Experience House project

Literature research report

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1. Introduction

This literature research report was conducted as a part of the project experience house in Zoetermeer, which is a collaboration project between the municipality of Zoetermeer, The Hague University of Applied Science, MBORijnland, Centrum voor Innovatief Vakmanschap (CIV) Smart Technology, and CIV Welzijn en Zorg. The experience house is a residential container that is furnished as a 'living room' for the elderly including innovative care technology, which tries to help residents of Zoetermeer to organize their own lives as much as possible. Our objective is to create a product that fits the needs of the experience house.

The purpose of our research is to understand what kind of product could improve the daily life of patients living with dementia. Since we are students with no prior knowledge of dementia, for us to proceed on this project, the initial step for us was to gain knowledge on various topics related to dementia; and we did this by conducting desk research on the literature at hand. This literature research report contains a literature review, the main research questions and research design and methodology of our project and how we will proceed from now on. With this literature research report, we were able to conduct a critical assessment of the literature to support our project, draw conclusions and pick up inconsistencies in prior studies. Also, identifying, analyzing and methods applied in the design thinking process are used with the goal of finding answers to our research questions and give a clear overview for the reader of the previous research on similar topics related to the goal of our project “What kind of product could improve the daily life of dementia patients”.

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2. Literature review

2.1 Introduction

Dementia is a syndrome that affects each patient differently. Common symptoms are memory impairment, language problems, motor speech disorder, sensory recognition problems and general body functioning disturbances (Prince et al., 2015). Patients are often still able to live on their own with help from nurses or caretakers. The Dutch government is trying to keep these patients home as long as possible, with the support from nurses, caretakers, and the patient' social environment. Dementia patients suffer more often from depression and often feel lonely because of their loss of capabilities including memory loss and communication difficulties. Technological based entertainment has been proven to help with these issues, but products need to be specified for the target group of dementia patients (Helle Nystrup Lund, et all., 2016).

This literature review discusses the literature we used to collect background information for our project. We focused our research on topics such as dementia in general, challenges of dementia for the patient and nurses, technical solutions, and existing product specifications. The aim of this literature view is to identify a possible gap in the current solutions and apply our knowledge and work on a solution. To achieve successful literature view, we defined what is already known, we used multiple sources and identified areas of debate. As for the research methodology used, we are using design thinking with its five stages.

2.2 Context

The Dutch government is trying to help older people live as independently as possible in their own homes. If necessary, the municipality can help at home under her Social Welfare Act 2015 (Wet maatchappelijke ondersteuning 2015). B. Programs that provide informal caregivers with daily activities, domestic help, or support. According to the Health Insurance Act (Zorgverzekeringswet), the Health Insurance Fund is responsible for home care until hospitalization. This gives healthcare providers and insurance companies more freedom to structure integrated care, for example when a patient is discharged or hospitalized, under the Health Insurance Act, you can receive medical care (nursing care) at home. The law also covers personal hygiene, such as helping with laundry. District nurses are responsible for organizing this care, they assess what is needed and draw up a care plan together with the client. Home care and personal care are covered by the standard care package, the mandatory excess does not apply to these services (Ministerie van Algemene Zaken, 2022). Other sources such as RIVM.nl and WHO.int agree with the rise of dementia, as the world becomes older on average. This causes shortages in nurses and time who can take care of dementia patients; thus, we are looking to assist these nurses in taking care of dementia patients (Symptomen Van Dementie, n.d., 2022).

Our project partner "The experience house in Zoetermeer", a collaboration between the municipality of Zoetermeer, The Hague University of Applied Science, MBORijnland, Centrum voor Innovatief Vakmanschap (CIV) Smart Technology, and CIV Welzijn en Zorg, is a residential container that is furnished as a 'living room' for elderly including innovative care technology. It should help the residents of Zoetermeer to organize their lives as much as possible and increase their autonomy, with the help of social networks and nursing technology. The aim of the project is to move furnished experience houses to different parts of Zoetermeer, where seniors can visit living rooms, learn about innovative care techniques, and discuss how to take control of their lives. (Experimenteerhuis Zoetermeer – CIV Welzijn & Zorg, undated).

2.3 Assignment and research purpose

Our assignment is to come up with innovative ICT solutions that would increase the time that older people can live independently, making their lives easier and more comfortable. We will work in close collaboration with healthcare students, elderly, and the project leader of the experience house. The focus is on the needs and requirements of residents, not on technology. With this research we want to find out what specifications a product needs to be successfully used by dementia patients in a way that improves their lives.

2.4 Technical solutions available to our team

Technical solutions available to us are search engines, the THUAS university's library databases, Google Scholar, US NIH (Pubmed), and other library database sources such as ProQuest. We will use these resources for our desk research. We aim at outlining the entire subject area. We gathered already existing data, paying attention to the point of view from which the topic has been studied previously and with which methods.

