Konzept einer App für die Reminiszenzarbeit entsprechend einer Änderung der Perspektive für das Konzipieren Assistiver Technologien für Menschen mit Demenz

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I hereby declare that I have written this work independently, have given full details of the sources and aids used, and have marked places in the work — including tables, maps and illustrations—which are taken from other works or from the Internet, either verbatim or in spirit, as borrowed, in any case indicating the source.

Vienna, 02.12.2020

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Abstract

Dementia is a growing problem of the 21th century. With the world’s population becoming older due to an increasing life expectancy, the number of people diagnosed with dementia is on the rise. Our society faces the challenge of coping with this in an ethical and financially sustainable way. One option to do so is via Assistive Technology (AT). AT can help by providing care and exchanging knowledge, therefore reducing the burden of caregivers.

The aim of this thesis is to examine the implication of AT in dementia care in a critical way by reviewing existing research and technology. There has been a shift in perspective towards a more person centered style of care in recent years, that also influences the design of AT. This shift and its implications on AT are analyzed, and examples for designs meeting new guidelines are given. A prototype for an application helping with reminiscence work is described. The concept is to combine information and media from archives and the internet with personal biographies as a door-opener for talking with a person with dementia.

Results from professional caregiver interviews show great potential for the app. The concept is perceived as very helpful and caregivers show high interest in using an app like this in their daily work with dementia patients.
**Kurzfassung**


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“As my father can no longer cross the bridge into my world, I have to go over to his. There, within the limits of his own mental state, beyond the wider society based on objectivity and linear goals, he still is an impressive man, and although not always very sensible by common standards, somehow brilliant.”

Arno Geiger, The old king in his exile
1. Introduction

1.1 Motivation and problem statement

Dementia is a term used for a cluster of symptoms evoked by the damage and destruction of brain cells. It has a profound effect on the cognitive abilities of a person. Dementia can significantly alter the quality of life and independence of people, interfering with the normal ageing process. The presentation of dementia is unique for every person and depends on severity, progress, type, and subjective experiences of the symptoms. There is no current cure for the condition. In the long term, dependence on care is given. Symptoms of the cognitive impairment may manifest themselves in language, communication, understanding, mood and mal handling of routine tasks. The neuropsychiatric symptoms include depression, stress, agitation, irritability, anxiety and forms of disinhibition.²

Assistive Technologies (AT) are systems that deliver assistive products and services. They should improve or maintain an individual’s functions and their independence, help participating in education and the labor market and ultimately promote well-being. Inevitably, they reduce the need for support services and caregivers.³

AT can provide vast benefits for people with dementia by providing low-cost, high-quality care to an ageing population. Also, they can educate and exchange knowledge, thus having a positive effect in three ways: Delaying the entry to institutional care, reducing the burden of caregivers and improving the QoL (Quality of Life) of dementia patients.⁴ A division of AT based on purpose of the devices is: Devices of daily life, telecare devices, safety devices, and devices to support social participation, engagement and leisure.⁵ As of now, the use of AT is mostly limited to basic aids, but the familiarity of older persons with the internet is growing, as is the global use of digital technologies which drives demand for more sophisticated solutions.⁶

Research on AT for people living with dementia topic has been given substantial attention worldwide, with many technologies and papers being released each year.⁷ However, there has been a shift in how AT for dementia patients are perceived in the past years. The perspective that we have towards people with dementia and designing AT for them determines our behavior and the social status they have. This shift in the perspective we have of disabilities (4.1 What does being disabled mean in the context of AT?) and of dementia is a starting point in a different way technology is designed (4.2 Implications on the use of AT to support people with dementia). A one-sided perspective on disability can be reducing and possibly dangerous, which has been recognized in recent works on AT.⁸,⁹ Also Ethics (3.3.3 Ethical and Human rights aspects) is one of the most important aspects when designing AT, especially for people with dementia, whose basic human rights are frequently denied to them.¹⁰
1.2 Expected results

This thesis should explore how AT was previously designed for dementia, showcasing the current trends and future perspective. This last point is underlined by an exemplary concept of an app for reminiscence work that was designed following ethical and design guidelines.

Recent developments in the perception of people with dementia are resulting in a significant shift in perspective when designing Assistive Technology for them. They are no longer perceived as a homogenous disabled group, but as individuals with experiences and abilities that should be allowed to participate in the designing process. In order to assess this shift in perspective in designing AT, papers and reviews containing keywords like “assistive technology”, “dementia”, “Alzheimer’s”, “new perspectives”, “shift”, “person centered care”, etc. in various combinations are considered. The selected articles will be analyzed. Furthermore, experts and caregivers will be interviewed to get a picture on how AT were used in the past, elucidating the status quo and what a future use might look like.

An app for reminiscence work will be conceptually developed. People with dementia enjoy reminiscence because when daily life gets more and more confusing, good memories can act as a safe haven. Caregivers use reminiscence work to calm people with dementia or to distract them from negative thoughts. However, it is often difficult to keep track of a person’s history, for example the things they liked as a child or their favorite songs. Here, technology can help by providing information stored online. The idea is to combine information from archives or the internet with personal biographies as a door-opener for conversations with a person. To design the app, research in scientific literature and expert interviews will be conducted. A first draft will be presented to caregivers for evaluation. According to this evaluation, a full concept for the app, including wireframes and design, will be created.

1.3 Relationship with Biomedical Engineering

One main goal in Biomedical Engineering is finding new technological ways to help people that have a medical condition. The field of Assistive Technology is part of this, trying to help people that are somehow differently abled to cope with their daily lives. Research in this field is for example taught in courses like Assistive Technology. Writing about AT for dementia patients follows personal interest in the illness and the growing number of cases around the world, which leads to a high demand for technologies to help.
2. Dementia

Dementia is a term for abnormal brain changes coming with a range of symptoms. Common are the loss of: Memory, thinking, orientation, comprehension, problem-solving, language communication, understanding, mood, and the mal handling of everyday tasks. The neuropsychiatric symptoms include depression, stress, agitation, irritability, anxiety and forms of disinhibition. Dementia symptoms usually become severe enough to interfere with everyday life.\(^{11}\)

Dementia is not defined as a single disease but covering different medical conditions, most prominently Alzheimer’s Disease (AD). Dementia can be seen as an overall term – similar to the term “heart disease”.

![Dementia Diagram](image)

Figure 1: Dementia as an umbrella term.\(^{11}\)

According to the WHO\(^{10}\), around 50 million people worldwide live with dementia and around 10 million new cases occur each year. Dementia is one of the major causes for disability in elderly people (5-8% of people over 60 are affected) and has an enormous impact on people living with it, their families, caregivers and our society. The number of people with dementia is rising and estimated to reach 82 million in 2030 and 152 million in 2050. This rise will mostly be caused by a higher number of people living with dementia in low- and middle-income countries. The economic impact of this will be enormous: In 2015, the total global societal cost of dementia was already an estimated 818 billion US$, which is an equivalent of 1.1% of global gross domestic product.
Alzheimer’s Disease (AD) is cause of 60-80% of dementia cases. Other forms include vascular dementia, which occurs because of blood vessel blockage and small bleedings in the brain, or Lewy body dementia. The term mixed dementia is used if multiple types of brain changes occur. Other conditions that cause symptoms of dementia can sometimes be reversible, for example vitamin deficiencies or thyroid problems.

Referring to dementia as “senility” is incorrect, as it implicates the widespread but false belief that dementia is an inevitable part of ageing. Serious mental decline is not necessarily part of ageing, but a symptom of a medical condition.

People suffering from memory loss often find it difficult to recognize when they have a problem. Signs of dementia are more obvious to family and friends. If someone experiences dementia-like symptoms, they should see a doctor as early as possible. 10-13

Risk factors for dementia include age obviously, but also a lack of sports, smoking, alcohol abuse, weight gain, an unhealthy diet and unhealthy blood values as well as psychological factors like depression or social isolation. 10

2.1 Signs and symptoms

Dementia cannot be generalized as it affects each person in a personal and specific way, depending on the type of disease and the individual’s personality. Symptoms of Dementia can be parted in three stages (vide infra), although the rate of progression of the disease varies. Symptoms can also be caused by other health issues, like depression, stress or diabetes. An examination by a doctor is therefore important before falsely diagnosing someone.

Early stage: This stage is often overlooked because of its gradual onset. The symptoms can be mistaken for natural ageing and the person can still function independently. Symptoms, which a doctor can already identify, include forgetfulness (mainly short-term memory), getting lost in familiar surroundings, increased trouble with organizing or losing track of time.

Middle stage: In this stage the symptoms and signs get clearer and the person gets more restricted. This stage is the longest and can last for several years. Persons forget recent events, personal events and familiar names, they can become lost at home, need extra help with their personal care. They usually experience difficulty with communicating and can exhibit initial behavioral changes, like wandering around or repetitive behavior, or become moody and withdrawn. A prominent symptom emerging is
called “living in the past”. In this case, individuals relive past moments as if they were happening in the present, their lives become more and more determined by remaining memories. For example, they might search for long gone relatives or things. The attempt to convince them that their reality is false can be conceived as a threat and might be problematic.

Late stage: In this stage, symptoms become severe and the person gets totally dependent on others. The (short term) memory is barely functioning and other symptoms become more obvious: They are unaware of time and place, cannot recognize relatives, have difficulty in intuitive actions like walking. They can exhibit more extreme changes in behavior, sometimes escalating into aggression. Individuals may also become more vulnerable to infections like pneumonia, which at the end of this stage often leads to death.10,11

“He had changed, his depressed expression was no more about the desperation of being forgetful, but about the deep homelessness of a person to whom the whole world had become alien.” Arno Geiger,
The old king in his exile1

2.2 Types of dementia

Most doctors can determine a person has dementia with a high level of certainty. Diagnosis of the type of dementia can be significantly harder, since symptoms overlap. The four main types of dementia are Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Other types exist, for example dementia as symptom of Parkinson’s disease or mixed dementia, combining several forms.11

2.2.1 Alzheimer’s disease (AD)

The most common (60-80% of cases)11 form of dementia is Alzheimer’s disease. It is characterized by a slow and gradual progression. Most people with the disease show first symptoms in their 60s or later.

Neurologically, microscopic changes happen long before the first symptoms occur. Why these happen is still subject to research, but what it certain is that brain cells in AD stop working the way they should. The damage of cells spreads, and more cells lose their function and eventually die, causing irreversible changes in the brain. Two structures have been identified as suspects in damaging the cells: Plaques, which are deposits of the protein fragment beta-amyloid in spaces between nerve cells, and tangles, twisted fibers of a protein building up inside cells. Building up plaques and tangles is a common ageing occurrence, but AD patients tend to develop far more of them. The pattern of development is predictable:
It starts in the areas associated with memory and afterwards spreads to other regions. Most likely, plaques and tangles play a role in blocking communication between nerve cells – and thereby disrupt processes that cells would need to survive. The cognitive and motoric function of a person living with AD declines as more and more cells get destroyed.

**Symptoms:**
ADs earliest symptom is difficulty to remember newly learned information as AD typically first occurs in the part of the brain that affects learning. Family or friends may notice forgetfulness, difficulty finding the right words, or changes in mood. As it advances through the brain, it can lead to increasing symptoms, including mood and behavior changes, disorientation, confusion about time and place, suspicions about people around oneself, more severe memory loss, behavior changes and difficulties in motoric functions like speaking or walking. Changes are obvious when people do or say things that are out of character. Everyday tasks become more difficult and disorientation causes AD patients to lose their sense of time and place, for example making them dress themselves in the middle of the night. During the middle stages of AD, delusions and hallucinations can be observed. In the late stages, impairments become more severe and people with AD can become totally dependent on others for their care. Language can be limited to affective responses, the behavior to walking around, sleeping and eating. In the end, AD leads to death, which can often be triggered by pneumonia or heart attack in the severely weakened patients.10–13

Nearly 45% of AD patients suffer from depression, and 10-45% from anxiety.5 The awareness of the patients of their disease is mostly given in the early stages of AD and declines as the disease progresses.

2.2.2 Vascular Dementia (VaD)

Vascular dementia, also called multi-infarct dementia, accounts for around 20% of the cases. Its cause are blocked blood vessels in the brain. Blockages prevent oxygen from reaching the surrounding brain cells, ultimately accounting for their death. It can thereby be said that VaD leads to small strokes in the brain.

**Symptoms:**
VaD is typically identified by an abrupt and stepwise progression. It can be identified if a person’s behavior or functioning suddenly changes. How exactly that change looks depends on the area affected in the brain. As more and more areas become impaired, the memory and thinking of a person progressively declines. VaD can be treated with therapies to reduce the risk of more strokes in the brain. So far, no cure has been found.10–13
2.2.3 Dementia with Lewy bodies (DLB)

10-15% of dementia cases are accounted by dementia with Lewy bodies. Lewy bodies can be described as protein deposits in the nerve cells of the brain. They interrupt the action of chemical messengers, leading to malfunctioning of the brain.

