

“Dementia-Friendly design for Aging Couples: An Architectural Perspective”

RESEARCH PLAN

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Dwelling Graduation Studio: Designing for Health and
Care in an Inclusive Environment

Research Plan

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INTRODUCTION

Key words: Dementia, living together, architecture, informal caregiving

■ With the growing elderly population in the Netherlands (in Dutch called 'vergrijzing') this also brings challenges for our existing housing options. Because there are more and more elderly, there is also an increasing amount of people that need care. In particular, the risk of dementia significantly increases with age. In 2015, the government implemented reforms for long-term care to ensure the future affordability of healthcare. To do this, recent policies have been focused on enabling people to live at home for longer. As a result, seniors often rely on services such as home care and informal caregiving (mantelzorg) (SCP, 2017).

Just to sketch an image of the current situation; 1 in 5 people in the Netherlands develops dementia (Alzheimer Nederland). About 68 percent of people with dementia lives at home and gets care from their family or close social network (Cijfers rond Dementie, 2023). There is a total of about 350.000 of these informal caregivers that take care of someone with dementia, with 31 percent dedicating more than 40 hours per week to this responsibility. Half of these informal caregivers live together with the person with dementia. When an informal caregiver can no longer manage the care for someone with dementia, it becomes a significant reason for considering admission to a nursing home or an assisted living facility.

This raises question for the partners of the person with dementia whether they want to move with their partner to a care facility. It is important for the spouse to consider if they can handle to live in an environment with other individuals with care needs (Alzheimer Nederland). In the current healthcare system, there are few options for both partners to continue living together when they wish to do so. According to Zorgkaartnederland, there are 1,735 nursing and care homes in the Netherlands. Out of these, 510 offer apartments for a couple to live together.

As the elderly population continues to expand, it is crucial to explore innovative living alternatives to ease the strain on informal caregivers and the healthcare system.

PROBLEM STATEMENT

- Many elderly couples have been living together for multiple decades, and would like to keep on living together. However, when one spouse starts developing dementia, living together will become increasingly burdensome on their partner that has to care for their partner. As has been mentioned before, there aren't many housing options for this situation. How do you design a complex where some inhabitants need care, and others don't? How do you deal with later stages of dementia, or even the situation where one of the partners passes away? And how can couples still remain a sense of couplehood for as long as possible, instead of a patient-caregiver relationship? These are issues that I have seen multiple times for myself in my surroundings.

The documentary "Uit elkaar" (separated (from each other)) also addresses these questions in a very touching way. It is a portrait of six couples who, as best as they can, try to find a place for dementia in their lives. Dementia changes their relationship; the healthy partner suddenly becomes not only a beloved but also a caregiver. The caregivers lovingly try to adapt to their partner's illness process. However, the care becomes increasingly burdensome. So burdensome that, at a certain point, it is no longer possible to continue living at home. Dementia forces them not only to say goodbye to a loved one but also to a shared life.

More than half of the caregivers for people with dementia in the Netherlands experience moderate to heavy levels of burden, and one in eight even admits to being severely overwhelmed (Dementiamonitor mantelzorg, 2022). New living solutions could make it possible for couples where one faces dementia to maintain their shared living arrangements and relieve the burden on the informal caregiver.

LITERATURE STUDY

■ An important criterion for the literature study that followed from the problem statement, is that it needed to revolve around dementia, caregivers, and architecture.

There has already been extensive research of the ways in which architecture impacts dementia (e.g. Marquardt, Bueter & Motzek (2014); Dirkse & Kroon (n.d.); Kuliga, Berwig & Roes (2021); Marquardt (2011)). In general, they focus on wayfinding, or the orientation ability of people with dementia. Other topics include; lighting, safety, ambience and visual cues. The article by Marquardt, Bueter, and Motzek (2014) summarizes the broad spectrum of research in the field of design for people with dementia. Dirkse and Kroon (n.d.) highlight four themes when adjusting an existing home to make it more dementia friendly; orientation, safety, behavior and freedom of movement. However, these articles do not focus on the different stages of dementia, and how the needs of people with dementia progresses over time.