2.5 Information about the research methodology applied

To create an empathic design focused on the needs of dementia patients, we will be using design thinking. We will try to understand dementia patients and what are their desires. Design Thinking consists of five stages: empathize, define, ideate, prototype, and test (Wolniak, R. 2017). To design a product that dementia patients and the nurses caring for them can use, we need to gain knowledge about them and understand their situation, struggles, pain points, likes, dislikes, and previous successes in offering care for the elderly. For this purpose, we need to make use of research methods.

In the first stage of the design, our goal is to explore our stakeholders' world. According to (Hanington, (2019), "Exploratory research is defined by user and product studies, intended to forge an empathic knowledge base, particularly when designers may be working in unfamiliar territory". We find this research methodology a good place to start since none of us has knowledge of dementia and the effects the syndrome has on the patients and those around them. To apply this methodology, we started by familiarizing ourselves with data collecting methods. According to (Simplilearn, 2022), this is "The process of gathering and analyzing accurate data from various sources to find answers to research problems, trends and probabilities, etc., to evaluate possible outcomes".

The first method we will implement is the expert interview. To conduct an expert interview, we will need to find someone who is an expert in our field of interest, and willing to share their knowledge (Expert Interview - ICT Research Methods, n.d.).

The second method we are going to use is desk research. Travis (2016) refers to desk research as another name for secondary research, which is a form of collecting already existing data. We find secondary research essential in our project because we have been told we will not be able to interact with dementia patients.

The third method we are going to use is surveying experts on the topic of dementia. According to (Hanington, (2019), "surveys are a method of collecting self-reported information from people about their characteristics, thoughts, feelings, perceptions, behaviors, or attitudes.". For the purpose of our project, we will carry out of a survey with the goal of gathering as much information as is possible. Our participants will be asked to answer questions about dementia, rather than themselves. For this purpose, all our participants will have to be experts in the field of caring for dementia patients.

The fourth method we are going to use is observation. According (Hanington, (2019), observation "requires attentive looking and systematic recording of phenomena- including people, artifacts,

environments, events, behaviors and interactions.". Our chosen method for analyzing data is affinity diagraming. To make an affinity diagram, we will organize our data into clusters and themes based on the relationships between them (Affinity Diagrams: How to Cluster Your Ideas and Reveal Insights, 2022).

To summarize, we will collect data making use of explorative techniques such as expert interview, desk research, surveys, and observation. The data will be organized and analyzed in an affinity diagram. By making use of these methods, we hope to enrich our knowledge of our target group.

2.6 Background information about dementia

Dementia is a syndrome that is caused by diseases that destroy a part of the brain. It affects a patient's capabilities, such as their memory and orientation. This leads to language problems, motor speech disorder, sensory recognition problems, and general body functioning disturbance. Dementia has physical, psychological, social, and economic impacts. It does not only cause damage on people's health but also on their careers, families, and society at large. (Dementia, 2022).

It is hard to generalize the syndrome's symptoms and care methods for dementia patients. "There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care. Dementia affects each person differently, depending upon the underlying causes, other health conditions, and the person's cognitive functioning before becoming ill" says the WHO (Dementia, 2022). Dementia affects neurological functioning, which leads to cognitive ability loss (Shoesmith, et al. 2022). The speech rate of the patients slows down, their hearing decreases, and it is harder for them to concentrate in a conversation. In addition to that, the vocabulary becomes simple, and they rather use active sentences than passive sentences (Gertrud d Teussen, 2019). In most cases, the patients are likely to talk less as the syndrome progresses because they are ashamed of their loss of capabilities. Repetitions of words and sentences become normality in conversations to cover their oblivion and loss of words (Gertrud Teussen, 2019). There is a variety of different forms of dementia. Alzheimer's disease is most common and is in 60-70% of most of all dementia cases. The boundaries between different forms of dementia are not clear and co-existing of different forms is possible as well (Dementia, 2022). Overall, while there are some symptoms patients are more likely to show as the syndrome progresses, every patient is different. The variety of forms dementia can take adds to the specificity of each case.

To better represent the signs and symptoms experts assigned them into three stages: early, medium, and advanced. The early stage of dementia is not easy to notice because the onset is unequal. The first symptoms could be forgetting things in their daily lives more often and becoming lost in familiar places. As dementia progresses the signs and symptoms become clearer. Common symptoms would be that the short-term memory and detail-knowledge deteriorate (Dementia, 2022). The late stage of dementia causes, according to the World Health Organization, unmissable problems in the patient's life. "Memory disturbances are serious, and the physical signs and symptoms become more obvious and may include becoming unaware of the time and place, having difficulty recognizing relatives and friends, having an increasing need for assisted self-care, having difficulty walking, and experiencing behavior changes that may escalate and include aggression." (Dementia, 2022). To summarize, there are three stages of dementia, symptoms aggravating as the syndrome progresses.

