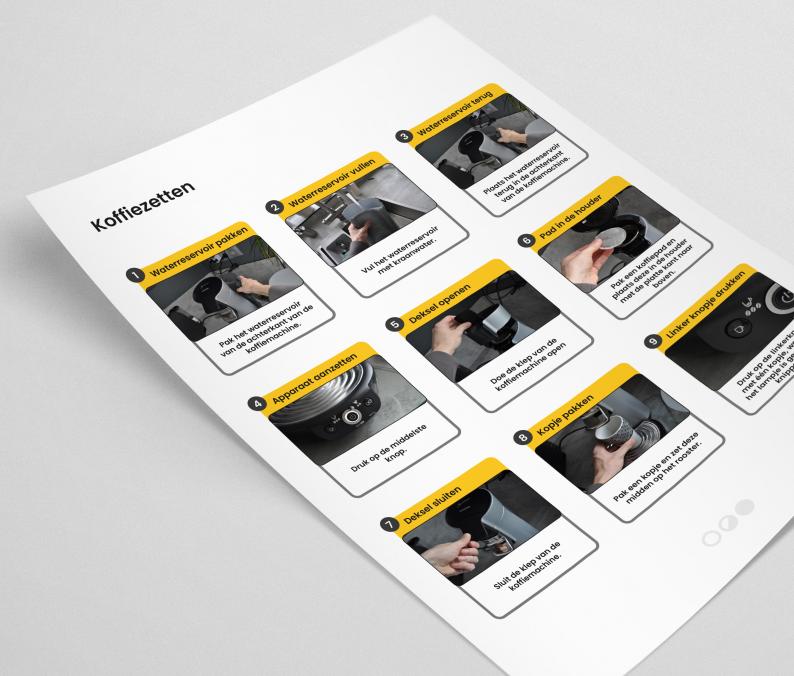
Learning with dementia:

(re)learning meaningful activities for people living with dementia

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Colophon

Master Thesis

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GGzE & Innovate Dementia

The Geestelijke Gezondheidszorg Eindhoven (Institution for Mental Health Eindhoven), in short GGzE, offers care and support to children, adolescents, adults and elderly with mental health problems.

Innovate Dementia is part of GGzE as a research group. It is involved in projects on innovations and solutions to generate tools to improve the functioning of people with dementia and to support their (informal) caregivers, with the goal to help people to maintain quality of life.

Innovate Dementia facilitates a Living Lab consisting of different stakeholders (i.a. people with dementia and their informal caregivers, formal caregivers, researchers and entrepreneurs) to explore, develop and test new solutions where the needs of people with dementia are centralized.







Abstract

At this point, around 280.000 people are living with dementia in the Netherlands and this number is expected to grow significantly in the coming decades due to the aging population. It is expected that by 2040 the number of people with dementia will grow to 520.000 and expand to over 620.000 people by 2050 (Alzheimer Nederland, 2018). This puts pressure on the Dutch healthcare system.

Despite their impaired memory, people with dementia still have the ability to (re)learn tasks when addressing the memory systems that are associated with automatic processes and performing activities, which are relatively spared in dementia (Eichenbaum, Cohen, Otto & Wilbe, 1992). These tasks include everyday activities such as knowing how to tie your shoes, how to make coffee and how to walk a certain route.

A learning method which makes use of the implicit memory is errorless learning. This is a highly structured learning method used in rehabilitation for people with dementia to (re) learn skills (De Werd, Boelen & Kessels, 2013). By regaining the ability to perform meaningful and important activities, people with dementia could maintain or improve their independence and quality of life (Cohen, Ylvisaker, Hamilton, Kemp, & Claiman, 2010).

Within this thesis, the aim was to research the possibilities of involving informal caregivers in the errorless learning process for people with dementia in the home environment. The insights gained from this research are used to develop a solution that supports informal caregivers to (re)learn meaningful tasks or activities to people with dementia to maintain or increase their independence.

In the analysis phase of the project, literature research was done on the errorless learning method to give an overview of how this method is applied in the current situation and which elements it consists of. Explorative research methods have been done to define what is needed to bring this method in the home environment and involve the informal caregiver in the process. This research consisted of interviews with experts on errorless learning and dementia care, hosting focus groups with people with dementia and informal caregivers, and performing two case studies.

Based on the literature and explorative research, the most important aspects concerning the errorless learning process in the home situation were described by discussing the needs and requirements per stakeholder. These included the person with dementia, the informal caregiver and the professional caregiver who should guide the learning process. This was translated into a vision on how errorless learning could be performed in the home environment by visualizing it in a desired journey.

A new design goal, opportunities for design, and design requirements were defined, which formed the base of the design phase. Individual and group ideation sessions were done which resulted in the proposal of a platform that was

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developed iteratively through low-fidelity tests, interviews and a focus group. Simultaneously the desired journey was refined.

The concept proposal *Leren met dementie* is a platform that informs, educates and guides the informal caregiver throughout the process of errorless learning to (re)learn meaningful activities to people with dementia. It provides information on why this learning method should be applied, how to apply it and how to approach the person with dementia. This is done through a website, booklet, and application. Part of this website and application is an online tool, the Stappenplan maker. With this tool, a (printed) step-by-step plan can be made with pictures and instructions tailored to the person with dementia to use during the learning sessions.

The concept proposal was validated in a focus group with the participation of people with dementia and informal caregivers. Secondly, the platform was evaluated with a professor of neuropsychology who is involved in research on errorless learning for people with dementia. This was done by describing the scenario as visualized in the desired journey and discussing the platform *Leren met dementie* to determine the desirability, feasibility, and viability of the proposal.

Based on the validation, it could be concluded that Leren met dementie could serve as a base to further develop, discuss, research and test the possibilities of errorless learning for people with dementia in the home environment by involving the informal caregiver. However, more research is needed to evaluate the usability and understandability of the platform for the target group. Secondly, the effects of involving the informal caregivers and the step-by-step plan on the learning effects for people with dementia should be researched.

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Enjoy the read,

Max van Manen



Table of contents

Colophon Abstract Acknowledgements		3
		4
ACKII	lowledgements	0
PA	RT 1 - Introduction	
Chapte	ter 1	
	oduction	12
1.1	Project aim	13
1.2	Project outline	14
Chapte		
Con	ntext	16
2.1	Society	17
2.2	Living with dementia	19
2.3 2.4	Quality of life Conclusion	21 23
PA	RT 2 - Literature research	
Chapte		00
	mory and learning in dementia	26
3.1	Memory formation	27
3.2 3.3	Long-term memory	28 30
3.4	Implicit learning methods Errorless learning in dementia	32
3.5	Conclusion	36
PA	RT 3 - Explorative research	
Chapte	ter 4	
The	errorless learning process	40
4.1	Research methods	41
4.2	Stakeholders in errorless learning	45
Chapte		
	sired journey	50
5.1	Personas	51
5.2	Desired journey	52
5.3	Conclusion	54

PART 4 - Design brief

Chapte	er 6	
Desi	ign focus	58
6.1	Design goal	59
6.2	Opportunities for design	61
6.3	Design requirements	62
PAI	RT 5 - Design	
Chapte		
ldea		66
7.1 7.2	Ideation approach Concept choice	67 70
Chapte		
Desi	ign exploration	72
8.1	Platform and desired journey	73
8.2	Step-by-step plan	74
Chapte		76
	cept proposal: Leren met dementie	76
9.1	Desired Journey	77
9.2 9.3	The platform Stappenplan maker	78 82
Chapte	er 10	
Desi	ign validation	84
10.1	Validation focus group	85
10.2	Validation with expert	87
10.3	Validation conclusion	89
10.4	Conclusion	91
PAI	RT 6 - Conclusion	
Chapte Droi		94
_	ect conclusion	_
11.1	Discussion Recommendations	96
11.∠	kecommendations	98
Refer	ences	102

Part 1 Introduction

Part 2 - Introduction describes the aim of the project, the project approach and the context around dementia, including societal aspects, living with dementia and quality of life.

Chapter 1

Introduction

At this point, there are around 280.000 people living with dementia in the Netherlands and this number is expected to grow significantly in the coming decades due to the aging population. It is expected that by 2040 the number of people with dementia will grow to 520.000 and expand to over 620.000 people by 2050 (Alzheimer Nederland, 2018).

People with dementia experience memory problems everyday which has a significant impact on everyday functioning and quality of life (Dröes, van der Roest, van Mierlo, & Meiland, 2011). This causes moments of insecurity, anxiety and helplessness during a person's day (De Werd, 2017).

Despite the impaired memory, people with dementia still have the ability to (re)learn tasks when addressing the implicit memory. This is the long-term memory system that is associated with automatic processes and performing activities, which are relatively spared in dementia (Eichenbaum, Cohen, Otto & Wilbe, 1992). These tasks include everyday activities such as knowing how to tie your shoes, how to make coffee and how to walk a certain route.

A learning method which makes use of the implicit memory is errorless learning. This is a highly structured learning method used in rehabilitation for people with dementia to

(re)learn skills (De Werd, Boelen & Kessels, 2013). By regaining the ability to perform meaningful and important activities, people with dementia could maintain or improve their independence and quality of life (Cohen, Ylvisaker, Hamilton, Kemp, & Claiman, 2010). Subsequently, this could result in a reduction of the burden on informal and professional caregivers and could reduce care costs (Kawaharada et al., 2019; Cohen et al., 2010).

Multiple studies have been conducted on the effectiveness of errorless learning on people with dementia and have shown positive results in (re)learning meaningful tasks, skills and activities in multiple stages of dementia (De Werd et al., 2013; Clare & Jones, 2008).

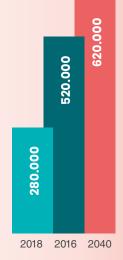


Figure 1: Growing number of people with dementia (Alzheimer Nederland, 2019)

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1.1 Project aim

Although errorless learning is acknowledged by the Dutch Healthcare Institution as an effective method for regaining independence in daily activities for people with dementia, it is little applied in the home environment (Oudman, 2019; Dorst et al., 2016).

The method consists of multiple learning sessions, preferably performed in a familiar environment, with guidance from an instructor. In research and in the current situation (if applied), errorless learning is taught by a professional caregiver, being a time intensive process. As 70% of the people with dementia live at home, there are opportunities to involve

the informal caregiver in the learning process and reduce the involvement of professional caregivers. Within this process, the experienced burden of the informal caregiver should not be overlooked. The project brief can be found in *Appendix 1*.

The aim of this project is to research the possibilities of involving informal caregivers in the errorless learning process for people with dementia in the home environment. The insights gained from this research are used to develop a solution which supports informal caregivers to (re)learn meaningful tasks or activities to people with dementia to maintain or increase their independence.

1.1.1 Research and design questions

Throughout this project, the following research and design questions were explored:

Research questions: Chapter 2

- How does dementia affect people with dementia and their surroundings?
 - How does dementia affect someone's brain?
 - How does dementia affect people's functioning?
 - How does dementia affect people's quality of life?

Research questions: Chapter 3 - Memory and learning in dementia

- How does dementia affect memory?
- Which memory systems are used in

learning with dementia?

- What is errorless learning?
 - o How is it applied in real-life?
 - What are the possibilities of errorless learning?
 - What are the advantages of errorless learning compared with other methods?

Design questions: Chapter 4

- How could errorless learning be applied within the home situation?
 - What role could an informal caregiver play in applying errorless learning in the home environment?
 - Which human factors could influence the success of errorless learning in the home environment?

1.2 Project outline

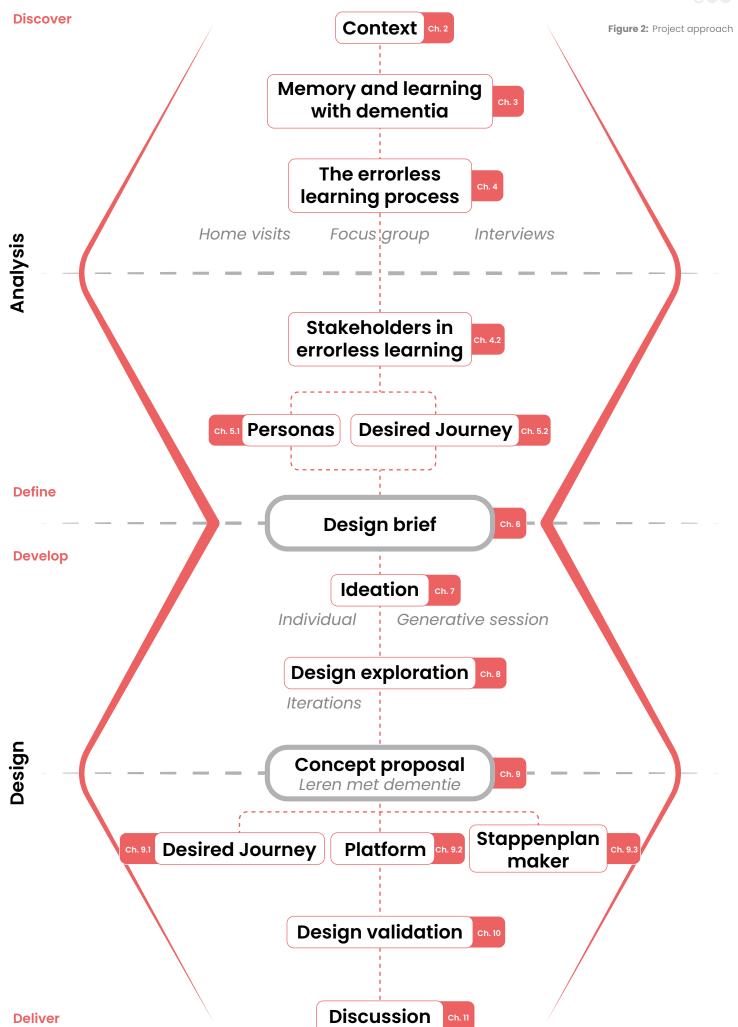
The process of this project is done according to the Double Diamond model, consisting of an analysis part and a design part (British Design Council, 2019). Within these parts, four phases can be distinguished: discover, define, develop and deliver. This report is structured into six parts: Introduction, Literature research, Explorative research, Design brief, Design and Discussion. An overview of this process and the parts it consists of is visualized in *Figure* 2. A user-centered design approach has been used throughout the project to discover the needs and wishes from the most important stakeholders.

During the discover-phase, information has been gathered through literature research, interviews with experts, focus groups with people with dementia and informal caregivers, and the analysis of real-life examples of learning with dementia. Secondly, two couples living with dementia have participated in a case study to explore errorless learning in practice.

