ANOTHER DEMENSION

Insight into the life of people with Young Onset Dementia and their relatives in order to design a care centre facilitating them in their well-being

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ABSTRACT

Although the established presence of people with Young Onset Dementia, specialised care facilities for them are lacking, which has a negative impact on their health related quality of life. Therefore, this thesis aims to get insight into their needs to create design guidelines for a specialised care centre for people with Young Onset Dementia. The NeedYD study is used as framework to build further on. With literature reviews, case studies and personal experiences, the fields of Young Onset Dementia, architecture and health are brought togehter to come to design solutions.

KEYWORDS

young onset dementia, architecture, health related quality of life, care centre, neuropsychiatric symptoms, unmet needs, healing architecture, design guidelines

Word count: 2999

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Chapter 2 – Design for Dementia

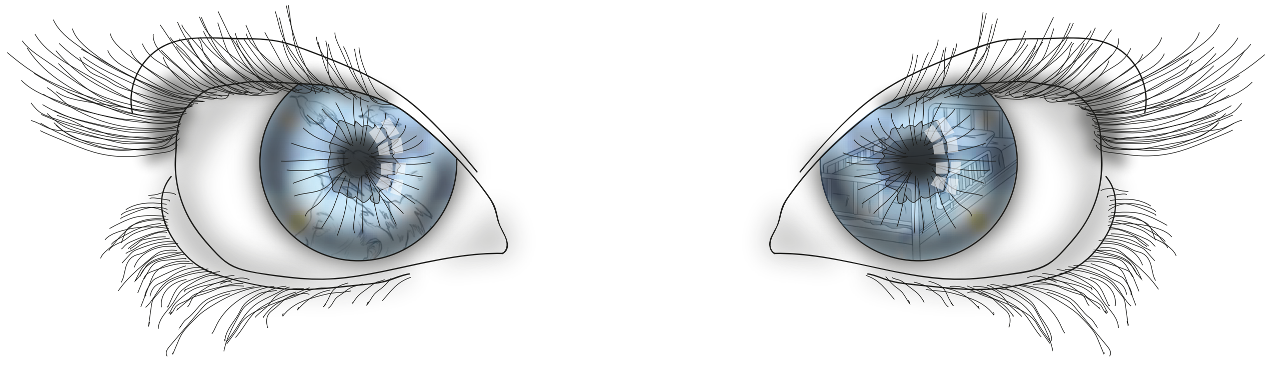
Chapter 3 – Design for Needs

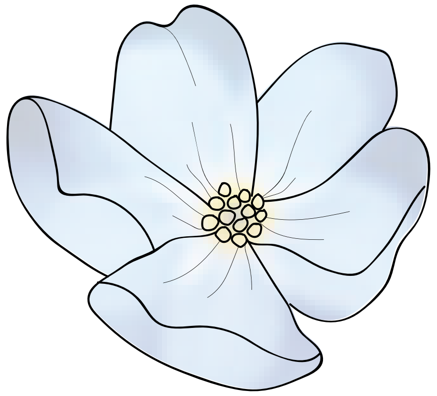
Chapter 4 – Design for Healing

Fascination

I have seen what it means when a loved one has
dementia at a young age and how important care
is when someone gets lost mentally

My desire is to improve their live and well-being.





CHAPTER

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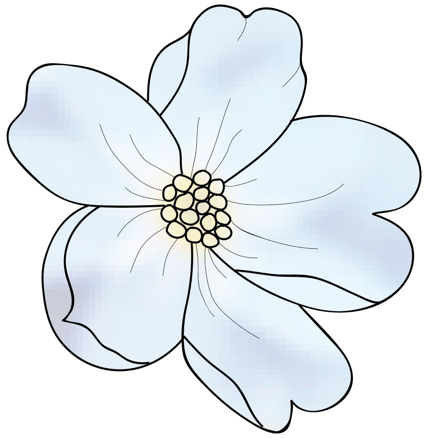
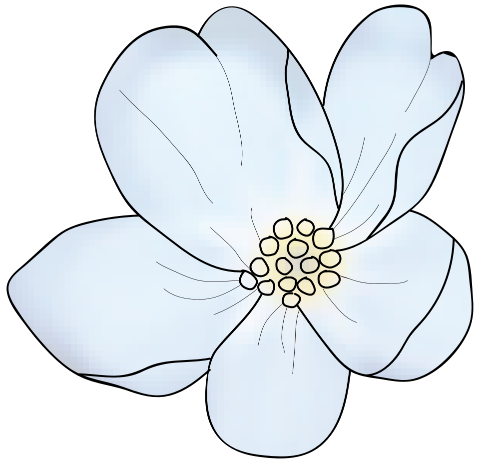




Research Plan

1.1 BACKGROUND

Dementia is a generally familiar brain disorder, by now one out of 3 women and one out of 7 men will deal with it themselves. Taking into account their surroundings, even more people come in contact with dementia in their lives. It is known that mainly due to our aging society, this number is rising. When there were 50.000 people suffering from dementia back in 1950, this is currently already 290.000 and the prognosis is that this amount will increase to 620.000 in 2050 (Alzheimer Nederland, 2021).