Preventing or delaying dementia is very important. There are several factors influencing whether someone gets dementia, such as age, gender, and genetics. While these factors cannot be controlled, there are also factors that can be controlled. The RIVM here names several factors, some

of them psychosocial and lifestyle related, which can cause dementia to appear earlier, such as: “smoking, alcohol consumption, physical activity, unhealthy foods”, “little social activity, depression, bad sleep.” (Leefstijlfactoren spelen een rol bij het voorkómen of uitstellen van dementie | RIVM, P. 2). These factors are important to keep in mind as there is currently no treatment available to cure dementia. Thus, an individual care program for each patient should be the highest priority (Shoesmith, E., Griffiths, A., Sass, C., & Charura, D. (2022)). Although movement can have a positive impact on their behavior, most patients live a sedentary lifestyle. Physical activity is hard to implement in care homes but very important (Bowes, A., Dawson, A., Greasley-Adams, C., Jepson, R., & McCabe, L. (2022). Overall, research points us to several factors influencing how likely someone is to get dementia and how soon they will get it. Although some of these factors, such as physical activity, can be influenced, doing so is sometimes difficult.

To summarize, dementia is a complex syndrome with various symptoms, manifesting differently for each patient and varying in severity depending on the stage, and several factors influencing how the syndrome will develop.

2.7 The impact dementia has on mental health

Dementia is also known to cause several issues for a patient's mental health.

Depression and anxiety are common amongst people with dementia (Shoesmith et al. 2022). According to Azermai et al., Reference Azermai, Petrovic, Elseviers, Bourgeois, Van Bortel, and Vander Stichele in 2012, the treatment of any symptoms of anxiety or depression should be seen as an essential component of dementia management.

Another pain point for a patient’s mental health is loneliness. Either Moyle, W., Kellett, U., Ballantyne, A., & Gracia, N. in their journal series of 2011 as well as Sutin, A. R., Stephan, Y., Luchetti, M., & Terracciano, A. in 2020 and Holwerda, T. J., Deeg, D. J., Beekman, A. T., van Tilburg, T. G., Stek, M. L., Jonker, C., & Schoevers, R. A. in 2014 agree in their studies that loneliness is one of the main pain points in a dementia patient´s life.

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according to APA 7th edition: https://morningside.libguides.com/APA7/authors#:~:text=Number%20of%20Authors%20to%20Include,(s)%20in%20every%20citation.&text=For%20a%20work%20with%20three,doing%20so%20would%20create%20ambiguity.

Entertainment and mental healthcare are just as important as medical care for dementia patients. Dementia can affect their orientation and reality perception which can have an impact on social inclusion and their feelings. According to Backhouse, T., & Ruston, A. in 2022 a great among of LTC residents having mental health issues during lockdown were dementia patients. Recent data suggests that upward of 60% of patients exhibited worsening cognitive decline due to social isolation (toleau-Bretonniere et al., 2020)." For LTC residents who were isolated and experiencing anxiety about contracting the virus (due to the high volume of COVID-19-related deaths in LTC) many became highly vulnerable to increased symptoms of nervousness, worry, and depression (Haider et al., 2020; Manca et al., 2020). In short, people with dementia are more vulnerable to developing mental health issues due to several factors surrounding the syndrome. Moreover, mental health issues can worsen the symptoms dementia causes.

Overall, dementia has an impact on people’s mental health, causing depression, anxiety, and the feeling on loneliness. This should not be ignored since decline in the quality of mental health leads to an increase in cognitive impairment.

2.8 Challenges faced by nurses carrying for dementia patients

Often there is a need for nurses to care for dementia patients. They must be aware of their actual condition and have the proper knowledge and skill set for managing people with dementia and their specific needs. They face several challenges when caring for dementia patients.

A first challenge when caring for patients is that everyone is different. According to WHO (World Health Organization): “Dementia affects each person in a different way, depending upon the underlying causes, other health conditions and the person’s cognitive functioning before becoming ill." (Dementia, 2022) P. 5). This calls for specific care tailored for each patient, the nurses having to treat each case individually.

Dementia also cases behavioral issues in patients. According to Strøm et al. (2019), nurses struggle with these behavioral issues when caring for patients.

Patient communication is playing an important role in changing the work environment and care provided to them. Dementia can cause communication issues leading to the nurses struggling to administer pain management medication to dementia patients. The staff recognizes the importance of the end-of-life care However, providing good end-of-life care is challenging at times. When dementia patients develop communication difficulties, the nurse-patient relationship is affected, and other challenges arise. Overall, communication issues affect the relationship between nurses and their patients negatively.

Prioritization of psychosocial and spiritual care leads to good palliative care. Work pressure affects the nurses’ perception of their patients. It is varied, some show compassionate care, and others are burned out and have physiological stress. Conflicting feelings were found among nurses as a result of wanting to spend more time with every patient to provide care, but at the same time, experiencing burnout and feeling pressure to help everyone. Most challenges were attributed to the behavioral symptoms of dementia, like agitation, irritability, physical aggression, and rejection of care (S. M. aghmour, 2021). Overall, a heavy workload negatively influences the relationship between nurses and their patients.

