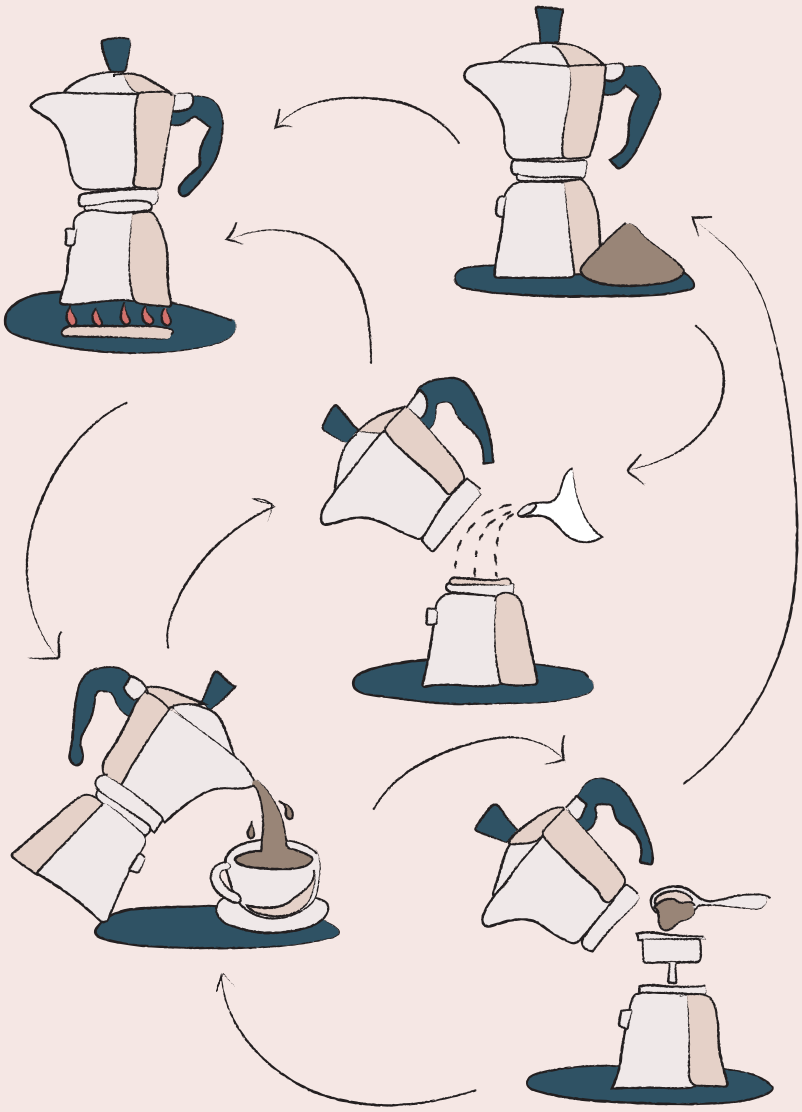

COOKING WITH DEMENTIA

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Master thesis

MSc Design for Interaction

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EXECUTIVE SUMMARY

People with dementia often quit cooking early on in their illness because it is too complex, tiring, or frustrating. With mild dementia, people struggle with planning and figuring out the order of the cooking steps. Also, they find it challenging to stay focussed on the tasks at hand. Furthermore, their short-term memory causes them to struggle to remember instructions and which steps they have already done.

However, cooking has immense benefits, such as giving a person a sense of autonomy, respect, and purpose and helping bring people closer together. Furthermore, cooking trains cognitive and motoric skills, which allow people with dementia to retain their skills for as long as possible. Currently, there exist recipes designed for people with cognitive impairment, but they do not meet the needs and desires of each individual. In contrast, occupational therapists create individual step-by-step plans, but these require much time and insight. Therefore, this thesis aims to help guide people with mild dementia through a cooking activity at home or at dementia meeting centres in collaboration with other clients or caregivers in a scalable yet personalised way.

Through an iterative approach with extensive involvement of the target group, a new recipe format was developed that suits the needs of people with dementia. The paper recipes use visual elements combined with textual descriptions to optimise understanding and following the recipe. Users navigate through the steps using a pawn to remember which step they are working on, and others can keep track of their progress. Caregivers are best aware of the person with dementia's instructional needs, cooking habits, and food preferences. Thus, our application Happje enables caregivers to write recipes themselves by writing the steps in a way that suits their client. Happje automatically adds corresponding icons, puts the steps in the correct layout, and helps with exporting or printing the recipe.

The recipe format was evaluated with the intended target group, context, and activity to see whether it helped achieve the design goal. Clients quickly understood the steps through the recipe's visuals, layout, and step formulation. However, navigating through the steps was more challenging as clients forgot to move the pawn consistently. The collaborative cooking activity was greatly enjoyed by participants and well suited for both families at home and friends at meeting centres. Most (but not all) caregivers appeared capable and motivated to write the recipes.

We recommend improving the navigation of the recipe by redesigning the pawn and adding a digital recipe mode to Happje. We suggest further developing Happje and testing its usability with the target group. Further studies could evaluate how practicing with the recipes could improve following the recipes, collaboration, and trust between caregivers and PwDs.

TERMINOLOGY

The terminology used in this thesis is explained below.

Dementia - A general term for loss of memory, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life.

Person with dementia (PwD or PwDs)– A person with dementia.

Clients - Another word for people with dementia.

Informal caregivers - People who give care to a person with dementia, such as friends or family, usually without any payment.

Formal caregivers – A paid professional who takes care of the person with dementia.

Early dementia - The first phase in the dementia progression.

Early-onset dementia - People who get dementia early on in their life, when they are younger than 65 years old.

Cooking - Anything to do with preparing food or drinks. It could be a four-course meal or a simple cup of tea.

Geriatric physician - Doctor that focuses on health care of older adults. They aim to promote health by preventing and treating diseases and disabilities in older adults.

Occupational therapist - Helps injured, ill, disabled, or elderly patients develop, recover, improve, and maintain the skills needed for daily living and working.

Case manager - Keeps in touch with the person with dementia starting from diagnosis until death or admission in a nursing home. Helps with arranging care, offering emotional guidance, and guiding the patient through the complicated world of care and wellbeing.

Restaurant Misverstand - A Dutch TV show in which a group of people with dementia temporarily run a restaurant under the guidance of a chef.

CONTENTS

Chapter 1
INTRODUCTION

This chapter introduces the topic of dementia and explains the focus and approach of this thesis.

1.1 BACKGROUND

Dementia is a syndrome in which a person's cognitive function (the ability to process thought) deteriorates beyond what is expected to be caused by normal ageing [1]. Dementia can result from various diseases, of which the most common is Alzheimer's disease [2]. As the population is ageing, the World Health Organisation [1] expects the number of people with dementia to rise from 55 million cases today to 78 million in 2030 and 139 million in 2050.

Although the progression of the symptoms depends on the type of dementia and the person, it can generally be understood the three stages depicted in Table 1.

Currently, no treatment is available to cure dementia [1]. Several risk factors, such as hearing loss, less education, and smoking [3], can be addressed to try and prevent dementia. However, as 60% of the risk factors are still unknown, and the condition is very complex, only a limited number of dementia cases can likely be prevented [4]. Thus as we cannot yet add years to life, we as designers should focus on adding life to the years they do have left.

	Care needs	Symptoms	Duration
None to very mild dementia	None	Difficulty with complex activities of daily life (cooking, handling money) Minor forgetfulness	2-7 years
Mild dementia	Rather Independently	Forgetfulness Losing track of time Becoming lost in familiar places Challenging to execute more complex activities of daily life (cooking, handling money)	2-4 years
Moderate dementia	Needs assistance with self-care such as bathing and dressing	Difficulty expressing thoughts Forgetful of recent events and people's names Becoming lost at home Needing help with personal care Behavioural changes	2-10 years
Severe dementia	Requires assistance 24 hours a day	Becoming unaware of the time and place Difficulty recognising relatives and friends Increasing need for assisted self-care Difficulty walking Escalating behaviour changes	1-3 years

Table 1: Four stages of the progression of dementia [1], [5]–[7]

1.2 THESIS FOCUS

People with mild dementia may start struggling with more complex activities of daily living such as driving a car, managing finances, and planning meals [8]. Although these daily abilities are familiar and usually routinely performed with ease, they require coordinating multiple cognitive processes such as object selection, sequencing multiple steps, and perceptual and motor operations [9]–[11]. As the cognition of people with dementia changes over time, errors start to happen more frequently and may prevent the person from successfully executing their daily tasks [12].

This reduction in abilities is also known as everyday action impairment and is a severe problem for people with dementia. It increases caregiver burden [8] as people with dementia start requiring help with daily tasks. Furthermore, it could lead to lower self-esteem and a loss of autonomy for the person with dementia, generating a sense of helplessness and hopelessness [8]. Functional disabilities with people with dementia can cause depression [13], and in turn, depression can further functional disabilities [14].

One of the most challenging complex activities of daily living is cooking, as it requires planning, multitasking, and problem-solving [15]. Thus, it is not surprising that it is commonly one of the first household tasks given up. However, cooking is also an activity that can bring joy and meaning to a person's life, bring people together, and increase a person's independence. Because cooking is challenging yet offers high rewards, this thesis will focus on improving the cooking experience for people with dementia.

1.3 THESIS APPROACH

This project will be approached according to the perspective of warm technology. Warm technology is a concept that aims to improve the quality of life of PwD by supporting and enhancing human potential, social connectedness, dignity, and self-reliance. The technology is warm when it is sensitive to old age's possibilities and unique qualities. Warm technology means developing with people with dementia and their environment to create technology that ensures both the needs of the people needing and providing are met [16]. The approach is similar to participatory design; "an approach to design that attempts to actively involve the people who are being served through design in the process to help ensure that the designed product/service meets their needs" [17].

Chapter 2: Context explores the context of cooking with dementia by analysing the stakeholders and context. We learn about their unique needs and desires by interviewing and observing the people with dementia and their caregivers. We end the chapter by defining the problem. Chapter 3: Current solutions looks into which solutions are currently out there and which have yet to be developed. Chapter 4: Design brief describes the design goal and interaction vision which help guide the solution for the problem definition.

Chapter 5: Conceptualisation explores the solution space with numerous iterative prototypes. Each prototype is introduced to the target group to learn how the design can fit their desired interaction style. The chapter ends with numerous insights into how we can and cannot improve the cooking experience for people with dementia and their caregivers.

Chapter 6: Design combines all these insights to create one coherent design. This design is evaluated in Chapter 7: Evaluation recipe and Chapter 8: Evaluation application by introducing designs to the intended context, users, and activity. Chapter 9: Discussion and recommendations discusses whether the design meets the challenges, needs, and desires of PwD set out in chapters 2, 3, and 4. It concludes with stating recommendations for the design and further research.

Chapter 2

CONTEXT RESEARCH

The statement 'cooking with dementia is difficult' is too broad and will lead to overly generalised solutions. Therefore, the first step is to dive into the context of cooking with dementia and talk to the stakeholders to define the problem precisely.

Three research questions were set up to help guide the exploration.

1. What is the current cooking situation for PwDs, and how has it changed over time?

2. How do PwDs and their caregivers feel about this change and what do they feel are the benefits and downsides of cooking?

3. What are the practical and emotional cooking challenges for PwDs

2.1 APPROACH

Several interviews were held with PwDs, their caregivers, and experts to answer the research questions. One brainstorming session was held with a PwD, and a TV show about PwDs running a restaurant was analysed.

