Supporting the Relationship Between a Person with Dementia and Their Caregiver using Haptics and Wearable Computing

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June 20

Abstract

When you get older, it is normal for some cognitive and physical abilities to somewhat deteriorate, but when it clouds your judgment or completely removes your short-term memory, it could be a sign of dementia. On average, 14,6% of Norwegian elderly suffer from dementia, with the chance of developing the disorder nearly doubling every year after reaching 60 years of age. With more families taking on a caregiver role, and nursing homes becoming less of an option, wearable technology could aid as a support for the relationship and communication between the person with dementia and their primary caregiver. In this thesis, I explore the underlying issues about the communication barrier between a person diagnosed with dementia and their primary caretaker and introduce wearable technology as an aid to support their relationship. I adopted a participatory design approach within the data collection process, which was derived from an extensive literature search. Both probing sessions and workshops were used in line with the participatory design approach. The thesis discovers the lack of communication between caretakers, as well as explores common miscommunication and struggles for both the person with dementia and the caretakers after the diagnosis, focusing on authentic partnership. In addition, the thesis reviews existing studies on the use of wearable technology within dementia care. This led to the interactive design of an application dedicated to supporting healthy communication between both the person with dementia and their caregiver, as well as between multiple caregivers. Further, the design is explained based on the proposed research questions, as to how this could aid in supporting their relationship.

Keywords: *Wearables, Dementia, Caregiving, Participatory Design, Authentic Partnership*

Acknowledgments

I would like to show my appreciation to my supervisor, Klaudia Carcani. Thank you for supporting me through the thesis, being there for good conversations, and brainstorming, and for your guidance. I would also like to thank my family for their support through the master's program, and my friends for their support and stimulating conversation on the subject that has given me more insight into the topic at hand. Lastly, I would like to thank my workplace, Horn Media, for being supportive and helping during the thesis writing, as well as joining in on the conversation and discussing ideas.

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Chapter 1

Introduction

1.1 Background and Motivation

When you get older, it is natural for some cognitive and physical abilities to somewhat deteriorate, such as having a worse short-term memory or getting more easily out of breath. However, when the deterioration of your cognitive abilities clouds your judgment, makes you forget where you live, or completely removes your short-term memory, it could be a sign of dementia. Dementia is a broad term used to describe several cognitive disorders, which are a result of damage to the parts of your brain responsible for learning, memory, decision making, and language [28,89]. Even though dementia is not a part of normal aging, most dementia cases are related to old age and do not yet have a cure [2,28]. On average, 14,6% of Norwegian elderly, or about 100.000 over the age of 70, suffer from dementia, where the chance of developing the disorder nearly doubles every four years [31]. However, due to the increase in average life expectancy, as well as the increase of elderly people due to the high birth rates after WWII, the number of people suffering from dementia is expected to double within 2050 [25,28,89]. With 2/3 of dementia patients currently living at home, helping partners or other family members through the process of becoming a caregiver will be of the utmost importance [27,28].

Dementia has an immense impact on family relationships, especially in the communication and dealing with the new caregiving role. It is seen that the partners that take on this role, even with it feeling like the most natural choice for them to make, experience symptoms of grief, depression, and anxiety because of the changes from partner to caregiver [10,51]. In addition, a negative effect on the caregiver's physical health, such as high blood pressure and a higher risk of heart disease, is recorded [50,3]. However, it is also recorded that caregivers who can get into a new daily pattern, can reflect on their current situation, and adapt their habits and patterns to the caregiving role experience a sense of a strengthened relationship and a sense of proficiency. The use of technology and digital applications have also been used to regain a better bond with family members and a more structured social life for the caregiver [87].

My main motivation behind this thesis stems from my relationship with my grandparents. My grandfather suffers from dementia and is currently in the stage of mild cognitive decline. This has given him significant difficulty navigating and traveling, handling money, as well as a terrible short-term memory. My family had wondered for quite some time if it could be possible that he had dementia, but due to my grandfather and his partner refusing to live separately and acknowledging that something was wrong, a proper diagnosis was ruled out for a long time. After the diagnosis, his long-term wife took on a caregiver role, where she is currently helping him with some menial tasks, as well as being assisted by my uncle a few times a week. However, the bond between them is truly inspiring and shows that even in darker times, it is possible to stay together with your loved one. While I do not have experience or background in healthcare or eldercare, I have been interested in assisting the elderly generation using wearable technology since my second year in my bachelor's program. This is due to my own experiences with the quick deterioration of my family members, as well as the recorded physiological and psychological deterioration of the elderly after being admitted into nursing homes [5,79]. It was not until I entered the "Interaction Design" program that I saw the possibilities of using today's technology within healthcare to further help the elderly generation. These experiences inspired me to use this project as a platform to demonstrate the use of haptics in the care of dementia patients living at home with their partners, to further help both the caretaker and the patient.

1.2 Purpose

The purpose of this study is to investigate how haptics and wearable technology are currently being used within dementia care, namely, to assist both the person suffering from dementia and their partner who has taken on a caregiver role. This master thesis aims to design a solution that focuses on supporting authentic partnership and effective communication aided by haptics and wearable technology. The resulting work would aid the person suffering from dementia to regain personhood by being able to help their partner out with menial tasks and daily activities. It would also lighten the psychological and physiological load of the partner. In addition, this project needs to address the barrier to digital literacy amongst the elderly and support the implementation of wearable technology and haptics in their daily life.

1.3 Research Questions

Based on the premise identified within the previous Section 1.2, this project will take a qualitative approach with the following research questions:

RQ1: How can wearable technology be introduced and used in the person with dementia and the primary caretaker's daily routine?

To answer this research question, we first need to investigate previous attempts to use haptic technology within dementia care and investigate the different techniques used. Based on this information, three sub research questions were added:

RQ1.1: Has wearable technology been used in dementia care, and what has been its effect on it?

RQ1.2: What participatory design techniques can be applied to co-design with people with dementia and the primary caretaker?

Based on the information found within RQ1 and its sub research questions, other areas of research were considered:

RQ2: How can wearable technology contribute to supporting the relationship between a person with dementia and their primary caretaker?

1.3.1 Deliverables

The deliverable within this project will be a solution based on data collection and related work that will support the relationship between the person with dementia and their primary caretaker.

1.4 Methods and Approaches

The purpose of this study, described in Section 1.3.1, has evolved throughout the project, taking on an explorative approach. This process has been incremental using several rounds of iteration before a final design was presented and tested with both people suffering from dementia and their caretakers, where potential end users were involved throughout the process. The following methods and methodologies have been used in the process:

Literature Review

A systematic review on dementia, wearable technology, and the use of haptic technology to aid in the support of the relationship between the person with dementia and the primary caretaker was performed. This was performed to accurately assess the potential haptic technology has on the state of togetherness, as well as the overall relationship.

Participatory Design

A core approach was chosen to accurately assess the needs of dementia patients and their primary caretakers. The chosen methodology was participatory design. This was chosen due to its active involvement of the stakeholders, in this case, the person with dementia and the primary caretaker. The participatory design approach was used within the data collection process to explore design ideas and to emphasize and understand the users.

Data Collection and Evaluation

To gain a broader understanding of the challenges and current circumstances within the stakeholders' lives, two workshops were held. The probing session aimed to gain a broader understanding of the challenges, tasks, and communication errors caregivers face while supporting and caring for a person with dementia. The workshop was performed to gain a broader perspective into the diagnosis from the person with dementia standpoint and to gain insight into the relationship between them and their caretaker.

Prototyping

After defining a prototyping goal within the data collection process, a design based on knowledge gathered within the literature review and the collected data will be presented. The design will be viewed and reviewed by the participants within the study to answer the research questions.

1.5 Report Outline

Each chapter within this thesis addresses various aspects of the research. The chapters are structured as follows:

Chapter 1: Introduction

The introduction chapter introduces the background and personal motivation behind the project. Within this chapter, the scope of the study is presented, which revolves around the subject of dementia patients living at home with their partner or a family member as the primary caregiver, and the incorporation of wearables and haptics to further assist both the patient and caregiver. A brief introduction to the methodologies used within the chapter is presented. Lastly, the research questions are outlined.

Chapter 2: Related Work

The related work chapter provides a review of previous research related to my project. The chapter is divided into three chapters: Dementia, haptics, and wearable computing. In the first chapter, the disorder dementia is investigated more thoroughly. The second chapter presents a look into haptics and their current use with dementia patients. Lastly, wearable computing and its related technology are presented.

Chapter 3: Methods and Approaches

The methodology chapter gives insight into the methods used during this project, as well as the reason behind them. The core approach, participatory design, is presented and discussed with a focus on its use within the project in practice. Further, the used data collection tools are outlined. Lastly, ethical considerations within the project are considered and discussed.

Chapter 4: Applying the Methods

Within this chapter, the methods and approaches discussed in the former section are applied. The process of applying the data collection methods is presented, as well as the results of these methods. Further, the brainstorming process and synthesizing of data are presented to gain a broader understanding of the needs of the person with dementia and their caretaker. The chapter concludes with an informed statement of the stakeholder's general needs.

Chapter 5: Prototype

The prototype chapter describes the entire process of designing and developing a high-fidelity prototype, from gathered data to a final product. The chapter is divided into two sections: The defining phase and designing the prototype. The defining phase shows the results of the data collection methods and the process of synthesizing the data.

Furthermore, it shows the specific requirements for the final prototype, which is based on information gathered within the data collection process. Within the second section, the whole designing process is presented, from a low-fidelity wire frame to a suggested prototype concept. The chapter concludes with a detailed description of how the prototype was designed and created.

Chapter 6: Results

In the results chapter, the findings from the evaluation of the prototype. These findings have been grouped into sections based on the features tested. This is followed by how the prototype can be used within at-home dementia care.

Chapter 7: Discussion

The discussion chapter provides a discussion on the findings from Chapter 6 concerning the research questions, as well as based on the previously established theoretical background and knowledge gathered from the data collection process. Further, I will reflect on the use of the core methodology and design choices. Lastly, I will reflect on the collaboration with the dementia patients, and the experiences and knowledge I have received.

Chapter 8: Conclusion

Chapter 9 presents the conclusion of the study, and briefly assesses some limitations to the study, as well as probable future work within this project.

Chapter 2

Related Work

This chapter provides insight into the incorporation of haptics into the domains of dementia and dementia care. As the thesis concerns dementia, the chapter begins by presenting the disorder and the various stages of decline. Further, the context of the thesis is framed by presenting haptics, relevant technology, as well as its current use within dementia care. Lastly, a summary will be presented to summarize the material within the chapter.

2.1 Dementia

The concept of dementia has been around since early civilization, first being recorded in around 600 A.D by Saint Isidore (560-636) where the term "dementia" was used in their book "Etymologies" [85]. However, dementia as a diagnosis was not accepted as a medical term until 1797 by the French doctor and psychiatrist Philippe Pinel (1745-1826), who described his patient's condition as "demence", or incoherence of their cognitive abilities [85,87]. Further, Pinel's pupil, Jean Etienne Esquirol (1772-1840) divided dementia into three categories: Acute, chronic, and senile. Esquirol described dementia as a cerebral disease characterized by an impairment of sensibility, intelligence, and will [9]. In modern days, dementia is seen as a broad term describing several cognitive disorders, which are a result of damage to the left hemisphere and the prefrontal cortex, which affects learning, memory, decision making, and language [28,81,89]. There are several diseases and disorders connected to dementia, such as Parkinson's, Lewy-body dementia, vascular dementia, as well as the most generic form of dementia, Alzheimer's disease, which constitutes 60% of dementia cases. However, the disorder can also occur due to environmental factors and lifestyles, such as excessive alcohol use, vitamin deficiency, head trauma, diseases and imbalances related to hormones and metabolism, as well as most diseases that affect the brain [28,60].

The symptoms of dementia vary from person to person, as well as from which part of the brain is affected, which gives us two separate groups of dementia. Cortical dementia happens because of problems in the cerebral cortex and plays a critical role in both memory and language. These types of dementia, such as Alzheimer’s disease and Creutzfeldt-Jakob disease, are usually related to severe memory loss and a worse understanding of language. Lastly, the second group of dementia refers to problems with the area underneath the cortex, where changes in the speed of thinking are drastically changed. Relevant diseases within this group are Parkinson’s disease, Huntington’s disease, and complications with HIV [81].

2.1.1 The Stages of Dementia

As per the Global Deterioration Scale (GDS), there are seven stages of cognitive decline. The GDS was developed by Dr. Barry Reisberg, and provides caregivers with the stages of cognitive function for those suffering from dementia, to give caregivers a rough idea of where their loved one lies [64]. The seven stages are viewable in Table 1. Within this project, the stages of mild to moderate decline and moderate decline are within the scope of the thesis.

Stages of cognitive decline	Common effects
No cognitive decline.	No subjective complaints of memory deficit. No memory deficit is evident during clinical interviews.
Very mild cognitive decline	Subjective complaints of memory deficit are common, most frequently in the following areas: Forgetting where one has placed familiar objects and forgetting names one formerly knew well. No objective evidence is found of memory deficit during clinical reviews.
Mild cognitive decline	During mild-moderate decline, it is the earliest clear-cut chance of catching the memory deficit. This is due to manifestations in more than one of the following areas; Patient may have gotten lost when traveling to an unfamiliar location; Colleagues become aware of the patient's relatively poor performance; Word and name finding deficit becomes evident to family and spouses; Patient may read a passage or a book and retain relatively little material; The patient may demonstrate decreased facility in remembering names upon introduction to new people; The patient may have misplaced or lost an object of value; Concentration deficit may be evident on clinical testing. This is where

	denial starts to manifest in the patient, as well as mild to moderate anxiety symptoms.
Moderate cognitive decline	There is a memory deficit during clinical trials. The memory deficit manifests in the following areas: Decreased knowledge of current and recent events; May exhibit some deficit in memory of one’s personal history; And a decreased ability to travel, handle finances, etc. For some, a deficit in the following areas is also possible; Orientation to time and place; Recognition of familiar people and faces; The inability to travel, handle finances, etc.; And the inability to complete complex tasks. It is easier for dementia patients to withdraw from challenging situations.
Moderately severe cognitive decline	The patient can no longer survive without some assistance. They are also unable to recall relevant aspects of their life such as an address or a phone number they have had for several years, the name of close family members, and so on. The patient at this stage retains knowledge of many major facts regarding themselves and others. They invariably know their names and generally know their spouse's and children's names. They require no assistance with toileting and eating but may have some difficulty choosing the proper clothing to wear.
Severe cognitive decline	In this stage, the patient may forget the name of their spouse and will be largely unaware of all recent events and experiences in their lives. They retain some knowledge of their past lives, but their memory is clouded. Within this stage, the patient may have difficulty counting from 10, both backward and sometimes forward. They may also need assistance in their daily life, due to the possibility of incontinence or with travel. A personality and emotional change are to be expected within this stage. These are quite variable and include: Delusional behavior, such as talking to imaginary people or themselves in a mirror; Obsessive symptoms, such as repeated activity; Anxiety symptoms, and some may experience violent behavior; And the loss of willpower due to the difficulty carrying one thought over some time.

Very severe cognitive decline	Within the last stage, all verbal abilities are lost throughout the stage. Frequently they are no longer able to speak properly, only in unintelligible utterances and rare emergences of seemingly forgotten words and phrases. Toilet assistance due to incontinence is also needed, as well as help eating. Within the progression of this stage, the ability to walk is lost, and a disconnect between the brain and body is noticeable.

Table 1 - Overview of the stages of cognitive decline

There are several ways to declare where the person with dementia is on the cognitive scale, such as using the Psychological Assessment Scales (PAS) which assists people to carry out psycho geriatric assessments [43], and the informant questionnaire on cognitive decline in the elderly (IQCODE) particularly used with subjects unable to undergo direct cognitive testing [44]. Both these methods for detecting cognitive decline are well documented and tested through the years by several researchers [45]. Within this study, I will mainly focus on patients within the stages of mild to moderate and moderate cognitive decline to narrow the scope of the study, as well as to perform the planned interviews.

