Reflection

"Towards a dementia proof society"

Designing for Care

Rozemarijn Peeters | 4382358
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Introduction

My graduation year has been a very eventful year. Due to the close cooperation with Habion and a stay in a nursing home, it was a very educational but also an emotional year. Stepping into the lives of the elderly is something I would not have wanted to miss. In this paper I will reflect on my graduation project, the process, the research (methodology) and my final design.

Research and Design

The graduation studio 'Designing for care - towards an inclusive living environment' is based on a human centred approach to gain insights in the target group; the elderly. This ethnographic approach was different from what I had learned in my bachelor and master at TU Delft. For the studio, we had to stay a week in an elderly home to fully engage in the everyday life of the elderly. I stayed in Huis Assendorp in Zwolle, a former nursery home which was transformed to house elderly with and without care. Due to this intensive way of conducting research first hand, I have stumbled upon some remarkable findings. For example; the bathrooms that were not suitable for care, the communal spaces that were not used because of their spatial design or the importance of acoustic qualities inside a residential building. It is this kind of research that uncovers the non-physical aspects of the built environment; the importance of good social relationships between residents. On these findings, I developed an important element of my concept; creating a small scale living environment where people get to know each other, live together and is aimed at creating more willingness to take care of each other.

The event that sparked my design goal for this graduation studio appears to be unscientific of character. It was my meeting with one of the residents of the house, Erica. Erica was a resident of Huis Assendorp and was experiencing the first symptoms of dementia. This made her wandering through the hallway at night, knocking on peoples doors, forgetting to walk her dog Dushi and losing her keys (while they were in the handbag she carried the whole day). Because of her dementia, Erica could not stay in her own home anymore but had to move to an enclosed care facility instead. Something I thought to be very unfair, since Huis Assendorp was supposed to be a living environment where you could stay for the rest of your life. As a consequence, the goal of my graduation project became creating an architectural setting in which people with dementia no longer have to move to an enclosed care facility. As this is unfeasible for people with dementia, removing them from their familiar surroundings contributes to the progression of the disease.

In addition to this human centred, ethnographic approach, I also read a great number of books and articles about dementia and healing environments. This helped me in creating a better understanding of the disease and enabled me to create architectural settings which are stimulating to persons suffering from dementia. This part of the research was materialised in the research paper I wrote on healing environments. By researching both dementia and healing environments, I was able to combine both topics in my design (e.g. material choices, importance of daylight).

For architects, location research is also of significant importance. For my graduation project I did an extensive research on the location of my design. Studying the location gave me specific information and ideas for the design which led me to several design tools (e.g. the presence of water, lack of greenery, surrounding buildings). But it is not only about the physical conditions of the location, it also provides information about the location in relation to the neighbourhood and the location as part of the city. All this information can be relevant in composing the design and therefore should not be forgotten. Although this project is designed at one specific location, more general ideas and design tools (e.g. use of natural materials, daylight, colours for recognition) I used for my design are relevant for other design projects.

Research and Design

All the research together (i.e. the ethnographic research, the literature and the location research) created a theoretical framework and gave me starting points for the design (an overview of my approach is provided at page 5). The first starting point was the goal of creating a small scale living environment in which people with dementia could live until they died. In order understand what is necessary for such a living environment, I started with doing more research on dementia and the different phases of the disease process. I made an overview of the four phases and what the persons experiences per phase (see page 6). My next step was to write down 'a day in the life of someone with dementia' and tried to combine architecture (e.g. spaces) with activities. This helped me to understand that the usage of different architectural spaces decreases with the development of the disease, while at the same time the care for these people increases. It made it clear to me that a lot of space becomes redundant with the illness progressing.

These renewed insights I used to further develop my design. I started at a small scale level, looking at what a person needs in their direct surroundings. I looked at what the requirements for a bedroom and bathroom were. Keeping the care in mind, how much space was needed? And how much daylight? But also; what should be possible in such a room (e.g. space for a hoist, storage place for a walker). Then I designed a flexible living unit, in which all these requirements were combined and which could be adapted to the wishes of the resident. As the person suffering from dementia is changing, so can the house.