INTERVIEWS WITH PWDS

Three semi-structured interviews with a PwD and their caregiver (Table 2) were held at the participants' homes to make them feel comfortable and see how their kitchens looked.

Code	Role	Name *	Age	Prior profession	Dementia phase **
I1	PwD	Leonie	50-55	Caregiver/nurse	Mild
	Caregiver	Maurits			
I2	PwD	Robin	75-80	Housewife	Moderate
	Caregiver	Pepijn			
I3	PwD	Frida	75-80	Housewife	Moderate
	Caregiver	Herman			

*Table 2: Participants of interviews with people with dementia. *All participants are described with made-up names for privacy purposes. **Dementia phase has been estimated to generalise how much dementia has impacted their abilities.*

Figure 1: Paper Premo's illustrating different emotions used during the interview to help participants express emotions

The sessions started by introducing ourselves, explaining the research goal, and signing the consent form (see Appendix A: Consent form context research). The caregiver signed the consent form for both participants if the PwD no longer had legal consent rights. Participants were also verbally asked whether they wanted to participate in the session and were reminded that they could withdraw. The interviews were recorded by audio.

First, we determined how and why the participants' cooking situation has changed since the diagnosis.

Next, we asked how they feel now and used to feel about cooking. As people often struggle with expressing how they feel, we used paper props called Premo's [18] to facilitate the conversation (Figure 1). Participants could look through all the emotions and pick the ones they most identified with.

In the third part, we developed a canvas based on the Leisure Time Canvas (LTC) [19] to determine which cooking tasks worked well and were challenging. The LTC uses paper cards with activities and asks participants to put these in sections 'do not like,' 'like doing,' and 'more often.' It helps facilitate interviews with older users as they can feel in control and steer the conversation by picking up the paper cards in an order they prefer. The cooking canvas of this research (Figure 2) used cards of different cooking activities and two sections of 'going well' and 'not going well.' Both sections were added to not solely focus on the challenging tasks and keep a positive conversation going. Participants were asked to go through the activity cards, put them in a section, and elaborate on their choice.

Lastly, participants were asked show their kitchen to understand better their cooking context and whether they had made any adjustments since the diagnosis.

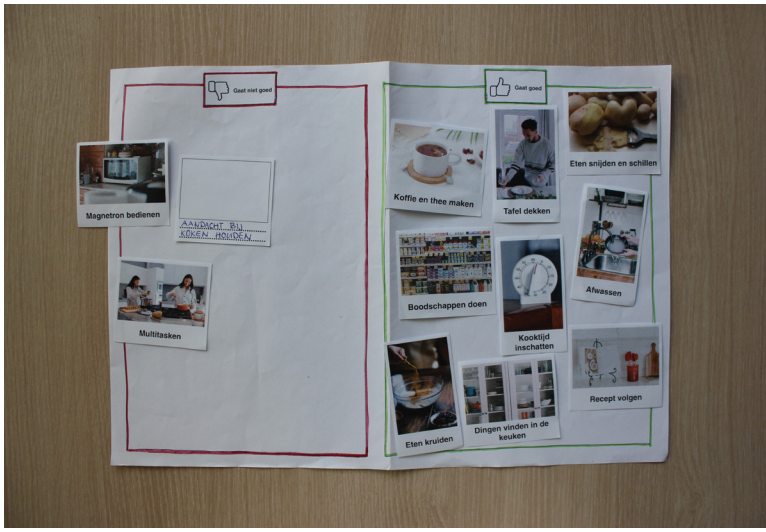


Figure 2: Cooking canvas with cooking activity cards and two sections 'not going well' and 'going well'

INTERVIEW WITH EXPERTS

We held four separate interviews with experts. The first two were with occupational therapists Sophie van Vugt and Jacolien de Haan to help define the cooking difficulties are for PwDs and how occupational therapists try to solve them. The third interview was with geriatric physician Serge Roufs to learn how dementia progresses and why dementia causes cooking difficulties. The last interview was held with chef Ron Blaauw, to understand better how they helped PwDs cook in the TV show Restaurant Misverstand. The interviews were recorded with audio.

BRAINSTORM WITH PWD

One brainstorm was held with a PwD, her friend, and PhD candidate Ans Tummers-Heemels to solve several cooking challenges (Table 3). Six potential cooking challenges were prepared and printed on separate pages (Figure 4). By brainstorming on all challenges, (Figure 5) we learned whether the participants experienced these challenges, when they occurred, and how they could potentially be solved.

Figure 3: Co-creation session with a PwD and her friend

Code	Role	Name *	Age	Prior profession	Dementia phase **
Br1	PwD	Sanne	50-55	Manager	Mild
	Friend	Wilma			

*Table 3: Participants of co-creation session. *All participants are described with made-up names for privacy purposes. **Dementia phase has been estimated to generalise how much dementia has impacted their abilities.*

Figure 4: Six cooking challenges printed on different pages

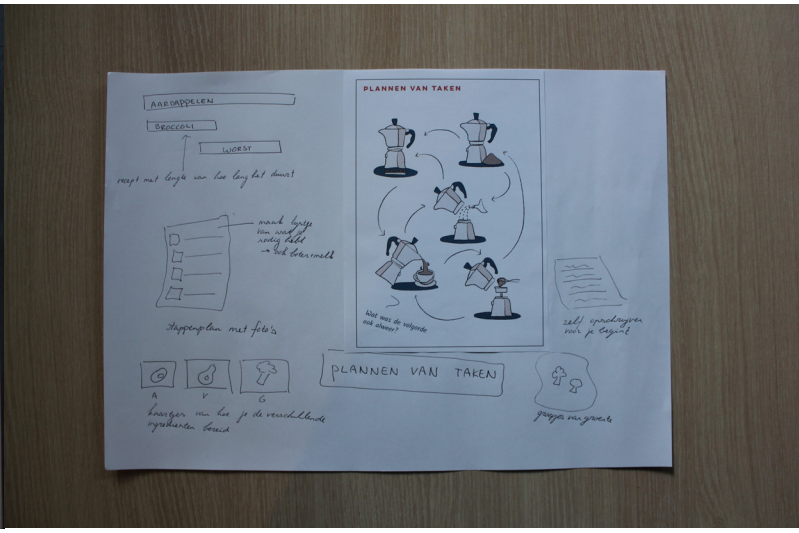


Figure 5: Large paper showing the brainstorm on the challenge 'planning the tasks'

TV SHOW

The TV show Restaurant Misverstand [20] (in English: Restaurant Misconceptions) documents how a dozen participants with dementia run a restaurant under the supervision of chef Ron Blaauw (see Figure 6). Two seasons of episodes show how several people with dementia cook in a restaurant kitchen, how working in the restaurant affects their wellbeing, and how dementia has impacted their and their loved ones' lives. Interesting excerpts were recorded and combined in a mini-documentary and transcribed for analysis.

Figure 6: Excerpt of the TV show Restaurant Misverstand. [20]

ANALYSIS

All interviews and recordings of the TV show were transcribed in Dutch. The interesting excerpts were selected, interpreted, and turned into statement cards (Figure 7). Statement cards help document both the data (quote) and information (interpretation), so they can better be interpreted and used for pattern finding [17].

We then used formed clusters of similar statements. These clusters help highlight underlying concerns or general principles at work [21] and are used in the following chapters to answer the research questions.

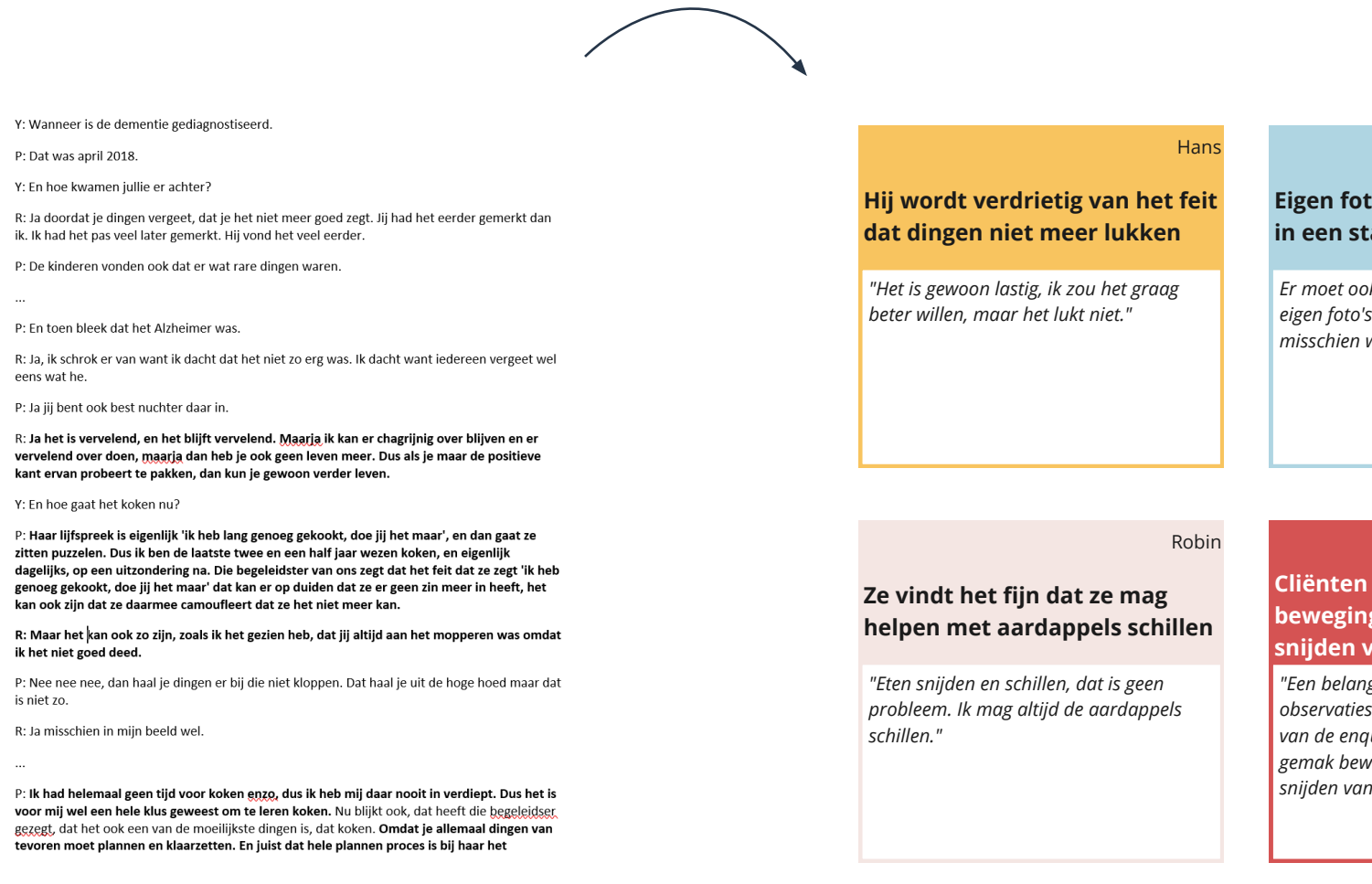


Figure 7: Interesting excerpts from the interview transcriptions (left) were turned into statement cards (middle) and clustered (right)

Sophie van Vugt

o's zijn erg waardevol
appenplan

k een mogelijkheid zijn om
in te brengen, al is dat
vel weer moeilijk.

