well- being of the relative. This means that informal caregivers only like to get a notification when a relative is inactive for a longer period, when a relative has fallen, wanders, or has nightly outdoor movements. Next to this, they indicated that privacy needs to be guaranteed, this could be done by restricted access to monitoring results. Furthermore, they would like one tailored system, this means that the system is tailored to the wishes of the customer and provides all information needed. The system should be reliable as otherwise it will not be used as users will not trust the outcomes.

Table 6

Values, attribute and functional and non- functional requirements of informal caregivers for lifestyle monitoring

Qoutes respondents	Value	Attribute	Functional requirements
"Mijn schoonmoeder het moet niet voor onrust zorgen. Als er allemaal geluidjes aan gekoppeld zijn.. ze werd daar heel onrustig van." (Respondent 1)	Prevent uneased feeling	Unobtrusive technology	The devices that are present in the homes of the relatives are small and unobtrusive in colour. The system and devices that are present in the homes of the relatives makes no sound and does not emit any light signals
"Het geeft je toch een stukje rust van nou ze wordt in ieder geval in de gaten gehouden en als ze zou vallen dan is er op een gegeven moment iemand die dat in de gaten heeft". (Respondent 2) *"Ik vind het belangrijkste dat ze veilig zijn. Dus die opzicht vind ik het wel interessant dat er inactiviteit gemonitord kan worden". (Respondent 3)* *" Dan zou ik eerder een sensor op de voordeur willen hebben, dat zou de enigste plek zijn en dan de nachtelijke uren dat ze niet 's avond na 20:00 uur op pad gaat want in principe gaat ze 's avonds nooit weg (Respondent 1)* *"Het moet ook een follow- up hebben van ja wat ga je dan met de gegevens doen en wie volgt het.. dat daar wel belangrijke afspraken over zijn." (Respondent 4)* *Ik hoef namelijk niet te weten hoe vaak mijn vader naar de wc gaat". (Respondent 2)*	Guaranteeing safety and well- being of the relative	Reassurance well- being of relative	The system registers deviations in lifestyle pattern of the relatives. Like inactivity, fall incidents and wandering. Informal and formal caregivers get a notification by a worrying deviation in the lifestyle pattern of the relative. The system signalling deviations in well- being of a relative and sent an alert to the caregivers by a worrying deviation
Qoutes respondents	**Value**	**Attribute**	**Non- functional requirements**
"Er moet niet zomaar iedereen op kunnen kijken, dat moet wel binnen beperken blijven natuurlijk. Kijk net als wat ik zeg het moet geen Big Brother worden". (Respondent 1)	Privacy guaranteed	Restricted access to monitoring results	The system data is only available for formal and informal caregivers
"Kijk het moet ook niet zo zijn dat je het gaat gebruiken. Ze hebben ook hun eigen leven." (Respondent 3) *"Dat er een functie is dat je aan en uit kunt zetten." (Informal caregiver 3)*	System needs to support and not controlling the relative	Tailored system	The system is tailored to the wishes of the customer (client and formal caregivers). This means that the system consist of several options that can be used, like an on and off function.
"Nee als nee volgens mij wordt je er alleen onrustiger van als je alles weet … Althans ik kan alle doemscenario's bedenken wat er allemaal fout kan gaan."(Respondent 1)	Receive only relevant information about relative	Tailored information	The system provides asses to relevant information via one interface. Informal caregivers only receive relevant information form the system Formal caregivers can adjust the system setting to your own needs.

3.2 Formal caregivers

Table 7 shows general information of the participating formal caregivers. In total ten formal caregivers, six district nurses and four case managers, participated in the interviews. All participants have the Dutch nationality. Six females and four male formal caregivers participated in the interviews. The formal caregivers had an on average (SD) 3,6 (2,9) years of work experience in the field of dementia care). Table 7 provides an overview of the formal caregivers, their gender and the number of years of experience as district nurse or as a case manager. In table 8 till 13 district nurses will be indicated by respondent group one and the case managers will be indicates by respondent group two.

Table 7
General information of participating formal caregivers

Formal caregivers	Gender	Work experience in years
District nurse	Male	1
District nurse	Male	2
District nurse	Female	2
District nurse	Female	2,5
District nurse	Female	3,5
District nurse	Female	6
Casemanager dementia	Female	1
Casemanager dementia	Male	1
Casemanager dementia	Female	7
Casemanager dementia	Male	10

3.2.1 Important functions of formal caregivers in dementia care

Table 8 shows important functions of formal caregivers in dementia care. Formal caregivers indicate that different aspects provide an added value for them, the client and the clients surrounding in dementia care. Formal caregivers want to give their client the possibility to be themselves, that they feel at ease with them and receive personal attention. It seems that social contact and interaction between formal caregivers and their clients is an essential added value. Next to this formal caregivers guide and support their clients and surroundings in the disease process. Formal caregivers accompany clients and informal caregivers. They provide structure and information where needed. Optimizing mental processing seems to be the most important aspect for formal caregivers in taking care of someone with dementia and their environment as they often have a coaching role