It is therefore not striking that dementia is typically regarded as an age-related disease, but with that, the occurrence of dementia at a younger age may be overlooked (Bakker, 2013). Younger people can be diagnosed with dementia as well, it is then called Young Onset Dementia, which means that the first symptoms manifest before the age of 65 (WHO, 2012).

According to the World Health Organisation (2012), 6-9% of all dementia cases are a young onset form. It is estimated that there are today between 12.000 and 24.000 people with dementia at a younger age in the Netherlands (de Vries & de Graaf, 2020). Due to late diagnosis, it is difficult to determine the exact number. In 2017, Alzheimer Nederland measured this at 12.000, but more recent research showed an amount of 24.000 people with dementia between 40 and 65 (Vektis, 2019). As well as dementia in general, the number of young onset dementia is expected to rise, roughly doubling every 5 year (WHO, 2012).

1.2 PROBLEM STATEMENT

The diagnosis of dementia has a big impact on those affected. According to doctors and researchers, dementia is the disease with the highest burden for the patient self (Alzheimer Nederland, 2021). It results in an important loss of the health related quality of life (Bakker, 2013). Especially Young Onset Dementia is recognized as an important psychosocial and medical health problem with serious consequences for patients and their families. Caregivers experience even a higher level of caregiver burden than those of older dementia patients.

Young Onset Dementia is not just dementia at a younger age, there are substantial differences with Late Onset Dementia (Mendez, 2017). At a younger age, cognitive, behavioural, and psychological symptoms are more common (de Vries & de Graaf, 2020), which leads to different needs for these younger patients and their caregivers.

First of all, Young Onset Dementia has another clinical manifestation (Bakker, 2013; Smits, 2013). Where the stereotype symptoms as memory problems and disorientation are more prevalent by Late Onset Dementia, the cognitive domains in the brain other than memory are often more affected by the younger people instead (Baptiste et al., 2016; Smits, 2013). They are therefore more likely to face cognitive problems such as deficits in language, visuospatial function and often have apraxia, which hamper functioning in daily life. Also behavioural problems are on the foreground. In fact, neuropsychiatric symptoms, such as depression, psychosis and agitation, are highly prevalent in Young Onset Dementia (Bakker, 2013; Smits, 2013; de Vries & de Graaf, 2020). Because younger patients are generally in a better physical condition, those symptoms have a more profound impact on them and their health related quality of life.

Second of all, young people with dementia are in a different phase of their lives (Bakker, 2013; Baptiste et al., 2016). They fulfil a more active role in society: they are often part of a family and are a parent, even with whether or not dependent children living at home, are still working and thereby usually a family provider, have a social life and are physically active. Compared to older people with dementia, the loss of roles and responsibilities therefore greater for people with Young Onset Dementia. Since they often have a more preserved awareness of this and more insight into the disease, it also has a greater psychological impact and adds to a lower health related quality of life (Bakker, 2013; Baptiste et al., 2016).

Despite these differences between Late and Young Onset Dementia, specialised care facilities for the younger are scarce in The Netherlands and their distribution is limited (Bakker, 2013). Hereby, specialized care often means more knowledge and care groups with young people, rather than a specific designed facility for them. Patients and their families are now forced to use the general dementia facilities, which are designed for the elderly and thus do not fit the different needs of the younger. Therefore, it is difficult for them to integrate in those mainstream facilities, resulting in being pushed from pillar to post in order to find a suitable care facility (Bakker, 2013; Baptiste et al., 2016).

Most families are now providing informal care to their loved ones with Young Onset Dementia. At a certain moment they cannot take care of themselves anymore and families gradually take over the care till late stages of the disease, in order to prevent institutionalisation for as long as possible (Bakker, 2013). They have concerns about the quality of external care for their relatives, since they consider the mainstream facilities as not suitable. Although this far-reaching informal care, research shows that this only has a postponing result. Institutionalisation is eventually inevitable, since at a certain moment it is not doable anymore.

Moving can already be challenging for the patients and can result in a, often temporary, fast decline in their process, since they lose all their familiar mechanisms. This can have a negative effect on their health related quality of life (Lambert, 2016).

In addition, it is known that unmet needs of people with Young Onset Dementia in care facilities can lead to or worsen their neuropsychiatric problems, and have an even bigger impact on their health related quality of life (Bakker, 2013). They thus end up in a downward spiral: due to their different symptoms as being sensitive for developing neuropsychiatric problems and the non-specialised care facilities, their needs are unfulfilled, causing more or worse neuropsychiatric problems.