Other articles are centered around what it is like to live together with dementia, and what the impact of dementia is on the life of both partners. Especially the importance of 'couplehood' for the well-being of both partners is stressed. Various articles provide in-depth interviews with couples where one partner has dementia. For example, the article by Bielsten, Lasrado, Keady, Kullberg, and Hellström (2018) focuses on how couples navigate their lives together and emphasizes the importance of shared experiences and activities. It explores the challenges and opportunities in maintaining a fulfilling life for both partners in the context of dementia.

These routines and habitual practices that make up the everyday life of a couple are referred to as 'habitus' by Gopinath, Peace, and Holland (2018). Dementia disrupts these routines, which couples have had for several decades. All this intimate knowledge that a spouse has of their partner with dementia, is incredibly important to enable meaningful participation and involvement, as well as maintaining so-called 'personhood' of their partner.

The importance of 'couplehood' is also stressed as important to maintain a sense of togetherness and connection as the condition progresses (Hellström, Nolan, and Lundh, 2005), as well as maintaining the wellbeing of both partners (Merric et al.: 2016; Hellström et al.: 2005).

An overview of the articles that have been found, and their main conclusions, can be found in the following image. It also shows the interconnectedness between the literature.



THEORETICAL FRAMEWORK

■ While all the literature reviewed is intriguing and relevant to this research, two articles best encompass the overarching themes of the reviewed literature's results. These two so-called theoretical frameworks are visualized in image 2 and 3. They are also highlighted in image 1.

The article by Marquardt, Bueter, and Motzek (2014) summarizes the broad spectrum of research in the field of design for people with dementia. In this article, a total of 169 studies were identified and categorized thematically into four main groups: basic design decisions, environmental attributes, ambience, and environmental information. Additionally, matrices were used to demonstrate the impact of interventions on the behavior, cognition, functionality, well-being, social abilities, orientation, and care outcomes among individuals with dementia. The outcomes within these categories is also confirmed by the other reviewed literature. The conclusions that have been established in this research can be easily be translated into design guidelines later on in the research.

The same applies to the second theoretical framework which is based on the research of Bielsten, Lasrado, Keady, Kullberg, and Hellström (2018). This research indicates four main themes with related subthemes that could serve as suitable focal points for maintaining a fulfilling life for both partners in the context of dementia. In this research, this is referred to as a self-management guide for couples (see image 3). Some highlights of this research are that couples confirmed the importance of meeting peers but none of the couples has had the opportunity to do so. This framework provides guidelines for the activities that are important for the well-being of both spouses, such as taking a walk, having a connection with the neighborhood and meeting friends and family. Also the importance of doing things separate from each other is important for the well-being of both partners. Additionally to this theme, the article of Gopinath, Peace, and Holland (2018) highlights that many couples make an 'escape' room – somewhere in their home for their own activities.