Table 8
Important functions of formal caregivers in dementia care

Added value	Quote
Personal attention to create comfortable feeling client	*"Het belangrijkste vind ik dat hij of zij op het zijn of haar gemak is bij mij. Dat ze open is, dat ze zich zelf durft te zijn." (Respondent 1)*
Confidential advisor	*"Vertrouwen, luisterend oor dat vind ik met dementerende en familie eigenlijk heel belangrijk." (Respondent 1)*
Support clients and their surrounding	*"Het begeleiden en ondersteunen van cliënten en hun netwerk erom heen." (Respondent 2)*
Information provision	*"Goede voorlichting aan de omgeving. Dat ze weten wat dementie is, hoe het in zijn werk gaat, wat er aan te pas komt. (Respondent 1)*
Guiding disease process	*"Ik wandel mee met de cliënt in het proces en hou de kwaliteit van leven voor ogen." (Respondent 2)*
Providing structure	*"Structuur bied, duidelijkheid geven wanneer wat moet plaatsvinden." (Respondent 1)*

3.2.3 Frustrations and needs of the current care

Table 9 shows the frustrations and needs of formal caregivers in the current care process. Despite the fact that formal caregivers are satisfied with the care they can provide, they also run into some barriers of the current care system. One of the remarkable things is bureaucratic care. Formal caregivers are now running into the fact that their clients have to stay longer at their home, which sometimes causes them to get entangled in the insurance laws. The formal caregivers are obliged to change health indication when a client needs more intensive care. This has major consequences for their client, often the costs increase for the clients as the care they need to receive is no longer sufficient. Furthermore, it has been indicated that there is a shortage of staff and formal caregivers are sometimes lacking specific knowledge about dementia.

So, to improve dementia care the formal caregivers would like to have better cooperation with other disciplines and one tailored system where all kinds of disciplines come together so make communication easier and quicker. Remarkable is that formal caregivers would like to deploy innovative systems or devices at their clients but often it is too expensive for a client to use the technical device. One of the reasons for this is that some devices can only be used in certain dementia stages. When the clients disease progresses, the devices are no longer sufficient. Formal caregivers would like to get a reimbursement for innovative start- up systems or devices so that deployment becomes easier. Furthermore, formal caregivers indicated that they need standardized transfer form, better knowledge facilitations like training about the disease and a tool overview.

Table 9
Frustrations and needs of the current care indicated by formal caregivers

Frustrations current care	**Respondent group**	**Quote**
Bureaucratic care	1& 2	*"Als ik een indicatie voor iemand moet aanvragen omdat die uiteindelijk moet verhuizen dan is een van de consequenties dat iemand een eigen bijdrage moet gaan betalen. Vaak zijn de wachtlijsten lang en op het moment dat iemand een indicatie heeft kunnen er misschien minder zorguren ingezet worden dan dat ze nu krijgen." (Respondent 2)*
Short of staff	2	*"Het is een landelijk probleem dat er een te kort is aan wijkverpleegkundigen en verzorgenden." (Respondent 2)*
Lack of specific knowledge	1	*"Ik heb tijdens de opleiding vast wel iets een keer over casemanagement gelezen of gehoord maar ik heb daar verder niet voor geleerd."(Respondent 1)*
Needs current care	**Respondent group**	***Quote***
Better cooperation with other disciplines	1	*"De samenwerking met de verschillende disciplines, dat zou ik graag verbeterd zien." (Respondent 1)*
One communication system	1& 2	*"Ik kan niet wachten op OZO; een communicatiesysteem waarin de cliënt centraal staat en daar voeg je de mantelzorgers en andere disciplines toe en daarin kun je communiceren " (Respondent 2)*
Reimbursement for innovative start-up systems	1& 2	*"Zonder geld kom je niet aan een systeem… Bijvoorbeeld met een vergoeding van de zorgverzekeraar." Respondent 2)*
Standardized transfer form	1	*"Het zou fijn zijn als er een gestandaardiseerde overdracht is voor voorgeschiedenis ect." (Respondent 2)*
Facilitating knowledge	1& 2	*"Als wij nog meer gespecialiseerde kennis krijgen dat kun je ook beter aansluiten bij de patiënt." (Respondent 2)*

3.2.2 Functional and non-functional requirements concerning lifestyle monitoring

Table 10 shows a requirements map of formal caregivers concerning lifestyle monitoring. In general a lot of values of informal and formal caregivers match, like unobtrusive, reliable and one tailored system. Next to this, both groups indicated that privacy is very important, but the content is different. Remarkable is the difference between informal caregivers and formal caregivers concerning the most important requirement. Informal caregivers indicated that they only want to receive confirmation that everything is going well with their relatives, they do not need more information. Formal caregivers, on the other hand, would like to be provided with more information about the patients. The system needs to support the caregivers by signalling deviations in lifestyle patterns of the patient, like deviations in daily activities to make sure that formal caregivers can provide better care. In the end the formal caregivers would like to use the system as a diagnostic instrument. Formal caregivers also indicated that the system needs to be user-friendly, the interface of the system plays an important role in the user- friendliness of the system. Furthermore, formal caregivers are concerned about the responsibility over the system, who will be responsible for what and where stops the responsibility. So clear agreements about who is responsible for want must be made.