In the define-phase insights from the different exploration methods have been clustered and organized to describe the different stakeholders in the process. Through a desired journey a vision on how errorless learning could be applied in the home situation is visualized. Based on the needs of the stakeholders and the patient journey, a refined design brief is formulated.

During the develop-phase three opportunities for design have been explored and ideated on. This was done through individual ideation and a generative session. A concept direction was chosen based on expert opinions and design requirements.

In the deliver-phase the concept was further developed into a design proposal, consisting of a platform and desired journey. Through interviews with stakeholders involved in the errorless learning process these were discussed and refined. The design proposal was validated in a focus group with four informal caregivers and five people with dementia and validated with a professor of neuropsychology.



Chapter 2

Context

Dementia is a disease which has a high impact on the lives of people living with dementia and the people who take care of them. As the number of people living with dementia is expected to grow significantly, this also affects society. This chapter describes what societal aspects are involved in the disease, how it affects the lives of people with dementia, and how this could affect their quality of life.

In this chapter, the following research questions were answered:

- How does dementia relate to Dutch society?
- How does dementia affect people with dementia and their surroundings?
 - o How does dementia affect people's functioning?
 - o How does dementia affect people's quality of life?

2.1 Society

Nowadays, elderly people keep living at home longer, while the number of people in care homes decreases. As people get older, their care needs become more complex, as is also seen in people with dementia (Ministerie van Volksgezondheid, Welzijn en Sport, 2018). This results in an increasing need for healthcare in the future, while the number of informal caregivers decreases (Ministerie van Volksgezondheid, Welzijn en Sport, 2019b).

Pressure on healthcare

The growing elderly population puts a high pressure on the healthcare sector, as almost half of the healthcare costs is spent on people older than 65 while this number keeps growing the coming years (Vektis, 2018). Almost 44% of the employees in healthcare experience a high or very high workload, caused by regulatory pressure, administrative burdens, new or more difficult tasks, and a lack of staff (CBS, 2019b). The increasing healthcare needs demands more people working in the healthcare sector, but also asks for different solutions to ensure the high-quality healthcare in the future (Ministerie van Volksgezondheid, Welzijn en Sport, 2019b).

In 2018, the Ministry for Health, Wellbeing and Sports initiated the *Langer Thuis*-program (Longer at home-program) with the aim to let elderly grow old independently in their familiar environment with good quality of life. They stress that informal caregivers play an important role in this goal and that support and collaboration with professional caregivers is essential.

Caregiver burden

However, providing informal care puts pressure on informal caregivers, certainly when people become older and keep living at home longer. This is seen particularly in informal caregivers taking care for people with dementia, as there is often a lack of knowledge, skills and support to provide good care (Ministerie van Volksgezondheid, Welzijn en Sport, 2018). From the 280.000 people living with dementia, 70% lives at home and is taken care of by one or more informal caregivers (Alzheimer Nederland, 2018). This care is often experienced as a high burden, as pictured in *Figure 3*. Indicators of this perceived burden are behavioral problems,

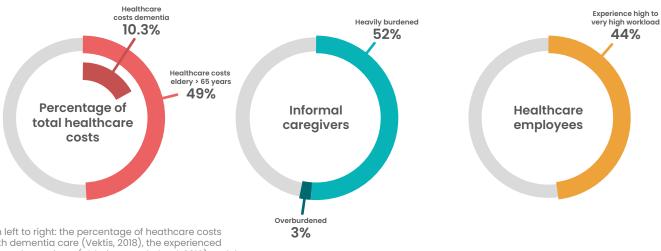


Figure 3: From left to right: the percentage of heathcare costs associated with dementia care (Vektis, 2018), the experienced burden on informal caregivers (Alzheimer Nederland, 2018) and the experienced workload in healthcare employees (CBS, 2019)

mood disorders, and the patient's ability to perform activities of daily living, where the first has the strongest effect (Bergvall et al., 2010). Other factors influencing this burden are changes in social contact with friends and family and feelings of loneliness (Van Der Heide, Van Den Buuse, & Francke, 2018).

Although providing informal care is experienced as a burden, many informal caregivers also experience positivity in providing informal care. This is experienced by feelings of satisfaction and being valued, and most caregivers still enjoy the valuable moments with their loved ones (Van Der Heide et al., 2018).

eHealth

In 2020, the committee for Toekomst zorg thuiswonende ouderen (Future care for elderly living at home) wrote an advice based on the goals in the Langer Thuis-program. One of their three main advices is: Go digital. The committee stresses the need of better integration of eHealth for elderly to maintain their independence and improve quality of life. Integration of smart, appropriate, digitally supported care is seen as one of the few solutions that can lead to greater intensity and quality of care without the need for more staff (Commissie Toekomst zorg thuiswonende ouderen, 2020). eHealth solutions could also decrease the burden experienced by informal caregivers when used appropriately (Nap, Lukkien, & Cornelisse, 2016).

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2.2 Living with dementia

Dementia is a chronic and/or progressive neurodegenerative disorder, in which a deterioration of cognitive functions is seen, abnormal in what is expected in normal ageing (World Health Organisation, 2019). It is characterized by deficits in multiple cognitive abilities, such as memory, spatial and temporal orientation, executive functioning, visual perception, object recognition, and language. It is commonly accompanied, and sometimes preceded, by changes in social behaviour, emotional control or apathy (De Werd, 2017).

Dementia is an overall term for over fifty medical conditions of which Alzheimer's disease is the most commonly occurring and therefore the best-known disease. Alzheimer's disease occurs in approximately seventy percent of people living with dementia, as seen in Figure 4 (Alzheimer Nederland, 2018). The key symptom of Alzheimer's disease is memory loss, at first expressing itself in difficulties to remember facts, events or conversations. Other symptoms include social withdrawal, troubles with language, agitation, a lack of judgment, planning and performing familiar tasks (Warner & Hammans, 2009; De Werd, Boelen, & Kessels, 2013). Description of other types of dementia can be found in Appendix 2.

2.2.1 Stages

Dementia is often categorized in stages which are person and disease specific. Different institutions use different categorizations, most commonly varying from three to seven stages. Where most stages are described based on a specific type of dementia, Alzheimer Nederland (n.d.) describes three different stages which gives a more general view on the course of dementia.

Early stage

Changes in behavior, personality and functioning are often the first signs of dementia.

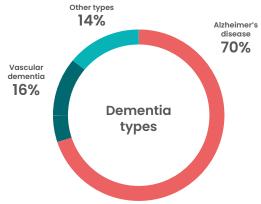


Figure 4: Percentages of dementia types (Alzheimer Nederland, 2018)

Dependent on the type of dementia, these changes express themselves in memory problems, speech problems, depression, insensitive behavior or multiple small strokes. Expression of these symptoms does not necessarily mean someone is suffering from dementia, since these changes could also be assigned to aging, dramatic events or having a burn-out or depression. Therefore, in this stage a diagnosis of dementia is difficult to make.

Mid stage

The changes in behavior, personality and functioning do not improve. Instead, the problems become worse and causes difficulties in performing daily tasks such as doing the dishes, shaving and riding the bicycle. People become more dependent on help from caregivers. A diagnosis can often be made in this stage of dementia.

Late stage

In the latest phase of dementia, people are no longer able to function independently. Typically, it takes years to get at this stage. At this point the brain is damaged significantly and performing daily tasks independently becomes too difficult or dangerous. In most cases, living at home is not an option anymore due to the demanded care for the patient.

2.2.2 Daily functioning

During the course of dementia, people with dementia will progressively experience trouble in daily functioning. In a study by Verlinden et al. (2015) where a population of 856 people with dementia and 1712 controls were followed over 18 years, people who developed dementia experienced the first complaints 16 years before diagnosis. At first people start having memory complaints and next show a decline in the cognitive functions, followed by problems in performing instrumental activities of daily living (IADL) and eventually with basic activities of daily living (ADL).

Executive functioning

People with dementia develop problems with executive functioning. This is expressed in problems with planning, keeping overview of a situation and correctly executing complex tasks. In daily life this causes problems with doing two things simultaneously, following a conversation between multiple people or unexpectedly being asked to prepare a meal for multiple persons (Dröes, Schols, & Scheltens, 2017).

Apraxia

Apraxia is the inability to perform coordinated motor skills, where correctly performing a procedural task is impaired or lost (Dröes, Schols, & Scheltens, 2017). The study by Verlinden et al. (2015) shows that people could experience difficulties in performing instrumental activities of daily living around seven years before diagnosis. These activities include maintaining the house, cooking a meal or using a coffee machine. Finally, difficulties in performing basic activities of daily life deteriorate as well, including eating, bathing, getting dressed, toileting, transferring, and continence.

2.3 Quality of life

Quality of life has been subject to discussion for decades and still is. The World Health Organisation describes quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organisation, 1997). This chapter will explain quality of life in dementia in respect to activities of daily life.

2.3.1 Aspects of quality of life in dementia

Factors influencing quality of life in people with dementia is different during the course of the disease and their different stages (Ettema et al., 2005). Since the project's focus is on people with dementia living at home, factors of quality of life in the earlier stages of dementia are looked into.

Gerritsen et al. (2010) described twelve domains associated with quality of life for people with mild to moderate dementia based on existing measuring tools, opinions from people with dementia and opinions from formal caregivers. These aspects are shown in *Figure 5*. The

and freedom and especially being useful/giving meaning.

and freedom and especially being useful/giving meaning.

2.3.2 Daily functioning and quality of life

This is underlined in the literature review by Martyr et al. (2018) where functional ability

Martyr et al. (2018) where functional ability was associated with improved quality of life. A study by Andersen et al. (2004) even describes it as the main factor influencing quality of life. Secondly, the level of independence in performing activities of daily life negatively influences the experienced burden and quality of life for informal caregivers of people with dementia (Kawaharada et al., 2019; Armstrong, Gitlin, Parisi, Roth, & Gross, 2018).

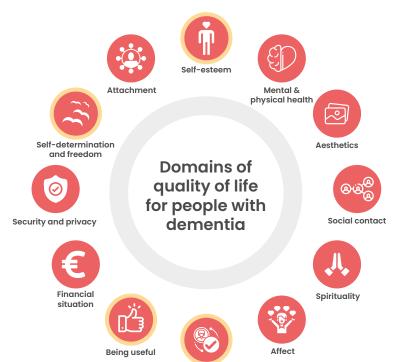
highlighted factors in the figure show which

factors could be associated with (re)learning

ciples. These factors are self-esteem/self-im-

age, enjoyment of activities, self-determination

activities of daily life and errorless learning prin-



Therefore, applying methods to improve daily functioning seems to positively impact quality of life of people with dementia. This is reflected in the study by Clare et al. (2019), where 475 people with mild-to-moderate dementia underwent individual goal-oriented cognitive rehabilitation therapy to set personally relevant goals to improve everyday functioning. Carrying out these personal relevant activities had a positive effect on coping with the disabilities of dementia, resulting in a feeling of empowerment, reduced anxiety, and improving well-being and quality of life.

Quality of life and errorless learning

When looking at the effects of errorless learning specifically, the case study by Cohen, Ylvisaker, Hamilton, Kemp, & Claiman (2010)

shows promising results. An individual with complicated memory and executive function problems was followed for seven years while relearning functional tasks through errorless learning principles. This resulted in a substantial improvement in everyday functioning and quality of life with a reduction in the needed care and reduced caregiver burden to an acceptable level.

There are no large sample studies measuring the influence of errorless learning on quality of life for people with dementia, but the application of errorless learning principles do show good results in regaining meaningful activities. Therefore, one could hypothesize that applying errorless learning could positively influence quality of life for people with dementia.

2.4 Conclusion

In Chapter 2 the context around dementia was discussed, including the societal trends, living with dementia, and quality of life of people with dementia. In this chapter the following research questions are answered:

1. How does dementia relate to Dutch society? In the Netherlands, dementia is the most expensive disease which covers more than 10% of the total healthcare costs and this is expected to grow in the coming years. At the same

time, healthcare employees experience high workloads.

eHealth is seen as a possible solution to maintain independence and improve quality of life for elderly people living at home.

2. How does dementia affect people with dementia and their surroundings?

Dementia is characterized by memory loss, social withdrawal, trouble with language, agitation, and performing familiar tasks. It can be divided in an early, mid and late stage.

More than half of informal caregivers of people with dementia experience giving care as a high burden and even 3% is overburdened. This is caused by mood and behavior problems, the ability to perform activities of daily life, and changes of social contacts.

a) How does dementia affect people's functioning?

At first people with dementia experience memory complaints, followed by problems in performing instrumental activities of daily life (IADL) and eventually basic activities of daily life (ADL).

It affects people's executive functioning, which means planning and executing complex tasks is compromised. Apraxia is the inability to perform coordinated motor skills.

b) How does dementia affect people's quality of life?

Domains that influence quality of life in people with mild to moderate dementia include self-esteem, mental & physical health, aesthetics, social contact, spirituality, affect, enjoymentt of activities, being useful, financial situation, security and privacy, self-determination and freedom, and attachment.

Functional ability does not only influence people with dementia, but also the informal caregiver's quality of life.

Improving daily functioning of people with dementia through cognitive rehabilitation, can positively effect coping with the disease, resulting in a feeling of empowerment, reduced anxiety, and improving well-being and quality of life

Errorless learning, which is a cognitive rehabilitation method, helps to regain the ability to perform meaningful activities. This could hypothetically improve quality of life, but is not yet confirmed in large sample studies.

Part 2

Literature research

Part 2 - *Literature research* describes the topic of memory in dementia and how the unaffected memory systems could be used to improve daily functioning for people with dementia by applying errorless learning principles.



Chapter 3

Memory and learning in dementia

Memory and learning are closely related cognitive functions. According to Squire (1987), this can be explained as follows: 'Learning is the process of acquiring new information, while memory refers to the persistence of learning in a state that can be revealed at a later time'.

People with dementia experience cognitive deficits which cause problems in memory, thinking, behaviour, and performing everyday activities (World Health Organization, 2019). Within this project there will be a focus on the latter. Although the cognitive functions of people with dementia deteriorate during the disease, functional disability can be reduced through cognitive rehabilitation methods (Clare et al., 2019). One of these methods is errorless learning.

This chapter explains the human memory, with a focus on the implicit long-term memory and how this could be used in learning for people with dementia. Next, the errorless learning process will be explained and how it could be applied.

In this chapter, the following research questions were answered:

- How does dementia affect memory?
- Which memory systems can be used in learning with dementia?
- What is errorless learning?
 - What are the advantages of errorless learning compared with other methods?
 - o How is it applied in real-life?