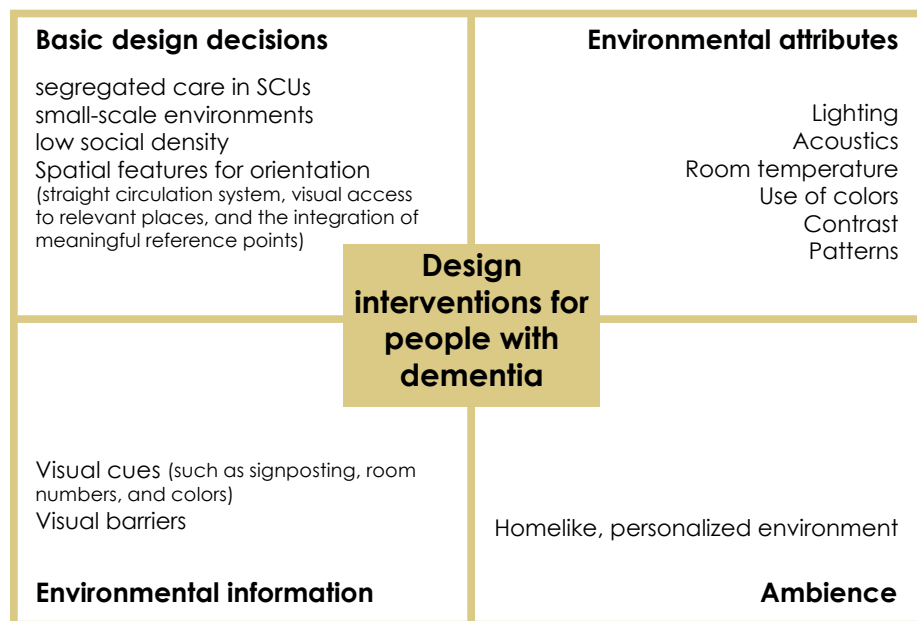


Image 2: Framework 1; design interventions for people with dementia. Based on the findings by Marquardt, Bueter, and Motzek (2014). Made by author.

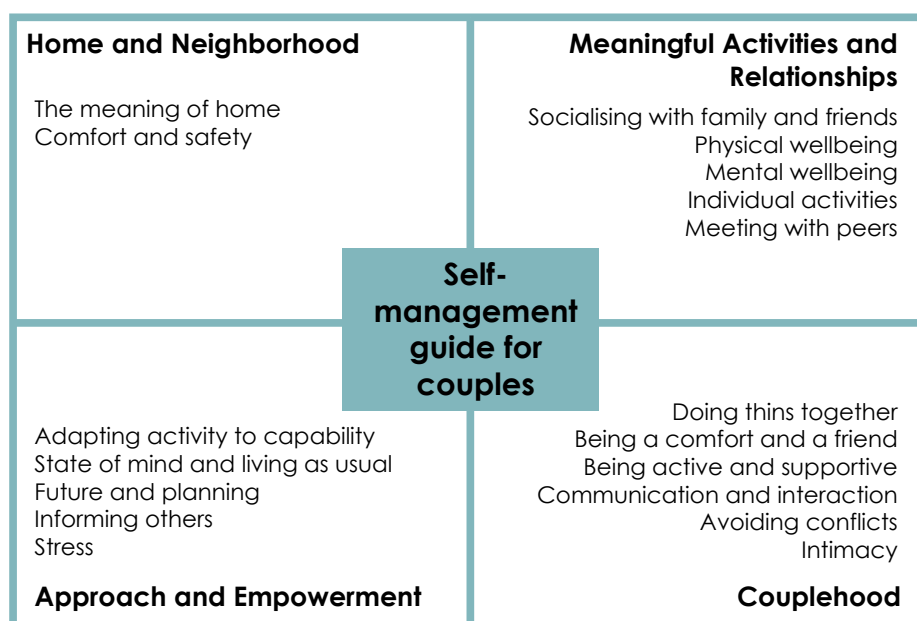


Image 3: Framework 2; maintaining a fulfilling life for both partners in the context of dementia. Based on the findings by Bielsten, Lasrado, Keady, Kullberg, and Hellström (2018). Made by author.

POSITIONING OF THE RESEARCH

The diverse topics found in the literature concerning dementia, architecture, informal caregiving, and living together with dementia can be structured in the presented diagram. This visual representation illustrates the interconnectedness of these themes.

The primary and subsidiary research questions will be derived from these themes, as depicted in the diagram. Although the articles presented in the literature study touch on the theme of 'home,' their primary focus isn't necessarily on architecture. This research aims to concentrate more on architecture and living environmental scale, to present a toolbox for designers.

Although there is separate research on the unique living environmental needs of individuals with dementia, and the themes for maintaining a fulfilling life for both partners in the context of dementia, there is a research gap where these two are combined.