After designing the private flexible living unit, I moved on to a larger scale; the residential building. How where these units connected and how should the collective space be designed to stimulate living and caring for each other as much as possible. After this I started to look at the other residential buildings on the plot. What will they look like and where do I put the entrances of the buildings? For making these decisions, my teachers pointed back at the research I had conducted. In this way I was able to decide what was best for the target group and thus for my design. For a visualisation of my design approach see image 1 below.

Image 1. A visualisation of the design approach; from small scale to the larger scale
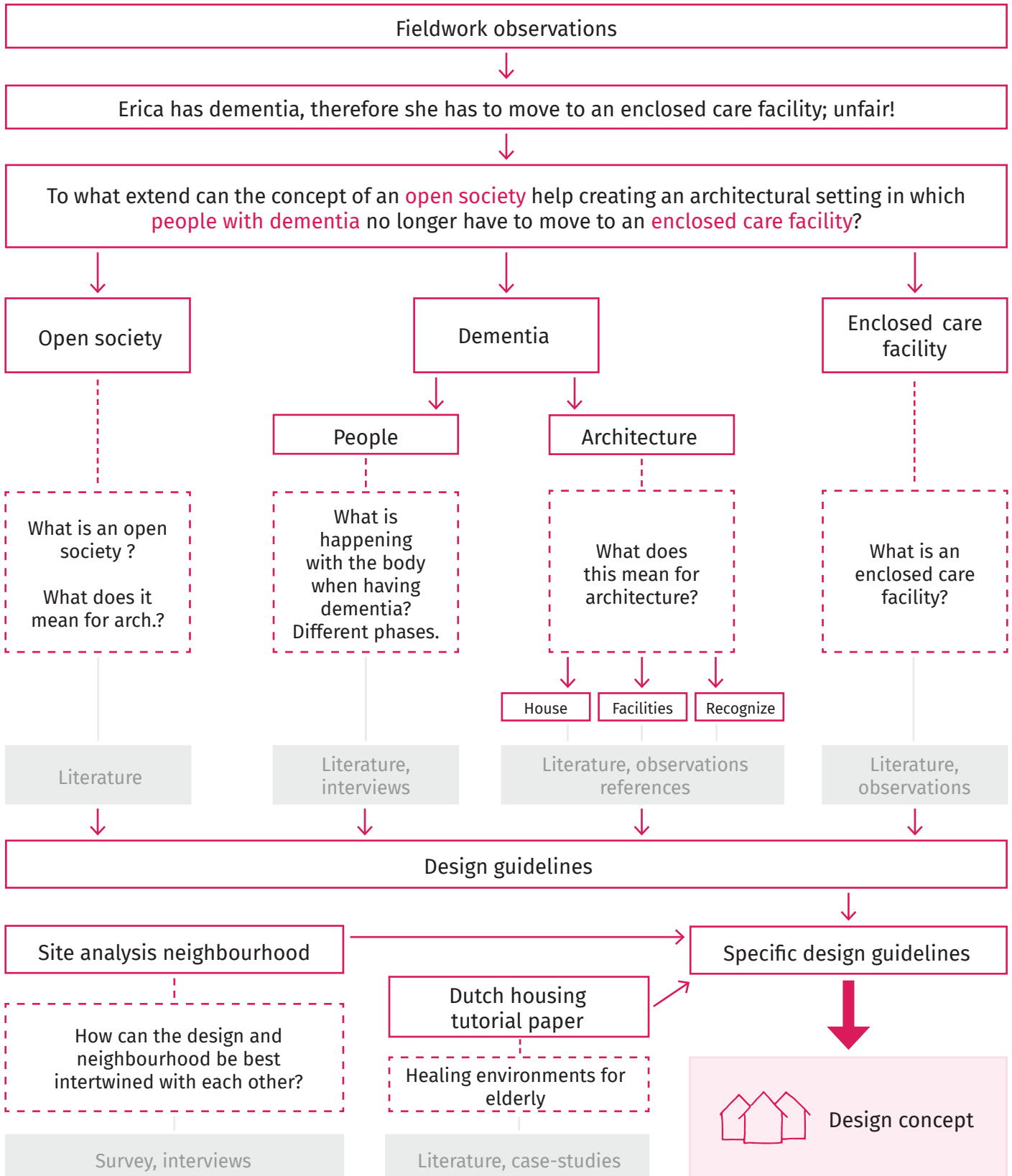
Every time I went up a step, until arrived at the embedding of the master plan in urban fabric. Once I had touched upon the biggest scale, I went back to the smaller scale; from designing the façades towards the smallest details.