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3.1 Memory formation

The three major processes involved in memory are encoding, storing and retrieving, which is displayed in *Figure 6* and more elaborately explained in *Appendix 3*. Information from the senses enters the sensory memory and is encoded into a form that the brain can cope with. It enters the short-term memory, also called the working memory, where limited amounts of information can be stored for short periods of time. When the information from the working memory is rehearsed or used, it can be consolidated into the long-term memory, where it can be stored for minutes up to a lifetime (McLeod, 2013).

3.1.1 Memory deficits in dementia

The hippocampus is the part of the brain which is important in storing memories from the working memory into the long-term memory. In Alzheimer's disease, cell degeneration damages the hippocampus and therefore, new information will not be stored into the long-term memory (Cherry, 2019b). Retrieving information from the long-term memory is still possible in the early stages, but when the disease affects different parts of the brain, older memories can vanish as well (De Werd, Boelen, & Kessels, 2013). Appendix 4 describes how other parts of the brain are affected by different dementia types.

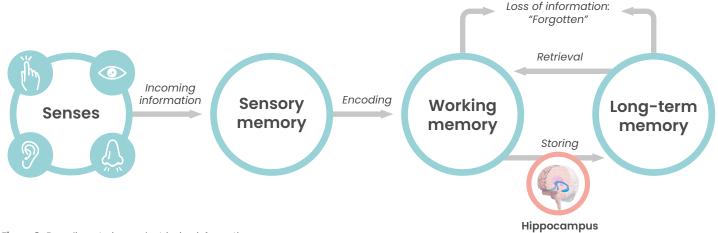


Figure 6: Encoding, storing and retrieving information (Atkinson & Shiffrin, 1968)

3.2 Long-term memory

In this chapter the model by Squire (2004) is used to explain the different systems within the long-term memory (*Figure 7*). This model divides the long-term memory into the explicit and implicit memory. The brain regions associated with the implicit memory are relatively spared in people with dementia (Eichenbaum, Cohen, Otto & Wilbe, 1992). Both memory systems can be divided in subsystems which will be briefly described.

3.2.1 Explicit memory

The outer part of the temporal lobes is where general information is stored (Alzheimer's Society, 2014). This memory is referred to as the explicit memory and deals with remembering facts, names of objects, and the meaning of words and events. This memory system is more elaborately explained in *Appendix 5*.

As the hippocampus is affected in Alzheimer's disease, people have troubles with processing day-to-day memories of personal experiences, such as remembering what you ate the day before. The outer parts of the temporal lobes are preserved for longer periods of time, resulting in longer preservation of memories from the past (Alzheimer's Society, 2014).

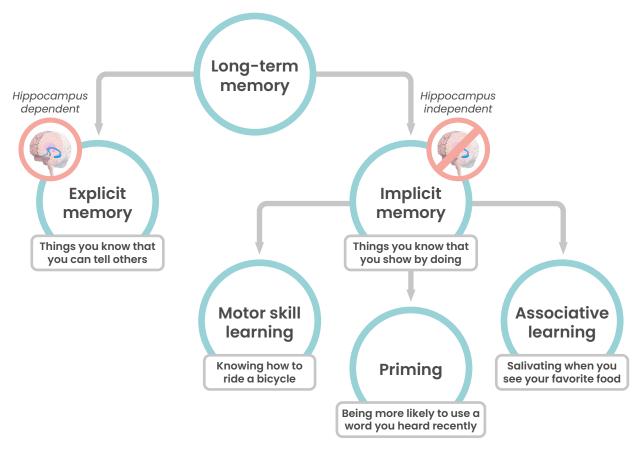


Figure 7: Division of the long-term memory by Squire (2004)

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3.2.2 Implicit memory in errorless learning

The implicit memory, also called the nondeclarative memory, is described by Harrison, Son, Kim, & Whall (2007) as an unconscious memory which cannot be recalled and described with words. It is based on previous experiences by subsequent task performance, without conscious recollection of the specific events (i.e. knowing how to ride a bicycle by doing it multiple times). As the brain regions linked to the implicit memory stay relatively well-preserved during the course of dementia, this memory system can be used to learn new things to people with an impaired explicit memory (Haslam & Kessels, 2018).

As the Squire (2004) model presents, the implicit memory consists of associative learning, priming, motor skill learning and non-associative learning. Priming, motor skill learning, and associative learning can be used in learning with people with dementia and will be shortly described.

Priming

Priming occurs when performance in speed or accuracy improves when recognizing an object that has been previously shown to someone (Harrison, Son, Kim, & Whall, 2007). Priming can be divided in conceptual priming and perceptual priming. Conceptual priming refers to an object's meaning, while perceptual priming refers to processing an object's physical features. In individuals with Alzheimer's disease, perceptual priming is spared and can be used to process information about an object faster or more accurately (Harrison et al., 2007).

Motor skill learning

Motor skill learning, also referred to as procedural learning, refers to the performance improvement by repeatedly executing a task (Dick, Hsieh, Bricker, & Dick-Muehlke, 2003). An example would be the high precision kick of a football player or knowing how much pressure to put on the brake of a car. This information is not consciously accessible or describable but is encoded in the muscles and joints (Rubenstein & Rakic, 2013). In errorless learning, motor skill learning is used by repeating specific steps, to encode the right procedure in the implicit memory.

Associative learning

In associative learning, associations are formed between two stimuli under specific conditions, resulting in a behavioral pattern (De Werd, 2017). An example would be a smell triggering a specific memory or avoiding certain foods because it made you sick a long time ago. People with dementia can learn new patterns, even if they cannot recall the exact moments in which it occurred (Eichenbaum et al., 1992).

Operant conditioning, a type of associative learning, is used in errorless learning by complimenting the person with dementia, no matter how small the achievement. This positive association is encoded in the implicit memory, which makes the learning experience more pleasurable and stimulates learning (Hoogeveen, Groenendaal, Caffò, & Perilli, 2014).

3.3 Implicit learning methods

Implicit learning in healthy individuals normally occurs in an unstructured way, which we know as trial and error learning. In research on (re)learning meaningful activities to people with dementia, errorless learning is often compared with trial and error learning.

3.3.1 Trial and error learning

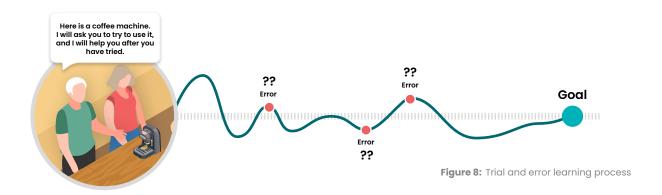
Trial and error learning is an often used learning method for people with dementia in clinical practice (De Werd, Boelen & Kessels, 2013). It consists of quessing, making errors and correcting these errors throughout the learning process. This requires someone to detect these errors and correct the procedure accordingly. In teaching activities to people with dementia, the patient is encouraged to perform the task by him/herself. In the study by Voigt-Radloff et al. (2017) the instructor intervened whenever irritations or frustrations occurred. When the patient did not succeed in performing the task, first open questions were asked, then verbal instructions would be given and eventually the right procedure was demonstrated.

3.3.2 Errorless learning

Errorless learning is the opposite of trial and error learning, as errors are reduced by encouraging someone not to guess during the learning process (Clare & Jones, 2008). In errorless learning, a task is divided in appropriate

steps. Each step is practiced together with an instructor, where he or she will first demonstrate the step accompanied with verbal instructions. The instructor will intervene when hesitations or errors occur, and the step will be repeated. Only when correctly performing a step, the next step will be practiced, until the whole task can be done independently without errors and hesitation (Voigt-Radloff et al., 2017).

The reason why errors are reduced in errorless learning is that executive functioning, which includes the ability to monitor errors, is impaired in people with dementia (Bettcher, Giovannetti, Macmullen, & Libon, 2008). This causes that errors made during tasks or activities are not noted as such. These errors could be stored into the implicit memory erroneously. When performing the task later these errors might be retrieved, resulting in a wrongly executed task (Bertens, 2016). By preventing errors, as is done in errorless learning, the goal is that only the correct procedure is stored in the implicit memory.



Multiple studies on the effects of errorless learning have been conducted. The majority of these studies show positive results in (re)learning meaningful daily activities in people with dementia compared to trial and error learning, especially in people with Alzheimer's disease (Haslam & Kessels, 2018). However, large controlled studies (Voigt-Radloff, Leonhart, Olde Rikkert, Kessels, & Hüll, 2011; Bourgeois et al., 2016; Voigt-Radloff et al., 2017), do not consistently show additional learning benefits of errorless learning compared to trial and error learning, although there are big differences between individuals (Haslam & Kessels, 2018).

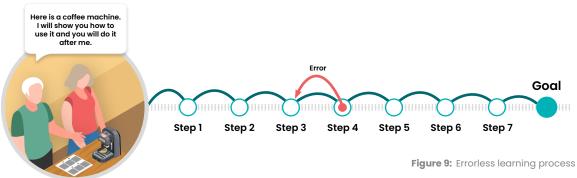
3.3.3 Errorless learning versus trial and error learning

Although both errorless learning and trial and error learning show positive effects in performing meaningful tasks, there are other differences which are relevant during the learning process, Figure 8 and Figure 9 schematically shows the differences between the methods.

When applying errorless learning, each task is tailored to the person with dementia by dividing it in an appropriate number of steps. Every completed step is followed by a compliment, which enhances the feeling of success and helps in memory formation and task performance (Broster, Blonder, & Jiang, 2012). This way, errorless learning evokes a feeling of success

in each learning session instead of feelings of failure, helplessness, and insecurity which could be experienced when using a trial and error learning approach (De Werd, Boelen, & Kessels, 2013).

As people with dementia experience feelings of failure and insecurity regularly during the day due to their cognitive impairments, preventing these feelings while learning is a good start. By guaranteeing success by dividing the task in steps and tailoring the process to the cognitive level of the person with dementia, errorless learning could induce the contrary: feelings of success and satisfaction. Therefore, there will be a focus on errorless learning in this project instead of trial and error learning.



3.4 **Errorless learning in dementia**

This chapter describes the process of errorless learning for people with dementia based on the manual by De Werd, Boelen and Kessels (2013). This manual is developed based on existing knowledge about errorless learning and with knowledge from care professionals in dementia care. The process consists of choosing the right activity, followed by a learning procedure with different auidelines and rules.

Lekeu, Wojtasik, Van der Linden and Salmon (2002) were the first to use errorless learning for regaining everyday tasks by teaching two individuals with Alzheimer's how to use a mobile phone. The literature review by De Werd, Kessels, Boelen and Olde Rikkert (2013) shows that since then, case studies have focused on multiple different tasks, such as walking a route, using a microwave, using a Senseo coffee machine, making tea, folding laundry, changing batteries and many more. The review showed positive results in skill learning through errorless learning methods which can be maintained for months. The possibilities of tasks are endless, as long as these are relevant to the person with dementia and they feel motivated to learn them.

3.4.1 Considerations of applying errorless learning

Errorless learning is a learning method which requires preparation, time, and effort from the people guiding the learning process, as displayed in Figure 10. An errorless learning

process consists of around nine learning sessions lasting 15 to 30 minutes, dependent on the level of cognition of the person with dementia and the task complexity (De Werd, Boelen and Kessels, 2013).

The RCT by Voigt-Radloff et al. (2017), where the earlier mentioned manual is used, showed positive effects that maintained for six months. However, it should be mentioned that this can never be guaranteed beforehand. It is recommended to practice at least once or twice a week and preferably on a daily basis. This way, a task can be (re)learned within two to three weeks.

A professional caregiver and informal caregiver should consider whether applying errorless learning would be worth the time and effort, since it can be experienced as an additional burden to the informal caregiver.

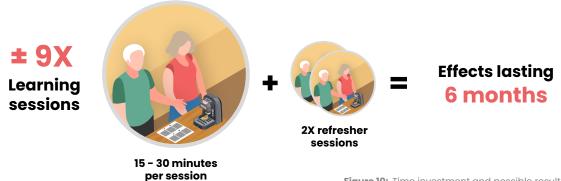


Figure 10: Time investment and possible result

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3.4.2 Activity choice

The most important criteria in errorless learning is that the person with dementia is motivated and willing to learn. The process is visualized in *Figure 11*. The chosen task should be meaningful and should be discussed with the person with dementia. An informal caregiver can assist the professional caregiver in this conversation to find a well-fitted activity for the person with dementia.

The person with dementia should perform the task without help first, to investigate how he or she performs the task and how well this goes. The task should not be too difficult nor too easy and the person with dementia should be able to perform at least one of the steps.

The task should be able to be divided in steps, with a clear beginning and ending. The order of the steps should be logical and familiar to how the person with dementia would perform it. Practicing should be done in the same environment as where it would be performed in daily life.

Figure 11: Process of determining the activity and division in steps







Determine the functional abilities



Divide the activity in steps

3.4.3 Errorless learning procedure

The errorless learning procedure contains the elements as described below.

This set of rules is called the basic procedure. It is advised to perform the basic procedure during at least half of the learning sessions until it has been performed without hesitance in two successive sessions.



The person with dementia is encouraged not to guess, since errors should be prevented.



The practitioner should repeat the series of steps several times consistently so only the correct course of action ends up in memory.



Step 1 → Step 2

I will show you

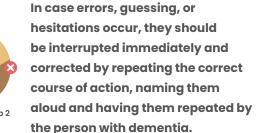
how it's done

Proceeding to the next step will only be done if the previous step can be carried out independently without errors, hesitation or guessing.



Step 1 ← Step 2

The practitioner shows the step first. The person with dementia should repeat this. This is called modelling. This way the person with dementia knows exactly what is expected so mistakes are prevented. This should be done with each step.





The practitioner uses verbal instruction to explain what the person with dementia should do.



It is essential that the person with dementia is rewarded for his or her performance, no matter how small.



The practitioner may use visual instruction, such as a step-by-step plan, pictures, pictograms or stickers with indications.

3.4.4 Fading

When the person with dementia has successfully, confidently and fluently performed the series of steps multiple times during several training sessions, the amount of instructions can be gradually reduced. This is called fading. At first, the instructor could stop modelling the steps and only giving spoken instructions while pointing at the materials where the steps should be performed. After further success, the cues could be reduced to only giving verbal instructions without pointing and eventually reduce the verbal instructions as well.

When errors or hesitations occur during the fading sessions, the instructor should go back to the basic procedure until he or she is sure the person with dementia can perform the steps independently again until proceeding with less cues.

As mentioned earlier, the learned activity can be maintained for six months after training. However, this cannot be guaranteed. It could occur that for whatever reason, the desired results will not be met. Then the decision can be made to choose a different task which is simpler, to perform only part of the task or to look for other options to reach a positive result. A possible scheme for the fading procedures is visualized in *Figure 12*.