**Symptoms:**
DLB has similarities to AD and dementia caused by Parkinson’s disease: It causes impairment of memory, reasoning and language. The rate of progression is similar to AD. However, the main difference is that the condition has characteristic fluctuations – people are not constantly affected but can have different attentive capabilities and states of confusion. A person with DLB’s abilities can change frequently, even by the hour. They can start an activity and later not be able to finish it, which can be interpreted as laziness if the disease is misunderstood. DLB can affect balance, movement, vision and recognition of things, which results in difficulty when moving. This in effect results in falls, slowness, and stiffness. Since hallucinations can be experienced, persons can become distressed and depressed or experience paranoia.¹⁰⁻¹³

2.2.4 Frontotemporal Dementia (FTD)

Damage to the frontal and temporal lobes can cause frontotemporal dementia. If neurons are damaged and die in the lobes, they suffer from atrophy, meaning they shrink.

**Symptoms:**
Difficulties in thinking and behavior gradually appear and become worse. The frontal lobes direct executive functioning, which includes planning and prioritizing. One symptom may for example be trouble in managing finances. The temporal lobes contain regions for memory and play a role in language and emotions. When they are damaged, one may experience difficulty in recognizing emotions and showing appropriate responses to them.¹¹
2.3 Treatment

Currently, there is no treatment available to cure dementia. Its progressive course cannot be altered. Many researchers are focusing on finding new treatments, with numerous of them being investigated in various stages of clinical trials.\cite{11}

However, there are ways of supporting people living with dementia in order to improve their and their caregivers lives: If the disease is diagnosed early, it can be managed in an optimal way. There are medications available that slow down the symptoms of cognitive decline like memory loss. Also, the person can be involved in the decision making about future care. Health, activity and well-being can be optimized by identifying and dealing with accompanying physical illnesses. Drug treatments can help improve the symptoms of a person living with dementia (for example antidepressants against low mood or antipsychotics against hallucinations or aggressive behavior).\cite{11} If behavioral and psychological symptoms are detected, they can be treated accordingly. Very importantly, information and support can be offered to carers.\cite{10}

2.4 Caring for someone with dementia

Caring for someone living with dementia is an enormous task and involves many different aspects. Dementia care needs to be provided around the clock for severe cases and involves a lot of physical and psychosocial strain for the carer. Most of the caring is provided by family members, as the WHO describes an integrated care system, where it is shown what levels of our care system are most important for people with dementia: First, close family members, followed by other family, relatives and friends. Then neighbors and the community, followed by the local and national governments and NGOs, and finally international organizations.\cite{14} Taking care of a person with dementia can be an overwhelming experience and the physical, financial and social pressure often is cause of great stress. Therefore, support by health and social systems is vital for caregivers.\cite{10}

One core principle when caring for a person affected by dementia is underlined by a guide of Bupa care services\cite{13}: It is most important to still see the individual, not only the disease - the person is still the same. It is crucial to remember that the disease and resulting symptoms are not their fault, they are merely trying to cope with frustrating changes in their ability to live. The person should be able to maintain a sense of self in order to feel more confident. This means they should be able to complete activities they have been doing all their life in order to feel the satisfaction of doing something. The changing individual preferences of people living with dementia, for example eating at strange hours, should be met by the carers in order to make the caring role easier. Explaining to others that a relative has dementia can take a huge burden away. Most people do know someone with dementia and will meet
the explanation with understanding. Familiar surroundings are reassuring for persons living with dementia and living at home for as long as possible can make them happier. People with dementia mostly respond well to routines and feel safer when maintaining certain routines throughout the day. Prompts about activities, like information on a notice board, can help structuring a day. Associated items should be kept together, like leaving tea next to the kettle. On the contrary, moving things around can be confusing for a person living with dementia since learning new things proves difficult. Other prompts are for example the labeling of cupboards. Large clocks displaying time, date and day of the week help in orienting a person.\textsuperscript{13}

Three important aspects of caring for someone with dementia are further discussed below: Safety and security, communication and activities. However, there is much more to the topic than meets the eye: Most things become very difficult as dementia progresses, for example dressing and personal care or using a toilet. For most people, residential care becomes indispensable at some point. Even though moving a loved one might seem like a ‘betrayal’ to some people, caring at home may not be the best thing for the person as their needs are changing. People living with dementia often reach a point where they are safer and more comfortable in the care of specialists (if financial resources allow this kind of care). Admitting this is an important step for family members in order to achieve collective peace of mind.\textsuperscript{13}

2.4.1 Safety and security

A person with dementia living at home alone can often be a reason for great concern of family members. Reduced concentration and judgement can place them in dangerous situations: Forgetting to lock the door, locking oneself in or welcoming strangers in the house are just a few examples of these. Carers can trust neighbors with a spare key and ask them to have an eye on the house. Further points that could be useful are a list of numbers besides the telephone, speaking to the local police and gas, electricity and water companies. Other inhouse modifications such as replacing old appliances with safer new ones, installing smoke detectors or removing locks from bathroom doors are equally important. One key point for safety and security are of course AT or Ambient Assisted Living (AAL). Personal alarms, like a button on the watch, or fall detectors around the house fall within this category and may bring peace of mind to the caregivers.

One additional factor of security is related to the managing of finances. Power could be cut off if bills are not paid or credit cards can be stolen and can in effect pose a risk to financial security. Therefore, it is vital to talk to the person with dementia to organize their affairs before their illness progresses too far. This means for example gathering important papers together and appointing an enduring power of attorney.\textsuperscript{13}
2.4.2 Communication

Communication is one main aspect of our lives. When living with dementia, it might at first be difficult to find the right words, later on it can be hard to even finish a sentence. This is a great factor of distress for both the person and their carers. It can be very frustrating having to answer the same questions again and again. It is vital to remember that the person really has forgotten that they already asked the question and carers are reassuring them by giving an answer again. Losing one’s temper or snapping back at a person can frighten them. It is important to give the person time to process information and also asking oneself if there is a reason behind a request or question. Trying to contradict a person’s believes can be more confusing and distressing to them than attempting to enter their own reality. Humor can be one big release for frustration – laughing about misunderstandings can help relatives feel closer to their loved one.

Body language is one form of communication at later stages of the disease. When spoken words get more and more difficult to phrase, body language and facial expression can tell a great deal of what a person is feeling.

If the person with dementia forgets what for example their partner does for them, this might be difficult to cope with but should never be taken personally. A book to write down visits might help here, as do labeled photos of family members and regular visitors. Encouraging family and friends to include and visit the person with dementia can be joyous for both sides. They should be told the person requires time to understand and topics should not rely on logical reasoning or recent memories. Often, many people want to talk to the person with dementia but simply do not know how. Here, carers can have a mediating role.

2.4.3 Activities

The quality of life is massively affected for a person living with dementia. Activities can help to improve it by providing stimulation and the possibility to express oneself. In early stages, the person should be encouraged to continue outside activities they enjoy and are still able to do. Sometimes a bit of prompting is enough to make them continue to do something. This can be done by verbally reminding them or by leaving equipment for the activity in an open space. Demonstrating what an activity looks like can help getting the person started. By keeping up activities they enjoy, a sense of self-identity and also purpose can be maintained.
Very important is the so called “calm-time” – filled with activities the person with dementia finds calming, like watching TV, knitting or listening to music together. These take the pressure of the caregivers as well and help improve the mood of everyone involved. More sophisticated activities are dancing or singing or a trip to the beauty salon. Also, household chores can be satisfying activities for the person living with dementia. They provide routine and the feeling of usefulness.

Despite all of this, it is important to remember that the person’s abilities depend on the type of dementia and its progress. Their condition may change from day to day or even hour to hour and an inappropriate task or activity might be very frustrating. When the disease becomes more severe and even talking about memories proves difficult, activities are limited to small moments like talking about a view or laughing while sipping on some tea. Television and radio are some of the most enjoyable things for many people living with dementia. However, they can also be distracting or confusing, so they should be turned off if the person is doing other things. History programs, old movies or an oldies radio station can be quite enjoyable, as are DVDs or CD of programs or music from the person’s younger days.

The Bupa offers some key points linked to activities:

- Encouragement for increased confidence
- Patience
- Instructions in a short and clear manner. Pointing and demonstration can be helpful to guide
- Too many choices or challenges can be hard to process
- Divide tasks into steps
- Keep tasks short for a shorter concentration span
- Use the person’s sense of humor

2.4.4 Reminiscence work

“If you take them back, be it with music from their earlier days, or with pictures or voices, you bring them to a time they feel safe in. It’s their feel-good time. They are happy there.” From an interview with care personnel

Reminiscence work is a widely used technique in dementia care. It is something intuitively done by people taking care of dementia patients since its effects are instant and obvious: People with dementia like to be in the past. They reminiscence of things and people long gone and past and their lives become more and more determined by remaining memories, a notion quite understandable when the present is confusing and unfamiliar.
Reminiscence therapy involves the recalling of one’s life events. It can help against depression and provide meaning and worth in life. Recalling positive experiences can have a positive effect on self-esteem. Furthermore, it has been scientifically proven that it has a positive effect on emotional and cognitive functions in people with dementia. In 2008, a study was conducted with an experimental group treated with reminiscence therapy and a control group simply having everyday conversations. The results: The experimental group was better in recalling words after the experiment, while the control group saw a decrease in recalled words. Also, the experimental group scored higher in tests on happiness and QoL.

Reminiscence therapy can be done in different ways: There are games where questions about the past are asked, pictures can be viewed, or music heard. Caregivers interviewed swear by the positive effects of singing, as it provokes many memories and emotions. Also, smells or sounds can act as a trigger for memories. Single memories, like “My mother wore a scarf like that” can act as a starting point for further conversation. A tip by the Bupa is keeping a box with items the person with dementia likes to reminisce about. Like this they can go through it and talk about the past. This can be quite enjoyable for old friends or younger relatives to hear. The box could contain old photos or other objects from the past, like trophies. In a nutshell, everything that brings a person back to a time the illness was not around can help.

Background for reminiscence is life story work, that means putting together information about the biography of a person with dementia. In many care institutions, sheets with questions are handed to the relatives of patients to be filled out. Like in a puzzle, different experiences, preferences and stories can be put together to get a picture of the person still behind the dementia. This can help in many ways: Carers know, whom or what a person is talking about and they can use this information to guide a person. As one caregiver stated: “The more you know, the closer you can get to a happy time in the person’s life – for example by putting on curtains or not. You can do good simply by knowing.” One example they talked about was an old man having trouble falling asleep at night. He was restless and left his bed several times to walk around and they did not know how to help him. When talking to his relatives, they learned that he was always the last one to leave the factory he was working in – switching off all the lights before heading home. As soon as they let him walk around the floor turning off all the lights before going to bed, there was no more trouble falling asleep.

Reminiscence work can therefore also ease the burden of care. By helping people with dementia to come to rest, pressure is taken off caregivers and the relationship is strengthened.
3. Assistive Technology (AT)

3.1 Definition and examples of AT

An Assistive Technology (AT) device is defined in the Assistive Technology act by the Senate of the United States of America as “any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.”

The WHO sees AT as an umbrella term covering systems that deliver assistive products and services. These are used to improve or maintain an individual’s functions and their independence, help participating in education and the labor market and ultimately promote well-being. They reduce the need for support services and caregivers. AT can provide benefits for people with disabilities, elder people, people with diseases like diabetes and people with mental health conditions like dementia. For them, activities of daily living (ADLs) can often be difficult. AT can help to ameliorate the effects of disabilities and help perform ADLs independently – in other words, it helps people work around their challenges. AT can, in simple words, act as an enhancement or an alternative. For example, a hearing aid enhances the sound perceived in order to understand it, similar to a magnifying glass enhancing a picture. A braille keyboard on the other hand acts an alternative to a normal keyboard, in a way similar to a wheelchair as an alternative to walking.

