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PREFACE

Before you lies the research report which is a part of my graduation project from the studio Health@BK lab within the master track Architecture at Delft University of Technology. This studio focuses on the aspect of healthcare within the architecture and the approach is centred around the user and their participation. Due to the fact that my interest laid in wayfinding of people with dementia, the studio's approach would give me a different perspective, from users and experts, that would enrich the project.

During the research process something caught my eye and therefore I chose to deviate slightly from the original topic, focusing more on how to give elderly migrants the possibility to age safely in the Netherlands. This is a topic that is an issue in the modern society that is often overseen and I believe the improvements can be made through architecture.

This research is a continuation on the documentary 'Thuis voelen in de zorg", where the lack of home-feeling in the healthcare architecture is explained together with the effects that it has on the users. Through this documentary, the idea of how different users experience healthcare architecture at the moment is showed. During this process, it was clear that the improvement on healthcare architecture was needed especially around elderly housing.

I would like to thank my supervisors for their excellent guidance and support during this process. I also wish to thank all the respondents, without whose cooperation I would not have been able to conduct this analysis.

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I. Introduction

1.1 Problem Statement



1_ INTRODUCTION

1.1 Problem Statement

The population of the Netherlands is aging. This well-known characteristic of the present-day's society is caused by multiple factors like low birth rate and improvement of healthcare. The number of elderly population older than 65 was 3,1 million people in 2017 and it is expected to expand to 4,7 million in 2040, which means that more than 25% of the population will consist out of elderly people. Dementia is one of the most common diseases that occurs to aged people. Number of people with dementia will double in size from 154.000 in 2015 to 330.000 in 2040.

Most people with severe dementia are usually situated in a nursing home where they are assisted by caregivers day and night. These are protected facilities, in both urban and suburban context, which are separated from the society and daily life. This leads to several issues such as isolation and loneliness within the nursing homes. Also, isolation simultaneously stigmatizes people with dementia. People who are still living in their homes and capable of functioning are being excluded from society.

However, nursing homes are often not an option for elderly migrants who are suffering from dementia. There are not enough institutions where they can seek help at the moment due to lack of anticipation – the Netherlands is not yet prepared for the considerable amount of dementia patients with migrant backgrounds who has different needs and wishes. This large group of people are excluded from the society and are taken care of by their families who are overloaded because they usually don't get help from professionals. Elderly who cannot get help are forced to return to their respective original countries, they are afraid to age in the Netherlands.

1.2 Relevance

This research will try to portray the importance of the relationship between architecture and how it can provide / create (informal) care for people, focusing on the Asian elderly migrants, in need of care which is an merging problem in the current society.

1.3 Research questions

Main research question

What architectural aspects can help people with dementia of all cultural backgrounds, to live safely with the possibility to social inclusion?

Keywords: Architecture, dementia, social inclusion, (stigma), cultural background

Research questions

- Why is there a need for a dementia friendly design for ageing migrants in the current society?
- What are the activities and elements that have a positive influence on a person with dementia?
- Dementia is a process, how can this be defined and which people are involved in this process?
- What kind of architectural principles are used in the living environment for people with dementia in the Netherlands and how does this affect the social status of people with dementia?

1.4 Methodology

Literature study

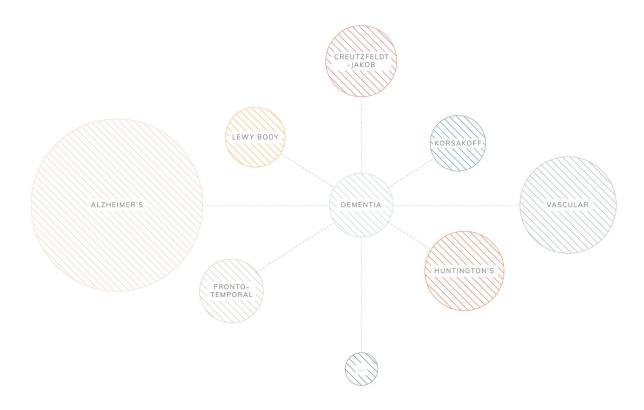
A study based on existing literature to research about dementia and all people involved in dementia (process).

Interviews

An extended interview with the caregiver of a person with dementia and comprehensive interview from people with migrant background in the Netherlands has been held to construct a detailed perspective from the user's end.

Case studies

Case studies of several projects of dementia care to point out the architectural elements that are used in the existing buildings and how they can be modified or improved to create more suitable and stress-free living environment for elderly.



2_ DEMENTIA

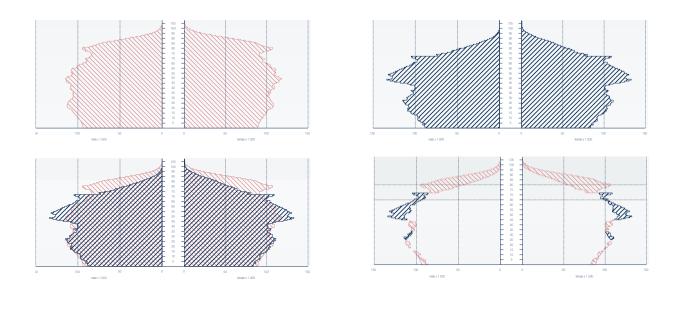
Dementia is not a specific disease. It's an overall term that describes a group of symptoms associated with a decline in memory that affects a person's ability to perform everyday activities. The most common types of dementia are Alzheimer's disease, which account for 60 to 80 percent of the cases, and vascular dementia which is the second most occurring type.

2.1 Aging Society

The population of the Netherlands is aging. This well-known characteristic of the present-day's society is caused by multiple factors such as longer life expectancy, due to improvement of healthcare, the post-war baby boom (1946-1955) which affects the average age of the population and low birth rate. The number of elderly population older than 65 was 3,1 million people in 2017 and it is expected to expand to 4,7 million in 2040, which means that more than 25% of the population will consist out of elderly people. This is an interesting phenomenon which can be found in every modern economies. In countries like Spain, Italy and Germany, South-Korea and Japan, this is a more severe issue considering the rapid escalation rate.¹

One of the biggest risk factor for dementia is age – it is more likely for people to develop the condition as they get older, but it is not an inevitable part of ageing. Around 8% of people that are older than 65 have dementia, increasing to 25% of people that are older than 80 and 40% of the people that are older than 90.

¹Rick de Kruif and Hans Langenberg, De Nederlandse Economie: Vergrijzing En De Nederlandse Economie (The Hague: Centraal Bureau voor de Statistiek, 2017), 3-5. Life expectancy for female is longer than man, which means that female have higher chance of having dementia. Also, because of "dubbele vergrijzing" in the Netherlands, which means that there is a large group of elderly people that are above 80, there is an accelerated growth of dementia patients. As a result, number of people with dementia is expected to double in size from 154.000 in 2015 to 330.000 in 2040.



Population diagram Netherlands according to age and gender, CBS 2019

2.2 History of living environment dementia

The concept of dementia has been around since early civilisations. In ancient society, scientists and philosophers considered mental decay as a normal part of aging. During the late 1800s, medical community gained ability to look inside the brain and analyse with the advancements in medicine. These improvement in medical field gave knowledge that diseases could cause this deterioration. In 1910, the most common dementia was named after Alois Alzheimer, a German psychiatrist. Only later did this symptom come to be commonly known by the more general term "dementia".

Living environment changed drastically over a century for people with dementia. After acknowledging that dementia is not a natural process of ageing, there was a shift in how people with dementia was treated. Before 1900s people with dementia were placed in asylums along with lunatics, maladjusted people, alcoholics, people in crisis and vagabonds. On one hand, these were facilities that were meant to provide shelter for people in need of help, but on the other hand this locked them away and isolated these vulnerable people, who were seen as a part that do not belong in society and have possibility of disturbing the social order.

It was around 1945 when the government decided to provide place for elderly people where they could get help with households and receive medical care. Its aim was to change the position and view towards elderly people through architecture, who were excluded from the society at that time, resulting into social integration of elderly. However, this was not accomplished due to the fact that these facilities were contextually isolated, located in the periphery of the city, where the elderly were seen as strangers. These were usually largely sized buildings that had architectural features of a hospital, distancing the elderly from the society which led to an aversion to moving into such facility. Daily life in these nursing homes were usually spent in bed where they slept, ate, sometimes talked with the visitors and read. The time that people spent in these facilities usually felt more like waiting till the end.

Till late 60's it was common that elderly in the instances were sharing large halls with 30 to 40 others where men and women are separated from each other. Also, married couples were separated without any choice to stay together. Privacy was absent and during the day, there were no organized activities for them.²

Around 80s, architects have tried to diminish the architectural features of a hospital in the nursing homes by bringing in the colours. Also the biggest problem, the isolation due to its location had to be solved and integration needed to be established – architect J.G.A. Heineman pointed this out by saying 'The people

² Miny Vroegindewey, "Ouderenzorg in Nederland," historien.nl, last modified April 4,2011, http://www.historien.nl/ ouderenzorg-in-nederland-door-de-eeuwen-heen/. that live in a nursing home are not a compilation of sick individuals, but we are in need to form a community, where the troubled and the able-bodied – inhabitants – can meet each other. The revalidation model was adjusted to housing model, which led to addition of more single rooms, reduction of the facility sizes, position of facilities and routing, people that lived in these nursing homes were no longer patients but inhabitants.³

Also, it was predicted that the number of people with dementia would expand in size in the near future. Since dementia is not curable, architects have tried to improve the quality of life inside nursing homes which can delay the dementia process. Living in smaller complexes resulted into more satisfied inhabitants and also the usage of medication was minimalized, also caregivers seem to enjoy their work more which led into less burn-outs and higher quality of care.