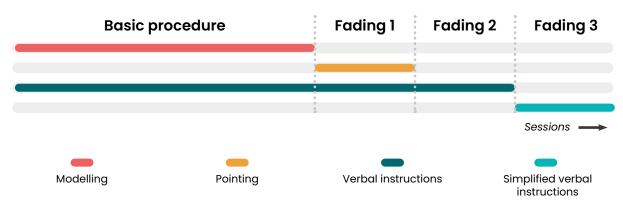


Figure 12: Steps in the fading process in errorless learning

3.5 Conclusion

In Chapter 3 dementia is discussed in relation to memory and learning. It has been discussed how memories are shaped, how this is different in people with dementia and which memory systems can be used to (re)learn meaningful activities. Errorless learning is introduced and explained how it could be used for people with dementia. In this chapter the following research questions are answered:

1. How does dementia affect memory?

In Alzheimer's disease, at first the hippocampus is impaired. This part of the brain plays an important role in memory formation. As it is damaged, new memories cannot be stored in the long-term memory and are therefore not retrievable. In later stages other parts of the brain are impaired which are associated with stored memories. This results in vanishing memories.

2. Which memory systems are used in learning with dementia?

The long-term memory can be divided into the explicit and implicit memory, where the first is affected by dementia and the latter is relatively spared in dementia. As the implicit memory is relatively spared, it can be used to learn meaningful activities to people with dementia. The implicit memory consists of priming, motor skill learning and associative learning, which are used in errorless learning.

3. What is errorless learning and how can it be applied?

Errorless learning is a highly structured learning method in which a meaningful activity is chosen, which can be learned in around nine learning sessions from 15 to 30 minutes. These are everyday tasks, such as walking a route, cooking a meal or making coffee. A task is divided in smaller steps and practiced with an instructor until performing the activity can be done independently without making errors.

Preventing errors and giving compliments while learning helps in correctly storing the activity into memory. Instructions can be decreased over time when the activity is performed correctly in multiple consecutive practicing sessions.

According to research by Voigt-Radloff et al. (2017) the learned activity can be maintained for six months after training.

Part 3

Explorative research

Part 3 - Explorative reserach describes the research done through interviews, focus groups and home visits. This part describes the subsequent insights from this research.

Chapter 4

The errorless learning process

Through the literature research, a picture was formed on how the errorless learning process is currently applied together with its possibilities. To explore this learning method better, an explorative research has been conducted.

The goal of this explorative research was to gain insights on how errorless learning could be incorporated in the home situation, who is involved in the process and what is needed to make this happen. This chapter explains the results that came forward from the different explorative research methods.

In this chapter, the following design questions were answered:

- How could errorless learning be applied within the home situation?
 - What role could an informal caregiver play in applying errorless learning in the home environment?
 - Which human factors could influence the success of errorless learning in the home environment?

4.1 Research methods

Different methods have been used to create deeper insights into the needs of the different stakeholders in the errorless learning process. Say, Do and Make tools (Figure 13) are used as described in the Convivial Toolbox to get insights on different levels (Elizabeth, Sanders, & Stappers, 2013, pp. 66-67). These tools generate insights on four knowledge levels: explicit, observative, tacit and latent. This knowledge can be generated by using interviews, observations and generative sessions, as displayed in Figure 14. Within this project, methods on all levels have been conducted. These include interviews, home visits and focus groups which will be briefly discussed.

4.1.1 Stakeholders

After the literature research, Dutch researchers on errorless learning for people with dementia were contacted and interviewed. Based on these first interviews and literature, a stakeholder map was made. Based on this, it was decided who should be included in the explorative research. An overview of the stakeholders is displayed in *Figure 15*. As mostly married couples participated in the research, the informal caregiver is mostly referred to as the partner of the person with dementia. In reality, the informal caregiver could also be someone else.



Figure 13: Say, Do and Make tools and techniques that complement and reinforce each other (Convivial Toolbox, 2013).

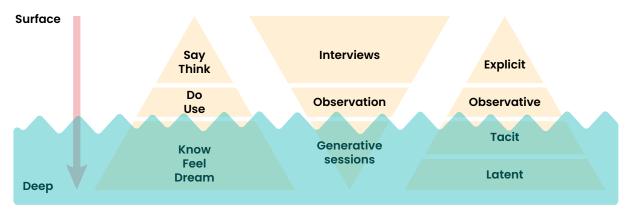


Figure 14: Methods that study what people Say, Do and Make to access different levels of knowledge (Convivial Toolbox, 2013).

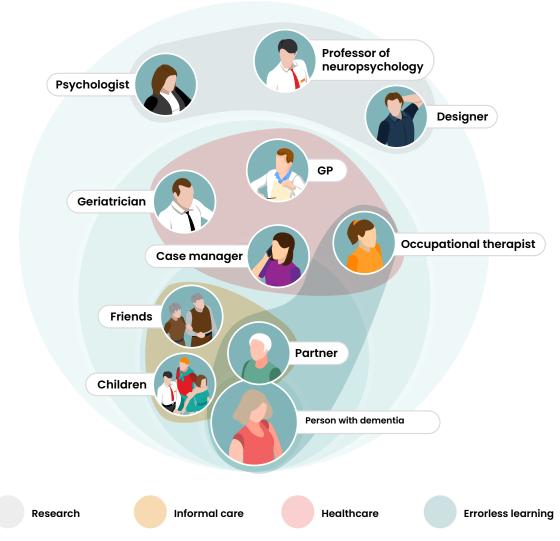
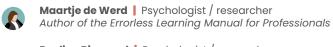


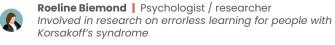
Figure 15: Stakeholders involved in errorless learning

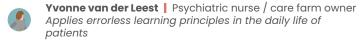
4.1.2 Interviews

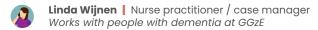
In this project, researchers on errorless learning have been interviewed to gain insights on the learning process and the possibilities of applying the method in the home situation. Case managers have been interviewed to see how the learning method could fit in the current situation and at last, an occupational therapist has been interviewed to see how a professional should be involved in the learning process. *Figure 16* shows the different interviewees.

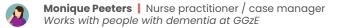
The semi-structured interviews were done in person or by phone and were guided with key questions and divided by topic headings (Robson, 2011, p. 285). An example of an interview guide, as well as the semi-transcript can be found in *Appendix 6*.



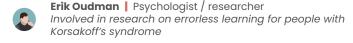








Roy Kessels | Professor of Neuropsychology Involved in research on errorless learning and co-author of the Errorless Learning Manual for Professionals



Netta van 't Leven | Occupational therapist / lecturer Involved in research on psychosocial interventions for people with dementia and their informal caregivers

4.1.3 Focus groups

Innovate Dementia hosts a focus group every month. This is a gathering of people living with dementia and informal caregivers to discuss innovations for people with dementia. During this project, I hosted the focus group twice.

The first to discuss meaningful activities for people with dementia and how these have changed, and the second to discuss the role of the informal caregiver in the learning process. Printed materials were used to engage people in the discussion and to encourage interaction, as shown in *Figure 17*. Through these sessions, insights on the following subjects were gathered:

- Meaningful moments and activities for people living with dementia
- The importance of role patterns in couples
- The meaning of being independent
- At what moment in time people are open to start with errorless learning

Results of this session were filled in sheets that gave an overview of tasks divided between the person with dementia and informal caregiver.

In Appendix 7 the sessions are explained more in-depth, together with the visuals and resulting sheets.

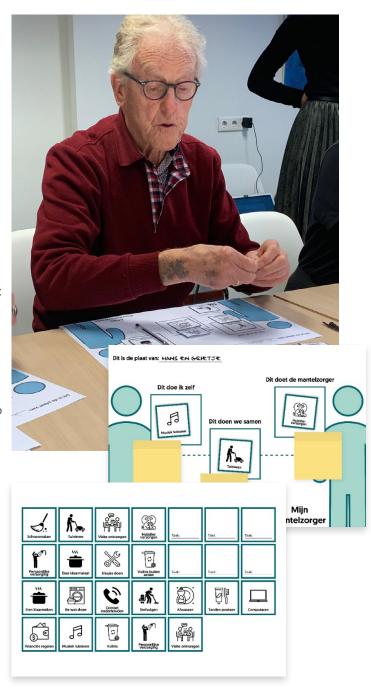


Figure 17: Interactive session during the first focus group, together with the printed materials

4.1.4 Case studies: Exploring errorless learning in practice

To get a better understanding of how errorless learning could be applied in the home environment, a Research through Design approach has been used. Which can be described as: "the production of knowledge by means of design activities" (Stappers & Giaccardi, 2017). During this research, the errorless learning method has been put partly into practice in the environment of two married couples of whom the partner suffers from Alzheimer's disease.

The goal of this research was to experience the process of errorless learning from the beginning up to the first learning sessions. This gave me, as the designer, the opportunity to experience what an informal caregiver might experience while applying errorless learning. This way, needs and wishes from the person with dementia and their informal caregivers were explored.

Each couple was visited three times. In the first visit, relevant and meaningful tasks within the home environment have been discussed, of which one or two tasks were chosen to practice. For each task, a step-by-step plan was made.

Small adjustments were done, like using a sticker to indicate which button to press. These plans have been put to practice in the second and third visit. The partner was instructed afterwards on how they could practice the task together.

The practiced tasks were turning on the television, using a digital radio and using a mobile phone to call the partner. These cases have produced insights in the process of learning in the home environment and in how the person with dementia and their partner experienced this process. Appendix 8 describes the case studies in more detail.

4.1.5 Clustering insights

Insights, quotes, statements and facts from the explorative research have been printed on cards and color-coded based on the source it came from. These sources include literature, experts, informal caregivers, people with dementia, observations, and professional caregivers.

The cards were clustered by topic on a large sheet of paper, as visualized in Figure 18. The most important clusters will be discussed in the next chapter.



4.2 Stakeholders in errorless learning

The explorative research aimed to answer the design questions: how could errorless learning be applied in the home situation, which role could the informal caregiver play, and which factors could influence the success of the learning process?

To answer these questions, the most important people within the errorless learning process are described. These include the person with dementia, the informal caregiver and the professional caregiver. Each role is described with their needs and needed competences.

4.2.1 Informal caregiver

The informal caregiver is the person who aids and supervises the daily care of the person with dementia. This could be someone's partner, child, family member or friend. Within this project, the informal caregiver has been approached as the partner of the person with dementia, as they participated in the explorative research.

The informal caregiver would be the ideal person to teach meaningful tasks to the person with dementia, but..

When applying errorless learning in the home environment, tasks should be practiced with

the person with dementia on a regular basis. The informal caregiver could take a prominent role in the learning process and is mentioned as "the ideal person" in multiple expert interviews. They are the people closest to the person with dementia, know them and their habits best, and see them daily.



In the current situation, the professional caregiver must come by every learning session. That's quite inefficient, while the informal caregiver could practice every day.

Although this seems to be the ideal person to practice meaningful tasks, there are some things to take into consideration when implementing errorless learning and involving the informal caregiver, such as the needed knowledge on errorless learning, their caregiving strategies and their approach towards the person with dementia.

.. informal caregiver should adopt a supporting care strategy

In the interviews with experts the *caregiver* strategy of the informal caregiver came forward as an important factor. In general, three



caregiver strategies could be distinguished: the nurturing, supporting and non-adapting (De Vugt et al., 2004), and are explained in *Appendix* 9. Informal caregivers who use a supporting strategy put effort in adapting to the functional abilities of the person with dementia and allowing them to do as many things as possible. The person with dementia is only assisted when needed and is openly discussing their support. They tend to be patient by adopting a calm and cautious attitude. They support the person with dementia in undertaking physical, social or household activities. Their patience and empathy are important aspects of this strategy.



Informal caregiver 1



A particular way of thinking should be developed, which make people aware that their partner changes and that it is caused by a disease. And that you should accept it which means you should adjust your own behavior. You need to get in this state of mind.

Patience during the learning process and empathizing with the person with dementia are crucial within the learning process.

Informal caregiver should become aware of the learning abilities of people with dementia..

Most people are not aware of the learning abilities of people with dementia, including informal caregivers. They should be made aware of these abilities and aspects of errorless learning before putting it in practice. Showing success stories could play an important role in creating awareness.



Informal caregiver 2



I show it to him every time [putting on the tv] but he is just not able do it anymore.

.. and the rules of the errorless learning method

The informal caregiver should become aware of the errorless learning method, as it is completely different form normal learning. The current manual on errorless learning, as described in Chapter 3.4, is meant for therapists and professional caregivers and therefore not fitted for a non-professional audience. The information on errorless learning should be simplified and tailored to informal caregivers.

Watch out for overburdening

Overburdening of the informal caregiver was an often-mentioned topic in the interviews. As errorless learning is an additional task that could be assigned to the caregiver, he or she could experience this as an extra burden. Both the caregiver and care professional should consider if involvement of the informal caregiver does not unnecessarily increase this burden.

Apply errorless learning at the right moment

Errorless learning is not something an informal caregiver would like to be informed on shortly after diagnosis, as they are confronted with lots of information and emotions. Although it should not be explicitly mentioned at first, they would like to be able to read information on how to cope with the situation. Booklets or flyers were mentioned as possibilities where they would expect to read about errorless learning.

Guidance creates confidence

Informal caregivers expressed the need for a professional to show them around the learning process to create confidence. They expressed that the interference of a professional caregiver could also act as an authority for the person with dementia to participate in the process easier as they listen to them better.

4.2.2 Person with dementia

In errorless learning, the person with dementia is put central. There are several things that should be taken into consideration when applying this method in the home environment. The needs and wishes for the people with dementia will be described, as well as important characteristics of people with dementia for success in errorless learning.

Find out which activities motivate the person with dementia

The motivation of the person with dementia is the most important criteria for (re)learning something, as he or she should have the feeling that the learning is relevant and meaningful. This motivation should be intrinsic and not imposed by their surroundings. Through asking the right questions on someone's likes and dislikes, a meaningful task should be chosen.

Example from case study

Practicing a meaningless activity was seen in of the case studies. The informal caregiver experienced irritations when her husband with Alzheimer's disease, put on the television wrongly whereby the internet router needed to be reset. Her husband, who typically shows little enthusiasm, agreed with this to be practiced. Only while practicing he expressed that this activity felt meaningless to him. Hereafter another activity was chosen which he was motivated to work on.

When not to apply errorless learning

When there are occurrences of depression, severe anxiety or severe apathy influencing their motivation, applying errorless learning will not be useful (De Werd, Boelen, & Kessels, 2013).

Include people with dementia in the process

People with dementia should be involved and informed during the learning process. They should be informed on what the learning encompasses, how it works and why it is done to prevent irritation and incomprehension.