Table 10
Values, attribute and requirements of formal caregivers for lifestyle monitoring

Qoutes respondents	Value	Attribute	Functional requirements
"Ik moet inzicht hebben in het activiteitenpatroon wat doet iemand 24 uur per dag, nu levert het vaak alleen maar vragen op waar niemand een antwoord op weet." (Respondent 2) *"Monitoren of iemand heel onrustig is over de dag, dat zou ik dan ook graag willen weten als dat afwijkt." (Respondent 2)* *"Ik wil weten wat iemand eet." (Respondent 2)* *"Het moet ondersteund zijn, daar ben ik heel scherp in want als het echt bepalend is dan is het niet goed… Niet van u heeft 7 dagen in uw bed gelegen of u heeft 4 keer op de grond gelegen want dat kunnen we aantonen en dat dan op basis daarvan iemand oppakt en laat verhuizen. (Respondent 1)* *"Het enige wat misschien wel zou kunnen is dat ze gaan controleren hoe vaak wij daar bijvoorbeeld over de vloer komen of hoe goed wij ons werk doen." (Respondent 2)* *"Het moet ondersteunend zijn dus niet veel valse meldingen, het moet maatwerk zijn op de cliënt." (Respondent 2)* *"Bij iets echts afwijkends, bij een risico op een afwijking. Ik wil niet bij elk*	Supporting system not a controlling system of clients or caregivers	Reliable diagnostic instrument	The system provides information about the health and well- being status of the clients. It supports the caregivers by signalling deviations in the health and well- being of the clients and it sent an alert when necessary. The system provides information about the activities that the patient with dementia carries out and does not generate false alarms. The system must offer the possibility to use camera images during an incident, but this option depends on wishes of the client.

wissewasje op de hoogte worden gebracht". (Respondent 2) *"Camerabeelden alleen toegankelijk als er een incident is." (Respondent 2)*			
"De cliënt moet er in ieder geval geen last van hebben."(Respondent 2) *"Het moet niet kwetsbaar zijn ander is het zo stuk." (Respondent 2)* *"De privacy voor de cliënt moet in acht genomen wordt en dat mensen zich niet bekeken en bespied voelen." (Respondent 2*	Prevent uneased feeling	Unobtrusive technology that is hufterproof	The devices that are present in the homes of the relatives are small and unobtrusive in colour. The system and devices that are present in the homes of the relatives makes no sound and does not emit any light signals
"Groen is goed, iets wat afwijkends is oranje en iets wat urgent is rood." (Respondent 1) *"Het mooiste vind ik wel met grafieken dat je het beloop kunt zien van dingen." (Respondent 2)*	Clear and traige data	Clear system display	The system provides a clear overview of all collected data. Triage of the data is important. The system shows graphs with observed activity of clients The system indicates urgent and not urgent with different colours.
"Verder zou ik het dan wel mooi vinden als dat portaal waar het op binnenkomt niet weer een los systeem komt maar dat het allemaal geïntegreerd kan worden met een systeem." (Respondent 1)	All information about the clients is together	Integration data in one system	All information relevant to the care of the relatives/ client has been integrated into one system.
Qoutes respondents	**Value**	**Attribute**	**Non- functional requirements**
"Het moet niet dat andere daar wat mee kunnen, het systeem moet heel veilig zijn." (Respondent 1) *"Privacy is wel een belangrijk onderwerp daarin omdat je te maken hebt met mensen die zelf niet altijd even goed voor zichzelf op kunnen komen, het ook niet kunnen overzien en inschatten wat de consequenties zijn. " (Formal caregiver 2)* *"Als het allemaal maar zorgvuldig gebeurd en met al die data wat doen ze daar mee?" (Respondent 2)* *"De privacy voor de cliënt moet in acht genomen wordt en dat mensen zich niet bekeken en bespied voelen." (Respondent 2*	Guarantee privacy	Secure system	The privacy of the client's is guaranteed. The information and monitoring data of a client is secure.
"Ik wil niet dat het de persoonlijke aandacht weg gaat nemen bij cliënten." (Respondent 1) *"Ik wil niet zeggen dat het altijd werk verminderd. Ik denk ook dat je daardoor extra dingen gaat zien en dat het dan alleen maar meer wordt." (Respondent 2)*	Retains personal contact and workload	Supported system	The system supports the formal caregiver in his work. It does not replace the personal contact and it does not increase the workload.

Wat vinden mensen daar zelf van en wat en welke keuze hebben mensen hier zelf in wat gemonitord wordt." (Respondent 2) *"Als cliënten zeggen van ik wil het niet mijn privacy wordt zo ontzettend aangetast." (Formal caregiver 2)*	Freedom of choice	Tailored system	The system is tailored to the wishes of the customer (client and formal caregivers). This means that clients can choose which options there will be used and which option will not be used.
"Dat er onderscheid word gemaakt voor wat voor jou relevant is, je hoeft niet alles te zien." (Respondent 1) *"Wanneer is het de verantwoordelijkheid van wie om actie te ondernemen op die meting… Ik vind het wel een discussie met hoever ga je in acties en in hoever laat je iemand zijn eigen leven lijden tot dat het spaak loopt." (Respondent 2)*	Receive only relevant information about clients and clear agreements are made about responsibility	Tailored information	The system provides asses to relevant information via one interface. Formal caregivers only receive relevant information form the system. Formal caregivers can adjust the system setting to your own needs.