³ Noor Mens and Cor Wagenaar. De architectuur van de ouderenhuisvesting: Bouwen voor wonen en zorg (NAi Uitgevers, 2009), 93-94

2.3 Stages

There are two ways that dementia stages can be defined, the 3 and 7-stage model. The 3 stage model is universal, meaning it can be applied to all types of dementia, and the 7 stage model is a more detailed model applied only to Alzheimer's disease, which majority of people with dementia has. The 3 stage model can be divided into early, middle and late stage.⁴

Early stage

- Problems are mild and almost unnoticeable.
- Symptoms vary depending on the area of the brain the disease effects.
- For example: Alzheimer's disease affects the area causing memory loss.
- Symptoms may easily dismissed for aging
- Mainly suffers lightly from: problems planning and organizing, problems with memory, mood swings: anger; depression; anxiety, decreased physical mobility and movement, cognitive decline, decreased attention and awareness, hallucinations, problems with speech and/or language, changes in behaviour: inappropriate and/or uncharacteristic.
- Usually takes about 2-3 till detection and early stage lasts about 2 years.

Mid stage

- The changes in the person with dementia are now obvious to people close to them.
- Daily life and relationships are affected.
- Mostly unable to do everyday tasks.

⁴ Alzheimer Nederland, "Dementie fasen Alzheimer Nederland", Retrieved October 1, 2018, https://www.alzheimer-nederland.nl/dementie/dementie-fasen/.

- Frustration, anger, mood swings, and conflicts are common.
- This is often a stressful and busy period for caregivers.
- Mainly suffers from symptoms from early stage along with: difficulty with everyday activities, forgetfulness, confusion and disorientation.
- General symptoms: changes in sleeping pattern, fear and paranoia, changes in behaviour: inappropriate and/or uncharacteristic.
- Usually lasts about 4 years and usually patients are advised to move to a nursing home where they are safer and can get help day and night when needed.

Late stage

- There is extensive damage to the brain by this stage.
- Dementia now affects almost all aspects of the sufferer's life.
- The physical changes are usually severe.
- They become dependent for all activities as mobility decreases.
- Their ability and willingness to talk reduces.
- Their health worsens on multiple fronts.
- Mainly suffers severely from symptoms from early and middle stage along with : difficulty recognizing people.
- General symptoms: Changes in sleeping pattern, fear and paranoia, changes in behaviour: inappropriate and/or uncharacteristic, cognitive decline, decreased physical mobility and movement.
- Usually lasts about 6-9 years.

The process of dementia varies from person to person, but the deterioration process does not develop gradually. The early and middle stages are rather stable in most cases, but in the period between middle and late stage the disease develops rapidly where the patient is not able to live at home anymore. Behavioural and psychological symptoms of dementia described as 'disruptive behaviour' 'inappropriate behaviour' and 'challenging behaviour' is often 1) dangerous for the person suffering from dementia or their environment, 2) stressful, frightening or frustrating for the patient, caregiver and others, 3) socially unaccepted or isolating.⁵

⁵ Paul Jeroen Verkade et al., "Geagiteerd Gedrag Van Dementerende Ouderen," Onderzoek & Praktijk 3 (2007).

The most occurring change of characteristic for people with dementia is described as following in the NVVA Richtlijn Probleemgedrag:

6 MEM Ypma-Bakker et al., "Richtlijn Probleemgedrag," Tijdschrift voor verpleeghuisgeneeskunde 26 (2002).

- Agitation: inner nature of restlessness leading to inefficient behaviour, with a strong repetitive characteristic. This can be divided into three subtypes: the motor agitation - where patient can't sit or lay still, wandering around continuously, tapping on the tables, rattling the doors. The verbal agitation - talking continuously, mumbling and the vocal agitation - yelling, shouting, singing, making stereotypical sounds.

- Aggression: patient shows violent behaviours, this can also be divided into two subtypes: verbal aggression involves cursing, swearing, blaming and threatening. Acting aggression striking, pushing, destroying, throwing objects, making threatening gestures, kicking, self-harm.
- Negativism: rejecting help and care, medication and food. Always having Reversed day- and night rhythm: problems with sleeping pattern or agitation during the evening and night time in combination with excessive drowsiness, apathy, lack of initiative during the day.
- Claiming behaviour: asking for attention and help in a way that might cause irritation to the caregivers.
- Petulance: the quality of being childishly sulky or bad-tempered.
- Disinhibition: behaviour that is characterised through its hyperactivity and loss of control. This can be divided into two subtypes: disinhibition of consumption eating without acknowledging that he/she is full, gluttony, voracity. Sexual disinhibition sexual intimidation, overfamiliar behaviour, making obscene gestures.
- Straying behaviour: walking around continuously with a purpose, searching for a route to a certain place, person or activity.
- Collecting behaviour: collecting and stealing / taking objectives.
- Deterioration in public decorum: failure to dress properly and adjust clothing, untidy eating habits, offensive language and gestures, deterioration in personal hygiene.
- Apathy: lack of interest, enthusiasm or concern, not showing emotions and difficult to participate in activities.
- Excessively showing emotions crying or laughing : spontaneously crying or laughing that often merge into each other.

2.4 Dementia and architecture

It is known that dementia changes the brain's ability to function and that it causes memory disorder, ability to think and to reason. However, it is lesser known that it also changes a person's hearing, sight, taste, smell and sense of touch. There are certain architectural guidelines, which can be used for both adjustment to the existing place or design of a new building, to keep people with dementia safe.⁷

Sight

The changes in brain can result into vision-related changes which can cause seniors to lose their ability to comprehend what or who is in front of them and may also alter their sense of depth perception. It is advised to use contrasted

7 "Sensory Changes with dementia", ahavajaa.org, Retrieved October 20, 2018, https://www.ahavajaa.org/ news/1520875846-sensory-changes-dementia

- ⁸ Eckhard Feddersen and Insa Lüdtke, Lost in Space: Architecture and Dementia (Birkhäuser, 2014), 106-07.
- ⁹ Yaroslau Compta et al., "Cerebrospinal Hypocretin, Daytime Sleepiness and Sleep Architecture in Parkinson's Disease Dementia," Brain 132, no. 12 (2009).

tones in the environments to aid perception of surfaces and objects, e.g. walls from floors, toilets from floors, food from plates, chairs from floors etc. Lack of contrast between joins in floor coverings can lead to confusion and danger since a step might be perceived when none exists. This feature can also be deliberately used to disguise the staff door for example. When it comes to lighting, at the age of 75 years a person requires twice the light that a 45-year-old needs to elicit the same visual response. This is crucial due to the fact that older people are more susceptible to slips, trips and falls which makes good lighting critical. Also elderly need significantly more amount of light to trigger the production of melatonin, to prevent day-time drowsiness and night-time alertness. At the age of 75 years a person needs three times the light that a 45-year-old needs to elicit the same circadian response. Few rules for dementia-friendly lighting would be:

- Increase light levels to twice "normal".
- Use daylight whenever possible.
- Expose people to the 24-hour cycle of light and dark.
- Use sufficient "domestic style" fittings to help promote recognition of place.
- Introduce contrast between the walls and floors to avoid confusion.
- Place brightly coloured tape on the edges of steps, highlighting the changes in height.
- Place pictures on doors of important rooms, such as the bathroom and the
- Avoid using fully-glazed walls, these are normal for architects, but not for patients. They might become more disoriented due to different views and reflections that ultimately lead to sensory overload.

Hearing

As in the case of the eyes, a patient could hear everything perfectly, but the processing of those sounds can be malfunctioning. It is advised to avoid excessive noise in the home and large gatherings of people. Hearing is an important sense because it gives them the ability to participate in conversations which prevents a person from getting lonely and feeling isolated. Hearing unknown noises can cause over-stimulation and lead to agitation. People with dementia benefits from good acoustic conditions for multiple reasons such as: improving the quality of sleep (by having a natural cycle of day and night), decrease in the amount of medication, reducing the number of readmissions, improved well-being of care givers and improved perceived performance, being able to participate and communicate which also leads to a better quality of care provided. There are five most significant acoustic issues that needs to be taken account into when creating spaces by architects

- Keep noise sources away. It is better to keep the external sources of noise, such as traffic, away. Spatial layout also needs to take into account of internal sources of noise atria, corridors and circulation spaces, nurse stations, service areas create high levels of noise, discomforting the inhabitants.
- Consider structure and construction.
- Consider reverberation time.
- Improve visibility. People with hearing impairment rely more on visual clues which makes a good lighting crucial. Also they tend to rely more on lip read, which makes talking face to face important and therefore seating should be arranged.
- Use assistive technologies. It must be remembered that the noise created by audible alarms can cause much anxiety and distress for people with dementia, leading into panic.