Process
Overview of the research

"Towards a dementia proof society"

Fieldwork observations

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Erica has dementia, therefore she has to move to an enclosed care facility; unfair!

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To what extend can the concept of an open society help creating an architectural setting in which people with dementia no longer have to move to an enclosed care facility?

Open society	Dementia		Enclosed care facility

Open society

What is an open society ?

What does it mean for arch.?

Literature

People

What is happening with the body when having dementia? Different phases.

Literature, interviews

Architecture

What does this mean for architecture?

House Facilities Recognize

Literature, observations references

Enclosed care facility

What is an enclosed care facility?

Literature, observations

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Design guidelines

Site analysis neighbourhood → Specific design guidelines

How can the design and neighbourhood be best intertwined with each other?

Survey, interviews

Dutch housing tutorial paper

Healing environments for elderly

Literature, case-studies

Design concept

Dementia and Architecture
4 fases

Four different phases of dementia can be distinguished. Sometimes phases run together, which makes it harder to distinguish. The loss of the 'I' experience occurs on a conductive scale.

	de bedreigde ik (the threatened me)	de verdwaalde ik (the lost me)	de verborgen ik (the hidden me)	de verzonken ik (the sunken me)
TIME	Lives in the present	Mixes past and present	Lives in the past	Lives in inner world
AWARE	Is aware of memory problem and deterioration, tries to hide problems	Limited awareness of memory problem and deterioration	No awareness of memory problem and deterioration	No awareness of memory problem and deterioration
EMOTIONS	Nervous, irritable, insecure, suspicious, angry, sadness and fear. Blame another.	Restless, fear, panic. Often shows emotions. Mood swings. Often 'on their way home'.	Often shows emotions. Mood swings. Cries / laughs for no apparent reason.	Emotions are difficult to perceive.
LANGUAGE	Verbal communication, uses correct words and sentences. Voice expresses emotion.	Verbal and non-verbal communication, problems with finding correct words. Voice is monotonous.	Primarily non-verbal communication. Major problems with wording. Voice melodic and slow. Repetition of words and sentences.	No verbal communication. Voice is weak and soundless.
PHYSICAL	Can perform most general daily life activities himself, sometimes needs help.	Needs guidance with general daily life activities. Sometimes incontinent by accident	General daily life activities must be taken over. Becomes more passive, can no longer walk independently. Incontinent.	Completely dependent on others. Complete passivity. Incontinent.
STIMULI	Conscious of environment	Usually, responds alert to environmental stimuli	Occasionally, stimuli from the environment still come in	Most of the stimuli from the environment don't come in anymore
ORIENTATION	Knows what time of day it is. Knows the way home. Recognizes family / caregivers.	Difficulties with time and day planning. Limited knowledge of way in and around the house. Limited recognition of family and caregivers.	No sense of time. Gets lost in own house and the immediate surroundings. No recognition of family and caregivers	Complete disorientation, has no idea of time, place and person.
OBJECTS	Recognizes the function of objects and uses them correctly.	Collects objects, often loses objects. Does not recognize the function of various objects and does not use them correctly.	A certain object can offer comfort. Hardly recognizes the function of objects.	Does not recognize the function of objects.