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To conclude, dementia poses several challenges to the nurses caring for patients. These challenges include the complexity of the syndrome, behavioral issues, and communication issues. Work pressure and the amount of workload also constitute pain points for the nurses.

2.9 Robotic application while caring for the patients

In the last few years, technological devices have helped elderly people at home with medical or security issues in their daily life, or just for entertainment improvement (Bryant, 2017). There are examples of robots and technology used to care for dementia patients. According to Aerschot (2020), there has been an initiative 25 years ago to design the “Elderly Caregiver”. As the population increases in longevity, there will be an increasing need for caregivers for the elderly. Although robots could fill this role, their use in human care has remained minimal despite the promises that they will revolutionize the way older people are cared for.

However, the value of the global service robotics market, including the care robot market, is still quite small. The paper argues that this is due to issues with R&D and production, rather than unfavorable user attitudes or ethical issues, which are the main reasons why robots are being used in care. There are not many consumer-level robot applications available that could help and support in providing for the needs of elderly people. Due to issues with kinetic robotic systems regarding health technology safety norms and regulations, designers focused mostly on robots supporting either instrumental tasks (household cleaners or medicine dispensers) or bonding tasks. So, rather than taking over the role of nurses, robots have only been having an adjuvant role.

An example of an experiment featuring robots caring for the elderly is the one conducted by D. Hebesberger, T. Koertner, C. Gisinger, J. Pripfl and C. Dondrup in 2016. This experiment is a mixed methods study about using autonomous robots as assistance in physical therapy for dementia patients. The dog toy and AIBO provide insights into robots performing bonding tasks with the patients. In the interventions with the toy dog and AIBO, the patients often spontaneously began to talk, describing the object's performance and commenting on its physical features. We have also learned that the dementia patients could only relive the past when they were in a comfortable environment. The patients clapped their hands, touched, and cared for the toy. Even though they know it is not a real dog, they still enjoyed this form of entertainment. Some patients spoke to the toy dog and picked it up which most likely made them remember their comfortable experiences with a dog in the past (Hebesberger, et al. 2016). This points us to the fact that there is most certainly a future for robots to be used to help dementia patients and their nurses.

To summarize, the robotics industry has not yet taken off due to several reasons, despite there being a need for extra help for dementia patients. However, the technology is not advanced enough at this moment to replace the role of nurses and human caregivers. At the same time, past successes with robots performing bonding tasks, such as the dog toy and AIBO, show future potential for robotic companions keeping patients entertained and preventing them from feeling lonely.

2.10 Product Specifications

As mentioned in the previous section, in recent years, the use of various technologies for offering purposeful activities in dementia care has been the subject of extensive research (Goodall & Kristin, 2020). We have been particularly interested in products that use audio with the goal of aiding with loneliness and tried to center our research around similar devices. By going through the sources used in each scientific paper we were able to find more relevant information.

We organized our literature research in a thematic way, using several key themes we found relevant when developing a product for dementia patients. One important aspect of our research was searching for literature on competitive products. This is because we need to identify trends and predict impediments that we may encounter, and the best way to do that is to consult other studies done with concrete data based on testing and the results.

We found various studies conducted on various products. However, there were some factors that influence the reliability of the data. These included: scientific papers being more theoretical than practical, the group's sample size, and the fact that all dementia patients are individuals with different needs and preferences. The scientific papers were more theoretical and based heavily on literature, while practical studies weren't as common.

The review "The use of various technologies for offering purposeful activities in dementia care" combines academic research and practice. An important conclusion of the review is that testing is needed to see how the products work in real life (Davison et al., 2016). Sample sizes in these were small, for example, in the product 'Memory box' developed for dementia patients with mental health issues to access independently music and photographs. There were only 16 of the 39 participants who satisfied the criteria for dementia and agitation in this study. However, in the end only 11 carried out the study till the end (Davison et al., 2016).

There have been several studies about helping dementia patients increase their food intake at a meal. A Study about how lighting and contrast affects food intake had a sample group of 13 people, the

study found significant increases in food (>25%) and fluid (>84%). Another study about creating a more homelike dining atmosphere and the effect it has on food intake included 11 participants, they found significantly more food was consumed. Additionally, a study about environmental ambiance and food consumption included 12 people and the consumption increased by 20% (Woodbridge & Sullivan, 2016). Small sample sizes pose the risk that we may not be able to obtain the same results. However, it is encouraging to know that external factors can improve the food intake of dementia patients.

Some of our research questions were related to the preferences of color, texture, and lighting in dementia patients. Finding information on these topics proved to be harder than expected; This is because it depends heavily on individual preference according to the nurse students and expert Nellie Klaassen we interviewed. The literature used also supported this statement. For example, in a systematic review about the use of the physical environment to support everyday activities for people with dementia, many of the collected studies were tailored specifically to individual needs (Woodbridge & Sullivan, 2016). In the project Vita, which is an audio-based technology, the individual's needs were emphasized; "In using Vita (sound pillow with an easily accessible interface), professional caregivers are required to continuously assess the individual responses of the residents to explore the specific potential value for each resident" (Houben, et al., 2020). This showed that that every patient requires a personalized product that can be customized according to their needs.