3.2.2 Needs for implementation lifestyle monitoring

Table 11 shows the needs of formal caregivers during the implementation of lifestyle monitoring. In order to implement lifestyle monitoring successfully, there are some adjustments required for the client and formal caregivers. The amenities at the homes of the client need to be improved to make sure that the system can function properly. Next to this it is important that formal caregivers get technical support and more knowledge about the system. For example they need to know how the system works and what is monitored.

Table 11
Needs by implementation of lifestyle monitoring concerning formal caregivers

Needs for implementation lifestyle monitoring	Respondent group	Quote
Amenities at clients home	1& 2	*"De voorzieningen in huis, want in de wijk is het zo langzamerhand op orde." (Respondent 3)*
Technical support	1	*"Denk dat het technische wel allemaal heel goed afgeschermd moet worden en in principe moet je dan koppelingen gaan maken, zou het wenselijk zijn dat je koppelingen maakt naar je ECD."(Respondent 2)*
Knowledge about lifestyle monitoring	1& 2	*"Ik moet heel goed weten wat voor techniek is het, wat doet het, want als mantelzorgers mij vragen van hoe werkt het? Dat wil ik dan exact weten want anders ga ik het niet doen." (Respondent 3)*

3.2.3 The added value of lifestyle monitoring

Formal caregivers indicated that lifestyle monitoring can certainly help to improve the quality of care and the quality of life. They expect that their work will become more preventive and at the same time more efficient as they have earlier insight. Formal caregivers indicated that it will reduce the restless feeling by clients as formal caregivers have to ask and check them less often. Table 12 shows the possible added value of lifestyle monitoring according too formal caregivers.

Table 12
The added value of lifestyle monitoring according to formal caregivers

Added value of lifestyle monitoring	Respondent group	Quote
Improved well-being/ improvement quality of life	1& 2	*"Ik denk dat ik er alleen meer dingen uit kan halen waardoor ik nog beter acties uit kan zetten om iemands welzijn te bevorderen." (Respondent 2)*
Improvement quality of care	1& 2	*"Als je door leefstijlmonitoring bepaalde problemen inzichtelijk kunt krijgen kun je daar ook adequaat in handelen en in dus in die zin kun je daardoor de kwaliteit van leven verbeteren." (Respondent 2)*
Preventing health deterioration	1& 2	*"Je krijgt iets meer zicht op het dagelijkse leven en daardoor kun je misschien preventieve maatregelingen nemen." (Respondent 3)*
Providing more efficient care	1& 2	*"Het eerder signaleren van problemen denk ik en ook niet problemen. Ik denk echt het vroegtijdig in kaart brengen. Dat je ziet van waar liggen de problemen of waar liggen niet de problemen." (Respondent 2)*
Reduce restless feeling	1& 2	*"Dat ik wat meer onrust weg neem dat ik iets meer, dat ik sommige dingen niet meer hoef na te vragen." (Respondent 2)*

3.2.4 Notification of lifestyle pattern

Table 15 shows how formal caregivers would like to receive a notification from the system. In conclusion, it can be said that the options of how formal caregivers would like to receive non- acute notifications from the system are diverse. It is indicated that they want to receive it per SMS, care file or by E-mail. However, it is clearly indicated that formal caregivers would like to be contacted through a phone call when there is an acute notification.

Table 15
Receiving a notification meant for the formal caregiver

Receive notification	Respondent group	Quote
SMS for non-acute notifications	1& 2	*"Die zou je nog wel gewoon als een berichtje op je telefoon krijgt kunnen kijken van houdt het langer aan of is het eenmalig." (Respondent 1)*
Care file for non-acute notifications	1	*"Kijk als je het digitaliseert dat het dan automatisch bijvoorbeeld in het ECD onder een bepaald kopje er bij komt staan."(Respondent 1)*
E-mail for non-acute notifications	1& 2	*"Dat je het per mail krijgt." (Respondent 1)*
Phone call	1& 2	*" Via de telefoon. Mooiste is nog een telefoon oproep dat zie ik." (Respondent 1)*

4. Discussion

The goal of this study was to identify the needs and barriers of informal and formal caregivers concerning lifestyle monitoring for patients with dementia who live at home. Based on the needs and barriers a requirements map is created.

This study revealed that informal caregivers mainly want to be reassured about the well- being of their relatives, formal caregivers want more and richer information about daytime activities of their clients. Both groups also clearly emphasized that they do not want to be harassed unnecessarily with information that is not relevant.

Lifestyle monitoring needs to monitor, detect and report deviations in activities in the life of patient with dementia by unobtrusive and reliable technology. The largest barriers for lifestyle monitoring are guaranteeing patients privacy, the expected increased workload for formal caregivers and the reliability of the system. These barriers need to be taken into account, otherwise the willingness of using the technology will decrease. This result corresponds to the findings of Nijhof et al. (2013). This study empathized that the system needs to adjust properly, it may not generate false alarms. When the system generates false alarms, the confidence of using the system will be under mind as the reliability of the system decreases (Nijhof et al. 2013). This means that the system should only send important and correct notifications to informal and formal caregivers. When reports are not properly coordinated, unnecessary reports are generated which will result in unnecessary worries (Nap et al., 2016). Therefore reliability is an important requirement of a lifestyle monitoring system as it affects the usage.