Smell / Taste

These two senses are distinctive, but they are linked in many ways. Usually, smell is the sense that is affected first by dementia. People with dementia also have a chance to become immune to little changes in smell in the surroundings, which can lead to dangerous situations such as: not being able to detect smoke or not being able to notice that the food is spoiled. On top of this, when taste also becomes damaged, people with dementia might consume spoiled food without noticing it. These situations can be prevented by:

- Keeping the refrigerator and pantry cleared of any outdated foods.
- Securing all hazardous objects or substances, including over-the-counter medications and cleaning supplies.
- Consider providing safe objects for the person to tongue or chew, such a wooden spoon.

Touch

As with other senses, sensitivity in touch decreases. They might not be able to tell whether an object is cold or hot and also it is harder for them to detect pain. Following features are suggested to keep people with dementia safely at home:

- Colour code water faucet handles.
- Place warning signs on the object that can contain heat.
- Avoid sharp edges of furniture, cover the edges if needed and keep the knives out of reach.

Positive influences on dementia

Music (and art)

There has been a lot of research on the relationship between music and the brain. The part of the brain that recognizes music and art is the aspect of brain that remains untouched when it comes to dementia. Music stimulates the brain functions, it can improve movement speed and coordination for people with Parkinson's and for people with Alzheimer's, it can bring back memories. It is known that these elements have positive influence on dementia and therefore it is often used as therapy because of some reasons as:10

- Music evokes emotions that bring back memories
- Musical aptitude and appreciation are two of the last remaining abilities in dementia patients
- Music can bring emotional and physical closeness
- Singing can be engaging
- Music can shift mood, manage stress and stimulate positive interactions

Dr. Muthesius – who works in the field of gerontopsychiatry – mentions that he was fascinated by the experience that when he made music with people with dementia, they were not ill, feeling normal, competent and healthy is an interesting experience for people with dementia as well as for the therapist. The form of therapy depends on the patient and their own experience with music. The goal is evoking memories and not to experience something new. For architecture, it is advised not to make a special music room, which can be disorienting, but to incorporate this in a space where people with dementia spend most of their time.¹¹

Dance

Dance is another feature that can stimulate the brain and have possibility to delay dementia's process. It is proven that the process of picking-up, which is of our fundamental abilities as humans such as to pretend and imitate, a sequence of movements stimulates the brain and that people are capable to solve different problems with easy after a dance lesson. The challenge during these lessons is not solemnly based physically, but also cognitive and emotional. Due to the fact that imitating is a process that transfers, and form a base through repetition which forms the foundation of creating memories and storing them. The place where this activity can occur needs to be free of any obstructions or tripping hazards. This does not mean that a room should be empty, constructive elements can help people with dementia to orient themselves. Promoting movement through dance can offer the chance to stimulate spatial orientation and the accompanying self-awareness, and of course it also helps physically – staying active delays dementia process and ease anxiety or depression.¹²

"5 Reasons Why Music Boosts Brain
Activity", Alzheimers.net, Retrieved
November 11, 2018, https://www.
ahavajaa.org/news/1520875846-senso-ry-changes-dementia

11 Feddersen and Lüdtke, 76-78.

12 Ibid., 80-83.

2.5 Daily Life

Daily life of people dementia is different from people who do not suffer from dementia. On one hand, they have a lot of free time due to their age, but on the other hand this time cannot be spent meaningfully because they lose the ability to perform tasks. Also the disturbed sleeping pattern makes it harder for people with dementia to connect and integrate with the society.

Once they move to nursing home, it is common for them to live in a group of eight people all with dementia. It is usually not possible to continue their lives as they were used to before moving into a nursing home.

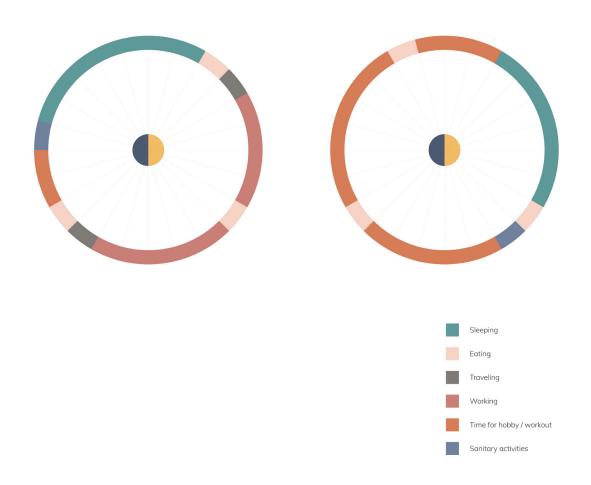
There is lack of activity inside a nursing home, most inhabitants spend 90 percent of daytime sitting or resting, daydreaming and watching tv, which leads to acceleration of dementia process. There are factors such as mobility issues and chronic illness among the inhabitants which explains this result, but there is also lack of meaningful activities – meaning activities that engage the person's attention and connect with their interests – for people with dementia.

Meaningful activities will help to let people with dementia feel a sense of purpose in their day. Other benefits of meaningful activities are:13

- Mental stimulation and cognitive health: slowing down the progression of dementia or even improve cognitive functioning for a time
- Physical activity and general health: activities involving physical exercise have benefits for the overall health and can prevent other health problems and help maintain functioning in activities of daily living and mobility.
- Social interaction: activities facilitate socialization, an important aspect of mental health, preventing person with dementia feeling lonely, isolated and depressed which are most common issues.
- Improved sleep habits: creating a routine for the day improves sleeping at night. It will minimize napping during the day and this will establish a sleeping pattern at night.
- Improvement in self-esteem: self-esteem often takes a beating when someone is diagnosed with dementia. Especially in the early stages people struggle with feelings of incompetence, depression and anxiety. Offering someone an activity that they can still perform can make them experience success, purpose and enjoyment.
- Minimize behavioural challenges: a study shows that there is a significant decrease in challenging behaviours such as shadowing, repetitive questioning, agitation and argumentative interactions when activities that were of interest and at the right skill level were offered to people with dementia.

13 Brenda Smart, "Meaningful work at Hogeweyk Dementia Village," filmed December 2015 at Finnish Institute of Occupational Health, Helsinki, video, 5:39, https://www.youtube.com/watch?v=IvNg2xzLYLY.

- Generally improves quality of life
- Caregivers benefit from it: when person with dementia is engaged with activities that they like, caregivers will be spending less time responding to problematic behaviours and more time enjoying positive interactions with them.



2.6 Target groups

There are many people involved when it comes to dementia during all stages. Generally, this can be divided into two stages: situation where people with dementia still live at home and situation where people with dementia move to a care facility. At the situation where people with dementia still live at home, there are few groups involved (usually non-professional) such as family, friends, neighbourhood and the casemanager. Casemanager is a counsellor for the people with dementia as well as their caregivers who gives information and answers to the questions about dementia when person with dementia is still living at home. He or she visits the home trying to solve the problems that occur after the diagnosis till the patient passes away or moves to a nursing home. Casemanager knows the kind of help a person can get in the region and can help with scheduling the daytime for people with dementia. 15

When a person with dementia moves to a nursing home, the groups that are involved gets much larger and the professionals get involved as well. An example of a nursing home's composition can be described as following:

- care nurses: trained to perform certain amounts of nursing tasks, but mainly caring tasks.
- care nurse plus: increased responsibility to draw up care plans after a multi-disciplinary meeting. He or she also keeps the contact person of the resident informed of any changes in their well-being.
- home supporter: hasn't got a caring or nursing skills, they are mainly based on housekeeping chores, helping to prepare the meal and serving the meal to the residents.
- care-nurse assistant: only has caring skills, works in one of the areas in a nursing home, she organizes her work by walking around in a nursing home and finding out whether there is extra help needed in care.
- physician: he or she is responsible for all-around medical care in the nursing home, but due to the shortage of physicians and the increasing amount of elderly needing care in the Netherlands, the position of a nurse practitioner has been created.
- nurse practitioner: performs 60% of the physician's medical tasks needed for specified residence groups like COPD, diabetes, hart-failure and wound care. Performs triage and attends to the meetings, educates nurses and carers, also works on projects to improve quality of care in general.
- psychologist & social coach: works together. Social coach screens any behaviour difficulty of residents, then advise the team how to approach the residents to their needs and aims to improve how the environment / surrounding approaches the residents.

- ¹⁴ Paul-Jeroen Verkade and Berno van Meijel, "Tien Jaar Casemanage-Ment Bij Dementie," tvz, no. 5 (2011).
- 15 Brenda Smart, "Meaningful work at Hogeweyk Dementia Village," filmed December 2015 at Finnish Institute of Occupational Health, Helsinki, video, 16:47, https://www.youtube.com/watch?v=IvNg2xzLYLY.