There are many examples of AT: Hearing and communication aids, wheelchairs, spectacles, prostheses or something as simple as a pill organizer. AT can be high-tech like special-purpose computers, but also low-tech like like a communication board drawn on paper. It can help people speaking, writing, pointing,
hearing, seeing, learning and walking amongst other things. It is difficult to properly express the boundaries of AT: If a prosthesis is seen as AT\(^2\) - what about a screw through a broken bone? As with many terms in natural and social sciences, the transition of how far devices can be defined as AT is a dubious one. Some AT are specialized devices, designed specifically for users with a certain disability, others have many features in common with mainstream technology. There is different AT for each different ability and disability and the market on tailored services is ever growing.\(^3,18\)

3.2 Socioeconomic aspects

AT can not only impact the well-being and health of a person, but also provide broader socioeconomic benefits. As an example, the proper use of hearing aids by young children can lead to significantly improved language skills, thereby giving them access to higher education and employment. According to the WHO, more than 1 billion people need one or more assistive product. This number will rise to 2 billion within 2030 with an ageing global population. Many older people need two or more AT to cope with daily life.\(^3\)

However, there is an unmet global need for AT. Around 200 million people with low vision do not have access to assistive products. Only 5-15% of those in need of a wheelchair have access to one. Countries with the highest occurrence of disabilities tend to be the ones with lowest supply of health workers skilled in helping with AT. The lack of affordable AT options in low-income countries leads to many people in need not possessing AT. Even in high income countries, AT is often not included social health and welfare schemes or highly rationed. As an example, it is a common policy in some European countries to provide people with hearing loss only with one hearing aid despite the fact that most people need aids on both ears. As a response, the WHO is coordinating a global cooperation on AT in order to improve access to high-quality affordable AT for everyone.\(^3\)
3.3 AT for people living with dementia

The demographic change is a global phenomenon due to the ever increasing life expectancy. People getting older increases the probability of them having numerous conditions, including dementia, which is why governments face the enormous challenge to cope with the growing need of social and health care. Besides this, the quality of care for patients with dementia and the support for caregivers has to be maintained or improved, which also increases costs. Even though AT may support people with a wide range of disabilities, focusing on care for elderly people and people with dementia is important given the aforementioned facts. In 2012, the WHO stated that “dementia poses one of the greatest societal challenges for the 21st century”.

AT can be essential tools in coping with this challenge by providing low-cost, high-quality care to an ageing population. They bear the potential to meet care needs of people with dementia and their caregivers. Also, they can educate and exchange knowledge in order to increase the standard of the care environment. Furthermore, AT can have a positive effect in three ways as they can delay the entry to institutional care, reduce the burden on caregivers and improve the QoL of dementia patients. Therefore, they support all users, including people with dementia, their families and caregivers. The aim of AT to support people living independently is sometimes referred to as ambient assisted living (AAL).
When thinking about AT for people with dementia, the whimsical nature of the disease should never be left unnoticed. Dementia shows a different face in each person, therefore one should be careful when trying to generalize design proposals: The needs of two people with dementia are never the same. From early childhood on, we are very different from another. Those differences only accumulate as we grow older and gain life experiences. Therefore, AT has to be tailored to specific needs of a person with dementia.

### 3.3.1 Examples of AT for people living with dementia

There exists a wide range of AT for people living with dementia. Research on this topic is done worldwide, with many technologies and papers being released each year and the amount of development rapidly increasing. A division of AT based on purpose of the devices is made in a review by Klimova et al. *vide infra*: Devices of daily life, telecare devices, safety devices, and devices to support social participation, engagement and leisure.

**Devices of daily life:** Technology included in this section helps people with AD and other forms of dementia with their memory, orientation and communication. The most common technologies are prospective memory aids like devices that help with time orientation, appointments or reminders of social activities. Calendar clocks can help to keep track of the date and time while orientation devices can help with finding the way or things. Additionally, adapted telephones fall into this category.

![Sample of the digital memory device MyHomeHelper](image)

**Figure 4: Sample of the digital memory device MyHomeHelper.**

**Safety devices:** Safety devices help reduce the worries of loved ones about people with dementia and enabling them to live independently. There are different devices assisting this goal: Automatic lights,
shut-off devices for gas supply, water tap devices to prevent flooding and fall sensors. Those devices are also able to collect data or characteristics of a person with dementia through wireless sensor systems. Safety devices also include location-monitoring or tracking devices that help to find a person if they get lost, enabling them to call for help.¹⁵

Figure 5: Bed leaving sensor mat to register activity during the night in order to prevent falls.²⁴

Telecare devices: Telecare refers to devices that monitor people living at home remotely. Like this, they can access support services when needed. Included in these are for example community alarms, movement detectors, assistive robots or more common things like video conferencing.⁵

Figure 6: Prototype of assistive robot Stevie that can for example initiate a round of bingo with dementia patients.²⁵
Devices to support engagement, social participation, and leisure: All devices that help to stay in touch with people and raise QoL. Examples for devices in this category include touchscreen picture frames that initiate a call with family members when clicked or tablets with pre-installed software like games.

A few example of available AT include:\textsuperscript{13}

- Prompts and reminders: Notice boards, large clocks (day/night), thermometers
- Mobility aids: Walking frames, wheelchairs, lifts, handrails
- Continence aids: Bed pans, incontinence products, raised toilet seats
- Washing aids: Sit-in showers, bath seats, hoists
- Special cutlery: Large handles, good grip, angled cutlery
- Kitchen adaptions: Glass-fronted fridge, gas safety switches
- Medication aids: Boxes for tablets
- Safety devices: Pressure mats to detect movement or falls, bed occupancy sensors, devices to control temperature of water, restricted flow taps

3.3.2 Designing AT for people living with dementia

Design is defined as “the way in which something is planned and made” by the Cambridge Dictionary. When generally talking about design, one often thinks about style or aesthetics.\textsuperscript{7} However, there is more
to this topic. For example, concepts as tools to talk about users’ needs are used in design sciences. They can be used to express oneself and identify problems with the design, leading to the or development of new ideas. Having come up with a concept, it can be tested by doing activities together (for example with people with dementia) to transform the design.\(^7\)

Designing AT especially for people living with dementia can pose a huge challenge. The whimsical nature of dementia can make it difficult to make generalized design proposals, requiring a sensitive and individual approach.\(^27\) Since each of the patients is individual and has unique needs, it is important and mandatory to assess those needs and in consequence tailor AT accordingly. In every case, doctors or carers should be approached and asked to judge the appropriateness of a device for a patients’ needs.\(^5\)

The most important guidelines for designing AT, among others, are: customizability, life-enhancing, extending capabilities, easy accessibility and intuitiveness.\(^28,29\) M. Marshall gives another important input: It should not be forgotten that the needs of people with dementia and their caregivers are the same needs that everyone else has.\(^7\)

One key aspect in the design process is empathy, thus it is always important to be mindful about everyone involved. The stigma of being a sufferer or victim should be avoided. This way, the person is more comfortable and not treated like being ill for example during a user study.\(^27\) Also, they should never be left to feel like a kid that does not know what it is doing - designing can be done in a way that they feel like their input is highly appreciated, and sometimes that they are being the experts (see RelivRing\(^27\) as an example for such). The size of the AT, its visibility and weight should be carefully considered to reduce the stigmatization and make it more user-friendly.\(^5\)

Some other key points are related to the biased perception of a device or application. Distinction of elements can be harder when living with dementia. Using colors and clear contrasts can resolve this issue. A color strongly contrasting the background can draw attention to certain features like a switch (Figure 8). Color can also be used to highlight certain hazards like sharp edges. It can also affect the way people feel, therefore it is important to consider its impact on the mood. Warmer colors like red or orange are sometimes easier to recognize than colder ones like blue. Lightning should be considered as well: Elderly and particularly people with sight loss find it more difficult to adapt to changing light conditions, therefore uniformity in lightning is preferable. Lights can indicate interactive elements in order to locate them more easily. Signage is also very important as it helps to locate certain things or gives clues on how to use a certain function.\(^27,30\)
Larger screens and print sizes make digital controls user friendlier. Also, control panels with tactile markings and an audible confirmation when a key is pressed make controls easier to use. Some people with dementia find analogue switches easier to use than digital controls. If an action is carried out, the function following it should happen immediately since delays could generate confusion. Tactile elements can be important to guide the person’s interaction with a device. This is especially important for people that are also visually impaired.\textsuperscript{30}

When thinking about which device to use, it is important to know most carers and family members are familiar with smartphones. Also, small mobile devices are preferred on the go. Designing an app could prove to be an easy way of integrating technology, as long as design and functionalities of the app are straightforward.\textsuperscript{28,31} Another recommendation is keeping the user interface (UI) simple. Like this, older adults without a special interest in technology can use its basic functions. Extended options could be included for the “experts”.\textsuperscript{28,32} Privacy is one key factor in designing AT: Security settings should monitor and moderate which users have access and when.\textsuperscript{28}

There is one factor not exactly linked to designing but equally important: For full comprehension of technologies and correct use of them, it is recommended for elder adults to start using them early. With that in mind, technology should be used in different stages of dementia. Acceptance will be higher if technology is embedded in daily routines.\textsuperscript{7,33}

Finally, the development of new assistive technologies should always be done with end-user involvement throughout all the different steps.\textsuperscript{5} A holistic perspective is important. For example in the paper by Luckner et al.\textsuperscript{28}, four different groups of people acted as stakeholders in designing for people with dementia: Elder adults without dementia to understand the living conditions of older adults, care personnel that provided valuable insight into dealing with situations occurring with dementia patients, relatives of people with dementia and patients themselves for first and second hand experiences with dementia. They designed workshops for the different groups (relatives and dementia patients were invited together as a group) to gather data about the context of living with dementia. Based on this data, different prototypes were designed.
Engaging in participatory design is especially difficult for people with dementia if it relies exclusively on cognitive abilities like communication of thought or working with abstraction. Therefore, sessions should focus on creativity and expression in a comfortable setting. By providing an informal atmosphere, a social connection between designer and participant based on an equal-power relation can be realized. In a setting like this, reactions and responses of people with dementia can more easily be observed and their meaning fully understood.\(^{15}\)

### 3.3.3 Ethical and Human rights aspects

Ethics is one of the most important aspects when designing AT, especially for people with dementia, as basic human rights are frequently denied to them: In some countries, chemical and physical restraints are excessively used in care homes, despite regulations to uphold the rights of people to freedom and choice. The WHO therefore suggests an appropriate and supportive legislation which is based on accepted human rights standards in order to ensure the highest quality of care.\(^{10}\)

In 2015, the United Nations adopted sustainable development goals (SDG) that included a new global health target: SDG 3 aims to „ensure healthy lives and promote well-being for all at all ages“.\(^{34}\) Since the number of people living with dementia is set to rise, dementia care of good quality is particularly important.\(^{35}\)

There has been little analysis whether AT for dementia care supports human rights in a way consistent with the UN Convention on Rights of Persons with Disabilities.\(^{36}\) It should always be kept in mind that technologies should be introduced only in ways supportive of human rights, especially the ones of vulnerable members of the community.\(^{35}\)

The UN Convention on the Rights of Persons with Disabilities should give a robust framework for governments concerning the use of AT in dementia care. It has the potential of transforming the care of people with disabilities in general, but some of its articles are particularly relevant for dementia care: For example, Article 4 states that States Parties are obliged to develop new AT and provide information about them. Article 9 binds them to enable persons with disabilities to live independently and Article 12 ensures equal recognition before the law. One implication of this article is particularly interesting: The move from substitute decision making (decisions are made for others) towards supported decision making promotes the rights and will of people living with some sort of cognitive impairment, such as dementia. Article 18 ensures the right of people with disabilities for liberty of movement and free choice of residence, recognizing the need for dementia-friendly surroundings. This encourages technologies like GPS tracking if they are used to enable people with dementia to have greater freedom of movement and stay longer in their own homes. Article 19 promotes the right to live independently and to be
included in the community. How AT support this (besides helping to live at home) is not clear, but it could also imply that barriers to outdoor spaces should be eliminated. Article 22 focuses on privacy: How much intrusion into privacy is justified to ensure safety and well-being of dementia patients? Could there be negative therapeutic consequences because of an impact on independence and autonomy? Arbitrary or unlawful interferences with privacy are banned within this article. Finally, Article 25 states the right to the highest attainable standard of health – implying that access to AT improving the health of people is essential for reaching SDG 3.\textsuperscript{35,36} To conclude, evaluating AT based on human rights is inevitable to ensure these technologies improve the lives of people with dementia.\textsuperscript{35}
4. Shift in perspective

Human rights and ethics (3.3.3 Ethical and Human rights aspects) are not the whole picture of treating people with dementia right. The perspective that we have towards them and designing AT for them determines our behavior and the social status they have. There has been a shift in the perspective we have of disabilities (4.1 What does being disabled mean in the context of AT?) and of dementia. These are the starting point in a different way technology is designed (4.2 Implications on the use of AT to support people with dementia).

4.1 What does being disabled mean in the context of AT?

To get an understanding about AT and their relationship to people with dementia, one must understand what the goals of AT are. In order to define its goals, one hast to first clearly present the problem. Therefore we will start this chapter by reviewing how a disability that needs support by AT has been defined in the past, and what the future perspectives are.

AT is seen as a field that explores the design of computing technology for the benefit of people with disabilities. As a consequence, the majority of work takes functional needs of people with disability as their starting point, matching them with the opportunities that technology has to offer. This approach can be seen as reductionist since it is a projection of functional limitations on people, as the experience of people with disabilities can be far richer and more complex.