According to a systematic review, even at more advanced stages of the disease, persons with dementia can learn how to use modern technologies but caregiver assistance will still be required (Goodall & Taraldsen, 2020). However, in the Vita it was given the impression that it enables people in advanced stages to play audio and no mention of assistance was mentioned (Houben et al., 2020). Thanks to these we can see that at some times that patients can still learn how to perform simple tasks, eventually with assistance.

One of the most important reasons that we have found on why color is so important, is because of the loss of visual capacity in elderly people. The main factor is mere aging, which reduces the ability to hear and see. But there are also cases in which dementia can affect visual-perceptual capacity. Reducing sensitivity to contrast detection and different colors, this includes the ability to read. This is where color plays an important role. "Use contrasting colors to draw attention to objects. For example, the lack of ability to differentiate between colors makes eating difficult. Evidence suggests that using a bright (e.g., red) plate, utensils, and cups might help your loved one recognize the food and encourage them to eat." (Dementia, Alzheimer's, and Eyesight: Symptoms and How to Help, 2021)." Because the retina has more receptors, red helps to make these items more recognizable. Researchers have found that bright red dramatically affects the patient's eating habits using tableware, utensils and cups that are red in color, has shown that food intake increased by 24% and liquid intake increased by 84%". (Wright, 2022). Here color is used with the aim of attracting attention and thus facilitating the patient's ability to recognize objects, which is why in many residences very bright colors tend to be used instead of more muted colors. But apart from attracting attention, the presence of certain colors can affect the patient's mood, a study published in the Journal of Dementia Care makes the following observations: Blue has a restful and calming effect; Green can lower activity of the central nervous system; creating a sense of calmness; Red stimulates the brain activity, draw attention; Orange, has many similarities with red properties. (Colors and Dementia: Yes, They Can Have an Impact!, s. f.). The conclusion that we can draw up from these findings is, that the product we are designing should be brightly colored to be easily noticeable for the patient in case of any visual impairment.

Another stimulus with a lot of positive effects is touch (texture), massages, touching well-known objects, or even petting animals as mentioned in this article: “Using direct tactile stimulation, researchers found improvement in short-term and long-term memory in subjects diagnosed with Alzheimer’s disease. They also noticed an improvement in general mood, and in socialization and participation in daily activities. After six weeks, these improvements partially remained. Tactile stimulation is equivalent to textures such as the fake cat robots and massage robots" (Schmid, 2020). For our project, this means we must also consider the preferred texture for our product to get the correct response from the patient, even though this is very heavily depended on individual preferences.

All this information is valuable to our knowledge because even small details have a noticeable improvement which can be noticed in the state of mind of patients with dementia. Also, their quality of life can be noticeably improved, which can also assist the nurses and give them more time for each patient. This also gives a direction to future designers on what they must work on with the client and which specifications, they must consider.

2.11 Conclusion

As there is currently no treatment available to cure dementia, there is a large body of research on the topic. Most importantly, the literature clearly indicates the importance of an individual care program for each patient to be the highest priority in managing the disorder. It is estimated by experts that depression and anxiety are common amongst people with dementia (Shoesmith et al., 2022). We found several recent articles supporting this claim. We are hoping for our project to tackle this problem in addition to supporting patients to live independently, which there is clearly a need for, considering the number of difficulties nurses are already facing with dementia. The amount and the strain of work for nurses is a concern that has been discussed extensively in the literature as well as media recently.

Literature search was also conducted on the current devices used in dementia aid and how successful they have been. This part of our research was in high of importance since our project is about developing a new product as well. Another difficulty we encountered was the scientific papers being more theoretical, based heavily on literature, while practical studies weren’t as common. However, the literature implies that tests have been conducted with positive results. In each case, we found, these devices have been tested on groups of dementia patients that were so small that no firm conclusion can be drawn. This is going to complicate the justifications we make in the later stages where we define features we are going to use.

Even at more advanced stages of the disease, persons with dementia can learn how to use modern technologies but caregiver assistance will still be required (Goodall & Taraldsen, 2020). However, the literature clearly indicates that each of these patients are individuals and symptoms manifest in them in different ways, which is a factor that influences our future work vastly. The literature review outcome reveals opportunities for us utilize the result of the previous product development outcomes and anticipate possible impediments.

3. Main research question and other sub questions

3.1 Main research question

Our assignment is to design a product that would increase the time the elderly can live independently at home. This led to the research question “What kind of product would improve dementia patients’ daily life?”. We define as “successful usage” that of a product dementia patients can learn how to use and then continue to use it every day, with no impediments.

To answer this question, it is important to understand the main pain points in the patient’s life, what product specifications they require and what are the most successful methods nurses implemented so far in caring for them. Answering this research question will give us an understanding of dementia patients and their needs. In conclusion to this, the sub-question that will guide our research are as follows.