Example from case study

Before the third visit, an instruction was sent by email to the informal caregiver on how to practice the chosen task. This was read by the partner with dementia who felt left out and felt like the instructions were childish. Therefore, openness during the learning procedure and sensitive information writing should prevent such situations.

Create a feeling of accomplishment

As people get confronted with their impaired memory every day, proof of their abilities to perform certain tasks or activities creates a feeling of accomplishment. People tell about their accomplishments and show pride in that.

A result of the case study was that the woman with Alzheimer's disease could put on their digital radio independently.





Informal caregiver 1



I see a happy smile every morning when the radio is started.



Woman with dementia



Then I say: Yes! And that is a good start of the day.

Keep in mind the changing role patterns

Although role patterns between husband and wife have changed over the last decades, traditional division of roles is still seen in Dutch society (Van Den Breemer, 2019). Involvement from the partner in tasks he has never dealt with could cause tension. When applying errorless learning principles, one should consider that a person with dementia might get the feeling the informal caregiver is taking over things he or she always did, while the goal is to maintain this activity.



Linda Wijnen



You want to work on a relationship pattern that has been around for 50 years. That is the big challenge.



Informal caregiver 1



We need to be on the same page, so she doesn't get the feeling that I am taking it [online banking] over completely. Then I should go upstairs secretly and practice internet banking. I don't want that!

4.2.3 Professional caregivers

The professional caregiver is needed during the learning process to guide and advice the informal caregiver and person with dementia. As an informal caregiver does not have the needed knowledge, guidance is needed in choosing the right task and in applying the right learning procedure.

Awareness on the learning abilities should increase

Different professions could apply errorless learning with people with dementia, including psychologists, case managers and occupational therapists. From multiple interviews it came forward that there still is little awareness of general practitioners, geriatricians and case managers of the possibility of the learning abilities in dementia and the accompanying methods.

Occupational therapist are well-suited to do the job

Occupational therapists have knowledge on analyzing what is meaningful for people with dementia and can translate these needs into concrete activities to improve one's daily functioning. These qualities make occupational

therapists well-suited to guide the errorless learning process.

Guide the informal caregiver through the process

A professional caregiver should analyze the impairments of the person with dementia and tailor the learning procedure accordingly. A case manager has good insights in this, as they regularly visit the patients in the home situation. This could be communicated towards the person guiding the learning process. The right task should be chosen, based on the needs, wishes and skills of the person with dementia while involving the informal caregiver. The professional caregiver should indicate whether the informal caregiver is competent in executing the errorless learning process, bearing in mind their caring strategy and experienced burden.



Chapter 5

Desired journey

The previous chapters are concluded and summarized in a desired journey: a vision on how the errorless learning process could take place based on the insights gathered from literature and explorative research. The key players in this journey are Albert and Eline, a fictional married couple who experience dementia and use the errorless learning principle to sustain a level of independence in performing daily activities. They are supported by a case manager and occupational therapist throughout the process.

Personas

5.1

The personas are made based on the people encountered during the explorative research, such as the home visits and focus groups. The personas are based on the *Evidence Based Dementia Personas* by Jais, Hignett, Estupiñan, and Hogervorst (2018).

Albert and Eline have been married for 45 years. They have three children and five grandchildren who they see almost every week. They enjoy going out together to visit museums and theaters and like going out for dinner. Eline has been diagnosed with Alzheimer's disease two years ago.

Albert had a fulltime job his whole career, while Eline took care of the children and had a part time job. She performed most household tasks, like doing the laundry, cleaning the house and cooking, although Albert helped with small tasks such as vacuum cleaning and unpacking the dishwasher. He took care of the finances.

Albert en Eline have made a promise to each other that they will take care of each other as good and as long as possible.

Albert

Informal caregiver, 72 years

Caring strategy: Albert is a kind and caring person who takes care of his wife who suffers from Alzheimer's disease. Due to his caring nature, he tends to take over tasks from his wife which she struggles with or which take long.

Occupation and hobbies: During his career, he has been working as a math teacher at secondary schools and has been retired for seven years. He loves cycling and visiting museums.

Coping with situation: Although he doesn't mind taking care of his wife, he does feel the burden of it. Their roll pattern is slightly shifting due to his wife's illness. He sometimes struggles with that.

Role patterns: During their marriage Albert performed some household tasks from time to time, such as vacuum cleaning and unpacking the dishwasher.

Living with dementia, 70 years

Eline has been diagnosed with Alzheimer's disease two years ago and is in the early stages of the disease.

Coping with situation: Although she feels comfortable receiving help, she is anxious to lose her independence and the ability to perform tasks such as cooking and household tasks.

Occupation and hobbies: During her career, Eline worked part time as a bank employee at a national bank, where she loved helping people. She enjoys making a walk through the forest and playing the piano and loves taking care of her grandchildren.

Role patterns: During their marriage Eline took care over the household and cooking most of the time.





5.2 **Desired** journey

Figure 19 shows the first version of the desired journey, which can be found in Appendix 10. Throughout the project, the journey has been discussed and adjusted. In the later versions of the journey the process is divided into the following seven phases: diagnosis, orientation, analysis, preparation, practicing, evaluation and result. The desired journey consists of three layers: The steps taken during the process, who is involved at what time and the emotions and thoughts of the informal caregiver and person with dementia. These are all derived from the gathered insights. Chapter 5.2 describes the final desired journey.

Diagnosis

When people get diagnosed with dementia, they and their surroundings must deal with lots of information and need to find out how to cope with this new situation. Nevertheless, they would like to get an overview of the possibilities on how to deal with dementia through a booklet or flyer.

Orientation

When the person with dementia shows difficulties in performing daily activities, they could inform about the possibilities with their case manager, general practitioner or geriatrician. When they think applying errorless learning might be beneficial, they can bring the informal caregiver in contact with a practitioner with knowledge about errorless learning, such as an occupational therapist. Information about the dementia severity and characteristics of the couple could be shared between professionals.

Analysis

The practitioner analyzes the skill level of the person with dementia and should consider if the errorless learning approach fits the person with dementia and their informal caregiver. Through identifying someone's needs, wishes, likes, dislikes and difficulties, they should find a meaningful and relevant task or activity together. The chosen task needs to be analyzed and written down in steps tailored to the skill level of the person with dementia.

Preparation

The informal caregiver should be instructed on digesting information about the learning abilities of people with dementia, the theory behind errorless learning, the rules on how to apply errorless learning and how to make a step-bystep manual.

Practicing

The first practicing session will be done together with the practitioner so he or she could provide feedback and answer questions from the informal caregiver. While practicing, the rules from the basic procedure as described in *Chapter 3.4.3* should be applied. These include:

- Encourage the person with dementia not to guess.
- The instructions given should be consistent throughout learning sessions.
- The practitioner shows the step first. The person with dementia should imitate this.
- Correct guessing or errors by repeating the previous sequence of steps.
- Reward every correctly executed step, no matter how small, with a compliment.
- Proceeding to the next step will only be done if the previous step can be carried out independently without errors, hesitation or guessing.

When all steps have been performed correctly according to the basic procedure, cues could be faded throughout the next practicing sessions to let the person with dementia perform the activity more independently.

Evaluation

Since the professional is not present at each practicing session, each session should be evaluated on how many steps have been performed correctly and how many times it has been practiced. Secondly, questions about the procedure can be written down. This gives the professional a better view on the progress and could indicate whether instructions could be faded in the next sessions.

Result

When the procedure has been practiced during multiple sessions and the instructions have been faded over time, it is possible that the person with dementia could perform the activity independently. But success could also entail partially performing the task or with the help of an instruction manual. If no progress is shown, a different approach could be used, or a simpler task could be chosen.

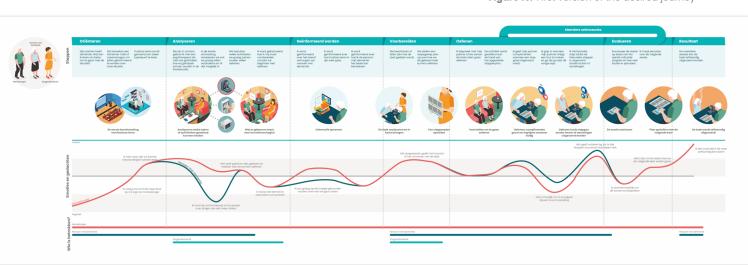


Figure 19: First version of the desired journey

5.3 Conclusion

In Chapter 4 and 5, the explorative research is discussed. Through interviews, focus groups and home visits, insights were gathered on how errorless learning could or should be applied in the home situation. Through clustering the insights, the most important topics were identified and discussed by the different stakeholders in the process. The desired journey summarizes the explorative research into a visual overview of the errorless learning process. Chapter 4 and 5 answered the following design question:

1. How could errorless learning be applied within the home situation?

When applying errorless learning methods into the home situation by involving the informal caregiver into the process, a few criteria should be met before it can succeed. Although the informal caregiver would be the ideal person to apply the learning principles, he or she should be empathic, patient and supportive, which could be described as someone using a supportive care strategy. The informal caregiver should feel space to adopt the role of an instructor in the learning process and not experience this as a high burden.

a) What role could an informal caregiver play in applying errorless learning in the home environment?

The informal caregiver could serve the role of instructor: quiding and teaching the learning procedure that was defined together with a professional caregiver. The informal caregiver must gain insights in why this way of learning is used for people with dementia, how this type of learning works in practice and how the person with dementia should be approached.

b) Which human factors could influence the success of errorless learning in the home environment?

Role patterns could play an important role within the errorless learning process, as the person with dementia could get the feeling that someone is taking over tasks while the contrary is true. The person with dementia should be involved to prevent this feeling and to keep them included into the process.

In terms of professional guidance in the learning process, an occupational therapist is well-suited as they are educated on translating the people's needs into concrete activities. They should guide the informal caregiver and person with dementia through the process to choose the right activity and to correctly apply the learning procedure. However, currently there is too little knowledge and awareness on errorless learning in people who are involved in dementia care, which could mean that people with dementia and informal caregiver never get to know about the learning process.

Part 4

Design brief

Part 4 - Design brief describes the refined design goal based on the literature and explorative research, including opportunities for design and design requirements.



Chapter 6

Design focus

In the previous chapters, insights and knowledge has been gathered which created a better view on the errorless learning process and who should participated to bring this in the home situation. This chapter describes the design focus of this project after the analysis phase, including the intended goal of the design and the qualities that should be included.

6.1 Design goal

Based on the research and explorative analysis, the refined design goal is defined. The design goal serves as a guide during ideation and can be referred to when evaluating the design.

Enable informal caregivers of people with **early to mid-stage dementia** to teach **meaningful activities** together with the required **guidance from a professional caregiver** within the home environment to create a **feeling of accomplishment** by providing a **transparent** and **unambiguous structure** throughout the learning process.

Enable

Often informal caregivers are surprised to hear that people with dementia still have learning abilities with which they can learn tasks that are meaningful to them. It is important to inform informal caregivers on how people with dementia can learn and that it is different from how people learn without a cognitive disorder.

Once people are aware of the learning abilities of people with dementia, they should become aware on how to approach the person with dementia while learning. This approach is different from what people are used to, since it is important to support the person with dementia instead of confronting them or taking over tasks too easily.

Enabling in this sense is providing the informal caregivers with the needed knowledge on how people with dementia can learn new tasks and which interactive qualities are needed to make it a successful and pleasant experience.

Early to mid-stage dementia

This project is focused on people with dementia living at home. The group that lives at typically suffer from early to mid-stage dementia. This is also the group in which errorless learning seems to be most effective.

Meaningful activities

There are many options on what someone with dementia could learn. But to prevent failure, frustration and demotivation, it is essential that an activity is chosen that is meaningful and relevant to the person with dementia. Otherwise, it could become an unpleasurable experience without good results.

Guidance from a professional caregiver

Errorless learning is something which is not familiar to most people and knowledge on the subject is crucial to apply it effectively without frustration. As the activity should be meaningful to the person with dementia, the professional caregiver should analyze a suitable activity.

Secondly, informal caregivers have shown the need to be supported by a professional caregiver to create confidence on how to apply the learning principles.

Feeling of accomplishment

In the analysis phase it became evident that people with dementia experienced a feeling of satisfaction when they were able to complete certain tasks independently, such as reading an article, sending an email, or speaking in a foreign language. The goal is to evoke this feeling of accomplishment during and after (re) learning meaningful tasks.

Transparent

Although people with dementia have a cognitive disability, this does not mean they should not be treated like an adult. Therefore, including them in the design and process is important. The process should be transparent, meaning that they should be included by providing dementia friendly information.

Unambiguous structure

As errorless learning is a highly structured way of learning. The information given to the informal caregiver and person with dementia should be unambiguous with as little room for interpretation as possible. This could prevent wrongly executed procedures.

6.2 Opportunities for design

Based on the desired journey, three opportunities for design have been identified which can be explored during the ideation phase of the design process, as seen in *Figure 20*. Each opportunity will be briefly discussed.

Informing and instructing the informal caregiver

The current manual on errorless learning by De Werd, Boelen, & Kessels (2013) is meant for care professionals with a certain education level and therefore not suitable for informal caregivers. There are opportunities in exploring how the information from the book could be translated and transformed into a simpler form that is understandable for informal caregivers. This should contain information about the reason behind errorless learning and how it should be put into practice.

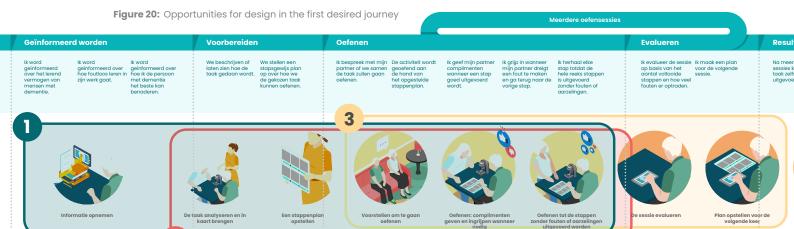
Guidance in making and executing step-by-step plan

At some point in the learning process an activity is broken down into steps and written down to create an overview of the steps that should be taught to the person with dementia. In some studies and real-life examples, visuals were used to create a manual. These give structure

to the practitioner teaching the person with dementia, as well as create an aid for people with dementia to independently follow the right steps. There is an opportunity in creating a tool which could be used by professional and informal caregivers to make a clear and tangible instruction.

Evaluation of the learning procedure

Errorless learning is a method in which instructions will be faded over time to gradually let people with dementia execute the activity more independently. However, since the professional caregiver is not always present to evaluate the progress of the person with dementia during learning, the informal caregiver could benefit from knowing when to proceed with which learning conditions. Evaluation of each learning session could help in determining how to proceed in the next learning sessions.