The main factor in how AT for disabilities is designed is the conceptualization of what a disability is. Mankoff et al. first used studies on disability to reflect on the work being done in the sector of AT. They saw that the way of looking at disability changed the way technology was created and evaluated.

So, what is a disability and how have disabilities been described in the past? In the 20th century, biological determinism was the dominant concept. Disability was seen as “abnormal” and heavily medicalized. Terms like “curing” and “caring” still bear this concept in them. It is useful for development of AT, since it provides simple requirements for design: The functional limitations of the users. Examples like augmentative communication devices can be designed without further questioning within this mindset. In the 1970s, with a growing number of disability rights activists, the Fundamental Principles of Disabilities were verbalized. A postulation was as follows: “Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.” The distinction between impairment (biological circumstance) and disability (social and environmental construction) was introduced as the core of the so-called social model of disability. This first shifted the cause of
disability from the individual to the society. The ideas of Disability Studies further moved on, first in a more materialist corner (disability is rooted in physical barriers in the environment or unequal access to labor market), then into a more cultural and socio-historical context (disability is rooted in our language and social practices). Instinctively, the second had wider implications, as it implies disabilities are created by ideology and the public discourse, therefore no matter how much barriers would get removed, the society would not be truly inclusive. This led to research into terminology and the public image of disabilities. The question “What is normal?” was raised, similarly to research about gender and race. Dismantling the implicit construction of categories as such can be described as the goal of asking such questions. Thus, in a nutshell, design can aim to shift from the disabilities to the strengths of users while rejecting normative assumptions.8,9

Frauenberger in his paper describes the medical model as oppressive and technology designed within this mindset is complicit in segregation of society.8 He also proposes another model as the best in describing the reality of disabilities: The critical realist one. This model, as opposed to the others, describes disability as an interaction between structural (attitude of others, environment, support systems), but also individual (nature of impairment, personality) factors. It is generally speaking a philosophy of science introduced to Disability Studies to discourse whether a disability is more of a social construct or a biological condition. People are seen as disabled by the society and their bodies. This approach is also adopted by the WHO in their International Classification of Functioning, Disability and Health (ICF).38 In the ICF, problems in human functioning are sorted in three areas (Figure 9): Impairments as problems with body function (blindness), activity limitations as difficulties doing activities (like walking) and participation restrictions as other problems with involvement in life (for example facing discrimination in employment). The ICF therefore leaves room for many ways in which the lives of people with disability can be improved.8

![Representation of the International Classification of Functioning, Disability and Health](image)

Figure 9: Representation of the ICF by the WHO.39

According to Frauenberger, the designers’ philosophical position in terms of disability changes the whole designing process, whether implicitly or explicitly. AT that focusses on removing barriers does
exist. For the critical realist approach however, this is not enough. It wants AT to work through the multiple layers that shape a “disability”: Biological, physical, psychological, psychosocial, emotional, socio-economic, normative and cultural. In the designing process, a number of questions should be answered:

- **“What is the purpose of the technology we design?”** Formerly, this question could be easily answered as reducing the functional limitations of the individual. Truthfully, a multiplicity of mechanisms and their interactions should be considered. We have many technologies that serve one specific purpose in living with a disability. Despite this fact, a holistic approach is often lacking.  

- **“How can we design such technology?”** Since technology can shift the experience in possibly unwanted ways, therefore Frauenberger suggests a diverse mix of methods can be used to probe it. This could for example include quantitative studies and design interventions to provoke social responses. Then, design needs to be developed by the understanding gained from this, with two components being essential: Participation and reflection. Constant reflection is key to refine ones understanding of technology and mechanisms. Participation of people with disabilities (as well as their caregivers) in the design process is mandatory for their unique insights into the complexity of the disabled experience. Mankoff adds another complement to the answer to this question: Designing AT defines who has access and who meets barriers from a perspective of disability studies. If an interface is badly designed, it creates users who are disabled to use that system.  

- **“What does it mean for technology to work well for people with disabilities?”** Contrary to earlier beliefs, it might not be sufficient to prove AT is delivering what was the initial goal unless it is clear how the interaction with other levels of disabled experience works. As an example, a rehabilitation device might also change the social peer pressure to do one’s exercises. Another difficulty is the evaluation of changes: What might be positive for policy makers can have negative effects on an individual.  

To conclude, a one-sided perspective on disability can be reducing and possibly dangerous, which has been recognized in this recent work on AT. A guiding principle in design of holistic AT should therefore be: **Never reduce the person to what they are struggling with.** Wellbeing should be in the center of design. Also, there might not be a “right problem” to tackle with AT. Thinking that people with disabilities can always be helped by designing technology is based on a wrong assumption. A need for a specific technology should therefore verified by asking the concerned before starting to work on it. Replicating technology development that is ineffective or unhelpful should also be avoided.
4.2 Implications on the use of AT to support people with dementia

To investigate the use of AT to support people with dementia, the question “What is dementia?” must be posed again. It has been answered in a medical way in the first chapter of this thesis. But what is in on an emotional level? How does the world look like from inside the disease? Is it helpful to think of dementia as a cognitive disability? These questions have long been overlooked and consequently not been considered in the design of AT. Recently, however, the focus on defining dementia in various ways, in part as a disability, has been brought forward. This is important, since if dementia and disability are connected, legislation against social discrimination of disability becomes eligible for people with dementia (3.3.3 Ethical and Human rights aspects) as well as other social gains already achieved by disability rights activists. However, according to Knall and Östlund, discussion on dementia was narrowed in part by its limitation to dementia being a disability. This plays into the hands of a focus on technical issues which does not take the context or the subject into consideration. In 2009, they stated: “Knowledge acquisition about the user perspective and understanding of the subjective world of the person with dementia has been delayed, and few have examined the use of technology from the user’s point of view.” (p. 30)

Initially, people with dementia have often been seen as a homogeneous group. A shift in perspective towards seeing them as individuals with different and unique experiences of the illness has occurred. This is fundamental for shifting towards a more person-centered care (PCC). In PCC, the role of caregivers is to build more personal relationships with people with dementia. This can be done through artifacts that support reflection on personal beliefs, values, thoughts and relations. Therefore, the interest in research on design and multisensorial technologies is rising. However, to successfully implement this into design, knowledge about the experiences of people with dementia is needed.15

An old person should never be considered from the outside eye. Inside of old people, every age of their life is retained. Ageing itself is not a part of one’s personality, but as dementia progresses, this can become difficult to see for others. From a salutogenic perspective (an approach to focus on the health and well-being rather than on the disease), people with dementia are not just ill – they inhabit healthy parts and their personality is still the same, even if sometimes shaded by the illness. According to Antonovsky et al., one must understand what can bring a sense of coherence to the person (which is still there, even if in an unusual way for other people). This can in turn lead to QoL. When thinking about technology for people living with dementia, it is important to understand this ‘hidden’ personality. Knall and Östlund compare this to a tree: From the outside, one can only see the last tree ring of a life. But a person is made of many tree rings, which become apparent when experience and memories are brought up. At the beginning, research was more limited to AT that help overcome
cognitive and physical disabilities resulting from dementia. More recent literature focuses on the more personal experiences of dementia, exploring the role of design in that respect. It is not meant to replace AT, but instead offer another perspective on it. The true power of design shows in its ability to engage with more personal experiences of people.

Important for research is therefore looking into the lives of people with dementia. Questions like “Where are they oppressed or excluded?” can be asked: Since people with dementia can neither work nor contribute unpaid community work (e.g. cannot look after their grandchildren), they are often perceived as problematic. Keeping them out of the way of „normal“ activities by keeping them at home or in a care institution is a widely used practice. Often this also implies to behaviorally restrain them through pharmaceutics. This can also be linked to AT, as described by B. Bennett et al:

“Traditionally, concerning behavior by people with a cognitive impairment, including dementia, has been dealt with using restrictive practices, such as physical restraint or medication. The use of assistive technologies in dementia care adds a new technological dimension: in addition to supporting people living with dementia and enhancing their living arrangements, assistive technologies may also provide new mechanisms for surveillance, for limiting privacy and for restricting movement.”

There exists justified concern that some of the available technologies have the potential to intrude privacy and restrict freedom of movement: For example home video surveillance can cause ethical concerns, as it leads to a moral conflict between safety, and freedom and privacy. Therefore, it is most important to examine human rights implications of these technologies. Without an evaluation, AT may not live up to their promise of improving the lives of people with dementia or could even have a negative effect: They could take highly valued rights and freedoms away from them. When, for example, considering the wandering of people with dementia, there are two extremes: One is to prevent them from wandering by medication or locking them up, the other to let them go wherever they want to since they are free that way. Compromises could be GPS trackers or accompanying them. Another solution sometimes implemented in care homes is building mazes without exists for endless wandering. This is compared to torture, since wandering patients always seek something which they obviously cannot find within a maze. Tracking should not be used for permanent surveillance but rather to support navigation. An example for such design is Way-key (4.3.2 Way-Key), where people can only be tracked in emergency situations previously defined.

As technology becomes more and more important, it becomes a vital part of our experience of the world. As a result, using it is getting more difficult in isolation – a challenge met by adopting a more situated, participatory approach. As Shinohara et al. put it: “Technology does not happen in a social vacuum” For example a navigation aid for blind people on the street might be designed without considering other people around them, be it positive as helping with directions or negative as stigmatizing the blind person.
All will have an effect on the situation and perception of the technology. The same can be said for designing technologies for other disabilities or illnesses like dementia: If we design for an individual, the technology will also interact with the environment and the other way around. Technologies should therefore recognize all different social mechanisms and how they interact. Even if a technology does not address all different perspectives, they should be kept in mind. Otherwise the trap of meaning good but also bringing unintended consequences lures.

Persons with dementia are also subjects and they strongly depend on context. When designing, this should always be considered by asking questions like: What do they want to achieve by escaping? What happens when they cry or when they watch a commercial on TV? Here, the term “unnecessary disability” comes into play: Some people with dementia can do less than they would be able to because their environment is disabling them. As an example, there was a man being perceived as very disabled because he would not get out of bed. In fact, it would have been an easy thing for him to do, but the floor in his bedroom was very shiny and reflected the light - as a result, he thought it was water and was afraid of stepping on it. Or the woman constantly moaning without visible reason: In reality, her chair was too high and the dangling feet left her with an aching back. If there is an action by a person with dementia, there probably is a reason for it.

When it comes to providing social experiences, technology is on the rise as well. Social robots like the Paro Seal (a robot seal interacting with people) are becoming more and more popular. But do they devalue care or even reduce social interactions? If a machine has human characteristics and a person treats them like a human, does this pose a problem? Is there a level of deception involved? Questions like these cannot be answered easily and make room for an ongoing debate whether AT enhance or lessen the dignity of people living with dementia.

Another interesting aspect to think about is the one of decision making and the potential role of AT in it. How could they help in advance care plans and as decision-making aids? If AT could extend the period a person is still capable of making their own decision, for example by splitting up complex decisions into a series of smaller ones, a dementia patient could still make their own choices about health care. However, this might bring a contradiction of Article 12 of the UN Convention on Rights of Persons with Disabilities (respect a person’s will despite cognitive impairment) and Article 25 (the right to health), for example if a decision being made is the one of withdrawing life-sustaining treatment. There is a difference between autonomy and self-determination. As dementia progresses, people inevitably lose autonomy and depend on others to lead their everyday lives. This might not be avoidable, but still people can make self-determined choices in safe spaces and routines. Ideally, this should be supported by technology in order to retain their personality.
Concerning the technological development, it is most important to let people with dementia or at least their caregivers participate to obtain meaningful results. Marshall thinks that for too long, caregivers and people with dementia have been seen as people on whom research is conducted. In reality, they should be active participants that also have subjective needs.\textsuperscript{7} Until recently, perceivably vulnerable people were sometimes excluded from participation in research.\textsuperscript{47} This was done to protect them from being exploited. The authors describe this as “protecting them to death” and welcome that vulnerable groups are no longer excluded from research, given the benefits of their participation.

However, how exactly the consent of a person with dementia to research should look like, or even if it exists at all, is still under negotiation.\textsuperscript{35} Consensus for participation in research, like in field studies, can be a difficult topic if it is given by people in the late stages of dementia: They might give it, but forget about it within a few minutes. The authors therefore do not see consensus as simply an issue of obtaining a signature. To respect it, people with dementia have to be treated as persons, not just as subjects.\textsuperscript{45} Informed consent signed by a person with dementia should only be seen as temporary.\textsuperscript{28} Sometimes, it is not possible to obtain consent in a meaningful way. If the dementia is at a very late stage or it is difficult to build up a relationship with the patient, alternative persons, like relatives, should be asked to participate in research.

To summarize, there are a lot of topics in dementia research that are still under discussion. Ethical guidelines are in most cases not straightforward, and many questions can be answered in different ways. Still technology is slowly turning towards a more person-centered approach, enabling people instead of restricting them.