(van de Ven, 2017)

kunnen met gemak
gen maken zoals
an fruit en groente

grijk punt dat zowel uit de
kwam als uit de resultaten
uête, dat de doelgroep met
egingen kan maken zoals het
fruit en groente."

Don't want to make mistakes

(Dirkse & Petit, 2009)
Mensen met dementie hebben vaak last van faalangst
"Faalangst komt vaak voor bij mensen met dementie. Hierdoor durven zij ook dingen die zij eigenlijk nog wel kunnen niet meer te doen. Dit is voor een buitenstaander niet altijd even makkelijk te scheiden van wat zij door dementie echt niet meer kunnen."

Ronald
Hij vindt het moeilijk te accepteren dat hij fouten maakt
"Je bent altijd al gewend, in je hele werkzame leven, om zo veel mogelijk geen fouten te maken. Nou gaat het natuurlijk minder makkelijk, maar ik vind het nog steeds lastig om te accepteren dat dingen minder lukken of dat ik toch fouten maak."

Christa
Ondanks dat ze weet dat fouten maken oke is, vindt ze het toch vervelend
"Maar dat vindt niemand leuk toch, om foutjes te maken?" "Ja maar als je ergens wil komen, dan zal je toch af en toe de mist in moeten gaan." "Ja, dat leer ik mijn kinderen ook, maar ja..."

Feeling like a burden to their family

Leonie
Ze vindt het pijnlijk dat ze thuis als last ervaren wordt
"Eigenlijk het feit dat ik naar een dagbesteding ga, ervaar ik al als dat ik een last ben. Maar ik begrijp het. Een last thuis, want anders breng je mij niet naar een dagbesteding, dan laat je mij gewoon ook thuis. Dus ik begrijp dat, maar om het te ervaren is het heel kwetsend. Het is heel pijnlijk en het maakt mij heel verdrietig."

(Gillies, 2000)
Failing to do something for someone nearest, not only makes them feel like they are letting them down, but also creating a burden of themselves
"When such failure affected relationships with those nearest to them, the discomfort was compounded through a sense of disappointing those who matter most. The internalized feelings of worthlessness were thus exacerbated not only in letting them down but in creating a burden of themselves"

Frida
Ze vindt dat ze soms niet de juiste partner als ze niet aardig is
"Ik ben soms wel een beetje niet de juiste partner, dat weet ik. Ik kan heel lelijk doen."

Wim
Hij voelt zich schuldig dat zijn vrouw ook beïnvloed wordt door zijn dementie.
"Zij [zijn vrouw] heeft het [dementie] ook gekregen hoor. Allerwel ze het niet heeft, ze heeft het ook gekregen. Ja dat vind ik pijnlijk eigenlijk." "Jij voelt je een beetje schuldig misschien?" "Ja eigenlijk wel. En dat hoeft niet, dat weet ik, maar ik voel het wel."

Not trusting own abilities or judgement

(van Wijngaarden, Alma, & The, 2019)
People with dementia no longer dared to trust their perception and tried to hide the strangeness
"Their whole bodily existence was profoundly put into question by the suspected signs of dementia. Some participants no longer dared to trust their perception and became quite uncertain about their own bodily performance. Confronted with their physical limitations, they tried to control the symptoms by feigning normalcy, and hiding the strangeness."

Anne-Marie
Ze vindt het vermoeiend om continu aan haar geheugen te twijfelen
"Het punt is, ik onthoud het niet, maar ik weet dan ongeveer hoe het zit. En dan ben je continu aan het invullen; ik weet het wel is het wel zo? Dat vergt heel veel energie. Dus eigenlijk, ja dat is heel plat gezegd, is het beter als ik een half jaar verder in het proces ben, dan is het rustiger."

(van Wijngaarden, Alma, & The, 2019)
People with dementia enter a very uncertain, unpredictable, and ambiguous period of life
"The findings show that living with dementia–from a first-person perspective–can be understood as a severely unsettling experience: the people concerned enter a very uncertain, unpredictable and ambiguous period of life."

Ron Blaauw - interview
De twijfel zorgt ervoor dat nog meer dingen fout gaan
"Zij zitten natuurlijk allemaal in een fase van ze doen het goed, maar dan komt de twijfel, en die twijfel gaat er weer voor zorgen dat ze het verkeerd doen. Wat sommige zeiden is ik zou liever een half jaar verder zitten, want dan weet ik dat ik dat niet meer doe, dan ben ik het gewoon vergeten. En nu zitten ze in een fase van ik ben iets vergeten, of ik zal het toch wel niet goed gedaan hebben."

(Steeman, de Casterle, Godderis, & Gorus, 2009)
Memory impairment can cause frustration, uncertainty, and fear when being faced with changes
"At early stages of memory loss, individuals use self-protecting and self-adjusting strategies to deal with perceived changes and threats. However, the memory impairment itself may make it difficult for an individual to deal with these changes, thereby causing frustration, uncertainty and fear."

Observation baking cookies
Participants kept asking whether they had done it correctly
"Perhaps the recipe could build in 'feedback' moments in which the participant is asked if they have done something correctly (showing the right texture of the dough) so they can fix their mistakes."

2.2 CURRENT COOKING SITUATION

People with dementia tend to give up cooking as their illness progresses. Cooking becomes too complex, or clients feel they have reached a point in their lives where it is no longer their responsibility to cook [22].

> *"I am delighted that they [my family] are cooking now. I feel like for years I have been doing everything, and now I can finally also just sit down at the table for once." – Leonie, PwD (I1)*

Caregivers are often motivated to try and let the client cook for as long as possible [23]. However, they frequently take over the tasks because they think it is faster, easier, safer, and kinder to the client.

> *"I used to ask her to cut the cabbage in this way, and I would show her exactly how to do it. And when I had given her the cabbage, she would cut it in a completely different manner. And then you are working on something else and see it and think shit... I can start all over again." – Herman, husband of PwD (I3)*

> *"We used to try mise en place [cooking with all ingredients perfectly laid out on the table]. At a certain point, that did not work anymore either. Then I thought, yeah, I can keep on explaining everything, but then she gets frustrated, and then I'll get frustrated." - Herman, husband of PwD (I3)*

> *"I kept noticing more and more that she would not prepare anything. So it [dinner] started to take longer and longer. 'Are we going to have some dinner?' 'Yes, yes', and then she would start cooking. That was even before the diagnosis; then I slowly started stepping in." – Pepijn, husband of PwD (I2)*

In some cases, clients remain eager to help in the kitchen. Some caregivers will give precise, simple tasks, such as 'peel the potatoes' to allow the client to help.

After clients quit cooking, they will get their meals from caregivers, by heating microwaved meals, by ordering food, or by subscribing to Meals on Wheels (a program that delivers meals to individuals at home who cannot purchase or prepare their meals).

2.3 EFFECT OF COOKING

Occupational therapists believe that many PwDs quit cooking earlier than necessary, while cooking actually has immense benefits [23], [24]. This chapter describes which two fundamental needs can be harmed and five can be fulfilled through cooking (Table 4). These fundamental needs lead to well-being when fulfilled and ill-being when unsatisfied [25].

Harmed needs	Fulfilled needs
Comfort	Autonomy
Security	Competence
	Purpose
	Recognition
	Relatedness

Table 4: Needs that can be harmed or fulfilled when PwD continue to cook

COMFORT

Cooking can become uncomfortable as it leads to exhaustion and feelings of frustration and sadness. As the memory declines, PwDs may start doubting their decisions and actions, which, combined with the cooking complexity, can be a tiring experience.

> *"The point is, I do not remember it, but I still kind of know what it is. And then you are continuously trying to fill it in; I know it, but is it really like this? That takes up much energy. So actually, yes, that is quite blunt. It is better if I am half a year further in the process, then it is a bit calmer." - Anne-Marie, PwD participant Restaurant Misverstand [20]*

Furthermore, if PwDs make mistakes while cooking, they are confronted with not being able to do things they used to find easy. This confrontation can lead to frustration and sadness. Sometimes, clients are still aware of what goes wrong but do not know how to solve it [23], [24].

> *"With dementia, it is just that every time, every moment, you see things that do not go well anymore. She is mostly frustrated because she cannot handle that she can no longer do it." - Herman, husband of PwD (I3)*

This is so much work!

Oh no! I totally forgot about these cookies!

I've made such a nice dough!

SAFETY

Problem-solving abilities, judgement, and memory are impacted by dementia, making it difficult for PwDs to make sound decisions when being in the kitchen. They may forget how to use objects safely or get distracted and leave the stove on.

> *"On some levels, cooking can be very unsafe when people lose their attention or start doing something else. Recently I came across something very strange, someone who had put the water cooker on the stove because he was used to using a kettle." - Sophie van Vugt, occupational therapist [23]*

COMPETENCE

Cooking can help clients feel competent by challenging them and letting them progress in skill.

> *"What do you enjoy about Restaurant Misverstand?" "Just being together and working towards something, and achieving it!" - Christa, participant Restaurant Misverstand [20]*

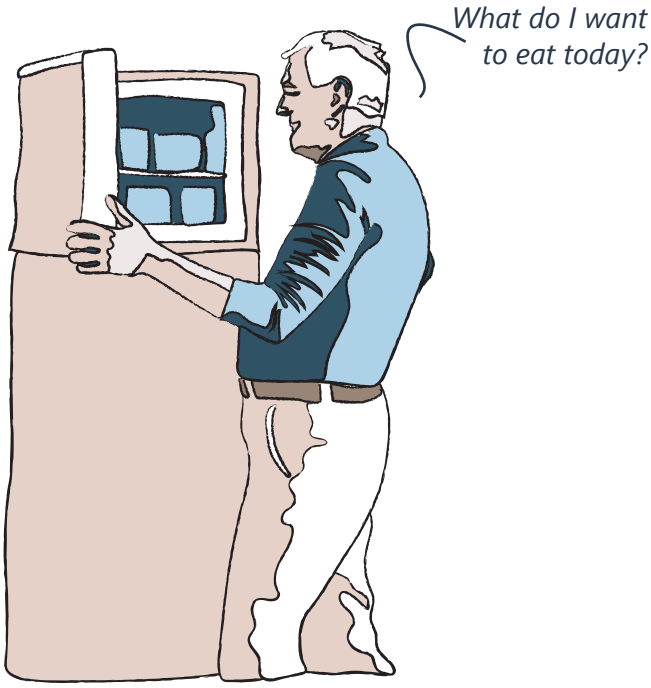
Also, challenging oneself through cooking activities works as cognitive and motoric training, which allows clients to maintain abilities for longer and regenerate skills [23], [26].

> *"Let us say nine out of ten [participants] became a completely different person [through participating in Restaurant Misverstand]. They became sharper by being together, through the recordings, and by being busy. Everything does start to work again at an accelerated pace." - Ron Blaauw, chef Restaurant Misverstand [27]*

AUTONOMY

Through cooking, clients can have the autonomy to decide when and what they want to eat. Some clients want to cook because they think takeaway meals are too expensive and not tasty [24].

Also, cooking increases clients' self-reliance as they can take care of themselves and their own needs. [26].



RECOGNITION

After diagnosis, PwDs may get treated differently by the world around them as others lose trust in the client's abilities. This change can leave the PwD feeling ignored, underappreciated, disrespected, and like they are no longer treated as complete human beings [7], [28]. By preparing a tasty meal for others and doing a good job, clients can regain a sense of appreciation and respect from the people around them.