This study emphasized that patients may not be bothered by the lifestyle monitoring system. An unobtrusive system can help with this. This means that the system may not emit any sound or light signals, this result is in line with the study of Nijhof et al. (2013). They stated that patients with dementia accept small sensors within the home quite quickly and that they are often unaware of it. When the patients are aware of it, it gave them a sense of safety and security as they know that caregivers will respond if there is a notable deterioration in the lifestyle (Nijhof et al. 2013). The main point is that the system does not attract attention from patients.

This study clearly pointed out that confirmation of the well- being status of relatives is the most valuable information for informal caregivers. This implies receiving a notification when there is a deviation, without knowing the exact activities from their relative. Informal caregivers expect an increased unease feeling when they know all daily activities of their relatives. This expectation can be caused by the fact that currently the informal caregivers do not have visibility on all daily activities of their relative. Lifestyle monitoring makes it possible to monitor people 24 hours a day and provides more visibility. Relatives can no longer hide from their informal caregivers. A possible result of lifestyle monitoring can be that it becomes clear that patients are no longer able to live on their own without 24- hours supervision. This visibility can cause an uneasy feeling by informal caregivers. This expectation does not match with the experience of informal caregivers in the research of Nap et al. (2016). In the study of Nap et al. (2016) it appears that informal caregivers are supported, reassured and confirmed of the situation when lifestyle monitoring is used. Informal caregivers are able to respond better to situations through relevant information that is collected by lifestyle monitoring. This difference can be explained by the different stages of dementia. In this study, only informal caregivers

were interviewed whose relatives receive home care several times a day. In the study of Nap et al. (2016), the group of informal caregivers was more diverse as the informal caregivers took care of patients in different stages of the disease.

This study emphasized that formal caregivers want to use lifestyle monitoring as a diagnostic tool. Formal caregivers expect that lifestyle monitoring will contribute to improve the quality and efficiency of care. This expectation is in line with the findings of Nijhof et al. (2013). Formal caregivers belief that lifestyle monitoring contributes to a decrease in the need for hospital visits and delaying admittance to a nursing home as it provides a more holistic picture of the health and well- being of the patient with dementia. This expectation can be explained by the fact that lifestyle monitoring makes it possible for formal caregivers to get access to information they had no access to before, this allows the deployment of more efficient interventions(Nijhof et al. 2013). Formal caregivers normally obtained their information through (health) care visits, whereby it is hard to get a good insight in all daily activities. Lifestyle monitoring allows formal caregivers to identify deviations earlier as it fills the daily gaps. In this way lifestyle monitoring can contribute to a more efficient care process.

One of the biggest problems that has been shown in this study is that formal caregivers get into problems with the required healthcare indications if a patients wants to stay at home but need 24-hour permanent supervision. Patients, informal and formal caregivers get into problems as there is no maximum budget per person at the Zorgverzekeringswet (ZVW) and Wet maatschappelijke ondersteuning (WMO), but in the Wet langdurige zorg (Wlz) there is a fixed budget for each patient. As a result, patients receive less care than they actual need while the need for care is more urgent than before. de Jonge (2018) indicated that the majority of patients can receive sufficient professional care with the budget of the Wlz, but there are patients for whom this budget is insufficient. These patients can be confronted with a decline in healthcare hours during the transition to the Wlz. In this situation, informal and formal caregivers need to provide the care demand in other ways. This contributes to unsustainable situations at home where district nurses can no longer meet the needs of their patients (Nursing, 2018). Lifestyle monitoring can support informal and formal caregivers in providing the care demand in other ways (Nap et al., 2017) The study of Nijhof et al. (2013) stated that lifestyle monitoring has the potential to deliver more personalized care and that it achieves cost savings compared to the costs of staying in nursing homes.

This study is bases on practical experience of respondents. Informal caregivers, district nurses and case managers were interviewed, they are the most important people in the healthcare process of patients with dementia who are living at home. Therefore it complements the existing literature on lifestyle monitoring. The sample size of this research is small with seven informal and ten formal caregivers. The group of informal caregivers with family members suffering from dementia is much more diverse than presented in this study due to the different stages of the disease. The disease stages of the dementia patients in this study where quite the same. This study does not reflect the entire target group of caregivers taking care of dementia patients. As a result full amount of needs and barriers of all caregivers involved in dementia care can be broader than indicated in this study. This means that the generalizability of this research needs to be carefully addressed as this research clearly reflects the needs of a specific part of the target group. Next to this, not all important stakeholders where involved in this study (patients, other indirect caregivers, managers of health care organizations and health insurance companies), they might have additional needs and barriers concerning lifestyle monitoring .

The outcomes are mainly focused on healthcare related to dementia patients in the later stages of disease. This indicates that more research is required to improve the accuracy and generalizability of the results of the entire population of caregivers of patients with dementia. More identical qualitative research with all stakeholder in a larger sample size will help to verify the results and to find out if there are additional needs and barriers related to different stages of the disease. The expectation is that caregivers of patients with early dementia have less or different needs than caregivers of patients with advanced or severe dementia. In this way the values and requirements will be substantiated to a larger extend. By intervening the values and requirements in the further development of future lifestyle monitoring will enhance usage, also the user satisfaction and acceptance of all stakeholders will improve as a result of this, this will improve the changes on a successful system implementation (van Gemert- Pijnen et al., 2013). Furthermore, a strong aspect of this study is that two formal caregivers had experience with lifestyle monitoring, they can base their responses on their experience instead of their needs. Next to this there may be some researcher bias. The coding of the data has been done by one researcher (L.W). To prevent as much researcher bias as possible, the coded data was discussed with the second researcher (A.B.) until consensus was reached.