2.1.2 The Effects and Tribulations of Living with Dementia

To live with dementia is a peculiar experience, seeing as the diagnosis affects everyone differently [7,71]. The worsening cognitive decline manifests in the areas of forgetting names, places, and common words, fewer relationships, difficulty retaining knowledge, and in other areas, it starts to mess with the person's mental stability [7,71]. According to Holst and Hallberg [39], living a life with dementia means struggling with preserving a sense of self and retaining one set of values in this newfound situation. The study also shows, from the interviews with dementia patients, that the people within the study showed difficulty reaching out to others and themselves, essentially becoming a stranger in their own life, which brought feelings of shame, sadness, and sorrow [39].

In de Boer et als [8] literature study on the patient's perspective of suffering from dementia, it is seen that there is a visible difference between how they and the people around them view the diagnosis. The onset of dementia involves a great variety of feelings, such as fear, insecurity, and disbelief, while for some, getting the diagnosis brings confusion, shock, or anxiety due to the uncertainty about what the decline involves, how to evaluate it, and what the future holds [8]. As the opinion people hold of them is important to a lot of people suffering from dementia, several participants expressed that they are worried about others finding out about the diagnosis due to the possibility of stigmatization, as well as the fear of not being heard or taken seriously [1,8]. However, it is also seen de Boer et als study [8] it is expressed that general well-being, cognitive function, and being able to take part in social activities with friends and family are essential for their quality of life. However, are not that well regarded in literature. However, these positive experiences that are essential for a better quality of life seem to come later post-diagnosis. In Ablitt et als study [1] dementia participants express three stages post and before their diagnosis:

Before diagnosis

Before the diagnosis, patients experience a lot of frustration and embarrassment about their deficit, which could result in denying the symptoms or that something is wrong in general [1,8].

First stages after diagnosis

After getting the diagnosis, patients may experience feelings of relief, shock, grief, and a wish to withdraw, which can cause coping mechanisms such as denial and avoidance, as well as externalization. People with dementia might defend themselves from the possibility of misplacing an item or outright deny the possibility of something being wrong even after diagnosis [1,8,84]

Post-diagnosis

Sometimes after the initial diagnosis, it is seen that both careers and participants with dementia experience a feeling of "holding on" and feeling more willing to work with their careers and sustain the relationship [1]. This can be done by maintaining involvement, sticking to a daily routine, and staying engaged in all sorts of activities to maintain control over their lives [1,8].

2.1.3 The Psychological and Physiological Struggles of Caregivers

Family caregivers provide most for the people with dementia living at home. However, it is shown that they have worse physical health, more absences from work, lower quality of life, and are more likely to experience depression and anxiety than non-careers [52]. It is said that caring for a close relative, or especially a spouse, who has become demented is one of the most demanding situations. Contributing factors of stress are due to the uncertainty due to the diagnosis being unpredictable, ambiguous, and over a long duration [6]. It is anticipated that the number of people with dementia will rise dramatically over the coming years, where the current number of 101'000 known cases will double within

2050, which makes it prevalent to explore the possible improvements to the caregiver's physical and psychological health [28].

There has been a growing recognition in literature of the importance of the nature behind the relationship between the career and the person with dementia, which could alter the experience for both parties [38,61,62]. Instead of polarising roles where the relationship between the career and the person being cared for is not considered, Sheard [67] argues that an inclusive approach that understands the person with dementia in the context of their significant relationship should be developed. With this, temporal models showcasing the experiences of the person with dementia have been proposed by several researchers. Keady's [48] model proposes three stages, "working together", "working apart", and "working through it", to incorporate the individual experiences of the person with dementia and their career [62]. Of these three models, the model of "working together" is seen as the more desirable outcome, due to it showing a mutual decision to share the struggles and work through events together despite the diagnosis [48]. Temporal models based on the experiences of couples within dementia care suggest that the relationship between them changes over time as their partner's cognitive functions change [62].

It is seen that families at first try to make sense of the situation, trying to adjust to the loss of the partner and life they knew while emerging into their new role as a caregiver [3,62]. While the struggles are dependent on variables mentioned before, it is shown that caregivers can experience challenges in their personal life, job prospects, social life, and other aspects of their life due to possible psychological distress. With the temporal models in mind, there is no "one size fits all" solution. However, being able to find a solution that supports better communication and cooperation between the person with dementia and their caretaker could be possible.

2.1.4 The Relationship Between the Person with Dementia and their Caregiver

Traditionally, nursing homes and other forms of healthcare facilities have the main responsibility for the formal care of dementia patients, giving planned care, setting expectations, and making sure the patients receive quality care [68]. However, in recent years, partners and children of people with dementia have taken over most of the at-home care, taking on a caregiving role [52]. However, due to a lot of stigma around the diagnosis, people with dementia are still excluded from being regarded as full partners when it comes to decision making, and other aspects of the relationship, making it harder for the person with dementia to work with their caregiver [20,21]. As seen in an open-discussion session at A Changing Melody 2008, a speaker announced that the care they received would've been better if the other person also had dementia, remarking on the current lack of understanding of the experience itself, making it harder to achieve "authentic partnership" [20].

An authentic partnership, as described by Dupuis et al [20], is a relationship that actively incorporates and values diverse perspectives and includes all stakeholder voices directly in decision making. To gain an authentic partnership is to go through a journey of both learnings together and unlearning old, misguided assumptions and paternalistic actions [20]. In an analysis conducted by Dupuis et al [20] on their previous partnership projects, they have gathered three guiding principles to serve as a moral compass for future projects, which are described below.

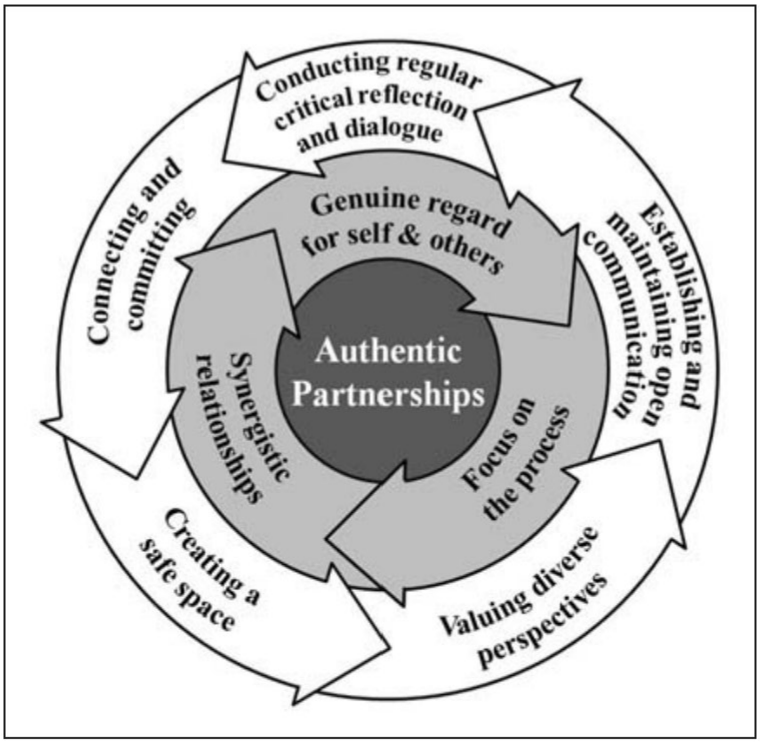

Figure 1 - A model of "authentic partnership"

Genuine regard for self and others

Genuine regard for self and others focuses on sharing mutual caring and concern for the betterment of others and recognizing the humanness in all parties of the partnership, which involves the recognition and responsibility to uphold individual rights. This includes the right to mutual respect, dignity, full engagement in life, and selfdetermination of all partners. It also emphasizes honoring individual uniqueness and the potential for human growth [20,74].

Synergetic relationships

Synergetic relationships recognize interconnectedness and interdependence of all involved, therefore focusing on reciprocity rather than notions of dependence. This will then build on the diversity of the partnership and incorporates the ability to generate new ideas and creative ways of doing things [20].

Focus on the process

Having a narrow outlook on the partnership can blind people from critical issues and impact the relationship which could unfold during the partnership. By focusing on the process, you learn to value, respect, and trust the other party, which allows for supportive modifications and creative responses. By focusing on the process, the partners recognize that learning and unlearning are never-ending and require flexibility and responsiveness to change. It also requires that both partners are open to learning from their mistakes and embrace creativity and the non-traditional ways of doing things.

2.2 Wearable technology

An early definition of wearable computing came from the Defense Advanced Research Projects Agency (DARPA) in 1996, where it was defined as “Data gathering and disseminating devices which enable the user to operate more efficiently. These devices are carried or worn by the user during normal execution of his/her tasks” [82]. This definition shows the key element of wearable computing, which is that it should be used in a natural, unobtrusive manner [82]. In a more modern definition, these values are carried on, whereas wearable computing refers to technologies or computers that are incorporated into items such as clothing and accessories that can be worn on the body [42,55]. Today, wearable devices can perform many of the same tasks as handheld technology, and in some cases even outperform them due to the technology usually being more sophisticated than the handheld technology on the market today [42,70]. Wearable technology has also gone commercial, where its technology is used in fitness trackers, smart watches, wearable cameras, and smart phones [82]. Smartphones, and other modern handheld devices, are not as powerful as a computer, but modern handhelds increasingly include powerful dual-core processors, RAM, SD storage capacity, an operating system, and native and add-on applications, and are often powered by dry cell lithium or similar battery [75].

2.2.1 The History of Wearable Technology

Inventions within wearable computing can be seen as far back as 1700 with the Abacus ring from China Qing Dynasty, which was often used by traders, and contained nine wires each had seven beads. These beads were so small that they could only be manipulated by small pins, and were used to quickly calculate large sums, and can be seen not only as the forerunner to the calculator but also as a good example of non-electronic wearable computing [82]. Using more modern iterations of wearable computing, a modern invention can be seen from the end of the 20th century. The following are some of the projects that shaped the wearable technologies to today's use.

Shoe Based Roulette Predictor (1960's)

The first modern invention of the wearable computer can be seen in Thorp and Shannon's shoe-based roulette predictor from the 1960s, where a cigarette box-sized wearable computer with twelve transistors was used, as well as a speaker behind the ear for output and a toe switch for input. Based on the physical models that were programmed into the computer, the device would predict which of the eight octants of the roulette wheel the ball would land is based on the shoe-based devices input timing information related to the ball position via toe switches. The device involved two people, one to input the data into the device and another to wirelessly receive the predictions via another shoe-based device and place the bet. Under laboratory conditions, it was determined that the device would result in a gain of +44%, which was validated in Vegas and yielded a $10,000 profit [55,82].

The Mann's Webcam (the 1980s)

In the early 1980s, a photographer named Steve Mann, a key figure in the MIT Wearable Laboratory and a former computer science student at MIT, built a wearable system with photography equipment. This was done using a system of flashlights, batteries, and cameras. This was used to capture the visible environment with a video camera and edit and project the image onto custom eyeglasses, starting the work for augmented and altered/mediated reality. The computer controls the image projected in the glasses and edits or adds images as programmed, such as replacing advertisements with natural scenery or other images. [55,56]

Personal Digital Assistant (the 1990s)

Personal digital assistants (PDAs) were a new type of commercial portable digital device, which included a phone and address book, a calendar, and usually could take notes with the use of a stylus. The first PDA, Newton, was launched in 1993 by Apple, and then in 1996, Palm Computing's Pilot was introduced. Within the year 2000, nearly 12 million PDA units were sold worldwide. The services provided in these PDAs are services that later were incorporated into smartphones and smart watches due to them being services that one would want a wearable to provide [55,83].

TAUT Smartphone App (the 2010s)

With the aid of psychologists, computer scientists, and statisticians, the TAUT smartphone app was designed to provide three core functions: Assistive reminders, data collection, and a context-aware sensor platform for use within dementia care. This study was conducted in 2014 and was developed as a context awareness platform to monitor and collect raw data on how assistive reminders could aid dementia patients, and how quickly the person with dementia was able to accept the reminder [35].

2.2.2 Haptics in Wearable Technology

The sense of touch is a big contributor to how we see and interact with the world around us, where it is used to assess an object's dynamic and material properties, for verification of engagement such as with the click of a button, and as continuous monitoring of an ongoing activity like the rattling of a vacuum [54,46]. The ability to simulate the sensation of touch through motors, vibrations, and other physical experiences can be described as haptic technology [22,41]. The word haptics was first introduced at the beginning of the twentieth century within the field of experimental psychology to refer to the sense of touch of real objects by humans. Later, its scope was enlarged to include all aspects of machine touch and human-machine touch interaction [22,69]. Currently, the term has brought together several disciplines, such as biomechanics, psychology, engineering, and computer science [22,37].

The use of haptics has a well-documented history starting in the mid-1900. In 1964 an exoskeleton using only the movements of the person maneuvering the invention was proposed for lifting heavy objects using only balance and their forearms [17,41]. Other inventions, such as using haptics within servo manipulators for force reflection with the aid of AC-driven servos, and a multifunction glove equipped with embedded tracking sensors to provide simple tactile clues are ways haptics were used and tested within the mid to late 1900s [66,73,80]. Today, the use of haptics is used in a wide range of applications, such as within games with the vibration of the controller, mobile and touchscreen interaction, education, and training by simulating systems with limited availability, arts and music production, as well as vehicle operation with haptic communication to alleviate stress in a fast-paced environment [22,37].

Haptic technology today is deeply integrated into our lives, where the most common examples are the vibrations on our smartphones, feedback given by a car's steering wheel when you veer out of your lane, as well as touchscreen feedback when touching a button. It is also commonly used in videogames, such as using gaming headsets where you can locate the sound of someone based on the direction your character is facing, as well as the feeling of a power buildup in a controller before an attack. This is done by force feedback, imitating the feeling of resistance, or manipulating the movement of an item held by the user, such as a controller, to simulate forces experienced within the realm of the game [14]. Haptic technology can be divided into three main categories; Graspable technology, touchable technology which are ta, and wearable technology. Graspable systems are usually kinesthetic, or force feedback, devices that are usually grounded to a surface and allow users to push on or through them by using a held tool. Graspable devices can also be ungrounded or tactical devices that are held in the hand [16]. Wearable systems are usually tactile devices that are mounted to the hands or other parts of the body and display sensation directly to the skin, where they provide cues such as vibration, lateral skin stretch, or normal skin deformation [16]. Lastly, touchable systems are displays that allow users to actively explore the entire surface and can be purely cutaneous devices that change their tactile properties based on location, or they can be hybrid cutaneous and kinesthetics devices that change their shape or surface [16].

2.3 Designing Technologies for People with Dementia

Actively involving both the person with dementia and their caretaker in the design process is an important contribution to reducing social isolation and depression for everyone involved [78]. Several researchers [13,19,50,51,65,76,76] have conducted studies on the premise of actively involving all parties as a partner rather than an object of the study, which shows the potential of tailoring technology toward the different stages of dementia and their respective symptoms. Being able to produce something with the contribution of the stakeholders, as well as with them in mind, is essential to the design process and shows the possibilities of working together. The following are some of the technologies that have been used in supporting people with dementia.

Sensory E-textiles

Treadway and Kenning's study [76] describes the design and development of sensory textiles to support the well-being of people with dementia based on relationship-centered care and positive design approaches to encourage joy, exploration, and cooperation. The sensory e-textiles are tailored to the users, focusing on delivering sensory stimulation to support subjective wellbeing, where they developed interactive design to stimulate the senses, promote positive emotion, and bring comfort in both an individual and social context. The results of the study show the participants want to continue with the study, as well as are willing to participate in further research.

LAUGH

Ludic Artifacts Using Gesture and Haptics (LAUGH) is a proposed design by Treadway et al [77] that investigates the design of playful objects for people with late-stage dementia. The study focuses on the importance of emotional memory and emotional expression in the care of people with late-stage dementia, the value of sensory triggers, and props to stimulate emotional remembering and promote high-quality social connections. The playful objects were created based on workshops promoting emotional and playful activity. The results of the study show that the participants were able to experience positive emotions in a safe environment, as well as explore their creativity and playfulness.