Relationship Master

The studio 'Designing for Care' stimulates students to think of new concepts on 'how elderly will live in the future' and is therefore highly relevant for the master of architecture and especially for the chair of dwelling. The increasing number of elderly and thus the increasing number people in need of care is something the current built environment responds very little to. Unfortunately, this is especially true for the elderly that suffer from dementia. Only a small part of this group ends up in a nursing home, the others continue to live at home, in a living environment that cannot meet their changed wishes and requirements. As a result, we, the future architects, have to look into new living concepts that will fit their needs, the needs of the elderly. Starting this search for a solution with a new breed of architecture students from the department of dwelling seems a sensible idea. With recent (scientific) knowledge of architecture and dwelling and fresh insights on elderly care, one has a solid foundation to think of new ways of living for the elderly. As this studio tries to mimic a real life design project as good as possible, the list of requirements is long. Consequentially, a great variety of topics discussed in the master program is touched upon, e.g. analysis of the location, experience of space, relation with immediate surroundings (genius loci), creating a proper floorplan and details.

However, the studio extends beyond the field of architecture. With its human centred approach, other disciplines such as healthcare, anthropology, psychology and urbanism are touched upon and should all be consulted in order to find the answers we look for. Designing for elderly, and especially designing for elderly with dementia, is a multidisciplinary topic and requires a harmonious orchestrated ballet around the subjects. This makes the studio not only relevant for the master track of Architecture, but also relevant for the other tracks. We are in need of landscape architects and urbanists to rethink our urban fabric, making them more healthy and more inclusive to all groups of society and ensure the new living concepts get a proper place in the urban plan. Together with our MBE (Management in the Built Environment) colleagues we must look for new financing models to make these new living concepts economically achievable. Even our colleagues from building technologies should play their role by looking for technical solutions that can improve the lives of the elderly. Only when combining all these disciplines, but also disciplines from other faculties and sciences, together with the knowledge of those working with the elderly every day, we are able to find solutions for this major challenge.

Scientific relevance

The scientific relevance of my project can be categorised in two categories. On the one hand the scientific relevance of the methodology and the other hand, the scientific relevance of the design as it incorporates design features that have not been directed at this target audience before.

The primary scientific relevance of my graduation studio lies in the combined methodology to find a suitable solution. The ethnographic approach that was chosen by the teachers of this graduation studio, combined architecture and anthropology to gain more insight in the target group. This allowed me, as a researcher, to receive first-hand information. The results from my human centred ethnographic approach shows the importance of a clear view on those you design for. In my research paper I further elaborated on how I achieved this. I expanded this beyond the ethnographic approach by combining it with second hand information, both from experts in related fields as well as from research conducted by others. This approach can benefit future research, whether it concerns designing for elderly or patients of any disease, by expanding beyond your own expertise and consulting others, the observations from ethnographic research will be much more valuable.

Furthermore, by discussing your observations with patients, caretakers, doctors and all others involved, more creative and complete solutions are found.

On the other hand, my design is scientifically relevant as it incorporates ideas and design features that have not been directed at this target audience before. By adapting a so called 'healing environment' into a 'caring environment', a proven method is used to offer relief to a different target audience.

In addition insights in disease development can also contribute to the design. By providing an outline of the different phases of the disease and its development, the changing requirements of the building become clear (i.e. the emphasis shifts towards the more private sphere with the disease developing). Additionally, the space has to be of use when a cure for the disease is developed, not only making the building disease cycle proof but expanding beyond the disease, looking forward to a brighter future. Although the development of other diseases can be very different, this principle can also benefit other (care) designers.

Social relevance

The number of elderly in the Netherlands and especially the number of people with dementia will significantly increase over the next decades. In 2050 the number of people with dementia is expected to be over 620.000[1]. Which, compared to 2018, is an increase of 230%! As a result, it is safe to say that this growing number of elderly, together with the challenges it brings, is a nation-wide problem. This studio initiates the thinking of new concepts and is a first step towards resolving a (part of) all the challenges an ageing society lays upon us. As stated before, it is without doubt an interdisciplinary challenge. A challenge which goes beyond mere architecture or design, a challenge which sooner or later will affect us all. The topic is social very relevant and its imminent rather than urgent character has motivated me as a student to expand beyond the paved roads.