-

Based on the main insights from the literature and explorative research, design requirements were extracted. These guide the design process to choose ideas and to develop a solution which fits the needs and the situation around errorless learning. The main design requirements are:

- The design should create confidence for the informal caregiver during the learning process
- Create a feeling of independence for the person with dementia
- The design should provide understandable and unambiguous information
- The design should support the learning process
- The design should be accessible for both people with dementia and informal caregivers
- It should provide guidance to the informal caregiver during the learning process
- The design should give the person with dementia a feeling of accomplishment

Part 5

Design

Part 5 - Design describes the design process that is done after the research, including ideation, design exploration, the concept proposal, and the concept validation.

Chapter 7

Ideation

After gathering insights from the method of errorless learning and about the needs and wishes of people involved in this learning process, the next step is the process of creating ideas.

This chapter describes the ideation process, which was done individually and through a generative session, the description of early ideas and the concept choice.

7.1 Ideation approach

Generative session

In the generative session six students from the faculty of Industrial Design Engineering were gathered, as seen in *Figure 22*. This two-hour session consisted of a presentation on the topic, defining How to-questions and generating ideas on these questions. From the generated ideas, clusters were made which were used to define concept ideas. The ideas generated during this session where used as inspiration during the remaining ideation phase. The planning of the generative session can be found in *Appendix 11*.

Individual ideation

The individual ideation started by generating ideas on the opportunities for design as defined in *Chapter 6.2*:

- Informing and instructing the informal caregiver
- Guidance in making and executing stepby-step plan
- Evaluation of the learning procedure

Each opportunity has been ideated on by defining "How to"-questions (Van Boeijen, Daalhuizen, van der Schoor, & Zijlstra, 2014, pp. 127) by looking at the different opportunities for design and the design requirements. These resulted in many post-it's with ideas ranging from useful to ridiculous. By combining post-it's, new ideas were created and plotted on the desired journey to put it in perspective of the different opportunities for design. This process is displayed in *Figure 21*.

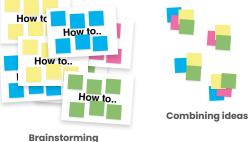
The next page shows the selected generated ideas based on the design opportunities and plotted on the desired journey, as seen in *Figure 23*. They are labeled with the different design requirements. Each idea will be shortly explained.

Figure 22: Generative session



Figure 21: Ideation process





67

Idea selection









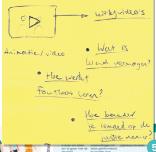












Examples and advice

A guide which shows examples of tasks that are possible to learn for people with dementia and who they could get in contact with. This could serve as inspiration and could convince someone to try learning with dementia.

Practical information

A guide with practical information that shows what small adjustments can be done to make a procedure more understandable for people with dementia. Such as using stickers, labels or colors and corresponding examples.

3. Learning platform

Platform where the professional caregiver oversees what information an informal caregiver will see and read based on their caring strategy and the skills of the person with dementia.

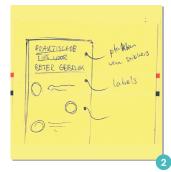
Informal caregiver quiz

A series of questions which should be answered by the informal caregiver to indicate whether he or she can participate in this process based on the criteria of errorless learning and his or her caring strategy. This results into an advice on which possibilities there are.

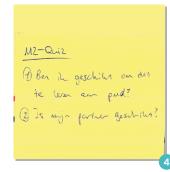
Informative videos

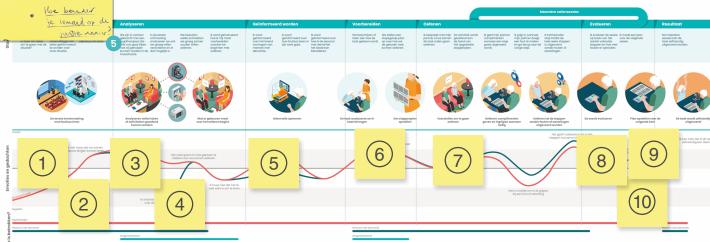
Videos for informal caregivers on how errorless learning is done and which aspects are important in the learning process.

























Step-by-step plan creator

A database with step-by-step plans on how certain tasks can be done. These could be used or adjusted to their situation by the professional or informal caregiver. They could serve as an inspiration or as a starting point for similar tasks. This could be displayed through an application or printed on paper.

Learning reminders

Reminders at the beginning of each learning session to refresh the informal caregiver's memory on how to apply the right procedure and what he or she should be aware of. In the shape of printed cards or through an application.

Instructional cards

Cards which show which instructions you should give and how you can minimize the instructions when the learning sessions go well to let the person with dementia execute the task more independently.

Evaluation app

An evaluation in an application after each practicing session with questions on how it went. Based on these questions an advice for the next practicing session could be given.

10. Progress app

Showing the progress of a task to give the person with dementia a feeling of accomplishment by always showing positivity in the app. A growing tree could be used to show the progress.











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7.2 **Concept choice**

Errorless learning is a process that takes time and patience to reach the goal of gaining more independence in performing meaningful activities for people with dementia. I thought that only elaborating on one idea within the defined "opportunities for design" could not fulfill all design requirements and therefore not lead to actual implementation of errorless learning in the home situation of people with dementia, although this was my goal from the beginning of the project.

7.2.1 Platform

I chose to focus on the bigger picture and to look at the whole process and **develop a concept for** a platform that serves the informal caregiver and person with dementia from the moment of diagnosis up to achieving results by practicing meaningful tasks. This went hand in hand with elaborating the desired journey and developing a solution which fits within this story. Some of the previously described ideas will be integrated within this platform, as schematically presented in Figure 24.

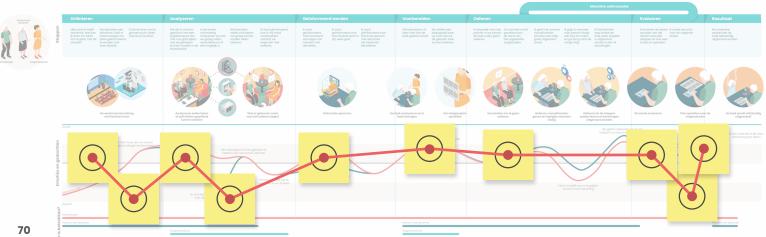
However, the graduation project does not offer the time to develop all ideas and content needed for such a platform. The decision was made to work out the desired journey, while globally working out the platform. Within this platform, one idea within will be worked out in more detail to show its possibilities.

Through a platform, the people involved in the learning process can be informed with the needed information on learning with dementia and how errorless learning works. It helps in creating awareness on the possibilities of errorless learning and the platform could support and guide the informal caregiver throughout the learning process.

The goal of the platform is to inform, educate and guide the informal caregiver and person with dementia in the errorless learning process.

Inform

Through the platform, the informal caregiver should be informed on the learning abilities of people with dementia. They need to know the possibilities of the learning method, how people with dementia can (re)learn meaningful activities and that this is different from learning





as people are used to. Otherwise, the informal caregiver might not understand why he or she should perform the errorless learning principles as they intended, which could negatively influence the outcome.

Educate

Once people are aware, they should be equipped with the right knowledge on how this learning could be used in practice. They should be educated on the procedures of errorless learning, such as making a step-by-step plan, knowing when to step in during learning sessions, and how the learning process evolves through fading.

Guide

The informal caregiver should be guided when to read or learn the needed information and when to apply the proper instructions. This can be done through the platform or through guidance from the professional caregiver. This aims to create confidence during the learning process.

7.2.2 Platform idea selection

One idea is developed into more detail to show the possibilities of the platform. During the interviews described in *Chapter 4.1.2*, some ideas have been discussed. A tool for creating a step-by-step manual was described as a valuable addition to learning with dementia by different interviewees.

Secondly, this idea meets the most design requirements as described in *Chapter 6.3*:



The design should create confidence for the informal caregiver during the learning process



Create a feeling of independence for the person with dementia



The design should provide understandable and unambiguous information



The design should support the learning process



The design should be accessible for both people with dementia and informal caregivers



It should provide guidance to the informal caregiver during the learning process

The idea hooks on the core principle of errorless learning. Creating a step-by-step manual means developing a plan fitted to the person with dementia and capture this in text and images of situations which are familiar to them. It creates a guideline for the person with dementia, who can see the different steps of an activity, as well as a guideline for the informal caregiver, who can use the plan to consistently practice the same steps. This creates feelings of independence, confidence, unambiguity and guidance during the learning process.

Given these advantages and the feedback by the interviewees, it was decided to further develop a tool to make a step-by-step plan.

Chapter 8

Design exploration

To show the development of the proposal of the platform, this chapter describes the decisions made during the design phase. As discussed, the platform aims to inform, educate and guide the informal caregiver throughout the learning process. *Table 1* shows the different phases from the desired journey and whether the platform will inform, educate or guide the informal caregiver.

The platform will be discussed together with the desired journey and how these have evolved during the design process. Different iterations of the step-by-step plan were made. The interface of the tool will be explained on its different elements.

	Diagnosis	Orientation	Analysis
Inform	Inform on the possibility of learning with dementia	Inform what learning with dementia is and what is possible	Inform on what should be learned by the informal caregiver
Educate			
		Cuido to find out if this fits the	

8.1 Platform and desired journey

The journey has been developed by discussing it with different stakeholders within the errorless learning process. In these conversations, the steps described in the desired journey been discussed, as well as the different ideas, as described in Chapter 7.1. The journey has been discussed with five informal caregivers during the focus group and with an occupational therapist.

Focus group

During the focus group, as described in Appendix 7, the journey has been discussed together with the basic procedure of the errorless learning method. This discussion focused on when to apply errorless learning, where they expect to hear from it, how they would like to be guided, and how to be informed on the learning procedure. This helped developing the diagnosis, orientation and analysis phases of the desired journey, as well as defining the needed media through which the information should be available. In this focus group, it was decided to both use print and web design within the platform.

Occupational therapist

The desired journey has been discussed with an occupational therapist who is involved in research on cognitive rehabilitation for people with dementia. This helped to develop the journey in terms of the involvement of a professional caregiver during the learning process and how often this could or should occur.

Different ideas on post-it's were plotted on the desired journey and discussed, with a focus on the step-by-step plan. This was acknowledged a valuable tool which could be used by both the occupational therapist as the informal caregiver.





This looks a lot better than the current situation, where a written piece of paper is used, maybe with some images from the internet.

During both occasions, the desired journey served as a communication tool to discuss the possibilities of errorless learning for people in the home situation. This helped in engaging people into the design process and in discussing the design proposal.

Table 1 - Informing, educating and guiding the informal caregiver and person with dementia in the different phases

Preparation	Practicing	Evaluation	Result
Inform how to make a step-by-step plan	Reminders about the errorless learning process		
Educate how to apply the basic procedure of errorless learning		Educate on how to minimize instructions	
Guide in making a step-by-step plan	Guide on which instructions to give in the learning session	Guide the evaluation of the learning session	Guide how to proceed after reaching result

8.2 Step-by-step plan

The step-by-step plan tool is part of the platform and consists of multiple parts:

- Instruction page on how to make good photos and instructions
- An digital tool where a step-by-step plan can be composed
- The printed step-by-step plan

These three parts have been developed by first analyzing existing interfaces of websites which offer an online tool to create collages, posters and other visual content. UX and UI elements from these websites have been used as inspiration, such as an image gallery, dragging and dropping photos and a Help-function (*Figure 25*). There has been an analysis on how to write clear instructions and how to make clear photos, which is summarized in an instruction page, which can be found in *Appendix 12*. At last, Dementia Digital Design Guidelines have been taken into consideration as described on the right (Williams, 2017).

Iterations

The interface of the step-by-step plan tool has been developed by creating wireframes, which have been tested on paper with five students who were asked to imagine being an elderly person and use the interface. They were asked to drag and drop photos, print the plan, add steps and resize certain elements of the interface. Three different iterations have been done before developing the interface in more detail.

Although these subjects do not resemble the actual target group, the tests gave better insights in how the interface could be simplified. *Figure 26* shows the different wireframes, which are displayed in *Appendix 13*.







Figure 25: Examples of websites where visual content is created

Accessible design

One of the design requirements is that the platform should be accessible for people with dementia and for their informal caregivers. As people with dementia deal with memory problems and possibly experience visuoperceptual changes, specific care should be paid to the visual design of the platform. This means carefully choosing colors and contrast, fonts and font sizes, page navigation, interface design, proper use of images and using the right language. In the spreadsheet by Rik Williams (2017) these different principles are described.

Although the number of people above the age of 75 who use devices with internet has grown significantly over the past few years (CBS, 2019a), people without internet access should not be excluded from the platform. Therefore, the most important information should be developed in a paper version as well.

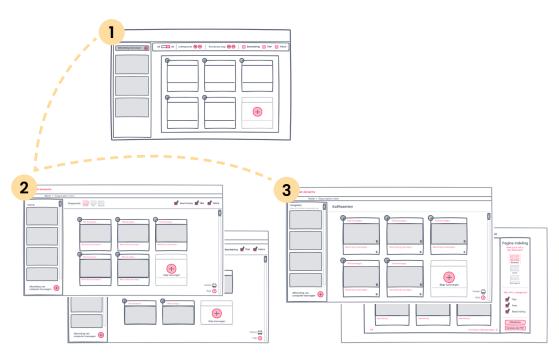


Figure 26: Wireframe iterations of the step-by-step plan tool

Chapter 9

Concept proposal: Leren met dementie

Leren met dementie (learning with dementia) is a concept for a platform which supports people with dementia and their informal caregivers to (re)learn meaningful activities to sustain or regain a certain level of independence. The platform creates awareness on the possibilities of the learning abilities with dementia and provides the needed knowledge and tools for informal caregivers to apply the errorless learning method. Informal caregivers are guided through the process with instructions from the platform and with the help of professional caregivers.

Information is provided through a website, an application and a booklet. This chapter describes the proposal of the different solutions which could be included in the platform and for what reason. One aspect of the platform, called the *Stappenplan Maker* (Step-by-step plan maker), will be explained in more detail.

Part of the proposal in this project is a Desired Journey: a developed view on how the platform could be used in real-life, based on literature and explorative research.

9.1 **Desired Journey**

The Desired Journey as portraited in *Figure 27 and Appendix 14* an envisioned scenario of a husband and his wife living with dementia. It describes the errorless learning process from the point of view of the informal caregiver from the moment of diagnosis to practicing up to the result. The journey consists of four different layers:

- **Process** The different steps that are taken in the process, including illustrations and descriptions of what happens in which step.
- People involved It shows when the informal caregiver, person with dementia, case manager or occupational therapist is involved and in what phase.
- **Emotions & thoughts** The emotions and thoughts of the informal caregivers and person with dementia are displayed.
- **Solutions** Per phase, the different solutions that are included in the platform are displayed.