Go&Grow

Go&Grow, proposed by Lin et al [51], is a 6-week mixed-method social exergame where flowers grow as participants increase physical activity and interact with other caregivers. This was proposed to support social, physical, and emotional wellbeing amongst primary caregivers of dementia patients. After 6 weeks, it was shown that Go&Grow helped participants relieve stress, increase physical activity, and develop empathy for and patience towards the dementia patient.

2.3.1 Haptic Technology and its Use Within Dementia Care

The use of haptics within dementia care is slowly on the rise, where they're currently studies finding ways to use haptics to improve communication [18], help the person with dementia better socialize and reach out to family and friends [18], as well as studies based on the person with dementia's need for physical contact [86]. The following studies were chosen due to their difference in the use of haptic technology, showing the range haptic technology within wearables could have within this thesis.

Multi-modal Album

Within the Czech et als study [18], the social issues that arise among members of dementia patients' social networks were analyzed. Based on the analysis and interviews held by the researchers, it was established that only verbal communication can limit the level of social engagement. Therefore, a multi-modal system that incorporates both passive and active elements into a book as a means to bridging social connections between verbal and non-verbal communicators. After initial testing, it was seen that the overall reactions to the multi-modal albums were positive, as it engaged socialization not only for the dementia patients with their family and friends but also initialized conversation between the patients and the nursing staff.

Traumreise

In Mertl et als exploratory field study [58], the use of multi-sensory digital media in the context of a dementia group was presented. It was seen that communication and interaction between people with dementia were stimulated using the device. Traumreise also acted as a relief as it mediated communication, as well as addressed several senses through video, sound, haptics, and smell.

Wearable Partner Agent

Within Yonezawa and Yamazoe's study [86], wearable partner agents were developed to simulate the physical touch which the dementia patient normally gets from a caregiver, which was simulated through a combination of the agent's motion and simultaneous haptic stimuli. This was done to simulate caregiver-like experiences during the user’s outings. This wearable partner was able to recognize and detect the user's clothing and posture, as well as being able to still be with the user while they were walking. In the results of the study, it was seen that this partner agent could serve as a positive partner. However, long-term studies were not performed to see the overall difference in behavior and positive outlook.

2.3.2 Wearable Computing Within Dementia Care

In recent years, the use of wearable technology within dementia care and preventative monitoring has been developed rapidly, to aid in the need for assistance with mundane tasks, daily living, and social connectedness [29,47]. In healthcare, wearable technology can be used to perceive, record, and analyze to maintain the user's health, and can even help with physiological and pathological information for self-monitoring with real-time accurate detection [47]. It can also be used to detect mental and emotional states in patients and to provide optimally timed assistance [63].

Memory Aids

As mentioned in Section 2.1, one of the main aspects of the disorder is memory loss, which could be distressing for a person with dementia. To aid in the loss of one's memories, Franklin et al [29] proposed a memory aid using hearing aids where the focus is on the everyday tasks of dementia patients, such as getting dressed, pill-taking, and tea-making, which are known struggles. These hearing aids would be used for activity modeling, intention modeling, and memory cues. Activity modeling would recognize facial expression and the person's physical activity and gestures, where the acoustic channel of the wearable enables the researchers to understand the environmental ambiance and audio events to model a patient's proxemic social context and interaction with physical objects. Intention modeling, as in the name, helps with understanding the patients' intentions, such as noticing the direction they have their head and their facial expression, which could indicate that they want a particular object. Lastly, memory cues provide cues in the acoustic channel, giving auditory stimuli, and with the privacy-preserving placement of the hearing aids, voice prompts and voice cues can aid in guiding the person.

Wearables to Assist Depressive Episodes

People with dementia of any type have a high incidence of major depression, where the occurrence of the first major depressive episode in older adults is a risk factor for developing dementia [49]. With this, Mathuvanthi et al [57] proposed a wrist-worn wearable that would sense the bio signals such as the heart rate, temperature, and movement, as well as sensors like an accelerometer, gyroscope, and galvanic skin response, which it is analyzed and relayed to the people involved, such as the person with dementia and their caretaker. Based on the gathered information, when spikes are noticed, the wearable would play a song, show pictures, or change the ambient temperature within the area to calm the person down.

Chapter 3

Methodology

In this section, the methods and techniques used in the project are explained in detail. Based on my core approach, I outline the methods used to answer the research questions established in Chapter 1.3. Participatory design was used as the main approach as it aids in the exploration of the needs of all stakeholders involved in this thesis. As explored in Chapter 2, it is seen that the initial cooperation and communication between the person with dementia and the primary caretaker after getting the diagnosis is heavily reliant on the state of the relationship beforehand. However, even with a stable relationship, there is a chance that the communication and cooperation post-diagnosis will be affected due to feelings of “holding on” and distress about others' perception of the diagnosis and themselves. This creates ground to explore how wearable technology and haptics can aid in the support of the relationship between the person with dementia and their primary caretaker.

I am aware that using a participatory design approach could result in a solution that may differ from the original idea. Therefore, the methods used with the core approach are presented. In addition, I have made an effort to apply methods relevant to the chosen approach, which would allow for critical reflection in later chapters.

3.1 Participatory Design

Participatory design, further abbreviated as PD, is an approach to design in IT that invites all users into the design process as a means of better understanding, meeting, and pre-empting their needs [11,23]. It is a democratic process for design, both social and technological, of systems involving human work, based on the argument that users should be involved in the designs they will be using, and that all stakeholders have equal input into interaction design [36]. The motivation for engaging in PD varies. On one side, it has a pragmatic view saying that the system will have a better chance of succeeding if the users have a stake in its development. On the other hand, is the political view, showing the ethical stance that participating users should be involved in all aspects of the design [11,12]. *Engaging in the practice of participatory IT development not only results in ‘new* *understandings about how designs could be arrived at and introduced into the workplace but also led to a broad base of new knowledge being built upon among workers and managers' that can be built into the design result* [11]. For this thesis, I needed methods and techniques that would allow me to explore the person with dementia's perception of technology, as well as the perception of the primary caretaker regarding supporting their relationship and daily communication. I argue that using a PD approach is the best research approach to explore the needs of both stakeholders, while also contributing to a realistic solution for both the person with dementia and their primary caretaker.

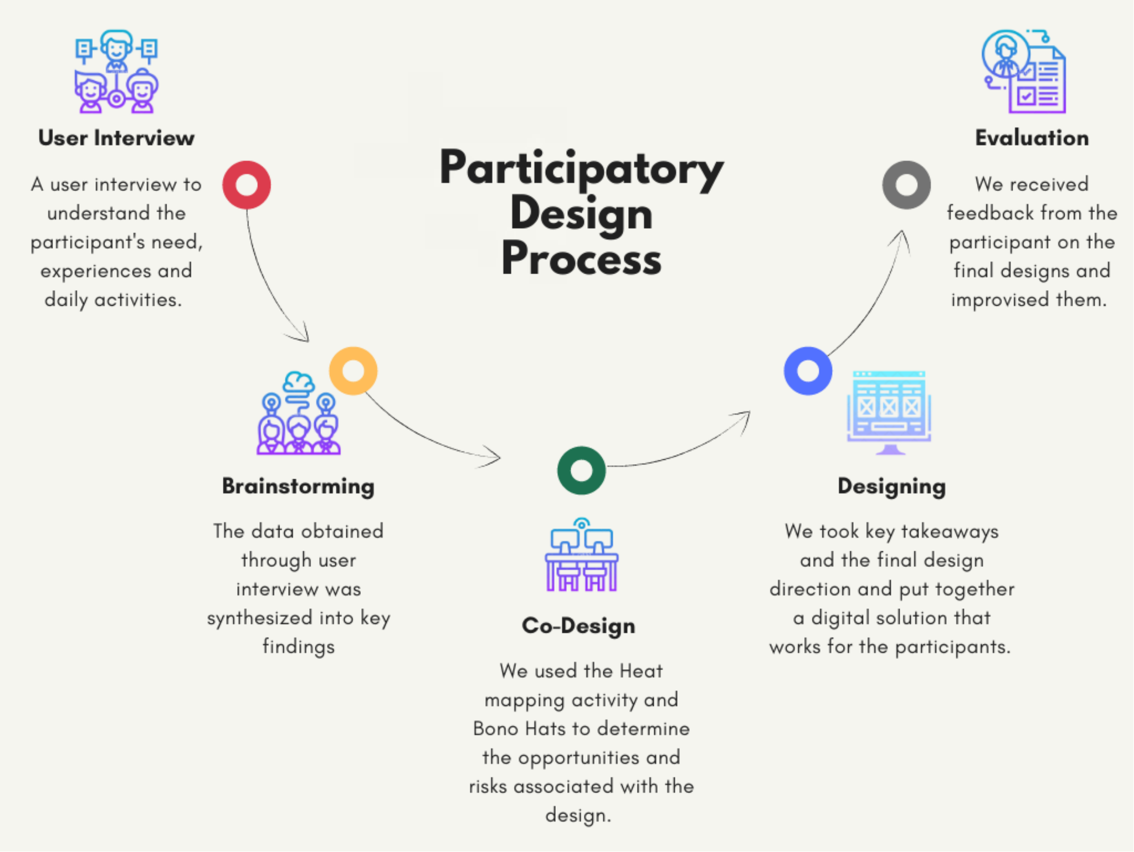

Figure 2 - Overview of the PD design process

According to John Chris Jones in Luck's article [45], "*People in the design world should begin to look deeper not only into the political sense but also into the possibility of helping people to change. Participation may be the educational approach to this.*" Luck also goes on to say that PD is not one single research method but rather rooted in a concern for located accountabilities, where each application is embedded and designed to suit the circumstances at hand [45]. Further, a PD approach is said to aid in equalizing power relations, mutual learning, helpful tools, and techniques for the stakeholders, as well as giving an alternative vision about technology, which all comes from users taking an active part in the research [10,45]. This is within the problem scope, as the project investigates how haptic technology could be used in supporting the relationship between the primary caretaker and the person with dementia.

Treadway et al [69] argue that the positive design methods of PD advocate as an appropriate design methodology to foster wellbeing, where the approach itself encourages a shift into the design focus of new products away from the material to more personal values to promote wellbeing. This is argued further by Slegers et al [61], where the use of PD principles was shown as crucial, as the participants involved stimulated the conversation with the person with dementia throughout the session, where it was seen that one of the more important insights into the study was made during the collaboration sessions with the different stakeholders, as it showed the best progress despite different background between the stakeholders.

Lindsay et al [43] study show the potential PD has on involving the person with dementia within the research stages properly, instead of only engaging the primary caregiver, where empowering them through engagement in design has the potential to alter how we think about the roles of technology in their lives. They further argue that when people with dementia are empowered by being given a voice in design, this has given rise to designs that address social interactions with others, as well as facilitate reminiscing about their past to help maintain autonomy through support for activities of daily living.

Halskov and Hansen [34] address some identified forgoing issues, which are mapping definitions of participation and clarifying the roles of the users. Firstly, concerning the issue with mapping the definition of participation in PD, historical developments within PD and their methods of user participation will be mapped to understand the PD practices as well as to map the practices used within this project. Regarding the second issue, a proper definition of how the users are involved will be presented and discussed before the data collection process.

3.1.1 Historical Developments within PD

PD has its roots in northern Europe where a combination of two research programs formed the PD methods and user involvement we see today [24]. It is said that PD was firstly developed from the Scandinavian “collective resource” program that focused on union empowerment in contract bargaining situations through the education of union officials. Secondly, PD was also formed by the study on socio-technical system design by British researchers which focused on the design of technologies to empower individual workers by enabling and supporting autonomous workgroups [24]. Several other projects have aided in the development of the PD method, marking the user participation and methods we use today.

Design at Work – Cooperative Design of Computer Systems

The start of the second generation of PD was marked by the Swedish and Danish UTOPIA project in 1981, which was made in response to discouraging results of previous union projects which showed the limitations of workers influencing the workplace. Therefore, UTOPIA targeted technology development as a place for user involvement to further the influence of the target group. By studying a group of typographers working without computer support, a graphics support product was developed for the graphic workers so there would be a commercial product the unions could use as an alternative to the deskilling products on the market. This project put a new focus on user participation of users when it came to designing discussions, which is carried out and seen as an essential feature of PD [32].

Creating Products – Customer's Demand

In mid-1993, the central engineering organization in Digital began the implementation of a re-engineering effort under the same name of Achieving Engineering Excellence (AEE). The re-engineering effort was inspired by a desire to streamline all dealings with customers, where one of the major goals was to reduce the amount of new project development cycles by 50%. The data collected from a survey of hundreds of Digital’s staff and an analysis of the corporate planning database found that on average 40% of the requirements specified in the Feasibility and Requirements phase of their projects were redefined after a few phases which made Digital on average spend 50% more than budgeted. This loss was sought to be eliminated by forming cross-functional design groups with members from marketing, service, management, and other parts of the company in addition to the engineers restructuring the requirements-gathering process into an iterative “listen-define-validate” model. This model relies on continuous feedback instead of an initial establishment of requirements [4,40]. With this, North-American companies started to apply PD methods and its process to transform both the problem of design and the standards of value for judging the design process and its products [4].

3.2 Data Collection and Evaluation

As mentioned in Section 1, this thesis takes a qualitative approach. Outlined ins a description of the involved users for which the solution is intended. Further, the methods for gathering data will be outlined.

3.2.1 Users

Users within this thesis are categorized as the ones who will contribute and be affected by the final product. Their roles and significance within the project are as follows.

Primary Caretaker

The caretakers will be the primary users of this project as they transition to digital literacy as skills between themselves and the person with dementia affects them directly. As the symptoms and cognitive abilities change, so does the needs of the person with dementia, which would change the way their relationship is supported, making it an iterative process. Additionally, the primary caretakers must take on several new responsibilities and struggles after the initial diagnosis, where the grieving process and communication style differ from person to person. It is therefore important for this thesis to investigate their needs.

Dementia Patients

The scope of the research will focus on the person with dementia, mainly within the stages of mild to moderate cognitive decline. As mentioned in Chapter 2.1.2, the person with dementia may experience a lot of frustration, and insecurities, and have a fear of not being taken seriously due to the stigmatization around the diagnosis. Additionally, it is seen that some dementia patients can become defensive over misplacements and be quicker to anger or irritation. Therefore, it will be necessary to have a proper introduction to the project even though the primary caretaker will be the primary user due to the person with dementia being directly affected.

3.2.2 Participant Sampling

According to Morse [59], the selection of a sample has a profound effect on the quality of the research, having a direct bearing on the reliability, validity, and generalizability of the study. Therefore, the study requires qualitative data from potential users of the project.

With that in mind, selecting caretakers of people with dementia could aid the study in obtaining data that is representative of primary caretakers of dementia patients. This is further supported by Creswell and Creswell [15], who show the importance of in-depth data from samplings rather than the number of subjects.

For a broader perspective, the project would benefit from a sampling of subjects consisting of two groups: Partners who took over the role of a caregiver and children who took over the role of a primary caregiver to a person with dementia. This would give an overall understanding of the perspectives of the different generations and family perspectives. In total, 4 participants were recruited. Out of the 4 participants, two were diagnosed with dementia, while the last two were children of the people with dementia. The first group, which consists of the dementia patient Egil and his son Morten, was included due to my family connection with them. Egil still lives at home with his wife, who originally took on the role of a caregiver, but due to her age, their son Morten took over most of the responsibilities. As they are family, the recruitment process was not hard, and they were glad to be able to help. The second group, consisting of Thune and her daughter Britt, was recruited using a Facebook support group for people with close relations with dementia patients. Thune still lives in her own house alone as her husband passed in 2008. However, her daughter and three sons help her with daily tasks, where Britt and her older brother share the main responsibilities. Britt was eager to join the study, which was welcomed. Two other groups were initially included in the study, consisting of a man with dementia and his wife, as well as a woman with dementia and her daughter, however, due to unforeseen circumstances, they were not able to participate in the study, and had to drop out of the study. Several institutions in Oslo were also contacted, to be able to gain insight from nurses in the field, however, there was no positive feedback from the institutions.