By focussing on the specific scenario of elderly couples where one has dementia, the research seeks to identify and propose design solutions that cater the collective requirements of both individuals. This involves recognizing the needs of the person with dementia while also acknowledging the partner's role as an informal caretaker and cohabitant.

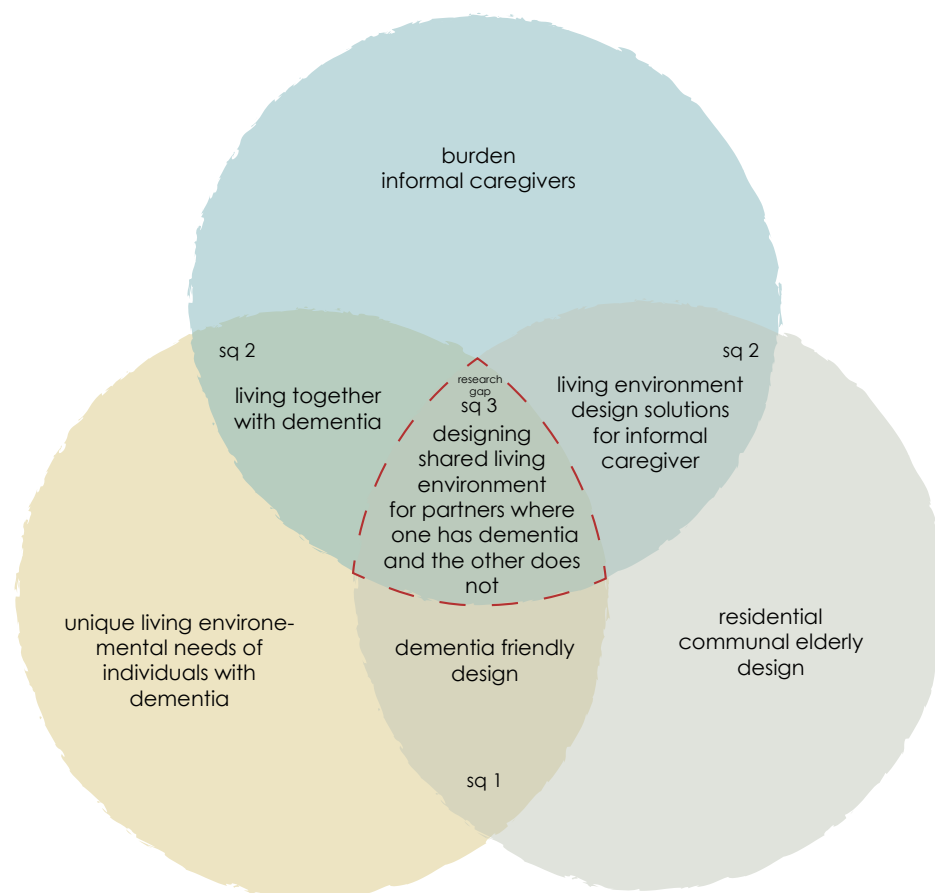


Image 4: Defining the position of the research and the subquestions. Made by author.

■ Research goals

The goal is for this research is to make it possible for the partner of someone with dementia to move with them to a form of a care facility where they can still continue their living arrangements, but where there is dementia care available. It should be comfortable for the partner without dementia to live there, while retaining involvement with the partner in the care of the partner, instead of a caregiver-patient relationship. While a focal point of the research is care and dementia, the main focus will be on architecture.

■ Hypothesis

This research will develop a series of design guide lines that can be implemented into an architectural design. Based on the research so far, it could be beneficial to design a complex of dwellings for couples with similar needs, where care could be closer to home when the dementia progresses. This way, couples could continue their shared living arrangements. With different couples living close to one another, they could find connection by sharing their experiences and offer support when needed. Most importantly, couples continuing to live together and sustain their shared living arrangements could be beneficial for the well-being of both partners.

Care extends beyond mere practicalities like administering medication and aiding with dressing; it embraces a humane approach—where there is attention for the person behind the illness and preserving their sense of self. This is something their partner could help a lot with.