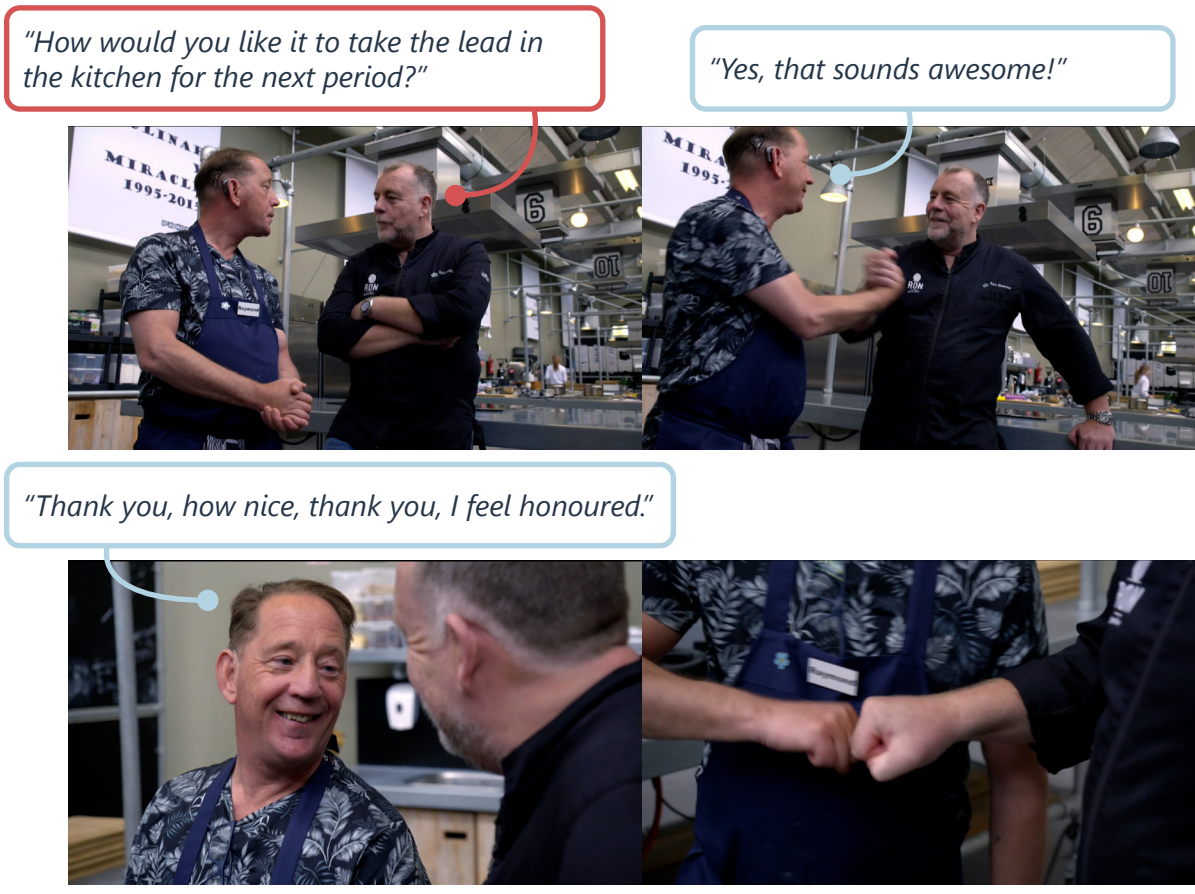


Figure 8: Raymond receives more responsibility in the kitchen [20]

Hey sweety, I've cooked you and the kids some dinner.

PURPOSE

Many clients see cooking as a meaningful activity that brings purpose to their lives and makes them feel useful. Feeling purposeful through cooking especially holds true for the older generation, as it was typically the woman's job to cook dinner for the family. When the client's responsibilities are taken away, they may feel like their life lacks direction, significance, or meaning.

> *"He always wants to do it [household tasks] very well for me, but sometimes he does too much. And then I will think, what can I still do now? Sometimes I do not know it then, what on earth I can still do." - Frida, PwD (I3)*

> *"It has no use to sit behind the geraniums. You have to be prepared to get up out of bed in time in the morning and do something useful. It does not always have to be for money, as long as you just keep yourself busy." - Maurice, PwD participant Restaurant Misverstand [20]*

Hey honey, would you like a cup of coffee?

RELATEDNESS

As dementia progresses, PwDs' relationships often shift from balanced (both parties take care of each other) to being unbalanced (PwD is solely the one being cared for) [28]. By helping with household tasks such as cooking, the PwD can take care of the caregiver and slightly rebalance the relationship.

> *"[If I receive a cooking task], then I'll make it and say that's all right, then I can help. That is the feeling I get then that I can help. Normally you [points at husband] cook nowadays always, and now and then I am allowed to help, and I enjoy that." - Robin, PwD (I2)*

2.4 COOKING CHALLENGES

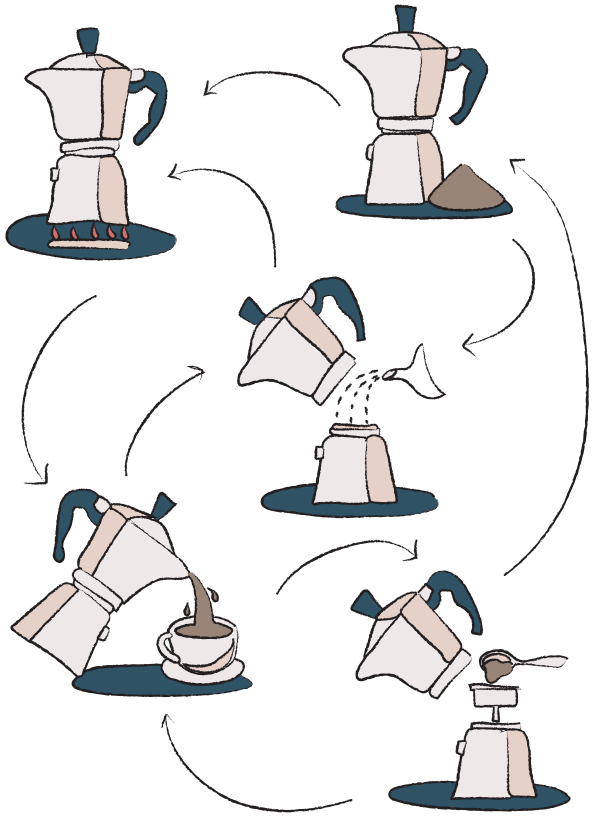
This chapter describes the most common cooking challenges for people with dementia in the four stages of cognitive decline (Table 5).

Dementia phase	Cooking challenges
None to very mild dementia	Planning cooking tasks
Mild dementia	Staying focused
	Remembering information
	Learning new routines
	Fearing making mistakes
Moderate dementia	Fine motor skills
	Identifying objects
Severe dementia	

Table 5: Cooking challenges of PwDs and when they occur in the four phases of dementia

PLANNING COOKING TASKS

With none to very mild dementia, clients start struggling with the complexity of cooking. PwDs with much cooking experience have formed fixed routines for sub-tasks such as peeling potatoes or dicing onions. They have executed these sub-tasks so often that they can be executed on autopilot [29]. However, PwDs struggle with using their conscious memory to stick all these sub-tasks together. Therefore PwDs find it challenging to plan the steps and think ahead [30].



"Baking an egg, heating soup, those things she can still do. But it is mostly the methodology, the cognitive part, that goes missing. Meaning how should I do it?" - Maurits, husband of PwD (I1)

Furthermore, as PwDs' judgement and problem-solving abilities decline, they find it challenging to estimate the number of ingredients and the cooking times.

"I have a lot more trouble with estimating how much rice I need for a certain amount of people." - Leonie, PwD (I1)

"Yes, I can clean the beans and cook them; that is not the issue. But how many spices should go in there and which ones..." - Robin, PwD (I2)

How nice you called! No, I'm not doing anything at the moment, how are you?

Figure 9: Sonja struggles with remembering the order in Restaurant Misverstand [20]

STAYING FOCUSED

With mild dementia, PwDs also tend to have reduced concentration and stimuli response, worsening as the day goes on. Some solely focus on the task at hand and do not notice other stimuli, such as the sound of boiling water. Others get distracted easily and forget they are cooking [22].

> *"It can be that the doorbell rings. They lose their attention and completely forget that they are cooking." - Sophie van Vugt, occupational therapist [23]*

REMEMBERING INFORMATION

As short-term memory declines, PwDs may quickly forget instructions and information (Figure 9).

> *"What I have underestimated is that you explain something, you turn around, you come back, and someone [PwD] has completely forgotten it." - Ron Blaauw, chef Restaurant Misverstand [27]*

Especially instructions with multiple tasks are complicated (Figure 10), as PwDs may forget the tasks before processing the entire instruction [20].

Furthermore, they may forget which tasks they have already executed and feel the need to keep checking if they are doing it correctly.

> *"There always remains doubt about whether I have done the previous step in the process or not; have I or have I not already added salt to the potatoes?"- Sonja, PwD Restaurant Misverstand [20]*

> *"I keep forgetting what I have just done. For example, I forget what is inside of the pans. If there is a lid on then, I have to keep lifting it to see what is inside." - Christa, PwD Restaurant Misverstand [20]*