3.2.3 Probing

The first activity within the data collection process in the PD approach was probing. The probing aimed to investigate the communication, struggles, and interactions between the person with dementia and their caregiver from the caregiver's perspective. This was done to gain a broader insight into their daily activities and where the problems with communication may originate. By concluding this research activity, I could further conceptualize which areas lacked effective communication and expand upon this during later research activities.

To explore the struggles in communication and the interactions between the caretaker and the person with dementia, probing as a research activity was deemed necessary. To understand how taking on the role of a caregiver can affect a person mentally and emotionally, gaining first-hand experience in the daily occurrences, conflicts and miscommunication would be beneficial. Gaining this information could show areas where technology could aid in the support of the relationship between the person with dementia and the primary caregiver.

Performing the Probing

Two groups consisted of a total of two dementia patients and 2 caretakers. The probing was performed to gain a better understanding of the day-to-day struggles with communication and daily tasks from the perspective of the caretaker. The workshop was inspired by the literature gathered in Section 2.1 where it is established that there are several routes couples, and family relations can go after gaining the initial diagnosis. In addition, it is seen in Section 2.1.3 that caring for a close relative diagnosed with dementia is one of the more demanding situations to be faced due to the stress from such an unpredictable diagnosis over a long duration. Within the probing, the caregivers were given the task to take one or several photographs each day for a week. These images aim to showcase the daily activities, struggles, and conflicts that may arise while caring for a person with dementia. The caretaker was tasked to take pictures of objects that represent a struggling area within the communication between the person with dementia and the caretaker or caretakers or showcase tasks where conflicts most often arise. Each image should be accompanied by a small paragraph illustrating the issue. The background for this probing session was to gain insight into the daily tasks of the primary caretaker, as well as problem areas from the caretaker's perspective.

The participants were informed about the background of the study before the probing. The assignment was sent out via email, where the participants had 7 days to complete the probing session. When the week is done, they sent the images to me via email, accompanied by a small description for each image.

Analyzing the Data

After the probing sessions, several images were received from both groups. Morten sent a total of 8 images accompanied with descriptions for each, and Britt sent 9 images accompanying descriptions. By using post-it notes, relevant struggles, activities, and daily tasks were written down and sorted to find a common theme. After analyzing the gathered data, reoccurring topics were outlined for further research and to use within the workshop.

3.2.4 Collaboratory Workshop

The second data gathering activity was the last session of the data collection process, where the PD method used in the workshop was journey mapping. Journey mapping is a method for participants to outline their experiences, including frustrations, challenges, and areas of opportunity and conflict [23]. By using journey mapping, it is possible to gain richer information by extracting it within the context of an entire experience [23]. The workshop aimed at discovering the feelings and struggles the person with dementia experiences in their daily life. As the probing session mainly focuses on the experiences and struggles of the primary caretaker, being able to gain insight from the person with dementia would broaden the overall perspective of the research.

To explore the needs of the person with dementia and their relationship with their primary caretaker, a second workshop was deemed necessary. With the information gathered from the caretakers within the first workshop, which gave insight into the caretaker's perspective of day-to-day ordeals, struggles, and conflicts, this workshop would help obtain information about the struggles and conflicts around the diagnosis directly from the person with dementias perspective. This would give me both perspectives to take into consideration.

Performing the Workshop

The workshop was performed to gain a better understanding of the diagnosis of a person with dementias viewpoint. This workshop was inspired by the literature gathered in Section 2.1.2, where it is seen that several dementia patients are afraid of people finding out about their diagnosis due to a fear of no longer being taken seriously or heard, as well as the general anxiety and insecurity about what the decline beholds, how to evaluate, and what the future holds. The workshop was conceptualized around the discussion of the dementia journey timeline. To facilitate the discussion of the timeline I prepared some cut-outs of objects and words that were supposed to facilitate the storytelling of the individual dementia journeys This timeline was divided into three parts; Life before getting the diagnosis, life the first few months after getting the diagnosis, and lastly how it is currently to live with the dementia diagnosis. This helped gain a broader understanding of the diagnosis from the person with dementias viewpoint, as well as give a chance to see how they communicate with their primary caretaker. The workshop was performed individually, where the person with dementia and their caretakers were involved.

Before the workshop took place, all participants were informed about the background of the study. The workshop was performed individually with the two groups over Google Meet. During the workshop, the person with dementia was guided through the making of the timelines using a question guide, which is viewable in Appendix A, with questions relating to the communication and relationship between the person with dementia and the primary caretaker.

Analyzing the Data

After the workshop was conducted, I went through the handwritten notes taken during the workshop, and using post-it notes, common themes in both workshops were taken notice. The results of the workshop can be viewed in Section 4.2.2.

3.3 Prototyping

Based on the information gathered during the literature review and data collection methods, a prototype was created, where the process can be viewed in Section 5. First, an initial concept definition was created to get an overview of the activities held, and how they tie into the scope of the study. Further, the goal of prototyping was established using themes seen in the probing activity and workshop, displaying the needs of the people with dementia and their caretakers. With this, a final concept was established.

3.4 Ethical Considerations

As in any research, you must be aware of the ethical implications when collecting data and information from subjects. As the work behind this project is on behalf of Østfold University College, I adhere to their research ethics guidelines [88]. The ethics guidelines state that I as the main researcher have an independent responsibility to ensure that all research takes place following the generally recognized ethical principles. The college has made a list of ethical guides, which I have followed throughout the project. Further, it is said that the work must have a beneficial value to society and avoid controversial implications while still contributing to relevant research. The work performed in this project has no harmful implications for society and carries a beneficial value to its future users.

In this project, the involvement of subjects is essential to the final design, as inviting potential users into the research and design process is crucial within PD methods.

All users within the project were informed about the data collection methods used within the study beforehand, and I obtained electronic consent from the users in the study. Before any interviews or workshops were held, the users were informed about the tasks and activities beforehand, and concerning the interviews, the users were given the interview guide before the interview. Lastly, I have ensured the users of their anonymity throughout the entire project.

Before starting the data collection, the Norwegian Centre of Research Data requires researchers to apply in case any personal information such as health records, names, and background information that could show who the person was used. I applied, registering that some health information would be used, however not to the extent of possibly taking away the person's anonymity. I did not need to register any other person's information from my subjects. Based on the aforementioned guidelines from Østfold University College [88], the research performed in the thesis adheres to ethical principles.

Chapter 4

Applying the Methods

This chapter goes through the data collection activities leading to the final prototype goal and design. The process that led to the data collection methods being used is based on the information gathered in Section 2. This section also shows the results of the probing activities and workshop performed, which are described in Sections 3.2.3 and 3.2.4. The results presented will be slightly analyzed for further use in Chapter 5.

4.1 Initial Concept Definition

To gain an understanding of how dementia can manifest differently from person to person and see how technology is currently being used within the lives of both caretakers and people with dementia, a literature review was conducted. The results of this work can be found in Section 2. In the literature review, I have covered the diagnosis of dementia and how it affects both the person diagnosed and their family and spouses. In addition, I have also explored how haptic and wearable technology is currently used within dementia care, and how it can be used to promote better communication between the person with dementia and their primary caretaker. The relationship between the person with dementia and the caregiver was also a key area to explore, as it would provide an understanding of where communication issues might occur.

The findings from the literature review formed my understanding of the dementia diagnosis, and how it develops differently from person to person. However, what are the more common struggles faced within the mild to moderate stages of cognitive decline? Despite the knowledge gained from the literature review, this thesis would benefit from exploring the real-life issues experienced by both caretakers and people with dementia. Therefore, two workshops were conducted to gain a broader understanding of how caretakers experience communication issues and handle daily tasks, as well as to see the progression of the diagnosis from the person with dementias viewpoint. This would also make it possible to see where technology could be used to support the relationship between the person with dementia and their primary caretaker. With an overview of my previous work, the data collected within the workshops based on the literature review will be explored.

4.2 Findings of the Data Collection

In this section, I present findings from the data collection. The background for the data collection methods, as presented in Section 3.2, is based on gaining a broader understanding of how a dementia diagnosis affects both the person diagnosed and their primary caretaker. In addition, they were held to explore possible struggles and areas of miscommunication between the person with dementia and their primary caretaker.

4.2.1 Findings of the Probing Activity

The focus of the probing sessions was the experiences and emotions of both spouses and family members who care for a person diagnosed with dementia. Two groups of participants were included in the probing activity. The first group consisted of Britt, who is a caretaker for her mother Thune, while the second group consisted of Morten who is the caretaker for his father Egil. The probing activity aimed to find areas of conflict, miscommunication, and struggles within their day-to-day activities. It also allowed me to explore what tasks were being mainly handled by the primary caretakers.

Findings from the probing session show that both groups show difficulties in communication between the person with dementia and their caretakers, as well as between the caretakers themselves. In the first group, Britt described feeling irritated by the rising pile of mail and magazines that were constantly coming into the house due to the lack of communication between her brother and his mother. She briefly explained in her photo description that even after her mother acknowledges the amount of spam mail and magazines she is getting is too much, that same behavior and communication is not present between the mother and her brother, which has led to more spam mail and magazines arriving at her house, furthering the irritation and tension. With this, it does not seem likely that a system is set in place to handle expectations and priorly set boundaries for one of the parties.

Figure 3 - Visualization of miscommunication in the second probing session

It was also seen that a lot of the daily tasks consisted of food shopping, cleaning, and sorting through the fridge and refrigerator. Britt describes her mother Thune as enjoying sorting through the groceries herself. However, she often forgets to check for supplies that have expired, as well as fruit from the garden that keeps being put in the freezer, and never picked up again. This is seen in several tasks that have been documented. Some conflict was also documented in both groups. In the second group, it is seen that one of the main tasks of Morten is to drive his father around the city due to his deteriorating physical health. It was documented by the participant that an ongoing discussion between him and his father, and with the father and his spouse as well, was about the use of a scooter to further promote his independence. The participant describes that it is because his father is stubborn. However, as seen in the literature in Section 2, this could be a reaction to needing mobility aid and the fear of being judged by his peers. In the first probing session, it is seen that a constant moment of irritation is the mother denying not having done certain tasks, such as sorting through the mail, changing her bedding, or cleaning up after holidays, such as removing Christmas decorations. The daughter always must double-check everything within the mother's home to make sure things are done as the mother has said, which usually is not the case. This creates agitation within the relationship.

Figure 4 - Visualization of daily tasks during the first probing session

For the first probing session, it was also seen that most of the miscommunication was between the siblings. One instance described was the difficulty of keeping and assigning appointments. If something was scheduled from the daughter's side, it was easy for her brother to forget what he was supposed to help the mother with the day off, causing irritation and discussions between them. However, this was one of the things the mother was able to write down on a note, which made her able to attend on her own. This could show a lot of anxiety around the diagnosis from the caretaker's standpoint, which might have led to unnecessary stress and overwork for both her and her brother. The daughter says that she has felt both irritation and despair with the diagnosis of her mother, as the mother is according to her quite stubborn. This is shown in the description of one of the photos she took, where the main issue surrounding it was the communication with her mother, which has always been concise.

4.2.2 Findings of the Collaboratory Workshop

The workshop was focused on the experiences of the person diagnosed with dementia, and their own experiences with their families' emotions and reactions around it. The people present in the workshop were Thune and Britt for the first group and Egil and Morten for the second group.

The years before the diagnosis

It is seen in both workshops that both dementia patients used to spend a lot of time with their families before their diagnosis. In the first workshop, Thune shows and describes with her timeline that she used to love having family over for big parties, and being able to cook for her family, it being her passion. She was also able to work two jobs, so she would be able to spoil all her grandkids. She also saw herself as a helper, especially with her youngest child, where she used to travel to his home and act as a cleaning lady while he spent time with his son. This was explained away with the reasoning being him being a single dad at the time., However, annoyance was seen in her daughter's expression when this was explained. Before the diagnosis, she also explained that she was an avid traveler, both to the summer houses she had helped build, but also to other countries. When talking about the years before the diagnosis, joy was seen on her face when she was reminiscing about her family and the relationship between them, showing that the relationship used to be good. For Egil, he explained that his wife and he used to be avid travelers, traveling for weeks at a time with no issues. He would also be the one driving his wife and himself to family gatherings, helping with food purchases and other menial tasks during the week. One of the greater memories he has from before the diagnosis was being able to properly play with his grandkids and being able to be there to take care of them. This is also something he said brought him closer to his family and was a way to spend more time with them outside of the normal visits and birthdays.

For both participants, it is seen that the relationship with their family before the diagnosis was strong. Britt described wanting to be there for her kids no matter what, which manifested in several calls to her family to check in on them and her grandkids, being the one who assembled the family for weekly dinners, and doing it all with a smile, as it was her way of showing her love. She describes her relationship with her family as loving and with open communication, and that she would do everything for them no matter the distance, where she was smiling while describing it, showing genuine happiness from the memories. In the second group, Egil describes loving to be a carpenter and helping his family with their houses, whether it was helping to paint, or helping with a new upgrade in the house. He describes his relationship with his family as close, where most family members were within a 10-minute drive, with open doors at all times. With a smile, he said that the family would often come over on the weekends with his grandchildren, where he would often join in on the shenanigans of the kids.

The months before the diagnosis

In the first workshop, it is seen that the person who was later diagnosed started pulling away from the family. With the caretakers in the room, Britt started explaining that she had started forgetting a lot of things, which made her irritated and confused, and as not to worry her family, she started calling less and less. She also explained dreading doing grocery shopping, as she was afraid of having forgotten her wallet or forgetting most of the things she was traveling down to get. Cooking as well, became more of a chore than the joy she experienced with it before, making her dinners smaller until she essentially mostly ate bread here and there. The caretakers chime in during this description, saying that this was the last straw before they wanted her to seek a diagnosis, as her whole personality changed. Another area she said changed when she started to assume something was wrong was that she started pulling away from family gatherings as well and stopped taking her trips to the summer houses, as this would be, in her own words, too much for her alone. This can also be seen in Section 2, of how it is often seen that the person who is diagnosed often retreats from the family due to their stress, insecurities, and worry about their health and how they will be perceived by their family. This could also be the case here. She also explains that she felt the relationship with her family was high strung, mostly due to the sudden change of roles that had to be done, but she also says that she is forever grateful for her daughter who, even before knowing about what she was dealing with, helped her as much as she could.

In the second group, the diagnosis played more into the physical aspect of Egil’s life. He explained the feeling of being less active and having a harder time walking around, both in the sense of forgetting the stores he was supposed to visit, but also in the sense of physically walking. He explains that he was annoyed at himself for not being able to do as much as he wanted, especially with the younger kids who still wanted him to play. However, he said he saw this as normal aging at first. Closer to getting the diagnosis, he describes the feeling of being confused and feeling a bit off, as it became harder to travel with his wife without needing extra help traveling around the country as he was not able to drive anymore or handle the money they had saved for the vacation. He says he did not know why at first, but his eldest son started coming around more often to help with cutting the grass and drive him around and remind him of his errands, which he explained at first was an annoyance to him as he saw himself as perfectly capable of doing these menial tasks himself without assistance. Closer to getting the diagnosis, he explains that he started to misplace his wallet and phone more often than usual and had a harder time getting out of the house, which also limited the places he traveled to visit his family. He explained that he felt more isolated not being able to drive himself to visit family members, and with a chuckle explained that his stubbornness made it, so he did not want to ask for a ride either. With this, he says that his relationship with his family was still strong, but unnecessary arguments and stubbornness were something that had a negative effect.

After the diagnosis and the current state of the relationships

There is a significant difference between the family relationships in the first and second workshops. In the first group, Britt describes not seeing her family nearly as much anymore, but that her four kids are often visiting to help her out with daily chores. She describes being confused and irritated at times with them helping her, as she sees herself as perfectly capable of doing daily tasks herself, whereas she also refused to get help from at-home nurses that could visit her. She also says that she is not seeing her grandchildren as much as she did before due to them not coming around as much, but not knowing why. This can be connected with the daughter's descriptions from the probing session, where it is seen that she has experienced a lot of stress and irritation with her mother after the diagnosis but does not go into detail about why. In the workshop, she described the relationship with her family as being a little tense, but that she still sees her children every week.

