



Thesis submitted in partial fulfillment of the requirements for the degree of Master of Arts in de Kunstwetenschappen en de Archeologie

**A la recherche du temps perdu.
Object handling, reminiscence and
storytelling practices for people with
Alzheimer's living in a nursing home.**

Astrid Julia R LUYPAERT

0565184

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Promotor: Karin Nys

Letteren & Wijsbegeerte

SUMMARY - SAMENVATTING

ENG: In Belgium, every day, 143 people are diagnosed with Alzheimer's disease. They gradually lose their memories, experience how their sensory experience changes and often feel useless and written off by society. The impact of their diagnosis is immense, on them, their environment and also our society in general. However, heritage can help them to raise their well-being and to stimulate their curiosity.

This project not only wants to give a status quo on heritage and dementiacare, but it will develop new opportunities in the field and bring the different participants together around the table. With all of them, the potential to offer heritage activities inside the nursing home will be explored. The pitfalls and benefits of all the fields will be mapped, leading to recommendations regarding the environment and methodology of these activities.

Through an experimental and empirical method, in which dialogue with patients and their environment is central, this project investigates the impact of heritage on dementia care. Using religious objects, both caregivers and researchers engage in dialogue with residential care residents with dementia to investigate the impact of object handling, multisensory storytelling and reminiscence practices. This thesis researches the preferences of people with dementia, the impact on their well-being and the benefits and pitfalls of the used methodologies.

In addition, the specific context of this project, the residential care home, will be considered. The project researches the impact of this context on how objects are perceived and how the participants experience the project. Also the potential added-value of 'heritage' objects will be questioned, as will the ability to touch and smell the artefacts.

The results of this research will lead to concrete recommendations for both museums and residential care centers, which should enable both to implement a similar project in their operations. In addition, we aim to embed and confirm scientifically researched knowledge, often known to caregivers for generations through their personal experiences and gut feelings. The ultimate findings of this thesis will not only be published in this paper, but are also part of an accessible booklet, available for everybody interested in the topic.

NL: In België krijgen elke dag 143 mensen de diagnose van Alzheimer. Zij verliezen geleidelijk aan hun geheugen, merken hoe hun zintuiglijke ervaring verandert en voelen zich vaak nutteloos en afgeschreven door de maatschappij. De impact van hun diagnose is immens, op henzelf, hun omgeving en ook op onze samenleving in het algemeen. Erfgoed kan hen echter helpen hun welbevinden te verhogen en hun nieuwsgierigheid te prikkelen.

Dit project wil niet alleen een stand van zaken geven over dit onderwerp, maar ook nieuwe mogelijkheden exploreren en de verschillende stakeholders rond de tafel brengen. Samen met hen zal het potentieel onderzocht worden om erfgoedactiviteiten binnen het woonzorgcentrum aan te bieden. De valkuilen en voordelen van beide domeinen zullen in kaart worden gebracht, wat zal leiden tot aanbevelingen met betrekking tot de omgeving en de methodologie van erfgoedactiviteiten.

Via een experimentele en empirische methode, waarin de dialoog met patiënten en hun omgeving centraal staat, onderzoekt dit project ook de impact van erfgoed op dementiezorg. Met behulp van religieuze objecten gaan zowel verzorgers als onderzoekers een dialoog aan met bewoners met dementie in woonzorgcentra, om de impact van object handling, multisensory storytelling en reminiscentiepraktijken te onderzoeken. Dit proefschrift onderzoekt de voorkeuren van mensen met dementie, de impact op hun welzijn en de voordelen en valkuilen van de gebruikte methodologieën.

Daarnaast wordt de specifieke context van dit project, het woonzorgcentrum, onder de loep genomen. Het project onderzoekt de impact van deze context op hoe objecten worden waargenomen en hoe de deelnemers het project ervaren. Ook de potentiële meerwaarde van 'erfgoed'-objecten zal in vraag worden gesteld, evenals de mogelijkheid om de artefacten aan te raken en te ruiken.

De resultaten van dit onderzoek zullen leiden tot concrete aanbevelingen voor zowel musea als woonzorgcentra, die beide in staat moeten stellen een soortgelijk project in hun werking te implementeren. Bovendien willen we wetenschappelijk onderzochte kennis, die zorgverleners vaak al generaties lang kennen via hun persoonlijke ervaringen en buikgevoel,

verankeren en bevestigen. De uiteindelijke bevindingen van dit proefschrift worden niet alleen in deze paper gepubliceerd, maar maken ook deel uit van een toegankelijk boekje, beschikbaar voor iedereen die geïnteresseerd is in het onderwerp.

ABSTRACT

Through an experimental and empirical method, in which dialogue with patients and their environment is central, this project investigates the potential of heritage objects and methodologies in dementia care. Using religious objects, both caregivers and researchers engage in dialogue with residential care residents with Alzheimer's to investigate whether the artefacts are useful for reminiscence and object handling practices, whether the memories of the participants can contribute to (scientific) knowledge about the objects and whether projects like this can improve the well-being of residential care home residents with Alzheimer's disease? The final results, containing recommendations about environment, methodology, beauty, curiosity, tactility and well-being, should inspire the cultural and caretaking field to work together and to think more outside-the-box.

KEYWORDS

NL: Dementie, Alzheimer, Erfgoed, Object Handling, Reminiscentie, Woonzorgcentrum, Multisensory Storytelling, Tactiliteit, Schoonheid, Zorg, Religie, Diversiteit.

ENG: Dementia, Alzheimer's, Heritage, Object Handling, Reminiscence, Nursing Home, Multisensory Storytelling, Tactility, Beauty, Care, Religion, Diversity.

"Forgetting is not a shortage of memories. On the contrary, a true memory contains an element of forgetfulness."

- Ike Kamphof & Stéphan Symons -

PREFACE

Working with people with dementia has been an enormous privilege. First of all, because of the warmth, enthusiasm, and interest, they gave me and the project. They challenged me and my worldview, both as an individual and researcher. Working with them and their caretakers entirely changed my perspective.

When I first visited Rome in the summer of 2015, one of the city guides reminded me of a fundamental life lesson: "Try not to remember everything you will see and learn in this city, as if you do not, that allows you to come back to the city and fully explore it all over again.". Although this might seem a strange lesson, especially as I also experienced the terrible gaps memory loss can induce for people with Alzheimer's Disease and their environment, I still find it an interesting approach.

When I returned to Rome in November 2022, I tried to escape the last memories I had made in the city; I tried to approach Rome with a completely different and fresh look. This attitude allowed me to get to know the city differently, think about it unexpectedly, and develop new thoughts. It allowed me to transcend the framework I had built, based on my education and previous memories. It turned out to be an approach that I found unexpectedly clarifying.

From my first encounter with the Alzheimer Liga to the last meeting I had with the participants in the nursing home, there was one red thread in this entire journey: People focused on what they still could do, what they still remembered, and on the opinions they still had. Although this approach was very different from the prevailing narrative in society, which focuses on the memories disappearing and the changing character of people with dementia, I knew from the first second that their approach would also become my central perspective. Therefore, this research focuses on investigating the possibilities for all engaging parties in bringing cultural activities towards people with dementia rather than investigating what we cannot do. While this paper will also list certain limitations, the main focus remains on the small changes we can implement to make life-changing differences for everybody involved.

I would therefore like to end this preface by expressing my greatest admiration for everyone involved in this project. First and foremost, the people with dementia and their informal caretakers gave me so much energy and input. Without them, this whole adventure would have been impossible. Also, I have the greatest admiration for the care professionals who have had anything but easy years due to the contemporary reputation of the sector and the aftermath of the Covid-19 pandemic.

Of course, my admiration also goes to all the participants from the cultural and heritage field. To all the museums that already have activities tailored to people with dementia: thank you for helping to pave that path, thank you for sharing your expertise with me, and thank you for entrusting me with your collections. To all the cultural institutions that do not yet offer activities: You have tremendous potential, I am sure! Inform yourselves, involve people with dementia and their caretakers, and seek the necessary support. You are making a difference with these activities!

Over the past few months, I have had to work with two very different sectors that also share a lot of common ground. Both fields often have to perform their tasks with a limited number of people and resources, both worlds came under significant pressure due to the corona crisis, and the work and impact of both sectors are still too much underestimated, as far as I am concerned. While I do not want to dismiss - sometimes unfortunately justified - criticism and comments without a particular form of debate, I also want to make this thesis a call to listen better to their needs and signals. Taking care of each other should become a priority of our society, whether we have to do it through the nursing centre or the museum. We need a changeover that gives both sectors the respect they deserve, makes care and well-being a political priority, and recognises and addresses the staff shortage and limited resources in both sectors.

This aim, however, will demand political and societal flexibility and ask nursing homes, caretakers, museums, and heritage communities to think out of the box, work together, and strengthen and use each other's benefits. As you will read in the recommendations of this paper, there is still much progression possible in that area. However, due to my partnering with both sectors, I am firmly

convinced that there is already tremendous potential out there and that projects and research like this can have plenty of success in the future.

Cherish your memories, seize every moment to learn, and, above all, don't forget to take care of each other.

Love,
Astrid

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OBJECTS AS A MEETING POINT

An introduction to this thesis

The starting point

In Belgium, every day 143 people are diagnosed with dementia.¹ They gradually lose their memories, experience how their sensory experience changes, and often feel useless and written off by society. The impact of their diagnosis is immense on them, their environment, and our community. Since 2022, Alzheimer's has been the number one cause of Death in Belgium.² Unfortunately, despite several attempts and a lot of progress during the past couple of years, the pharmaceutical sector has not yet found a clear-cut medicine that can completely cure the disease.³

Through an experimental and empirical method, in which dialogue with patients and their environment is central, this project investigates the potential of heritage objects and methodologies in dementia care. Using religious objects, both caregivers and researchers engage in dialogue with residential care residents with Alzheimer's to investigate whether the artefacts are useful for reminiscence and object handling practices, whether the memories of the participants can contribute to (scientific) knowledge about the objects and whether projects like this can improve the well-being of residential care home residents with Alzheimer's disease?

¹ 'Dementie in cijfers: nieuw onderzoek bereidt ons voor op de toekomst', *Vlaamse Ouderraad*, January 2020, last visited 20th May 2023, <https://www.vlaamse-oudereraad.be/onderzoek/welzijn-gezondheid-en-zorg/dementie-cijfers-nieuw-onderzoek-bereidt-ons-voor-op-de>.

² 'Dementie wordt de belangrijkste doodsoorzaak in België', *Sciensano*, 2nd December 2022, visited last on 18 May 2023, <https://www.sciensano.be/nl/pershoek/dementie-wordt-de-belangrijkste-doodsoorzaak-belgie#:~:text=Tussen%202004%20en%202019%20klom,nieuwe%20analyses%20van%20gezondheidsinstituut%20Sciensano.>

³ More information on this 'race for cure' on page 19.

In addition, the specific context of this project, the nursing home, will be considered. The impact of this context on how objects are perceived and how the project is experienced in general will be researched. What makes the nursing home, in some cases, more suitable for heritage activities than most museums? What are the possible challenges and obstacles of this transfer?

The results of this research will lead to concrete recommendations for museums and nursing homes. In addition, the methodologies and references should enable both facilities to implement a similar project in their operations. Within this strategy, I aim to embed and confirm scientifically researched knowledge, often known to caregivers for generations through their personal experiences and gut feelings.

As the title of this research demonstrates, the multisensorial basis of object handling and our experiences, in general, was another vital starting point. The title of this thesis, 'A la recherche du temps perdu' was named after the famous novel by Marcel Proust, who described for one of the first times in popular culture the later called 'Proust-effect', with the main character of his book being catapulted back into his childhood by the taste of a lemon madeleine.⁴ This story shows the power of our senses and the vital stimulus a sensorial experience can be. Therefore, senses like smelling and touching are extensively covered in this study, as they are markedly modified by dementia but also can be a valuable trigger for lost memories.

The outline

In the first chapter, the general framework of this thesis is sketched. What is dementia, and what is Alzheimer's? What are the symptoms, the implications,

⁴ CAMPEN, Crétien, *The Proust Effect: Senses as doorways to lost memories*, Oxford: Oxford University Press, 2013.

and the challenges of the Alzheimer's disease? What are essential insights from recent research? How can we apply these to the specific Belgian situation? This chapter also elaborates on the nursing home context and how it changed during the past couple of years.

The second chapter deals with Alzheimer's and Heritage Care in the (recent) past. What were some good and bad practices? Which research was already done? Furthermore, what are the scientific gaps that still need to be filled in? Finally, how can you create a cultural but pleasant environment for people with Alzheimer's, and why is the usual museum context not always suited for that?

These states of investigation also form the basis for the third chapter, in which my research position, methodology, and other vital factors are critically analysed and explained. For example, how was the location of this experiment designed? Which objects were used and why? Who is everybody involved in this dialogue? And what are the challenges for museums and nursing homes when setting up reminiscence and object-handling projects for people with Alzheimer's Disease?

The fourth chapter reports the experiment and presents the qualitative and quantitative output. What is the answer to the research questions, and what are the gaps still left to research in the future?

The results of the fourth chapter are presented in the final part of this thesis, the conclusion, where recommendations are made for museums and nursing homes, cultural workers and caretakers, professionals and other interested parties. What changes can you make to create a dementia-friendly cultural activity within your institution? How can different parties get more involved with each other and cultural activities? What are the opportunities for methods like

reminiscence and object handling, and what can be the pitfalls of these methodologies?

A pocket-size manual

The last part of this project is based on a specific demand of the Alzheimer Liga and on specific needs I noticed during this research. Although research about Alzheimer's and the use of heritage in dementia care has seen a sharp rise during the last few years, not enough caretakers nor heritage professionals have found their way to this specific research. By adding a pocket-size manual to this thesis, with a modest summary of the study, but above all with practical tips and concrete recommendations, I hope to reduce the gap between the academic world and the working field, but also between heritage institutions and the healthcare field. This booklet will be published in Dutch first, and made available for free to anyone who can use it.

You can explore in for free on the website of this project:
<https://astridluypaert1.wixsite.com/erfgoed-alzheimer>.

CHAPTER 1

THE SEARCH FOR GLOBAL CURE AND CARE

On dementia, Alzheimer's and the nursing home

ON DEMENTIA

The status quo of a global fight

A global definition

The World Health Organisation (WHO) was founded in 1948 by the United Nations as an agency that develops campaigns, research and connections about care, health and human safety. It developed a definition, gathered global numbers and wrote different recommendations about dementia and its global evolution. Their research and numbers will be one of the guidelines in this first chapter. The WHO defines dementia as:

"a syndrome that can be caused by several diseases which over time destroy nerve cells and damage the brain, typically leading to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. While consciousness is not affected, the impairment in cognitive function is commonly accompanied, and occasionally preceded, by changes in mood, emotional control, behaviour, or motivation.

Dementia has physical, psychological, social and economic impacts, not only for people living with dementia but also for their carers, families and society. There is often a lack of awareness and understanding of dementia, resulting in stigmatisation and barriers to diagnosis and care." ⁵

Fifty-five million people worldwide are currently diagnosed with dementia, and the expectations are a raise until 75 million within five years from now. By 2050,

⁵ WORLD HEALTH ORGANISATION, *Global Action Plan on the public health responses to dementia: 2017-2025*, Genève: WHO Document Production Services, 2017, p. 2-4; 'Fact Sheets: Dementia', *World Health Organisation*, 15 March 2023, visited last on 18 May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

an estimation of 132 million people will suffer from dementia. Furthermore, the disease is in the top seven causes of death and is one of the biggest causes of disability and dependency among older people worldwide.⁶ In Belgium, the place of execution of this research, dementia has been the number one death cause since 2022.⁷

The illness also comes with some costs, globally estimated around at least 1,3 trillion dollars, not only provided for professional care but also half invested in more informal care practices, for example, by family and friends (the so-called 'mantelzorgers' in Dutch) who provide around five hours of daily care and control.⁸

Symptoms

The diagnosis of dementia can be difficult, as symptoms are different in every patient and are not always directly recognised by the environment or the affected person. As described above, dementia is an umbrella term for more than 50 diseases, including Alzheimer's, Vascular Dementia, Frontotemporal Dementia and Lewy Body Dementia.⁹ Because different forms of dementia are indistinct and regularly occur together, this thesis will first report the most common signs and symptoms of dementia in general and the things that increase the risk of a form of the disease. The second part of this chapter will deal with

⁶ WORLD HEALTH ORGANIZATION, *The epidemiology and impact of dementia: current state and future trends*, Geneva: World Health Organization, 2015; WHO, *Global Action Plan*, 2017, p. 2-4.

⁷ 'Dementie wordt de belangrijkste doodsoorzaak in België', *Sciensano*, 2nd December 2022, visited last on 18th of May 2023, <https://www.sciensano.be/nl/pershoek/dementie-wordt-de-belangrijkste-doodsoorzaak-belgie#:~:text=Tussen%202004%20en%202019%20klom,nieuwe%20analyses%20van%20gezondheidsinstituut%20Sciensano>.

⁸ 'Fact Sheets: Dementia', *World Health Organisation*, 15 March 2023, visited last on 18th of May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

⁹ 'Fact Sheets: Dementia', *World Health Organisation*, 15 March 2023, visited last on 18th of May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

the specificity of Alzheimer's Disease, as it is the most common and known form of dementia and the specific disease researched in this project.

Some early symptoms described by the WHO that you have to take into account when working with people with dementia are:

- “forgetting things or recent events
- losing or misplacing things
- getting lost when walking or driving
- being confused, even in familiar places
- losing track of time
- difficulties solving problems or making decisions
- problems following conversations or trouble finding words
- difficulties performing familiar tasks
- misjudging distances to objects visually.”¹⁰

For this project, especially the loss of memories is an important symptom. As research suggests, objects can bring back specific memories, especially childhood-related ones.¹¹ As people with dementia can also experience difficulties following conversations or expressing their thoughts or sentiments, the research will encourage them to try safely. In the third chapter on methodology, these symptoms are actively used to create an activity that suits the sometimes specific needs of people with dementia. By introducing a

¹⁰ WHO, *Global Action Plan*, 2017, p. 22-25; ‘Fact Sheets: Dementia’, *World Health Organisation*, 15 March 2023, visited last on 18th of May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

¹¹ EUN KYOUNG, Choe, *Tangible Memories and Elders: Objects as Containers, Reminders and Instruments*, unpublished thesis, Berkley University, 2006.

participant-led approach as part of the methodology, this project hopes to respond to the diverse symptoms and needs of people with dementia.

Nevertheless, also when it comes to emotions, moods and well-being, subjects researched in this thesis, the WHO made the following list. People with dementia often experience the following:

- “feeling anxious, sad, or angry about memory loss
- personality changes
- inappropriate behaviour
- withdrawal from work or social activities
- being less interested in other people's emotions.”¹²

Risk factors

Very remarkable is that a few of these early symptoms, like depressed feelings or the withdrawal of social activities, are, at the same time, factors that increase the degree of dementia and the rate at which the illness progresses. Recent research shows that, by reversing your lifestyle, some forms of dementia can be made irreversible at an early stage. A sufficient amount of social contact, physical touch and general high well-being are vital to slow down the progression of the disease.¹³ Therefore, these aspects are one of this research's many focuses and will be encouraged and measured during this project.

Also, other aspects of a person's lifestyle are essential risk factors for dementia. The WHO mentions the following, based on extensive research:

¹² WHO, *Global Action Plan*, 2017, p. 22-25; ‘Fact Sheets: Dementia’, *World Health Organisation*, 15 March 2023, visited last on 18th of May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

¹³ NELS, Michael, *Geef Alzheimer geen Kans*, Aartselaar: Zuidnederlandse Uitgeverij, 2019, p. 18-24.

- “age (more common in those of 65 or older)
- high blood pressure (hypertension)
- high blood sugar (diabetes)
- being overweight or obese
- smoking
- drinking too much alcohol
- being physically inactive
- being socially isolated
- depression.”¹⁴

Although the scientific and pharmaceutical fields have progressed much during the last few years, we still have a long way to go. We understand the illness and its brain image better than a few years ago, and the first medicines that slow down Alzheimer's were developed. However, dementia, in all its different shapes, turned out to be way more complicated than scientists initially thought.¹⁵ At the same time, ethical insights and approaches about how we have to take care of and how we should cure dementia are shifting, and our public image of caretaking systems changed after the Covid-19 crisis. (See p. 21, Human Rights and Gender Roles)

¹⁴ WHO, *Global Action Plan*, 2017, p. 22-25; ‘Fact Sheets: Dementia’, *World Health Organisation*, 15 March 2023, visited last on 18th of May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

¹⁵ TORFS, Michaël, ‘Voor het eerst kan een geneesmiddel de ziekte van Alzheimer vertragen: "Absoluut een doorbraak, maar geen wondermiddel"', *VRT NWS*, 30th of november 2022, visited last on 18th of May 2023, <https://www.vrt.be/vrtnws/nl/2022/11/30/veelbelovend-geneesmiddel-voor-de-ziekte-van-alzheimer-beteken/>; CHRISTOPHER, H., SWANSON, Chad, ‘Lecanemab in Early Alzheimer’s Disease’, *The New England Journal of Medicine*, 388, 5th of January 2023, p. 9-21.