However, besides this shift in perspective, the importance of long tested devices like time aids or alarm systems should of course not be underestimated.\textsuperscript{7} AT has improved the life of persons with dementia in many ways, partly by easing the burden of care for caregivers. Society has come a long way from simply seating the eldest in a corner for their last years to pass to treating people with dementia as persons with their own emotions and wishes. To continue this way, a focus on the person and their abilities as well as their human rights and emotions has to be at the core of designing AT for people with dementia.

“I am convinced that an anti-reductionist position and a focus on understanding is part of the road that will take us beyond surveillance of persons with dementia into a deeper and more sophisticated development of technological support for these people’s life quality.” \textsuperscript{7} (p. 31)
4.3 Examples of devices

Two examples for devices that were designed following this shift in perspective and moral guidelines shall be presented here. The RelivRing is a device for remembering and reliving social activities by paying voice messages, project WayKey was designed to promote mobility in people with dementia by tracking where they are, but only interfering if necessary.

4.3.1 RelivRing

The RelivRing is a device developed for reliving social activities for people with dementia. After a visit, relatives can store voice messages on it that the person with dementia might otherwise have forgotten. The positive experience of a visit can be brought up again when listening to the messages. They designed the device according to literature and a user study (Figure 11). In order to design the device, a study was conducted where people with dementia should act as the experts and tell the researchers how to use “old-fashioned” products (for example an old radio or telephone). It was found that a rotating handle like in a bean cutter and a phone horn were quite intuitive for people with dementia. Afterwards, a prototype was developed and tested with the persons. It was found that the handle did not seem familiar anymore when incorporated into a different product. The phone handle also did not prove to be well suited, as it only allowed to listen to the messages privately while the residents showed more interest to share their messages. This resulted in both features being removed. Pictures of the family member that left the message were incorporated on the buttons to listen to them, which evoked very positive responses. The fact that the messages were pre-recorded did not bother the persons with dementia, the same went for listening to the message several times. Both residents that were given this prototype smiled a lot and verbally responded to the message. In a third iteration, another prototype with higher fidelity was built. It evoked the same positive responses but the pictures of family members, which had not been changed, were not recognized this time. The authors think this was because of the surrounding material, which was blue instead of white for this prototype. Also, the buttons were not recognized and repeatedly mistaken for the speaker. In the final rendered version of the RelivRing, the speaker was lowered and made out of a material with a more visible speaker grid to resolve this issue (Figure 10). An outer ring of pulsating light was added to remind people with dementia of the device and show an incoming message. Those can be sent and uploaded to the RelivRing simply via WhatsApp. Also, small details were included in the design, like the device being cable powered in order to prevent battery death without the caretaker noticing. The tendency of people with dementia to hoard (others) material is met by the need to openly plug the device in. Therefore it cannot be used in secret and is useless when hidden in a cupboard. One of the risks of the RelivRing is openly discussed in the paper: The one of reminding the user of their own forgetfulness when listening to the messages, which could lead to sadness or confusion. Also, the burden for caretakers to explain the device should be considered.
However, the positive effect of hearing voice messages of relatives that evoke happy emotions sets a path to a promising design direction with great potential for future research.\textsuperscript{27}

4.3.2 Way-Key

Maintaining a certain level of mobility can help delay dementia symptoms but encouraging people with dementia to wander bears risks like falling or getting lost. Technical solutions therefore mostly focus on the monitoring and possibly restricting of mobility, making people with dementia only passive users of them. Way-Key, however, was designed to promote mobility in persons with early to medium stage dementia. For them, independent mobility is a legitimate need and should be supported by technology. Way-key was designed to guide them to their goal and back home without the need for care personnel.
while respecting privacy and ethics. For this, the team talked to different interview partners, including caregivers, management of care homes and people with early-stage dementia. They concluded that people in the early stages of dementia still are mostly independent. They like to have a detailed day structure and use tools as day planners. The authors suggest that people with dementia like to use technology if it is already known to them and has some sort of fixed place in their routine.

The project ended with three prototypes. The first was a cooperative day planner, where people with dementia and their caregivers can structure the upcoming day in the morning. Together, they define to-dos as easily graspable blocks on a board, where each block is associated with one certain activity. The board can make activities visible for family and caregivers via an online connection.

![Figure 12: First prototype. Left side shows time of day, right side shows activities.](image)

The second prototype is called a context aware guide designed to help people in a moment of disorientation to find their way back home. Situations like this are often stressful or near a panic attack, which is why help should easily be provided in such situations. An emergency button is carried around for example on a watch or in a smartphone cover. When pressed, a list of pre-defined people are called until someone picks up. Depending where the person is, the system can even retrieve context data form apps like the AccessibleMap and the caller can guide the person home or to a safe space to wait.
The third prototype is a geo-fence application that is customized to the person. Ideally, this geofence also adapts to different times in the day, for example the supermarket could be within it, but not at 3am. They user only needs to take a tracker with them and as long as they stay within the geo-fenced area, the application does not need to react in any way. As they go beyond the border of their area, the system is aware of that a caregiver can see and maybe check in with the person. If they get completely lost, however, caregivers are alerted of a potentially dangerous situation.

Figure 13: Second prototype showing the interface presented to caregivers. The disoriented person is shown in the middle.

Figure 14: Third prototype showing different stages of the red alert.
5. Case study: Designing an application

In the last two chapters of this thesis, an case study of an application for people with dementia will be described. While writing about dementia and talking to people that are in contact with it in their daily lives, ideas for AT were discussed and exchanged, many of which have turned out to already have been implemented. However, one specific idea for an application popped up when talking about the topic with family caregivers and went on to be refined during interviews with care personnel in a hospital. It is about an app to help reminiscence work with people living with dementia.

5.1 Developing a design concept

5.1.1 Research

The starting point for this idea was a literature review by Evans et al. by which had one particular statement in it:

“The clearest finding of this systematic review is a lack of research exploring technologies to support leisure activities.”

105 articles describing 233 technologies were reviewed by the authors. These were grouped into general themes: Out of those technologies, 70 were safety devices, 58 memory aids, 37 aimed to prevent social isolation, 33 supported everyday tasks, 28 were clinical devices but only 7 could be attributed to the group of leisure activities. This findings are underlined by a review by Klimova et al. conducted in 2018 concerning the use of AT especially for AD patients. Keywords were for example Alzheimer’s and AT, or social devices and AT. After removing irrelevant or duplicated papers, the authors included 10 studies in the analysis. Of the 10 studies, only 2 were focused on devices to support leisure engagement and cognitive training, the main part was aimed at safety and daily living of patients.

Also, a manual provided by the WHO for training and support of caregivers of people with dementia involves more than 250 pages of tips for coping with dementia. It spans from the involvement of others in caring to reducing stress in everyday life to toilet and continence care. However, there is not a designated chapter for leisure of the person with dementia themselves – which perfectly elucidates how underrated and underexplored this topic still is.

As most of the people with dementia are retired, much of their time could be spent with activities to enhance their QoL. Recreational activities could also have numerous cognitive benefits. However, the
Reviews by Evans and Klimova suggest that technologies to support these suggestions that they “simply do not exist” 48 (p. 9).

A visit in a care home underlined this in a most painful way: Care personnel went into the room of a person with dementia to wake her up and get her dressed. Afterwards, the person was sat at a table waiting for breakfast. The care personnel left to get other persons ready for the day and when they came back after more than one hour with breakfast, the person with dementia was still sitting in the exact same spot – without being able to distract herself in any way, without having moved, simply waiting. After breakfast, the care personnel left and the person with dementia had to wait again. This pattern is repeated every day, as the care giver confirmed. Hours of waiting, every day, maybe sometimes interrupted by a family visit (Care personnel of a hospital were upset when told about this incident in later interviews. Leaving people with dementia alone without distraction is not a practice normally exercised. However, at the time of this incident, I did not know of this.)

The initial idea therefore was designing a device for the leisure time of people with dementia. What can make them feel good? How can they spend their time? In further research and talking to caregivers, the importance of memories and reminiscence was mentioned very often. Therefore, the idea of combining technology for leisure activities for people with dementia with reminiscence work (2.4.4 Reminiscence work) was the next step in the design development.

The idea was to design an app showing the person with dementia pictures and music of their past. When talking to care personnel of a hospital, this idea was refined to not focus on the person with dementia, but also help with care work.

“We have a system for life story work, asking relatives a lot of things. But sometimes you cannot go into too much detail, or the relative does not know something. An app could really help with that – helping someone remember what a person has already told them about. […] I think an app with historical facts could be innovative.” From an interview with care personnel

When further discussing the topic of historical facts, she stated:

“Care givers often don’t have the time to read about stuff, but if it’s prepared and presented in an easy way, one could have a look at it before going into the room of a person with dementia.”

Caregivers often do not have time to look up information for each patient, so they stick with what they already know. Much information still memorized by the patients gets lost like this. If facts from the life of a person get presented to care personnel in an easy, quick and intuitive way, they might be able to
have a look at it, for example before waking the patient up and getting them ready for the day. If the patient is confused or scared, the newly gained information can have a positive effect right away.

“This wouldn’t only be possible in a stationary setting. A grandchild could also sit down with the app and talk to their relative.”

It is very important for elderly people to stay connected to their loved ones, even if family members are busy, and finding time to talk about their lives. The app could help with that as well.

5.1.2 Related work

After the initial research was done, related work was investigated. Interestingly, the connection of archives with dementia work did not give as many results as for example life story work. A few examples of the two shall be addressed here.

Perlen Project is funded by the German Ministry for Education and Research. It is about documenting the biography and daily routines of persons with dementia, since they often cannot communicate or remember them anymore. Giving care personnel access to this information could lead to more QoL as in the status quo, therefore the declared goal of the Perlen Project was to implement an IT-System for personal documentation of people with dementia. A multimedia collection (photos, videos, audio) can be created and accessed by relatives, care personnel and persons with dementia. Like this, important biographical data can be stored for further care. They also focused on the relationship between diabetes and dementia, since people with diabetes are over proportionally affected by the disease.
My House of Memories is an application by the National Museums of Liverpool that allows you to explore objects from the past. It includes pictures of objects from different decades, connected with sound and music for helping to remember. The objects can be browsed and saved to a memory tree, memory box, or a timeline. They can be accessed by themes and personal photos can be uploaded. The app is visually pleasant and is dementia-friendly designed with big buttons, high contrasts and auditory feedback and overall a good example of how an app could look like. The only limitation is that only objects and pictures stored in the system can be accessed. There is no “search” function or algorithm that includes objects personally linked to the user. Also, the range of options can feel a bit overwhelming, it is hard to get an overview of the functions and how to use them.
The My Life Story app is a digital photo album where music and audio can be added. What is special about this app is the focus on being user friendly: There is always only one action possible in the setup to keep things simple. The advanced settings, where for example pictures can be deleted, is “hidden” behind the viewing mode of the album, so that a person with dementia has no access to it. Photos are automatically played; the pause button is hidden.

Figure 16: Screenshots from the My House of Memories App for iPad.
Another interesting concept is the one of BBC RemArc. This is a website created by the BBC offering different content of their archives (pictures, video, audio) to people with dementia. The media can be accessed in two ways: According to theme or decade. For each piece of media, a short piece of information is given. The website is designed for easy access and understanding, although not all designing guidelines for dementia have been followed. The content is limited to what was uploaded.
Other companies, like Nestlé, also looked into their archives to help people remember. In the case of Nestlé, they implemented a reminiscence pack together with the Alzheimer’s society UK. The concept is that old packaging of familiar brands can be printed at home and put on certain goods. This should help trigger memories of happy days.

All of these examples provided a lot of information which entered the first concept of the application. Interestingly, the connection of life story work and archives did not occur directly, which is exactly the point our application wants to cover.

5.1.3 First concept
Assembling this information and related research, a first draft of a concept was made (Figure 20). The app is to be used on a touchscreen device, preferably with a big screen like a tablet.

**CONCEPT: APP FOR REMINISCENCE IN PEOPLE LIVING WITH DEMENTIA**

**IDEA**
Designing an app to help reminiscence work with people living with dementia. Combining information from archives/internet with personal biographies as a door-opener for talking with a person.

**WHY IS IT NEEDED?**
People with dementia enjoy reminiscence. When daily life gets more and more confusing, good memories can act as a safe haven. Caregivers use reminiscence work to calm people with dementia, to distract them from negative thoughts or simply for having a good time with them. However, often it’s difficult to keep track of a person’s history, like the things they liked as a child or their favorite songs. And if there is no trigger to do so, a person with dementia will probably not start talking about certain events in the past, especially in stressful situations.

Caregivers often don’t have time to look up information like this for each patient, so they stick with what they already know. Many information still memorized by the patient gets lost like this. If facts from the life of a person get presented to care personnel in an easy, quick and intuitive way, they might be able to have a look at it for example before waking the patient up and getting them ready for the day. If the patient is confused or scared, the newly gained info can have a positive effect right away.