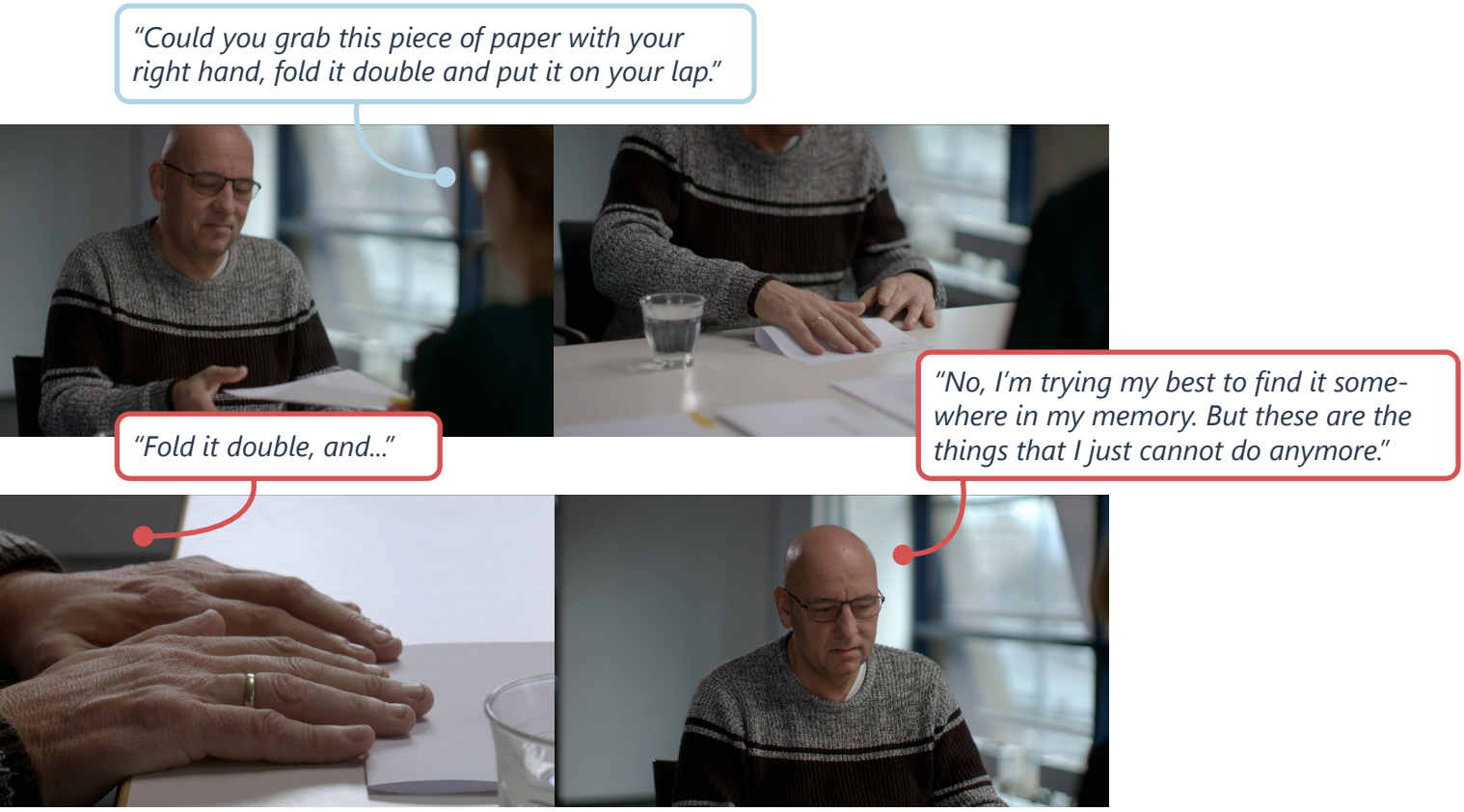


Figure 10: Hans has difficulty with executing a sequence of tasks in Restaurant Misverstand [20]

LEARNING NEW ROUTINES

As the learning abilities decline, clients find it difficult to adjust or form new routines. As mentioned before, the older, fixed routines can be done on autopilot. Nevertheless, clients need much time and practice to form new connections in their brains.

> *"I said once, oh, let us buy an air fryer. You will be able to use that easily! However, she said she could not work with it because she could not understand all the buttons."- Herman, husband of PwD (I3)*

> *"I can also make coffee and tea. But that new coffee machine he has now, I do not know my way around it yet." - Robin, PwD (I2)*

FEARING MAKING MISTAKES

PwDs tend to make more cooking mistakes because of the challenges mentioned above. Some PwDs struggle with accepting that they are making these mistakes.

> *"In your whole working life, you are used to making the least amount of mistakes. Now, of course, that has become a bit more difficult. But I still struggle to accept the fact that things do not go as well as before or that I am making mistakes." - Ronald, PwD Restaurant Misverstand [20]*

Sometimes people with dementia will try and hide their mistakes because they feel ashamed and do not want to show their vulnerable side [20].

"Sometimes I cannot come to words, and then I, of course, feel ashamed that I cannot find the right words." - Wim, PwD Restaurant Misverstand [20]

Furthermore, clients could be afraid of the judgement or reactions of others.

"She is afraid to make mistakes, afraid that he will kick her out of the house, those kinds of things. That, of course, is totally not realistic, but people do have those thoughts. Thoughts like I cannot make mistakes because then I will be put into a home." - Sophie van Vugt, occupational therapist [23]

It could also be because they do not want to add to the burden of their care-giver [31].

"The fact that I go to a day-care facility, I experience as though I am a burden. A burden at home, because otherwise, you would not bring me to a day-care. You would leave me at home. I understand it, but to experience, it is very hurtful." - Leonie, PwD (I1)

The fear of making mistakes could lead to performance anxiety, causing PwDs to no longer dare to do things they are still capable of [20] and avoid challenging situations [31]. This avoidance shows by a client's lack of initiation, and over time, 72% of Alzheimer's patients suffer from apathy [32].

"That phase is now over. Now she just lets me do it [cooking]. She always used to ask whether she could help or whatever, but now nothing." - Herman, husband of PwD (I3)

FINE MOTOR SKILLS

With moderate dementia clients' fine motor skills start to decline [33]. They can no longer do the hand movements necessary to cut or peel ingredients.

IDENTIFYING OBJECTS

PwDs may lose the ability to recognise and understand how to use objects [22]. Thus they will not remember how to hold a knife properly or what a mixer is for.

"Last week, for instance, I saw someone using a toothbrush to brush his hair. They may have known what it is or what it is called, but they did not know what to do with it anymore." - Sophie van Vugt, occupational therapist [23]

2.5 DISCUSSION

Although cooking is complex for people with dementia, it can have immense benefits for their sense of agency, self-image, relationships, and cognitive training. Their cooking experience can be improved by making it less exhausting, less frustrating, and safer. If a PwD's cooking becomes more efficient, safer, and enjoyable, the caregiver will also be less inclined to take the cooking task out of their hands.

The main cooking challenge, which occurs early in the progression, is planning the cooking tasks. Therefore the central focus of this project will be on helping PwDs figure out which cooking tasks to do in which order. Other challenges we have to face, which occur with mild dementia, are staying focused, remembering information, learning new routines, and fearing making mistakes. The project will not focus on the challenges of moderate dementia, namely fine motor skills and identifying objects, to limit the problems we aim to tackle.

LIMITATIONS

Previous results may not represent all people with dementia as the study only included Dutch female participants with dementia with much cooking experience who still lived with their partners. Other demographics may face different challenges and have different expectations, needs, and desires concerning cooking.

The additional observation of participants of the tv show Restaurant Misverstand does help map out the cooking challenges of a larger group of people with dementia. However, as these are recorded in a restaurant, they may differ from the challenges faced at home. Furthermore, as this is a TV show, it may only show the highlights and not the more mundane challenges.

Furthermore, one researcher documented and analysed all data, making the results less objective.

All in all, although the results may not represent every person with dementia in every scenario, it does give a clear overview of the challenges and needs concerning cooking with dementia and can be used as a start of the design process.

Chapter 3

CURRENT SOLUTIONS

In this chapter, we look into products that have been developed to help people with dementia with cooking to see which problem is not yet solved.

3.1 CURRENT SOLUTIONS

Various products aim to make cooking more accessible for people with dementia, ranging from recipes to automatic stoves. The three that best fit our main challenge of helping people with dementia with the cooking steps are described below.

MASS ACCESSIBLE RECIPES

The first solutions are digital and physical recipes developed by cooks, developers, and volunteers to make cooking more accessible for people with cognitive impairment. Figure 11 depicts a cooking application with written instructions that users can mark when finished. Figure 12 shows a cookbook with images, and Figure 13 one with icons. They all have in common that they try to split up the cooking process into smaller tangible tasks.

The benefits of these generalised recipes are that they can be mass shared with a large audience. However, clients have little choice in the recipes used and cannot adjust the recipe to fit their dietary preferences. Additionally, the recipes cannot be adjusted to fit each client's instructional need and cannot evolve to keep up with their decline.

Figure 11: Cooking application for cognitive impairment [35]

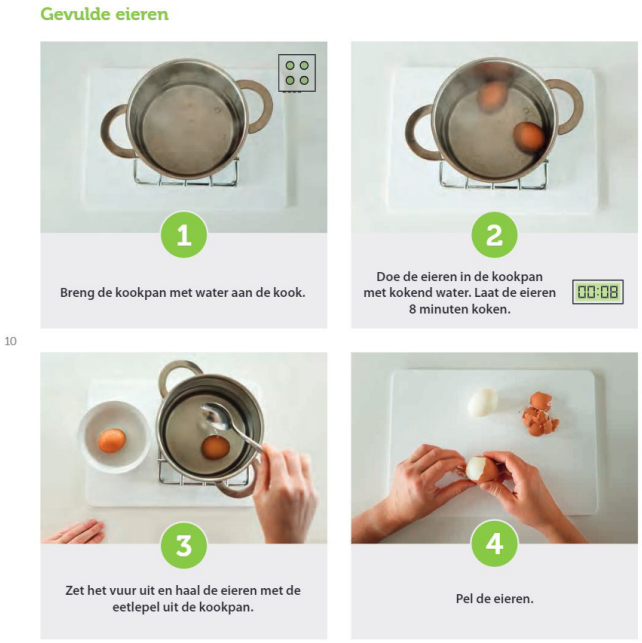


Figure 12: Cookbook Kook met me mee! [36]

Figure 13: Cookbook Look 'n Cook with icons [34]

Figure 14: Individual step-by-step plan with images showing how to use the coffee machine [37]

Figure 15: Individual step-by-step plan with videos showing how to use a coffee machine [38]

PERSONALISED STEP-BY-STEP PLANS

On the other end of the spectrum are personalised step-by-step plans created by occupational therapists. These plans are developed by first observing and defining the problem with the client. They can only contain text, have additional icons or pictures (Figure 14), or use videos (Figure 15).

As the plan is developed with one client in mind, they suit their needs, desires, and context perfectly. However, making these plans takes up much of the occupational therapist's time and requires significant insight into the person with dementia and their context. Moreover, as the plan is personalised, it will only suit one client and cannot be mass shared.

ONLINE RECIPE CREATOR

A compromise seems to be The Accessible Chef (Figure 16 and Figure 17), an online recipe creator. The web page includes a tool users can use to create recipes by adding steps and images. Also, it contains a database where users can share their recipes.

The online recipe creator helps individuals write personalised recipes more efficiently. However, creating a recipe still takes time; the user has to drag and drop all images themselves, and the user experience is not that friendly. The web page gives the user no guidance on writing the recipe, and the generated recipe does not seem to cater to the needs of people with dementia.

Figure 16: Accessible Chef interface to create your own recipe [39]

3.2 DISCUSSION

Looking at the shortcomings of existing solutions, we conclude that a tool to help occupational therapists and caregivers build cooking guidance for PwDs could offer the efficiency and personalisation our planning cooking tasks problem needs. However, research needs to be conducted into how this guidance can best be presented to PwDs. We need to study how this guidance can best be created, making it more scalable while keeping it personalised.