4.1 Further research

With this study a start has been made further development of lifestyle monitoring that is user-centered designed. The outcomes supports companies that focus on the development of lifestyle monitoring. This study has developed requirements for lifestyle monitoring based on the information received from formal and informal caregivers. This value map makes it possible to develop a lifestyle monitoring system that satisfies needs of the end-users.

For further research a number of suggestions can be given. In this study only two important stakeholders are asked about the needs and barriers concerning lifestyle monitoring. Therefore the most important field for further research is to approach all stakeholders (patients, other indirect caregivers, managers of health care organizations and health insurance companies) for participation in a Delphi study to verify the requirements map. A Delphi study makes it possible to reach consensus about the requirements concerning lifestyle monitoring. This will lead to a better adoption of the lifestyle monitoring system as it is user- centered designed. Afterwards it is important to test whether this user-centered designed system meets the users' needs as expected. This could be done by quantitative research, like a usability survey. By collecting these opinions it might be possible to determine for which stakeholders lifestyle monitoring is an added value and for which is not.

This study emphasized that caregivers expect positive effects of the efficient and the quality of care when lifestyle monitoring is used. However, there is no clear evidence of this yet. Therefor it may be interesting to carry out longitudinal research that focuses on those effects once lifestyle monitoring is deployed by patients with dementia.

Technology can create new opportunities in providing care. The workload for formal caregivers can decrease when technology is applied. In the case of the deployment of lifestyle monitoring this does not seem to be the case. The workload probably increases when there are no clear agreements about lifestyle monitoring as caregivers will receive more information of the patient with dementia than before. Given the expected shortage of healthcare staff it is important that the workload does not increase. Therefore it is important that further research focuses on how the system can

support formal caregivers as much as possible and identifies which new agreements about the responsibilities of formal caregivers should be made. This applies in particular to signalizing a deviation and follow-up of an alarm that was triggered by the system.

As a conclusion, informal caregivers and formal caregivers emphasize that lifestyle monitoring could have an added value in the dementia care when the system monitors, detects and reports deviations in activities in the life of the patients. Next to this, the technology needs to be unobtrusive and the privacy of the patient with dementia needs to be guaranteed. Otherwise, the willingness to use lifestyle monitoring will decrease. Further research needs to focus on verifying the requirements map with additional stakeholders. When lifestyle monitoring will be developed from a user centered point of view instead of a technical point of view it can support the caregivers in the dementia care when the retrenchment in health care sector and staff shortage continues. Additionally, it is important that the maximum budget will increased so that the necessary health care for everyone can be delivered at home. So with these adjustments it is possible to overcome the bottleneck of the increased number of patients with dementia and the current shortage of professional healthcare givers in combination with the governmental focus to let these patients stay at home as long as possible.

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6. Appendix

Appendix 1: Table of interview questions for informal and formal caregivers

Table 1

Interview questions for informal caregivers

Algemene vragen functie/ taken

1. Wat is uw functie?

Algemene vragen over de zorg rondom een dementerende cliënt

2. Wat vindt u van de huidig zorg dat de organisatie levert aan dementerende cliënten?
3. Wat is er nodig om de kwaliteit van uw dementerende cliënt te optimaliseren? Noem een voorbeeld..
    - Waarom lukt dat nu wel en niet?
4. Wat heeft u nodig om de zelfredzaamheid van dementerende cliënten te vergroten? (waarom, wanneer?)
5. Wat heeft u nodig om veiligheid van dementerende cliënten te kunnen waarborgen?
    - Wat gaat er nu goed en wat gaat er niet goed?
    - Wat zou u willen? (waar bent u bang voor?)
6. In hoeverre wordt er bij het waarborgen van de veiligheid binnen uw organisatie rekening gehouden met de privacy van de cliënt ?
    - Wat vindt u daarvan?
    - Wat zijn de uitdagingen?
    - Wat zijn de risico's?
    - Hoe zou de veiligheid van de cliënt verbeterd kunnen worden?
    - Wat zou u niet willen? (Waar bent u bang voor?)
    - Is het gevoel van veiligheid belangrijker dan het waarborgen van de privacy? (waarom)?
7. Wat is voor u het belangrijkste om inzichtelijk te krijgen bij een dementerende cliënt? (welke fase, waarom, wanneer?)
8. Welke informatie wilt u wanneer weten van de dementerende cliënt? (waarom?)
9. Welke informatie is voor u het belangrijkste (prioritering)?
10. Welke informatie deelt u wanneer met andere zorgprofessionals? (waarom?)
    - Op welke manier deelt u dit?
    - Wat gaat er goed?
    - Wat gaat er niet goed?
    - Waar heeft u behoefte aan als het gaat om het delen van informatie met andere zorgprofessionals? (Op welke manier? Waarom?)
    - Wat zou u juist niet willen als het gaat om het communiceren/ het delen van informatie met andere zorgprofessionals?
11. Welke informatie deelt u wanneer met de mantelzorgers?
    - Op welke manier deelt u dit?
    - Welke invloed heeft dit op de zorg voor uw cliënt?
    - Wat gaat er goed?
    - Wat gaat er niet goed?
    - Waar heeft u behoefte aan als het gaat om het delen van informatie met mantelzorgers? (Op welke manier? Waarom?)
    - Wat zou u juist niet willen als het gaat om het communiceren/ het delen van informatie met mantelzorgers?