In the second group, Egil explains that he now sees his family more often than right before the diagnosis, where his son is the one to drive him for daily errands, to visit his old friends, and visit family, making it so he can visit different family members each week. Laughing, he says that he is still as stubborn as before, but with his kids having the same stubborn gene, they have helped him accept the help more. He says that he still experiences irritation and frustration around the fact that there are certain things he is not able to do by himself, such as going down to the café in the city center to meet his old friends, however, he is accepting that he needs some help and is happy his son and wife are supporting him. When it comes to the relationship with his family, he feels it is as strong as it was before, even with him having difficulties with some tasks himself. He explains that the family is incredibly supportive and is in close contact with both his children and grandchildren.

The Use of Technology

During the workshops, relevant wearable technology was presented to both the caretaker and the person with dementia to assess their technological level. Wearable technology such as smartwatches, tablets, and smartphones was presented. In both workshops, a similar technological level was found.

With smartwatches, both caretakers and the participants with dementia had a similar technological background. The caretakers had seen and had some experience with the smartwatch; however, none had the interest in using them. In the first workshop, the caretakers explained that due to their age, they had no interest in learning the ins and outs of smartwatches, even with them having a general knowledge of how to use them. Similarly in the second workshop, the caretaker had a general knowledge of how to use a smartwatch, however, did not see the reasoning in buying the technology just for this reason. The people with dementia had never used a smartwatch before, even though they were familiar with the technology from their grandkids. In the first workshop, the participant with dementia explained that she would not need a new watch, as she still used and favored the one given to her by her late husband. In the second workshop, the participant with dementia explained that he in general had no interest in getting to know the technology and would rather not use the money on such things as he saw it as wasteful.

For the use of tablets and smartphones, the technological background was a bit more expanded upon. The caretakers, had extensive knowledge in the use of both technologies, where they all use smartphones every day, as well as some using tablets for at-home purposes. In the first workshop, the caretakers explained that they both used their smartphones actively, mostly using applications such as Facebook, Outlook, and Messenger, but also using smartphones to pay their bills. With this, they showed a general level of technological competence. One of the caretakers explains however that she mostly uses Facebook and Messenger to keep up with her family and to plan family gatherings using a Facebook group she made in 2018. This could indicate that a simple, minimalistic design would be practical. In the second workshop, the caretaker had a higher level of technological competence, where he daily uses applications such as Facebook, Instagram, Messenger, and different mobile game applications. Due to his age, he has been using a smartphone and tablet for several years and would count himself quite skilled in these technologies. For dementia patients, the use of smartphones and tablets was a bit less. In the first workshop, the participant shows that she has general knowledge of what smartwatches and tablets are, which she explains are due to her older grandkids teaching her the technology. However, she mostly uses it to pay her bills, with help from her caretakers. In the second workshop, the participant showed a bit more knowledge of the use of both smartphones and tablets. He explains that he has his tablet, just like his wife, where he uses both Facebook, email, and applications to pay the household bills. He explains having learned to use Facebook from his wife, who is an avid user of innovative technology.

Chapter 5

Prototype

This chapter revolves around the design activities leading up to the final prototype, as well as a presentation of the final design and future prototype activities. The final prototype will also provide further exploration of the research questions presented in Section 1.3. The steps toward the final prototype designs taken revolve around the initial ideas behind the prototype and show the thought process after the data collection results. I start by presenting the initial concept definition of the prototype, and the requirements for the application. Secondly, a practical review will be presented, showing the technology that will be used for the design, as well as earlier studies on how wearable technology has been used to support the relationship between a person with dementia and their caretaker. Then, the final concept will be presented, as well as the initial sketches for the prototype. Lastly, the finished prototype design will be presented and slightly discussed.

In the process descriptions, I have explained my thought process between each method applied, as well as the directions I took towards the final prototype to provide a detailed explanation of how the methods were applied.

5.1 Defining the Goal of Prototyping

After gaining theoretical knowledge from the literature review, and the conceptual knowledge gathered through the probing sessions and workshops, some requirements for the prototype have been made:

- There is a need to develop something that supports healthy communication between the person with dementia and the primary caretakers.
- The solution needs to support an honest relationship between the person with dementia and the caretaker.
- The solution must have a low threshold in terms of usability
- The solution needs to be compliant with the rules of WCAG 2.1 to cater to older users.

I wanted to provide the person with dementia and their caretakers with something tangible. My first thought was to look at existing solutions, which can be seen in Section 2. Further, I needed to find relevant technology based on information gathered during the workshop so I would know what would work within the scope of the study.

5.2 Final Concept of Prototype

After completing the project evaluation, I decided to go through the collected data to finalize a potential solution. The underlying theme resulting from my preliminary research was that communication between the person with dementia and their caretaker was overall lacking, where discussions, irritation, and frustration from both sides were often the outcome. The method of how this can be introduced within the care for dementia patients would be the main challenge. With this, it should not replace proper communication between the person with dementia and their caretaker, but rather support it. Therefore, the final prototype will operate as a smartphone application that will support better communication between a caretaker and the person with dementia, as well as between caretakers, and support the independence of the person with dementia. The application would have three core functions:

- Assistive reminders
- Shared calendar
- Announcement system

With assistive reminders, the personhood and independence of the person with dementia can be addressed. The reminders would be set by the caretakers, either on a daily schedule, weekly, or set to certain days depending on the background of the reminder. As seen in the TAUNT smartphone application [35], the reminder would send out an ongoing notification sound that would last 40 seconds. If the notification was not logged as seen or accepted after the 40 seconds, a notification would be sent to the caretakers. This way, the monitoring of the person with dementia would be less intrusive, as seen in Section 4, and caretakers would also be able to keep up with the daily tasks of the person with dementia. The calendar system would also be viewable to the person with dementia in the design of post-it notes, where caretakers would be able to add events, birthdays, appointments, and family gatherings to the calendar for the person with dementia to see and keep updated. The calendar would also give out reminders to the caretakers, so if the caretaker should take the person with dementia to an appointment, both parties would be updated. Lastly, the announcement system would aid in the conversation between the caretakers, where they could start discussions on things to bring to events, share experiences, update each other on things that need to be done, and keep a united front with the person with dementia.

5.3 Designing the Prototype

I began my design by sorting the content of the application as seen in Figure 5. Findings from the project evaluation suggest that the application should be inclusive of different generations, due to the possible difference in age between the person with dementia and their caretaker. Therefore, it must be assumed that the person using the application does not have extensive experience in using wearable technology. Therefore, the application will contain the following:

- An FAQ for new family caretakers containing information about the person diagnosed with dementia, their current cognitive abilities, and general guidelines developed by a healthcare professional on how to care for a person with dementia.
- A calendar system where caretakers can insert activities, family gatherings, and other useful information. This will automatically update all relevant caretakers both when added to the calendar and the day before the activity.
- A notification system where caretakers can send out notifications to other caretakers and the person with dementia for general reminders have shopping lists, an overview of what the person with dementia has at home when it comes to food, etc.
- A post-it-note system is available for both the person with dementia and the caretakers, where both parties can make notes of notable events or daily tasks for the person with dementia to accomplish.

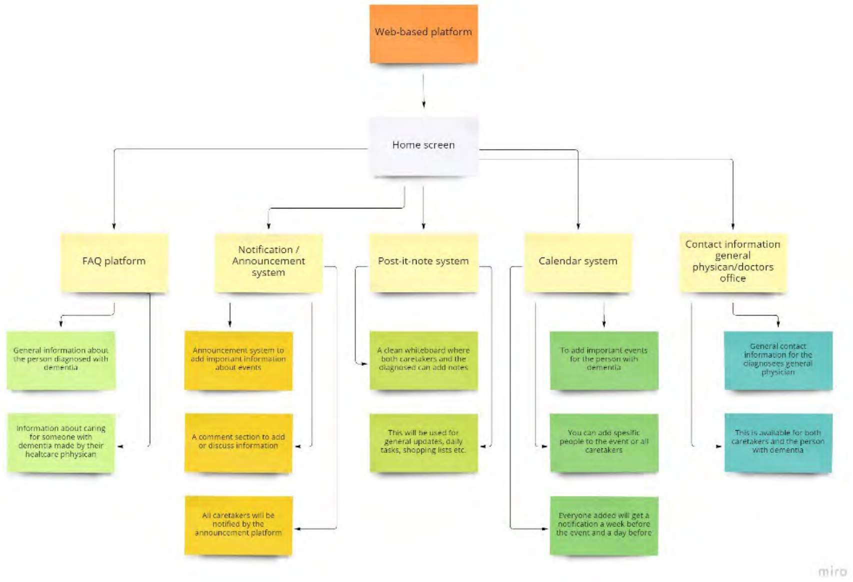

Figure 5 - Content of the interactive application

5.3.1 Sketching the layout

Before designing the application, I decided to sketch out my layout. The layout is presented in low-fidelity wireframes. I wanted the application to be minimalistic with clearly sectioned columns of information to not confuse the user. Figure 6 presents the layout of the homepage of the application. On this page, the whole application is summarized to ease the navigation for the users. First, the next event and the newest announcement are presented with a small description underneath both sections. This is followed by a FAQ section for the caretakers to browse, containing both valuable information about the person with dementia's needs and information about how to care for a person diagnosed with dementia. Lastly, the person with dementia's primary physician is listed to make it easier to contact them in case of an emergency, as well as a list of upcoming events or family gatherings

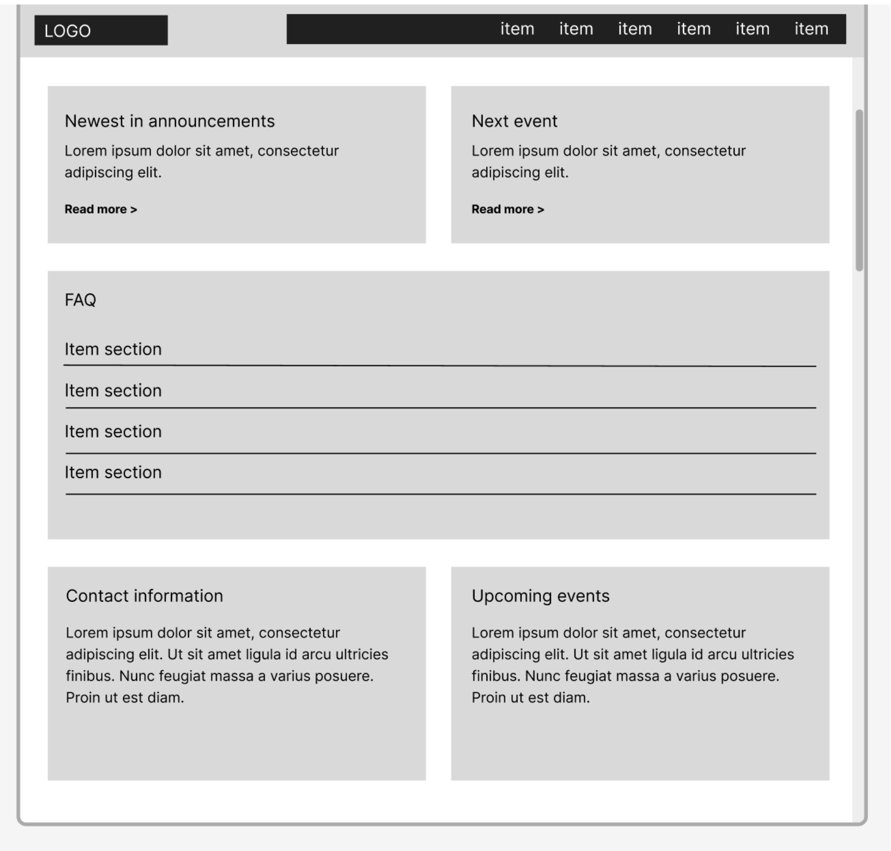

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Figure 6 - Sketch of the home page for the application.

The second page I sketched focused on the announcement page as shown in Figure 7. It focuses on the internal page where caretakers can comment on the announcement and make their own. The clean, minimalist design is continued on this page, where the comment section and announcement section are sectioned. Based on the information gathered in Section 4.2.2, it is seen that the caretakers are used to media such as messenger, Facebook, and other types of social media, as well as being used to use wearables such as tablets and smartphones. With this in mind, the announcement area has taken inspiration from social media with its design to make it easy to use.

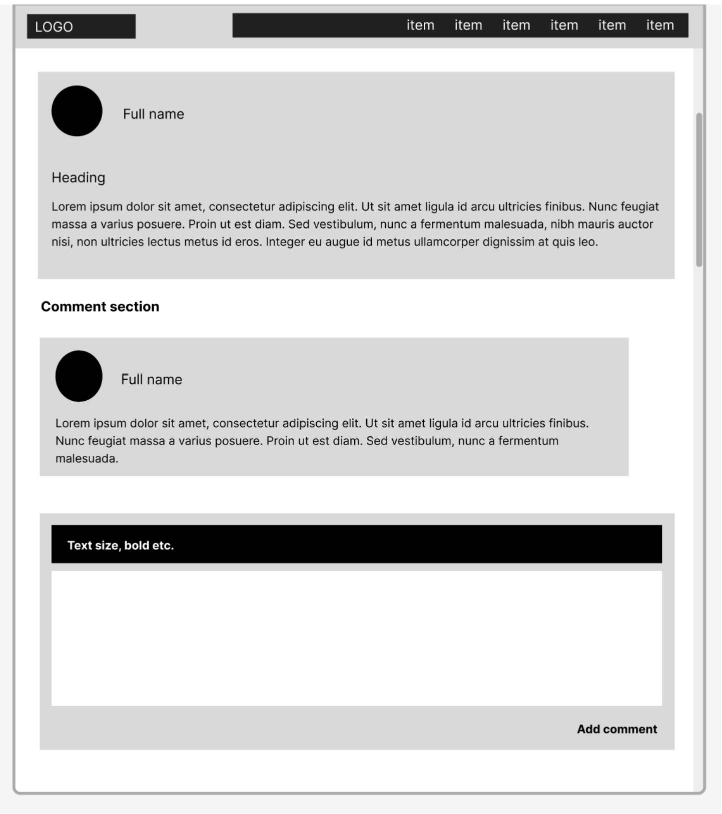


Figure 7 - Sketch of the announcement page

The last page I sketched as shown in Figure 8 focuses on the post-it note page which is accessible to both caretakers and the person with dementia. Based on information gathered during the data collection methods, as shown in Sections 4.1 and 4.2, there was a lack of notifications for both the person with dementia and the caretakers, which resulted in unnecessary irritation and conflicts. When creating a post-it note, the user can decide if they want it added to the calendar, or if it should be regarded as an announcement. If added to the calendar, it would send out a notification to all users, with two extra notifications a week before the event, a day before the event, and the day to remind both the caretakers and the person with dementia. The person with dementia would also have a stationary tablet where this page would always be open for them to look at, and with the possibility to navigate to the calendar to view upcoming events. As a security measure, if the person with dementia does not go back to the post-it note page after a set amount of time, it would automatically go back to make sure that the relevant information will always be available and for notifications and announcements to go through properly. With this being connected to the calendar system, a similar design will be used for this.