Here, technology can help by providing information stored online.

If the app knows some stations in one’s life, it can deduct certain information from it – for example, as a person born in the 1990s in Austria, you’ll most likely have watched SpongeBob at some point, so it might present a picture of him to help you remember and calm down. Similarly, the app could know you’ve seen the Stephansdom if you’ve lived some years in Vienna or that you’ve experienced Michael Häupl as its mayor.

**WHY IS IT NEW?**
There are lots of applications for reminiscence work. However, most life story apps just use information typed in by the users or pictures uploaded by them. Also, archives of picture/video/audio exist especially for dementia patients – but they don’t have a personalized structure. The combination of personal biographies with information from the internet is what’s new in this concept.

**DESIGN SPECIFICATIONS**
The app should be usable both by caregivers (relatives are often 50+ years old) and persons with dementia. Therefore, the design rules include among others: Customizable, easily accessible, intuitive, colorful, high contrast; uniform lightning, clear signage, large print sizes, audible confirmation when pressing a key, immediate action after pressing a key, simple UI with possibility of using extended functions.

**INTENDED FEATURES**
- Search and present personalized historical facts to care personnel for starting a conversation
- Search and present personalized historical artifacts (photos, video, audio) with descriptions
- Search and present personalized historical artifacts (photos, video, audio) with descriptions

**POSSIBLE FEATURES**
- Search and present pictures/videos related to personal experiences/memories
- Search and present music from different life stages
- Upload personal data and descriptions
- Link data to life story book
- Possibility to leave marks for caregivers
- Sort data according to e.g. mood (folder with pictures when agitated/angry/...)

**POSSIBLE INFORMATION SOURCES**
- Newspaper archives
- Music charts websites
- Google search with keywords
- ORF Archive
- Databases of dementia associations

**MEDIA CONTENT**
- Pictures
- Videos
- Music
- Audio
- Notes
- Voice memos
- Personalized life story book

**TARGET GROUP**
- People with moderate dementia
- Care personnel in care homes or hospitals
- Relatives, friends and other social contacts

**INSPIRATION**
- BBC RemArc, PERLEN Project, My house of memories, Music memory box, My life story
A clickable wireframe was created to suggest how the app could work and how the handling would function (Figure 21).

Figure 21: Screenshots of the clickable wireframe presented to caregivers.

Also, two drafts of possible designs for the app were created (Figure 22).
To evaluate the concept, expert interviews with care personnel were conducted.

5.2 Evaluation of the design in expert interviews

In qualitative interviews, the app was presented to care personnel in hospitals. The goal was not to conduct a representative study, but to collect subjective and extensive feedback on the concept. Caregivers had different backgrounds and levels of familiarity with technology. The interviews were done one-on-one in an informal setting (n = 3). Caregivers were asked to speak freely and mention any idea that came up. They clicked through the wireframe and had a look at the first drafts of design. Afterwards, a number of questions about the idea, design and handling were asked (see
Appendix A – Interview with caregivers). Care personnel in general appeared curious about the idea and the feedback was strongly positive. The importance of features that should be implemented is summarized in Table 1.

Table 1: Average importance of features as indicated in caregiver interviews.

<table>
<thead>
<tr>
<th>Which features would you implement? 1 = least important, 5 = most important</th>
<th>( \bar{x} )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search and present personalized historical media (photos, video, audio) with descriptions</td>
<td>5</td>
</tr>
<tr>
<td>Search and present personalized historical facts in order to start a conversation</td>
<td>3.8</td>
</tr>
<tr>
<td>Search and present music from different life stages</td>
<td>5</td>
</tr>
<tr>
<td>Personal Pictures/Videos (made by themselves/relatives…) with descriptions</td>
<td>4.3</td>
</tr>
<tr>
<td>Link data to life story book (with different stations in one’s life to go through)</td>
<td>4.6</td>
</tr>
<tr>
<td>Possibility to leave remarks for caregivers (e.g. hates to go to bed without listening to some music)</td>
<td>2.6</td>
</tr>
</tbody>
</table>

Regarding the content of this table, some important remarks were made by the caregivers: The upload of personal media was seen as a positive addition. Especially when contact to close ones is limited, media showing loved ones could strengthen relationships and calm the person with dementia. However, personal media and media from archives or the web should be kept separate according to one caregiver. Another caregiver added that uploading media might be too laborious in a clinical setting and that this feature might just be something for a setting at home.

Linking data to a life story book could be a feature to save time: If a person is talking about a certain time in their life having access to data of that time in an easy way could be helpful in generating ideas where to dig deeper. This could again save time for caregivers, as they have an easy way of relating to that period in their patient’s life.

The possibility to leave general remarks was perceived more critically, since it is not something explicitly necessary. Nearly every care home or hospital already has the infrastructure of writing down notes like this. This feature will therefore not be followed further.

Caregivers agreed on the description of media to be an important feature which should definitely be implemented. The idea came up to hide information behind the title: For example if a photo of Michael Häupl is shown, the title could be “Major Michael Häupl”. When clicking on this title, additional information unfolds. The length of this information was seen as optimal being 2 to 3 sentences.

“I see it as a first contact to a subject, combining media with information. If you already have a clue what it’s about, you can start talking to each other.” From an interview with care personnel
The opportunity to take notes besides media (for example how a person with dementia reacted to a photo or if she remembered anything related to this) was highly praised by two caregivers. They saw the positive effect of an information transfer to a later point in time, where maybe these memories would already be lost.

“It’s not like you’d write a novel in there, just small hints: Where can you dig deeper, where not because the person might get aggressive. That could be helpful”

Another professional caregiver, however, saw the feature more critical: For her, it was questionable whether this feature would really be used, as it consumes time to type in remarks.

The Like and Dislike buttons were seen positively, the opportunity of a third button (“no reaction”) was discussed. However, since it is questionable whether this button would have any additional functionality, it was decided not to further pursue this idea. If there is no reaction shown, swiping to the next content without liking or disliking can be seen as hitting the “no reaction” button. This of course has to be clearly communicated when using the app for the first time. The opportunity to sort data according to mood was also seen as helpful, and the like and dislike button could be sufficient to do so. A class (besides e.g. stations in one’s life) to choose from will be “Liked”. Only media previously liked and therefore having a positive impact on the mood will be shown when choosing this class.

The other classes were discussed as well. One caregiver thought that not exclusively media that directly relates to a person’s life could be shown, but also generally known items, e.g. the Eiffel tower. This could be done in an extra class, for example “buildings”. She added that it could feel like a success to the person with dementia if she or he recognized something and could talk about it, even if it is not specifically linked to her or his life. These generally known items could also be a preset feature of the app.

One main concern was the phrase “person with dementia”. As people with first and mild symptoms of dementia are often ashamed of their condition, this phase could be interpreted negatively, care givers advised to change it. Since “patient” (as used in hospitals) and “resident” (as used in care homes) also have a unfavorable touch, the term “client” was agreed upon. Also, the term “dementia mode” was discarded in this context and is therefore renamed to “client mode”.

Regarding the client mode, the feedback was also positive. A caregiver stated that she was confident the client mode could be used for a long time if it is kept as simple as in the mockup. While she was in favor of shuffling the media randomly when using client mode, another caregiver thought this could be too
much for a person with more severe dementia. There should be the option to show media according to topics as well. We also discussed that there should be sounds when pressing a button, preferably even the content of the button could be spoken out loud by a voice: “Back”, “Photos”, “Music”. This could help with orientation, even if vision is very low. There should also be a sound when pressing somewhere else on the touchscreen, like an “error sound”.

“A lot of them know those sounds, many have for example played bingo. They know those sounds you get when you are right, and the ones when you make an error. That could help.”

However, another caregiver stated that a friendlier sound might be more pleasant for users. Nobody likes to be reminded they made a mistake. Maybe the solution lies in between here, having a sound that reminds of an “error sound”, but in a friendly and unagitated way.

One problem was intensely discussed: The switch from client to caregiver mode. This switch should of course not happen too easily or just by clicking a button since otherwise persons with dementia might accidentally change into caregiver mode. There, they might be overwhelmed by the options or change something in the settings. Therefore, my initial idea was swiping once up, then once down to get into the caregiver mode, similar to something like a child lock. This idea was rejected by caregivers: Persons with dementia often become erratic when feeling uneasy, this motion would therefore likely occur in such a situation. Also a “hidden” button could be clicked by accident. A sequence of long swipes (right – right – left) was proposed as an alternative. It is unlikely that a person with dementia accidentally swipes right twice, as it is not a natural movement.

“A restless patient always swipes back and forth. I think the probability to swipe in one direction multiple times is relatively small. If they do so, then only to the left, as this is something they know – it’s like turning the page of a book.”

When asked about data privacy, caregivers did not seem to be concerned. The consensus was that the data required is not sensitive and can be shared. The question “Would you share information like this about a relative?” was answered with yes in all interviews. One caregiver mentioned she thinks the information gained could also be interesting for dementia research by answering questions like: What kind of media do they like to see? How are they influenced by that media? Another aspect that was added by a caregiver is that she would trust an app like this in particular since there is no advertisement shown in the mockup. This is surely an important point, as advertisement often gives the appearance of something being cheap and less trustworthy to her.
The setup seemed to be intuitive and easily understandable. The questions were deemed appropriate, although one caregiver wanted to add a question about a trusted person of the person with dementia. Her idea was to incorporate pictures of this trusted person into the app, so that these could be viewed if the patient is anxious. A picture of a known face can be the one of the most calming things for a person with dementia to see. Another caregiver added that questions about family members could be asked. She also wanted to have more options to customize the dementia mode, for example whether sounds are played when clicking.

The two design proposals were also discussed. Caregivers preferred the second, white design. They seemed confident that they could use it as it was shown, especially the buttons showing graphically what they do were highly praised. No significant changes to be made were discussed.

One possible hurdle was mentioned: In some hospitals, care homes or houses, there still is no reliable internet connection. This could highly influence the usability of the app as it is designed, since information has to be downloaded. However, it is not a problem unsolvable: One solution would be that the app directly downloads content after the setup and stores it on the device. This would of course take a few minutes, but afterwards the media could be used without a connection. A possibility to gain further media if everything has already been viewed would then be to add a “Download more media” button to the setup.

The general feedback was strongly positive:

“Exactly as it is I think everything is covered. An instrument to see what the patient likes and needs.”

“It’s well built, easy, clear, structured – I’d like to try it right now.”

“You often don’t reach them anymore, except with pictures and memories. This would be an enormous time gain to simply get those.”

“Doing activities with them is often difficult, because they think they can’t do stuff anymore. So I like the idea of having a tool to activate them and spend time together.”

“I’d definitely use this tool. Even if just for 5 or 10 minutes, it’s nice to have something you don’t have to prepare a lot for.”

All of the interviewed stated they would like to try the app. One person interviewed was the director of nursing in a hospital, she stated that both caregiver and client mode would be tested and potentially used in that hospital if the app existed.

All changes and additions mentioned in caregiver interviews were considered, and most of them were included in the final concept.
5.3 Summarized final Concept

The finalized concept can be summarized as follows:

**Design of an app to help reminiscence work with people living with dementia. Combining information from archives/the internet with personal biographies as a door-opener for talking with a person.**

5.3.1 Wireframe and design

A possible wireframe of the app is shown in Figure 23.
The functions of the app are explained according to the different interfaces shown in this wireframe.

**Welcome screen:** This is the first screen shown after opening the app. Here, it is evaluated who has the tablet in hands (client = person with dementia, or caregiver). The client option is far bigger and more contrast rich in order to guide a person with dementia to click there first. If client is pressed, one is immediately forwarded to the screen “Client mode”. If caregiver is pressed and the app is opened for the first time, the setup is opened to be filled in right away. If the app has been used before, one is forwarded to caregiver mode.
Setup 1: Here, the caregiver can enter personal data of the patient. Questions asked (Table 2):

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>-</td>
</tr>
<tr>
<td>Year of Birth</td>
<td>-</td>
</tr>
<tr>
<td>Country of Birth</td>
<td>-</td>
</tr>
<tr>
<td>Country of residence</td>
<td>-</td>
</tr>
<tr>
<td>City of residence (if known)</td>
<td>-</td>
</tr>
<tr>
<td>Years lived there (if known)</td>
<td>-</td>
</tr>
<tr>
<td>Multiple entries can be added</td>
<td></td>
</tr>
</tbody>
</table>

When all possible fields have been filled out, “done” is clicked to get forwarded to Setup 2.