RESEARCH QUESTIONS

■ The main research question for this thesis will be:

What architectural and built environmental features can support elderly couples who wish to live together while one of them experiences dementia, to maintain their shared living arrangements?

To answer this question, I will answer the following sub-questions:

1. What are the different stages of dementia and what are their needs in their living environment?
2. What is the impact of living together when one spouse experiences dementia, and what are the living environmental needs of a person living with a partner with dementia?
3. What kind of living situations do already exist in the Netherlands for elderly couples where one experiences dementia?

■ Research Scope and limitations

Because this research takes place in the Netherlands, the findings of this research might not apply to a wider range of contexts. The problem statement is also specific to the Netherlands, so the problem of couples where one has dementia to not be able to share their shared living arrangements in later stages of dementia, might not be applicable in a different cultural and social context of other countries. The research also only focusses on couples where just one has dementia, and not both. Consequently, the outcomes may not be entirely relevant to that particular scenario.

DEFINITIONS

■ **Architectural and built environmental features**

The main research question gives room for a more broad answer for design principles. Architectural features include the layout, spatial configurations, interior design, and aesthetics. Built environmental features encompass a broader scope; external environmental elements (community, accessibility, infrastructure, green spaces, etc.).

■ **Living environment**

The living environment refers to the immediate surroundings, spaces, and conditions in which individuals or communities reside and interact on a daily basis.

■ **Stages of dementia**

Dementia is just an umbrella term of multiple forms of this illness. Alzheimer's is the most common form of dementia, and therefore I will focus on this type. Alzheimer's can range from mild symptoms to someone being very forgetful and not being able to self-suffice. Because it is not a fixed illness but instead it progresses, I will include all these stages. The Alzheimer's Association distinguished three stages; mild, moderate and severe.

■ **Elderly couples**

Elderly is a subjective term and often used for people who are 65 years or older. Its main traits include unemployment and age-related impairments. (NHS England, n.d.)

■ **Living together**

Living together can mean different things, like living together in an independent home, in a living group or complex, or living together some days in the week, and being apart for other days.

■ **Caregiver burden**

The term 'caregiver burden' is most often used to describe this phenomenon. Zarit et al. (1986) defined caregiver burden as 'the degree to which a carer's emotional or physical health, social life or financial status had suffered as a result of caring for their relative' (p. 261).

RESEARCH METHODS

To answer the research questions, different types of research will be conducted. This segment will elaborate how to implement and execute these distinct research techniques. How each research method is applied to the different research questions, and how they subsequently answer the main question of the research, can be found in the research scheme. The two theoretical frameworks that have been established, will form the base for the fieldwork observations and interviews.

■ Literature study

The foundation of the research will consist of a literature review of books and articles as well as an analysis of existing research, concerning the topic of dementia design and couples living together with dementia. Exact information can be found in the 'Theoretical framework' section and bibliography. The literature review will provide answers to all three of the sub-questions. To find relevant literature, there will be searched using key-words such as 'dementia', 'informal caretaker', 'living together', 'couplehood', and 'architecture'. Additionally, an examination was conducted on the articles cited within the research that was found.

■ Fieldwork/observations

During the fieldwork week I will visit two care facilities for people with dementia. I will also spend the night there to get a complete view of what happens there. Here I will make observations of people's daily lives and routines, and how their partner is involved in their life. These observations will consist of making a timeline of some of the inhabitants, where I will track for each hour of the day what they are doing, to gain an understanding of their daily habits and living arrangements I will also make supplementary sketches of the activities that they do during the day. With these timelines I want to create 'personas' that are a generalisation of someone's life at the care facility. I will also make observations by taking picture series of the fieldwork location, of the aspects of the living environment is specifically designed for the use of people with dementia. For the observations, I will specifically look at the environmental attributes that have been established in the first theoretical framework (see image 2).