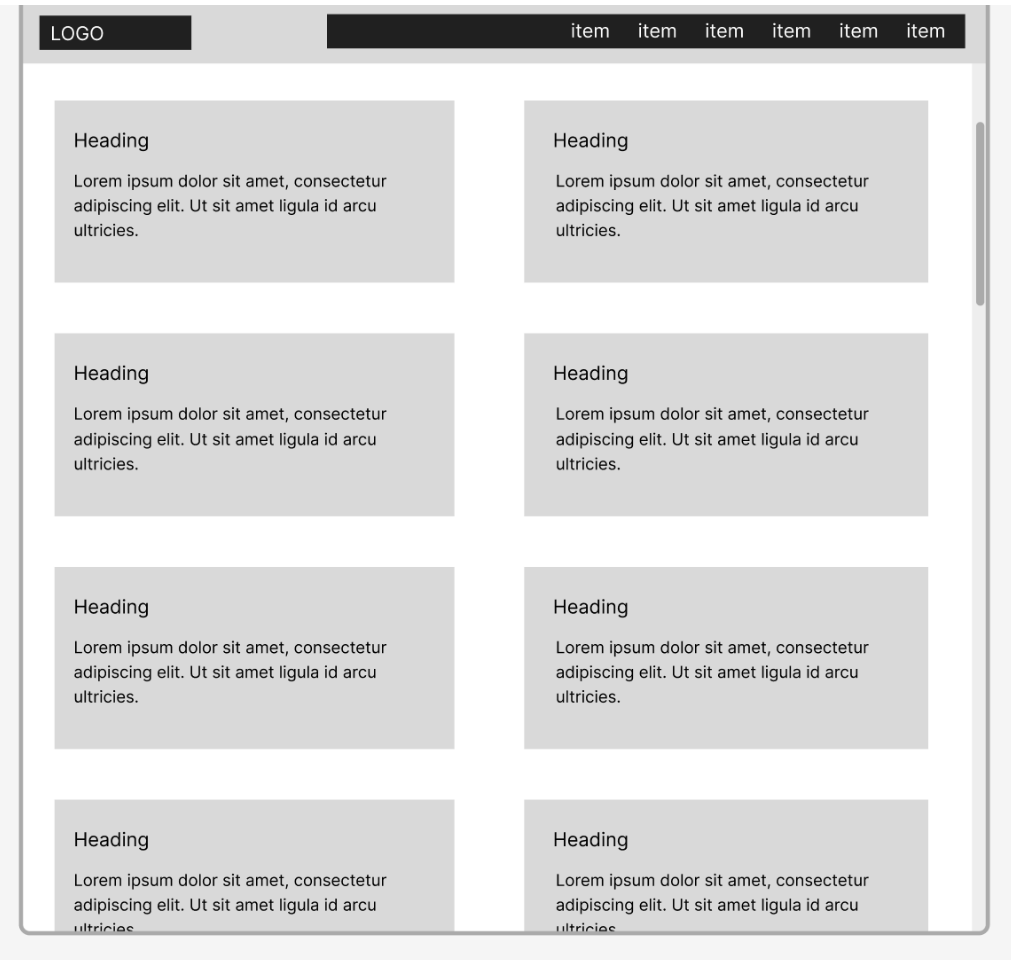


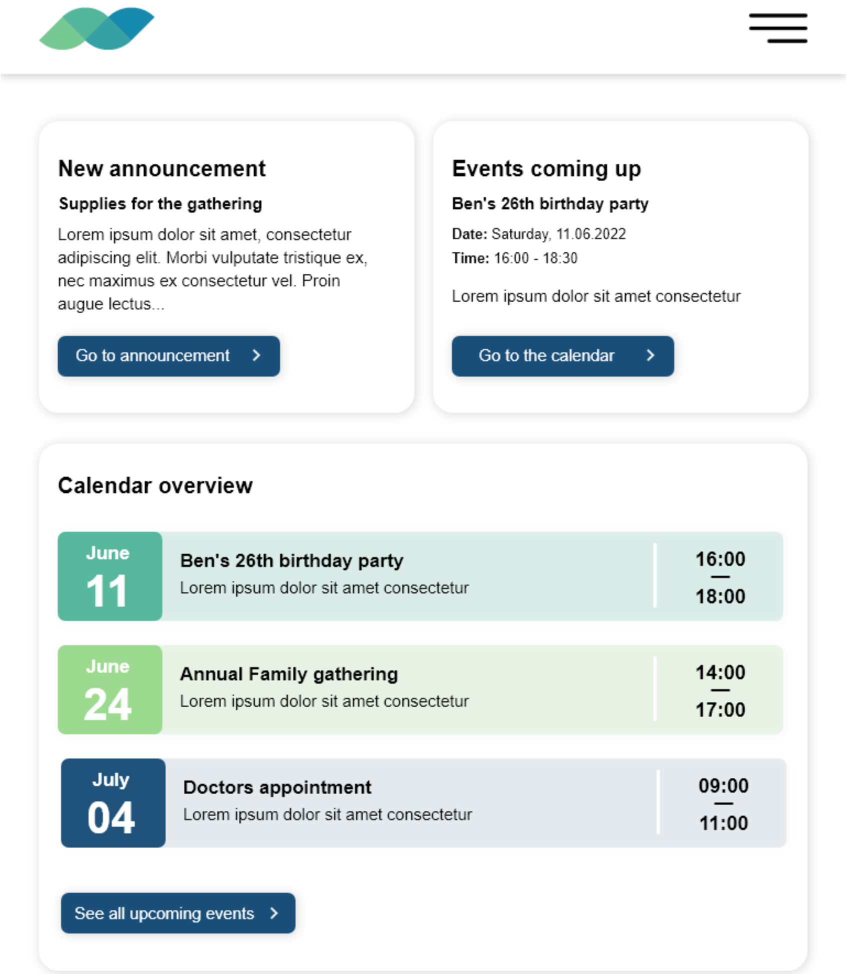
Figure 8 - Sketch of post-it note in the application

5.4 The Final Prototype

This section presents the final prototype design based on the design from the previous chapter. The application consists of three main pages; The home page, the announcements system, and the post-it note system. Lastly, a method of design evaluation is presented, where the results will be shown in Chapter 6.

5.4.1 Home Page

Figure 9-11 illustrates the key features of the application, giving the newest updates and announcements to the user. The newest updates and information are displayed at the top to keep the user up to date on current events and announcements made by the other caretakers in the family. An overview of the calendar is also viewable on the front page, where the three upcoming events are displayed. Lastly, in Figure 11, you can see that it also has a FAQ section, where regular questions about caring for someone with dementia are answered, and facts they might need to have to effectively communicate and aid the person with dementia. The users will also have a menu displayed in the top right corner, where the users will be able to go to the main pages of the application. This way, users have several ways to keep up to date, and several ways to navigate through the applications.



New announcement

Supplies for the gathering

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Events coming up

Ben's 26th birthday party

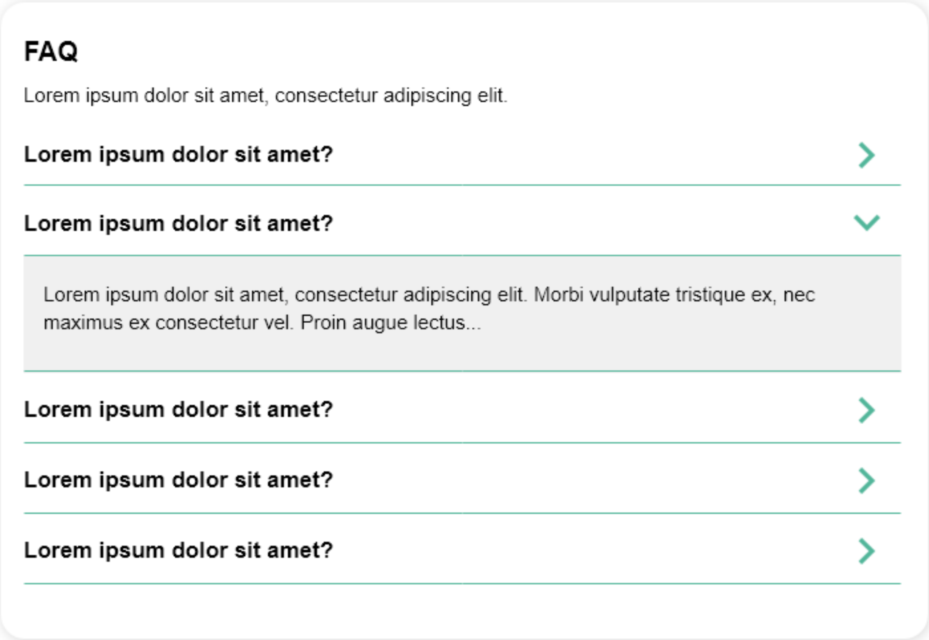
Date: Saturday, 11.06.2022
Time: 16:00 - 18:30

Lorem ipsum dolor sit amet consectetur

Calendar overview

June 11	**Ben's 26th birthday party** Lorem ipsum dolor sit amet consectetur	16:00 — 18:00
June 24	**Annual Family gathering** Lorem ipsum dolor sit amet consectetur	14:00 — 17:00
July 04	**Doctors appointment** Lorem ipsum dolor sit amet consectetur	09:00 — 11:00

Figure 9 – Upper front page of the prototype



FAQ

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Figure 10 - The lower part of the home page prototype

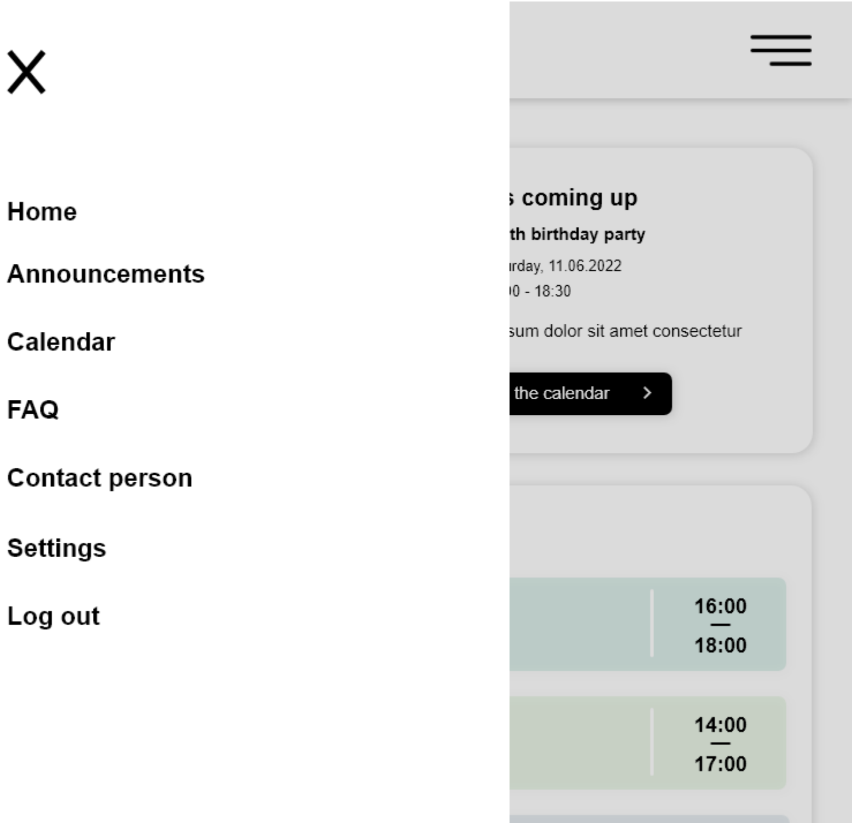
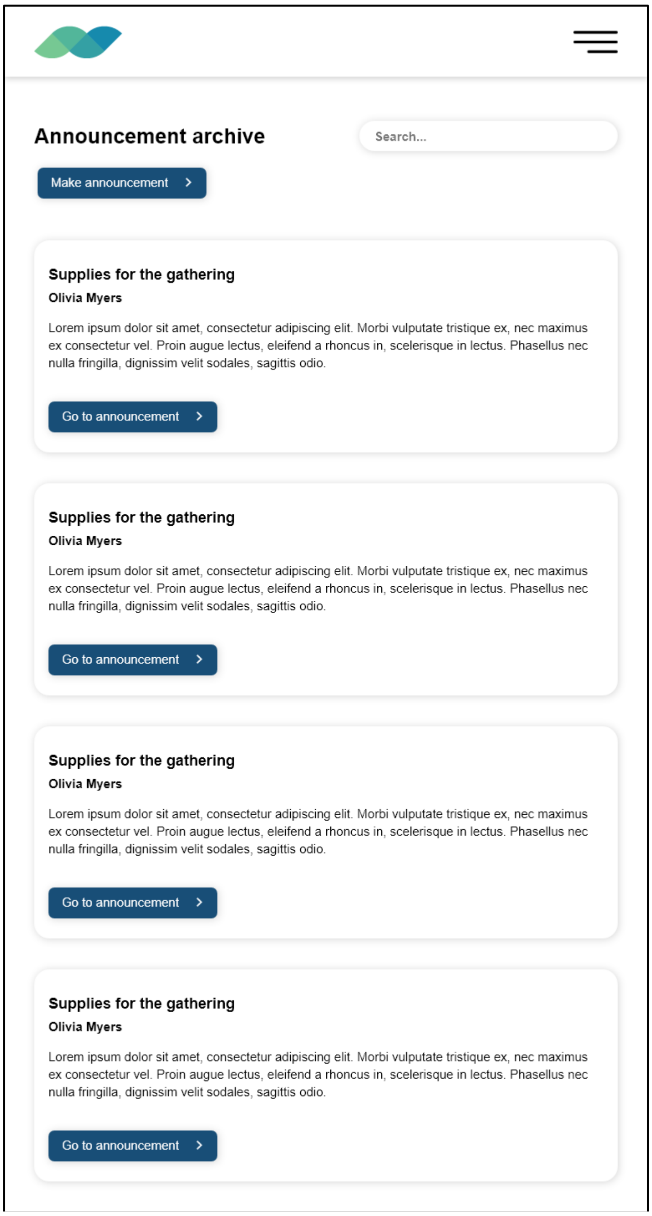


Figure 11 - Visualization of the menu structure

5.4.2 Announcement System

Figures 12 and 13 illustrate the announcement system which will be used in the application. Firstly, in Figure 12 the announcement archive is viewable. The users will be able to navigate through previous announcements, make their own, and view the announcements based on dates, months, and years they were posted, so that they will be able to search through the previously posted announcements easier. In figure 13, the announcement page is shown, where the users will see who posted the announcement, and what date, and they will be able to comment to keep each other up to date.



Announcement archive

Supplies for the gathering
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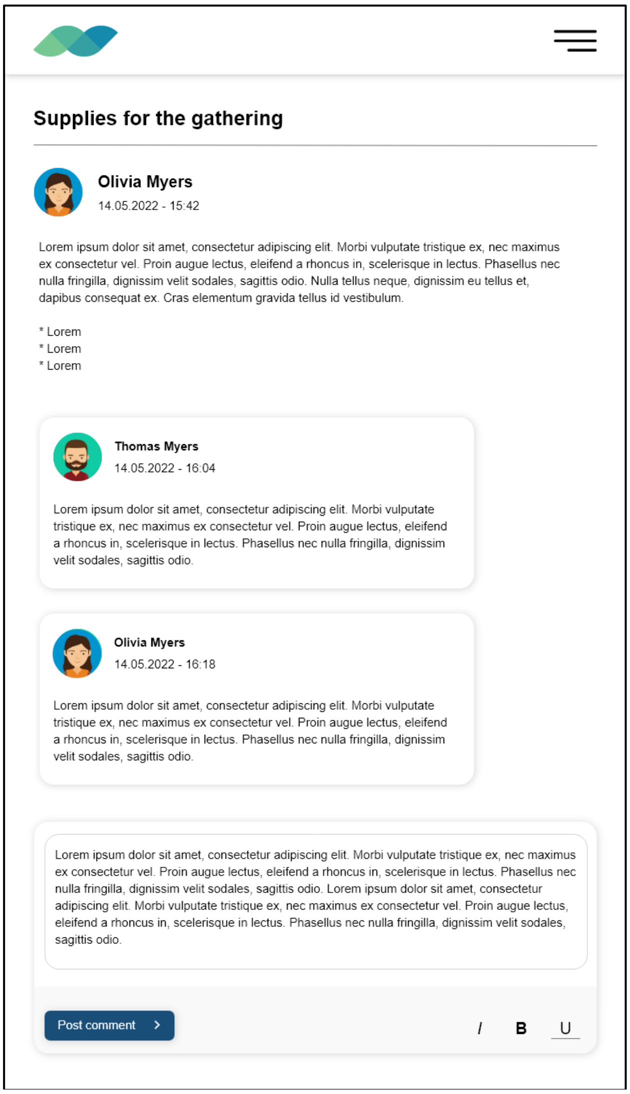
Figure 12 - Archive of the announcement system



Supplies for the gathering

Olivia Myers
14.05.2022 - 15:42

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Thomas Myers
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Olivia Myers
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Figure 13 - Announcement with comments

5.4.3 Calendar System

Figure 14 shows the visualization of the calendar system, which will be viewable for both the person with dementia and the caretakers. Each event or gathering is shown with assorted colors to differentiate between them more easily, where the date is made bigger than the rest of the text, to be more viewable for all users. On this page, users will be able to add things to the calendar, categorize it as an event, family gathering, birthday, and other terms, and add a brief description of what will happen during the event. The categorization is there to show the users more easily what will happen during the event, as headings might not always be as informative at times.