Learning process

The process consists of seven phases: diagnosis, orientation, analysis, preparation, practicing, evaluation and result. It encompasses around eight learning sessions of 15 to 30 minutes and three or more visits from an occupational therapist or professional with knowledge on the subject.

How to use the journey?

The journey can be used as a communication tool to explain the platform or scenario to researchers, informal caregivers, professional caregivers or organisations. The journey is only one representation of how the process could take place, based on the research done in this project. By using for example post-it's it can be an interactive tool to discuss the steps taken in the journey and the solutions proposed in the platform. This process can be repeated with different stakeholders.

For instance, with professional caregivers it can be used to discuss the involvement of a professional and how this should happen. The informal caregiver could be asked whether the emotions and thoughts are accurate and what concerns or wishes they have during the process. And with researchers it could be used to discuss a research plan.

Leren met dementie

Figure 27: Final desired journey

9.2 The platform

The platform is explained based on the different phases that the errorless learning process consists of. The function of the proposed solutions are explained in short and describe how they contribute to either informing, educating or guiding the informal caregiver within the process.

Leren met dementie

Grip krijgen op wat voor u belangrijk is

The term *Errorless learning* has been replaced by *Leren met dementie* (learning with dementia), which is the title of the platform. Informal caregivers explained that putting emphasis on *errors* could carry a negative association. A subtitle is added: *Grip krijgen op wat voor u belangrijk is* (Get a grip on what is important to you), as it gives context to the title and better explains what the platform is about.

Website, application and booklet

The platform consists of three different parts: a website, a booklet and an application, as seen in *Figure 28*. Information on learning with dementia, the learning procedure and practical information about the learning process can be found in both the booklet and website. The booklet only provides the necessary information, while more elaborate information can be found on the website. The booklet is introduced to include people without a computer or internet connection or for who prefer reading information on paper. People can get this booklet via the website or a professional caregiver.

The application serves as an aid throughout the learning process to make a step-by-step plan, to remind the informal caregiver, to evaluate sessions and to keep track of the learning progress.

Role of the professional

The professional caregiver guides the informal caregiver and person with dementia through the learning process. They serve the most important role during the *Analysis*-phase, as it is important to chose a suitable and meaningful task, which needs to be divided in appropriate steps.

The professional caregiver can attend the informal caregiver on the needed information and get insights on the progress through the platform.

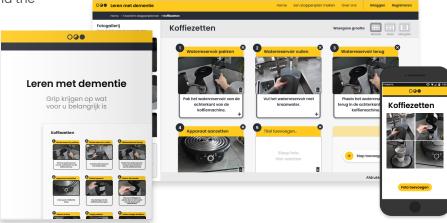


Figure 28: Booklet, website and application of the platform









Diagnosis

To make people aware that there are possibilities in the future, a brochure or flyer could be given. This should explain the possibilities of *Leren met dementia* and who they should get in contact with to apply it.

Inform

Orientation

People might get in contact with the platform without the intervention of a professional. On the website, there should be an introduction on what the learning abilities of people with dementia, examples of what can be learned and success stories of other people to create confidence in the learning method.

Inform

Learning with dementia is not suited for every informal caregiver or for every person with dementia, as explained in *Chapter 4.2*. Therefore, informal caregivers can read information about the requirements for learning with dementia and answer questions. Based on their answers, an advice could be given. It should show who the informal caregiver should get in contact with to further explore the possibilities.

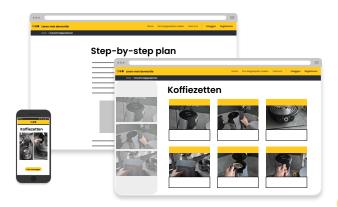
Guide

Analysis

During the analysis phase, the participation of a professional caregiver, such as an occupational therapist, is crucial. In this phase, the professional should determine the abilities of the person with dementia, analyze which tasks or activities would be meaningful and beneficial and the professional should help in breaking down the task in appropriate steps. All of which specific knowledge and insight in the disease is needed.

Guide









Preparation

When learning with dementia will be initiated, the informal caregiver should be educated on how the basic learning procedure, as described in *Chapter 4.2*, should be applied. Example videos that show this procedure together with textual information. Showing examples of do's and don'ts help in creating understanding on the method.

Inform | Educate

Next to the learning procedure the informal caregiver will be guided in making a step-by-step plan. Through an instruction page and the online tool, a step-by-step plan can be created. This will be more elaborately explained on page 82.

Inform | Guide

Practicing

As the basic procedure might require someone to remember a lot of information and rules, reminders before each learning session can help the informal caregiver in correctly applying the learning method. These short reminders could be printed on cards, incorporated in the book or shown through the app.

Guide

The printed step-by-step plan will be used during the learning sessions to consistently give the same instructions and as an aid for the person with dementia in executing the right procedure. This will be explained in-depth on page 82.

Guide







Evaluation

The occupational therapist will not be present during most learning sessions. To help the informal caregiver in determining how to proceed the next learning session, he or she could evaluate each learning by answering questions about the performed session.

- How many times was the activity practiced?
- Which steps were successfully performed at the end of the session?
- Were all steps performed in the right order?

By answering these questions, a standardized advice could be given on how to proceed the next learning session. This could also give the professional a realistic view on the progress during an in between visit.

Guide

When progress is made during the learning process, instructions can be minimized until the person with dementia can do it (almost) independently. The informal caregiver should be educated on how these instructions should be given. This information will be shared in the website and booklet.

Educate



Result

Whenever the person with dementia shows progress in performing the task and can do it independently, it is possible to look for other meaningful activities to practice and the informal caregiver can develop a new step-bystep plan in consultation with the therapist. The same applies when the expected result is not met, and an easier activity can be chosen and worked out.

9.3 Stappenplan maker

A tool to create a step-by-step plan is worked out in more detail. This tool consists of four different elements: an instruction page, the Stappenplan maker, the Leren met dementie-application, and a printed step-by-step plan. Each part will be explained according to Figure 30. By scanning the QR-code, a prototype of the website can be visited. The screens are displayed in Appendix 12.

The informal caregiver needs to register to the platform, which can be done with the help of the professional caregiver. This gives them access to information about the learning process and enables the Stappenplan maker and the application.

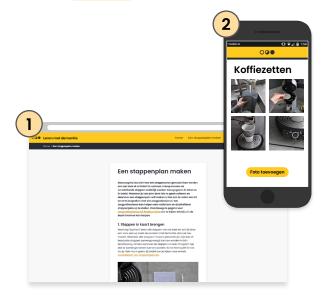
1 Instruction page

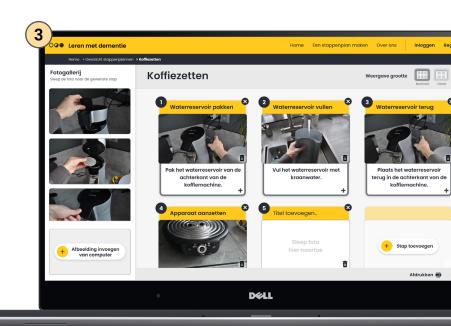
As making a clear step-by-step plan is not as easy as it sounds, an instruction page provides (3) Stappenplan maker tips on how to write instructions and how to make clear photos with a smartphone. These should be photos of the real-life situation, as these are most recognisable for the person with dementia. The whole page can be seen in Appendix 12 and by scanning clicking the QR-code.

2 Leren met dementie-application

As elderly increasingly make use of smartphones, an application will be used to easily transfer the photos from the smartphone to the online tool. Whenever the photos are added to the task or activity within the app, they will be synchronized and ready for use in the Image gallery within the online tool.

The Stappenplan maker is an online tool and part of the Leren met dementie-website. The tool offers a simple interface, with an image gallery where images from the app are synchronized. There is still the possibility to add images from the computer.





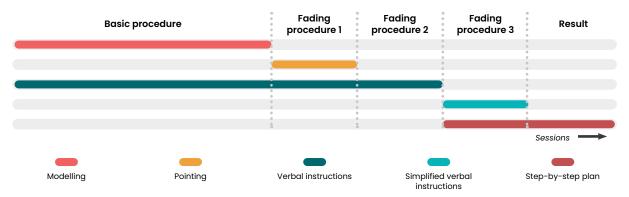


Figure 29: Fading procedure including the step-by-step plan

Users can add steps, and fill in a title and description. Images can be dragged and dropped in the right field. The size of the displayed steps can be enlarged if necessary. The user can use the *Help*-function when they need explaining about the tool.

4 The plan can be printed on one or multiple A4-papers. The user can choose three different sizes of the steps: normal, large and extra large. Different configurations of the plan can be made. The title, photo or description can be unchecked to minimize the given instructions and to promote independently performing the activity.

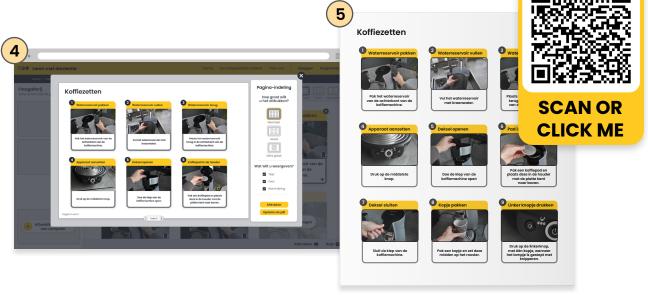
Printed plan

5 Once the plan is printed, it can be used during the learning process. During the first learning sessions the informal caregiver will use it as a reminder to teach the right sequence and to give the same instructions over and over.

When the basic procedure, as explained in Chapter 3.4.3, has been correctly executed during multiple learning sessions in succession, instructions can be faded, as seen in Figure 29. Then the printed plan can be used as a reminder for the person with dementia. The informal caregiver will only give simplified verbal instructions, such as the titles of the steps, and point to the step-by-step plan in order to let the person with dementia use the plan during the task. This way, the person with dementia can do the activity independently with the help of the plan. Appendix 15 shows three different step-by-step plans.

Building up a database

When multiple plans will be added to the platform, a database will be build up with examples which can be used and altered by other users or inspire people on developing one themselves.



Chapter 10

Design validation

The design as proposed in the previous chapter is a concept for a not yet existing platform. This means that the needed content is not available yet, which asks for a different approach to test and validate with the intended users.

To validate the proposed concept, the platform and desired journey have been discussed in a focus group with people living with dementia and informal caregivers, and with Roy Kessels, professor of neuropsychology at the Radboud University Nijmegen. By discussing the process, journey and the platform, a better picture of the feasability, viability and desirability of the concept can be made.

Within this chapter the validation with the focus group and Roy Kessels will be discussed together with the results from this validation.

From this validation, final adjustments are proposed to both the journey and the platform.

10.1 Validation focus group

During the focus group, the process of the proposed concept has been discussed with four people with dementia and four informal caregivers. This meeting consisted of a short introduction on the topic, followed by a described scenario which was derived from the Desired Journey. This was done through an interactive presentation, as seen in *Figure 32*.

The goal of the validation was to determine whether informal caregivers and people with dementia would endorse the proposed solution and whether they would agree with the described scenario.

A conscious choice has been made to present the platform with a focus on the booklet as the leading source of information instead of using the website and the application, since previous focus groups have shown that discussing interfaces and the use of technology could distract from the essence of the discussion. The scenario that was presented is seen in *Figure 31* and *Appendix 16*.

The presentation and discussion took 45 minutes and was audio recorded. The scenario was presented in sixteen steps and inbetween steps questions were asked about the process and the proposed solutions. Questions were asked about the involvement of a professional caregiver, the willingness to construct a step-by-step plan, the use and readability of the printed step-by-step plan, and practicing activities.



Figure 32: Discussion and presentation during the focus group



Figure 31: Part of the presented scenario during the focus group.

10.1.1 Validation results

The results from the validation with the focus group are summarized and supported by quotes from this meeting.

Involvement of the professional caregiver

The informal caregivers confirmed the desire of the presence professional caregiver, as they can show the procedures and tell them about the right information, while they also serve as an authority for the person with dementia.



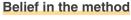
Informal caregiver 1

A professional can give you tips and can say:
"You need to do it a little bit differently." Things
you might not be aware of you did or said wrong.
Then she can immediately correct it.



Informal caregiver 2

They listen more easily to an outsider than to an informal caregiver.



People expressed their belief in learning with dementia, especially the people who already participated in the case study or people who already made a step-by-step plan themselves.



Informal caregiver 3

It works and I am convinced that it works. The keyword is patience. And yes, sometimes it goes wrong. But then I experience that the shock reaction, the frustration is many times less than it was before. And that there is something stored in memory that says: I can do it.

Adjusting the plan

Within the focus group it has been discussed that the plan could be adjusted when the plan

does not work (anymore). Some doubt about this was expressed during the focus group, as well during the validation with Roy Kessels, as described in the next paragraph.



Informal caregiver 2

But if you start adjusting it and more elaborately, I wonder. Is it still understood what it says?

Clear printed plan

While passing around the printed step-by-step plans, people confirmed it was readable and that the photos made the procedure clear.

Setting-up the plan

When asked whether informal caregivers would be able to make the photos themselves and set-up a step-by-step plan they agreed that they would be willing and capable of that. A man with dementia expressed doubt whether such plan are really always linear.



Man with dementia

I cannot imagine that you will get a linear stepby-step plan from all those things. When making coffee you first have to top up the water. It is rare that it all really follows one after the other. There are variations every time.

Unsuspected occurances during practicing

The participants were wondering what they should do when something unexpected would occur during following the step-by-step plan and how that could be solved.



Informal caregiver 1

With some coffee machines a light sometimes blinks that says: "this is full, this is empty".



10.2 Validation with expert

Roy Kessels is a professor of neuropsychology and has been involved in the research on errorless learning from the early beginning and is co-author of the book *Foutloos leren bij dementie*. The platform has been evaluated by discussing it based on the different steps in the desired journey together with the proposed solutions.

The goal of the validation was to discuss the different deliverables. The proposed journey, the platform and the different components were discussed to be able to define the desirability, feasability and viability of the concept.

During the one-hour meeting the desired journey was printed and used as a discussion tool to evaluate the different aspects of the platform. The digital prototype of the Stappenplan maker was discussed together with the instruction page and the printed plans.

10.2.1 Validation results

The results from the validation with Roy Kessels are summarized and supported by quotes from this meeting.