Furthermore, another problem in those mainstream dementia facilities is the normalised use of psychopharmaceuticals. One out of three clients in The Netherlands get this medical treatment for their so called 'unwanted and restless' behaviour (van Marum et al., 2014; den Tek, 2022), which are typical neuropsychiatric symptoms people with Young Onset Dementia show, to get them quiet and calm. It has been shown that these antipsychotic medication and benzodiazepines have a low efficiency and harmful side effects, such as physical and cognitive decline and a state of sedation (Rochon et al., 2017; Wang et al., 2018). This again is a downward spiral and lowers their health related quality of life.

People with Young Onset Dementia, as well as their family, thus face consequences on their health related quality of life, because of the lack of specialised care facilities.

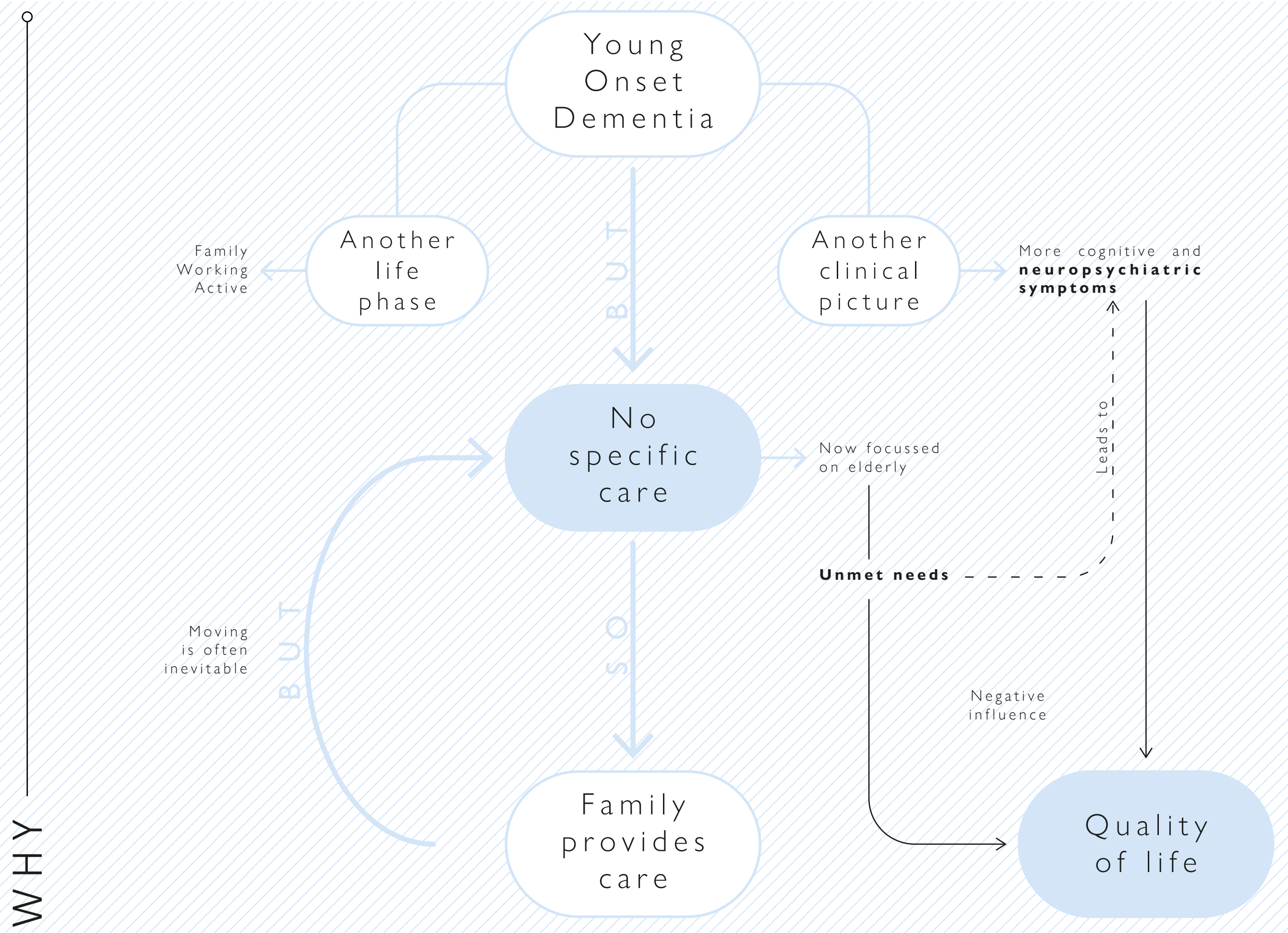


Figure 1 | Problem statement (own image)

1.3 GOAL

It is clear that specialised care facilities for people with Young Onset Dementia are needed. The main goal of this thesis is to create architectural guidelines for a care centre for people with Young Onset Dementia, where they are able to live a meaningful in an environment working in their (health) favour, in order to maintain their (health related) quality of life.