Calendar overview

June 11
Ben's 26th birthday party
Lorem ipsum dolor sit amet consectetur
16:00 — 18:00

June 24
Annual Family gathering
Lorem ipsum dolor sit amet consectetur
14:00 — 17:00

July 04
Doctors appointment
Lorem ipsum dolor sit amet consectetur
09:00 — 11:00

June 11
Ben's 26th birthday party
Lorem ipsum dolor sit amet consectetur
16:00 — 18:00

June 24
Annual Family gathering
Lorem ipsum dolor sit amet consectetur
14:00 — 17:00

July 04
Doctors appointment
Lorem ipsum dolor sit amet consectetur
09:00 — 11:00

June 11
Ben's 26th birthday party
Lorem ipsum dolor sit amet consectetur
16:00 — 18:00

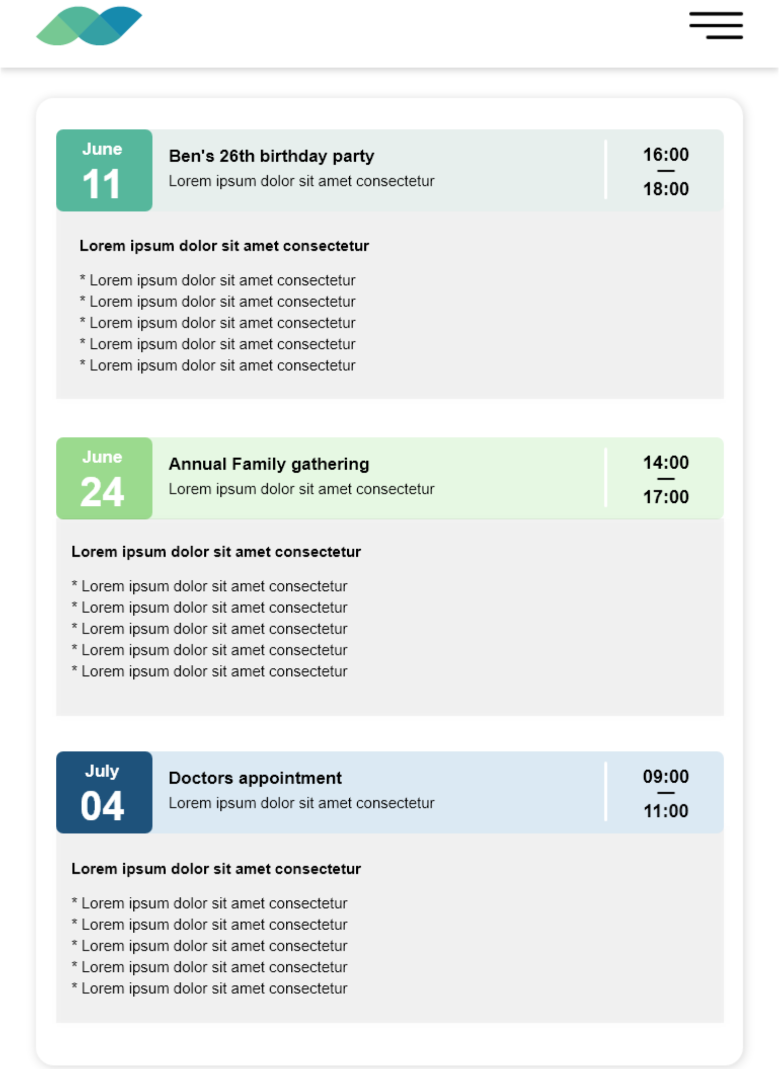
June 24
Annual Family gathering
Lorem ipsum dolor sit amet consectetur
14:00 — 17:00

July 04
Doctors appointment
Lorem ipsum dolor sit amet consectetur
09:00 — 11:00

Figure 14 - Visualization of the calendar system

5.4.4 Post-it note System

Lastly, in Figure 15 the post-it note system is shown. This will be viewable for both the person with dementia and the caretakers. This is used to easily display daily tasks for the person with dementia, as well as reminders such as birthdays, shopping lists, and more. If a caretaker adds something to the post-it note page, this will automatically be updated on all devices, including the device of the person with dementia. A notification will also go out, to make sure everyone involved is up to date.


June 11

Ben's 26th birthday party
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16:00 — 18:00

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June 24

Annual Family gathering
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14:00 — 17:00

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July 04

Doctors appointment
Lorem ipsum dolor sit amet consectetur

09:00 — 11:00

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Figure 15 - Visualization of the post-it note system

5.4.5 Evaluation of the Prototype

To rigorously evaluate the need and usability of the application, the previous participants were gathered for the last workshop. With this, the application's design was made interactive, to accurately assess the navigation aspects, usability, and general design of the application. Using the thinking aloud method, which is a method where participants verbalize their thoughts and spontaneously report everything that is going through their minds while exploring the application [33], the participants were given directions on where to explore and what to look for. These prompts were used to engage the user, and to see how they would navigate through the application. The prompts are as follows:

- Find the newest announcement using the menu.
- Navigate to the calendar page.
- Navigate to the FAQ section.
- Find the announcement archive. When this is found, navigate back to the home page.
- Find the reminders page.

5.4.5.1 Planning the evaluation

After the users have explored the application, they were asked a series of questions about the usability and design.

Usability

The goal of the prototype was to have a universal design where all users, no matter their age, can navigate and understand the layout of the application. To assess the experience of the participants, the following questions were asked:

- How was it to navigate between the pages?
- How difficult was it to find the correct pages from the prompts?
- Was it easy for you to navigate between the announcements?
- How would it be to navigate between reminders?
- Is it easy to find your way back to the home page?

Design

To make sure the design is usable for all ages, some questions about the fonts, colors, and overall layout was asked:

- How difficult was it to differentiate between the sections of the first page?
- Did you have any trouble with the colors that are used in the application?
- How is it to read the text used?
- Is the design easy to use?

Relevance

Lastly, the relevance of such an application needed to be addressed, to make sure that this application would be usable for the participants in the future. Therefore, questions to further explore the participant's experience of the application were asked:

- How relevant would this application be for you in the care of a person with dementia?
- Do you think such an application would aid in your daily activities?
- Does the homepage have the information you need?
- How likely would you be to use this application as a caretaker?
- Would an announcement system that delivers notifications and reminders be of use to you?
- How likely would you be to use the reminders/post-it note page?
- Would the reminders page be of use to you in caring for a person with dementia?
- Would a system that collects the means of communication aid you in supporting a person with dementia?

5.4.5.2 Performing the evaluation

The evaluation was performed to gain insight into the thoughts and perspective of the participants on the designed application and was inspired by the data analyzed in Section 4, where it was seen that miscommunication and the lack of reminders was a huge point of irritation and unnecessary conflicts between the person with dementia and the caretakers. The evaluation was performed over Google Meet, where the participants screen shared the application, to keep an eye on how they used the application, and how they navigated through the prompts. After going through the prompts, the participants were interviewed using the questions listed in Section 5.4.5.2. These questions were asked to gain broader insight into their possible use of the application, its usability, and the general design. The evaluation was performed individually, where the participants were informed about the background of the study before the evaluation.

After the evaluation was conducted, the answers to the questions in Section 5.4.5.2 were gathered. The results of the evaluation will be presented in Chapter 6.

Chapter 6

Results

This chapter presents the findings from the evaluation of the final prototype outlined in Section 5.4. The evaluation was performed with the caretakers in the study, Britt and Egil, where I will summarize the findings. As seen in Section 5.4.5, a list of both prompts for navigating the website, and a list of questions for the participants was outlined. Based on the nature of the questions, the evaluation was divided into three parts; Usability, Layout and design, and the relevance of the application. The first part of the evaluation went over the prompts outlined in Section 5.4.5, as to be able to evaluate the navigation of the application. Second was the evaluation of the layout, where the color palette, font, layout, and the easiness of the design was evaluated. Lastly, the last section goes over the relevance of the application in the participants daily activities, and to which extent this would aid them in caring for someone with dementia.

6.1 Usability

This section covers the findings pretraining to the navigation of the application for the participants. When going through the prompts for navigating between the different pages and sections of the applications, the caretakers seemed to easily navigate. This was confirmed with the questions related to usability. Both caretakers said that it was easy to navigate through the pages, and to find the information needed when the prompts were given. Navigating back to the homepage was also not difficult for either participant. Britt had some concerns regarding the navigation when it comes to her mother, as she is not the best at using application, even though she has started to get used to using a smartphone. For Morten, he had no worries about his father using the application for reminders and for the calendar, as he was well versed in both the use of a smartphone and a tablet, where his grandchildren had taught him what he needed to know.

6.2 Layout and Design

This section covers the findings pretraining to the layout and design of the application. With the home page, the caretakers found the design easy to follow, where the sections were clear. This made it easier for them to differentiate between new announcements and the upcoming events. Britt adds, *"Being able to see announcements and events next to each other like that would make it easier to see what we need to do. I mean, the chance of the announcement being related to the upcoming event is big."* With the colors, the participant like that it was easy to differentiate between the different events in the calendar. However, some suggestions were made by Morten, *"I think it would be good if we were able to choose the color of the event, so that birthdays had their own, as the same with family gatherings. It could be easier for both my mom and me to see what is happening just by a quick look at the screen."* When it came to the font and font size, Morten found it easy to read. Britt on the other hand some difficulty with the size of the text, suggesting that it would be easier if the text was a bit bigger.

6.3 The Applications Relevance

This section covers the findings pretraining to the relevance of the application in the daily lives of the participants, and how likely they would be to use this as an aid in supporting their relationship with the person with dementia. When it came to the relevance of the application, both caretakers said that it would aid them in keeping track of the person with dementia, and help communicating with the family. Both participants agreed that the homepage had the overview they needed, however, not all of the functions were relevant to all participants. Morten said, *"As I am the only person taking care of my father, I wouldn't need an FAQ section. Neither would my mom as they live together. Would it be possible to choose what would be on the front page?"* For Britt, she though the FAQ section on the front page would be beneficial for her family. *"If I was able to add some information there myself, it could help my older brother actually communicate with our mom. Maybe even make him want to visit more often."*

For the announcement system, both caretakers found it quite nice, with several possibilities of gathering the communication with their family, as it now was spread across several platforms. Britt commented, *"This would be amazing to have. I would not have to go between the Facebook group, messenger messages and normal text to get the family involved."* For Morten, he mainly communicates with his mother regarding the care and chauffeuring of his father, however he does believe that being able to have his brothers using the announcements would help navigate what to do for birthdays or gatherings.

Further, with the calendar system, the participants found that it would be helpful when it came to keep everyone in the family up to date on the events that were coming up, as well as for their own contributions. Britt said, *"Being able to add events for everyone to see would be amazing. However, if I was able to add certain people to the events and make them get notifications that would be great. That way, everyone wouldn't get a reminder for a doctor's apportionment if only one person is going to help them get to the appointment."* This could be further researched. Being able to add events to the reminders of the people with dementia was also seen as a quite positive aspect of the application. Morten said, *"If my father was able to see and get notifications for birthdays or events, it could help him feel more involved."*

Lastly, the reminders page was seen as truly relevant for both caretakers. Morten, as mentioned earlier, found that the page would help his father feel more involved in the lives of his family members. For Britt, she believed that being able to help her mother with the tasks she needed to do daily, without being over her shoulder, could aid their relationship as well as make her mother feel more at ease. Britt said, *"My mom always takes notes trying to remember birthdays, appointments, honestly everything she wants to remember that has to do with the family. If I could also help her getting some of the things she must do every day on that list, or even write down what she has in her freezer it could help her."* Given the circumstances; the application seems to be relevant in the daily lives of the caretakers.

Chapter 7

Discussion

In this chapter, I discuss my research questions based on the findings presented from the results of the evaluation of the application in Chapter 6. Further, I will also use the findings extracted from the literature review performed in Chapter 2, and the findings from the probing session and workshop presented in Chapter 4. The research questions are as follows:

RQ1: How can wearable technology be introduced and used in the person with dementia and the primary caretaker's daily routine?

This is divided into two sub-research questions.

RQ1.1: Has wearable technology been used in dementia care, and what has been its effect on it?

RQ1.2: What participatory design techniques can be applied to co-design with people with dementia and the primary caretaker?

Based on the information found within RQ1 and its sub research questions, other areas of research were considered:

RQ2: How can wearable technology contribute to supporting the relationship between a person with dementia and their primary caretaker?

In the following sections, I outline the effects of integrating wearable technology within at-home dementia care for supporting both the person with dementia and the primary caretaker. This begins with a discussion on how wearable and haptic technology should be introduced to people with dementia and caretakers. This addresses the first research question, and the sub-research questions attached. Secondly, I discuss the second research question using the results of the evaluation and gathered data collected during the data collection process. Lastly, I will address the core approach of the study, and reflect on the design choices made thought the course of the study.

7.1 Using Wearable Technology in Dementia Care

This section answers the first research question and the accompanied first sub-research question with a discussion on how wearable technology and haptics can be introduced in the context of at-home dementia care. Wearable technology, which has been around more commercially since 1996, has become mainstream in the last few years, where the technology is now being used in smartwatches, fitness trackers, and smartphones [82]. Wearable technology has also in the last few years been used in the care of dementia patients, both at home and in institutions. Several studies [35,76,77,85] show how wearable technology can be both used and introduced to people with dementia as an aid to support their relationship with their family, and to encourage a more authentic partnership with family and themselves. With the growing elder population, and the expected rise in dementia cases due to the increased life expectancy and high birth rates after WWII, a shifted lifestyle for both people diagnosed with dementia and caretakers is to be expected [27,28,47]. In recent years, several studies [29,35,76,77,85] have shown how wearable technology can be introduced and used to support both the person with dementia and their caretakers. Studies show [26,30] that the growing elderly population has an interest in learning how to use new technology, where it is reported that 18% of elders in the Pew Report [30] use either smartphones or tablets daily. However, there are some barriers for elders to start using modern technology. According to Gitlow et al [30], there are two main factors for elders to not pursue new technology, (1) the mistrust towards computers and internet use, and (2) the lack of education on the topic. This has had a limiting factor for elders who wish to engage in using new technology such as smartphones [30]. Making sure that the elders get a proper introduction to the use of modern technology and applications is necessary to support the relationship between a person with dementia and their caretaker and to support the independence of the person with dementia.