Setup 2: A second screen for entering data of the patient. Questions asked (Table 3):

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job</td>
<td>Multiple entries can be added</td>
</tr>
</tbody>
</table>
Furthermore, this would be the place to implement the upload of personal data, if wished. A button can be clicked, afterwards photos/videos/music can be accessed and uploaded to the app. Personal data does not have to be uploaded to the internet to ensure data privacy, but are exclusively accessed locally. A cloud storage is of course possible, in order to access/upload data independent of location. However, such a function was not discussed by caregivers and does not seem to be a priority and should therefore not be implemented in the first prototype.

Another button to be added here is the one to download media. This should be used if no stable internet connection is possible at all times, e.g. in a hospital without wifi. With this button, media can be stored on the device for use without a connection. When pressed, new media is added to the already downloaded one, giving the opportunity to always view new content.

When all possible fields have been filled out, one clicks done to get forwarded to the Caregiver Mode screen.

**Caregiver mode:** This is the main screen for caregivers. Here, they can access photos, videos, music, history and the client mode or can change something in the setup. The screen is designed in an elegant, minimalistic way with big symbols supporting the text on the buttons. Limiting options to 6 buttons helps to make navigation and handling easy and intuitive.
Photos Caregiver Mode: Here, photos can be looked at by the caregiver alone or with a person with dementia. A photography is displayed full screen in the back. Handling is intuitive: One can swipe left or right to get to the previous or next picture. A title with a few words is shown on the upper right corner. If the title is clicked, further information on the picture unfolds for the caregiver. Under the title there is a field for notes. If clicked, previous notes can be seen and edited or a new note started. A like and dislike button can be clicked according to the patient’s reaction: If he smiles, speaks or moves, “Like” can be clicked in order to save the photo to the “Liked” folder and to get an algorithm to show this picture more often. If the patient gets anxious or sad and therefore “Dislike” is clicked, the photo gets “deleted” (saying it will not be shown again). If there is no reaction from the patient, one can simply proceed to the next picture. In the lower right corner, the topic can be chosen, e.g. “Vienna” (possibly even subtopics “Vienna” – “1960s”). Also, a folder with personal uploaded photos (possibly subdivided into photo albums) can be accessed here. The liked photos are shown by corresponding topic, but also go in a folder that can be accessed separately. At least one topic should contain general items that are shown no matter what the background of the person is (e.g. Eiffel tower, Statue of Liberty or a sunflower). The return button in the lower left corner gets one back to the home screen of caregiver mode.

Videos Caregiver Mode: The video screen is built up similar to the photo screen, with the exception that a video can be played, paused, rewound and fast forwarded. Standard button symbols on the video screen are used to do so. All other controls and settings are similar to the photo screen.

Music Caregiver Mode: The music screen is also built up similar to the photo screen, except that the song can be paused and played using a pause and play button. Songs are categorized according to decade and place. The background is an album cover of photo of the singer of the current song.
History Caregiver Mode: The history mode is meant to present short text to caregivers about historical events that happened in the patient’s past. Ideally, the description is a few sentences long and comes with a heading and small photo. Controls are similar to the photo screen, except there is no heading/text displayed in the upper right corner. Notes can be made by clicking on the notes button beneath the photo. An example for a short text that can be seen in history mode is shown below (Table 4).

Table 4: An exemplary text for history mode.

<table>
<thead>
<tr>
<th>The Year 1968</th>
</tr>
</thead>
<tbody>
<tr>
<td>The occurrences of 1968 mark the worldwide climax of a decade of societal, cultural and political changes. Centers of rebellion against old-fashioned social structures (“Establishment”) and capitalism were mostly the USA, France and Germany. It was carried by a young post war generation and mostly University students that questioned the old authoritarian structures (that were also predominant in Universities). In Austria and at the University of Vienna, the protests were comparatively calm.</td>
</tr>
</tbody>
</table>

The initial idea for the history mode, showing one article per day, has not been discarded and is integrated in the concept by showing one new article as the first one each day. If the caregiver however decides he or she wants to read something else or more articles, the options to decide what to see are there.

One remark concerning the history mode: In caregiver interviews, this feature has not been found to be the most important one. If the technical implementation proves to be difficult, it is therefore a feature that can be discarded without great consequence on the usability and effectiveness of the app.

Client Mode: The client mode is designed to be used by a person with mild to moderate dementia by themselves. Therefore, the options are limited to four things: Access photos, videos and music, and getting back to the caregiver mode. Big, contrast rich buttons that produce a sound when clicked are used to access media. To get back to caregiver mode, one hast to do three long swipes (right, right, left) beneath the buttons, as discussed with caregivers. This should prevent accidental change to caregiver mode by the patient.


Photos Client Mode: The photo screen is kept as simple as possible. A photo is displayed full screen, with three possible options to proceed: Forward to next photo, back to previous photo, return to home screen of client mode. Auditive feedback is given when pressing any button. There are no further options to choose from, however information from caregiver mode is processed: Liked photos are shown more often, disliked photos are not shown at all. Other than this, photos are displayed randomly. This way, a patient has more stimuli than if photos of one topic were shown in consecutive order. Also, since usage should be possible without a caregiver, a variation of topics seems favorable, since the patient could otherwise be “stuck” with a topic he or she does not want to see right now.

Videos Client Mode: Videos are displayed similar to photos in client mode. There is an additional button for playing or pausing the video in the center of the screen.

Music Client Mode: Music is displayed in the same way as videos. An album cover or photo of the singer is displayed as background.

Generally, there are different design specifications that should be met when designing for people with dementia (see 3.3.2 Designing AT for people living with dementia), like customizable, easily accessible, intuitive, colorful, including high contrasts, uniform lightning, clear signage, large print sizes, immediate action after pressing a key, simple UI with possibility of using extended functions.
Important as well is always showing that something is happening, so if a video is loading for example, a loading sign must be shown. In client mode, auditory feedback is given after pressing a key, preferably by speaking out the content of the button clicked (“photos”, “return”, “forward”). There should also be an “error sound” when pressing somewhere else on the touchscreen. The sounds should be preferably be simple and familiar but friendly, an example could be the typical Windows Error sound.

Another aspect is a sudden change of lights: This can feel uncomfortable, especially for elderly people where the pupil is not as fast in adapting to changing light conditions anymore. Therefore, the transition to the next frame or picture should somehow be smooth, maybe happening over a time span close to a second.

Meeting all these design specifications was tried with the wireframe. The app was simplified as much as possible while still trying to build in a range of features that seemed important. Still, using it for the first time and grasping the concept can be a challenge for caregivers as well as patients. Therefore, an explanatory video or a tutorial for the first use should be provided.

### 5.3.1 Technical background

The app is designed for a touchscreen device. In a setup, personal biographic data about the person can be entered. With this information, personalized media relating to the biography is searched and presented. The media is collected according to different life stages, countries of residence and years spent there.

The search could for example be conducted by combining information of the setup, fears are excluded from the search. This could look like the following in a Google search:

A person lived in Vienna between 1930 to 1954. He was a tram driver and liked to watch football. He is afraid of fire and spiders now.

Some searches:

```
Vienna 1930..1954 ~tram -spiders -fire
```

To search for Vienna in the years he lived there having something to do with a tram. Spiders, fire or something similar are excluded from the search.

```
Austria 1930..1954 ~soccer -spiders -fire
```

To search for soccer games in that happened while he was in Austria.
This is just an explanatory example, however the results obtained with these simple searches are quite reliable. Still, a strong algorithm is needed to better analyze and filter them.

Possible sources of media are internet searches and archive searches. One example of an archive that could be used for this is the ORF archive, which contains all material that was used in the ORF from 1955 until this day. It is not openly accessible, but for example some universities have access to it. mARCo is a tool to search within this archive in an easy way. Another archive is ANNO, the digital newspaper archive of Austria, containing 22 million newspaper pages from the years 1689 to 1949. The Austrian Mediathek which is provided by the Technical Museum of Vienna stores more than 2 million video and audio files of Austrian history and is openly accessible.

5.3.2 Summarized scientific background of the features

Besides the design specifications, the finished concept of the app (Table 5) wants to unite different scientific aspects that could be enjoyable for both people with dementia and their caregivers.

<table>
<thead>
<tr>
<th>Background</th>
<th>Consequences for the app</th>
<th>Feature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social contacts can have a positive impact on cognition and well-being of people living with dementia.</td>
<td>App should support engagement and conversation between people with dementia and their surroundings. The app is not thought to replace the active interaction with people, but support and start it.</td>
<td>Media and historical facts searched and presented to caregivers for them to start a conversation.</td>
</tr>
<tr>
<td>Reminiscence therapy has beneficial effects on people with dementia.</td>
<td>Intended to support reminiscence as a way of stimulating patients.</td>
<td>Show media from the individual’s past. Integrate their life story in order to show accurate results.</td>
</tr>
<tr>
<td>Music, images and videos can be used to prompt memories.</td>
<td>Not just one type of media should be presented, but multiple.</td>
<td>Different media.</td>
</tr>
<tr>
<td>It is recommended to use music and sounds to stay connected to the person with dementia. Also, memories and more extrovert behavior, for example joking, can be triggered by rich auditory stimulation.</td>
<td>Music is to play a big role in the application.</td>
<td>Emphasis on music and videos.</td>
</tr>
<tr>
<td>Interesting sounds provide people with sensory stimulation. Rich sensory stimulation can have positive emotional effects.</td>
<td>Sounds should be part of the interaction with the app if dementia patients use it.</td>
<td>A response of the program makes it easier to use, which is why a sound after pressing a button should be played.</td>
</tr>
</tbody>
</table>
To enhance cohesiveness and interaction of families, memories obtained after the onset of dementia should be taken into account when designing. Memories that are more recent should also be reviewed. Possibility to upload pictures, timeframe of presented media can reach until the present.

Leisure activities are a way of engaging people. They have a positive effect on mood and cognitive functions. App should not be forced onto people, but be fun to use. Make it enjoyable to use, by providing much input related to hobbies or interests.

### 5.3.3 Exemplary case of use

The following is an exemplary description of how the app could be used in a hospital setting. It is purely fictional and the persons included are not real.

Martha is a 93-year old woman. She was diagnosed with Alzheimer’s five years ago when she was wandering on the streets with no direction. Her illness has gradually become worse, nowadays she has days where she cannot recognize her daughter anymore. Martha fell down the stairs a few weeks ago and broke her hip, which is why she is staying in the hospital right now.

When she was admitted, the hospital staff asked her husband and daughter to fill out a form regarding Martha’s life. Additionally, they were asked if they would consent for a new type of reminiscence work that could be done with Martha. The data they entered in the form would be used to set up an app that automatically shows Martha media content that makes her remember her past. They agreed.

Today, Martha is woken by a caregiver at around 7.30 am. The caregiver comes into her room, turns on the light and asks her how she is. Every second day she needs to be washed, something that Martha does not like. But the caregiver is prepared: He has used the reminiscence app to find about an event in Martha’s past to talk to her about. For example, the app has told him that Martha’s village in Tyrol was under French occupation after the second world war. Martha seems scared when the caregiver tries to wash her, so he starts talking about the time of French occupation. Martha’s face lights up, she remembers this time really well, she talks about how the French sometimes played her songs on the gramophone. Before she even notices, the caregiver was able to wash her.

She now gets breakfast together with other patients. She is still talking about the time after the war, and her friends can relate to that. Some can also tell anecdotes, others like to listen to the stories. After breakfast, Martha usually sits in the common room, where she likes to look at pictures. She first starts by scrolling through her favorite album, afterwards the caregivers already know to hand her over an iPad with the reminiscence app installed. She knows how to use the client mode of this app and is happily
looking at photos for a few minutes. Sometimes she also listens to music from the app. In the beginning, she could get very emotional when doing so and asked for her mother. The caregivers since have marked some of her favorite songs that bring her in a good mood. The app now preferably plays these songs, so the problem has been solved.

After other activities and having lunch, Martha is visited by her daughter. Today is a good day, she remembers her and is very talkative. She talks a lot about the time she lived in Vienna in her twenties. Her daughter wants her to keep talking and asks a nurse whether she could have the iPad with the reminiscence app. She already knows how to handle this app and opens the caregiver mode. There she enters the photo mode and opens the album that is dealing with the time in Vienna. Her mother shares anecdotes about the photos she sees. When a photo of the Votiv church is shown, she gets confused – which church was this again? Her daughter quickly reads the information on the Votiv church and tells Martha it is located in the ninth district, right next to the University of Vienna. A caregiver has already left a note by this photo telling Martha went to this church every Sunday because the sermons were very moving to her. When Martha gets reminded about this, she is in her element again. She talks about how handsome the priest was and his calm voice. The conversation goes on for over an hour, Martha’s daughter learns a lot of things she did not know about her mother.