Algemene vragen over leefstijlmonitoring:

Uitleg leefstijlmonitoring:

Leefstijlmonitoring geeft informatie over het dagelijks leefpatroon van een bewoner door een netwerk van bewegingssensoren op gangbare plekken in de woning. Deze volgen de activiteiten (frequentie en locatie) van de bewoner, die op een digitaal platform worden gevisualiseerd. Het systeem analyseert de activiteitsdata continu, waardoor subtiele veranderingen vroegtijdig kunnen worden ontdekt. Eventuele alarmering is mogelijk als een cliënt bijvoorbeeld lang geen activiteit vertoont.

12. Waarom zou u leefstijlmonitoring in (willen) zetten bij een alleenwonende dementerende cliënt?
13. Waarom zou u besluiten om geen gebruik te gaan maken van leefstijlmonitoring bij een alleenwonende dementerende cliënt?
14. Hoe denkt u dat de inzet van leefstijlmonitoring bij alleenwonende dementerende cliënten het uitvoeren van uw werk zal beïnvloeden?
15. Hoe denkt u dat de inzet van leefstijlmonitoring de zorg rondom uw cliënt zal beïnvloeden?
16. Hoe denkt u dat de inzet van leefstijlmonitoring de kwaliteit van het leven van uw cliënt beïnvloedt?
17. In hoeverre denkt u dat de huidige organisatorische en technische infrastructuur het gebruik van de huidige technologie ondersteunt?
18. Welke faciliteiten heeft u nodig om gebruik te kunnen maken van de leefstijlmonitoring?

Behoeftes rondom leefstijlmonitoring

19. Wat wilt u inzichtelijk krijgen met de inzet van leefstijlmonitoring? (waarom wilt u dit inzichtelijk krijgen)?/ Welke activiteiten wilt u inzichtelijk krijgen met de inzet van leefstijlmonitoring?
    - Wanneer wilt u op de hoogte gebracht worden van een verandering in de leefstijl van de cliënt?/ wanneer wilt u op de hoogte gebracht worden van een activiteit?
    - Hoe wilt u hiervan op de hoogte gebracht worden?
    - Hoe wit u dat de informatie die verkregen wordt door de inzet van leefstijlmonitoring bij u komt?
    - Hoe gedetailleerd moet deze informatie inzichtelijk zijn (bijv. bewegingstijden (seconden, minuten, uren ect.)?
20. Wat heeft u nodig om leefstijlmonitoring in te kunnen zetten bij een alleenwonende dementerende cliënt?
    - Wanneer heeft u dit nodig?
21. Aan welke eisen moet leefstijlmonitoring volgens u aan voldoen? Aan functies/ mogelijkheden heeft u behoefte aan als het gaat om leefstijlmonitoring?
    - Waar moet de inzet van leefstijlmonitoring aan voldoen om u te ondersteunen in uw werkzaamheden?
    - Waar moet de leefstijlmonitoring aan voldoen om u te ondersteunen bij de zorg rondom uw cliënt?
22. Wat is/ wat kan de meerwaarde van leefstijlmonitoring rondom de zorg van dementerenden ten opzichte van voorheen (zijn)?

Barrières rondom leefstijlmonitoring

23. Wat zou u weerhouden om leefstijlmonitoring bij een alleenwonende dementerende cliënt in te zetten?
24. Waardoor zou u leefstijlmonitoring niet gaan inzetten?/ door welke omstandigheden zou u leefstijlmonitoring niet in gaan zetten?
25. Wat zou u niet willen als het gaat om de inzet van leefstijlmonitoring? (waarom wilt u dit niet)
26. Welke dingen ziet u als een bedreiging voor u zelf als het gaat om de inzet van leefstijlmonitoring?
27. Welke dingen ziet u als een bedreiging voor uw cliënt als het gaat om de inzet van leefstijlmonitoring?

Table 2

Interview questions for informal caregivers

Algemene vragen mantelzorger

1. Hoelang bent u al mantelzorger voor uw dierbare?
2. Hoe ziet de zorg rondom uw dierbare eruit?
3. Hoe zien uw taken / verantwoordelijkheden rondom uw dierbare eruit?
4. Hoeveel uur gemiddeld per week zorgt u voor uw dierbare?