- staff-nurse: works on evenings and weekends when the nurse practitioners aren't available. He or she organizes staff during her shifts and sometimes performs triage.
- coach: helping the home teams in organizing any difficulties in care or running the home.
- physiotherapist: helps residents by using mechanical force and movements that promotes mobility and function.

3_ ELDERLY WITH ASIAN MIGRANT BACKGROUND AND DEMENTIA

3.1 Characteristics Asian migrant

The number of people with migrant background in the Netherlands is rising. Around 20% of the total population in the Netherlands consists of migrants and 20% (637.918) of them are Asian. In 2009, there were 166.000 non-western, first generation migrants whose age was older than 55. It is expected that this will expand to a size of 330.000 in 2020. This also means that the number of migrants with dementia will increase from 38.000 in 2020 to 60.000 in 2030. 16

All Asian migrants came to the Netherlands for different reasons since 1910, the most important reasons being work and family. They can be divided into four types:¹⁷

- Group that migrated before 1990 and have lived longer than 20 years in the Netherlands
- Group that migrated between 1990 and 2000 who have lived in the Netherlands for 10-20 years
- Third group that came after 2000. Half of these group consists of students and the other half of people that came for work and family.
- Second generation Asian migrants.

Despite their long history in the Netherlands, in comparison with the four biggest groups of migrants (Turkish, Moroccan, Surinamese and people from Antilles), there is relatively limited data about this group. They are known as the hard-working people that are oriented strongly towards their own community, introverted and barely participating in the Dutch society. Due to the secrecy, this group of people are "invisible". This led to lack of attention and anticipation for these people, making them vulnerable in variable aspects. There are in total 315.282 first generation Asian migrants that are aging and the Dutch

- 16 Alzheimer Nederland, "Cijfers En Feiten over Dementia En Allochtonen," (2010).
- ¹⁷ Mérove Gijsberts, Willem Huijnk, and Ria Vogels, "Chinese Nederlanders," (2011): 22-23.

healthcare system is not yet prepared for these group of people. They have different needs and wishes, due to the cultural differences, a standard Dutch nursing home would not be suitable for them to live in due to difficulties such as language and food.

Linguistics

A considerable amount of first generation Asian people have difficulties with speaking Dutch, or do not speak the language at all. This has several explanation. Firstly, Dutch is less spoken at home, over 75% of Asians speak their native language at home making it harder for first generation to learn Dutch. There is no language barrier for second generation since they are well integrated at school. Secondly, the language courses for Dutch was established around 1990, which means the first generation migrants were most of the times too old to participate in these courses. Another reason is that a lot of Asian migrants came to the Netherlands with the idea that they were staying temporarily, with that idea migrants prioritized learning English over Dutch since communicating in English does not cause difficulties in the Netherlands and is more useful when they return to their respective country. After working for a longer time, they are satisfied with their quality of life in the Netherlands and their children and grandchildren live in the Netherlands which makes it harder for them to return because they are afraid of losing contacts with them.¹⁸

18 Ibid., 62-64.

Elderly Asian migrants who do not speak Dutch and cannot live at home any longer because of their health can't find a place in a nursing home due to the language barrier and are forced to live at home, cared by their families. On the other hand, people who did manage to learn Dutch also have difficulties living in a nursing home. When bilingual individuals of first generation migrants start to suffer from dementia, there is a high chance that they regress to their primary language due to the fact that they have spent their early years in their respective country of origin. This isolates them from the caregivers, who do not speak their language.

The children of these first generation migrants do not necessarily learn to speak the mother tongue of their parents. ¹⁹ This might be a choice that parents make, hoping that their children would integrate better in the society. This causes a problem when one of the parent gets dementia. There is a direct language barrier, which makes the communication between child and parent difficult. The children who do not speak their parents mother tongue leads to a dementia patient who gets isolated. This causes extra stress which adds tension, fear and aggression.

¹⁹ Ibid., 69-71.

3.2 Current situation for elderly migrants with dementia

Migrants and dementia

Migrants usually do not make use of (intra- or extramural) care for elderly. They are often not aware of what types of care there are available for them or the provided care is not correspond to their needs and wishes. ²⁰ The biggest difference between natives and immigrants are that when the problem occurs, natives can easily find someone in the surrounding who were in same position as they are in the past. This way, they can get information and advice that they need that will lead to a solution to their problem. Immigrants do not get this opportunity due to their closed community and dementia has not yet been an issue. The first generation migrants still need to understand the problem and find a way how they can establish a place for people who cannot live at home any longer. ²¹

General practitioners and caregivers that are occupied at memory clinics of hospitals are getting increased amount of elderly migrants with dementia. Due to the language barrier is it difficult to determine the accurate state of dementia of a patient. ²² The first visit, therefore the diagnosis, to general practitioner regarding dementia of an immigrant is often later than when it occurs to a native. One of the main reasons for deficits in the care of migrant patients with dementia is the taboo on the disease and the stigma of the people suffering from the disease. After the diagnosis, it is highly unlikely that they can find a suitable home who can provide and fulfil the needs and wishes that are different from the ones of natives. ²³

This forces migrant people with dementia to stay at home where they are cared by their children. 70% of the natives with dementia live at home and are cared by their family and loved ones in combination with professional care such as case manager and other caregivers. With migrants, the percentage of people living at home rises to 99% and usually they do not make use of professional help which causes a lot of stress and tension at home. The caregivers therefore, which is family most of the time, are heavily overburdened or have a bigger risk on overloading themselves.

For second generation is this a conflicting issue. It is common in Asia, when it comes to dementia, family usually get more distanced from the person with dementia.²⁴ There is general hate and stigmatism for elderly people, that usually live in poverty and causes trouble for many people, leading them to be locked away in a care facility that is invisible in suburbs and they are therefore totally excluded from the society. People with dementia is mostly cared by caregivers and family has a secondary role, visiting them once in a while because of the

²⁰ B Nitsche and F Suijker, "Allochtone Ouderen En Wonen," Geraadpleegd op 13 (2003).

²¹ J Van Wieringen, "Wie Zorgt Voor Oudere Migranten," De rol van mantelzorgers, sleutelfiguren, professionals, gemeenten en ouderen zelf. Utrecht: Pharos Expertisecentrum Gezondheidsverschillen (2014): 13-17.

²² Ibid., 31-33.

²³ Ibid., 16.

²⁴ Cor Hoffer, Allochtone Ouderen: De Onverwachte Oude Dag in Nederland (Stedelijke Adviescommissie Ouderenbeleid (SAO), 2005). long distanced locations of the nursing homes. Knowing this, second generation generally feels even more overburdened caring for their parents knowing that it is not usual for them to take part in caring as primary role.

Return / Stay

Due to the fact that a lot of migrants are afraid to age in the Netherlands, they are forced to return to their countries of origin before they might encounter health issues even if they are willing to stay. It is a difficult choice for them to make due to few reasons. ²⁵ On one hand they are afraid to age in the Netherlands knowing that there aren't suitable nursing homes for them, forcing their families to look after for them knowing that they will become a burden for them. On the other hand, they are willing to stay in the Netherlands due to the fact that: ²⁶

- they are afraid to lose their job and income
- their children and grandchildren live in the Netherlands and they want to keep close contact with them
- they are partially integrated in the Netherlands, making them a foreigner in their respective country of origin and they will have to reintegrate when they return
- they are satisfied with the low-tempo / low-stress lifestyle in the Netherlands

- ²³ Giang Bui et al., "Kleurrijke Vergrijzing," Een onderzoek naar de woonwensen van de huidige en toekomstige oudere migranten in Nederland.
 Eindhoven: Technische Universiteit
 Eindhoven (2011).
- ²⁶ TM Meulenkamp et al., "Kwaliteit Van Leven Bij Migranten in De Ouderenzorg: Een Onderzoek Onder Turkse, Marokkaanse, Surinaamse, Antilliaanse/ Arubaanse En Chinese Ouderen," (2010).









3.3 Asian architectural elements for modified housing

To be able to work on designing a place where elderly with migration background can safely age in the Netherlands, we have to take a look at what the important features are in eastern Asian architecture that can be adapted and translated into the design to meet the wishes and needs of the users.

Housing in the Eastern-Asian countries have different characteristics from housing in Europe due to the different habits and lifestyle that are in some parts visible and expressed in several architectural elements. The traditional architecture is not used any longer in the current society, the wish to live in the big cities (e.g. 50% of the population lives in the capital, Seoul) led to overpopulation in the cities and this resulted into a cityscape that is often filled with high-rise apartment buildings.

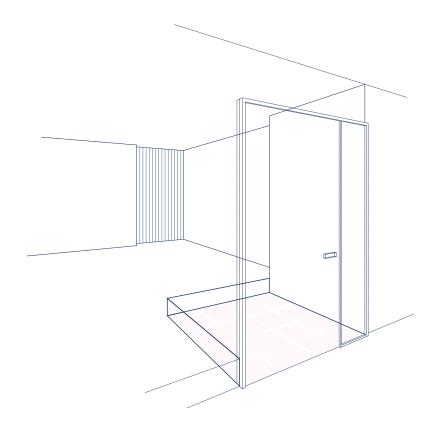
One of the characteristic feature in these modern apartment buildings can be found at the entrance of a housing unit. Since the lifestyle of people in South-Korea or Japan is based around the floor level (meaning that a lot of activities are held at the floor-level and not the chair-level) the most important part that differs is that the entrance is designed to facilitate the act of taking the shoes off before you enter the house. Having the rest of the house lifted from the entrance, the transit from public to private is accentuated. Also, this has a lot of practical reasons such as keeping your floor clean and making floor heating possible, which was a common tradition in Korea. This "step" into the living area also highlights the feeling of "getting home" for a lot of Asian people.