In this graduation studio, I focussed especially on elderly with dementia. While conducting research on this topic, it has become clear to me that, unfortunately we still know so little about it and that a cure for the disease is still far away.

Therefore, this group of elderly needs some special attention. In the Netherlands, only people with the heaviest care indication get a place in a care home. This also means that a very large share of those suffering from dementia continues to live at home; in an environment that is not suitable for one suffering from dementia. They fall between two stools. The current system for people with dementia is untenable and in need of new solutions to become future-proof.

By designing a building that is truly focussed on creating a suitable environment for those suffering from dementia and incorporating the current (scientific) knowledge regarding this topic I have hinted how we can further progress in our quest of at least resolving a part of this issue. Of course, architecture alone cannot create this. A different mindset of the co-residents, caretakers and society is needed. Yet, I strongly believe that architecture can create (and is essential in creating) the preconditions that make such a caring concept possible.

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[1] Stichting Alzheimer Nederland. (2018). *Factsheet dementie per gemeente.* Retrieved from https://www.alzheimer-nederland.nl/sites/default/files/directupload/factsheet-dementie-per-gemeente.pdf

Ethical issues

In my opinion, my entire graduation design is aimed at providing (part of) a solution to a number of ethical issues. My design is about dignity and the position of people with dementia in our society. In my design I have tried to give those suffering from dementia a worthy place, in which they are included as a valuable part. Related to this are other ethical issues such as collectivity, inclusivity and freedom.

For the purpose of discussing the ethical relevance of my project, the notion of freedom can be taken as an example. In the current system, elderly people who enter a care home, and in particular those with dementia, are locked up for their own safety. Locking up must prevent people from wandering, running away or getting lost. This is something the care home is liable for, resulting in the so-called 'enclosed care departments'. One not needs to be a philosopher to grasp the unfeasibility of locking up innocent elderly.

Instead of trying to prevent the manifestation, the wandering behaviour, I tried to look at what the underlying problem of the behaviour was. By having knowledge of the underlying causes, you can respond to this in the design. If the underlying cause is tackled in the design, confinement for security reasons is not necessary anymore. Do not lock them up, but encourage them to walk around in the 'safe' environment and ensure a lot of recognition, by using different colours and materials.

Every part of the design is suitable for people with dementia. Everyone has the right to die at home, in their own surroundings. The whole design is made so that people, whatever care they need, can stay in the home and surroundings that are familiar to them. No one deserves to be put away in an enclosed care facility, far away from society.

Conclusion

What did I learn?

The whole graduation year was a great educational experience. My project has learned me a lot about the elderly, their desires and needs, but also the problems they face in their everyday lives. When I started this project, I already knew some parts, experienced with my own grandfather suffering from dementia. However, the fieldwork week at an elderly home expanded my knowledge of elderly. Besides elderly, my knowledge about dementia, the disease and its meanings for architecture has increased enormously. More than ever I realise that the built environment has a huge impact on the health and wellbeing of someone who suffers from dementia, or actually the well-being and health of every living being. This is something every designer should consider in their design. The knowledge about what is good for peoples health and well-being is already there, but it is far from being widely used. Therefore, I would like to start to create awareness of the knowledge there already is and also encourage architects to make use of this kind of information. Using this information is so important in creating healthy buildings and does not every architect want to create something that contributes to the health and well - being of its fellow humans?

This project has allowed me to grow in all aspects, not only personally and professionally, but it also made me realise what I stand for as a person and architect. I want to design for the vulnerable people in society and contribute to creating a healthy and safe living environment. Making the world a slightly better place.

What is next?

In the last phase of my graduation I will focus on creating some impressions of the atmosphere I had in mind for the inside. Although this is a graduation studio within the architecture track, for my target group, the interior of my design is just as important as the outside. Therefore this needs to be addressed in the final presentation too. Besides this, all the drawings need their finishing touches and should all be combined in a design booklet. This design booklet, together with the research booklet, will form a well-documented story of my entire graduation work.