Therby, his research only focuses on patients and care facilities in the Netherlands and only involves an architectural level and thus not medical examination, organisational policies and supporting services.

To achieve this, there are three research aims:

1) Insight in the current facilities for people with (Young Onset) Dementia

2) Insight in the needs of people with Young Onset Dementia and their relatives

3) Insight in the relationship between architecture and healing

1.4 RESEARCH QUESTIONS

Main research question:

How can a care centre for people with Young Onset Dementia be designed in such a way that it facilitates them, and their relatives, in maintaining their health related quality of life?

Sub-questions:

1) How do current care centres for people with Young Onset Dementia look?

2) Which design principles are used for people with dementia?

3) What are the spatial needs of people with Young Onset Dementia?

4) What is the perspective of relatives on the spatial needs in daily life?

5) How can a healing environment facilitate people with Young Onset Dementia?

1.5 DESIGN HYPOTHESIS

By bringing the fields of Young Onset Dementia, Architecture and Health togehter, design guidelines for a care centre which improves the quality of life will be found.

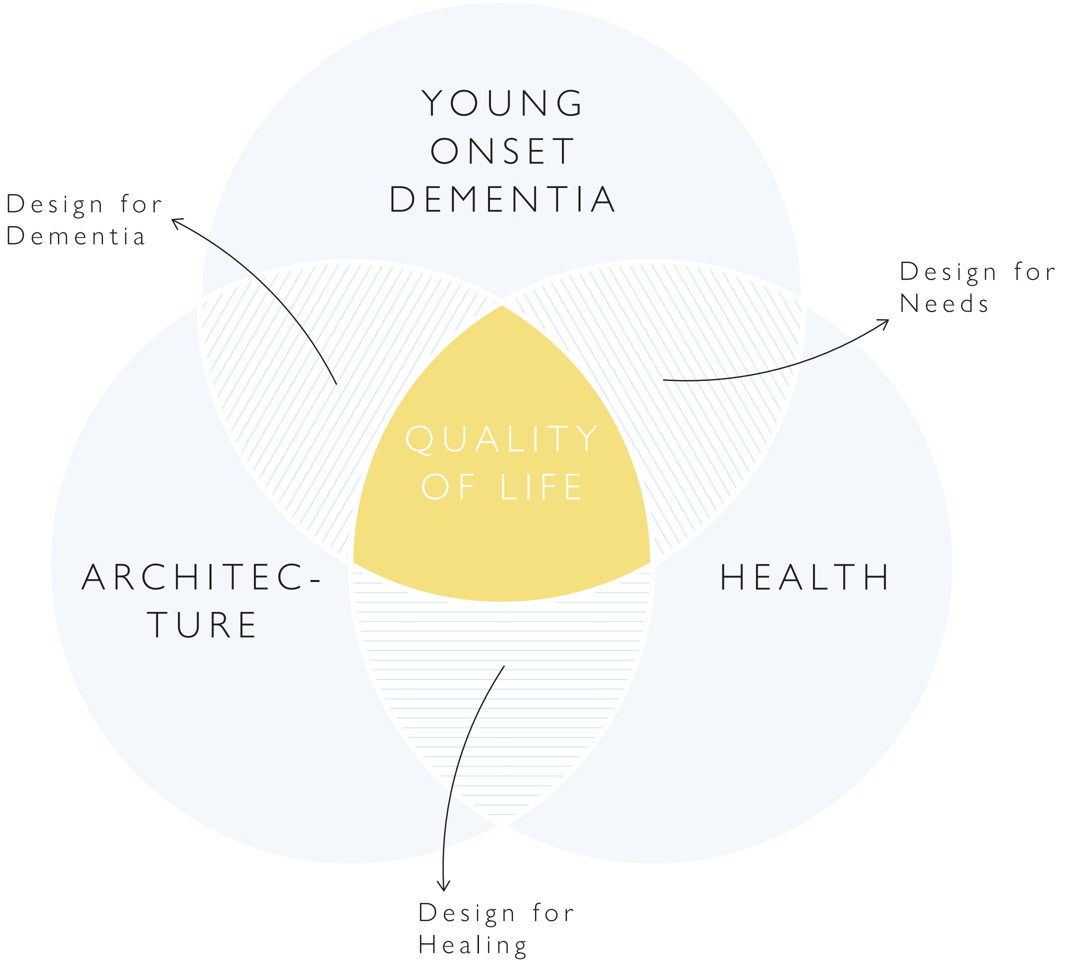


Figure 2 | Research structure (own image)

1.6 THEORETICAL FRAMEWORK

This thesis builds furhter on the Dutch NeedYD study, meaning Needs in Young Onset Dementia, which was started in 2007 as the first prospective study in this field, because specific knowledge was largely lacking and is essential for the development of an effective care offer. It is a collaboration between several Alzheimer organisations in the Netherlands and researchers. The aim of this research is to map the functioning and (care) needs of young people with dementia and their relatives and to investigate the course of neuropsychiatric symptoms, in order to give them the best possible support in their home situation so institutionalisation can be postponed or even be prevented.