1. What challenges does dementia cause for patients and those around them?
2. What specifications does a product needs to have to be successfully used by dementia patients in a way that improves their life?
3. What are the most successful methods nurses implemented so far in providing care for dementia patients?

3.2 Challenges caused by dementia

To create a product that improves their life, we need to understand their current pain points. For answering this question, we want to explore the challenges patients face in their daily life, the challenges related to dementia that their friends and family face, and the challenges related to dementia that the nurses caring for the patients face. We also want to understand the relationship dynamics between dementia patients, their friends and family, and the nurses.

3.3 Product specification requirements

Most dementia patients are elderly people, so they are not likely knowledgeable regarding technology. We need to understand what product specifications they require to successfully use a product. We define as successful a product that they can learn how to use and continue to use in their daily lives. The topics we want to explore are the complexity level and learning curve dementia patients can master, color and graphic conventions dementia patients recognize, the audio and tactile specifications dementia patients require to successfully use a product, how dementia patients react to color and light, best products already existing on the market with their strong points and places for improvement.

3.4 Successful methods already implemented by nurses

During the introduction meeting, our client introduced us to a few products nurses are already implementing in caring for patients. We decided to research successful products and methods to learn from past successes and to be able to design a product that nurses can implement in their already existing routines. We want to understand how the nurses are currently organized, what products are they currently using, what are the most successful products, and what are the most entertaining products.

4. Research design and methodology

4.1 Research design

4.1.1 Research methodology

Our methodological approach is inspired by ethnography. Our research will be vastly explorative because we need to expand our knowledge on our main stakeholders- dementia patients, their friends and family, and the nurses caring for the patients. However, since working with dementia patients is not possible, most of our research techniques will fall under the umbrella of library research, unlike in an ethnographic study. We will be collecting data through desk research, expert interviews, observations, and surveys. The data will be processed into data cards and analyzed in an affinity diagram to discover insights.

4.1.2 Purpose of research

The purpose of our research is to understand what product could improve the lives of dementia patients. To do this, we will research the main pain points caused by dementia that the patients, their family and friends, and their nurses experience, what specifications a product needs to meet to be successfully used by patients, and what are the most successful methods already used by the nurses in caring for patients.

4.1.3 Techniques implemented for collecting and analyzing research

4.1.3.1 Collecting data

We will collect data using library techniques. Due to privacy concerns, we are not able to include dementia patients in our research, so collecting field data will not be possible. We will collect data by the means of desk research, expert interviews with our client, Nellie Klassen and the nurses at MBO Rijnland, surveys with the nurses at MBO Rijnland, and possibly an observation.

4.1.3.2 Analyzing data

We will analyze the raw data collected by processing it into data cards. This will allow us to combine data from different sources. We will sort the data cards in an affinity diagram to identify insights. When analyzing the data in the affinity diagram we will triangulate data from different sources and research techniques.

4.1.4 Timeline

Research phases	Week 2	Week 3	Week 4	Week 5	Week 6
Literature research					
Purpose of research					
Research methodology					
Collecting data					
Analyzing data					

The research may extend if we find collecting and analyzing more data necessary.

4.1.5 Settings for the research study

We will collect desk research data using our personal computers. We will mostly use the THUAS university's library databases, Google Scholar, US NIH (Pubmed), and other library database sources such as ProQuest. We will use official websites about dementia with certified information. The expert interviews will happen in person at THUAS or via MS Teams. They will be recoded via the MS Teams recording option or using our phones. The survey will take place at THUAS. It will be created in Google Forms and accessed via a QR code.

4.2 Research methodology

4.2.1 Research aim

Dementia is an important topic with already existing scientific literature discussing it. The purpose of our research is to better understand the patients and their needs, to be able to design a product that can improve their lives and solving one of their pain-points. We are going to conduct exploratory research that will help us understand the patients and those around them.

4.2.2 Collecting data

In our data collection, we focus on collecting qualitative data. This is because the data we are looking for is based on experience, judgment, emotions, and feelings that cannot be quantified. Due to privacy protection, we are not able to be in contact with dementia patients, so our focus will be on collecting library data through various techniques. We will collect data using desk research focused on research papers, online testimonies, and certified websites about dementia. We will also conduct expert interviews with our client, Nellie Klassen, and with the nurses at MBO Rijnland, and surveys with the nurses at MBO Rijnland. We are considering at this point in research the possibility of having an observation, where we would focus on how nurses interact with products.

4.2.2.1 Desk research

In our desk research, we will make use of research papers, certified websites about dementia, and online testimonies. Our focus will be answering our research sub questions. We will collect data using the topics related to each question. The data will be collected as data cards. This will allow us to merge findings from different sources to discover insights.

4.2.2.2 Interviews

We will conduct several expert interviews with participants who have relevant knowledge about dementia.

Our first participant will be our client, Nellie Klassen. She has knowledge about dementia and products currently available and in use.