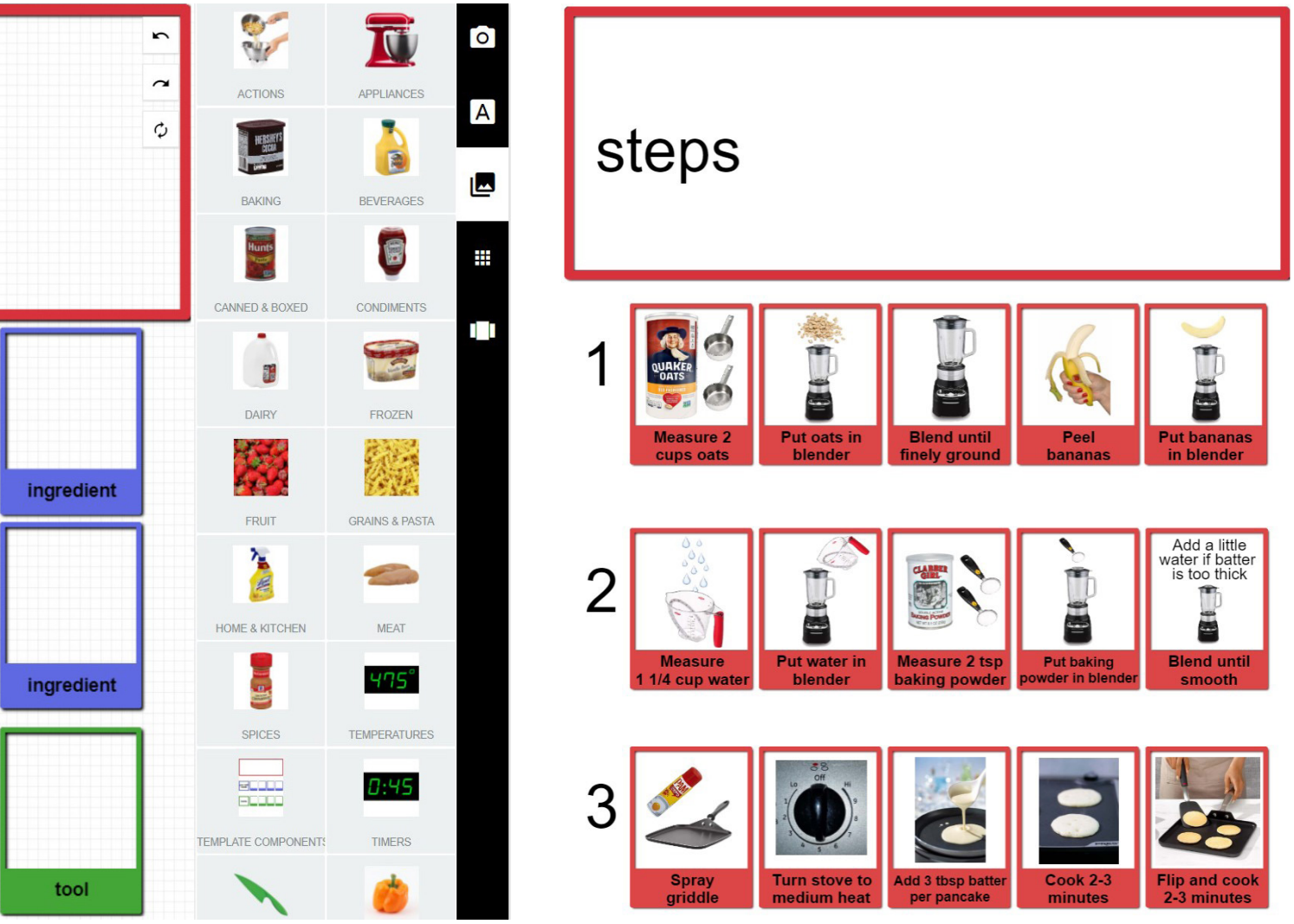


Figure 17: Generated recipe of Accessible Chef [39]

Chapter 4

DESIGN BRIEF

Based on the problem definition in the previous chapter, this chapter states the design goal and interaction vision. These two will help guide the conceptualisation process.

4.1 DESIGN GOAL

This design goal specifies the intended effect of the designed concept.

THE DESIGN GOAL IS TO HELP GUIDE PEOPLE WITH MILD DEMENTIA THROUGH A COOKING ACTIVITY AT HOME OR AT DEMENTIA MEETING CENTERS IN COLLABORATION WITH OTHER CLIENTS OR CAREGIVERS IN A SCALABLE AND PERSONALISED WAY.

The main challenge of cooking with dementia is to follow or think of the steps necessary to cook, so the design goal is to guide the client through the cooking activity.

Mild dementia is chosen as usually, people in this phase are still motivated to cook and can still be trusted to handle kitchen utensils safely.

Collaborating while cooking makes the activity more social, reduces the fear of making mistakes, and reduces safety hazards. Thus, the aim is not to let the client cook individually but to make it a shared experience.

The design should bring out the scalability of cookbooks and cooking applications to reach as many people as possible. At the same time, it should offer the personalisation of the personalised step-by-step plans to cater to each client's individual needs and desires.

Homes and meeting centers are both locations where cooking is done frequently by PwDs or caregivers. Both locations are chosen as they offer different cooking contexts and rewards. PwDs can cook together with their partner in their kitchen to take care of themselves at home. At meeting centres at caring facilities or community centres, PwDs can cook together.

4.2 INTERACTION VISION

This interaction vision describes the intended qualities and characteristics of the interaction with the design. It describes how the design should address the design goal.

THE INTERACTION CREATED BY THE DESIGN SHOULD BE LIKE SALSA DANCING WITH A PARTNER.

COMFORTABLE

The music, company, and location of salsa dancing create a comfortable, pleasant environment where people can feel relaxed.

GUIDING

The rhythm of the music guides people through the steps as it gives them the pace of the movements. Furthermore, as the leader decides most of the movement, the follower does not have to make many decisions.

COLLABORATIVE

Although the leader makes most of the decisions, the leader still needs the follower to dance. Only through working together, can they participate in the activity.

TRUSTWORTHY

Both the leader and follower trust each other while dancing. The leader trusts the follower will follow his movements and the follower trusts the leader will give the right signals in time.

Chapter 5

CONCEPTUALISATION

This chapter explores how to achieve the design goal while keeping the interaction vision in mind. We aim to address the following design challenges;

1. How can we guide PwDs through the cooking process in a comfortable way?

2. How can multiple PwDs, or PwDs and caregivers, collaborate while cooking and trust each other?

3. How can the design be scalable yet fit each PwD's individual needs and desires?

First, we describe the approach of the conceptualisation phase and introduce all iterative prototypes. Then we report the insights gained from the prototypes about the step formulation, visuals, materials, navigation, and recipe writing.

5.1 APPROACH

Figure 18: User test at a participant's home

Figure 19: User test at a meeting centre

People with dementia have unique needs and desires, so it is essential to involve them in the design process. Designing with instead of for the target group allows the design to suit their needs and the target group to feel valued. Therefore, the conceptualisation is done with an iterative approach. Each prototype is introduced to the target group, evaluated, and adjusted. This sequence repeats over and over until a satisfactory design is created. The collaborative approach gives the target group a chance to give their opinion on the proposed design and helps us designers not design based on our assumptions.

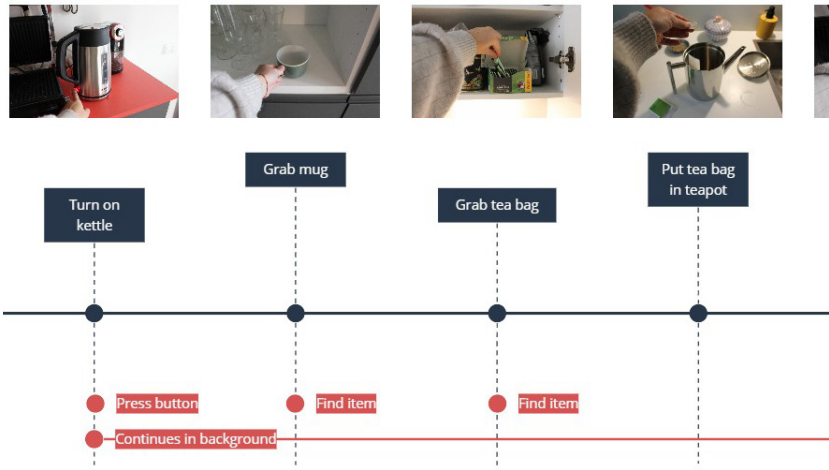
In total, we developed thirteen prototypes which we introduced to twenty-four participants (11 PwDs) in four homes (Figure 18) and two meeting centres (Figure 19). Appendix B: Participants conceptualisation lists the number of participants per prototype. Alternating between the two locations helped develop the design for both a family home and a friendly workshop setting.

Every participant was asked to sign a consent form (see Appendix C: consent form conceptualisation), which used simple vocabulary, short sentences, and enlarged font. The caregiver signed both forms if the PwD could no longer sign their own. The formal caregiver filled in the consent form at the meeting centres, and the visitors were asked for verbal consent.

During the sessions, the participants were introduced to the prototype and asked to use it to make a dish. We observed and asked questions about the experience afterwards.

5.2 PROTOTYPES

This section shows the thirteen iterative prototypes with their main research questions in chronological order to depict the link between the prototypes. The next sections will describe the findings in more detail.



1. Steps to make tea

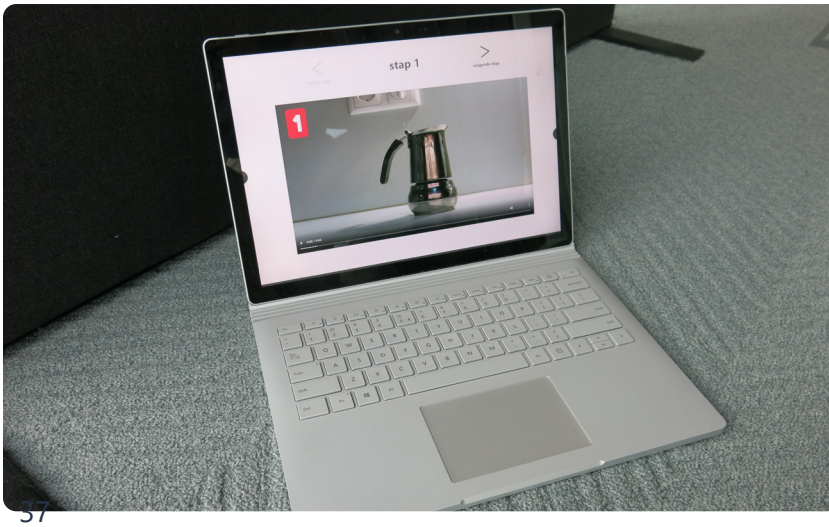
How many steps does it take to make simple dishes?

Many steps, 11 for a cup of tea and 41 for pasta Bolognese.

2. Booklet recipe with pictures (cookies)

Can we convey all these steps on paper with pictures and text?

Yes, but pictures cannot convey movement, and PwDs forget which steps they have done.



3. Video recipe (cappuccinos)

What if we use videos?

They show the movements better, but they must be cut into chunks only to show one task per video.

4. Video recipe (bonbons)

If the videos are cut into chunks, are they better than using pictures?

Although PwDs cannot lose their place in the recipe with video chunks, PwD sare extremely hesitant to interact with a laptop.

5. Projections

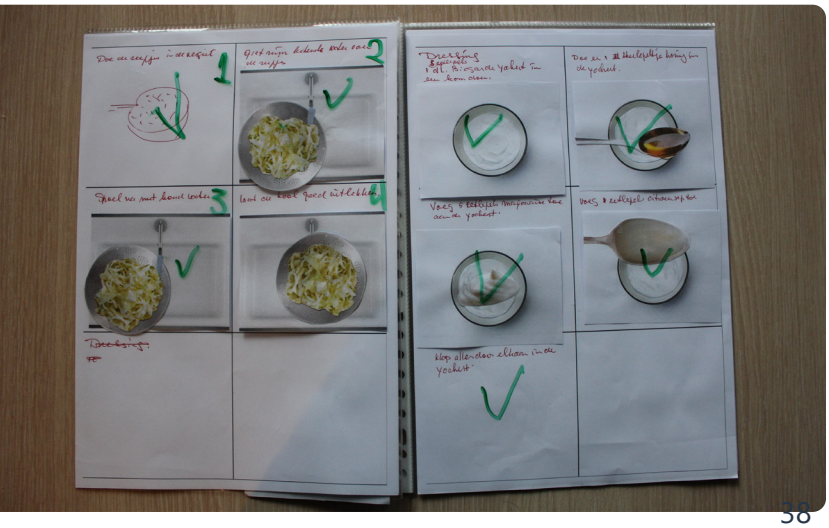
What if we use projections?