215 people with Young Onset Dementia and their families were followed for two years originally. At the start, their average age was 61,1 with the average occurrence of symptoms for 7,1 years. Every 6 months both the patient and caregiver were assessed in the original study. In the follow-up study, the same participants, where possible, were assessed after three, four and six years. For mapping the (un)met needs, the Camberwell Assessment of Needs in the Elderly (CANE) was used. This is a semi-structured interview consisting of 24 domains covering social, physical, psychological and environmental needs, with each one open question followed by several rating questions. The Neuropsychiatric Inventory (NPI) was used for investigating the course of neuropsychiatric symptoms. This is a structured interview, consisting of closed questions, with the caregiver and health care professional.

Since the start of the NeedYD study, four researchers have written a dissertation based on the collected data. Van Vliet (2012) and Bakker (2013) used the first two years of the NeedYD study as base, focussing mainly on the pre-diagnostic phase and on the (un)met needs and use of (in)formal care respectively. Millenaar (2016) and Gerritsen (2020) also used the extended NeedYD study. They focussed mainly on the impact on the patient, their relatives and on the course of thedisease respectively. These dissertations together give a good insight in the characteristics of the disease, namely the difficulties which are faced in the time before the diagnosis and after, such as misunderstanding, conflicts with family and work, changing behaviour, neuropsychiatric problems, taking care and finding help and support for that and the impact on the relatives and their live, such as dealing with the loss, managing their own life, having new responsibilities, experiences of burden and concerns. These studies thus provide a good basis for the global understanding of the challenges faced with Young Onset Dementia.

Although, the dissertations mainly face the psychological impact, rather than the practical needs. Corresponding with the research aim, resulting solutions focus on awareness, information and external support of professionals and fellow sufferers, to get mental support for dealing with the situation at home in the first stages of the disease facing diagnosis and giving informal care to light formal care. When it comes to the patient, the NeedYD study is based on closed and rating questions, which can be shallow. Also further research and relationships between outcomes in the dissertations are mainly based on statistical and quantitative research, with only one personal case study.

A more human-centred approach is needed, to investigate what people with Young Onset Dementia and their relatives need in their daily lives in a more practical way. Standard questionnaires miss out on the bigger picture, it is important to get to know the stories behind it, in order to understand their behaviour and needs in relation to underlying causes, especially when people are mental ill. Also another dimension in this research is required, focusing on the later stages of the disease. Despite the finding that families consider external care as inappropriate and facing most worrisome problems with that, it remains unclear how it can be facilitated from the perspective of the patient and caregiver.