Our second participant group are the MBO Rijnland nurses. Throughout the project, we have an opportunity to ask for assistance from the nurse students and interview them. The participant quantity of this group is still unclear, but it will be a small group. They experience working with dementia patients and understand the syndrome and how it affects patients and their loved ones. They have knowledge about methods and products currently available and in use.

A third possible participant group are friends and family of dementia patients. They know how dementia is affecting the lives of their loved ones struggling with the syndrome. When interviewing them we would also be interested to know what challenges the dementia brought in their personal lives. We proposed this idea to our client, and she promised to come back to us if this would be

possible to implement. However, at this point in research, we do not know if someone from this group will be available for interviewing.

To conduct the expert interviews, we are going to have a protocol with questions and topics we want to discuss with our interviewees. When conducting the interviews, we are going to be flexible and ask follow-up questions based on interesting data we learn during the interview.

The interviews will be conducted in teams of 2 people, but, preferably, the entire group. This way there is always one interviewer going through the protocol and at least one observant writing down notes and asking follow-up questions. We will be recording the interviews using our phones or the recording option in MS Teams. We decided to record the interviews to have as much raw data as possible.

4.2.2.3 Survey

We will also create a survey so that the nurses that are not comfortable with being interviewed also have the option to share their knowledge.

The themes of the survey are about the challenges of dementia patients and further defining them. We also want to collect data on how the nurses are currently organized, how they patients and what are the biggest challenges they are faced with. The nature of our questions requires them to be open-ended questions. Based on the responses we hope to discover new problem areas that we can focus on to come up with a solution and expand our understanding.

We will prepare the survey in Google Forms and let them access it through a QR code.

4.2.2.4 Observation

Observation is one possibility as it could be conducted about how nurses who are not familiar with technology, use our product. Our client says that most nurses are older, and not very knowledgeable when it comes to technology. This way we could passively measure the success and usability of the product. Also, active feedback would be collected from the nurses directly.

4.2.3 Analyzing data

To analyze the raw data we will have collected, we will first process it into data cards. We chose this method because it allows us to combine data from various sources to obtain more powerful insights.

We will create the data cards using this template. The raw data will be added to the second field. We will write a statement derived from the raw data on the top of the data card. The source will be added at the bottom of the data card, as well as a data card number.

<Statement>	
<excerpt from raw data (transcript/picture/observation)>	
<source >	<Card #>

We will interpret the data by sorting the data cards in an affinity diagram. We will look for connections and relations between our data cards to discover insights.

User insights will be then organized in the report using this template. We would add the raw data supporting the insight and the source of the data. We would write the insight statement in a few words and give more details in the description.

<Insight Statement>
<Description>
<Source> <Raw data 1>
<Source> <Raw data 2>
<Source> <Raw data 3>

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6. Appendix

Expert Interview Protocol with Nellie Klassen

Organizational

Do not forget to ask if it's okay to record the interview both before and after the recording starts. We can start by telling her that we looked over the list of assignments she gave us and that they are too technical for our team to handle. Then we can explain what we are planning to do- understand the struggles of dementia patients and those around them and design a product that addresses some of these struggles. How can we get in touch with the nurses?

Questions

1. Can you tell us about the challenges dementia causes for patients? Then, if she did not already mention it, ask about loneliness.

2. Can you tell us about the challenges dementia causes for the nurses?

3. Can you tell us about the challenges dementia causes for the friends and family of the patient?

4. How active are the patients, what are they able to do on their own?

5. What is their environment, how many devices do they already have at home? For example, do they have a tv, radio, what medical devices?

6. How often are the patents visited by nurses?

7. We would like to know how the nurses are trained and organized. Can you tell us more about their training and how they function when they start working with patients?

8. Can you tell us a bit about the top 5 most successful products/ methods the nurses have implemented so far? *(In case she did not already say it in the answer ask what made each of these products successful)*

9. What do you think of this tony box, do you see any successful qualities in it? Could you see a concept like this implemented in a product you could use?

10. We would like to know if the physical characteristics of a product influence how the patients use it. Do they still recognize graphic conventions such as red means no and green means yes? If yes, do you have other examples of graphic conventions they still recognize? Do you have any resources we can investigate regarding the subject?

11. Do they react to colour in any specific way? Do you know if colours can have a calming effect on them?

12. Are there any audio specifications dementia patients require in order to be able to use a product?

13. Do lights on a product influence in any way how a patient interacts with the product?

14. How should a product feel for the patients to be able to use it? Should the buttons feel different than the rest of the product? Do they have any preferences for any textures? Anything texture related that you know they dislike?

15. Can you tell us how complex can a product be for a patient to still be able to master it? How many steps should it have? Can it offer different options, or should the user flow be linear?

Expert Interview Protocol with the nurses

We will start by giving a presentation about the project we are working on and why we need their help.

Presentation slides

WELCOME

To the Haque university of applied sciences

Agenda

- Who are we?
- What are we doing?
- Why/how can you help?
- Questionaire & Interviews

  How can we help you?