Treatment

Although there is no cure for dementia, some medicines and self-care methods can be reached to slow down the disease or reduce its symptoms. This thesis will mainly focus on non-drug-related treatments and therapies, as object handling and reminiscence practice are related to these caretaking methods. According to the WHO, the following self-care methods can help people with dementia to manage their symptoms:

- “Stay physically active.
- Eat healthily.
- Stop smoking and drinking alcohol.
- Get regular check-ups with your doctor.
- Write down everyday tasks and appointments to help you remember important things.
- Keep up your hobbies and do things that you enjoy.
- Try new ways to keep your mind active.
- Spend time with friends and family and engage in community life.”¹⁶

Especially for the last three bullet points, group activities related to culture, history and art can be relevant, as they provide media for dialogue, remembrance and enjoyment.

Dementia and the environment

Not only for people diagnosed with dementia, but also for their environment, the diagnosis can hit hard and present a challenge. For professional and informal

¹⁶ WHO, *Global Action Plan*, 2017, p. 22-25; ‘Fact Sheets: Dementia’, *World Health Organisation*, 15 March 2023, visited last on 18th of May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

caretakers, the loss of memory, behavioural changes and the intensive, necessary care require effort and can impact their emotions and well-being.¹⁷ By involving them in the preparations for this project and the activities themselves, this research will also try to improve the impact on their well-being.

Human Rights and gender roles

Women are significantly affected by dementia. Due to their higher life expectancy in countries with a high standard of living, they are more likely to develop dementia. Especially when caring for people with dementia, women spend excessively more time in caretaking roles in the professional and informal context.¹⁸ Therefore, research about dementia is necessary to reach Sustainable Development Goal number three, 'Good Health and Well-being', but it can, among others, also be necessary for the fifth Goal of 'Gender Equality'. In the case of this thesis, heritage is part of the topic, so this research also contributes to Goal eleven: 'Sustainable Cities and Communities'.¹⁹

In May 2017, the WHO released a '[Global action plan on the public health response to Dementia 2017-2025](#)'. The plan describes different points of action on the global, national and local levels. It recognises dementia as a public health priority and developed the [Global Dementia Observatory](#).²⁰ This digital database collects data about the seven strategic areas and its 35 key dementia indicators formulated in the action plan to raise awareness, reduce the risk and provide sufficient cure and care in a dementia-friendly environment.

¹⁷ WHO, *Global Action Plan*, 2017, p. 22-25; 'Fact Sheets: Dementia', *World Health Organisation*, 15 March 2023, visited last on 18th of May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

¹⁸ WHO, *Global Action Plan*, 2017, p. 22-25; 'Fact Sheets: Dementia', *World Health Organisation*, 15 March 2023, visited last on 18th of May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

¹⁹ 'The 17 Goals', *UN*, 2023, last visited on 18th of May 2023, <https://sdgs.un.org/goals>.

²⁰ 'Global Dementia Observatory', *World Health Organisation*, August 2021, last visited on 18th of May 2023, <https://www.who.int/data/gho/data/themes/global-dementia-observatory-gdo>.

The tool was developed to measure and fight the systematic denial of human rights and fundamental freedom many dementia patients suffer. Even in countries with sufficient regulation, like Belgium, where this research is executed, physical and chemical restraints are used in care homes and acute care settings. For example, Belgian research from 2019 showed that 40% of care home residents are tied up at night and 20% of them during the day.²¹ Following research in 2018, 39% of the care home residents in Belgium are given antidepressants²², while considerable research showed these have non or little impact on the well-being of people with dementia. Antidepressants can even be dangerous for people with dementia, given, for example, the increased risk of falls due to the effects of these drugs.²³ Although some progress was made during the last years, some challenges remain, as also described in the 'Kennisagenda'²⁴ of the Flemish Alzheimer Liga, which will be discussed later in this chapter.

²¹ TRUYTS, Joris, DELOOF, Wim, 'Woon-zorg centra binden nog te vaak hun bewoners vast', *VRT NWS*, 11 April 2019, visited last on 18 May 2023, <https://www.vrt.be/vrtnws/nl/2019/04/11/woon-zorgcentra-bewoners-vastbinden/>.

²² TRUYTS, Joris, DELOOF, Wim, 'Bijna 4 op 10 bewoners van woonzorgcentra nemen antidepressiva', *VRT NWS*, 8 March 2018, visited last on 19 May 2023, <https://www.vrt.be/vrtnws/nl/2018/03/08/bijna-4-op-de-10-bewoners-van-woonzorgcentra-nemen-antidepressiv/#:~:text=39%20procent%20van%20de%20bewoners,noemt%20de%20cijfers%20%22almerend%22.>

²³ ROSENBERG, Paul, DRYE, Lea, et al., 'Sertraline for the treatment of depression in Alzheimer disease', *American Journal for Geriatric Psychiatry*, 18, 2010, p. 136-145; DUDAS, R., MALOUF, R., et al., 'Zijn antidepressiva zinvol bij patiënten met dementie en depressie?', *Minerva*, 20, 2020, p. 19-23.

²⁴ STEYAERT, Jan, TORDOIR, Krisje, *Kennisagenda 2022. Op weg naar moderne dementiezorg*, Antwerpen-Berchem: Expertisecentrum Dementie Vlaanderen vzw, 2022.

ON ALZHEIMER'S DISEASE

The most common form of dementia

Alzheimer's: A brain image

Alzheimer's Disease (AD) is the most common form of dementia, with over 70% of people with dementia affected by it. AD can be a single diagnosis, but it is often combined with other forms of dementia or diseases like Parkinson's.²⁵ Extensive research has been done on the cerebral changes induced by Alzheimer's Disease. At least the following two changes in the brain are related to the disease, and each has an impact on the symptoms of the illness:

Clumping together of amyloid proteins

These amyloids pile up in the brain, forming 'plaques' that complicate communication between brain cells. Most of the time, these accumulations occur in the brain's frontal part, where memories are collected and stored. Therefore, memory loss is one of the first symptoms of AD.²⁶

Adaptations of Tau-protein tangles

In the brain of people with AD, the sequence of Tau-tangles is altered, causing the transport of nutrients to the brain cell to go wrong. As a result, the cell does not receive sufficient nutrition, which eventually causes it to die.²⁷

²⁵ 'Oorzaken Alzheimer', *Alzheimer Nederland*, 2023, last visited 18 May 2023, <https://www.alzheimer-nederland.nl/dementie/oorzaken-preventie/oorzaken-alzheimer>.

²⁶ DETURE, M.A., DICKSON, D.W, 'The neuropathological diagnosis of Alzheimer's disease', *Molecular Neurodegeneration*, 14, 2019, p. 32; 'Oorzaken Alzheimer', *Alzheimer Nederland*, 2023, last visited 18 May 2023, <https://www.alzheimer-nederland.nl/dementie/oorzaken-preventie/oorzaken-alzheimer>.

²⁷ DETURE, M.A., *The neuropathological diagnosis*, 2019, p. 32; 'Oorzaken Alzheimer', *Alzheimer Nederland*, 2023, last visited 18 May 2023, <https://www.alzheimer-nederland.nl/dementie/oorzaken-preventie/oorzaken-alzheimer>.

Research is unsure whether changing Tau tangles and clumping amyloids are a consequence or a cause of AD.²⁸ Recent science, however, shows that an unhealthy diet, depression and limited social contact accelerate these clumping and tangling processes. These lifestyle aspects are, therefore, fundamental to slowing down and avoiding AD.²⁹ In addition, two brain processes that also speed up the development of AD are the following:

Glial Cells:

Glial cells are, among others, responsible for the breakdown of amyloid proteins. When these latter accumulate in the brain more than usual, the glial cells might react aggressively. This hasty reaction can, unfortunately, accelerate the disease because it allows more amyloids to accumulate in the brain.³⁰

The blood-brain barrier

Our blood-brain barrier filters harmful substances from our brain tissue, including amyloid proteins. As this mechanism fails, the proteins accumulate, which can accelerate the symptoms of AD.³¹

²⁸ DETURE, M.A., *The neuropathological diagnosis*, 2019, p. 32; 'Oorzaken Alzheimer', *Alzheimer Nederland*, 2023, last visited 18 May 2023, <https://www.alzheimer-nederland.nl/dementie/oorzaken-preventie/oorzaken-alzheimer>.

²⁹ NELS, *Geef Alzheimer geen Kans*, 2019, p. 18-24.

³⁰ DETURE, M.A., *The neuropathological diagnosis*, 2019, p. 32; 'Oorzaken Alzheimer', *Alzheimer Nederland*, 2023, last visited 18 May 2023, <https://www.alzheimer-nederland.nl/dementie/oorzaken-preventie/oorzaken-alzheimer>.

³¹ DETURE, M.A., *The neuropathological diagnosis*, 2019, p. 32; 'Oorzaken Alzheimer', *Alzheimer Nederland*, 2023, last visited 18 May 2023, <https://www.alzheimer-nederland.nl/dementie/oorzaken-preventie/oorzaken-alzheimer>.

The stages of AD

The proteins described above damage more brain cells over time, allowing the disease to progress. The exact progression of AD differs from person to person, but in general, we can distinguish three phases³²:

The early stage:

Small changes in a person's behaviour, personality, and memory can occur. A person in the early phase of Alzheimer's may:

- “forget recent conversations or events;
- repeat themselves;
- understand new ideas more slowly;
- lose the thread of a story;
- be confused;
- speaking less fluently;
- find it challenging to make decisions;
- lose interest in other people and activities.”³³

³² This distinguishment is based on basic literature. Other research speaks of seven different phases. They among others include the phase before the diagnosis, and even before the first symptoms. This research uses the distinguishment in three stages, because it is the one that is generally excepted, and also the one used in most nursing homes to track the different patients. Although this paper presents the phases as distinguishable, these are of course related to each other. The development of every patient is unique and not all symptoms occur in every person with AD.

The description of the symptoms was mainly based on the information of the Dutch Alzheimer Organisation. They published a clear guide for both patients and caretakers. Because their information is accessible, but also detailed and based on extensive research, this paper will use their explanation as guidelines and will directly quote the symptoms they mention.

‘Het verloop van Alzheimer in fases’, *Alzheimer Nederland*, 2023, last visited on 20th May 2023, <https://www.alzheimer-nederland.nl/dementie/soorten-vormen/ziekte-van-alzheimer/fases>.

³³ ‘Het verloop van Alzheimer in fases’, *Alzheimer Nederland*, 2023, last visited on 20th May 2023, <https://www.alzheimer-nederland.nl/dementie/soorten-vormen/ziekte-van-alzheimer/fases>.

The moderate stage:

Changes in the patient's behaviour become more apparent, especially in daily tasks, such as dressing and washing, which can be challenging. Also, recognising people and remembering events might become more arduous. In general, a person in the intermediate phase of Alzheimer's disease may:

- “become more quickly upset, angry, aggressive or suspicious;
- be confused about where they are;
- run away or lose their way;
- be confused about time;
- get up at night because their sleep/wake rhythm is disrupted;
- put themselves or others in danger because of their forgetfulness - for example, by not turning off the gas from the cooker;
- behave in unusual ways, such as going out in their nightclothes;
- have problems with perception and, in some cases, have hallucinations.”³⁴

The last stage:

In this phase, the person relies almost entirely on others. Memory loss is severe: people, familiar objects or places are no longer recognised. A person in the final stage of Alzheimer's disease may:

- “have difficulty chewing and swallowing;
- lose much weight, despite overeating;
- become incontinent, first for urine and later for faeces;

³⁴ ‘Het verloop van Alzheimer in fases’, *Alzheimer Nederland*, 2023, last visited on 20th May 2023, <https://www.alzheimer-nederland.nl/dementie/soorten-vormen/ziekte-van-alzheimer/fases>.

- gradually lose speech, although they sometimes keep repeating a few words or shouting from time to time;
- becoming restless and looking for something or someone;
- being sad or aggressive, especially when feeling threatened;
- become angry during personal care, usually because he does not understand what is being asked of him.”³⁵

The duration of these different phases depends on the patient. People with AD have a life expectancy of 3 to 20 years, with an average of 6 to 7. The diagnosis is not only made based on these generic symptoms, but supported by test results and brain scans.³⁶

An early diagnosis of Alzheimer's and a thorough assessment of the symptoms are important. More effective and different treatments are possible at an early stage. This early attention also allows for detecting and treating other problems that are symptomatically similar to Alzheimer's, such as depression. The earlier this is detected, whether it is Alzheimer's or depression, the better, as both symptoms have a huge impact on a person's quality of life.³⁷

In addition, an AD diagnosis is particularly complex, and it may be easier to talk to the person with dementia about the various care options or the diagnosis itself in the early phase of the disease.³⁸

³⁵ 'Het verloop van Alzheimer in fases', *Alzheimer Nederland*, 2023, last visited on 20th May 2023, <https://www.alzheimer-nederland.nl/dementie/soorten-vormen/ziekte-van-alzheimer/fases>.

³⁶ 'Het verloop van Alzheimer in fases', *Alzheimer Nederland*, 2023, last visited on 20th May 2023, <https://www.alzheimer-nederland.nl/dementie/soorten-vormen/ziekte-van-alzheimer/fases>.

³⁷ 'Het verloop van Alzheimer in fases', *Alzheimer Nederland*, 2023, last visited on 20th May 2023, <https://www.alzheimer-nederland.nl/dementie/soorten-vormen/ziekte-van-alzheimer/fases>.

³⁸ 'Het verloop van Alzheimer in fases', *Alzheimer Nederland*, 2023, last visited on 20th May 2023, <https://www.alzheimer-nederland.nl/dementie/soorten-vormen/ziekte-van-alzheimer/fases>.

This research will mainly focus on people in the early or moderate phase of AD. In the chapters on methodology and the results, an analysis of the different candidates and their symptoms is made and described.

ALZHEIMER IN BELGIUM

Policy and partners

In Belgium, over 140 000 people are diagnosed with AD.³⁹ At least 8374 are younger than 65 years old.⁴⁰ Both numbers are rising yearly because there is more attention for the disease and a quicker diagnosis, but primarily because more people are affected by the disease in the country due to the ever-increasing population ageing. It is therefore expected that, just as in the worldwide predictions of the WHO, this figure will continue to rise in Belgium in the coming years.⁴¹ Fortunately, both the government and civil society have taken more and more initiatives in recent years to make dementia a priority, to represent the interests of the various actors in the field and to release budgets for both care practices and scientific research. Unfortunately, even in Belgium, there is still a long way to go.

The Flemish government

In 2021, the Flemish government released their '2021-2025 Dementia Plan'⁴². It focuses on the following subjects, geared to the general needs, but mainly also to the powers of the Flemish government: prevention, optimising the quality of care – both in the home environment and in residential care centres –, informal care support and the dissemination of a taboo-breaking and nuanced image of

³⁹ 'Dementie in België', *Stop Alzheimer*, 2023, last visited 20th of May 2023, <https://www.stopalzheimer.be/over-alzheimer/dementie-in-belgie/>.

The number '140 000' only describes people with AD and dates from 2020 (the last general measurement). Around 202 402 were diagnosed with one or other form of dementia back then. The exact number for 2023 is unsure, as one of the attention points for Alzheimer research is to better map how the disease demographically evolves.

⁴⁰ 'De Belangrijkste cijfers op een rijtje', *Expertisecentrum Dementie Vlaanderen*, 2018, last visited 20th May 2023, <https://www.dementie.be/home/wat-is-dementie/prevalentie/>.

⁴¹ 'De Belangrijkste cijfers op een rijtje', *Expertisecentrum Dementie Vlaanderen*, 2018, last visited 20th May 2023, <https://www.dementie.be/home/wat-is-dementie/prevalentie/>; 'Dementie in België', *Stop Alzheimer*, 2023, last visited 20th of May 2023, <https://www.stopalzheimer.be/over-alzheimer/dementie-in-belgie/>.

⁴² 'Nieuw Dementieplan 2021-2025', *Agentschap Zorg en Gezondheid*, 20 September 2021, last visited 20th May 2023, <https://www.zorg-en-gezondheid.be/nieuw-dementieplan-2021-2025>.

the disorder, are the priorities of this plan. In addition, it wants to work on offering psycho-education, discussion groups and attention to interaction and meetings.⁴³ All these elements were also part of this research since they are also the points of attention of one of the partner organisations of this study: the Flemish Alzheimer Liga.

The Alzheimer Liga Flanders

The Alzheimer Liga Flanders was one of the essential partners in the construction of the research question of this thesis. The Liga defines itself as the point of contact for people with dementia, their caretakers (both at home and in a nursing home context) and anyone affected by dementia. They, among others, engage in different social initiatives, support academic research and organise awareness and recruitment campaigns.⁴⁴ Both their 'Kennisagenda (Research Agenda)⁴⁵ and personal talks with one of their experts formed the solid base for the research question and methodology of this thesis.

'De Kennisagenda 2022. Op weg naar moderne dementiezorg.'

'The Planning Agenda 2022, on our way to a more modern Dementia Care'⁴⁶ is a joint project from 'the Alzheimer Liga Vlaanderen vzw' and 'the Centre of Expertise for Dementia Flanders vzw'. It maps the challenges for academic research about dementia in the near future. In addition, the agenda gives recommendations about necessary inquiry topics captured from focus groups with people with dementia, professional researchers, nurses and caretakers.⁴⁷

⁴³'Nieuw Dementieplan 2021-2025', *Agentschap Zorg en Gezondheid*, 20 September 2021, last visited 20th May 2023, <https://www.zorg-en-gezondheid.be/nieuw-dementieplan-2021-2025>.

⁴⁴ 'Over Ons', *Alzheimer Liga*, 2023, last visited 20th May 2023, <https://www.alzheimerliga.be/nl/over-ons>.

⁴⁵ STEYAERT, *Kennisagenda*, 2022.

⁴⁶ STEYAERT, *Kennisagenda*, 2022.

⁴⁷ STEYAERT, *Kennisagenda*, 2022.

They start their agenda with three rather methodological points of attention for all researchers.⁴⁸ They were essential pillars in formulating my research question and methodology. I would like to repeat them below and will explain how they shaped the formation of my research question and methodology.

'Nothing about us, without us.'

The first point of attention might seem obvious, but it is still too often overlooked. In researching dementia, dementia care and people with dementia, the patients and their caregivers must be central points of information and actively questioned about their needs.⁴⁹ Since the startup of my thesis, the Alzheimer Liga has been my point of contact for questions and information and, among others, their 'Kennisagenda' has been an important source. Also, nursing home staff and non-professional caregivers were questioned repeatedly throughout the different phases of this research. As the Alzheimer Liga states, inspired by the publication of Doors in 2019, this co-research approach must lead to the inclusion of 'co-design, co-production and co-delivery'⁵⁰.

'Let us roll up our sleeves.'

Their second focal point is all about the need for practical knowledge. How can we improve caretaking processes? How can academic research be implemented into daily operations? Furthermore, how do we ensure that innovative knowledge gets to the right people? The 'Kennisagenda' encourages researchers to publish open access and to rescale their results to media that reach a wider

⁴⁸ STEYAERT, *Kennisagenda*, 2022, p. 7-9.

⁴⁹ STEYAERT, *Kennisagenda*, 2022, p. 7.

⁵⁰ DOORS, O., SWARBRICK, C., 'Editorial: Rebalancing the research agenda', *Dementia*, 19, 2019, p.3-5.

audience. In the case of Flanders, Dutch translations and summaries are also necessary, as not all target audiences have sufficient knowledge of English.⁵¹

The concrete implementation of this action point can be found in the outcome of this project. A small manual guide with specific tips for the cultural and caretaking fields will be added. It will contain concrete recommendations derived from the project's results and a bold summary of the status quaestionis of the topic. This document will be published in Dutch (and later in French and English) to reach a broad public.⁵² Also, in the methodology described in detail in the third chapter, the convenient approach forms a red thread.

Knowledge is (not always) power.

In researching dementia, people with AD, and caretaking, a more quantitative approach is intensively used. Nevertheless, qualitative concepts like 'integrated', 'person-driven' or 'warm' care should be more often noticed due to these methods.⁵³

Focusing on people's well-being, life quality and personal memories, the research question results from an also qualitative attitude. The more practical approach that I use and the different measuring methods described in the following chapters are also the results of this third point of attention from the 'Kennisagenda'.

Specific research questions

Besides these broad recommendations, the Alzheimer Liga and the Center of Expertise for Dementia formulated specific research topics and questions. In the first place, this thesis tries to answer some questions from the 'kennisagenda'

⁵¹ STEYAERT, *Kennisagenda*, 2022, p. 8.

⁵² You can find a draft of the booklet on my website: <https://astridluypaert1.wixsite.com/erfgoed-alzheimer>.