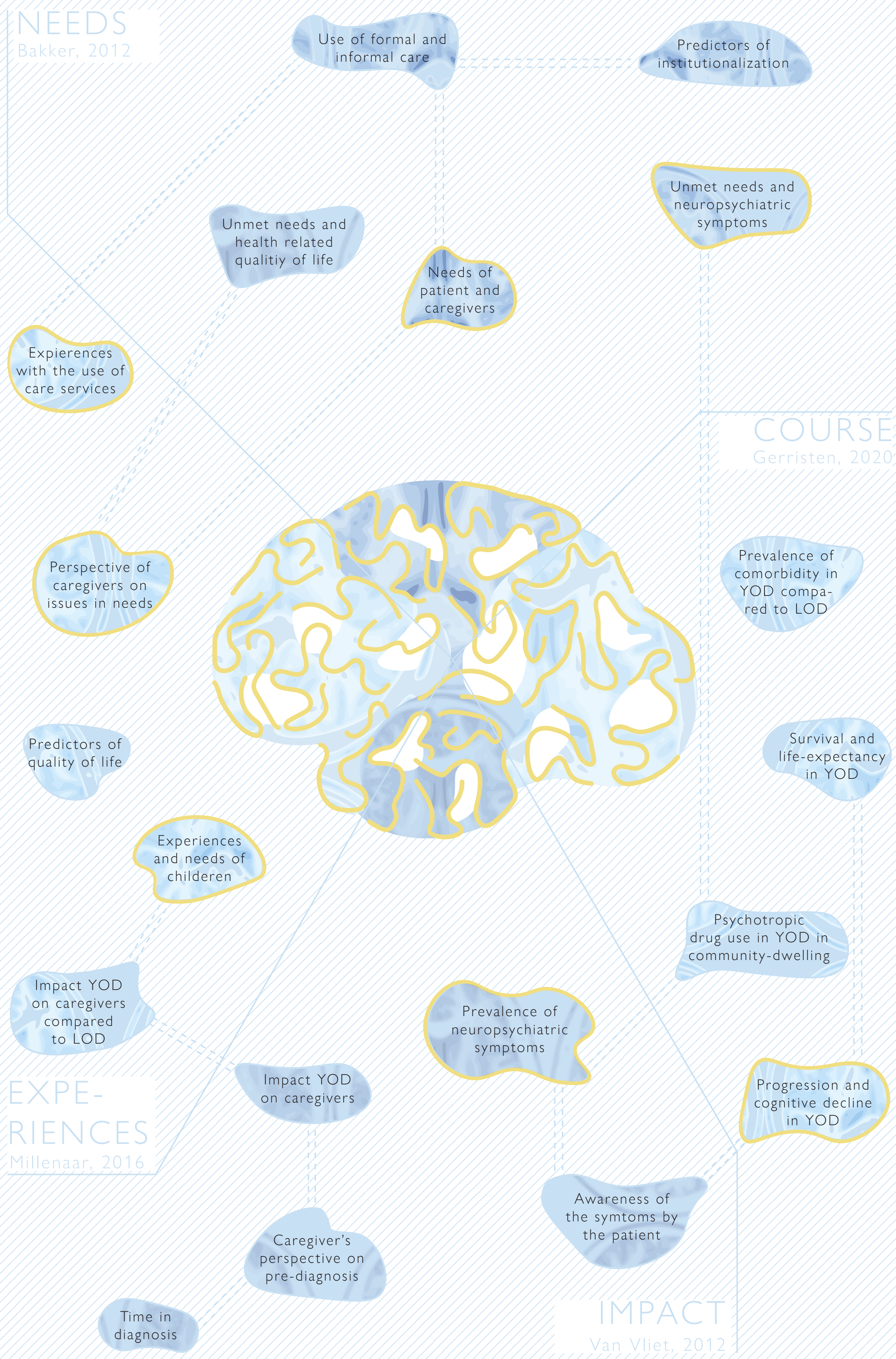


Figure 3 | Theoretical position scheme (own image)

1.7 METHODS

This thesis is divided into three main sections, each with its own subject and the corresponding sub-questions. The methods used are part of qualitative research for a human-centred approach.

Chapter 2 'Design for Dementia' looks into the current care facilities and design principles for (young) people with dementia and answers the first and second sub-questions.

By a typological research, there will be investigated which kinds of specific build care facilities there are and how they work. First an inventory of the facilities for people with Young Onset Dementia is made and described to give a general overview. Then they are sort by typology and some of them are analysed. For that, a (visual) matrix with the characteristics of those facilities, such as sizes of living groups, patient rooms, outdoor spaces, additional facilities, clustering, openness and typical architectural dementia features, needs to be created. Since there are not many care facilities for young people and facilities for elderly are often used, they are taken into account as well. With this, the aim is to get an overview of the existing care facilities and their architectural principles. Some of those care facilities are thus analysed as a case study. Three of them will be the location where the fieldwork is carried out. The aim of these case studies is to look deeper inside such a care facility, so how it is used by patients, family and caregivers, in order to get an understanding of how such a facility functions in practice.

By a literature review, there will be dived deeper into the design principles for dementia, which has already been researched in the past, in order to get a better understanding of the reason behind currently used design principles. For this, *Holding on to home* by Cohen and *Dimensies voor dementie* by Nillesen and Opitz are used.

Chapter 3 'Design for Needs' looks into the needs and daily life of a person with Young Onset Dementia and their relatives and answers the third and fourth sub-questions.

By a literature review, there will be outlined what dementia is, by describing the different forms, stages and symptoms, specific for those with Young Onset Dementia, in order to make clear what the clinical picture is and what the main differences are with the more common known Late Onset Dementia.

By observations and interviews, the persons behind the disease will be get to know, in order to understand the clinical picture and how a care centre could support young people with dementia and their relatives, according to their life and spatial needs. For that, an overview with desired answers and assumptions is needed, covering which symptoms they show, how they behave and which care is provided. Since it is not possible to interview the people with dementia themselves, the experiences of relatives and their caregivers are used to get answers and a more thorough understanding. To also get to know the relatives, desired outcomes cover their thoughts of providing care, way of living and satisfactions or problems they face. In addition, media is used like the film *Still Alice*, documentaries as *Frank & Alzheimer* and the tv-programme *Restaurant Misverstand*, in order to get a broader picture of the persons behind the disease and the influence on their life.

Chapter 4 'Design for Healing' looks into the relationship between architecture and health and answers the fifth sub-question.

By a literature review, more is learned about healing- and neuroarchitecture. The principles of these approaches and the influence on patients will be described, in order to understand how these principles could be applied in favour of the health and well-being for people with dementia, according to heal or prevent certain behavioural or neuropsychiatric symptoms.

By case studies of existing care facilities where these principles are already applied, mostly in hospitals and psychiatric care, will be investigated how this functions in practice, to see how these principles could be translated into architecture.