If we take a look at the traditional eastern Asian housing, they have few elements in common. The inner courtyard ("madang" in Korean) is the first area that you see after entering the main gate. It is an open-air area which is surrounded by the house. Around the time where these types of housing was popular, the family size was bigger than in the current society. It was common that three generations shared the same house. The madang was a place that had different atmosphere according to the season or the household. It served as a playground for children, a place to play games on special occasions, a garden or as an extra space to process the harvested fruits and grains in the autumn.

The transit between the courtyard and the surrounding rooms is a gradual sequence of public to private which is enabled through usage of maru. Maru is a raised hallway with a roofing that connects all the rooms in the exterior and it is a space that much works like a balcony in the western apartment buildings when it comes to programme. It is an extended space (it is also always the same

level) of the interior.

When looked at the interior, all the rooms are divided with a wall of sliding doors unlike the common solid walls. By opening these doors, the rooms are connected with each other and the whole interior becomes one homogeneous space. This will help to enlarge the space of small rooms and also will help with creating a clear view inside a house which will benefit a dementia patient since there are no doors that "hides" the spaces behind it.



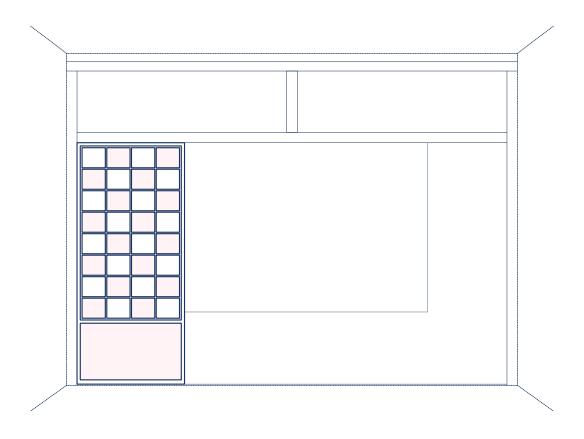
Entrance

Transition from public to private through difference in height Accentuates the "home feeling" and creates a lifestyle around floor-height



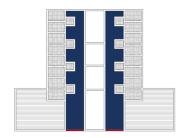
Maru

High-leveled terrace around courtyard Extension of the interior floor that works as a furniture, creating a place for small gatherings and different activities



Midagi

Concept of a wall is replaced by doors that can slide open When the doors are openend, all the spaces within a house are connected which helps with orientation for people with dementia



Pieter van Foreest Delft

1 Locked Entrance
each group

Long Hallway single direction



Nursing Home Groningen 1

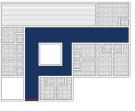
1 Locked Entrance

Long Hallway single direction



Nursing Home Groningen 2 1 Locked Entrance

Long Hallway single direction



Nursing Home Groningen 3 1 Locked Entrance

Long Hallway multiple direction possibility to wander

4_ CASE STUDIES

4.1 Typical Nursing Homes

The following plans are nursing homes drawn from memory of excursion to Pieter van Foreest nursing home placed in Delft. Also the sketches of nursing homes in Groningen that the interviewee, who is a caregiver of her mother that is suffering from dementia, are drawn / explained by her which were options that she got presented with when looking for a suited nursing home for her mother. These examples are group homes for people with dementia for 8-10 inhabitants. There are a lot of similarities between these projects which all have slightly different architectural expression, but generally they share the same concept. All of these group homes consists out of 1 shared living room and 8-10 units of bed / bathroom. In three out of for cases the bathrooms are shared amongst two patients. These units are slightly bigger than a standard bedroom to be able to receive visitation from time to time. These units are usually connected with a long hallway with a locked door at the end. This is to prevent patients to go outside which might bring a lot of risk.

In these group homes, due to its concept of sharing private spaces such as bathroom and living room, the home-feeling is usually absent. The inhabitants are allowed to bring few pieces of small furniture to place it in their bedrooms, but the reality is that the rooms are not big enough to fill with furniture from patient's homes to establish the home-feeling. Also, due to the fact that these people are locked up with other people with the same symptoms, of which are the only social contact they have on daily basis, it brings a lot of stress along with the social exclusiveness of people with dementia. They are not free to go outside and have fresh-air whenever they want and this results into several problems amongst the patients such as feeling lonely and confined which eventually leads into a high-stress level that has negative effects on the disease.

4.2 Hogeweyk Dementia village

Hogeweyk is a nursing home that consists out of 23 group homes where a total of 152 dementia patients can be facilitated. It is one village where the inhabitants are allowed to wander around outside with programmes such as supermarket, hairdresser, café, pub, library, cinema etc. are placed so the daily life that they are used to have can continue within a safe environment.

Inside this village, architectural elements that form a village can be found such as: a little park, boulevard, smaller and bigger squares that together form a diverse exterior where the communication and social exchange between the inhabitants is stimulated.

A lot of existing nursing homes are based on a medical approach, whereas in this village they focus on the continuation of the daily lives of the patients. Even though they still share a group home with 6-7 other people where they have to share a living room and bathroom, people generally feel more at ease and are satisfied with their lives due to the active social life and the freedom. Therefore the problems that occur inside a traditional nursing home such as feeling lonely and confined are less occurring in this village. From a societal perspective, these people are still locked up in this village and are not allowed to go outside and make contact with people without dementia, which means that the patients are socially excluded.

From several studies, it is known that the overall happiness of the patients have a positive influence on the progression of the disease, which means that the process will be delayed and the patients live longer than in a traditional nursing homes. Also due to the fact that they have the required space and programmes to stay active during the day, they take less medication and do not have the problem of sleeplessness during the night. Since the habitants require less attention, this also results into the medical staff being less stressed which helps with the overall quality of care that is provided.





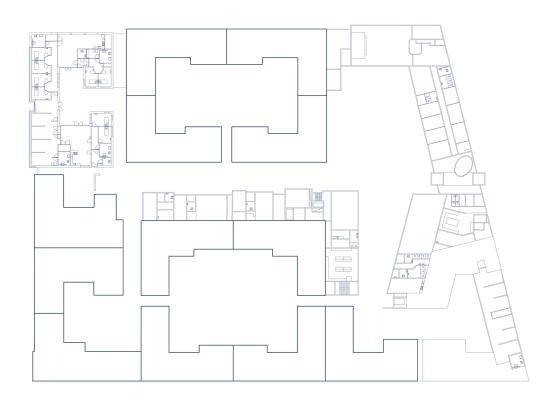






Hogeweyk

Group of 8 units Shared bathroom 2 units Shared living room



HOGEWEYK DEMENTIA VILLAGE - WEESP



4.3 Dementia clinic Sayanomoto

Sayanomoto clinic by Yamazaki Kentaro Design Workshop is a project that is based in Saga, Japan. With the increasing amount of elderly in Japan, and therefore increasing size of population with dementia, a place where people with dementia of early to mid-stages (and their families and caregivers) is created. The main focus of this project is centred around spreading the knowledge about dementia with the aim to establish a place where people can freely talk about mental health without worrying about stigmatism in a casual setting.

Whereas the common healthcare facilities are designed from the perspective and advice of healthcare professionals with intention of creating a place with maximum efficiency of treating the patients, this project focuses itself on "learning" aspect for patients with dementia and their care givers. The "learning" space enables to make a starting point for the visitors with the condition of dementia on any stages.

The waiting room, which can be a stressful environment, is designed like a small library with open façade creating a non-medical atmosphere which helps to diffuse the idea of stigmatism around dementia.





5_ CONCLUSION

This research tried to portray the importance of the architecture in healthcare architecture with people with dementia, also it tried to focus on the Asian elderly migrants and why there is a need for a specialized nursing home for this target group in the current society.

To give answer to the question: What architectural aspects can help people with dementia of all cultural backgrounds, to live safely with the possibility to social inclusion? The research focused on the needs and wishes of different target groups and how architecture can translate those into an architectural language.

Conclusion for nursing homes for elderly migrants

This research consists out of a list of psychological needs and architectural elements that can be used to improve the quality of (informal) care and daily life inside a nursing home. The detailed architectural details can be found in chapter 2 and 3.