⁵³ STEYAERT, *Kennisagenda*, 2022, p. 8.

that are explicitly related to cultural work and museums. The chapter 'Meaningful and Significant'⁵⁴ expresses the need for every day, participatory and meaningful activities designed for people with AD. These projects should benefit the task or pursuit itself and its secondary benefits, like social contact, movement, or creating a bond between patient and caregiver. Therefore, the following questions are stated by the Alzheimer Liga and will be researched in this thesis:

- “How do cultural experiences affect the well-being and well-being of the person with dementia?”
- We are firmly committed to the normalisation principle: being able to continue to participate in ordinary everyday life. How can we strengthen its implementation, for example, in meaningful daycare?”⁵⁵

Also, the nursing home environment is a challenge for future research. In the chapter 'Optimal Residential Care'⁵⁶, the importance of qualitative care is underlined. In designing our care accommodations and activities, we need more scientific data about, for example, group dynamics, -sizes, and divisions. What are the benefits of homo- and/or heterogeneous groups? In other words: can it be beneficial to bring people with different stages of dementia into one living group or activity? What is the ideal group size? How do the different senses influence this? How can we guarantee individual, customised care despite the very diverse group of people living in a nursing home? The chapter 'Optimal Residential Care' provides us with the following research questions, which I will

⁵⁴ STEYAERT, *Kennisagenda*, 2022, p. 29-32.

⁵⁵ Questions stated in: STEYAERT, *Kennisagenda*, 2022, p. 8. I translated these questions literally from Dutch into English, as the 'Kennisagenda' is only published in Dutch.

⁵⁶ STEYAERT, *Kennisagenda*, 2022, p. 25-27.

partially try to answer for the context of reminiscence and object handling activities:

- “What is the ideal group size? What is the influence of light - sound - colour - recognition - experience angles?”
- Group dynamics in the residential care home: How do we ensure harmony? What lessons can we learn?”⁵⁷

Projects of reminiscence and object handling have a high participatory and social character. Therefore, this thesis also contributes to research questions about the link between the participation of both residents and caregivers and their well-being. In the chapters' social network⁵⁸ and 'care offer'⁵⁹, the following questions relevant to this thesis are stated:

- “How do residents of residential care homes and their families experience life in a participatory setting?”
- How do professional carers working in a participatory organisation feel about their work? Is their well-being greater than that of others? What is the effect on turnover?”⁶⁰
- “How does a solid social network relate to the well-being of a carer and/or a person with dementia? Is it true that the two have a causal relationship? How can we capitalise on this?”⁶¹

⁵⁷ STEYAERT, *Kennisagenda*, 2022, p. 25-27. I translated these questions literally from Dutch into English, as the 'Kennisagenda' is only published in Dutch.

⁵⁸ STEYAERT, *Kennisagenda*, 2022, p. 21-23.

⁵⁹ STEYAERT, *Kennisagenda*, 2022, p. 23-25.

⁶⁰ STEYAERT, *Kennisagenda*, 2022, p. 23. I translated these questions literally from Dutch into English, as the 'Kennisagenda' is only published in Dutch.

⁶¹ STEYAERT, *Kennisagenda*, 2022, p. 25. I translated this question literally from Dutch into English, as the 'Kennisagenda' is only published in Dutch.

The exact selection process of the objects for this project is described later in this chapter. However, the thematic approach and the focus on religious and spiritual artefacts were deliberately made. With super-diversity that arises in society and thus in the nursing home context, the challenges to create personal care and leave room for spiritual expressions are growing. Therefore, to research future abilities, religious objects were selected to partly answer questions posed in the chapter about the 'Philosophy of Life'⁶²:

- “We need a methodology to identify a person's spiritual needs and multiple methodologies to raise these needs.
- How to organise dementia care for diversity other than ethnic diversity? Consider, for example, religion, sexual preferences, gender identity, and lifestyle.”⁶³

Heritage in the nursing home

During the last decades, residential care homes have tried to incorporate cultural activities into their daily operations and were already able to partly answer some of the demands and questions stated above. For example, some nursing homes introduced the concept of the memory book⁶⁴: an album where photographs, testimonies and little objects of an owner's youth and life are gathered by the resident him/herself or by friends and family members. When memories get lost over time, the memory book becomes a tool to talk about one's past: Where did you live before? Who are your family members? What are some extraordinary

⁶² STEYAERT, *Kennisagenda*, 2022, p. 32-35.

⁶³ STEYAERT, *Kennisagenda*, 2022, p. 35. I translated this question literally from Dutch into English, as the 'Kennisagenda' is only published in Dutch.

⁶⁴ HUIZING, Wout, *Mijn Leven in Kaart*, Bilthoven: Perspectief Uitgevers, 2020.

memories you would like to share? This memory book can be constructed preventively, even before somebody is diagnosed with dementia, or compiled during the disease's first stages. However, when it is put together too late, something that unfortunately still happens, some memories might get lost, making reminiscence a frustrating, painful and stressful situation for everybody involved. Another obstacle to this practice can be the pressure to 'remember certain things', especially when the album is used repeatedly and when it becomes noticeable that the person with dementia remembers less and less.

Another tactile medium developed to bring heritage to the nursing home is the reminiscence suitcase.⁶⁵ Inside these cases, old objects, photographs, music tapes and many other media are collected, accompanied by an explanation of their meaning and the possible strategies to discuss them. Nursing homes can borrow these suitcases from local heritage sites, libraries or museums to develop their activities within the nursing home.

Although this method is definitely an added value, it has its obstacles. The nursing staff does not always find their way to the suitcases, and they sometimes do not have the time, confidence and skills to extensively use it. In an environment under tremendous pressure and suffering from a systematic staff shortage, taking time for reminiscence practices might not be the priority and, in some cases, may even be at the expense of the staff's other care duties. Care providers also experience a barrier to organising these activities: they do not find their way to the right tools and feel insufficiently trained about the objects and methods.⁶⁶

⁶⁵ 'Aanbod voor ouderen/voor mensen met dementie', *FARO*, 2023, last visited 20 May 2023, <https://faro.be/kennis/inclusief-werken/aanbod-voor-ouderen-en-mensen-met-dementie>.

⁶⁶ This conclusion derived from my own research. More information on these dynamics will be discussed in the 4th chapter.

THE CONTEXT OF THE NURSING HOME

The importance of an environment

The nursing home

Within this thesis, however, we will bring the museum collection into the nursing home, an option that, for various reasons, still needs to be considered and that will be discussed in detail in the next chapter. This particular context of the nursing home will be researched. The residential care centres came under heavy pressure due to stories of neglect and isolation, especially during the covid-19 pandemic.⁶⁷ Many organisations and the government sprang into action to guarantee more control and redefine the concept and interpretation of care centres in Flanders and Belgium. Culture, and the right for culture, became an essential part of this redefinition.

Koning Boudewijn Stichting

The 'Koning Boudewijn Stichting' developed and published a particular example of such a project. In their publication 'Kiezen moet kunnen. Ook voor Ouderen. De Woonzorgomgeving van de toekomst.'⁶⁸, they argue for more autonomy for elderly. They define and encourage their different rights, among others, their right for 'culture' and 'beauty', and they encourage participation and the ability to fulfil aspirations throughout their operations. The publication also underlines the importance of social contact and connectedness, and they have exceptional attention to digitalisation and diversity. All these topics are included in this research, and the research question and methodologies touch upon these themes. Also, in the search for a specific testing location, these qualities were

⁶⁷ 'Mensenrechten in woonzorgcentra en covid-19: een ongelukkig huwelijk', *Unia*, 1 oktober 2021, last visited 20 May 2023, <https://www.unia.be/nl/artikels/mensenrechten-in-woonzorgcentra-en-covid-19-eeen-ongelukig-huwelijk>.

⁶⁸ DE RYNCK, Patrick, DISPA, Marie-Françoise, *Kiezen moet kunnen, ook voor ouderen*, Brussel: KBS, 2022, p. 1-12.

kept in mind. The guidelines from the 'Koning Boudewijn Stichting' were created with experts but mainly based on surveys of people in the care centres. This participation makes the research and its recommendations extra valuable.

Heilig Hart Kortrijk

The search for a testing location started with the research question and the 'Kennisagenda' in mind. After a potential partnership with De Wingerd in Leuven, 'Heilig Hart', a nursing home in the middle of the city centre of Kortrijk, was selected as the test location for this project, as well as a partner organisation for information about dementia, AD care and the caregivers. The nurses, caregivers, and, of course, the patients with dementia in the nursing home were part of the experiment and the questioning.

'Heilig Hart' is the living environment of 66 people with dementia who live together in four communities. In addition to people with dementia living in a protected ward, the centre also offers space for other elderly and people with mental or physical disabilities.

The residential care centre pays much attention to creating a homely environment, for example, through a sensory room or some cosy decoration. They also focus on cultural visits with their residents, for example, to museums or heritage activities, and also try to bring culture within their walls, for example, through reminiscence suitcases.

However, during our talks, the Heilig Hart staff indicated some museum visits were unpleasant for some residents. During previous experiences, different problems appeared, such as the problematic reachability of museums (for example, those in an urban context) and the inaccessibility of museum buildings for people with reduced mobility. In addition, a busy bus ride and walk over

cobblestones towards the museum, or just too many sensorial stimuli in general, can feel unpleasant for people with dementia. This transport also asks a lot of preparation time from the staff of the 'Heilig Hart', as well as more colleagues than usual to guide the trip. Also, the high cost of transport and the special guided tours in the museums are common hindrances.

These obstacles formed another starting point for this thesis and supported the development of an alternative within the nursing home context. In the following chapter, I will discuss the importance of the environment in detail. However, the specific context of the experiments is thus mainly prompted by the caretaking field.

'Heilig Hart' also has a very open policy towards caregivers and volunteers, who will also be part of our experiment. This choice is also related to 'Connected Care', a concept promoted by, among others, the Alzheimer's Liga.⁶⁹ Allowing acquaintances to be part of the activity creates comfort but also changes the group dynamics that will be studied.

⁶⁹ STEYAERT, *Kennisagenda*, 2022, p. 21-23.

CHAPTER 2

**REMINISCENCE, OBJECT HANDLING &
MULTISENSORIAL STORY TELLING**

Heritage & dementia care

Not only from the caretaking field but also from the heritage field, the attention to dementia and AD has grown in the last few years. More and more museums developed tailor-made activities or guided tours that incorporate people with AD and their caretakers. Heritage organisations developed reminiscence suitcases, and the museum 'Huis van Alijn' in Ghent developed the country's first 'collection library'. Also, the effectiveness of heritage methodologies, like reminiscence and object handling, is becoming more and more studied, and the scripts of it are used, shared and adapted. A great example are the multiple, practical guides, published during the last years by FARO.⁷⁰

This chapter tries to map out the current status quo in that area, summarises good and bad practices about the topic, and discusses extensively the cultural partners of this research. It will introduce three essential methodologies of this project: reminiscence, object handling and multisensorial storytelling. Together with the previous chapter of this thesis, it reflects the status quo in the field and shapes the different elements of the research question and methods of this thesis. Therefore, not only methodologies and previous research about the topic will be discussed, but there is also a broader interest in the changing sensory experience of people with AD, which has an impact on these practices but has been little researched in the past.

⁷⁰ 'Publicaties', FARO, 2023, last visited 20th of May 2023, <https://faro.be/publicaties#>.

REMINISCENCE

Remember the past

What is reminiscence?

Reminiscence is a methodology that encourages pulling up memories, among others, through artefacts, artworks, photographs, music and other media. The conversation starts from known objects, for example, from the participant's childhood, that stimulate the senses and the comeback of memories.⁷¹

Reminiscence can be helpful and enjoyable for all of us, but it mainly works for people with dementia. People with AD gradually lose their memories, starting with the more recent ones, like a doctor's appointment or the daily news. However, their long-term memories, especially in the first two phases of the disease, are longer preserved. As reminiscence mainly focuses on memories from their childhood or practices and objects they have known their entire life, reminiscence conversations might not only be more comfortable for them but can also offer them competence and confidence, as they use a skill they do still have.⁷²

Also, in their changing identity, reminiscence might play a comforting role. People with AD often have the feeling they are useless, written off by society, and demand a disproportional amount of care. By placing them and their

⁷¹ DE NIL, Bart, DELY, Herlinde, *Erfgoed en Dementie: Creëren van een aanbod rond reminiscentie voor personen met dementia en hun mantelzorgers*, Gent: Politeia, 2015; WOODS, Bob, O'PHILBIN, Laura, 'Reminiscence therapy for dementia', *Cochrane Database of Systematic reviews*, 1st March 2018, last visited 20th of May 2023, <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD001120.pub3/full>; CUEVAS, Pearl, DAVIDSON, Patricia, et al., 'Reminiscence therapy for older adults with Alzheimer's disease: a literature review', *International Journal of Mental Health*, 29, 2020, p. 364-371; 'Reminiscence for people with dementia', *Social Care Institute for excellence*, October 2020, last visited 20th May 2023, scie.org.uk/dementia/living-with-dementia/keeping-active/reminiscence; 'The European Reminiscence Network', *The European Reminiscence Network*, 2023, last visited 20th May 2023, www.europeanreminiscencenetwork.org.

⁷² WOODS, *Reminiscence therapy for dementia*; CUEVAS, *Reminiscence: a literature review*, p. 364-371; 'Reminiscence for people with dementia', *Social Care Institute for excellence*, October 2020, last visited 20th May 2023, scie.org.uk/dementia/living-with-dementia/keeping-active/reminiscence; 'The European Reminiscence Network', *The European Reminiscence Network*, 2023, last visited 20th May 2023, www.europeanreminiscencenetwork.org; 'Methodieken', *Huis van Alijn*, 2023, last visited 20th of May 2023, <https://huisvanalijn.be/nl/methodieken>.

memories in the picture, they can offer something back, especially if the other participants do not know the object and/or are very interested.⁷³

Because of its effectiveness, reminiscence is a frequently used method.⁷⁴ However, it also comes with some flaws and remarks. As the method works with 'known' objects, participants might feel pressure to tell things from the past they 'should' remember. Especially when caretakers or family members are involved, reactions like 'Don't you remember?' or 'You should know that!' can occur. This creates confusion and disappointment rather than it gives comfort or empowerment. Because of the focus on the past within this methodology rather than on the present, this method is not suitable for every participant.

On the other hand, the confrontation with objects from the past can be very pleasant and effective. It can bring back memories, but it can also confront people with memory loss gently but effectively. However, it is crucial not to focus on whether the told stories and shared memories are 'correct' but instead on what the activity can cause and fulfil.⁷⁵

People with AD see the world differently

Another point of interest in this methodology is the changing sensorial experience of people with dementia. A person's sight and imagination can be affected strongly by AD. Research about the oeuvre of artists with dementia, like Willem de Kooning, is an excellent indicator of how people with AD perceive colours, shapes and details differently. Most of them shift through more primary

⁷³ 'Reminiscence for people with dementia', *Social Care Institute for excellence*, October 2020, last visited 20th May 2023, scie.org.uk/dementia/living-with-dementia/keeping-active/reminiscence; 'The European Reminiscence Network', *The European Reminiscence Network*, 2023, last visited 20th May 2023, www.europeanreminiscencenetwork.org.

⁷⁴ Woods, *Reminiscence therapy for dementia*; CUEVAS, *Reminiscence: a literature review*, p. 364-371.

⁷⁵ 'Reminiscence for people with dementia', *Social Care Institute for excellence*, October 2020, last visited 20th May 2023, scie.org.uk/dementia/living-with-dementia/keeping-active/reminiscence; 'The European Reminiscence Network', *The European Reminiscence Network*, 2023, last visited 20th May 2023, www.europeanreminiscencenetwork.org.

colours, fewer details and a more abstract style after their diagnosis, a change supported by research about the impact of dementia on our brains.⁷⁶ These alterations can partly explain why people with dementia perceive the world, and thus some objects, differently, although more senses are involved. It is, therefore, vital to focus on the patient's experiences, what they feel and pass through during the activity, and to allow their sometimes different description of the object. By confronting them with a specific object they know, as the reminiscence method does, you give them some handles to tell stories or start a conversation. The sight is, therefore, the first trigger.

How can we offer fulfilling and enjoyable reminiscence therapy for everybody involved?

Within the methodology of reminiscence, different approaches and media can be used. The method is also suitable for both group- and one-on-one activities. However, as the monitor of reminiscence therapy, you have an essential task: keep the conversation pleasant and comfortable for everybody involved. Therefore, the following strategies can be used.

Try to avoid a lot and very specific questions, especially at the beginning of the conversation. Plain, factual questions can be challenging for some participants to answer, creating stress and the sense they forgot many things. A better strategy might be to start by sharing your memory about an object.⁷⁷ In this project, candles were presented to the participants because of the extensive traditions they are part of. You could, for example, start that conversation with:

⁷⁶ MILLER, Bruce, HOU, C.E., 'Portraits of Artists: Emergence of Visual Creativity in Dementia', *Arch Neurol.*, 61, 2004, p. 842–844; MILLER, Bruce, YENER, Görsev, 'Artistic Patterns in Dementia', *Journal of Neurological Sciences*, 22, 2005, p. 245-249.

⁷⁷ Reminiscence for people with dementia', *Social Care Institute for excellence*, October 2020, last visited 20th May 2023, scie.org.uk/dementia/living-with-dementia/keeping-active/reminiscence.

'Already since I was very young, I always light a candle with my grandmother when I have an important task or exam coming up! I believe it helped me during these more difficult or stressful moments. Did you ever light a candle yourself, or what would you light a candle for today?' By sharing your memory and asking a very open question, one that not only deals with the past but also allows a wish for the present, you can make this experience more comfortable for some people with AD.

You can also ask some more specific questions in a gentler way. By, for example, not presuming the participants know the object, you lower the pressure for them to give 'the right' answer. You can, for example, ask:

Do you know the object? What could it be? Where or how could it be used? For example, if it is a photograph, you can ask: 'Do you recognise somebody or something in the photograph?'

It can also be very helpful, and even recommended, to not only talk about an object or memory but also to invite a person to AD to show the use of the object or a particular skill from their past. Among others, you can ask the following questions:

How was the object used? Have you ever used it yourself? Can you show us how it was used?

This not only gives them the opportunity to touch the object, or maybe smell it as well, but also to trigger previous handlings in their mind, which can stimulate different memories or emotions and behaviour from their past.⁷⁸

⁷⁸ Reminiscence for people with dementia', *Social Care Intstitute for excellence*, October 2020, last visited 20th May 2023, scie.org.uk/dementia/living-with-dementia/keeping-active/reminiscence.

Also, when it comes to sharing memories, it is recommended to offer a participant-led approach. Try to avoid asking for their 'most favourite' experience and give them the lead in the conversation. Doing so lowers the pressure to give a specific or 'the most wishful' answer and creates a much more open dialogue. Also, offer them the necessary time and freedom to share their stories and listen carefully to them. Sharing memories might be hard in general, but sometimes negative sentiments or experiences might be involved, or they might be confronted with memory loss at that exact moment. Therefore, ask them:

Would you like to share a memory of these objects? Do you still use some of them? Do you recognise my memory or the sentiment of others?

As is the case for most heritage methods for people with AD, there are no delineated strategies. Although these questions can be a great starting point, every dialogue will be different. Try to listen to the participants and their needs and allow the conversation or activity to develop in an organic way. Don't listen only to a person's words; also be aware of their non-verbal communication, like facial expression and body language. Humor can be key in a conversation as well, as it gives more lightness to the dialogue and can lower pressure and stress.⁷⁹

Prioritising a concrete end result in advance can, on the other hand, increase the pressure and anxiety of participants, but in some cases, it can also create stimulation and fulfilment. An alternative for reminiscence is, therefore, Object Storytelling, a method that will not be used in this project but that will be introduced shortly in the following paragraph.

⁷⁹ Reminiscence for people with dementia', *Social Care Institute for excellence*, October 2020, last visited 20th May 2023, scie.org.uk/dementia/living-with-dementia/keeping-active/reminiscence.

Object Storytelling

In the case of Object Storytelling, the participant chooses an object from the museum or collection. This artefact or artwork is the starting point for a conversation, where the participant shares a story. This story can be true, and thus a specific memory or experience, but it is also allowed that this story is fictional. From this conversation, through multiple guided sessions, the participants each work towards an ending product, such as a poem, movie, short story, video... Everybody then presents his/her elaborations during the final session, where the stories are further discussed.⁸⁰

Reminiscence media

The media for reminiscence are almost endless and can vary from daily objects to famous artworks and from photographs to the internet. Mostly photographs and music were involved in the past, but thanks to recent research, we know a combination of objects and methods is the most effective.⁸¹

Although the multisensorial experience of artefacts and artworks is unique, the internet can also provide many resources for reminiscence therapy. This medium has enormous potential as it connects music, movies, photographs and text. This potential will not be researched in this thesis, but the incorporation of digital heritage forms with no doubt a challenge in the future!

⁸⁰ Methodieken', *Huis van Alijn*, 2023, last visited 20th of May 2023, <https://huisvanalijn.be/nl/methodieken>.

⁸¹ Woods, *Reminiscence therapy for dementia*; CUEVAS, *Remniscence: a literature review*, p. 364-371; 'Reminiscence for people with dementia', *Social Care Intstitute for excellence*, October 2020, last visited 20th May 2023, scie.org.uk/dementia/living-with-dementia/keeping-active/reminiscence; 'The European Reminiscence Network', *The European Reminiscence Network*, 2023, last visited 20th May 2023, www.europeanreminiscencenetwork.org.