Involvement of the occupational therapist

The involvement of the occupational therapist as the professional caregiver was discussed.

Occupational therapist would fit the needed capabilities, although this is not broadly known.



Roy Kessels

In practice, it would be ideal if the occupational would do this, since they are trained. I think the case manager is not aware of this. A barrier could be that case managers do not know this or want to solve the problem themselves.

Practicing frequency

During the discussion, it was advised to practice on a daily basis within the limits of the informal caregiver and person with dementia. It is possible to practice more than one task at the same time.

Adjusting the plan

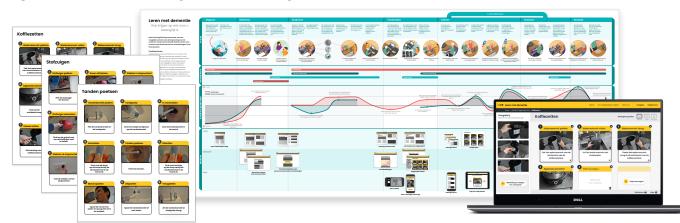
While discussing how to adjust the step-by-step plan, it was advised not to make adjustments to the existing plan.



Roy Kessels

I would not adjust the step-by-step plan. I would start with such a step-by-step plan, worked out in this way.





It was suggested that if the person with dementia fails the task after a while, the task could be practiced again or a simpler task should be chosen to practice.

Platform name

The use of the name *Leren met dementie* was discussed and agreed upon.



Roy Kessels

In the past one of the names was active learning. I think learning with dementia is even better. In principle, the informal caregivers have nothing to do with the term errorless learning. I also find calling them "mistakes" rather than "errors" to be a nice one.

Evaluating the learning sessions

The evaluation questions in the application were discussed. It was concluded that asking questions after a training session through an app or written in a booklet could be of added value. These could be used to advice on how to proceed with the learning sessions and whether instructions could be faded.



Roy Kessels

Maybe it could be done by using a score? That you have done the first session and you indicate how many steps went well and that you can check or uncheck all steps that went well.

Use an application on smartphone and tablet

It was suggested to not only focus on a website and smartphone application, but also on a tablet application, as many people use tablets instead of computers.



Roy Kessels

You suggest a website that is very computer-based. But many elderly people have a tablet and not a PC. You have to make sure it works on all those platforms. Shouldn't you think of an app for the tablet and an app for the smartphone?

Use of a tablet while learning

It was suggested that the tablet could be used during learning as well and could be clearer to the person with dementia. It could be used to indicate which step is performed by looking at the tablet. The paper version might display too much information during practicing, but could be used as an overview to do it independently after training is completed.



Roy Kessels

The caregiver could also use the app for this. That you first show the first step on the tablet, then the second step, etc. A patient himself will probably not be able to do this independently. Then a printed version would be best.

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10.3 Validation conclusion

The goal of the validation was to make a statement on the viability, desirability and feasability of the concept and the scenario described in the journey. In the two meetings the proposed journey, platform and the Stappenplan maker are discussed.

Desirability

In the focus group, the concept of learning with dementia was explained by means of a scenario and by discussing the step-by-step plans. During the meeting, most informal caregiver showed believe and interest in the concept. Although it is promising, a more in-depth validation would be needed, since the concept was only broadly described. In this validation the platform could be shown with more elobarote content and real life demonstrations, to conclude whether informal caregivers would be able to perform this learning process together with the person living with dementia. The people with dementia showed understanding in the subject and in the printed step-by-step plans, although a good explanation would be needed to create understanding why this is done.

In the meeting with Roy Kessels, the platform was seen as a valuable addition to the current method of errorless learning. However, certain adjustments could be done to the platform, such as integrating a tablet application for making the plan as well as to use during the learning process.

Viability

As with most projects for people with dementia, funding is needed to realize the needed research and development, as these projects often don't generate income. Such funds are available in the Netherlands, which will be discussed in the recommendations in *Chapter* 11.2

Feasability

The conclusion from the validation with Roy Kessels is that building such a platform would be possible when involving the right people in the development of the platform. This means involving a designer to further develop the user interface of the platform, a developer to translate the design into a working prototype and a researcher to research the effectiveness of the platform with people living with dementia. This will be more elaborately discussed in *Chapter 11.2* as well.

10.3.1 Final adjustments

Based on the validation meetings, a few final adjustments have been done to the concept proposal and to the desired journey, which will be briefly discussed. The adjustments will be added to the desired journey, which can be found in *Appendix 14. Figure 34* shows on which aspects the adjustments have been done.

Platform

- The questions asked in the application to evaluate the learning session. These questions are already used in the design proposal in Chapter 9.2.
- A tablet appiclation could better fit the target group of elderly people, instead of using a computer. Figure 34 shows how the application could look like.
 With the application, an activity could be practiced step-by-step without overwhelming the person with dementia with all the information displayed on the step-by-step plan. The whole plan can be used when the activity is performed independently as a reminder.

Desired journey

- The practicing frequency, as well as the amount of activities that can be learned simultaneously.
- Making adjustments to the initial step-by-step plan is not recommended, as these changes would require the procedure to be practiced again. Practicing the same procedure or choosing a different activity would be recommended.



10.4 Conclusion

Leren met dementie is a first iteration and set-up for a platform that could serve people with dementia and their informal caregiver(s) to (re)learn meaningful activities in the home situation.

The proposed platform is described on how it should inform, educate or guide the informal caregiver through the process by briefly explaining the different components of the website, booklet and application.

The Stappenplan maker together with the printed step-by-step plans, are worked out in more detail to show how the platform could look like and how it could be used by the person with dementia and the informal caregiver.

To conclude, the concept proposal can serve as a base to further develop, discuss, research and test the possibilities of errorless learning for people with dementia in the home environment by involving the informal caregiver. The desired journey, together with the description of the platform, can play a role in this by using it as a tool for discussing the content with stakeholders.

More research is needed to evaluate the usability and understandability of the platform, as well as the influence of involving the informal caregivers and the step-by-step plan on the learning effects for people with dementia.

Part 6

Conclusion

In this chapter an overall conclusion of the project is described, together with adiscussion about the project approach and recommendations for further development.

Chapter 11

Project conclusion

Within this thesis the aim was to research the possibilities of involving informal caregivers in the errorless learning process for people with dementia in the home environment. Based on the research done on this topic, a concept proposal should be developed to support informal caregivers to (re)learn meaningful tasks or activities to people with dementia to maintain or increase their independence.

In the analysis phase of the project, literature research was done on the errorless learning method. This gave an overview of how this method is applied in the current situation and which elements it consists of. To define what is needed to bring this method in the home environment and involve the informal caregiver into the process, an explorative research has been conducted. This research consisted of doing interviews with experts on errorless learning and dementia care, hosting focus groups with people with dementia and informal caregivers, and performing case studies by visiting two couples living with dementia to partly apply the errorless procedure.

Based on the literature and explorative research, the most important aspects concerning the errorless learning process in the home situation were described. This was done by describing the gathered insights about the most important stakeholders in the errorless learning: the person with dementia, the informal caregiver, and the professional caregiver who should guide the learning process. This was translated into a vision on how errorless learning could be performed in the home environment by visualizing it in a desired journey.

A new design goal, opportunities for design, and design requirements where defined, which formed the base of the design phase. Individual and group ideation sessions were done which resulted into the proposal of a platform which was developed iteratively through low-fidelity tests, interviews, and a focus group.

Simutaneously the desired journey was refined.

The concept proposal *Leren met dementie* is a platform which informs, educates, and guides the informal caregiver throughout the process of errorless learning to (re)learn meaningful activites to people with dementia. It provides information on why this learning method should be applied, how to apply it, and how to approach the person with dementia. This is done through a website, booklet, and application. Part of this website and application is an online tool, the Stappenplan maker. With this tool a (printed) step-by-step plan can be made with pictures and instructions tailored to the person with dementia to use during the learning sessions.

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The concept proposal was validated in a focus group where five people with dementia and four informal caregivers participated. Secondly, the platform was evaluated with a professor of neuropsychology who is involved in research on errorless learning for people with dementia. This was done by describing the scenario as visualized in the desired journey and discussing the platform *Leren met dementie* with the goal to determine the desirability, feasability and viability of the proposal.

Based on the validation, it could be concluded that Leren met dementie could serve as a base to further develop, discuss, research and test the possibilities of errorless learning for people with dementia in the home environment by involving the informal caregiver. However, more research is needed to evaluate the usability and understandability of the platform for the target group. Secondly, the influence of involving the informal caregivers and the step-by-step plan on the learning effects for people with dementia should be researched.

11.1 Discussion

This chapter discusses the project based on the context of the project, as described in Chapter 2.1 and the approach used throughout the project.

11.1.1 Context

In Chapter 2.1 societal trends are discussed that are related to care for people with dementia. These topics included pressure on healthcare, caregiver burden and eHealth. Each topic will be discussed in relation to the proposed concept Leren met dementie.

Caregiver burden

Over half of the informal caregivers experiences giving care to a person with dementia as a high burden. As discussed in Chapter 2.3.2 the functional abilities of people with dementia influence the experienced burden of informal caregivers. It could be hypothesized that creating more independence for people with dementia through errorless learning principles could positively influence this burden. However, in the proposed concept, the informal caregiver is given an extra task, as being the instructor in the learning sessions. It should be researched whether the proposed way of teaching the person with dementia increases the caregiver burden.

Pressure on healthcare

Dementia care costs are about 10% of the total healthcare costs in the Netherlands. Most of these costs are made in treating people in nursing homes. The question arises whether the proposed concept could postpone the admission to a nursing home and decrease the need of professional help in the home situation.

Admission to a nursing home is often caused by the the high burden or overburdening of the informal caregiver. If people with dementia

can live at home longer by sustaining a level of independence due to applying errorless learning principles, costs could be reduced by postponing the admission to nursing homes. Again, research should be done to test this hypothesis.

Secondly, the concept proposal increases the involvement of the informal caregiver, while the professional caregiver serves a more guiding role. Minimizing the role of the professional caregiver could reduce costs, but this should be researched and compared with the current situation.

Whether the platform could minimize the workload of a professional caregiver can also not be concluded yet.

eHealth

The committee for Toekomst zorg thuiswonende ouderen expressed in a statement that the integration of smart, appropriate, digitally supported care is seen as one of the few solutions that can lead to greater intensity and quality of care without the need for more staff. The proposed platform could play a role in gathering data about the factors influencing the outcome of applying errorless learning and could optimize the current method. However, more research is needed to define which data would be gathered and how this could be done legally.

11.1.2 Project approach

The limitations of project approach will be discussed on the different phases of the project.

Analysis

The analysis phase consisted of a literature research and an explorative research. The explorative research has been done with focus groups, interviews and home vists.

The home visits have been conducted as a research by design approach by visiting the two couples in their home environment. Limitations of the performed approach was that a fourth meeting could have been organized were the process was evaluated with the person with dementia and the informal caregiver, as this could have created better insights in the experiences and the gained effects from the case study.

Design

After the decision was made to work out the proposed platform, limited time was left to work out the concept in detail. From this moment up to the end of the design phase, iterations could have been tested and discussed more intensively with the target group and experts on errorless learning. This would have resulted in a more elaborate concept and stronger design.

Testing and validation

Testing the platform for the informal caregivers and people with dementia was done through presenting a scenario where elements of the platform were discussed. This was done without focusing on the digital elements of the design, as this has caused discussion during previous focus groups. This compromises the validation, as the digital platform has not been discussed in detail.

11.1.3 Project evaluation

The goal of this project was to bring errorless learning closer to people with dementia together with the informal caregiver by offering a solution that can guide the learning process. Part of this goal was to create a feeling of accomplishment for the person with dementia.

Within this project I have seen that (re)learning something minor as turning on a digital radio, can already bring happiness to a person's life, as it gives them a feeling of success in a world of insecurity due to their deteriorating memory. However, the concept proposal *Leren met dementie* has not explicitly incorporated creating an extra of accomplishment, which could have been brought forward better.

Although lots of aspects still should be researched, I think the concept proposal can be a base for further developing a platform that can support errorless learning and hopefully create awareness on the possibilities for people with dementia. I hope the desired journey can play an important in this.

11.2 Recommendations

Looking back at the concept proposal, recommendations can be given on how to further develop the concept and its different elements. These recommendations will be discussed per topic.

Platform design

The different elements of the platform are described briefly. Information that should be taught to informal caregivers can be found in the book Foutloos leren met dementie: een praktische handleiding by De Werd, Boelen and Kessels (2013). It is advised that people who would further develop the platform take good notice of the information in this book. This information should be altered and "translated" into a shape that is understandable for informal caregivers. It is advised to involve informal caregivers in this writing process to optimize the understandability.

Within this project, only one occupational therapist has been involved in the project. It is advised to **further investigate what role an** occupational therapist or other professional caregiver should play within the platform and how they can use the platform in their advantage.

Accessible design is important as it makes sure that elderly and people with dementia can be included into the platform. It is advised to take notice of the design principles as are discussed in Chapter 8.2. It is advised to test the usability, visual readability and understandability of the platform through user tests with people with dementia and informal caregivers.

Further development

To further develop the platform, the following steps could be taken:

Funding is needed to pay for further development of the concept. There are funds and organisations that offer funding to projects and innovations in dementia care. Examples of possibilites are Alzheimer Nederland, Fonds NutsOhra, and WZH Innovatiefonds, which have been discussed in the interviews. This should be further explored if it is decided to continue this project.

Research will be needed to develop the platform. At first, the most important elements of the platform should be worked out. These include writing the information for the informal caregiver for understanding and applying the learning method. Secondly, a prototype of the platform should be developed which can generate a step-by-step plan. A research plan for a pilot study should be set-up and performed with people with dementia and informal caregivers, accompanied with a researcher who guides the process. Within this pilot study the following aspects could be researched:

- Usability of setting up a step-by-step plan through the interface
- Usability of the step-by-step plan
- Usability and understandability of the written information
- Evaluating the learning sessions on paper or digitally to advice on how to proceed the next learning sessions
- Informal caregiver's capabilities of teaching activities with the errorless learning principles to people with dementia

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 Needed assistance and guidance of a professional caregiver throughout the learning process

Based on the results of the pilot study, further steps could be taken.

Awareness of errorless learning

From the interviews, it appeared that the knowledge about the learning abilities of people with dementia and methods such as errorless learning are not always present in people associated with dementia care. These include general practitioners, case managers, and occupational therapists. There should be thought about a way to create awareness on these possibilities for people with dementia.

Use outside errorless learning

Using the platform outside the target group of people with dementia could be explored. These could include **children with autism, people with Korsakoff syndrome or people with other mental disorders**.

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