Nursing home for elderly Asian migrants:

Privacy / feeling "home"

- Individual "living" space needs to be established (bedroom, bathroom, living room, kitchenette)
- Gradual sequence from private to public where a habitant can have enough "safe" place to wander around
- Physical space that can provides the possibility for the visitors to stay
- Housing with east Asian architectural elements to make the settling process easier

Freedom / informal care

- Provide outside space to take a walk without guidance that can be controlled through informal care
- Usage of small exterior place in clusters of units that can enhance informal care
- Small terrace \prime balcony that is easily accessible for the habitants to enjoy fresh air
- Freedom to make contact with outside world under surveillance, this will enhance the possibility to social inclusion

Professional (informal) care

- Place for staff to exchange ideas and information to improve individual care
- Place where habitants can visit for medical treatment with possibility to talk in their native language
- Restaurant with meals that are adapted to their migration background
- Activities organised / possible in their native language

Programmes

- Cultural specific supermarket, hairdresser, café and restaurants available nearby
- Cultural specific organized (daily) activities such as Tai Chi or tea ceremonies

Social inclusion

- Possibility to make contact with people from outside of different age groups such as: children, students, starters and seniors that don't live in the building
- Make the living area and activities visible for the society
- Share the programmes inside the building with people that do not live in the building

6_ REFLECTION

Interest and motivation

After writing the thesis about sacred architecture, I became interested in way-finding and orientation inside architecture. Then the idea of "what if people do not have the ability to orient themselves inside a building" which eventually led to curiosity towards people with dementia. This was the most important reason why I chose to graduate at Health@BK Lab, that would guide me through the process and provide knowledge and expertise in the healthcare field.

During the research, I was focused on the aspect of social inclusion / exclusion of people with dementia and how architecture could create possibility to fade the stigmatism around the disease and opt for a scenario where people with mental illness can still be socially included.

As the research went on, I discovered that there were group of people, elderly migrants that are ageing in the Netherlands. that were vulnerable, but yet neglected and was becoming an uprising social problem in the current society. Soon, I became passionate about this topic, which was a natural process due to my own migration background, I was designing something for my parents, and even myself, a place that would give them the feeling of assurance and safety to age in the Netherlands where they can go to when in need of care that was cultural specific.

Research Method

The approach of Health@BK which is user-centred and starts with defining wishes and needs from the user's end. Since the starting point of the research doesn't begin with the design principles according to the preferences of the healthcare professionals, the outcome is very different. Also, by involving the

end-user to the design process, the outcome will be a design that is satisfactory to the user.

Through the main research method which was making use of interviews, I was able to track the requirements for the design from the user's perspective which was an interesting approach. The user analysis that was held was with a care giver of someone with dementia, a group's discussion / interview with people in the Netherlands with migration background of longer than five years (the average age of this group was late 40's and they had started thinking about whether they should stay in the Netherlands or return to South Korea to age safely). Lastly, I was very fortunate to have had an occasion to visit my own grandma in Korea where I got the chance to talk and gain insight towards her daily routine / life and learn about important elements and the social status of elderly in Korea.

The process in total was a combination of quantitative as well as qualitative research, which is crucial to make evidence-based design work. Qualitative research method for a user-centred analysis is effective because you can talk about the details and design principles about a certain space from a smaller scale. Quantitative research method is an extension of the qualitative research, where the social - cultural aspect is added to it. Quantitative research also reduces the gap between subjectivity and objectivity where method becomes scientific. To prove that these facts that are extracted from interviews are correct, literature study had been added. To be able to translate the wishes and needs of an user to an actual architectural component / language, a literature study of dementia in general and what design principles are used inside the current nursing homes has been conducted. Whereas the general part of dementia was easy to validate due to the amount of existing studies, the part for the elderly migrants was more difficult to confirm due to the minimal amount of studies there had been done, due to the fact that this is still a phenomena that just had started and was an issue that had been neglected for a long period.

Case studies also helped to enrich the research where I took a look at what the stronger and weaker architectural features were inside the current nursing homes. The research of these nursing homes was a combination of projects that was based on a detailed explanation if nursing homes that the interviewee had visited and also a project that I was able to visit. Also, by studying Hogeweyk dementia village, which is more of a promising project, gave me insight how the design that is based on the user's preference can have an enormously different outcome. This was still a project where the social inclusion of people with dementia was not a focus point, so I decided to search for projects that tried to fade the barrier between people with dementia and the society. As discussed

in the research, Sayanomoto clinic based in Japan is a project that enables the concept of talking about dementia on a casual level, which can have an impact on the stigmatism towards dementia itself. By making this vulnerable group of people visible, and creating a space where people can casually talk about mental illness, a possibility towards social inclusion had been made.

Process / dilemma

After finishing the theoretical research, I knew that the perfect location for this project, elderly housing for elderly Asian migrants, would be in the stadsdrie-hoek near the China Town in Rotterdam. The choice for the location and the program was mainly based on the user's preferences. The only problem that I've encountered was that I couldn't go back to the location for the second time due to the outbreak and the lockdown regarding corona virus. Luckily, I was able to gain a lot of information on the first time I've visited the site and also, there were quite a lot of articles about the and its environment where I could base my design on.

Regarding the design, the biggest challenge was to create an environment for elderly, which is a group of people that is vulnerable due to their physical and mental condition, that would provide freedom for them with the possibility to social inclusion which was also safe at the same time. Finding the right balance between maximum freedom and establishing a safe place for these people was not an easy process. To have programmes that are shared with the society and housing which is private in the same building, preferably by a porous barrier between the public and private to maximize the rich social active life of elderly (where interaction between the elderly and other groups of people such as children, students, starters etc.), was a long process of adjusting and balancing the project.

During the design process, sometimes I made choices based on my own esthetical preferences, but thanks to the my tutors and their feedback, reminding what questions I should be asking, helped me to make right design decisions, I was able to come up with a design that had a balance between the practicality and visuality. Also by constantly getting feedback from the user's point of view, the final result is something that is adapted to the cultural specific preferences and tries to portray a suggestion on how elderly Asian migrants can age safely in the Netherlands where they have the possibility to interact with the society and have a socially active life

7_ BIBLIOGRAPHY

- Alzheimer Nederland, "Dementie fasen Alzheimer Nederland", Retrieved Octo ber 1, 2019, https://www.alzheimer-nederland.nl/dementie/dementie-fasen/.
- Bui, Giang, J Smeets, W Heijs, and Y Witter. "Kleurrijke Vergrijzing." Een onderzoek naar de woonwensen van de huidige en toekomstige oudere migranten in Nederland. Eindhoven: Technische Universiteit Eindhoven (2011).
- Compta, Yaroslau, Joan Santamaria, Luca Ratti, Eduardo Tolosa, Alex Iranzo,
 Esteban Munoz, Francesc Valldeoriola, et al. "Cerebrospinal Hypocretin, Daytime Sleepiness and Sleep Architecture in Parkinson's Disease
 Dementia." Brain 132, no. 12 (2009): 3308-17.
- de Kruif, Rick, and Hans Langenberg. De Nederlandse Economie: Vergrijzing En De Nederlandse Economie. The Hague: Centraal Bureau voor de Statistiek, 2017.
- Feddersen, Eckhard, and Insa Lüdtke. Lost in Space: Architecture and Dementia.

 Birkhäuser, 2014.
- Gijsberts, Mérove, Willem Huijnk, and Ria Vogels. "Chinese Nederlanders." (2011).
- Hoffer, Cor. Allochtone Ouderen: De Onverwachte Oude Dag in Nederland. Stedelijke Adviescommissie Ouderenbeleid (SAO), 2005.
- Meulenkamp, TM, APA van Beek, DL Gerritsen, FM de Graaff, and AL Francke.

 "Kwaliteit Van Leven Bij Migranten in De Ouderenzorg: Een Onderzoek Onder Turkse, Marokkaanse, Surinaamse, Antilliaanse/Arubaanse En Chinese Ouderen." (2010).
- Nederland, Alzheimer. "Cijfers En Feiten over Dementia En Allochtonen." (2010).
- Nitsche, B, and F Suijker. "Allochtone Ouderen En Wonen." Geraadpleegd op 13 (2003).
- Smart, Brenda. "Meaningful work at Hogeweyk Dementia Village." Filmed

 December 2015 at Finnish Institute of Occupational Health, Helsinki,
 video, 5:39

- Van Wieringen, J. "Wie Zorgt Voor Oudere Migranten." De rol van mantelzorgers, sleutelfiguren, professionals, gemeenten en ouderen zelf. Utrecht: Pharos Expertisecentrum Gezondheidsverschillen (2014).
- Verkade, Paul-Jeroen, and Berno van Meijel. "Tien Jaar Casemanage-Ment Bij Dementie." tvz, no. 5 (2011): 51.
- Verkade, Paul Jeroen, Berno Van Meijel, Cindy Brink, Pascalle Schmitz, and
 Rieneke Peijnenburg. "Geagiteerd Gedrag Van Dementerende Ouderen."
 Onderzoek & Praktijk 3 (2007): 38-41.
- Ypma-Bakker, MEM, ER Glas, JHAM Hagens, JGH Hensels, AALM Rondas, ML Saltet, LA Willemstein, and WJFM Bollen. "Richtlijn Probleemgedrag."

 Tijdschrift voor verpleeghuisgeneeskunde 26 (2002): 5-31.

8_ APPENDIX

Appendix A

Interview with a caregiver of a person (her mother in this case) with dementia, her mother recently moved to a nursing home due to the development of her conditions.