OBJECT HANDLING

The power of the unknown

The importance of touch

Touch is the first sense the human body develops, so you can imagine the importance of it in general, but also very specifically for people with dementia. Touch is very principal to prevent us from dangerous situations -think of the reflex of pulling your hand away when you are too close to fire or heat- but it can also offer us comfort and safety -think of hugs or gentle touches-. All the senses gradually change in the different phases of dementia. However, the tactile stimulus is one of the last, sometimes even the only one, that penetrates a person's brain in the final stages of AD. Most of them enjoy massages, for example - mainly of the hands and feet- and the nursing homes encourage familiar visitors to touch and hug their acquaintance. People with dementia sometimes feel that they are losing the contours of their body, something gentle and moderate touch can prevent from happening, although it remains important to listen to the person with AD and its boundaries in the first place.⁸²

During our project, the participants get in touch -literally- with different objects and materials. As a result, they experience different sensations that can trigger memories, give them comfort or offer the opportunity to keep in touch with their own body. Research showed that the sense of touch is not only important and recommended to succeed in the process of reminiscence but also to comfort the participants during and after the activity.⁸³

⁸² VAN DER PLAATS, Anneke, *Het Demente Brein*, s.l.: Anneke Van der Plaats, 2018; 'Voelen en dementie', *Zorgcentra De Betuwe*, 2023, last visited 20th of May 2023, <https://www.zorgcentradebetuwe.nl/ouderen/hulp-en-zorg-thuis/omgaan-met-dementie/dementie-zintuigen/voelen-en-dementie/>.

⁸³ KIM, E.J., BUSCHMAN, M.T., 'The effect of expressive physical touch on patients with dementia', *International Journal for Nursing Studies*, 36, 1999, p 235-243; 'Voelen en dementie', *Zorgcentra De Betuwe*, 2023, last visited 20th of May 2023, <https://www.zorgcentradebetuwe.nl/ouderen/hulp-en-zorg-thuis/omgaan-met-dementie/dementie-zintuigen/voelen-en-dementie/>.

What is object handling?

The methodology of object handling appreciates an object primarily for its therapeutic value. Mainly its tactile characteristics are used to stimulate learning, the different senses and the connection with your own body, and with other participants. It develops a connection between the mind and the body and promotes different, not always obvious, paths of thinking. The method can also create a feeling of intimacy, safety and pleasure for all of us, but especially for people with dementia.⁸⁴

An essential benefit of this method, especially for people with AD, is that it deals with the here and now. What do you experience at this moment? What do you feel? What do you think? This 'participant-led discovery' stimulates participation but is also beneficial because there are no 'right' or 'wrong' answers to these questions. Through this methodology, the activity focuses on what people know rather than what they 'forgot' or 'don't remember any more'. This shift can be significant, as the loss of memories is, of course, characteristic of AD but also the main focus of society. Breaking free from these thinking patterns, as a person with AD, as a caregiver or as a society, can create feelings like freedom, equality and connection.

Most of the time, unknown objects are used for object handling. These create a certain freedom and challenge the participants to observe everything differently.⁸⁵ For example, suppose nobody knows the object on the table. In that case, you are designated to look at the material, the shape, the colour, and other characteristics of the object in a different way. The identification

⁸⁴ PELICON, Petra, *EFFECT VAN OBJECTHANDLING MET ERFGOEDOBJECTEN BIJ THUISWONENDE PERSONEN MET DEMENTIE EN HUN MANTELZORGERS: EEN MIXED METHODS STUDIE*, unpublished thesis, VUB, 2019, p. 11;

'Methodieken', *Huis van Alijn*, 2023, last visited 20th of May 2023, <https://huisvanalijn.be/nl/methodieken>.

⁸⁵ 'Methodieken', *Huis van Alijn*, 2023, last visited 20th of May 2023, <https://huisvanalijn.be/nl/methodieken>.

stimulates your imagination and encourages participants to work together, learn from one another, and listen to each other, which encourages social contact and connection.

As a 'heritage attendant', this method demands you to ask little questions, give little information and encourage the participants to speak for themselves. You encourage the participants to contribute to the understanding of the object and ask open questions such as:

- Do you like the object? Do you find it beautiful?
- What would be the purpose? What would be the value of this object?
- Where does this object come from? Have you ever seen something like this?

Other object-handling practices are more guided, as participants are given concrete assignments. You can ask participants to order the objects following a specific feeling or theme or from rough to soft materials, for example. Also, other media like sound can be introduced, followed by the demand to determine which object best suits the music or vice versa. When alone, these methods create peace and lower anxiety; when executed in a group, they stimulate learning and discussion.⁸⁶

Although scientific research is clear about the benefits of touch in caretaking practices⁸⁷, both for the participant and the project itself, most museums find it

⁸⁶ 'Methodieken', *Huis van Alijn*, 2023, last visited 20th of May 2023, <https://huisvanalijn.be/nl/methodieken>.

⁸⁷ KIM, *The effect of expressive physical touch*, p 235-243; Voelen en dementie', *Zorgcentra De Betuwe*, 2023, last visited 20th of May 2023, <https://www.zorgcentradebetuwe.nl/ouderen/hulp-en-zorg-thuis/omgaan-met-dementie/dementie-zintuigen/voelen-en-dementie/>.

hard to loan their artefacts and artworks, let alone allow people to touch them. To solve this problem, I would like to recommend the importance and creation of a so-called 'collection library', for example, already established by the Ghent-based museum 'Huis van Alijn'.⁸⁸

Huis van Alijn: a reference and great partner

Huis van Alijn is a museum about daily life in Ghent and beyond. It collects visual materials, objects and other (material) testimonies about festivities, religion, stages of life and many more themes and traditions. Their focus on utilitarian objects, their outreach lab and collections library, and their dementia-friendly activities made the museum an excellent partner for this project.

Although much of their methodologies are based on years of experience and academic research about heritage practices, they indicate the urge for more scientific inquiry about the topic, particularly on the impact of cultural activities on social relationships, well-being and the entire context of the nursing home.⁸⁹ Therefore, this thesis should not only answer the explicit questions of the Alzheimer Liga but also fill in some gaps for museums and cultural organisations to better tailor their operations, specifically those outside the museum.

Huis van Alijn, on the other hand, forms an interesting partner, as they have already developed several programs for people with AD to participate in. However, they have not yet established an activity that takes place within the nursing home and is therefore accompanied by a heritage professional. They developed some travelling suitcases and expositions, but their guided tours and

⁸⁸ 'Manifest voor een collectiebibliotheek', *Huis van Alijn*, 2023, last visited 20th May 2023, <https://huisvanalijn.be/nl/manifest-voor-een-collectiebibliotheek>.

⁸⁹ 'Outreachlab', *Huis van Alijn*, 2023, last visited 20th of May 2023, <https://huisvanalijn.be/nl/outreachlab>.

object-handling activities thus far always took place in the museum buildings.⁹⁰ Therefore, the shift towards another location, the one of the nursing home, is a crucial part of this thesis. The location of these activities has an impact, as later in this paper extensively described, and the demand from the care context towards the cultural field to enter their operations is growing, as already stated in the 'Kennisagenda' of the Alzheimer Liga, that was discussed in the first chapter. With their collection library, however, Huis van Alijn leads by example...

Collection Library of Alijn: A good practice

The 'Huis van Alijn' in Ghent (Belgium) is the first museum in the country with a collection library. It is created specifically to gather objects that are meant to be touched, used and lent out. The collection pieces can be used outside the museum buildings, but also for specific social practices within the museum walls. Healthcare institutions and people with dementia are one of the most important targets of this project.⁹¹

The intrinsic criteria an artefact has to hold to enter this library of things is slightly different from the general selection procedure of the museum. Among others, the following questions about the meaning of an object need a positive answer for it to be part of the library:

- “Does the object connect to any of the themes around which the collection is taking place?”
- Does the object tell a story that encourages dialogue?
- Is there specific demand for the object from healthcare institutions?

⁹⁰ 'Outreachlab', *Huis van Alijn*, 2023, last visited 20th of May 2023, <https://huisvanalijn.be/nl/outreachlab>.

⁹¹ 'Manifest voor een collectiebibliotheek', *Huis van Alijn*, 2023, last visited 20th May 2023, <https://huisvanalijn.be/nl/manifest-voor-een-collectiebibliotheek>.

- Is it mysterious or just a very recognisable object?”⁹²

Also, some conditional criteria were added to ensure the object is in sufficiently good condition to be touched, used and transported. The artefact should also be insect free and may not contain harmful substances or too sharp edges.⁹³

A third set of criteria are sensorial. In other words: Can the object stimulate specific or different senses? How does the object feel? Does it make noise? Does it have a smell? ⁹⁴

The last term for an object to be included in the library is that no similar items are already part of the collection. It is also included if the object has an added value to or is a suitable replacement for other artefacts in the library. ⁹⁵

The collection library of 'Huis van Alijn' is also part of a bigger outreach lab of the museum. Through cultural heritage, this laboratory wants to impact the health and well-being of people, specifically those admitted to the health- and caretaking field. The lab has double output. On the one hand, it organises activities for the elderly, people with dementia and people who need more care (for example, due to illness). Most of these activities are organised within the museum or in a space next to the building. If a transfer is impossible, the museum provides a thematic suitcase for caregivers to get started at home or in the care centre. On the other hand, the laboratory also organises training for nursing staff, engages in academic research and has a broad offer of materials

⁹² 'Manifest voor een collectiebibliotheek', *Huis van Alijn*, 2023, last visited 20th May 2023, <https://huisvanalijn.be/nl/manifest-voor-een-collectiebibliotheek>.

⁹³ 'Manifest voor een collectiebibliotheek', *Huis van Alijn*, 2023, last visited 20th May 2023, <https://huisvanalijn.be/nl/manifest-voor-een-collectiebibliotheek>.

⁹⁴ 'Manifest voor een collectiebibliotheek', *Huis van Alijn*, 2023, last visited 20th May 2023, <https://huisvanalijn.be/nl/manifest-voor-een-collectiebibliotheek>.

⁹⁵ 'Manifest voor een collectiebibliotheek', *Huis van Alijn*, 2023, last visited 20th May 2023, <https://huisvanalijn.be/nl/manifest-voor-een-collectiebibliotheek>.

and literature about heritage as a form of care for everybody interested in the topic.⁹⁶

As 'Huis van Alijn' works around daily life, the themes and objects they offer might seem more straightforward to give on loan. Many objects in their object library are artefacts with a utilitarian past, so they were meant to be touched and transported, making a library collection seem more obvious. Their collection is entirely different from the one of a museum for modern art or a collection about ancient Egypt. If you deal with old, fragile, unique or very big objects, it can be challenging for a museum to give them on loan, let alone allow people to touch them. There are, however, among others, the following alternatives:

Physical alternatives

Daily-life objects, often meant to touch anyways, are great conversation pieces and memory triggers. They were most of the time designed to touch and use, and sometimes also trigger other senses like smell or taste. When memories are gradually lost in the brain due to AD, memories from youth or daily rituals are often the last souvenirs of a person's life history. Working with a museum is not explicitly necessary if you want to loan these daily or ritual objects, as you can also approach local churches (for religious objects), factories (for industrial heritage), city archives (for photographic material or local traditional objects) ... and many more places. In some cases, these objects can even be found at the patient's, a caretaker's or somebody else's house as these utensils, or a variant, are still often used. In this case, the added heritage value (more information on this topic on the next page) might be lost, but the object remains a vital conversation piece and trigger.

⁹⁶ 'Outreachlab', *Huis van Alijn*, 2023, last visited 20th of May 2023, <https://huisvanalijn.be/nl/outreachlab>.

As this research will prove, it's also not necessary that the participant knows the object. For example, an unknown postcard, abstract drawing on paper or an archaeological artefact can be a great conversation piece to bring into the nursing home.

Transporting the specific object to the nursing home, like a painting of a still life with flowers, is sometimes even unnecessary. Instead, a photograph of the original can be projected during the activity, whereas the actual flowers, fruits and vases that are depicted can be shown, smelled and touched in real life. In this way, an artefact or painting comes to life without needing to be transported or touched.

if it is impossible to get the real artefact into the nursing home, due to conservation, transportation or other reasons, replicas are also a great option. Sometimes, museums have already created copies for educational purposes themselves, for example, for their guided tours for blind and visually impaired people. If you want a particular material to stimulate the sense of touch, you can offer contemporary made materials, as done in some industrial museums these days, for example in Texture, a museum about flax production in Flanders, that will be discussed later in this chapter. The flax of previous centuries feels and smells similar to what it does today. By offering a recently produced patch of flax, no objects of high historical value are damaged, but a sensorial experience is yet guaranteed.

Virtual reality & heritage value

Although the multisensorial experience of handling an object is lost within this solution, especially since the 'touch' component is tough to imitate, digital

reconstructions can be helpful. A more traditional medium is photographs or movies, which can show objects, but also particular places or people, that bring back memories. More recent research also deepened the possibility of VR reconstructions. Recent projects already introduced VR goggles into dementia care, for example, to play games, but also to encourage meditation or decrease anxiety.⁹⁷

However, the use of VR-reconstructed objects in processes of reminiscence and object handling is not thoroughly researched yet, although several experts already have questions about its effectiveness. The project 'Touching the Past - the Role of Physical and Digital Replicas in Museums' from the University of Stirling researched the difference between original heritage objects, replicas and digital reconstructions.⁹⁸ They write the following when it comes to the importance of touch:

“Overall, the multisensory nature of object handling was by far the most powerful experience, sparking personal associations and more considered interpretations. Subsequent experiments conducted with Dr Akira O’Connor (School of Psychology and Neuroscience) have shown that the heightened engagement with original artefacts also improves memory and learning.”⁹⁹

⁹⁷ BOSSELOO, ‘WZC Markizaat Laureaat in Dementiezorgtraject’, *Nieuwsblad*, 7th April 2023, last visited 20th of May 2023, https://www.nieuwsblad.be/cnt/dmf20230407_94733181.

⁹⁸ FOSTER, Sally, HADFIELD, Alison, ‘Touching the past – the role of physical and digital replicas in museums’, *University of Sterling*, 21st of August 2020, last visited 20th May 2023, <https://replicas.stir.ac.uk/2020/08/21/touching-the-past-the-role-of-physical-and-digital-replicas-in-museums-by-alison-hadfield/>.

⁹⁹ FOSTER, Sally, HADFIELD, Alison, ‘Touching the past – the role of physical and digital replicas in museums’, *University of Sterling*, 21st of August 2020, last visited 20th May 2023, <https://replicas.stir.ac.uk/2020/08/21/touching-the-past-the-role-of-physical-and-digital-replicas-in-museums-by-alison-hadfield/>.

The difference between an original artefact or artwork and a replica is already slightly researched.¹⁰⁰ Also, the library of things from 'Huis van Alijn' underlines the importance of added heritage value when it comes to touch experiences or activities like reminiscence.¹⁰¹ Although the objects in this library are meant to transport and used, everything is registered in detail. Every object is labelled, described and monitored. The fact that an object is described and treated as 'heritage' might not make a difference for the art historian, heritage expert or archaeologist involved in the project, but inquiries showed us that this added value of 'heritage' indeed makes a difference.¹⁰² Even if only a simple 'utensil' is used, when it is wrapped up, labelled and treated with care, it shows the object's significance for the museum and society, and thus also demonstrates the importance participants have in this project. Due to the mental and physical changes caused by dementia itself, the societal response to the disease and the traditional caretaking facilities, people with AD feel useless and written off by society. By encouraging them to share their thoughts and stories, they are not only helpful, but they also feel helpful themselves. We may thus not underestimate this added heritage value, but further research is necessary to examine how differences between original artefacts, replicas and digital reconstructions are perceived in both museological and caretaking environments and projects.

¹⁰⁰ FOSTER, Sally, HADFIELD, Alison, 'Touching the past – the role of physical and digital replicas in museums', *University of Sterling*, 21st of August 2020, last visited 20th May 2023, <https://replicas.stir.ac.uk/2020/08/21/touching-the-past-the-role-of-physical-and-digital-replicas-in-museums-by-alison-hadfield/>.

¹⁰¹ 'Manifest voor een collectiebibliotheek', *Huis van Alijn*, 2023, last visited 20th May 2023, <https://huisvanalijn.be/nl/manifest-voor-een-collectiebibliotheek>.

¹⁰² 'Manifest voor een collectiebibliotheek', *Huis van Alijn*, 2023, last visited 20th May 2023, <https://huisvanalijn.be/nl/manifest-voor-een-collectiebibliotheek>.

MULTISENSORY STORYTELLING

Triggering curiosity

A heritage methodology specifically related to the different senses, and perfectly suitable to bring into the nursing home together with reminiscence and object handling, is the one of multisensory storytelling. This method was developed by the PAMIS (Promoting a More Inclusive Society) research group of Dundee University (Scotland). It was tailored to people with multiple disabilities but has been used in the broader healthcare field for the last couple of years. It is very suitable to apply to heritage practices because of the multisensory nature of the method and because there are multiple stories to tell about every object, tradition or work of art.¹⁰³

In the general set-up, a narrator tells a five-minute story to the participants, in this case, people with AD. This story is supported and told through various incentives based on different stimuli from different objects that stimulate the different senses.¹⁰⁴ For example, the stories can tell the different purposes of an object, its biography, its different uses or the traditions it was part of. Also, other photographic materials, smells related to the objects, or some music can be introduced. In the case of this project, the narrator will always tell true stories and academically acquired knowledge so that the participants can better discover the objects in an accessible, playful and safe way, but can also learn about them or even collaborate in the story. It can also be helpful to tailor the story to the participants, based on their interests or background. However, this thesis also wants to show that this is not necessary. In other contexts, fictional

¹⁰³ MULTIPLUS, *Handleiding: Multi-sensory storytelling. Verhalen voor mensen met ernstige meervoudige beperkingen*, Leuven: Multiplus, 2008, p. 4-15; YOUNG, Hannah, LAMBE, Loretto, 'Multi-Sensory Storytelling: For people with profound and Multiple Learning Disabilities', *PMLD LINK*, 23, 2011, p. 29-31.

¹⁰⁴ Multiplus, *Handleiding*, p. 8-15; Young, *Multi-Sensory Storytelling*, p. 29-31.

stories can be told as well, which are then supported by non-fictional objects or stimuli.

With this method, especially if it is used in collaboration with people with AD, it is always advisable to limit the various stimuli in advance (for example, via a written script) and ensure during the activity that participants are not overstimulated. Due to the intensive use of the various senses, this can sometimes happen, especially in people with AD, who are more sensitive to many intense stimuli. This sensitivity to senses, extensively used in the method of multisensory storytelling, brings us back to the original goal of this project: to bring the museum and its collection into the care centre, which often feels more accessible, safer and more pleasant for people with Alzheimer's than the average museum building.

THE BEST OF BOTH WORLDS

Exploring the museum in an Alzheimer-friendly environment

The Context of Heritage Practices

An element that was not sufficiently researched in the past, is the impact of the context on these methods and, most importantly, on the activity and its participants. Museums working with people with AD inside their building and caretakers using culture within nursing home activities are not new. In and outside the Belgian borders, reminiscence has been researched and practiced since the 1970s.¹⁰⁵ So-called 'dementia friendly museums' like the Belgian SMAK (Ghent) and Middelheim (Antwerp), as well as more archaeology or heritage-oriented museums like 'Het Huis van Alijn' (Ghent), TEXTURE (Kortrijk) or MAS (Antwerp), offer guided tours, activities and events for people with dementia and their caretakers.¹⁰⁶ These projects often focus on reminiscence within the museum, where people are challenged to share their memories about museum objects and where different senses are gently stimulated.

TEXTURE

TEXTURE, a museum about flax production and the Leie in Kortrijk, is a one of the best examples of a museum that established a qualitative, dementia-friendly activity within the museum. They work together with a lot of partners and developed their project together with people with AD, their caretakers and experts. The museum uses its separate 'Wonder Room' to offer people with dementia and their caretakers a museum experience. People are informed about

¹⁰⁵ WOODS, *Reminiscence therapy for dementia*; CUEVAS, *Remniscence: a literature review*, p. 364-371; 'Reminiscence for people with dementia', *Social Care Institute for excellence*, October 2020, last visited 20th May 2023, scie.org.uk/dementia/living-with-dementia/keeping-active/reminiscence; 'The European Reminiscence Network', *The European Reminiscence Network*, 2023, last visited 20th May 2023, www.europeanreminiscencenetwork.org.

¹⁰⁶ 'Toerisme voor personen die leven met dementie', *Expertisecentrum Dementie Vlaanderen*, 2020, last visited 20th May 2023, <https://www.dementie.be/themas/cascade/toerisme-voor-personen-die-leven-met-dementie/>.

the history of flax making and distribution through photographs, explanations and objects. However, they are specifically encouraged to touch, smell and taste, as the museum correctly indicates that these senses are important in reminiscence. These dementia-friendly activities are also organised Wednesday and Friday afternoons, the museum's quietest and calm opening hours, to avoid confrontations with loud school groups or crowded weekend activities. The number of participants is limited to five people, all accompanied by a caretaker. This amount is supported by science and has proven to be an ideal number for group events. Also, the duration of the activity is limited, a maximum of one hour. TEXTURE interacts with partner organisations, like social welfare, to try to guarantee a comfortable care provision for everybody involved. ¹⁰⁷

Meet me at MoMA

An international precursor of these reminiscence activities is the 'Meet Me at MoMA' project of the Museum of Modern Art in New York, an activity that was first established in 2007. The program runs until today and allows people with AD and their caretakers to be involved with art in the MoMA on the basis of different programs and formulas. Also, this project included a publication with recommendations, a website and a conference with training. ¹⁰⁸

Different media and artworks are introduced with modules like 'Music and Art', 'Photography and Creative Documentation' and 'Everyday Images and Objects'. These are not only used to discuss the past and one's memories but also focus on present experiences and learning. ¹⁰⁹

¹⁰⁷ 'Texture Prikkelt', *Texture Kortrijk*, 2023, last visited 20th May 2023, <https://www.texturekortrijk.be/Dementievriendelijke%20rondleiding>.