- Questions can be asked along the way.

  Anton Speaks Dutch if you prefer to ask questions in Dutch or need a (short) translation.

Who are we?

- (Mostly) international students.

- Morline Guderjan
- Jamine Donovan
- Vanda Dumitrescu
- Gonzalo lopez Gonzalez
- Anton de Weijs

We are IT specialists.

We can design and prototype.

What are we doing?

Experience house
Empathize phase
Design a product

Would a product similar to this work?
https://www.youtube.com/watch?v=Bl6ASNPT0Ow

Why/How can you help?

- We are IT specialists.
  We can design and prototype.
- We have little knowledge about:
- Dementia
- Work of the nurses
- What would a product need

Our research questions:

This is where you come in: Questionaire & Interviews

- Questionnaire
- Interviews

After this presentation we will take the nurses who want to be interviewed to a separate room and ask them these questions.

Questions

1. Can you tell us about the challenges dementia causes for patients? Then, if she did not already mention it, ask about loneliness.

2. Can you tell us about the challenges dementia causes for the nurses?

3. Can you tell us about the challenges dementia causes for the friends and family of the patient?

4. How active are the patients, what are they able to do on their own?

5. What is their environment, how many devices do they already have at home? For example, do they have a tv, radio, what medical devices?

6. How often are the patents visited by nurses?

7. We would like to know how the nurses are trained and organized. Can you tell us more about their training and how they function when they start working with patients?

8. Can you tell us a bit about the top 5 most successful products/ methods the nurses have implemented so far? *(In case she did noth already say it in the answer ask what made each of these products successful)*

9. What do you think of this tony box, do you see any successful qualities in it? Could you see a concept like this implemented in a product you could use?

10. We would like to know if the physical characteristics of a product influence how the patients use it. Do they still recognize graphic conventions such as red means no and green means yes? If yes, do you have other examples of graphic conventions they still recognize? Do you have any resources we can investigate regarding the subject?

11. Do they react to colour in any specific way? Do you know if colours can have a calming effect on them?

12. Are there any audio specifications dementia patients require in order to be able to use a product?

13. Do lights on a product influence in any way how a patient interacts with the product?

14. How should a product feel for the patients to be able to use it? Should the buttons feel different than the rest of the product? Do they have any preferences for any textures? Anything texture related that you know they dislike?

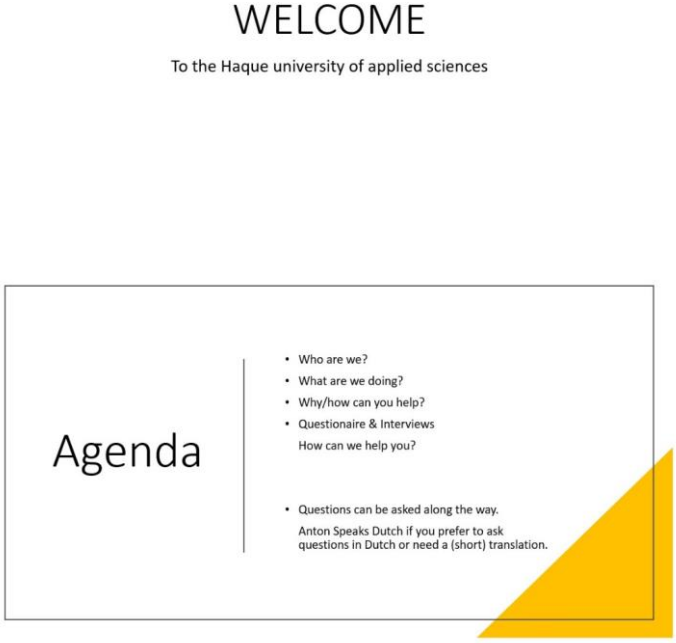
15. Can you tell us how complex can a product be for a patient to still be able to master it? How many steps should it have? Can it offer different options, or should the user flow be linear?

Survey Protocol with the nurses

We will start by giving a presentation about the project we are working on and why we need their help.

Commented [G(3]: This presentation slide are repeated

Commented [VD(4R3]: Because both the surveying and interviewing protocol start with that



What are we doing?

Experience house
Empathize phase
Design a product

Would a product similar to this work?
https://www.youtube.com/watch?v=Bl6ASNPT0Ow

Why/How can you help?

- We are IT specialists.
  We can design and prototype.
- We have little knowledge about:
- Dementia
- Work of the nurses
- What would a product need

Our research questions:

This is where you come in: Questionaire & Interviews

- Questionnaire
- Interviews

At the end of the presentation the nurses will be asked to scan the QR code in order to access the survey. The survey will consist of these following questions.

What are challenges dementia causes for patients?

What are the differences about caring for dementia patients than for others?

When you talk to patients, which topics are the most common ones?

Can you tell us how complex can a product be for a patient to still be able to master it? How many steps should it have? What is something they absolutely love/hate?

What are product specifications those patients prefer?