■ Interviews

To answer the research questions, interviews will be conducted with healthcare providers during the fieldwork week, with partners/family members of individuals with dementia residing the-

re, and possibly with individuals affiliated with an organization specializing in the subject of caregivers, dementia, and housing. The responses will likely overlap at times, providing complementary information across several sub-questions.

Caregivers of people with dementia

I want to learn from the experience of caregivers what the needs are of people with dementia, specifically in their living environment. This will help answer the first research question. The design guidelines that I will gain from these interviews, I could most likely also find in literature and by making observations of how people with dementia use space (i.e. walking in certain places, taking certain routes, going to the bathroom, etc.).

I would also like to know from the caregivers if they have experience where the informal caregiver of a person with dementia still cares for them, and what kind of arrangements are made where they as a formal caregiver jump in.

Examples of questions are; How could you as a caregiver, work together with an informal caregiver? and; Is it better for elderly individuals with dementia to live at home for as long as possible or is it better for them to adapt to a care facility earlier?

Partners of someone with dementia

With the interviews of a partner of someone with dementia, I want to test the framework that has been presented by Bielsten et. al. (2018). I want to know what activities couples still do together, where they need specialized care and how dementia has impacted the life of both partners. This question will help give answer to the first, but mostly the second sub-question. Therefore, I will ask couples to make a timeline of their day, whether or not they still live together.

Examples of questions are: What is it like to live with someone with dementia? What impact did this have on your life? What were your shared living arrangements before and after dementia?

Dirkse and Kroon (n.d.) of Platform 31 have prepared a manual on how to adapt an existing home with minor modifications for someone with dementia. They also provided a questionnaire to identify potential issues within the home.

family members

Depending on whether the person with dementia still lives in an idenpendant home or care institution, I want to have a conver-

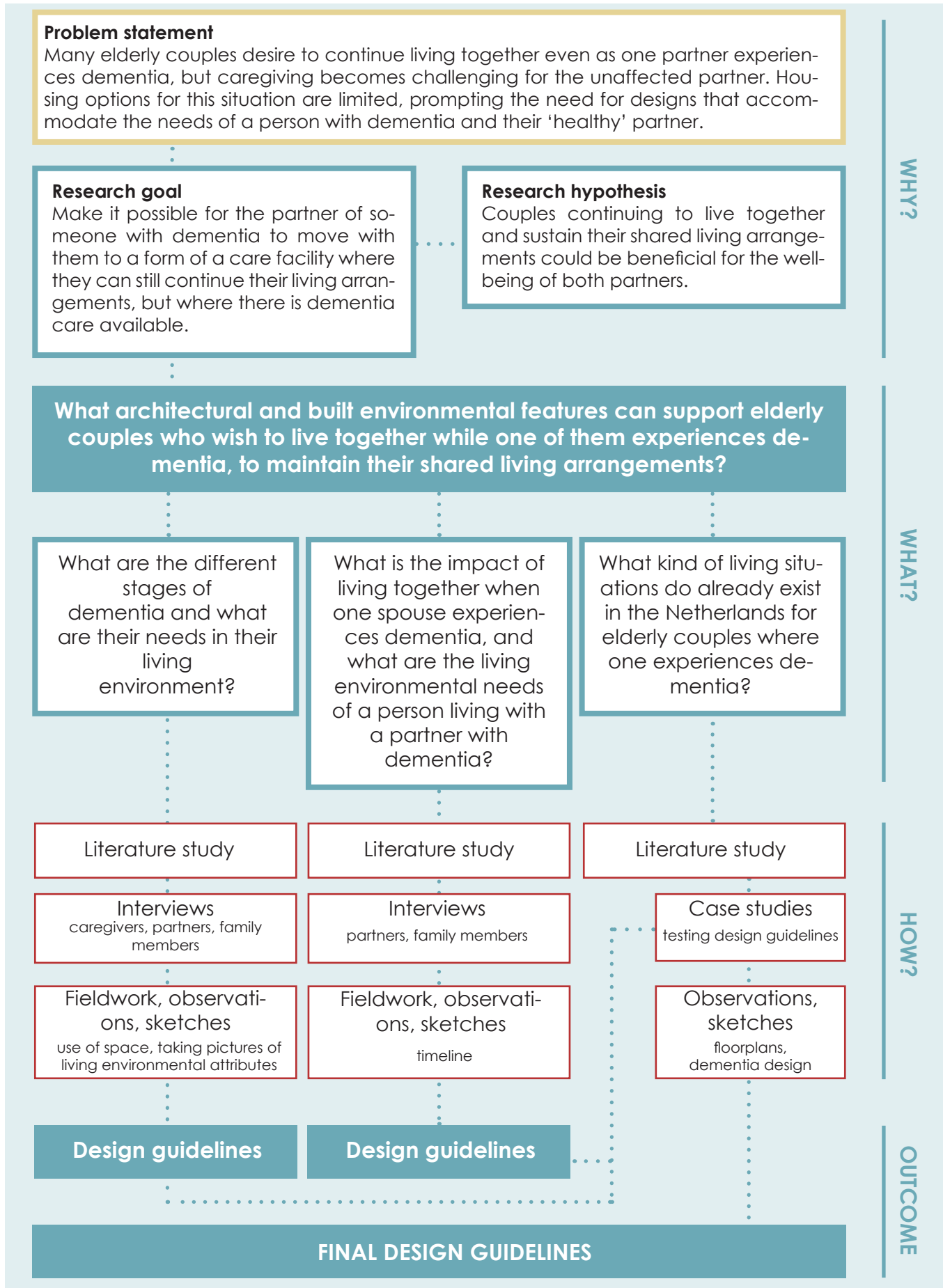
sation with family members of individuals with dementia. Asking questions like; What was the selection process for considering future housing options? Were you looking for options that weren't there (nearby)? These questions will primarily answer the third subquestion, testing if people experience the shortage in living options for couples where one has a diagnosis of dementia.