Algemene vragen over de behoeftes rondom de zorg van uw dierbare

5. Hoe ervaart u de huidig zorg rondom uw dierbare op dit moment?
6. Zijn er dingen waar u tegen aan loopt in de zorg rondom uw dierbare?
    - Zo ja, welke zijn dit dan?
    - Wat is er voor nodig om dit te verminderen?
7. Wat kan er volgens u beter in de zorg rondom uw dierbare?
    - Hoe kan dit beter?
8. Waar heeft u behoefte aan in de zorg rondom uw dierbare?
9. Wat heeft u nodig om veiligheid van uw dierbare te kunnen waarborgen?
    - Wat gaat er nu goed en wat gaat er niet goed?
    - Wat zou u willen? (waar bent u bang voor?)
        - Wat zijn de uitdagingen?
        - Wat zijn de risico's?
    - Gaat het gevoel van veiligheid belangrijker dan het waarborgen van de privacy? (waarom)?
10. Wat is voor u het belangrijkste om inzichtelijk te krijgen bij uw dierbare? (waarom)?
11. Welk inzicht/ informatie is voor u het belangrijkste? (prioritering)
12. Welke informatie/ inzicht wilt u wanneer weten van uw dierbare?
13. Welke informatie wilt u wanneer de zorgprofessionals delen?
    - Waarom wel/niet?
14. Hoe verloopt de communicatie met zorgprofessionals?
    - Hoe communiceert u naar de zorgprofessional?
    - Wat gaat er goed qua communicatie met de zorgprofessional?
    - Wat gaat er niet goed qua communicatie met de zorgprofessional?
    - Waar heeft u behoefte aan als het gaat om het communiceren met de zorgprofessional?
    - Wat wilt u juist niet als het gaat om het communiceren met de zorgprofessional?
15. Als u terug kijk naar het begin van de zorg rondom uw dierbare, wat had u wanneer nodig gehad?
    - Wat heeft u in het verleden gemist?

Algemene vragen over leefstijlmonitoring

Uitleg leefstijlmonitoring:

Leefstijlmonitoring geeft informatie over het dagelijks leefpatroon van een bewoner door een netwerk van bewegingssensoren op gangbare plekken in de woning. Deze volgen de activiteiten (frequentie en locatie) van de bewoner, die op een digitaal platform worden gevisualiseerd. Het systeem analyseert de activiteitsdata continu, waardoor subtiele veranderingen vroegtijdig kunnen worden ontdekt. Eventuele alarmering is mogelijk als een cliënt bijvoorbeeld lang geen activiteit vertoont.

16. Waarom zou u leefstijlmonitoring in (willen) zitten bij uw dierbare?
17. Waarom zou u besluiten om geen gebruik te gaan maken van leefstijlmonitoring bij uw dierbare?
18. Hoe denkt u dat de inzet van leefstijlmonitoring bij uw dierbare uw taken als mantelzorgers zal beïnvloeden?
19. Hoe denkt u dat de inzet van leefstijlmonitoring de zorg rondom uw dierbare zal beïnvloeden?

20. Denkt u dat door de inzet van leefstijlmonitoring de kwaliteit van leven van uw dierbare verbeterd worden?
    - Waarom wel en waarom niet?

Behoeftes rondom leefstijlmonitoring

21. Wat wilt u inzichtelijk krijgen met de inzet van leefstijlmonitoring? (waarom wilt u dit inzichtelijk krijgen)?/ Welke activiteiten wilt u inzichtelijk krijgen met de inzet van leefstijlmonitoring?
    - Wanneer wilt u op de hoogte gebracht worden van een verandering in de leefstijl van de dierbare?/Wanneer wilt u op de hoogte gebracht worden van een activiteit?
    - Hoe wilt u hiervan op de hoogte gebracht worden?
    - Hoe wilt u dat de informatie die verkregen wordt door de inzet van leefstijlmonitoring bij u komt?
    - Hoe gedetailleerd moet deze informatie inzichtelijk zijn (bijv. bewegingstijden (seconden, minuten, uren ect.)?
22. Wat heeft u nodig om leefstijlmonitoring in te kunnen zetten bij uw dierbare?
    - Wanneer heeft u dit nodig?
23. Welke faciliteiten heeft u nodig om leefstijlmonitoring in te zetten bij uw dierbare?
    - Wanneer heeft u dit nodig?
24. Aan welke eisen moet leefstijlmonitoring volgens u voldoen? Aan welke functies/ mogelijkheden heeft u behoefte aan als het gaat om leefstijlmonitoring?
    - Waar moet de inzet van leefstijlmonitoring aan voldoen om u te ondersteunen in uw taken als mantelzorger?
    - Waar moet de leefstijlmonitoring aan voldoen om u te ondersteunen bij de zorg rondom uw dierbare?
25. Wat is/ wat kan de meerwaarde van leefstijlmonitoring rondom de zorg van uw dierbare ten opzichte van voorheen (zijn)?

Barrières rondom leefstijlmonitoring

26. Wat zou u weerhouden om leefstijlmonitoring bij uw dierbare in te zetten?
27. Waardoor zou u leefstijlmonitoring niet gaan inzetten?/ door welke omstandigheden zou u leefstijlmonitoring niet in gaan zetten?
28. Wat zou u niet willen als het gaat om de inzet van leefstijlmonitoring? (waarom wilt u dit niet)
29. Welke dingen ziet u als een bedreiging voor u zelf als het gaat om de inzet van leefstijlmonitoring?
30. Welke dingen ziet u als een bedreiging voor uw dierbare als het gaat om de inzet van leefstijlmonitoring?