Q: Hoelang zijn jullie al mantelzorgers?

A: Ik denk zeker wel een jaartje of tien. Mijn Moeder heeft eerst hier op het pleintje gewoond, hier vlakbij, en ze is toen op bepaald moment naar het huisje aan de andere kant van het park gaan wonen (die ook nabij ligt) en vanaf dat moment hebben we eigenlijk ook heel vaak de boodschappen gedaan, en steeds meer deden we dan in de mantelzorg. Voor de verhuizing viel het wel mee, maar na de verhuizing hebben we dat voor haar geregeld en dat is dan een jaartje of acht geleden.

Q: Ze woonde toen nog thuis, en hoe was de leefomstandigheden toen ze nog thuis woonde eigenlijk?

A: Ja, gaandeweg had ze steeds meer hulp nodig. Bijvoorbeeld met schoonmaken had ze iemand voor, dat hebben wij niet voor haar gedaan, en de boodschappen deden wij, gaandeweg kwam ze eigenlijk niet meer goed koken, dus toen zijn wij voor haar gaan koken en dan maaltijden voor haar ingevroren en we zorgden voor de medicijnen, maar op een bepaald moment heeft de thuiszorg dat overgenomen en die kwamen op het laatst iets van drie vier keer per dag. Langzamerhand doe je steeds meer. We hadden ook een traplift in het huis geplaatst omdat ze moeite had met op en aflopen van een trap. De zorg hebben wij gedaan, maar naarmate het slecht ging, werd dat overgenomen door de wijkzorg. Ze had steeds meer hulp nodig in haar dagelijkse leven waardoor er steeds vaker had ze iemand nodig meerdere keren per dag en drie keer per dag

werd ons best lastig.

Q: Dat is inderdaad heel goed voor te stellen. Kunnen jullie dan misschien meer vertellen over wat er goed was toen ze nog thuis woonde, voor de verhuizing, wat waren de voordelen en nadelen van thuis wonen ten opzichte van een verpleeghuis?

A: Zij wilde natuurlijk ook heel graag zelfstandig blijven wonen, dat was denk ik voor haar wel een voordeel. Ze had nog zelf het idee dat ze zelf naar buiten kon, maar de laatste jaar was dat meer een idee dan dat ze dat feitelijk deed, maar in principe zag ze dat als een voordeel. Voor ons werd het wel steeds lastiger, ook om te zorgen voor haar veiligheid en de veiligheid voor de omwonenden. Dus op een bepaald moment hebben we ervoor moeten zorgen dat ze niet meer zelf iets aan kon zetten wat kan branden (magnetron ect.). We hadden een incident waarbij de magnetron ontploften en elektrisch koken vonden we eigenlijk ook te gevaarlijk voor haar, toen hebben we de fornuis weggedaan zodat daar geen ongelukken mee kon gebeuren. Met de verhuizing, wordt er eigenlijk gezorgd voor haar veiligheid, als ze valt is er altijd iemand in de buurt. Ze kan ieder moment vallen natuurlijk, en ook al woon je dichtbij soms ben je al gauw 1-3 dagen niet en dan is het niet meer veilig om alleen thuis te wonen. In een verpleeghuis is er altijd toezicht, we kregen het niet meer voor elkaar zonder dat we het gevoel hadden dat het goed is.

Q : Dus eigenlijk was het niet meer veilig om thuis te wonen en daarom is er een keuze gemaakt om te verhuizen.

A: Ja, het was niet veilig voor haar en de omwonenden op dat moment. Het is door de buren ontdekt dat er rook uit de woning kwam, en mijn moeder en de buren dachten dat het niet meer veilig was. Een van de keren was het dus ook door de buren ontdekt, dus dachten wij toen "het kan eigenlijk niet zo". Vervolgens was er ook een heel traject ook met de dokter, want die zag natuurlijk ook dat ze steeds minder werd, en ook vergeetachtiger werd, en dan is er team 290 heet dat, een team van psycholoog, geriatrische verpleegkundige, iemand die weet hoe het zit met de regels en zij hebben toen mijn moeder bezocht wanneer ik erbij was en gediagnostiseerd. We hebben steeds gekeken met de dokter en met een contactpersoon gaat dat nog, gaat dat niet, en op een bepaald moment was het duidelijk dat het echt niet meer ging. Toen ben ik met mijn zus verpleeghuizen gaan bezoeken en dat was het dan zo van een uitzoeken waarvan je denk dat is een goede, en dan maar afwachten dat je daar terecht kan. Die "brand", iets dat was gesmolten was met rookontwikkeling, was wel het moment dat we dachten dat we actie moesten ondernemen. Het proces in het geheel gaat heel langzaam, elk keer wordt zij een stapje minder en moeten wij een stapje meer doen tot het moment dat je denkt van "nou kan ik niet meer verder".

Q: Hoelang was het proces al bezig toen ze ging verhuizen naar het verpleeghuis?

A: Ik denk toch wel acht jaar, het proces gaat heel langzaam, na de eerste verhuizing (wat meer een woning was die geschikt was voor ouderen), merkten we pas dat ze eigenlijk helemaal niks meer zelf kon regelen. Ze wist helemaal niet meer hoe je dingen afzegt en aanmeldt, dingen betaald, vanaf dat moment hebben we ook alle administratieve dingen geregeld voor haar, dat bleek eigenlijk ook helemaal niet te willen. Een verhuizing is iets wat ingewikkeld is, maar toen hebben we echt alles voor haar gedaan, op een rijtje gezet en beschreven en dan werd ze wel weer rustig van, maar ze kon het niet meer zelf bedenken. En toen dachten we al van "ze wordt oud", we dachten alleen "ze wordt oud", naarmate gebeuren er toch dingen dat je denkt van "he dat is toch wel bijzonder" en op een gegeven moment krijg je de diagnose, ze had vasculaire dementie, en dat verklaart het heel veel.

Q: Op basis van wat hebben jullie het verpleeghuis gekozen?

A: Wij hebben er drie bezocht, allemaal in Groningen. Wat we daar heel erg leuk vonden was dat je het tuin in kon lopen daar. Het is een begeleide tuin met bushalte voor mensen die dacht dat ze weg moesten. Ze konden daar gewoon de tuin inlopen en in het huis zonder dat ze daarvoor een toestemming moesten vragen. Maar toen we daar binnen kwamen, het interieur was verouderd, er zaten mensen die heel erg ver waren in het dementieproces, het was een lange witte gang met kamertjes waarvan ik helemaal niet goed bij voelde. Tuintje was heel erg leuk, maar het interieur voelde niet thuis aan en het was ook verste weg van ons waardoor we al een snel keuze konden maken. Dichtbij was ons ook belangrijk. Tweede locatie die we hadden bezocht, was ook wat ouder, het waren trouwens alle drie verpleeghuizen met woning waar tien mensen op zitten, je hebt ook een huis voor de dementerende die wat "moeilijker" zijn en dat zijn meestal afdelingen waar mensen zitten, maar dit zijn woningen. Alle drie hadden een huiskamer en elke bewoner heeft een eigen slaapkamer / huiskamertje. Tweede waar we geweest waren was ook zo'n complexje en het was ontzettend gezellig, maar je moest daar wel een sluisje door, je moest een hokje in en dan gaan de deuren achter jou dicht en moest je wachten totdat de deuren naar de woongroep open ging. Hier had je echt het gevoel van, je komt in een gesloten inrichteng terecht. Dat is gedaan omdat er toen een vrouw was weggelopen en overleden was door de kou. Ze waren toen zo geschrokken dat ze dachten van "daar moet extra beveiliging in". Maar dat gaf zo'n onprettig gevoel en toen we daar eenmaal in die huiskamer kwamen, was het ontzettend gezellig. Er waren mensen aan het koken van de verpleging, en mensen die nog wat konden doen hielpen mee, de andere zaten een krantje te lezen en een puzzeltje te doen. Dan heb je vervolgens als je de huiskamer uitloopt een gangetje met kamertjes aan