Organisation that is connected to the topic of this research

I would like to interview organizations such as platform 31 or others to test whether they recognize problem that has been stated and what experiences they have with it. What solutions do they think would work?

■ Case studies

Case studies do not permit generalization per se but may provide insights that can be 'transferred' or 'recontextualised' to other like situations. By testing them on the design guidelines that have been conducted while answering the first and second sub-question, a review can be made about the projects. The selection of these case studies is based on several criteria: the facility must cater to individuals with dementia while also accommodating residences for those without dementia. Ideally, the project includes apartments designed for couples and is situated in the Netherlands. One of the projects that will be analyzed is the Eltheto Housing and Healthcare Complex, designed by 2by4-architects.



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APPENDIX - FIELDWORK PREPARATIONS

Weekplan

We are planning on visiting two different care facilities that are solely for people suffering from dementia. On both locations we will be conducting the same interviews and workshops in order to distinguish differences and / or similarities between the two locations after visiting them (concept, size, type of care, daily routines etc.). In this diagram we have displayed what we are planning to do during this fieldwork week on both different locations.

	MONDAY 13th November	TUESDAY 14th November	WEDNESDAY 14th November	THURSDAY 15th November	FRIDAY 16th November
MORNING	Introduction Tour Location 1 and meeting the residents Observing Day in the life of a space	Observing Day in the life of a resident	Interview Founder Location 1	Introduction Tour Location 2 and meeting the residents Observing Day in the life of a space	Observing Day in the life of a resident
AFTERNOON	 Interviews Family-member(s) of residents	 Workshop daycare Draw your room from memory	Interview Employee(s) Location 1	 Workshop Residents Draw your room from memory	Interview Employee(s) Location 2 Interviews Familymember(s) of residents
EVENING		Workshop Residents Draw your room from memory			

← --- LOCATION 1 --- → ← --- LOCATION 2 --- →

■ Interview questions

These questions are a starting point for the interviews. However, the interview will also be guided by what the person in question has to say. Additional questions will be devised on the spot, which can later be read in the transcript.