¹⁰⁸ 'Meet me at MoMA', *MoMA*, 2023, last visited 20th May 2023, <https://www.moma.org/visit/accessibility/meetme/>.

¹⁰⁹ 'Lessons for Engagement with Art', *MoMA*, 2023, last visited 20th May 2023, <https://www.moma.org/visit/accessibility/meetme/modules/>.

The MoMA activities were, in some way, a guideline for this project. MoMA also engaged an Alzheimer Association, some people from the museum, dementia experts and the people with AD and their caretakers to participate. Their testimonies and recommendations were gathered in a publication, which contains tips and tricks to set up an own program for art viewing practices. 'Practice: Foundations for Engagement with Art' proposes interesting themes and topics, as the ones in the previous paragraph, introduces helpful methodologies and questions, and offers facilitation strategies.¹¹⁰ This information was not only published tailored to museum workers, but also a publication for healthcare experts, informal caretakers and people with dementia was made.¹¹¹ They propose the following steps when creating a tour for people with AD:

1. Select a theme: this creates unity and guides the activity.
2. Select the works of art: these can be from different artists and periods, as long as they are related to the central theme.
3. Prepare art historical information: this offers a framework, both for the museum guide, but also in case the participants have questions.
4. Prepare the right questions: interesting questions are central in these conversations. These can be general questions, like: 'Is this art?', 'Do you think it is beautiful?', and 'What do you see or experience?', but these can also be

¹¹⁰ MoMA, *Foundations for Engagement with Art*, New York: The Museum of Modern Art, 2009, p. 112-124.

¹¹¹ 'Guides for Creating Art Programs', MoMA, 2023, last visited on 20th May 2023, <https://www.moma.org/visit/accessibility/meetme/practice/>.

related to one artwork, like: 'How many shapes and colours are used in this artwork?', or 'How is the title of this work related to what is depicted?'.

5. Small-group conversation: they use a turn and talk system. During the guided tour, the first part offers participants the opportunity to share their own insights. In the second part, an art-historical framework is offered to them, with information about the different works.¹¹²

In the third chapter, in which the methodology is discussed, some parallels with this approach will occur. However, this project for different reasons also deliberately differs from the MoMA techniques. 'Meet me at the MoMA' explicitly invites people with dementia into the museum, which was back in 2007 a huge turning point. This project works the other way around, as it will try to bring the museum into the nursing home. This activity also emphasizes tactility and tries to introduce other triggers than the visual, which becomes clear in the selected objects and the used methodologies.

The importance of the proper context

Although much progress has been made in the last decade, among others, through initiatives such as that of the MoMA, there are still institutions without dementia-friendly activities, despite having very suitable collections or infrastructure. For example, the recently opened Royal Museum for Fine Arts in Antwerp has, despite its focus on public relations, not yet established a dementia-friendly tour, let alone art initiatives with its collection outside the museum. Moreover, when activities are present, they are not always framed as well as in the TEXTURE museum or are rarely sufficiently known to their target

¹¹² MoMA, *Foundations for Engagement with Art*, p. 118-122.

groups. Also, the approaches and creativity in the methods used in these projects are limited, often focusing on reminiscence alone, especially in more archaeological-themed museums.

Most of the time, the museum remains not the most comfortable setting for people with dementia. Some loud noises, weird smells or simply the change of environment, things that for most of us seem very normal and acceptable, can cause a very unpleasant experience for people with dementia. Although museums and their public servants have great intentions, they are often not specifically trained to work with people with dementia. For institutions like the Technopolis Museum in Mechelen, a museum full of technical experiments, organising a dementia-friendly activity on a general opening day would be impossible, as the building is too crowded, and the noise is too loud for most people with dementia to enjoy the activity. If you think about how we shape museums these days, with block-buster expositions, activities for children and as vibrant and vivid places in the middle of our communities, it comes to mind how hard it can be to incorporate the needs of people with dementia within this; a symptom also reflects within the general museum landscape, as well as in the projects described above. Although the intentions are often genuine, and we can remark on a shift towards more sensorial and participatory museums, as I will prove in the following paragraphs, it can be hard to incorporate Alzheimer-friendly experiences within the museum site.

Also, in terms of access for people with less mobility, many museums have some issues. Since AD mainly affects the elderly, many patients also suffer from other age-related ailments, such as poor hearing, a loss of speech, and minimal mobility. Not all museums are accessible in wheelchairs or walkers, especially for larger groups. The building itself and the interpretation we give it bump up some

limits, which may eventually lead to the exclusion of some people with dementia from participating in cultural activities. Especially sound significantly impacts people with dementia, and loud noises can quickly lead to overstimulation.

The importance of a silent environment

Earlier research already showed the impact of the auditory environment on our mental and physical health. However, in the case of patients with Alzheimer's disease, the sense of hearing has an even more significant impact, being the most delicate sense when it comes to quality of life and comfort. Even within the comfortable context of the nursing home, the reduced ability of Alzheimer's patients to consciously value sensorial experiences, as extensively researched in a 2010 experiment by Van Hoof, causes a higher sensitivity to hard and harmful noises.¹¹³ Detrimental sounds can cause direct reactions, like feeling uncomfortable, stressed or anxious, but also influence feelings of apathy, a decrease in social interactions, sleep disturbance and thus a general decline in quality of life in the long term.¹¹⁴ Considering the general museum context, creating an experience with limited sound interruptions within such a building can be tricky. This sound sensitivity was an important motivator to let this activity occur in a nursing home, as sound is more controllable and adjustable over there. Also, the trained caretakers close by are a benefit, as it can be challenging for people with Alzheimer's to explain their needs, especially when it comes to abstract things like noise. Therefore, it is helpful to have some educated staff around to pick up indications or sound the alarm when the location is too noisy.

¹¹³ VAN HOOF, J., KORT, H. S., et al., 'The indoor environment and the integrated design of homes for older people with dementia', *Building Environment*, 45, 2010, p. 1244–1261; JANUS, Sarah, KOSTERS, Janouk, 'Sounds in nursing homes and their effect on health in dementia: a systematic review', *International Psychogeriatrics*, 3, 2021, p. 627-644.

¹¹⁴ VAN HOOF, *The indoor environment*, p. 1244-1261; JANUS, *Sounds in nursing homes*, p. 627-644.

If we look at scientific research, we find some recent recommendations about pleasant sound levels during activities with people with dementia. As described and researched by Berglund in 1999 and supported by current research from the psychogeriatric department of the University of Cambridge, enjoyable and safe sound intensity for people with dementia varies between 35 and 45 dB(A), which matches with a calm conversation within a silent room.¹¹⁵ The same research, however, also measured that, even within the context of the nursing home, this barrier is easily crossed, especially in locations with older facilities or in houses where bedrooms and living rooms are shared. So even within the nursing home itself, it is important to carefully select which room is suitable for your type of activity.¹¹⁶ Let us nevertheless compare the average sound levels of a residential care home (around 50 dB (A)) with the ones of an average museum (61-66 dB (A), measured on a day without activities or guided tours¹¹⁷). The beneficial context of the nursing home becomes clear in numbers as well.

The same research from Cambridge University also evaluated the impact of music on activities and conversations with people with AD. Music as a medium for reminiscence is the topic of independent research. However, there is a consensus these days that background music can be beneficial for the patient's well-being and comfort as long as it is not too loud, too distracting or combined with other intense stimuli that demand one's attention.¹¹⁸

¹¹⁵ BERGLUND, B., 'Guidelines for community noise', WHO, 1999, last visited 20th May 2023, <https://www.who.int/docstore/peh/noise/guidelines2.html>; JANUS, *Sounds in nursing homes*, p. 627-644.

¹¹⁶ JANUS, *Sounds in nursing homes*, p. 627-644.

¹¹⁷ CARVALHO, Antonio, GONCALVES, Helder, 'Acoustics of Modern and Old Museums', *Noise Conference*, 2013, p.1-9.

¹¹⁸ JANUS, *Sounds in nursing homes*, p. 627-644.

The influence of other senses

Besides hearing, previous paragraphs already dealt with the importance of touch and sight. Also, the other senses influence the sensorial experience of people with AD, and thus also the way they perceive museums or objects.

For example, the nose is related to AD, as recent research showed that a faster decline of the sense of smell might be an early indicator of dementia.¹¹⁹ In general, the older we get, the more difficult it becomes for most of us to detect (subtle) smells.¹²⁰ Therefore, objects with a very strong or particular smell might be a better option to incorporate into activities for people with AD. As this region of the brain is also involved in tasting, also losing the pleasure of eating and drinking might occur. To seek comfort or to explore the object, people with dementia might also try to put 'unusual' things into their mouth: like a photograph, a candle or just any other object. Especially people with frontotemporal dementia have a hyper-oral phase, in which they put everything into their mouth. Although this can feel very unusual for the caretakers, it feels very comforting for them.¹²¹

Smelling, but especially tasting, might not always be safe. Most materials or objects were made to see, touch or smell but not intended to be tasted or eaten. If it is safe for the participants and the object to be placed in the mouth, you can allow this during activities. Another exciting way to incorporate the nose and the mouth into cultural activities in nursing homes is to introduce food. This can be done during the daily eating moments, but also by providing spices, sweets or other goodies, for example. These treats and their scents can sometimes have a link to a person's childhood, so becoming a trigger for lost memories, or they can

¹¹⁹ PACYNA, Rachel, HAN, Duke, 'Rapid olfactory decline during aging predicts dementia and GMV loss in AD brain regions', *Alzheimer's & Dementia*, 19, p. 1479-1490.

¹²⁰ PACYNA, *Rapid olfactory decline*, p. 1479-1490.

¹²¹ GOEDERT, Michel, GHETTI, Bernardino, et al., 'Frontotemporal Dementia: Implications for Understanding Alzheimer's Disease', *Cold Spring Harb Perspect Med.*, 2, 2012, p. 2.

be completely unknown, which can stimulate imagination and curiosity. In addition, smells and flavours are very transportable, making it much easier to bring them into the nursing home rather than some artefacts and paintings. However, these foods, fruits or spices do not always have the tactility, esthetical value or heritage value of objects. Therefore, they do not form the centre of this research.

The best of both worlds

The past two chapters discussed the benefits of museums and nursing homes. Also, multiple approaches and methods were introduced. Rather than opting for one or the other, and without excluding or refuting other initiatives, this study takes a different approach: What if we take the benefits of both locations and fields? What if we combine the best of both worlds?

As described above, most museums are not very dementia-friendly environments. The staff isn't particularly trained to deal with the complexity of symptoms and needs of people with dementia, and the museum sites are too crowded and noisy. On the other hand, museums offer a variety of objects, stories and knowledge which form the ideal starting points for activities of reminiscence and storytelling. By bringing these conversation pieces into the residential care home, we guarantee the necessary safekeeping of participants and offer them a space that suits their particular needs without substituting their demand for culture and sharing memories and thoughts. As these objects will be accompanied by a professional heritage researcher, not only the objects are transported, but also the stories and knowledge related to them.

But making the very deliberate decision to bring the museum, or more specifically its collection and knowledge, inside the residential care centre, which is naturally a more dementia-friendly environment, also comes with some

challenges. It demands that museums and residential care homes step out of their comfort zone and slightly alter their usual mode of operations.

In the next chapter, the methodology, together with the particular challenges related to it, is explained. The script tries to take the benefits of both fields and attempts to align this research with the needs of both domains.

CHAPTER 3

THERE IS NO PLACE LIKE HOME

Methodology

In this chapter, I will elaborate on the methodologies I will use and the script I will follow during this research. The third chapter starts by discussing my position as a researcher. Afterwards, the selection process of the participants and the objects will be discussed, as well as the specific context and set-up of the experiments. The last part will talk about the query of the participants and the processing of the data.

‘ELK HUISJE HEEFT Z’N KRUISJE’

My position as an art historian, archaeologist and heritage worker

As a Master student in art history and archaeology, working with people with Alzheimer's is not what I was exceptionally trained for. During a student job a few summers ago, covid-19 did not exist yet; I had the opportunity to work for 'Erfgoedcel Kusterfgoed' in a nursing home with people with and without dementia. I brought photographs with me, hoping these would be a catalysator for rekindling memories about a time I had never experienced: the '40s, '50s, '60s and '70s. Their stories formed the basis for identifying objects, locations and people in the photographs. In the end, they even became part of the broader compilation 'Eb en vloed op Camping Kust', a little booklet about the history of camping at the Belgian coast.¹²² Back then, however, I already experienced that this project was not only beneficial for me, the heritage worker, and my organisation but also for the participants themselves. People were enthusiastic and created a bond with each other, and I even had the feeling that, in some cases, the photographs brought more back than only memories. This event formed a catalyst for further interest in the topic and it is the original basis of this project. Most of my activities and responses back then were the result of my gut feeling, a phenomenon I often remarked on during this academic research a few years later, especially with the participants having a background in the cultural, archaeological or art historical field. Therefore, I now want to research this topic from a more academical point of view, although the project remains very practical and participation oriented.

Before explaining my further methodology, I believe it is vital to research my position within this project. As it deals with my observations and opinions, I

¹²² *Eb en Vloed op Camping Kust*, Oostende: Erfgoedcel Kusterfgoed, 2019.

decided to write this part and some of the following chapters in the first person. This is a strategy that is being used more and more regularly, also in the field of the humanities. I will use it mainly to explain my position and make a clear distinction between my observations and the qualitative data from the measurements or other research. In the past, this approach was seen as non-academic or non-professional. However, I believe that delineating your position and indicating your own observations are very beneficial to the quality of academic research.

Although I have read a lot about Alzheimer, caretaking, and memory studies in the past years, particularly the last year of my master's research, I was never trained as, nor have I the experience of a professional doctor, psychologist, nurse or even caregiver. Although this paper contains some chapters about dementia and the healthcare sector, these paragraphs are more meant to provide readers with context and clarify the framework I used for my research and observations. I'm certainly not an expert in these topics, and they are also not the specific focus of my research question.

This fear was also a frequent reaction of various experts involved. Why should someone with my background do this kind of research? 'You are not trained as nursing staff, but also not to measure well-being or other social dynamics?' And if I am honest myself, I also doubted at first when it came to working outside of the museum and with a public I am not used to. During my research, however, I discovered the following types of expertise I could offer and some pitfalls that I tried to solve and anticipate along the way:

As an art historian and archaeologist, you are used to working with objects. You understand the different values an object can have and try to utilise its full

potential. This was an enormous benefit during the selection of the objects but also during the development of the methodology or during the activity itself. Suppose we, for example, look at methodologies like reminiscence and object handling, which were explained in the previous chapter. In that case, it becomes clear that those are mainly developed by people within the heritage and cultural field, as they, just like I, try to seek the full potential of objects. Also, public outreach and diversity are hot topics within the field, and to research these in a cultural context, I am specifically trained. Therefore, as well as to underline the importance of a heritage value, during the activity and within this research, a heritage worker can be an important actor.

Although the nursing home might not be the most apparent terrain for an art historian or archaeologist to research, I also believe this thesis is an important step. By going outside of the museum building, a lot of new research potential is developed. As a person trained in museology, I know the potential of museums and their collections, but I also know their challenges and unaccomplished tasks. I believe museums, as we know them today, are the product of some specific (western) dynamics and choices. I support the latest movements in the field that try to reshape what the usual museum, collections and their operations look like. Comparing the context of a museum with the one of a nursing home is an essential component of this thesis. The project uses various museological and heritage techniques, which are also perfectly applicable outside the walls of the museum.

Most similar research and projects as this one, which measure well-being related to cultural activities, are executed by sociologists or healthcare researchers.¹²³ However, they use another approach, which is entirely qualitative in most cases and not oriented explicitly on building bridges between the two fields. There is little attention to the objects and their different tactile benefits, and the specific context of cultural activities is not considered. Some of these researches do not even explain their location.¹²⁴

Rather than only research specific numbers and measurements, which I will also do and is indeed essential, I see this project as an opportunity to create a more significant framework or script for cultural activities, like reminiscence and object handling. Heritage workers already partly developed these methodologies, and we already know their impact through a few compact guides. However, in my opinion, they are not much oriented on both the context and the specific demands of the caretaking field. I hope this project can become an example, both for museums and nursing homes, to open their doors for visitors and step out of their doors to talk, discuss and, most importantly, work together on these topics. Of course, this demands flexibility and out-of-the-box thinking from both fields, but during this activity, I measured so much enthusiasm and interest that I believe we can make this work in the future. Important, therefore, is enough trained staff, enough time and thus also enough resources. By proving the importance and impact of object handling and reminiscence activities within the nursing home, I hope to stimulate the necessary resources for both fields to develop similar activities in the future.

¹²³ You find a discussion of these researches in the last chapter, when I discuss the results of measuring well-being.

¹²⁴ CUEVAS, *Reminiscence therapy*, p. 364-371.

These will impact not only the people with dementia in Belgium, but also their environments, like their friends and family, and even the nursing staff. Ultimately, these investments are paying off not only for them but for the entire Social Security system.

Related to my own position, I would also like to discuss what I won't be able to research. This experiment measures the well-being of the participants, but it doesn't do that in-depth, nor in the long term. Some more sociological and psychological research already happened on this topic for object handling, reminiscence and storytelling. Also, the cognitive impact of these methods will not be researched, such as the long-term impact on the brain, memory or social engagement of people with AD. After all, research into this has already been done by psychologists, although they usually opted for the museum or the house of the person with dementia.¹²⁵ The specific context of the care centre is generally still underexposed.

Although some more visual objects are incorporated, like an old educational poster, this research will not focus on art or the perception of it by people with AD. Based on the results, some research options can be suggested, or the findings of this thesis can be linked to previous studies on art and Alzheimer's. In any case, the excellent research potential of this topic is further elaborated in the last chapter of this paper, which also explains the results.

¹²⁵ JOHNSON, Johanna, CULVERWEL, Alison, 'Museum activities in dementia care: Using visual analog scales to measure subjective wellbeing', *Dementia*, 16, 2015, p. 361-390; CAMIC, Paul, HULBERT, Sabina, et al., 'Museum object handling: A health-promoting community-based activity for dementia care', *Journal of Health Psychology*, 24, 2017, p. 24-37; CUEVAS, *Reminiscence therapy*, p. 364-371.

But what will be investigated? And how will this entire investigation take place?
The whole set-up of the sessions is further explained in the following paragraphs.

METHODOLOGY

Set up of this activity

In the nursing home, two activities will take place with a selection of religious objects. In every activity, five or six people with dementia, two nurses and one caregiver are included. They sit around the table to share, through different heritage methodologies, their memories and thoughts about the objects with each other. The activity is guided by me, a heritage professional with background information about the objects and the different methods. Everybody around the table is approached as equal, and this activity should allow the participants to take up different roles as they are used to. Informal and professional caretakers are encouraged to loosen their caretaking role, while people with AD are given the opportunity to share their insights and opinions. This should benefit well-being, comfort and group dynamics.

Selection of the participants

Eleven people with AD will participate in the experiments, together with four nurses and two caregivers. All participants are divided into two groups, as two measurements will take place. Although I strive for gender equality during both experiments, slightly more women will be questioned, as they have a higher risk for dementia and Alzheimer's in general.¹²⁶ Together with the nurses, and also based on both the research question and previous inquiries, a specific selection of the following different profiles was made:

The first experiment will be carried out with a heterogeneous group of people. They have different stages of Alzheimer's (from very light to moderate)¹²⁷ and

¹²⁶ 'Fact Sheets: Dementia', *World Health Organisation*, 15 March 2023, visited last on 18 May 2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

¹²⁷ These different stages of AD and their symptoms are explained in the first chapter.

different backgrounds in this activity's topic (religion). Some have never been religious, some were religious in the past, and some still are. Also, other parameters more strongly differ: They come from different regions, vary in their mobility -some can still walk independently, others need some help, and others are seated in a wheelchair- and they have different degrees of speech and hearing loss. Although these criteria were kept in mind while selecting the participants, the primary motivation for participation was their excitement and interest. Their partaking also depended on the day the activity takes place, as their mood, sense of social contact and need for an active daily schedule hangs down obviously from day to day.

The second group was selected as more homogenous. People were diagnosed with a similar stage of Alzheimer, had a more common background in general, and had related needs regarding movability, hearing and speech. In addition, all the people in the group had been religious recently or still are.

These two groups were picked to research a potential difference in dynamics, a probably different approach towards the objects and a perhaps different need in methodology.

A well-considered decision was also made in which caregivers would participate. Two nurses will accompany both groups: a so-called 'living figure' and a professional caretaker. The 'living figure' also has a degree in nursing, but its bond and relationship towards the residents are different. They are less burdened with care tasks in order to have more 'informal' time for residents. They join them for a chat, take them to informal activities and, for example, don't wear a uniform. The 'nursing figure', who will also participate in both sessions, wears a uniform and is responsible for the daily care tasks, such as helping to wash, eat and dress, but also to make sure the residents take the right

medication and are provided with all kinds of care. Both roles work very complementarily in the care centre. During the conversation, however, they are also challenged to step out of this classic division of roles and to participate and interact so that they will hopefully get to know the residents differently.