Martha takes a nap after the visit. When she wakes up again, she is agitated. Where is she, where are her parents? She wants to see her father right now. The caregivers try to calm her but quickly notice Martha is not reasonable right now. So they tell her that her father is working at the moment, but she will be here soon. Martha says she wants to go home, the cows need to be milked. In this moment, home means her parent’s house in Tyrol. The caregivers remember that Martha’s father knew a lot of folk songs and always sang them while working in the barn, so they try something: They open music mode of the reminiscence app and play the album where tyrolean songs are stored. Martha does not know the first one, so they click on dislike. She starts to smile when the second song begins to play and sings along. The caregivers give this song a like. After the song is finished, Martha is much calmer. She talks about how her father loved to sing this song and tried to teach her a second voice for it. She happily hums the song and the caregivers decide she can now be left to reminiscence on her own.

After eating in the evening and watching some TV in the common room, Martha quickly falls asleep. Her brain did a lot of work today, it remembered quite a lot of things and many emotions were triggered. Martha’s cognitive functions are slowly declining, but the rate of decline has been slowed down since reminiscence work has been actively done with her, at least this is what her daughter has noticed. She already got the log-in data for the reminiscence app from the hospital and has bought a tablet to continue the reminiscence work when her mother is able to go home again.
5.3.4 Further ideas

Some other ideas have been developed after productive discussions with caregivers. These are very helpful and could ultimately be included in the design, however, for simplicity of a first concept they have so far been left out.

In a care home or hospital setting, there should be a possibility to change the current patient. This could be done after the first screen, asking who has the tablet in hands. If caregiver is clicked, there could be a second screen, asking: “Whom are you caring for right now?” and possible options: “Emma”, “Margit”, etc. In the setup, two additional buttons are implemented with possibility to create a new person or to delete the current person (with a security question afterwards).

The linking data to a life story book, which was highly praised by caregivers, would also be interesting to be implemented. Having direct access to the time a person is referring to could be helpful in a conversation and save time for caregivers.

In a more advanced version of the app, custom settings should be possible, e.g. whether sounds are played in client mode. The possibility to play music in the background while watching photos could be another feature. Linking this music or sounds to the content shown would even go one step further (for example playing fair music when showing a fun fair or bird chirping when showing a wood).

In a cloud-based solution, the possibility for relatives that live remote to upload media is given. Like this, media could be collected not only by the primary caregiver, but also by others. This reduces the burden on the primary caregiver to select and collect media to upload and gives others the opportunity to help. A custom profile could be set-up for the patient that anyone can access with their password. This could also be helpful in professional settings, since caregivers in a hospital or care home often do not have access to media like this.

Establishing an online platform could be the ultimate goal. If two persons have the same background or similar features in their biography, what has been learned from the first person could be implemented on the second person as well. For example: Both persons were born in 1940 and lived in Austria from 1940 – 1950. Person A loves pictures of chocolate bars that were given to him by American soldiers after the war. The probability that the same happened to person B is high, therefore showing the same picture to this person should be attempted.
The opportunities for further features of such an app are endless. The primary focus of this work has been on the connection between biography and personalized media. Countless other features for dementia patients, like games, have already been implemented in other apps and would fit here as well. Since an all-in-one solution is not presented so far, this could be very interesting for further research.
6. Summary

6.1 Summarized chapters

In this thesis, the relationship between dementia and AT has been researched. Furthermore, an app for reminiscence work has been conceptually developed. The thesis is divided into five main chapters.

Chapter 1 gave a short introduction into the topic, formulated the motivation to work on it as well as a short problem statement. The expected results are discussed, as well as the relationship between the topic and Biomedical Engineering.

Chapter 2 focused on the medical conditions that are summarized under the umbrella term dementia. The definition of dementia was given, as well as risk factors, and it was described as one of the major causes for disability in elderly people. Statistics by the WHO were presented: Around 50 million people worldwide live with it, and 10 million new cases occur each year.

Signs and symptoms were described in early, middle and late stages, including loss of memory, thinking, orientation, comprehension or bad mood. Different types of dementia (AD, VaD, DLB, FTB) and their specific symptoms were discussed. Treatment and care options for someone with dementia were described in detail: How to keep them safe, how to communicate with them in an empathic manner and which activities are still possible. Another section focuses on reminiscence work and its importance for care and QoL. Reminiscence work was described as a widely used technique in dementia care since people with dementia like to be in the past. It can help against depression and provide meaning in life. The different ways of doing reminiscence therapy were described as well as its background in life story work.

Chapter 3 focused on Assistive Technology. The definition for AT as items that maintain or increase functional capabilities was given, as well as explanations by the WHO seeing AT as an umbrella term that covers systems delivering assistive products and services. Examples for AT such as hearing and communication aids were provided. Socioeconomic aspects were discussed: AT have an impact on well-being and health and therefore provide broader socioeconomic benefits. However, there is an unmet global need for them. AT specifically designed for people with dementia were described in great detail. They include devices of daily life, safety devices, telecare devices and devices to support engagement and leisure. Based on the demographic change, these will become much more essential. As dementia poses one of the greatest societal challenges in our century, the need for suitable AT is enormous. The most important design guidelines were described. Designing AT for people with dementia is not straightforward, since there are many needs that must considered. Especially generalized design proposals are difficult due to the whimsical nature of the disease. Other points mentioned were for
example the need for high screen contrast and big buttons. One very important aspect to consider when thinking about AT for people with dementia are ethical and human rights aspects, as basic human rights are sometimes denied to them. Ensuring AT for dementia care supports human rights can be done by proving consistency with the UN Convention on Rights of Persons with Disabilities.

Chapter 4 describes a shift in perspective on people with dementia and the use of AT to care for them. To do so, the chapter starts with a clear problem definition: It was reviewed how disabilities that need support by the use of AT have been defined in the past and what the perspective is in the present. Important questions that need to be asked in the designing process of AT were summarized. A conclusion of the guiding principles for design was seen as: Never reduce the person to what they are struggling with. The implications on the use of AT to support people with dementia were studied next. It was found that the traditional practices to meet dementia needs were restrictive ones, such as physical restraint or medication. AT may also provide new mechanisms, for example surveillance or further restriction of movement. However, technology is slowly turning towards a more person-centered approach, enabling people instead of restricting them. Examples of devices that follow this new approach, WayKey and RelivRing, are described. RelivRing is a device developed for reliving social activities for people with dementia, WayKey is a device designed to promote mobility in persons with early to medium stage dementia.

Chapter 5 finally describes a case study for designing an application that helps in the work with people with dementia. While writing about dementia, one specific idea for an application developed. This development, as well as the research conducted is described. There is a lack of technologies designed to support leisure activities in people with dementia. This is a real loss, since most of the people with dementia are retired, most of their time could be spent with activities enhancing QoL. The initial idea of combining technology for leisure activities with reminiscence work was followed and refined: If facts from the life of a person could be presented in an easy way, one could have a look at them together. Related work in this field was searched for, with interesting applications being found. Interestingly, the connection of life story work and archives did not occur directly. A first draft of a concept that fits in this gap was written and implemented in a clickable wireframe. Wireframe and a design proposal were presented to professional caregivers, with encouraging responses:

“Exactly this, this new aspect of personalized media search, is what really astonishes me. Exactly this connection is what’s needed.” From an interview with caregivers

“It’s sometimes difficult to be creative and think about things to do. If they can’t read or knit anymore, you just cannot have ideas to occupy them all the time. There this app would really help.”
These expert interviews were recorded and thoroughly reviewed, all changes and additions mentioned were considered and finally a second concept developed. This concept was written down and explained using a wireframe and refined designs. Every button, every screen was captured in a detailed way as well as a technical and summarized scientific background. Finally, further and extended ideas for the app that emerged from interviews and research were written down.
6.2 Conclusion

To conclude, this thesis was written to examine the way AT is designed for dementia patients. It was shown that the perspective we have on people that live with dementia is slowly changing as we further understand the nature of the disease and of disabilities in general. Furthermore, a concept of an app that can help with reminiscence work was developed. There is no such app that combines biographical data with internet sources yet – which seems like a big gap to be filled by this newly conceptualized app. The possible impact it could have is reducing the burden of care and bringing more leisure to people with dementia.

After all, living with the disease can be extremely challenging, and every possible way to raise the QoL of dementia patients should be considered and hopefully implemented.

6.3 Future work

Future work will primarily include the programming of this app. It is intended to dedicate a Bachelor’s or Diploma Thesis of a computer science student to this work. Furthermore, as soon as a first prototype is implemented, user tests will become necessary focusing on the primary users: Persons with dementia. Simply talking about the app has not been possible with patients, as it is not an easy concept to grasp. Having something to show and let them touch will help enormously with user evaluation. The app can then be refined, and features added or deleted. A final concept will need some more iterations on design and content.

Other future work could be developing designing guidelines for AT for dementia care. These guidelines could be presented for example by designing set cards. Also, developments of AT could be rated according to their usefulness, user-friendliness, ethical aspects and human rights aspects. Developing guidelines for this assessment could be another aspect of future work, as well is having a closer look at which outdated AT are still in use and where.
# 7. Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAL</td>
<td>Ambient Assisted Living</td>
</tr>
<tr>
<td>AD</td>
<td>Alzheimer’s Disease</td>
</tr>
<tr>
<td>ADLs</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>AT</td>
<td>Assistive Technology</td>
</tr>
<tr>
<td>DLB</td>
<td>Dementia with Lewy bodies</td>
</tr>
<tr>
<td>FTD</td>
<td>Frontotemporal Dementia</td>
</tr>
<tr>
<td>HCI</td>
<td>Human-Computer Interaction</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>PCC</td>
<td>Person-centered care</td>
</tr>
<tr>
<td>QoL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>SDG</td>
<td>Sustainable development goal</td>
</tr>
<tr>
<td>UI</td>
<td>User Interface</td>
</tr>
<tr>
<td>VaD</td>
<td>Vascular Dementia</td>
</tr>
</tbody>
</table>
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10. Appendix A – Interview with caregivers

The following information was presented to caregivers. The questions were answered in an interview-like setting, answers were recorded.

Thank you for participating in this study. Please fill out the questionnaire below in order to refine the application. Please remember: The prototype is not about the design of the application, more about how to handle it. Designing will be done at a later stage.

About yourself: (Please circle)
- I am a **professional caregiver** / **not professional** caregiver (relative, friend…).
- I am **used** / **not used** to work with tablets and applications.
- I feel **secure** / **insecure** when working with technology.
- I think technology **can help** / **cannot help** when working with dementia.

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think an app like this could be useful?</td>
</tr>
<tr>
<td>Was there anything you liked in particular?</td>
</tr>
<tr>
<td>Was there anything you disliked in particular?</td>
</tr>
<tr>
<td>Was the handling clear and intuitive to you? Do you think a 60-year old could use it?</td>
</tr>
<tr>
<td>If not, what bothered you/needs to be changed?</td>
</tr>
<tr>
<td>Would you prefer an app focusing only on caregivers?</td>
</tr>
<tr>
<td>Would you add short descriptions to the media in the caregiver mode?</td>
</tr>
<tr>
<td>Would you add the possibility to leave notes on the media to the caregiver mode?</td>
</tr>
<tr>
<td>Would you prefer a design both caregivers and people with dementia can use?</td>
</tr>
<tr>
<td>If yes, did you like the dementia mode?</td>
</tr>
<tr>
<td>Do you think a person with mild dementia could use it?</td>
</tr>
<tr>
<td>What would you change about the dementia mode?</td>
</tr>
<tr>
<td>Do you think swiping twice (up/down) is sufficient to stop a person with dementia accidentally changing to caregiver mode?</td>
</tr>
<tr>
<td>If not, how would you stop that from happening? (Hidden buttons?)</td>
</tr>
<tr>
<td>Was the set up intuitive?</td>
</tr>
<tr>
<td>Would you share information like this about a relative?</td>
</tr>
<tr>
<td>Would you be concerned about data privacy?</td>
</tr>
<tr>
<td>Would you ask other questions you think are important? Which?</td>
</tr>
</tbody>
</table>
Which design would you prefer?
What do you like about this design?
What would you change about it?
Was there anything you expected to find that was not there?
What else would you change in this application, if anything?

<table>
<thead>
<tr>
<th>Which features would you implement? Please write a number (1 = least, 5 = most) on the side to say how important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search and present personalized historical media (photos, video, audio) with descriptions</td>
</tr>
<tr>
<td>Search and present personalized historical facts in order to start a conversation</td>
</tr>
<tr>
<td>Search and present music from different life stages</td>
</tr>
<tr>
<td>Personal Pictures/Videos (made by themselves/relatives…) + descriptions</td>
</tr>
<tr>
<td>Link data to life story book (with different stations in one’s life to go through)</td>
</tr>
<tr>
<td>Possibility to leave remarks for caregivers (e.g. hates to go to bed without listening to some music)</td>
</tr>
</tbody>
</table>
11. Literature


(19) Assistive Technologien, Tablets und Apps für die inklusive Jugendarbeit – Netzwerk Inklusion mit Medien.


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