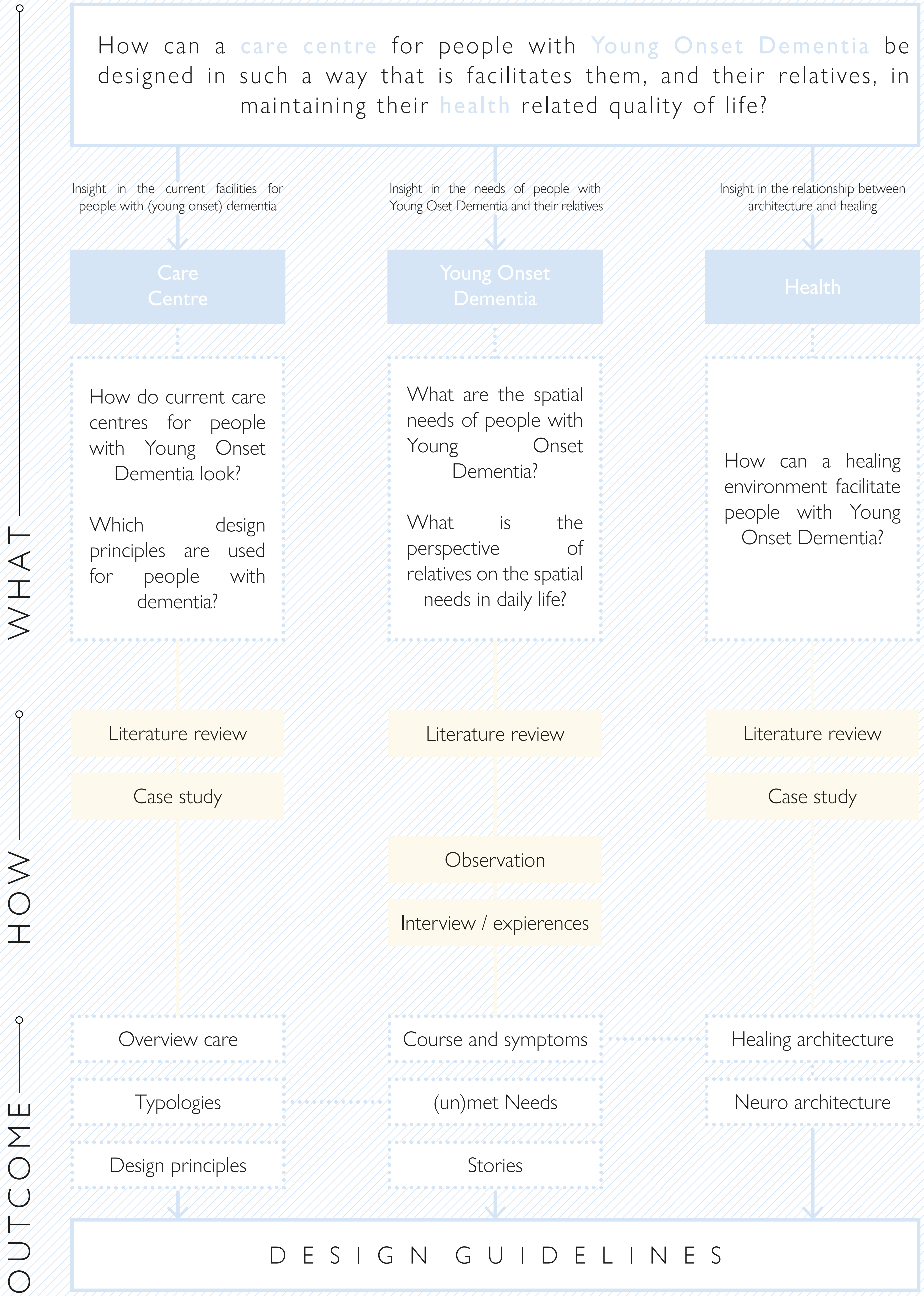
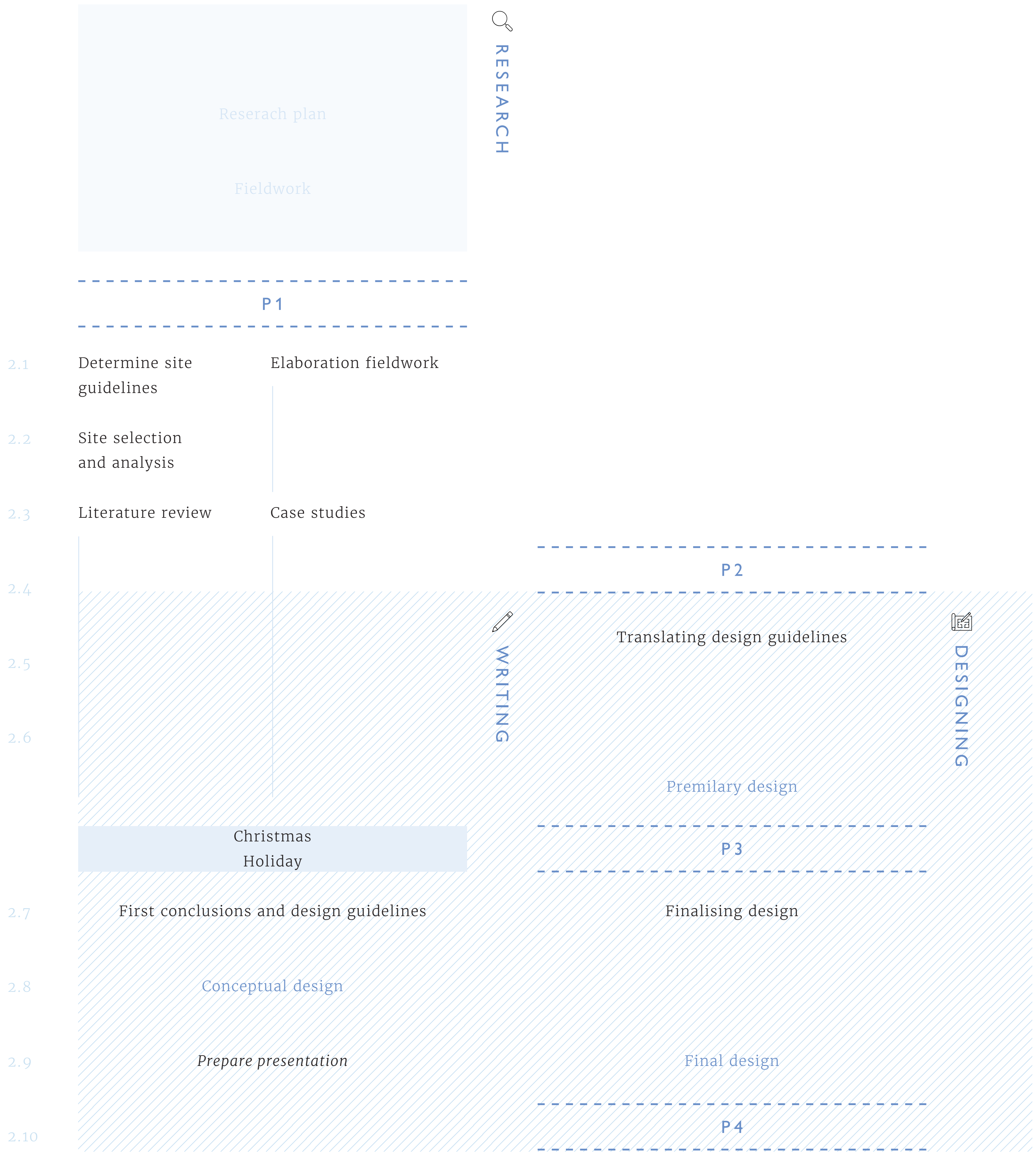