In addition, two informal caretakers with very different profiles were selected. The first one is the daughter of a resident, who visits her mom daily in the nursing home and provides the necessary care. She fits the classic profile of the 'informal carer' (in Dutch: 'de mantelzorger'). The second informal caretaker has a slightly different profile. He lives in the nursing home himself, in the dementia ward, in order to be able to take care of his wife. She first moved by herself to the Heilig Hart, but very soon turned out that she missed her husband immensely. She could no longer live happily without him around. Therefore, he decided to move to the centre to care for her and keep her company. This may seem like an atypical form of 'informal care', but in Flanders alone, around 232 couple rooms are currently provided in care centres.¹²⁸ This form of housing is also on the rise because it is increasingly apparent that it leads to happier residents.

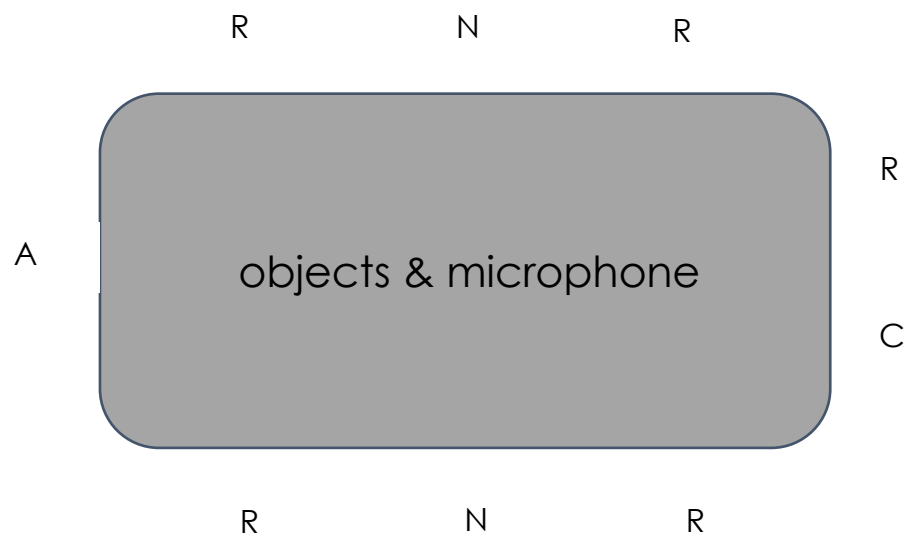
Thus, in total, 5 or 6 people with AD, divided into a homo- and heterogeneous group, will participate in each session. Also, two nurses and an informal caretaker will join the activity. The next part will explain how they will be placed around the table to promote their interaction.

¹²⁸ DE JONCKHEERE, Barbara, 'West-Vlaamse woonzorgcentra hebben het hoogste aantal koppelkamers', *VRT NWS*, 21st January 2022, last visited 20th op April 2023, <https://www.vrt.be/vrtnws/nl/2022/01/21/west-vlaanderen-grootste-aantal-koppelkamers-rusthuizen/>.

Location and table setting

As argued extensively in the previous chapters, the activity occurs in the nursing home. The main reasons are the limited transportation of participants, the cosy and silent environment and the familiarity of the room and people around them. This should provide people with AD with more comfort and avoid relocation, which can often lead to stress and overstimulation. This will allow them -hopefully- to enjoy this activity to the fullest.

Within the nursing home, a cosy and homely room was selected. The room has large windows, there is thus a lot of natural daylight. It is decorated with plants, some other exciting and domestic objects, like an old clock and some photographs, and cosy seats and a large table are present. All participants already know the room, as it is used for other activities and also open during the night to snuggle. The room is also well insulated and has a door that can be closed, for example, if there is too much noise in the corridor. All of this should minimise noise nuisance.



All participants will be placed around a large table. People with AD and the nurses are alternated to allow maximum interaction. The caregiver sits next to

the person with dementia he/she is familiar with. During the activity, the nurses are asked to observe the participants around them and to afterwards write down the necessary remarks on the questionnaire. During the conversation, everybody tries to engage as much as possible. It is important that there is little difference between everybody involved and that all of them can really engage with each other and the objects.

Objects

During the selection of the objects, the participants' background was considered. However, the same objects are selected for both sessions, and the same script is followed to ensure an equal measurement was more likely. To create variation and ensure the two methodologies of reminiscence and object handling were incorporated, both 'known' and 'less known' objects are selected.

The choice for religious objects derived from the demands in the 'Kennissagenda'. This publication specifically demands research on the topic of religion, religious diversity and on incorporating spirituality in a creative way into the daily activities of people with dementia. ¹²⁹

The following selection was made from the collection library of 'Het Huis van Alijn', in which only a limited number of objects are included. Photographs of the objects, and their use during the activity, are part of the first attachment of this thesis:

Known objects

To practice reminiscence techniques, a few widely known religious (Catholic) objects were selected (attachment 1.2).

¹²⁹ STEYAERT, *Kennisagenda*, p. 23-25.

The first one is a rosary (1.2 & 1.10), a classic religious object known by Christians but also by people with other beliefs or no religious background at all. Roman Catholics use this tool to pray, as it indicates which prayers to say in which order. It is an ideal object for reminiscence practices, as it is known, often used and also in general associated with Christian traditions. It is made to touch, out of different exciting materials, which makes it a great conversation piece, and thus a great memory trigger.

The candle (1.2) is another very general object. It is interesting to incorporate, as it is related to many practices and can symbolise various things, both religious and non-religious. For example, maybe the participants know the practice of 'lighting a candle for good luck?'. Or perhaps they relate it with advent practices or to something completely else? The candle is interesting in this conversation because it is such a widely known and used object, for example, also related to birthday cakes, making it ideal for the reminiscence methodology. However, I also included it because of its material: wax. Wax has a particular feeling and an even more specific smell. The touch and smell of it can make the activity very comfortable and is a great and necessary stimulus for the senses, as described above.

The educational school print (1.2 & 1.6) also fits the row of these more obvious or probably more known objects. This poster was once used to educate young people about religion and its history. The participants possibly know the format, which is a great conversation piece. Also, the depicted things can be an exciting topic for the reminiscence method. I added this object because of its more visual interpretation options. Will this visual object, depicting Catholics converting the Franks, be a different trigger? Does this change the dialogue, and if so, how?

Also, a pocket Maria and a pocket bible (1.2) are included in the selection. These objects are very transportable and tactile, often used daily or brought from a pilgrimage as souvenirs. Their limited size makes it easy to displace them to the nursing home, but I hope they can be an incentive to tinker with during our conversations, which can reduce stress and anxiety. They were also included because of their widespread use and more general shapes: You don't have to be religious to notice that the objects are a book or a little statue.

Unknown objects

The artefacts described above are ideal for reminiscence, as they are familiar, often used, and known by many people over different generations. However, I also selected some fewer known objects, that are, through their shape, colour or material, and because they are less known, great starting points for the object handling or storytelling techniques. These, presumably, less known objects will be a specific focus of this research, as I believe they will change the group dynamics, the conversation methodology and the experiment's outcome entirely. These questions will be researched among others: How will people react when they do not know something? Do they prefer talks about known or unknown objects? And will these unknown objects change the dynamics between nursing staff and residents?

The first, somewhat unknown object that is included is a catechism in Braille (1.2 & 1.7). The catechism on its own is a very known concept, used over generations to learn about God, Christian practices and religious issues. For a long time, before making their solemn communion, children had to memorise the catechism and then answer questions about, among others, the divine, concepts

like 'guilt and innocence' and church traditions. The concept of the catechism is very known, but this variant for blind or visually impaired people is less common. What would their reaction be if there were no texts or images included? Will they specifically like the tactile character of this object? The object allows this research to particularly understand their favourite stimuli: words, images and/or the tactility of things.

Another object with a very high tactility and a somehow mysterious outlook is added: a mourning car or horse decoration (1.2 & 1.8). These plumes were/are placed on the cars or the horses that accompany the funeral procession. They are less widely known than the objects described above, but due to their black colour, associated with death in Western Europe, and their elegant design and weight, they might be recognisable to some people. In case the object is unknown by some participants, what you might expect, given the limited context when the plumes are introduced, is a great conversation piece due to its weird shape, high tactility and different functionalities.

The third rather unknown object is a piggy bracelet (1.2 & 1.9). Little pigs are an international symbol of luck. They are drawn on new year's letters, sold in the form of marzipan or, as seen in this case, worn around the neck or wrist as a good luck charm. Sayings such as 'on the pig's back' and 'the pig is the gentleman who pays the rent' represent this functionality. This artefact is great for object handling practices, as the symbol of the pig is only sporadically known in our region, but it is tactile, playful and wearable.

The last object in the selection is a Turkish bracelet (1.2). The bracelet is worn as a lucky charm representing Turkish Eyes and the Hand of Fatima. Although these

symbols are known globally, the object is interesting because of its non-catholic background, atypical material (plastics) and very wearable nature. Therefore, the activity will not only find out whether this object is known to participants of different generations (without a specific Turkish background), but above all, it will also gauge their reaction to unknown objects, which also do not necessarily have a relationship with the Western European culture in which they live and grew up.¹³⁰

Script

A detailed script of the operations was developed to ensure all measurements are equal and the two sessions are guided similarly.

The introduction

The activity starts with a short introduction. The program's course will be explained, and the participants will be offered a questionnaire that collects their primary data, consent to the recording, and general well-being. The following data is gathered from people with AD:

- > Name
- > Date of birth
- > Place of birth
- > Gender
- > How long do you live in the nursing home?
- > Are you religious?

¹³⁰ The explanation about the use and origin of all these different objects, was provided to me by Liesa Nusaert from the 'Huis van Alijn'.

The same information is gathered from the informal and professional caretakers, using the same questions and methods. This is done to increase the sentiment of equality in the group. The only question that differs is:

> How long do you live in the nursing home?

This one is replaced by:

> How long are you a professional or informal caretaker?

Also, the well-being of all participants, people with AD and the caretakers, is measured in the same, following way:

Track emotions

Two different methods track the short-term impact of the activity on the participant's well-being. Both models will be filled in right before the session and directly afterwards. Because this activity is new -they don't really know what to expect, and they don't know me either- I will not only ask about their sentiments right before the start of the activity but also about their general feelings during the day of the experiment.

Two complementary methods will be used to measure the participant's well-being. They are first asked to fill in a general scale of well-being (Attachment 2.1). This scale contains numbers from 0 to 100 and is accompanied by three emoticons. The residents and nursing staff are asked to indicate how they feel. They indicate this feeling with a cross on this scale, of which the place then results in a concrete number between 0 and 100. A complementary, more

nuanced model supplements this measuring instrument: James Russel's circumplex diagram (Attachment 2.2). This can be an exciting starting point for a conversation about emotions that can make more abstract sentiments easier to describe. It was, among others, used in the past as a heritage methodology, whereby participants were asked which emotions were evoked by particular objects.¹³¹ The circumplex diagram divides our feelings into four different groups based on two axes: one for valence and one for action. The participants are then asked which emotions they recognise and experience. Contrary emotions were placed across each other on the model. Prototypical Emotion Episodes are included in the margin, as they are often evoked by a specific event rather than a general sentiment.¹³²

Both instruments were used in dementia research in the past, as examination showed they are specifically helpful in questioning people with dementia -or in general, people with challenges in defining their emotions.¹³³ Using the same measurement techniques allows us to compare the results of different studies. Although in most research, only one of both methods is used, I prefer to involve both. I believe 'the scale of well-being' lacks a review of the different dynamics and sentiments about the number indicated by participants. The James Russel model, however, can be abstract, not only for the person who fills it in but also for the person who interprets it. For example, certain emotions can have different connotations. In general, 'less active' emotions are seen as negative in this model, while participants do not necessarily experience these feelings as

¹³¹ 'Methodieken', *Huis van Alijn*, 2023, last visited 20th of May 2023, <https://huisvanalijn.be/nl/methodieken>.

¹³² 'Russell's Circumplex Model', in: YARWOOD, *Psychology of Human Emotion: An Open Acces Textbook*, Pennsylvania: Pennstate Pressbooks, 2023, last visited 20th May 2023, <https://psu.pb.unizin.org/psych425/chapter/circumplex-models/>.

¹³³ JOHNSON, *Museum activities in dementia care*, p. 361-380; CAMIC, *Museum Object Handling*, p. 24-37; CUEVAS, *Reminiscence therapy*, p. 364-371.

exclusively negative. Since both are an exciting complement to each other and can act as a control mechanism, both parameters were collected and used for this study.

In addition, a lot of freedom was explicitly given to the participants in this part of the measurement, allowing them to write down other feelings or add extra explanations.

Informed consent

All participants will be asked to sign a form to give their informed consent to record the session and to take photographs of the activity. Because people with dementia, certainly from a legal point of view, are not always seen as able to give such consent, because of the symptoms they experience, their relatives are also informed. They are kept informed, asked for permission by the nursing staff and were also able to leave their email address. This approach was discussed in advance and recommended by the Alzheimer Liga.

Mapping the degree of AD

Besides this basic data, the nursing staff also gives me a list of necessary medical information from all participants. Their stage of AD will be listed, together with eventually other diseases like other forms of dementia or diseases like Parkinson's. Also, their mobility and general speech and hearing level will be notified. Some informal facts about the resident will be shared as well: Do they like history, does the person have a history in the theme of religion, or does the participant have a great affinity with the daily news, for example? Maybe some participants have already discussed the existence of a god and the institutionalisation of religion before?

Rules

After this small questionnaire, the objects are placed on the table. They are taken out of their protective box and unwrapped in the presence of everybody to show the heritage value of the artefacts and to introduce some specific rules. It is made very clear that they are part of a museum library, which demands some specific guidelines if we move and touch them:

- It is allowed to touch, smell and handle these objects, but please always be careful with them.
- We always do this above the table if we handle and pass an object.
- After the activity, the objects must be placed again in their original packaging, with the original label.

This approach, connected with these specific rules, should underline the heritage value of the objects. Whether this impacts the activity or the participants themselves, the poll will question after the session.

The session itself

Once the objects are placed on the table, the actual activity can start. The experiment is participant-led, so the participants mainly choose the objects and topics we will discuss. We start with a visual trigger, and afterwards, other senses like touch are introduced.

The first question is the following:

> Which object, from the sight, catches your attention? Why?

This question opens the conversation, but it also tries to leave out any pressure about 'knowing' or 'not knowing' or 'sharing' or 'not sharing' specific thoughts and memories. By laying the focus of the conversation in the present, we remove anxiety and gauge the initial and primary triggers of people with dementia. By not immediately assuming that an object is known, as a technique like reminiscence usually does, the conversational possibilities become broader and more pleasant for people who do not know the objects or cannot remember certain aspects about them (anymore).

The participants now decide the sequel of the conversation. When they choose an object because they know it or have specific memories about it, they are free to share their thoughts and knowledge. In that case, the following questions, part of the reminiscence method, can be asked:

- > What is it?
- > What was it used for? Where is it used? Can you demonstrate that?
- > By whom is it used? Have you ever used/do you still use it yourself?
- > What are the materials? What do these materials evoke in you? Were objects like this always made of that material?
- > Do you think it's beautiful? Or ugly?
- > Do you want to share a memory or anecdote related to this object?
- > Do you have specific questions about the object?
- > Which thoughts or emotions come to mind when you see, touch or smell the object?

When the object is unknown, or the participants don't want to share specific memories, more open questions are asked. These are based on their present

experiences rather than on knowledge or specific memories from the past. They are encouraged to touch and smell the object and focus more on its tactile character and esthetic value. For these unknown objects, the method of object handling will be used, leading to, among others, the following questions:

- > What do you see? What do you feel?
- > What is the material? Do you know it? Do you find it pleasant?
- > Do you find the object interesting? Or beautiful? Or ugly?
- > What do you think of the shape?
- > Do you like the colour(s)? Why?
- > How does it affect you that these objects are on the table? Does it evoke certain feelings and thoughts in you?
- > Does this emotion/expression/thought change/enhance when you are allowed/able to touch an object?

Also, a third methodology will be used, one already introduced in the previous chapter: multisensory storytelling. This method will be used organically because the evolution of the session cannot be predicted and scripted. Due to the participant-led approach, I will not introduce the objects with storytelling. I want to avoid that I become the dominant narrative of the conversation or immediately steer the interpretations of an object in a particular direction. Multisensory storytelling is, therefore, more likely to be used to conclude the conversation about an object. When the residents ask me what the object is, how it was used and why it is so unique, this method can be used to answer. It is important that this question actively comes from them. Also, multisensory storytelling can offer an alternative view when a discussion arises in the group

or when there is division about an object. It can actively encourage participants to touch and smell the objects and to engage with them.

During the talk, three heritage methodologies are thus combined, although they are often used separately. This can be scripted in some cases, but its course and use also depends on how the conversation evolves and on what the exact degree of participation is.

The end of the conversation

Before the participants are asked to fill in the second part of the poll, the activity is closed through a summary, to show the session is now over. This moment should give a recap of the different objects, their connections and their different meanings. All participants are also given the opportunity to ask questions, about the objects or about something else, and they are invited to share some thoughts they were not able to tell yet. Afterwards, the objects will also be wrapped and placed in boxes together, to once again underline their heritage value. After a short questionnaire, which will be discussed in the following paragraphs, the participants will also have coffee together, giving them the opportunity to socialise and chat with each other about the session. This way, the activity ends less abruptly.

Data collection and processing

Both interviews will be recorded and later analysed. From that transcription, interesting passages are selected:

- provide information about the objects
- confirm or invalidate the heritage value of the objects
- teach us about how the objects are experienced

- show the (changing) impact of the methods and the objects on group dynamics
- explore the impact of diversity on the group and the activity
- help investigate the impact of the context, the care centre
- study the interaction between carers, people with AD and the heritage worker
- by striking or just confirming specific hypotheses
- contribute to the research question in other ways.

To avoid the conclusion of this thesis must rely solely on this qualitative data, and to support or refute observations, a questionnaire will also be administered after the session. In it, several elements were addressed, which should help answer the different parts of the research question. In this second part, the questions for the people with AD differ from the ones of their caretakers, although the same topics are covered.

The objects

The first question deals with the objects. To find out which objects appeal most and why, the following question is asked:

> What was your favourite object on the table? Why?

The answer to this question can not only give us insights into what kind of objects appeal most to people with AD, but it can also help us better understand and fine-tune the impact of various methodologies.

Also, the multisensorial character of the objects and the explicit possibility of touching, wearing, and smelling them is questioned. There is not only asked whether touch and smell have an impact but also in what way:

> Did you find it pleasant that you were allowed to touch, smell, etc., the objects, something not allowed in most museums? Did this change your experience or emotions about the objects?

To make the question more manageable and to align the answers more with the used methods, people with AD are given the following choices:

- Yes, it triggered different memories.
- Yes, I experienced the objects differently.
- Yes, I liked the feeling of touching or smelling them.
- No, it didn't.
- different: ...

The heritage value of these objects will also be questioned to research the potential impact of it on participants with very different backgrounds. This question should probe for that possible 'heritage-added-value' in a subtle and accessible way:

> Did you find the activity today more special because not usual things but objects from the museum were involved?

The impact of the objects, their multisensorial character and their possible heritage value, will also be questioned to the caregivers. Their responses serve as a control mechanism on the one hand but should also indicate how the caretakers themselves experienced the activity. They will be asked the following questions related to the objects:

- > What was your favourite object on the table? Why?
- > In your opinion, did the ability to touch and smell differentiate the experience for the residents?
- > Do you think that the heritage and museum background of the objects adds an 'added value' and makes this activity more special for the residents?

The context

Researching the importance of the context of heritage activities for people with AD, and especially the possible benefits of the nursing home environment, is one of the main goals of this thesis. Therefore, the context itself and its influence will be extensively questioned based on the following questions:

- > Do you know the museum 'Huis van Alijn'?
- > Would you like to visit the museum to see similar objects?

These first questions deal with the resident's bond with the museum and gauge their interest in visiting it. The following are more specific about the nursing home and its possible benefits:

- > Did you find it pleasant to do the activity in a familiar context, in the place where you live in?
- > Did you find it less stressful not to relocate yourself to see the objects?
- > Had the context of the nursing home an impact how you experienced the objects or the activity?

Participants will also be asked which location they specifically prefer for these activities: the museum or the care centre:

- > I would prefer the activity to take place in...
- the nursing home
- the museum
- somewhere else
- > Why?

The impact of the context, and its possible benefits, will also be queried by the caregivers. They are asked to discuss the influence of the environment on participants with AD and how that impacted themselves and their daily functioning.

- > Do you know the museum 'Huis van Alijn'?
- > Would you like to visit the museum with the residents to see similar objects?
- > Did you find it an added value that objects came to the nursing home so people didn't have to relocate themselves?
- > Is it less stressful for you that the objects come to the nursing home?

- > I would prefer the activity to take place in...
- the nursing home
- the museum
- somewhere else
- > Why?

- > Would the residents experience the project differently in another location?