Although dynamic projections can be shown directly on the work surface without getting dirty, the kitchen should be dark to see the projections.

6. Auto-generated images

Can we make auto-generated collages from a text recipe instead of taking pictures?

It is possible by using a program with an extensive cooking images database.



7. Recipe with auto-generated images (cabbage salad)

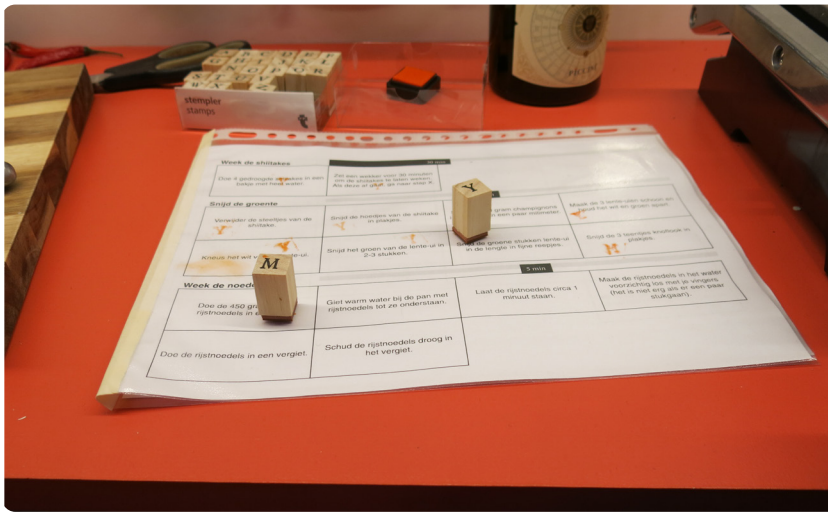
Can caregivers write recipes using these auto-generated images?

Yes, the caregiver can define the steps, and the auto-generated images help PwDs follow the steps.

8. Boardgame recipe (noodles)

Does it help two people collaborate if they both have a stamp with their initials to mark the steps?

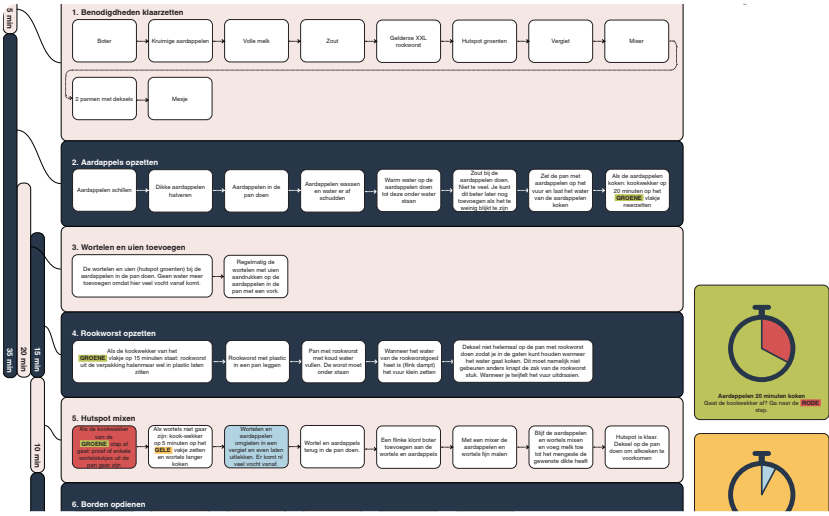
Yes, it helps both parties understand which steps are done and which they can do next.



9. Flow chart recipe (hutspot)

Could we use a flow-chart without images?

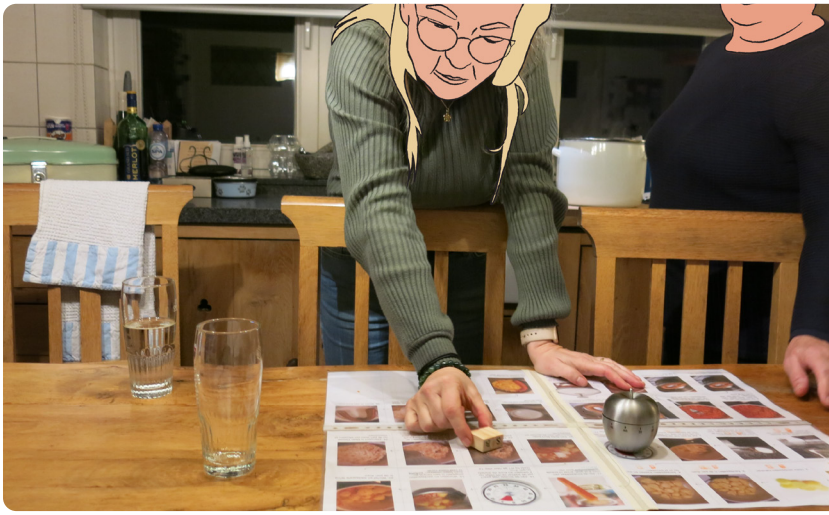
No, we need some visuals to make the recipe less overwhelming and help PwDs understand the steps.



10. Boardgame recipe with photos (hutspot)

Could a pawn be used to keep track of the steps?

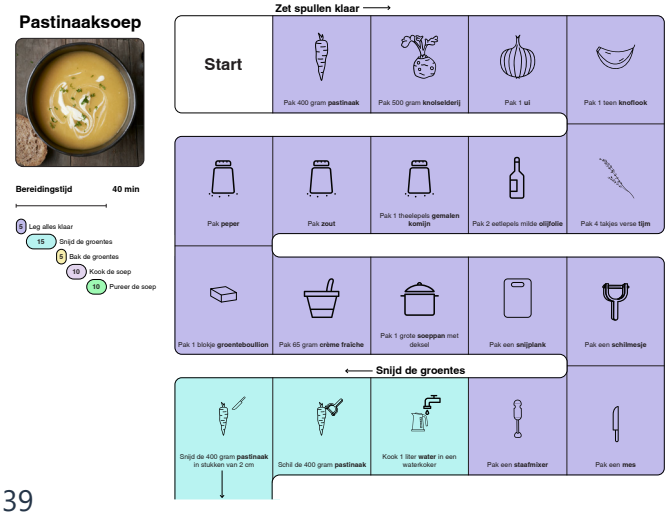
Yes, the pawn is intuitive to move and helps indicate the current step.

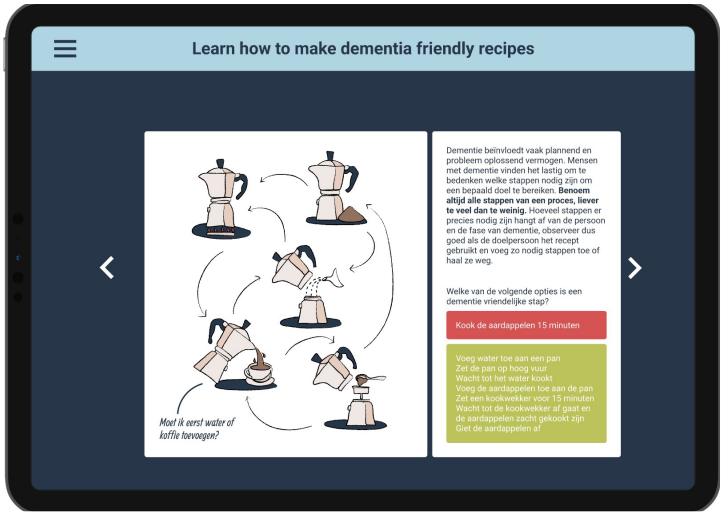


11. Zig-zag boardgame (parsnip soup)

Could we use auto-generated icons and make the recipe look like a board game?

Yes, icons are calmer, clearer, and easier generated than pictures. However, moving left in the swirl is difficult, so the steps should be left to right.

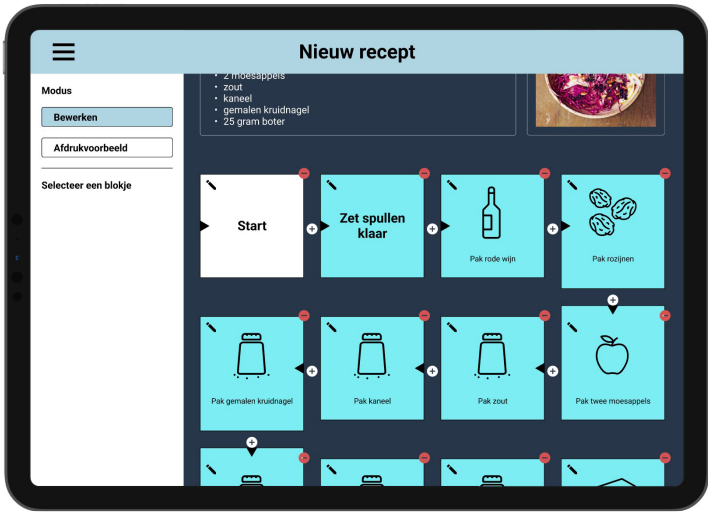




12. Training for writing recipes

Could we train caregivers in how to write the steps?

Yes, multiple-choice questions help caregivers understand the guidelines, but examples should be added for further understanding.



13. Interface for writing recipes

How can caregivers be assisted in writing the recipe?

With an application in which caregivers create separate blocks for each step that can be moved and deleted. The software automatically adds the icons based on the steps.

5.3 FORMULATING STEPS

ONE ACTION PER STEP

Prototype 3 consisted of eight videos to show making a cappuccino but still included multiple steps in each video (add the milk to the cup, add the espresso). When participants finished watching the video, they had forgotten the first step already and did not know what to do. Subsequently, another prototype in which the process is split into smaller chunks, with each step only mentioning one action, was more successful in guiding participants (Figure 20).

GROUP STEPS

Naming all steps of a recipe creates a long list; making a simple cup of tea already requires eleven steps (Prototype 1). Grouping steps (Figure 21) with titles and colours organised the information and helped participants quickly understand the recipe's structure.