Figure 4 | Research scheme (own image)

1.8 WORKPLANNING



1.9 DEFINITIONS

Care centre is a build residential institution where care is provided on a daily or permanent base to people with mental or physical diseases or infirmities

Care facilities are build and supporting care services.

Dementia is a collective name for around 50 brain diseases, causing progressive brain damage, which hampers the brain in processing information properly (Alzheimer Nederland, a.d.; Dementie.nl, a.d.).

Design guideline, principle and solution are three consecutive notions. A design guideline is a written recommondation of a certain performance. This can be translated into different design principles, which are the practical operations. The design solution is the final form in how it is applied.

Healing environment is an physical setting that promotes well-being of patients, family and employees and reduce stress, aiming a faster recovery or a situation where the consequences of a disease or infirmity do not get worse.

Health is, according to the WHO (1946) "*a state of complete physical, metal and social well-being and not merly the absence of disease or infirmity*" The fundamental difference in this thesis is that despite having a disease or infirmity, a person should still be able to experience health.

Therfore health is seen as being able to intergrate physical, mental and social challenges in life by maintaining or developing a state of well-being (Huber, 2014; van der Stel, 2016).

Health-related Quality of Life (HRQoL) is based on the relation between health and the QoL. It evaluates how a health status is perceived and reacts to nonmedical aspects of human live (Lin et al., 2013).

Late Onset Dementia (LOD) is the most common form of dementia, afflicting people aged above 65.

Spatial needs are essential qualities of a physical setting requires.

Quality of Life (QoL) refers to the goodness of life as a whole, covering all aspects of human life by evaluating the perspective on well-being and satisfaction (Lin et al., 2013).

Young Onset Dementia (YOD) is dementia at a younger age, with symptoms manifesting before the age of 65. This number is rather an indication of the different life phase based on the general retirement age. In this thesis, the age rage is set between 30 and 65, although in some literature the rage between 40 and 65 is used (Lambert, 2016).

The term Early Onset Dementia, which has the same meaning, is the medical term for this disease and also widely used in literature. However, this term can be misinterpreted as an early stage of dementia and is therefore not used.

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