Group dynamics

The dynamics within the group, and for example, the impact of different stages of AD, will mainly be researched through the transcription. However, the retrospective survey also included two specific questions about group dynamics. These questions aim to gauge the impact of the activity on the bond between residents mutually and with their caregivers, which can be derived less explicitly through analysis of the session alone.

- > Did you find it pleasant the activity was organised in a group? Did it strengthen your bond with the other residents?
- > Did the activity stimulate your bond with the caretakers positively?

Very similar questions will be posed to the caregivers:

- > Did you like that the activity took place in a group? Did it change the dynamics between residents, with you or between you and your colleagues?

Theme and feedback

Also, the theme of the session, religion, will be questioned, and participants will be able to offer a new topic. Then, through another question, they can give feedback and evaluate whether a heritage worker has an added value for these activities. The following questions will be offered to both residents with AD and the professional and informal caretakers:

- > What did you think of the theme of today: religion?
- > What can we do to make this activity better?

> Was Astrid, the independent heritage worker, an added value for the activity?
Did you like that somebody unknown moderated the activity?

Heritage and their daily operations

The poll of the professional caretakers also includes several questions about incorporating this activity into their daily operations. In addition, the extent to which they themselves would like to supervise such an activity in the centre and what kind of support they would need to do so was also assessed:

> Was it easy to incorporate this activity into your daily operations?
> Would you like to moderate an activity yourself in the future?
> What would help you to elaborate on such an activity?
> Would it help if a heritage worker would give a few sessions to inspire you, after which you can work with the residents for several months?

Well-being and emotions

The last part of the poll will demand the participants to again fill in the scale of well-being and the James Russel diagram. Thanks to the poll just before and after the activity, we can track the evolution of their well-being and emotions in the short term.

Besides the two models, the professional nursing staff is also asked whether they see a change in the resident's mood after the activity. They will be asked:

> Did this activity have a positive or negative impact on the well-being of the residents? How is that noticeable? And in case their mood did indeed change, why did it so?

Processing of data

The answers to the questions stated above will be confronted with the transcription of the sessions and linked to the generic data of the participants. It will also be checked against previous research and produce concrete recommendations for the two sectors involved. The results are presented in the following chapter.

CHAPTER 4

TACTILITY, BEAUTY, CURIOSITY

The results & recommendations

PARTICIPANTS

People with AD

All participants were given a number, to guarantee their anonymity. The table below outlines the profile of the various participants with AD on the basis of a number of fixed characteristics. A heterogeneous selection was deliberately made for the first group (P1-P6), bringing together people with various religious backgrounds, but also with different stages of AD's. The second group (P7-P11) was selected more homogenous, to study the impact of both constellations on the group dynamics. Besides a year and place of birth and their sex, also their clinical picture was mapped before the start of the experiment. Not only AD-related symptoms were taken into account, but also possible other medical and social problems.

In addition, the final selection of the participants was made just before the start of the activity, because this choice also took into account the 'mood' of the participants on the specific day of the experiment. After all, the symptoms of AD can vary from day to day. The final choice to partake ultimately rested with the participants themselves.

	P1	P2	P3
Year of birth	1934	1930	1938
Months in nursing home	4	24	/
Sex	female	female	female
Religion	Catholic	Not religious	Catholic

Stage of Alzheimer	Deliberate	Light	Deliberate
Additional remarks from the nursing staff			
Scale of happiness	85	100	100
James Russel diagram	Active, tense	Active, happy	Happy, calm, excited, relaxed

	P4	P5	P6
Year of birth	/	1934	1932
Months in nursing home	2	78	24
Sex	female	female	male
Religion	Not religious	Catholic	Not religious
Stage of Alzheimer	Deliberate	Deliberate	Very light
Additional remarks from the nursing staff	Finds it hard to have conversations, confused,	Was city Guide in Ghent, very interested in the past, finds it hard	Very interested in the daily news, hard of hearing

	sometimes speaks off topic	to express her thoughts	
Scale of happiness	50	90	50
James Russel diagram	Happy, bit nervous	Serene	Relaxed, calm

	P7	P8	P9
Year of birth	1931	1934	1929
Months in nursing home	48	7	/
Seks	female	female	female
Religion	Catholic	Catholic	Catholic
Stage of Alzheimer	Deliberate	Deliberate	Deliberate
Additional remarks from the nursing staff			Very creative
Scale of happiness	100	100	100
James Russel diagram	Stressed	Happy	Calm

	P10	P11
Year of birth	1936	1931
Months in nursing home	/	11
Sex	male	female
Religion	Not religious	Catholic
Stage of Alzheimer	Deliberate	Deliberate
Additional remarks from the nursing staff	Has a hard time to find his words since his diagnosis	
Scale of happiness	/	80
James Russell diagram	happy	Relaxed

Informal and professional caretakers

Also professional and informal caretakers have been questioned. Three different professional caretakers participated in the project (N1, N2, N3). N2 was part of both sessions. Two informal caretakers partook as well, one was the husband of a patient with AD (C1), one was the daughter (C2).

THE RESULTS

Well-being

The impact on well-being of people with AD

Before the start of the activity, the mood of the participants was gauged using the James Russel model and the general scale of wellbeing. For people with dementia, this resulted in the following statistics:

On the scale of wellbeing, eight out of eleven people described their mood as very happy, rating their happiness level between 80/100 and 100/100. Two people gave their well-being a rather mediocre score: 50/100. These results were supported by the answers on the James Russel model. The word 'active' was underlined twice, the words 'calm' and 'relaxed' three times. 'Happy' was indicated the most, five times in total. Three participants however indicated they felt a bit 'tense', 'stressed' or 'nervous' during the day. In two of the three participants, these feelings were also farthest out on the scale of wellbeing, because they gave themselves a lower score (50 and 85) than the rest of the group.

If we compare these results with the measurement right after the activity, then we can observe a maintenance or even improvement of the well-being of most participants. Four residents obtained the same numbers on the well-being scale (P2 (100), P3 (100), P4 (50), P9 (100)). For two participants (P1 and P11), there was a light raise on the scale of wellbeing (from 85 to 90 and from 80 to 90). In the case of one participant (P6), there was a spectacular raise on the scale of wellbeing, as he indicated a 70/100 after the activity, instead of a 50/100 before. For two participants (P7 and P8), both female and both part of the homogenous

group, we saw a decline in well-being, from 100 to 80. However, this lower figure did not translate into negative feelings, on the contrary. In the James Russel diagram, P7 reported experiencing stress before the activity, while circling afterwards to feel 'serene'. P8 indicated 'happy' before the start of the session and afterwards chose the same word to describe her mood.

The answers on the James Russell diagram also support and explain the raise or maintenance of the participant's mood. Those that indicated sentiments like 'nervosity' and 'tension' before the start of the activity (P1 & P6), now indicate to be 'happy', 'satisfied' and 'relaxed'. The people with AD that were already 'happy' (P2, P3, P4, P8 & P10) or 'active' (P1& P2), and 'relaxed' (P3, P6 & P11) or 'calm' (P3, P6 & P9) before the session, indicated these same words afterwards. One participant also indicated he was more 'alert' after the session (P6).

The positive impact on the wellbeing of the residents is confirmed by the healthcare staff. N1 indicates that 'the participants were very engaging and present, even if they were non-religious. Everybody was interested in the objects that were presented'. N3 explains the objects were a stimulation to share more than usual and that the positive effect of the activity is proved, as they all 'told a lot'.

Although wellbeing was only measured in the short term, and only right after the activity, these results are consistent with previous research. Recent papers from 2017 and 2019 indicate an increase of wellbeing after object handling activities,

especially for people with a light form of dementia.¹³⁴ The result of this research shows the same tendency. 2019 research examined the impact on the wellbeing of people with dementia between a simple refreshment break or an object handling and art viewing activity.¹³⁵ The break had virtually no positive impact on participants, while the cultural activities clearly improved their mood. For activities of reminiscence, the results about the improvement of well-being were less clear. Although a slightly positive impact was shown in 2020 research, that paper itself indicates there is more inquiry necessary in the future to clear out these results.¹³⁶

A very important side note about most of this previous research, is the context in which the activities took place and in which the impact of wellbeing was examined. In some cases, this environment was not particularly researched, or not even mentioned. In most research, the measurements took place in the museum. This specifically had some benefits, as already discussed in the previous chapters. No artefacts or artworks must be moved, the knowledge about them was already present and leaving the nursing home was a pleasant change for some residents. However, by using this strategy, some people with dementia were excluded from this activity, because of very different reasons. Limited mobility, too many incentives or a higher cost price are some of the common ones. Thus, their input was not included in the results of these surveys. As a result, certain target groups may not have been included in similar papers like these for years. As this thesis shows, the positive impact of wellbeing

¹³⁴ JOHNSON, *Museum activities in dementia care*, p. 361-380; CAMIC, *Museum Object Handling*, p. 24-37; CUEVAS, *Reminiscence therapy*, p. 364-371.

¹³⁵ JOHNSON, *Museum activities in dementia care*, p. 361-380; CAMIC, *Museum Object Handling*, p. 24-37; CUEVAS, *Reminiscence therapy*, p. 364-371.

¹³⁶ JOHNSON, *Museum activities in dementia care*, p. 361-380; CAMIC, *Museum Object Handling*, p. 24-37; CUEVAS, *Reminiscence therapy*, p. 364-371.

through reminiscence and object handling activities in the nursing home is similar with the raise of happiness in the museum, or when someone lives with their caretaker.

The impact on the wellbeing of caretakers

Not only the emotions of the people with AD were tracked, also their professional and informal caretakers were questioned. Very remarkable is the beneficial impact of these practices on their mood. In case of all the professional caretakers, we see a rise in their happiness on the scale of well-being. For two of them, their number on the scale climbs with 10 points, going from 80 to 90 (N1) and from 70 to 80 (N3). In case of nurse (N2), we even see a jump of 20 points, from 70 to 90.

Also the answers of the James Russell diagram show this beneficial impact. Two nurses indicated to be 'happy' before the start of the session (N1 & N3). For both of them, that feeling lasted until after the activity. The most striking answer, however, comes from N2, who indicated that she was 'tired' before the start, while after the activity she indicated that she felt 'satisfied'. N3 also shared that feeling of 'satisfaction'.

This feeling of 'satisfaction' is shared by the informal caretakers, who also indicated a positive impact on their well-being. Both informal caretakers maintained their feeling of happiness on the scale and they felt more active and satisfied after the activity.

This general feeling of 'satisfaction' is remarkable, but is probably related to the noticeable positive impact of the session on the well-being of the residents. As a result, all caregivers felt they were an added value. They helped people with AD

and let them flourish, which made them feel better about themselves, whether they were a relative of the resident or a professional caretaker.

The environment

The impact of the location, with both the possible benefits and pitfalls, was examined in detail by this research. In the previous chapters, a theoretical framework was offered, which was also confirmed by the results of the surveys after the activities. 90% of the participants with AD indicated they enjoyed the activity more because it was held in a familiar context. 63% answered that they found it less stressful than an activity in the museum, because they didn't have to move themselves towards an external location. When asked which location they would prefer more, the museum or the nursing home, 90% of the participants indicated their current location, because of very divergent reasons. For 50% of the participants, their home is their favorite location, because it is close by and they don't have to move themselves, which makes it way easier for them to participate. 27% of the people with AD preferred this location, because they feel safer and calmer here than they would in the museum. One of the residents with AD liked the nursing home more, because she found it a more spontaneous location. She can decide at the moment whether she would like to participate and should not have to go through a whole relocation process towards the museum before being able to start.

It is striking that the one person that would prefer the museum as the location for object handling and reminiscence activities, has the lightest form of AD. He indicates that relocation is not an obstacle and that he would find the museum, where a different kind of experience takes place and more objects are present, a nice variation in their daily schedule. One participant indicates the location

doesn't really matter. She argues that both environments have their benefits and that she is open for both experiences.

The benefits of the nursing home environment become clear in the answers of the nursing staff as well. All of them prefer the context of the nursing home. They call it 'more accessible for the residents', and indicate it is more practical and less stressful for them and for the residents. N2 also indicates that the stimuli are limited and more manageable in the nursing home.

When asked about the influence of the environment on the residents, the nurses all indicated that the people with AD were calmer at the care centre, because they are familiar with the environment. The location was even described as an 'added-value' for the activity by all of them, because it made this project more accessible, especially for residents with a limited mobility or a high sensitivity for stimuli. They also indicated that a project in the nursing home was more practical for them than one in the museum.

Another important comment the nurses made, was the lower cost for this activity. Because the activity was offered for free and in the nursing home, they didn't have to pay transportation costs, entrance tickets or a guided tour. Also, less staff had to be deployed than for an outing. In a country with rising poverty rates, especially among the elderly, and high rest home costs, such a low price is very advantageous. The caretakers indicated that when they organize activities that cost extra money, some of the residents drop out because they simply cannot afford the outing. By organising heritage activities within the nursing home, by volunteers or at a lower cost, culture can become more accessible for more residents.

Group dynamics

The poll after the sessions showed a positive impact on the social connections and the internal bonds between the participants. All people with AD indicated this activity strengthens the bond with the other residents. They all preferred the group setting. For most residents, also their bond with the caretakers was stimulated in a positive way. 7 out of 11 participants (P2, P3, P4, P5, P7, P9 & P11) indicated the bond became stronger and the session gave them the opportunity to get to know their informal and professional care takers in a new way. The other four indicated the bond remained the same. None of the participants indicated that the bond deteriorated. Also all caretakers, informal and professional, indicated that the group was an added value. They however also warned that this approach would not be suitable for every person with AD and that some would benefit more from a one-on-one session.

After all, that the caretakers and patients were brought together, created a very interesting dynamic, as they could both step out of their daily role. Very often the caretakers knew much less about the objects, or they did not have the same insights about their beauty, material or shape. This reversed the usual relationship between patient and caretakers, so that the people with dementia looked back on the conversation with pride and also indicated that they had met their caretakers in a different way. Both formal and informal caretakers were able to step out of their care taking role during the conversations. They were focused on having a dialogue, on understanding each other and discussing what they did or didn't know yet or agree upon.

It is very clear that this activity is also a stimulator for social contact. As discussed in the first chapter, social isolation and limited conversations can accelerate the

development of AD. In the rush of their day, caretakers might not always have time for a little chat. In addition, there is sometimes a lack of topics to talk about. By bringing objects to the nursing home and putting everyone around one table, more time can be consciously made available to listen to each other. This is not only beneficial for the well-being of all participants, but can also help delay dementia and maintain, for example, the ability to speak and listen.

Also, the objects itself, and the conscious selection process behind them, played a role in the group dynamics during the talk. I could observe among others the following:

The objects

Based on an axial analysis of the recordings and the answers of the survey, we can distinguish three categories in the objects that were offered during the activity.

The first category are the objects that were known by all participants, even if they are not religious or have memory issues due to a moderate diagnosis of AD. The following artefacts were part of this category: the rosary, the church booklet, the candles and the little Mary. For these objects, the method of reminiscence clearly worked for most people. Very soon, the participants explained me the use of a rosary, the practices around candles and they told how they brought a little statue from Lourdes themselves. At first sight, there was also no difference between the homogenous and heterogenous group when it came to group dynamics, except perhaps that the conversation in the homogeneous group was a bit more serene.

When conversations were held about these known objects, the same dynamics always occurred: Since everyone knew the object, the participants who were most talkative took the lead, after which their stories were confirmed and small additions were made by the more silent or less confident participants. P6 for example, who was a history teacher before, was very confident of himself and gave an entire explanation and determination of the objects he had recognized on the table. As a result, participants such as P5, whose speech, according to the nurses, had deteriorated sharply in recent weeks due to AD, became insecure and had less time to organise and formulate their thoughts in peace. These dynamics were already clear during the conversation, which ensured that an attempt was made by the caretakers, the moderator and ultimately the residents themselves to also involve quieter participants in the conversation.

We see similar dynamics for other objects, the catechism in Braille and the educational poster. These were not known or recognized by all residents and therefore, the lead in the conversation was soon taken by the participants that could identify the object and had vivid memories about it. Although recognizing the objects was never the main goal of this activity, the dynamics of the conversation quickly evolved in that direction, as participants who knew the object prevailed.

These events made two things very clear: First and foremost, that this gradient is not necessarily exclusively negative for participants who do not know or recognize the objects. They indicated that they liked to learn about the subject for participants that do know it, they often tried to catch up and they entered into discussion with the rest of the group on the basis of critical questions.

In addition, it was also noticeable that if the caretakers perceived discomfort or doubt in a resident, because he/she couldn't remember the object, they were

very capable to ask questions to calm them down or make them more confident. During these moments, the conversation shifted towards a discussion about present, subjective observations, about the beauty, the design or the feel of an object. This was specifically the case with the catechism in Braille. As none of the participants was able to read what was inside, and only a few were certain about the original purpose of this booklet, the conversation soon shifted to the tactile capabilities of the object. People told how they liked to touch the braille, how it calmed them down and how they believed it was great that blind people were able to read thanks to this invention.

Another interesting observation about the Braille Catechism deals with the very unique character of this object within the selection. It is the only object with such a limited visual stimulus, as it contains no figurative representation or text, which changes the incentive for the topic of conversation. When the object was first shown to both groups, some residents new it was a booklet in braille, but nobody could tell what it was about. When I dropped the name catechism, a different kind of conversation was opened. Nobody started talking about the look, the feel or the use of the object, as they did for the other things, but the conversation suddenly turned to the possible content of the book. Because most participants had to memorize their catechism when they were younger, the substantive discussion was also much easier. Several participants, even some with a moderate form of AD, started to recite their catechism by heart. Many caregivers were very surprised by this, but actually this event mainly shows the effectiveness of the reminiscence method for some residents.

I remarked the same dynamics for old church songs. When a little maria was shown, one of the participants with a moderate form of AD started singing eucharist songs about the holy woman. Several residents spontaneously started

singing along. Because the chorus of the song was fairly simple, the other participants of the heterogeneous group, and therefore also the people who did not know the song, were able to join in.

Both cases show the willingness of people with dementia to continue learning. They also show that simple stories, songs or asking the right, open-ended questions enable us to involve the whole group in the conversation, even if part of the group is not familiar with the object. Instead of a medium for exclusion, the object then becomes a potential 'conversation piece'.

The best example of these dynamics is the mourning decoration. In both the homogenous and heterogenous group, none of the participants was directly able to identify this object. In the heterogenous group however, a striking process occurred. After a discussion about the beauty and material object, the participants asked me what the purpose of these plums is. I told them to take a guess and we started a tour de table. It was only the last participant who explicitly thought about the shape of the object, which reminded her of the decoration on the heads of horses during a procession. Another participant picked up on this and thought the color was rather sad for such a festive event. After all, such a headdress usually has brighter colors. Another resident said that the color, black, reminded her of mourning. In the end, through working together as a group, they did something they thought was impossible: they were able to identify the object without my help. This clearly made the participants proud, fostered group spirit and promoted cooperation with each other and their caretakers.

I saw this effect even more pronounced when, if the objects were completely unfamiliar, I had to switch to object handling and multisensory storytelling techniques. This was the case for the pig and the Turkish bracelet. Some of the participants indeed recognized the piggies, but they had absolutely no idea why this object was incorporated into an activity on the topic of 'believe or religion'. Therefore, the main focus of the conversation was about the colour, the beauty and wearability of the object. P9 indicated that she found it such a beautiful object, with a cute colour, and that she had never seen something like this before. P7 directly wanted to wear it and asked whether she could hold it in her room.¹³⁷ Also in the more heterogenous group, the bracelet was a great success. P3 and P4 both called it their favourite object, just like N1 and N3 did.

At the end of both sessions, some participants asked me to explain what the bracelet was and why it was incorporated. To tell them, I used the multisensory storytelling method. I told them pigs were a sign of good luck, in the past also incorporate in new year's wishes or sold in the shape of marzipan as a lucky charm for a new beginning. Some of the people with AD remembered these practices, and shared some memories about it, but others just enjoyed listening to the stories.

I observed the same reaction when I told them about the purpose of the Turkish Bracelet. After a chat about the beauty of it, a lot of the participants liked the colour, shape and material, still nobody recognized this object, and both groups strongly debated whether it was a catholic object or not. P4 and P6 were sure it was a variety on the rosary. P10 also thought it was Catholic, until P9 and her caretaker remarked the shapes of hand and eyes. That made them doubt the Catholic attribution. When I explained the origin of the bracelet and the meaning

¹³⁷ She was later given a new one by the nurses, because she had lost hers.

of the eye and the hand, a lot of people were surprised. They liked learning something new and the story stimulated their curiosity.

Favourite objects

When asked in the poll what their favourite object on the table was and why, all participants with AD, except for one, chose an object they didn't know. One person (P1) indicated the Turkish bracelet was her preference (P1), because she thought it was beautiful and she liked that it was still usefull. Three people preferred the piggy bracelet, because they found it nice to learn something new, found it a pretty object and liked the tactility of it. Two people opted for the cathecism in braille (P6 & P10), because they found it a great invention for blind people that they never saw before. Two people (P5 & P8) found the mourning decoration the most interesting, because they never saw something like this and liked the elegance and feeling of this object. One person had no preference (P11), because he thought 'the total of the objects was interesting, because it offered different stimuli and diversity'. He indicated there was 'always something interesting for somebody'. Only one person selected an object that she knew before (P7), but she had a very good reason for doing so. She picked the rosary, because she lost hers when she moved to the nursing home. She therefore wanted a new one to help her with the prayers.