Wearables can be introduced to people with dementia in several ways. A study conducted by Mertl et al [58] which introduces an interactive multimedia device called "Traumreis" shows a more personal approach to gaining insight into the daily activities of dementia patients. The researchers started by visiting the participants in the study to gain insight into their technological level and to understand the procedure of the group, the activities, and the atmosphere the observations were going to be held. Following this, the researchers discussed the device with the participants, and how it could be integrated into the weekly activities of the dementia support group. By doing this, they have gained proper insight into the way the diagnosis has manifested in the patients in the group and found a way to integrate the experience into their lives in a non-intrusive way, while still giving them the proper time and education they need to gain positive experiences with the technology. After the initial observations, the workshop was held, where the participants got to use the device properly, showing that the device was seen as a meaningful addition to the dementia patient's support group, as long as it was used in a restrictive way, to be able to keep it special to the patients. The use of the device showed a positive impact on the patients present in the group when socializing and general conversations surrounding both the device and the experiences around it, leading to increased attention presence in the people diagnosed with dementia. With increased attention to the experiences around them, more positive communication was seen between the caretakers and their family members with dementia, as well as within the support group. Within the support group, the reaction and communication with the volunteers increased, showing that the device helped spark genuine conversation between dementia patients and volunteers present. As seen in Section 2, being able to preserve a sense of self is difficult for the person with dementia due to the diagnosis taking over, making it harder to socialize and keep genuine connections. By inspiring genuine conversation and communication between both family and friends, a sense of independence and security could arise for the person diagnosed. It was also seen that the family caregivers present for the observations were instructed to be a part of the experience, and by being encouraged to ask questions about the device during the first observations, while they were asked to stay present and talk about the device and the experience in the second observation. With this, it was shown that the device in itself, even though it sparked conversation and new experiences, was not the biggest factor for more independence or better conversation. However, the inclusion of the caregivers was one of the bigger factors to stimulate conversation, as it engaged the dementia patients in the group more to have family there to support them. This can also be seen in the literature in Section 2.1.4, where it is shown that working towards an authentic partnership, which incorporates both values and perspectives of the caretakers and the person with dementia, is necessary to have open communication and a better understanding of self. The question of open communication was seen in both the probing session and the workshop in Section 4 as a current problem with the participants in some ways. By encouraging proper communication and a better understanding of the new roles and family relations, a better sense of self could become present in the people with dementia, as well as encourage more open communication and support for all involved.

With the study, the performed literature review, and the results of the data collection activities, it is seen that with proper communication and education, wearable technology can be introduced into the lives of dementia patients.

7.2 Applying Participatory Design Techniques in Dementia Care

This section addresses how PD and its following methods can be used to support people diagnosed with dementia and their primary caretaker. PD is an approach to design in IT that invites all users into the design process as a means of better understanding, meeting, and pre-empting their needs [12,23]. It is a democratic process for design, both social and technological, of systems involving human work, based on the argument that users should be involved in the designs they will be using, and that all stakeholders have equal input into interaction design [36]. With the scope of the study, being able to involve the stakeholders in all areas of research and the design process, and not just keep them in mind as with UX design, it was seen as beneficial for the study. Luck [53] also goes on to say that PD is not one single research method but rooted in a concern for located accountabilities, where each application is embedded and designed to suit the circumstances at hand. Further, a PD approach is said to aid in equalizing power relations, mutual learning, helpful tools, and techniques for the stakeholders, as well as giving an alternative vision about technology, which all comes from users taking an active part in the research [10,53]. These are the reasons PD was chosen as a core approach within this thesis. Several studies [10,23,34] show the benefits of using PD as an approach with people with dementia, as well as the preferred methods to be used during the data collection activities.

By understanding how someone would solve a challenge they face directly, can often make new insights about their experiences surface, which in return better informs how designers focus their efforts [23]. With this, several methods can be used to gather information from participants and help form the studies. In Elizarova and Dowds study [23], several PD data collection methods were analyzed and discussed, where their outcome from previous studies were shown, showing the benefits of using PD as an approach. Journey mapping, which was also used within this study, is a method where participants can map out their experiences, including pain points, frustrations, and challenges [23]. Using this method could extract richer information from the participants experiences, making the design process easier. This was also seen in Elizarovas and Dowds experience [23], where using the method uncovered insights that had gone unnoticed by other researchers, which helped expand upon the study. This can also be seen in the case of the thesis, where after the journey mapping exercise in the workshop the people with dementia talked more openly about their feelings around their diagnosis and the change in roles. Being able to be more authentic helped uncover several areas of miscommunication, as well as uncover conflicts that could be avoided by commuting properly. One of the more important aspects of using PD methods is to tailor the methods to the study at hand, as to thoroughly investigate the problem. This can be seen in Halskov and Hansens study [34] where in one of the PD studies they analyzed how the play between method and enactment of methods could aid in certain studies. It was seen that by being able to analyze how IT managers uses whiteboards to control the planning phase as a control strategy, gaining further insight into the scope of the study was possible. This shows that PD can be used and molded to fit the study at hand, while also giving more honest and factual information from the participants. This goes for both the person with dementia and the caretakers. As seen in the probing sessions, by being able to explore the activities and experiences through images, the caretakers were able to properly express their communication problems between each other and the person with dementia, while still experiencing and exploring what it means to be a caretaker, binding the roles from method to the methods enactment.

7.3 The Need for Communication in Authentic Partnerships

This section goes over how proper communication between a person with dementia and their caretaker can benefit their relationship after the diagnosis. Further, using the results of the evaluation, I will demonstrate how the prototype and wearables can be beneficial for better communication and aid in supporting their relationship. Due to a lot of stigma around the diagnosis, people with dementia are still excluded from being regarded as full partners when it comes to decision making, and other aspects of the relationship, making it harder for the person with dementia to work with their caregiver [20,21]. As seen in an open-discussion session at A Changing Melody 2008, a speaker announced that the care they received would've been better if the other person also had dementia, remarking on the current lack of understanding of the experience of living with it. By learning together, and unlearning old, misguided assumptions and paternalistic actions, a more diverse perspective could be reached, and strengthen the voice of the person with dementia. Difficulties of not understanding the experiences of the person with dementia can be seen within this thesis, where the common struggles and conflicts often arouse from misguided feelings of changing roles or the feeling of overbearingness.

During the probing session, it was seen that a lot of the conflicts arose from the frustration of having to double check tasks due to the stubbornness of the person with dementia. With Britt, it came down to hiding that the tasks were not done that started conflicts, whereas with Egil it came down to the feeling of still being able to do these tasks himself. As seen in Section 2.1.2, living with dementia means living with fear, anxiety, uncertainty over what will happen in the future. With this, the fear of family and friends treating you different after the diagnosis is also quite present. This can be seen in the journey mapping workshop, where Thune describes feeling insecure in the sudden change of roles, starting of as being the provided and helper in the family, to becoming the one who needs the help. This could have brought along a lot of stress and anxiety of the new role she had to get used to, and with the constant surveillance from her children, she might not have felt secure enough to ask for help with certain tasks or reminders. It is also seen in Section 2.1.2 that being able to still be included in social activities, family gatherings, and other activities expands upon the general wellbeing of the person with dementia. However, it is also seen that in both workshop that the participants drew back from their family after getting the diagnosis. Both Egil and Thune started making less contact with their family, where in Egil's case he was annoyed that he wasn't as able to keep a more active part in the lives of his younger grandchildren, while still feeling like he should be able to. This could give a feeling of being less secure in his own identity, becoming more self-conscious about the choices to come, and what would happen later in life. From the caretaker's point of view, the sudden lack of communication was what made them insecure about their own relationship, in Britt's case both with her mother and with her siblings. Britt describes in the probing session feeling both irritated and a sense of despair around the diagnosis of her mother. These feelings arouse both from feeling like she had to take care of everything with the family, like her mother used to, as well as being the one to connect and communicate with her siblings to get things done. She describes it being hard communicating with her siblings around the diagnosis, as some still have accepted the diagnosis, while others don't understand it. These were the main points to tackle with the prototype, where the evaluation shows that there is a way to strengthen the communication between the person with dementia and the caretakers, while still fixing the problems at hand.

[HOW WOULD THE PROTOTYPE HELPED THE PARTICIPANTS]

7.4 Participatory Design as an Approach for the Thesis

In this thesis, being able to actively involve both the person with dementia and their caretaker and see their experiences from all angels was important to me. I was also new to the field of dementia care and wanted to understand the underlying issues with miscommunication and bad cooperation between the family caretaker and the person with dementia, due to my own family connections. Further, I needed an approach that could structure the design activities, and aid with stimulating workshops and data collection methods for the participants. This led to the choice of using participatory design as my core approach. As explained in Section 3, I needed methods and techniques that would allow me to explore the person with dementia's perception of technology, as well as the perception of the primary caretaker regarding supporting their relationship and daily communication. I argued that using PD as an approach to explore the needs of both stakeholders, while also contributing to a realistic solution for both the person with dementia and their primary caretaker would be beneficial. As I explained with a quote by John Chris Jones [53], "*People in the design world should begin to look deeper not only into the political sense but also into the possibility of helping people to change. Participation may be the educational approach to this*." Further, PD is seen as rooted in concern for located abilities, where each study is tailored to suit the circumstances. The probing activity was planned and started based on this. By gaining more information about the inner workings of the relationship using images as a focus point, the caretakers were able to explore their own feelings around the person with dementia, while being able to tell their own story in a more comfortable way. Gaining these experiences from the caretakers is what shaped the journey mapping workshop. Being able to see the struggles described from the person with dementias perspective could aid in understanding why some of the conflicts arose, which is where PD really helped. However, with the caretakers butting in during the workshop at times, it could have compromised some of the information the person with dementia was comfortable sharing. By using another method which excluded the caretakers a bit more from the workshop, the person with dementia could be more inclined to speak more freely. This is something that could be explored further. However, due to the limited time on the project, this was not something that was possible within the timeframe. Still, the information gathered during the data collection methods did give a lot of information on their personal issues, that could be avoided.

Chapter 8

Conclusion

In this thesis, I have explored how technology could support the relationship between a person with dementia and their family that has taken on a caregiver role, with a theoretical background. Further, I have explored how wearables can aid in bettering the communication between the person with dementia and their caretaker. Throughout the study, I applied participatory design as my core approach, adopting data collection methods to structure the basis of my work. The activities that followed helped form the creation of the prototype that supports better and more honest communication between a person with dementia and their caretaker, as well as better communication between co-caretakers, laying the groundwork for a more authentic partnership. The application prototype introduces (1) a platform to ease the communication between caretakers, collecting all maters on one platform, and (2) supporting the independence of the person with dementia, by having tasks and daily goals clear while they are within the stages of mild to moderate decline. Further, intending to implement the prototype in the homes of people with dementia, and introduce wearable technology as an aid, I evaluated the prototype with two people with dementia and two caretakers.

The results of the study has broadened our understanding of how wearable technology can be used in the care of someone with dementia and support their relationship between them and their caretaker. Further, the results of this study suggests that caretakers can use an application to cover most of the conversation, tasks, and daily reminders associated with the person with dementia, as well as it supports their independence. The work from this study shows that the participants are interested in a collected platform for keeping track of the daily tasks of the person with dementia, and to collect the conversation and reminders related to them. The application was seen as easy to navigate by the caretakers, where the information they needed to keep up to date was easily displayed. There were some confusions about the FAQ section on the front page, as this would not be necessary for Morten. However, Britt found this to be a good addition, as it could aid her siblings in understanding how to communicate and support their mother. When it came to the design, the participants were happy about the light colors used, as it made the application look happier and more organized compared to the gloominess around the diagnosis. The application was also seen as quite relevant for all participants, as it would aid in collecting and summarizing the tasks, reminders and communication needed in caring for their family member. There is a need for proper education of the reminders section and calendar functions of the application to the people with dementia, and the caretakers depending on their age. With proper education of the application, both caretakers and the people with dementia would be able to communicate and work together without the care being seen as overbearing. Lastly, the evaluation shows that personalizing the information on the application to the caretakers, such as making it possible to add or remove sections on the front page would be beneficial, as all cases are different.

I hope to contribute to supporting better communication not only by presenting the results of the evaluation but also by sharing the documentation of my design process and using participatory design as an approach. Further, the contributions from this thesis will also come from the results of the data collection process and the extensive literature review on wearable technology and the use of haptics within at-home dementia care. Lastly, the following sections will show suggestions for future work, and limitations within the study.

8.1 Limitations

This section presents and discusses the limitations of the study that may have affected the design of the prototype and the results of the data collection process and evaluation.

8.1.1 Participants

There was a total of four participants in the study for both the data collection process and the evaluation of the final prototype. The project would have benefited from having more people included in the study, to gain a broader insight into the various parts of mild to moderate decline, as well as different family dynamics. Being able to look at families in various parts of the country would also be beneficial, as their needs may vary based on their location, and support from nurses may vary based on the need in the area. As two of the participants are my relatives, this could have influenced their perception of the study. The relationship with the author may also have impacted their attitude towards the study, making their reactions more positive. This should be regarded as a possible limitation of the study.

8.1.2 The Data Collection Process

This section follows the topic presented in the previous section. The study would have benefited from using other methods of data collection in addition to the methods already used. Being able to physically show the prototype to the participants in a more neutral and common setting than over the computer could have provided more reliable results for the evaluation. Another limitation is the data collected from the journey mapping, as I was only able to observe the workshop over the computer. With this, the people diagnosed with dementia in the study might not have been as comfortable as they would have been in a more neutral and controlled setting. This should then be seen as a possible limitation to the study.

8.2 Future Work

This section outlines different suggestions for future work to expand upon the thesis, or for research in a similar scope. The suggestions made are rooted in existing literature presented in the thesis and from the available data collected during the data collection process.

8.2.1 Collecting More Data

With all research it is always beneficial to collect more data, however in this case, gathering more data on how at-home dementia care is carried out in Norway could be practical, and also include at-home nurses that may aid the primary caretaker. This could be achieved by further adding to the literature review and by conducting more observations in the homes of people with dementia. Further, by including expert interviews with leaders of nursing homes or dementia villages, as to add in-depth insight into the other aspects of the research topic.

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Glossary

Cutaneous: *Relating to or affecting the skin.*

Generalizability: *A measure of how useful the results of a study are*

Kinesthetic: *Having to do with movement and/or sensation especially with the body.*

Paternalistic: *A controlling and/or condescending authority figure*

Tactile: *Designed to be perceived by touch, tangible.*

Appendix A

Journey Mapping Interview Guide

Purpose

To gain information about the relationship between the person with dementia and their primary caretaker and get a sense of how the disorder has affected them.

Introduction

Before starting the workshop, the participants were reminded of the theme of the workshop, as well as the reasoning behind the workshop.

1. Before the Diagnosis

- How would you describe your everyday life before the diagnosis?
- How would you describe your relationship with your family?
- How often were you in contact with your family?
- How often did your family visit?
- How often did you visit your family members?
- How would you describe your role in the family?
- Was there any conflicts in the family?

2. The Months After the Diagnosis

- Was there a change in communication between you and your family?
- How often did your family come to visit?
- Was there a change in routine with the family members?
- Was there a change in roles after the diagnosis?
- Was there any conflict in the family?

3. The Current State of the Relationships

- How would you describe your role in the family?

- Has the relationship changed?
- How often to you talk/visit family members?
- How would you describe the communication between you and your family?
- Does your family help you with any tasks?

Appendix B

Evaluation Guide

Purpose

Explore the application design and proposed system with the stakeholders, and how the prototype could be used in their daily life.

Introduction

Before starting the evaluation, the participants were reminded of the theme of the evaluation, as well as the reasoning behind the evaluation.

Main evaluation

The participants were given a link to the interactive prototype, where they would navigate through the application using the following prompts:

- Find the newest announcement using the menu.
- Navigate to the calendar page.
- Navigate to the FAQ section.
- Find the announcement archive.
- Navigate from the announcement archive back to the homepage.
- Find the reminders page.

Evaluation of the Prototype

After going through the aforementioned prompts, the participant was asked several questions based on the design, usability, and the applications relevance in their daily life's. The questions are as follows.

Usability

- How was it to navigate between the pages?
- How difficult was it to find the correct pages from the prompts?

- Was it easy for you to navigate between the announcements?
- How would it be to navigate between reminders?
- Is it easy to find your way back to the home page?

Design

- How difficult was it to differentiate between the sections of the first page?
- Did you have any trouble with the colours that are used in the application?
- How is it to read the text used?
- Is the design easy to use?

Relevance

- How relevant would this application be for you in the care of a person with dementia?
- Do you think such an application would aid in your daily activities?
- Does the homepage have the information you need?
- How likely would you be to use this application as a caretaker?
- Would an announcement system that delivers notifications and reminders be of use for you?
- How likely would you be to use the reminders/post-it note page?
- Would the reminders page be of use to you in caring for a person with dementia?
- Would a system that collects the means of communication aid you in supporting the person with dementia?

Appendix C

Link to the interactive prototype

The participants were given an ineractive prototype for the evaltion. The prototyoe is linked here: https://xd.adobe.com/view/994ede89-3a76-43f1-b9fa-43f1bc9888d0-cc1d/