We will interview various people, including the owners of the healthcare institution, healthcare workers, volunteers and relatives of residents.

☐ Algemeen

- Wie bent u?
- Wat is uw functie binnen [locatie]?
- Beschrijf [locatie] in 3 woorden?
- Hoe ziet u de balans voor zich tussen bescherming en vrijheid van de bewoners? (Hoe ver ga je voor hun veiligheid?)
- Is het een open of gesloten woning?

☐ Concept woning

- Hoelang blijven mensen daar wonen? Kunnen ze blijven wonen tot het einde van hun leven?
- Hoe wordt er beslist wie er wel of niet kan wonen (indicatie / sollicitatie / loting)?
- Welk stadium van dementie hebben mensen hier? Wonen mensen met verschillende stadia met elkaar?
- Kunnen mensen daar samenwonen met een partner?

☐ Zorg bewoners

- Vanaf welk punt zie je dat ouderen met dementie jouw intensievere zorg nodig hebben? Welke dingen kunnen ze nog wel zelfstandig?
- Wat zijn jouw taken? Hoe ziet je dag eruit?
- Zijn er situaties waarbij beide van het stel samen in dezelfde zorginstelling wonen? Gebeurt dit wel eens en wat zijn volgens jou de voor en nadelen?
- Kunnen ouderen met dementie het beste zo lang mogelijk thuis wonen, of beter vroeg naar een zorginstelling om daar te wennen?
- Hoe zou jij als officiële zorgverlener kunnen samenwerken met een mantelzorger?

☐ **Ontwerp leefomgeving**

- Hoe denkt u dat het verschilt ten opzichte van andere zorginstellingen?
 - Zijn er speciale ontwerpelementen toegevoegd aan deze locatie om bij te dragen aan het verlichten van de symptomen?
 - Waarom is er gekozen voor een woning in combinatie met een boerderij?
- Wat is het voordeel van kleinschalig wonen?
- Hoe denkt u dat de leefomgeving waarin de woning zich bevindt bijdraagt aan het welzijn van de bewoners?
 - Is de locatie gekozen om zijn leefomgeving of is de leefomgeving ingericht naar wens?
- Wat maakt een kamer voor iemand met dementie uniek (ontwerpelementen)?
- Zijn er specifieke momenten op de dag waarop problemen?
 - Speelt de leefomgeving daar een rol in?
- Zijn er ontwerpelementen die je mist op deze locatie die zouden kunnen bijdragen aan het dagelijkse ritme van de bewoners (makkelijkere routes, vorm van ruimtes etc.)?

☐ **Dagelijks leven bewoners**

- Op wat voor manier worden deze mensen gestimuleerd/ actief gehouden?
- Hoeveel doen deze mensen zelf? Waar moeten ze bij geholpen worden?
- Kunnen de bezoekers altijd langskomen (specifieke bezoeken)?

☐ **Bezoekers (familieleden en overige bezoekers)**

- Voelt u zich hier op u gemak als u uw familieleden bezoekt?
 - Zo ja / nee, wat draagt bij aan dit gevoel?
- Wat was het keuzeproces om toekomstige woonmogelijkheden te overwegen?
- Waarom is er voor [locatie] gekozen?
 - Zocht je naar opties die er niet (in de buurt) waren?
 - Komt de bewoner uit deze regio?

☐ Partner

- Wat is de impact op je leven om een partner te hebben met dementie? Waaraan merk je dit het meest?
- Wat zijn de uitdagingen die zich voordoen om met iemand dementie te wonen?
- Heb je weleens afstand nodig van je partner met dementie? Hoeveel afstand heb je nodig?
- Zou je ook in latere fases van de dementie nog met je partner samen kunnen/willen wonen?
 - ☐ Waarom zou dat wel/niet kunnen?
 - ☐ Hoe zou dat eruit zien?
- Denk je dat het bevorderlijk is voor het welzijn van je partner om samen te blijven wonen?