The importance of beauty, touch and curiosity

The analysis above can teach us a lot. It is striking that almost all participants choose an object they had never seen before. In their explanation, they show that three different arguments were important in their selection.

The first one is beauty. People with AD, just like all of us, like objects they think have a beautiful shape, a striking colour or a nice appearance. They like to have aesthetic objects around, a statement also supported by previous research on art viewing and the recommendations of the focus groups of the Royal Baldwin Foundation.¹³⁸ Although reminiscence is often practiced in the elderly, and especially in people with dementia, they are at least as much in need of a conversation about the beauty or look of an artifact or artwork. Object handling, which responds strongly to these qualities, is the ideal conversation technique for this, but it is not yet widely known, certainly not within the healthcare field. Multisensory storytelling can also respond to this aesthetic need, because it can help focus on the physical and tactile characteristics of an object or offer a new perspective on an image or work of art.

The second striking argument is the tactility of the objects. Different participants indicated that they opted for a bracelet, because they could wear it, or for the cathecism in braille, because they liked the touch of it. Also in the poll afterwards, they indicated the benefits of touch. 54 % of the people with AD indicated that the tactility of the objects triggered different memories. 27% indicated they experienced the objects in a different way because they were allowed to touch them. Also 27% argued they felt more comfortable after touching them and they like the feeling or smell of these objects. Particularly participants with the most severe diagnosis of Alzheimer's within the group indicated this option. Only one participant indicated that being able to touch the objects, didn't change her experience (P1).

This argument shows the importance of the senses, and how important it can be to keep stimulating those, through methodologies and different objects. People

¹³⁸ DE RYNCK, *Kiezen moet kunnen*, p. 3.

with AD experience that their senses are changing, and therefore find it even more comfortable than people without a diagnosis to touch or smell different objects.

A third argument was the stimulation of their curiosity. Especially the two bracelets, the mourning decoration and the catechism were chosen because they were unknown to (almost) the entire group. These objects stimulated more questions and the group also spent more time thinking about them. This demonstrates the power of a technique like multisensory storytelling, as it gave all participants the opportunity to learn in an informal way. This finding also goes against a strong stereotype about people with Alzheimer's: because they seem to forget everything, they are no longer curious and don't eager to learn anymore. However, this activity has proven otherwise.

It is also striking that these arguments didn't have any relationship with the phase of AD, the religion or the background of the participants. They, in the end all used the same motivation, and showed their need for esthetics, tactility and curiosity. This analysis, however, is not that strange as it might seem. The caretakers also chose these same, unknown objects and used exactly the same arguments as the people with Alzheimer's.

The heritage value

Also the heritage value and its impact was questioned. When asked whether it made a difference these artefacts came from the museum, 72% of the people with AD answered it made the activity and the objects more special. Also 75% of the caretakers thought this had an impact, and made the people approach these objects in a different way. A great example was P10, who usually had a

hard time picking up and holding objects, because of his combined diagnosis of Alzheimer's and Parkinson's. Because of the special dimension of these objects, however, he experienced a difference and found it easier to pick up the items. We see a similar result in other research, not only with people with AD, but also with a diagnosis of Parkinson's, MS or ALS.¹³⁹

Another dimension of this heritage value was the heritage worker: an unknown person who brings the objects to the nursing home, guides the session and tells different stories about the artefacts. When asked if people enjoyed this approach and whether the heritage worker was an added value, the answer was unanimous: yes. The arguments for this answer could differ, but the three main reasons were: the knowledge and stories the person brings, the fact that this person is independent and knows different methodologies, and one of the nurses also tells that a new face is always extra appealing. Especially if that heritage expert comes towards the nursing home, it becomes easier to plan these types of activities in the day-to-day operation of a care centre. This was also indicated by the caretakers and residents themselves.

Adjustments & daily operations

To the question 'Was it easy to incorporate this activity into your daily operations?', all nurses and participants answered it was. They all prefer the afternoon, especially between 2pm and 4pm, because residents are the most active then. At this moment of the day, the activity can also be combined with a coffee break afterwards, which gives the opportunity to end the session in a gentle way and to discuss further if the participants wish to. After the both

¹³⁹ COHEN, Henri, GAGNÉ, Marie-Hélène, 'Emotion and object processing in MS, ALS and Parkinson's disease', *Brain Cognition*, 72, 2010, p. 457-463.

sessions, all participants could also give feedback. Some caretakers indicated that the group size was on its limit, especially in the heterogeneous group, as they were afraid that even more participants would not give anybody the opportunity anymore to talk, a concern that I share. Six people with AD and their caretakers is also the maximum recommended in other research, although I also want to nuance this. The ideal group size among other demands on the different characters, different backgrounds, different phases of AD and different needs of the participants. Here too, the secret weapon appears: ask the participants themselves, invite them to indicate their limits and to share feedback if they wish!

When professional caretakers were asked if they would like to moderate a similar activity in the future themselves, only one nurse (N3) indicated she would consider that. Another one doubted, because she believed it didn't fit her rather supportive role. The other caretakers didn't feel comfortable in doing so, although one of the informal caretakers indicated she would like to take her mother with AD to a local museum.

When asked what the caretakers would help in organizing object handling or multisensory storytelling projects themselves, they indicated that a suitcase about different themes, fiches with instructions and an explanation about the different methodologies would help a lot. It would be a great help as well if a heritage worker comes to the museum for a few sessions, so that caretakers have an example and the necessary time to get to know the format.

CONCLUSION

This research on the one hand confirms previous research on object handling and reminiscence, making it clear that both can have a positive impact on the well-being, and in the long term even cognitive decline, of people with AD. Their caregivers also benefit from this type of activity: their well-being increases, they feel fulfilled as a person and in their care task and they also experience less stress due to the specific setting of the activity.

This research also underlines the importance of touch, beauty and curiosity in heritage activities for people with AD. Although, through the partnership with Huis van Alijn, especially this element of tactility may seem easier to achieve for this specific project, it can be valuable for an institution to think about how you can make optimal use of your collection for tactile activities as well. Some examples are given in the second chapter, but the possibilities are endless. They simply require sufficient creativity, and sometimes also people and resources. However, the two other elements are a much more feasible opportunity for most heritage institutions: after all, they are working every day with beautiful and special objects that have numerous stories and knowledge associated with them.

Recent research showed that people without dementia go to the museum:

- out of curiosity
- to learn
- to find beauty, tranquility or a special experience¹⁴⁰

¹⁴⁰ COTTER, Katherine, FEKETE, Anna, 'Why do people visit Museums?', *Visit Motivations*, 1, 2020, p.3-13.

It might not surprise you that, in picking their favourite object, we see the same dynamics for people with AD. After their diagnosis, these desires do not disappear, but because of how we perceive them and take care of them, they are very often not fulfilled anymore. Also in previous research and projects, a part of the people with AD was overlooked, because for them, the transfer to the museum (or any other place) is not always as evident as it likes.

Through the specific setting of previous research, and because museums and its collections remain too often within the wall, the basic rights of an entire group of people were denied.

The best example of the necessity of heritage activities, is another example from the nursing home. After my last session, I packed all the objects and was walking towards the exit to catch my train. On my way to the door, one of the participants stopped me, and he asked me whether he could see the educational poster again, because he hadn't completely understood the explication I gave about it. In about 10 seconds, all the people in the corridor were gathered around me, listening to my story and each other. This shows their interest, their curiosity and their need for these kinds of objects and stories, which increase their quality of life and well-being, even in the short term. Their great attention shows how necessary and welcome these initiatives are in the nursing home.

Every person with dementia is unique, as is every caregiver. This thesis showed the importance of the right context. For some people with AD, a museum visit or activity can be hard, because there are too much stimuli or the displacement to the location causes stress or anxiety. Therefore, it is incredibly important not to ignore these people's needs.

However, this thesis is not a plea to only offer cultural activities for people with dementia in residential care centres, on the contrary. Above all, it wants to be a

call to make those projects as diverse as possible, to actively listen to the needs of people with dementia and their caretakers and to try to meet the increasing diversity in both fields. We must establish more activities outside the heritage institutions, and increase the amount and quality of the one's already existing. I would therefore like to offer the following recommendations to both museums and healthcare institutions:

Don't see diversity as a problem, but as an asset

In the 'Kennisagenda' of the Alzheimer Liga, growing diversity is a point of attention.¹⁴¹ Both among people with dementia and among their caretakers, the amount of people with another gender expression, different religions, or a divergent background, is growing. This research shows that, although some challenges remain, diversity can also be an opportunity for a new approach. As residents and caretakers in nursing homes become more diverse, finding objects with a common ground, what usually happens for reminiscence talks, can be a hard task. This research, however, showed that methodologies of object handling and multisensory storytelling, especially when combined with curious and unknown objects, are great techniques for dialogues. They stimulate curiosity and learning, and are the perfect fit for a more diverse group.

It takes a village... to care for each other

The social isolation of elderly is growing in Belgium, especially for people with AD. However, recent research shows the enormous importance of social contact, for the person's well-being, but also to slow down the symptoms of AD. On the other hand, the focus on heritage communities is growing strongly the last two decades. For example, many museums and heritage institutions today can count

¹⁴¹ STEYAERT, *Kennisagenda*, p. 23-25.

on volunteers to maintain their operations, a characteristic they share with some nursing homes. These volunteers, whether they mainly work in the museum or in a care institution, often have a great interest in general themes such as history and art, or a more specific attention for matters such as religion, sports, music or any other theme. As volunteers, they usually are interested in caring for and helping others. They have the perfect profile for a training in heritage technique and to establish object handling, reminiscence or storytelling practices in a nursing home in their neighborhood. If we can roll out these small-scale projects all over the country, with a few volunteers for every region who receive a one-off training, we can offer these types of projects to people in residential care centers in no time. By working with volunteers, these projects are not only very accessible, but also cheaper to implement and less burdensome for the museums and heritage institutions themselves.

Have a look outside your walls

Having a look outside your walls is a challenge for all of us. During the set-up of this project, it was remarkable how hard it seemed for the cultural and caretaking field to find each other. There is absolutely interest in heritage activities from the care sector, but due to limited accessibility or because they were not known, these projects are not yet part of the operation of most nursing homes. Sometimes there are no initiatives at all on the side of museums or heritage cells. If there are projects, they are often small-scale and limited, because there simply is not enough budget or personnel available. The fact that the few reminiscence suitcases that 'Huis van Alijn' offers, are almost always borrowed, shows that the demand is high and the supply is small and sometimes too unknown.

This thesis is therefore a call to both fields to meet each other, to look at the possibilities and to try to tailor activities as much as possible to the needs of people with Alzheimer's.

We need a great diversity of initiatives that respond to the different needs of people with dementia. Some prefer reminiscing, others are curious about new objects. One can move around easily, the other prefers the museum to come to his / her home. Due to poor hearing or stress to speak, group size and format must also be better adapted to people with dementia and their caretakers. Speak to them, listen to them and think outside the box. Look for formats that are easy to develop, sustainable and reusable. I hope both fields try to remove as many barriers as possible, and hope they will find each other along the way.

Work on meaningful daily activities

People with AD often feel useless or written off by society. If they are approached differently after their diagnosis, or if they are placed in a residential care center with a monotonous operation, this feeling can be reinforced. Involving them in heritage activities not only gives them the feeling that they can give something back to society and their caretakers, but they actually do so. Through their memories they can bring the objects back to life. Or because their frame of reference is partly lost due to AD, they look in a very innovative way at objects that feel very normal and logical to people without AD. By talking to them as a researcher or caretaker, you get a lot of new perspectives. Meaningful activities are thus not only beneficial for them, but also for the cultural and caretaking field in general.

In addition, cultural or spiritual experience can also be given a little more place by means of these types of objects. Due to a transfer to the care center, not all

items from the old house can be taken along, residents can no longer go to the places of worship of their religion and there may be less room to experience their spirituality, whether it be Catholic, Muslim, atheist or something else. By also bringing religious objects or images, they can relive that religion, deepen it, or get to know someone else's. Identity, spirituality and existential questions, which can become confused due to dementia, are given a place again.

Impact on the long term and a broader scale

The impact of this one session, was not only limited to the talk and the day of the project. Afterwards, several people with AD outed their wish to have another session, on a new or on the same topic. Two people with AD visited 'Huis van Alijn' after this project, together with an informal caretaker, something they never did anymore since their diagnosis. Also within the nursing home, they became even more attentive for the importance of heritage, culture and identity. A resident that lost her rosary after she moved there, has now been provided with a new one. The staff is already brainstorming about future topics and projects, also in other departments of the nursing home. This entire project started with one e-mail towards them, and after a few months, they are already creating ideas and impact on the long term.

Speak with and listen to people with Alzheimer's and their caretakers, cherish their diversity and use it as a benefit. Have a look outside your walls, think outside the box and make work of meaningful activities, as they benefit both the caretaking and the cultural field, on the short, but also on the long term. Little projects and alterations make a big difference!

In case you have any questions on this research, or if you would like to receive its transcriptions or results in detail, please contact me through: astrid.julia.r.luypaert@vub.be. As this information contains too much personal, private elements, this will not be shared open access and only be provided for sufficient reasons.

However, please have a look at the little booklet that was made of this thesis.

You find a digital version on my website:

<https://astridluypaert1.wixsite.com/erfgoed-alzheimer>.

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ATTACHMENT 1

This attachment contains an overview of photographs, taken in advance and during the session. All participants gave their explicit consent to be photographed and allowed these pictures to be published.

ATTACHMENT 1



1.1 - Overview of the table setting and the environment of the heterogenous session before the start of the activity. (c) Astrid Luybaert

ATTACHMENT 1



1.2 - All the objects are placed on the table. At the top, you can see the educational poster (rolled up), the blue Turkish bracelet, with next to it the little bible. Under the blue bracelet, we have the bracelet with pigs, with next to it the rosary and the candles. The objects at the bottom are the catechism in Braille, on the left, and the mourning decoration, on the right of this photograph. © Astrid Luypaert

ATTACHMENT 1



1.3- Astrid is briefing some nurses before the start of the activity. (c) Astrid Luypaert



1.4 - All participants fill in the forms before the start of the activity (c) Astrid Luybaert



1.5 - During the preparations of this activity, nursing staff and residents are already interacting. (c) Astrid Luybaert



1.6 - Participants observing the educational poster. (c) Astrid Luybaert

ATTACHMENT 1



1.7 - A participant touches the catechism in braille. (c) Astrid Luybaert



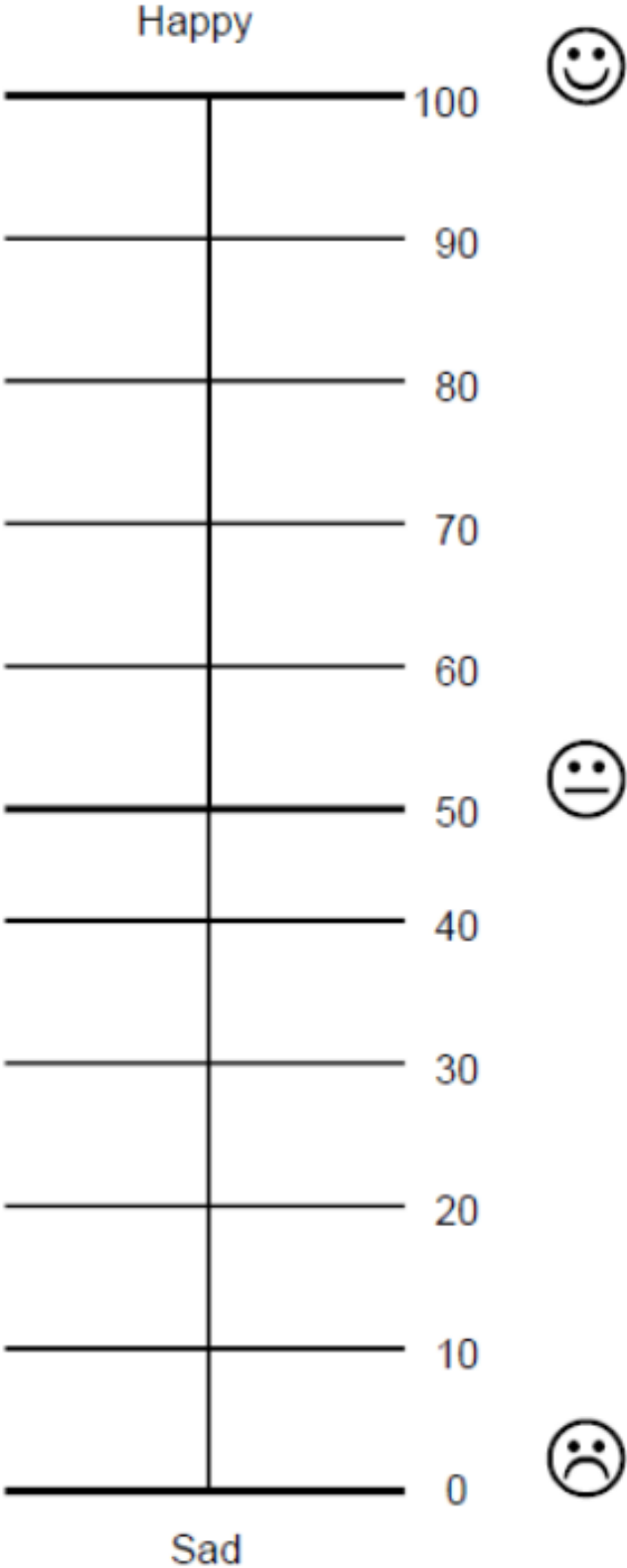
1.8 - The history of this mourning decoration is explained. (c) Astrid Luypaert



1.9 - Residents interacting about the piggy bracelet. (c) Astrid Luybaert

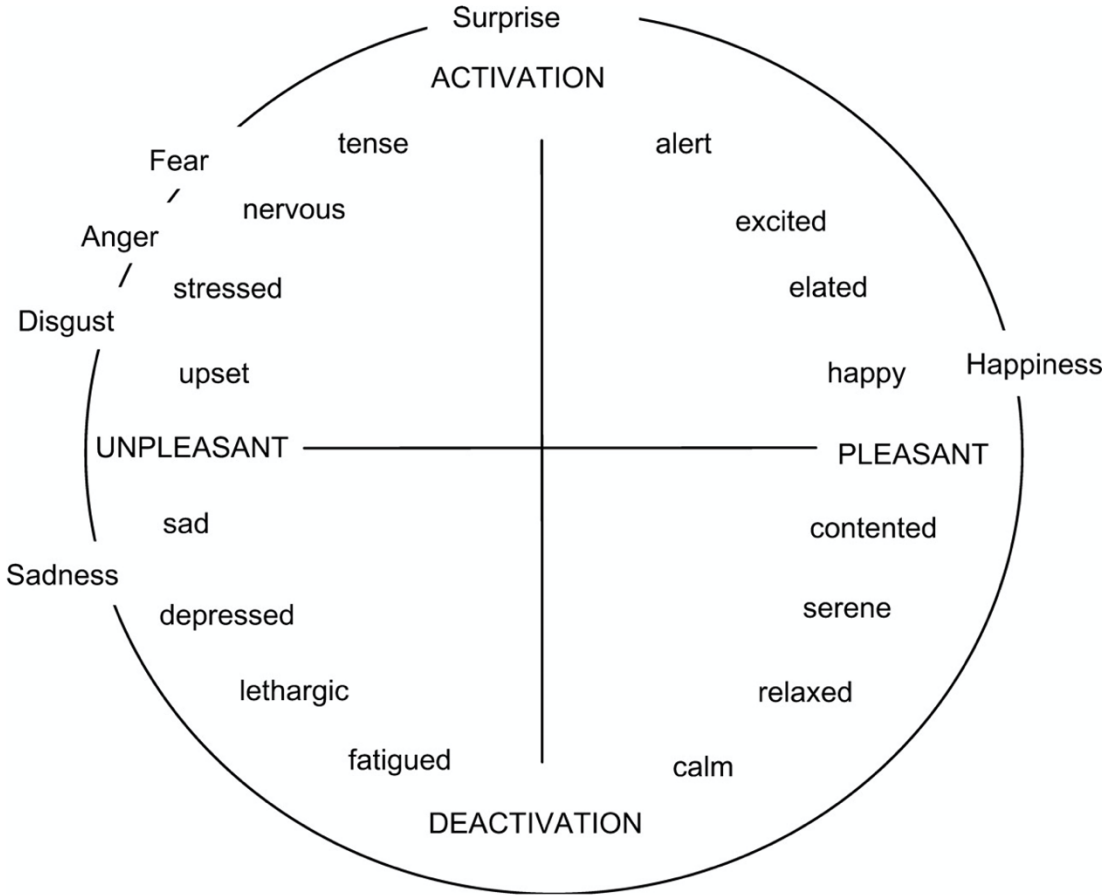


1.10 - A resident explains the use of a rosary. (c) Astrid Luypaert



2.1 - General scale of wellbeing. (c) Astrid Luybaert

ATTACHMENT 2



2.2 - James Russell's Model (c) Pennsylvania State University