beide kanten de kamers en net zoals het eerste verpleeghuis had dit verpleeghuis een gedeelde badkamer. Doordat er maar één iemand tegelijkertijd gebruik kan maken van de badkamer, en mijn moede is nogal gesteld op haar hygiëne en maakt ook vaak gebruik van wc, wat een rede was dat we dachten (net zoals bij de eerste verpleeghuis) dat we niet deze moesten kiezen. De derde was de nieuwste van alle drie en ze is ook daar terecht gekomen. Bij de eerste twee verpleeghuizen had je allebei een gang met een deur op het einde die iedereen ziet en weet dat je niet erdoorheen mag. Voor de nieuwe hebben ze bedacht dat de deur niet direct zichtbaar is en de gang is zodanig ingericht dat je rondjes kan lopen, bij de anderen loop je hele tijd die gang op en neer en doordat de deur zichtbaar is het je heel erg een opgesloten gevoel. Toevallig kwam er een kamertje vrij die twee keer zo groot was als anderen en daar is mijn moeder nu terecht gekomen (20m2). Ze heeft een ruim kamer met een mooi venster en uitzicht, en een eigen badkamer. Daar zijn wij zo verschrikkelijk blij mee dat we daarom ook voor deze hebben gekozen voor deze verpleeghuis, het zou best wel problematisch geweest zijn als zij een badkamer moest delen met iemand anders waar je dan natuurlijk het gevoel van privacy niet meer hebt. Mijn moeder was niet overal mee geweest om te kijken maar bij deze hadden we haar wel meegebracht, en omdat het gerenoveerd is en alles nieuw is vond ze het eigenlijk niet erg. Je liep binnen in het gebouw en dat leek op een hotel lobby en zag er loungeachtig uit. Op de kamer was het ook toevallig heel gezellig en werd ze ontvangen en er was een 105 jarige mevrouw die daar zit die ook nog gesprekken kon voeren en het was meteen een klik. Team 290 had ook tegen ons gezegd dat we mijn moeder naar elk verpleeghuis mee moest nemen, maar dat we zelf de keuze moesten maken, als je haar de keuze laat maken kom je er niet uit en dat wordt veel te ingewikkeld voor haar en ook is het zo dat als iemand echt niet wilt kan je ook niet kiezen. Ook denk ik dat het verstandig was geweest. Het heeft anderhalve maand geduurd, vrij snel vind ik zelf. Gelukkig was er snel een kamer vrijgekomen die groot was en toen hebben we tegen mijn ma gezegd "mama nu is er zelfs die grote kamer vrijgekomen". Want ze was wel bang dat het te weinig ruimte zou zijn voor haar spulletjes, maar doordat er een mooi kamer vrijkwam ging het allemaal wel soepel, geen drama.

Appendix B

Interview with Asian migrants in the Netherlands

The following part contains thoughts of eight candidates who originate from South-Korea and have been living in the Netherlands for longer than 5 years, also this was a more of a groups discussion rather than a 1 on 1 interview.

- What was the reason of migration?
- 1. Family
- 2. Work
- 3. Work
- 4. Family
- 5. Study and work, dreams

chose to stay in the Netherlands.

- 6. Work
- 7. Work
- 8. Family and work

Q: Would you like to age in the Netherlands or return to the respective country and what would be the reason?

1. I do not speak the language and would like to return if possible due to the language barrier, but on the other hand if my child decides to stay in the Netherlands, I would prefer to stay together with her. I can see myself returning before I'm 70 or 80 but I feel like after that age it is better to stay in the Netherlands. The reason that I'd go back is to spend time with my parents but when I'm 80 they won't be there any longer as well as my friends. Also I feel like it would be hard to adjust and reintegrate in the society that has changed over the years. Also I have children here which is a big reason for me to stay in the Netherlands.

2. I am satisfied with the situation in the Netherlands and would like to stay. At

- the moment there aren't many facilities where I can go to when I'm not able to live at home any longer, so nursing home is needed. I would love to play games with other Korean elderly and play pool etc. The location of the nursing home does not matter for me, I am willing to move to another city or town since we move a lot anyways and do not have an attached feeling towards neighbourhood.

 3. I always planned to spend my elderly years in Korea and also have my savings there. The option for staying in the Netherlands is open, if there is place for me to grow old, together with people from Korean community which is very important. The problem is that usually all the elderly return to Korea and you're left with no friends in the Netherlands which makes it lonely for the people that
- 4. Personally, I would like to return since the rest of my family members still lives in Korea and I would like to spend more time together with them. Also, I believe that healthcare system in Korea is better and although I speak the language, it's more comforting for me to go to a hospital where they speak Korean so I can specifically talk about details when I age and get sick. The perfect

solution is to "commute" where I can spend half of the year in the Netherlands and the other half in Korea. The problem with this is that the flight takes over 10 hours which is very long and might not be possible when I'm too old.

- 5. Yes and no, I would like to go back temporarily to achieve some goals for myself, but then I am still planning to come back to the Netherlands after that.
- 6. I would like to age in the Netherlands, but if something happens with my family I would like to take care of them in Korea.
- 7. I wouldn't want to live in Korea, my children will be living in the Netherlands and I would like to stay with them. Care for elderly in the Netherlands is better than in Korea when it comes to nursing homes. Also there is stigma for elderly people in Korea which I do not like, they usually live in a poor and isolated environment. They don't have that in the Netherlands, which is also a reason why I would like to get old in the Netherlands.
- 8. I have siblings in Korea and would like to grow old together with them.

Q: Do you feel safe aging in the Netherlands? What if you are not able to live at your home any longer?

- 1. Generally, I do because of the fact that healthcare system for elderly in the Netherlands is better than in Korea. People are willing to help elderly people rather than hating and stigmatizing them. As a Korean, it is hard when I think of a situation where I cannot live home any longer and I don't feel like a Dutch nursing home would be a place where I can feel safe and home.
- 2. I do not feel safe aging in the Netherlands because there is not enough facility for elderly Koreans.
- 3. It is hard to imagine that I would spend my elderly days in the Netherlands, because there are no nursing homes where I can move into when I get older. That has been the reason why I planned to grow old in Korea.
- 4. I don't feel safe when it comes to healthcare system. It is hard to get treatments straightaway in the Netherlands, you need to see a general practitioner first and then you might or not might be able to go to a hospital. In Korea, that is different. You can see a specialist when you want with an easier procedure, also they have better equipment's available for everyone.
- 5. I do feel safe aging in the Netherlands. Generally, there is no stigmatization for nursing homes which is the case in Korea. Not many people are willing to move to a nursing facility in Korea, but here they see it as a natural process of life.
- 6. Generally speaking, it is safe to get old in the Netherlands due to its high quality of nursing homes. The elderly are not socially excluded from the society, they are visible in daily lives of people (the nursing homes are placed where people live and not somewhere in suburb). Personally, I doubt whether I can adapt to a Dutch nursing home.

- 7. Yes, there are a lot of volunteers and the quality of nursing homes in the Netherlands are generally better than in Korea. In Korea, there is a huge gap between the qualities of nursing homes since you have to pay it yourself. I feel like there is room for people to continue their lives and you are allowed to keep your personal interests.
- 8. Personally, I do not feel safe aging in the Netherlands. I am afraid that I can't get any help when I'm not able to live at home any longer and then it might be too late to go back to Korea, so I was planning to go back earlier when I'm still healthy so that I can adapt to life in Korea.

Q: Can you imagine yourself living in a Dutch nursing home?

- 1. Not really, I can't speak Dutch and I do not think I can adapt to the food they serve. But I do feel the difference between Korean nursing home and Dutch nursing home is huge. In Korea, going to a nursing home is considered as a failure and usually the homes are hidden away from normal people. In the Netherlands, they are visible and not separated from the society. It is more perceived as a natural process of life and not a taboo.
- 2. Dutch nursing home will be difficult for me to live in. The culture is different and I don't think there will be room for Korean culture. I do feel like there are more people available for help if needed, but I wonder if there will be any available for me that speaks my language. I also feel like that the care givers in the Netherlands are way more supportive and are prepared to care with love whereas in Korea the staff work because it is their work.
- 3. It would be better than a Korean nursing home, but still the food and language will be a problem. If it that is the only option for me, I would have to accept it if there are nursing homes that are open to Asians.
- 4. No, I don't think there will be any Dutch nursing home where I can feel safe and home due to food and culture. I hope the AI will develop in such a matter where the language barrier wouldn't be a problem. I also am worried that I might disturb other Dutch people with Korean food which they might feel like it's too different.
- 5. No, I would like to continue eating Korean food, and I'm afraid that's not an option in a Dutch nursing home. Also I would like to stay with Korean people around me whom I can talk to.
- 6. Yes, but I would miss the food and people. I am willing to adapt if I do not have any other option.
- 7. Yes, I am willing to adapt if that is needed, it will still be better than most of the nursing homes in Korea.
- 8. No, due to the reasons that are already mentioned.

- Q: Would it be more attractive to stay in the Netherlands when a nursing home specialized for Asian people is provided? And what kind of facilities will be needed in these nursing homes?
- 1. Yes, I would love to go to a such nursing home. Then there is possibility for me to stay in the same country as my child (grandchild). I would like to have a community centre where I can meet people and talk to during daytime.
- 2. I would move to a Asian nursing home when it is provided. I am religious myself, and I would love to have a place where I can continue my religious activities.
- 3. Generally speaking, there are a lot of first generation Koreans that are getting old at the moment and they are willing to stay in the Netherlands. They are not just expats or students that return to Korea, but they are several issues that isn't solved when it comes to nursing homes. I would like to stay if there is a specialized nursing home for Koreans and I would love to have a karaoke.
- 4. Yes. I would like to have healthcare facilities, such as acupuncturist where I can go to and a Korean general practitioner.
- 5. Yes. It would be perfect and I would feel safe aging in the Netherlands, knowing that there is such a facility.
- 6. Yes. I really miss a library for Korean books. It is hard to come by.
- 7. Yes, it would also be nice to have place to educate Korean children.
- 8. I would like to move to a Korean nursing home if I can go there with people that I like. A community centre where we can have Korean activities would be nice to have.