Figure 20: Prototype 4 – video recipe, each step only contains one action

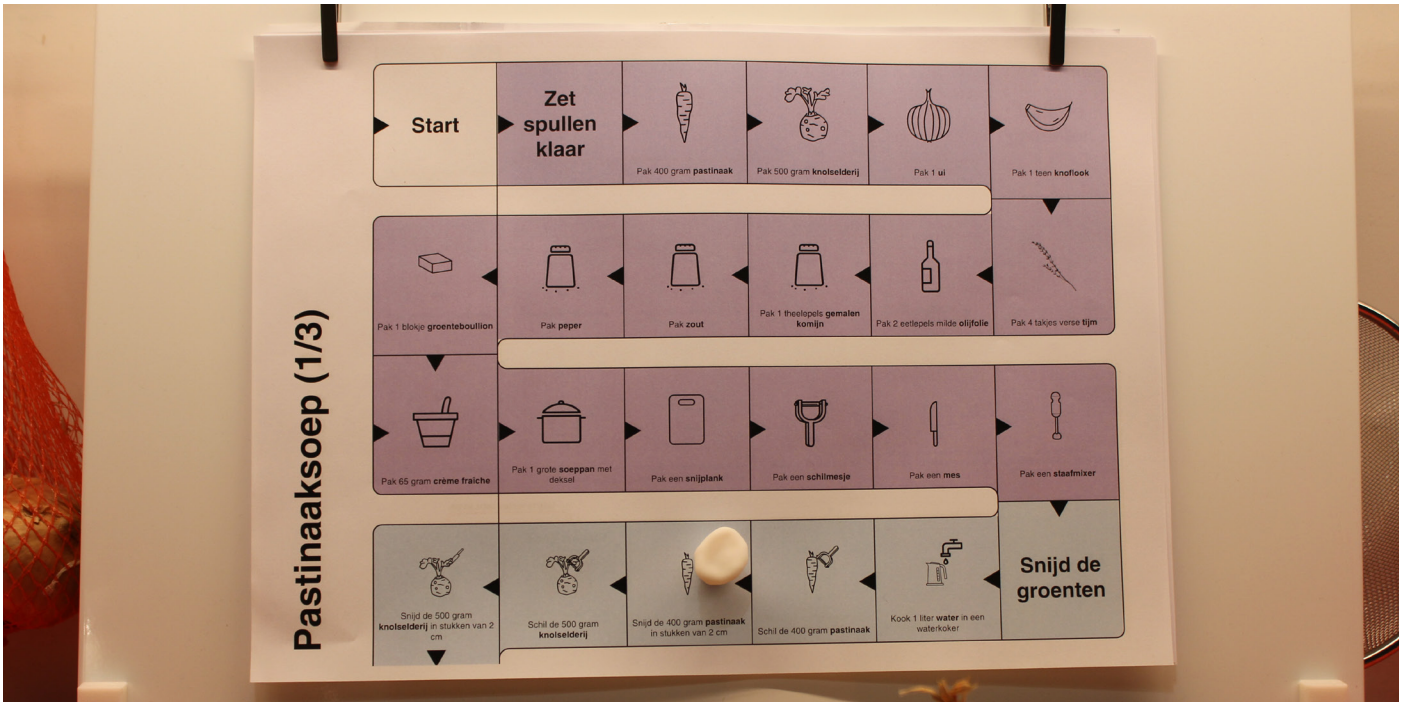


Figure 21: Prototype 11 - steps are grouped by colour and have a title

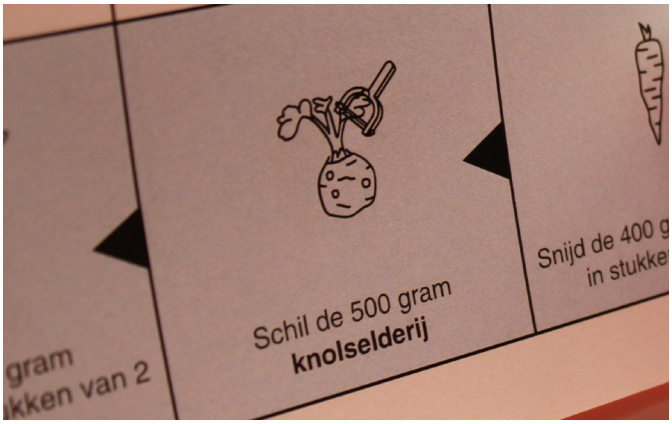


Figure 22: Prototype 11 - each step mentions the number and allocation of ingredients

MENTION ALL INFORMATION IN EACH STEP

One participant (Prototype 7) could not remember she had been working on a sauce when reading 'Add the honey.' Thus, she did not know where to add the honey. Therefore, the steps should not rely on information mentioned in previous steps, and each step should mention the number of ingredients and where they should be added (Figure 22).

ADD SPECIAL STEPS

Another participant (Prototype 10) felt restless after setting a timer, and instead of waiting, she kept checking the recipe to see if she had to do anything. Thus, 'wait' steps are added (Figure 24) to indicate it is time to relax and not do anything. Furthermore, 'set a timer' steps that clearly indicate what the timer is set for are also appreciated by participants.

Moreover, steps can be added to ensure all kitchen utensils are turned off, such as 'turn off the stove' at the end of every recipe (Figure 23).

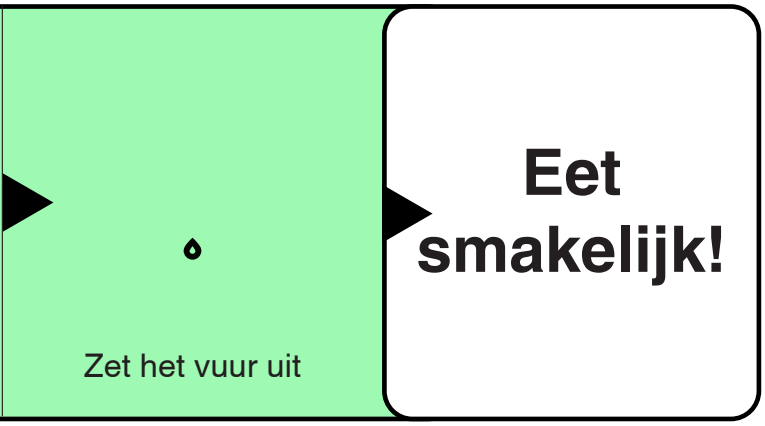


Figure 23: Prototype 11 - turn off the fire step at the end of the recipe

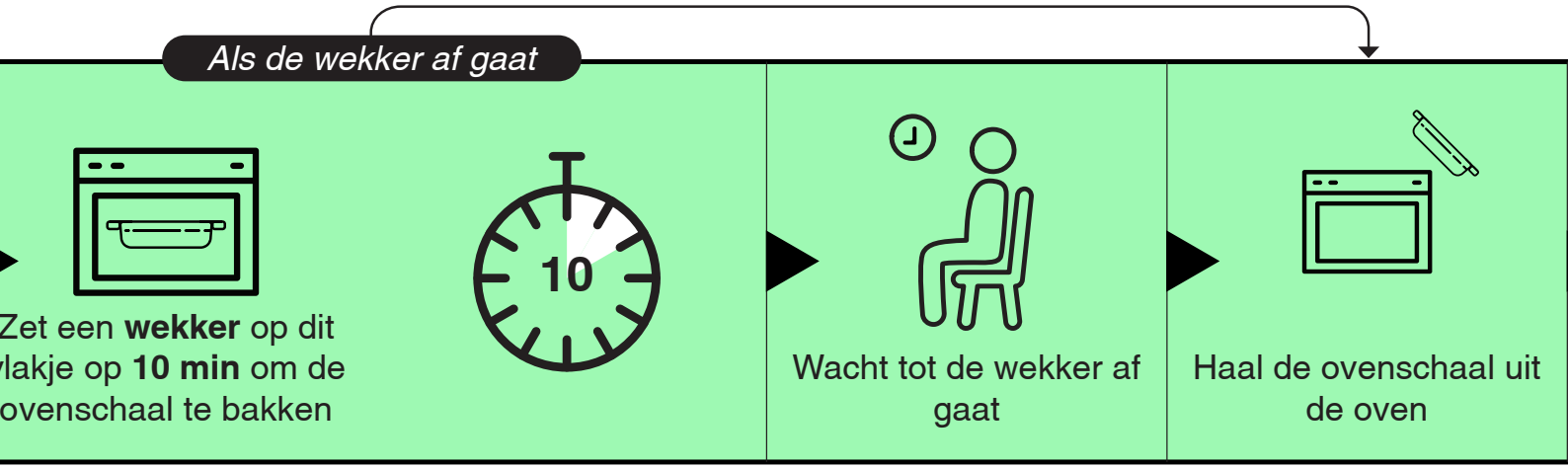


Figure 24: Prototype 11 - wait step to indicate it is time to do nothing and wait

5.4 VISUALS

In some cases, dementia impacts the reading ability of clients, making it challenging for them to follow written instructions. Visuals can add extra information besides the text. The visuals should clearly depict the action without giving unrealistic expectations. They should also easily be created to make the guidance scalable.

NO VISUALS

Without visuals in prototype 9 (Figure 25), participants found the prototype overwhelming to look at because they felt they had to read every step before understanding the recipe.

> *"I prefer to have as little text as possible; the images have to be clear on their own."*
> *– Sanne, PwD prototype 9*

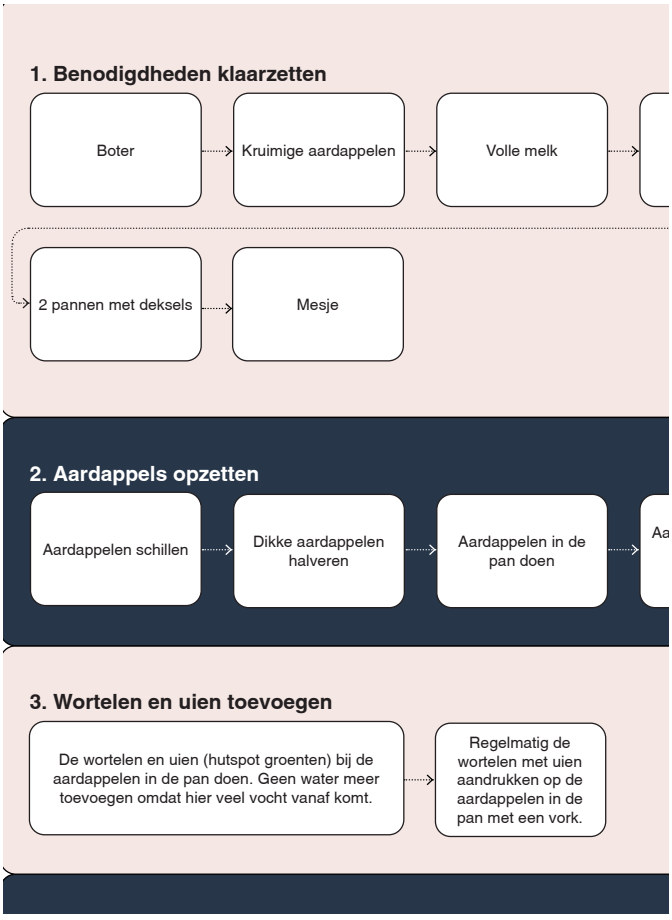


Figure 25: Prototype 9 – flow chart recipe without using any visuals

PICTURES

Pictures (Figure 26) realistically depicted the actions. However, they were sometimes too realistic as participants found it challenging to use different supplies from those used in the pictures. Furthermore, the pictures could not explain complex actions (like rolling out the dough), took up much space on the pages, and required the writer to cook the entire dish before writing the recipe.

Figure 26: Prototype 2 – recipe with pictures

VIDEOS

Video tutorials for each of the tasks (Figure 27) were better at explaining complex actions to participants but required even more time to film and edit. Interestingly, one of the videos (melting chocolate) was sped up to save time, but this led to unrealistic time expectations of the participants, who got impatient and confused when their chocolate did not melt as fast.

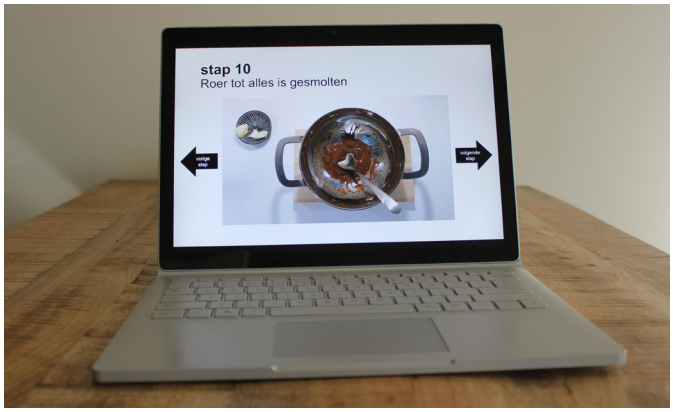
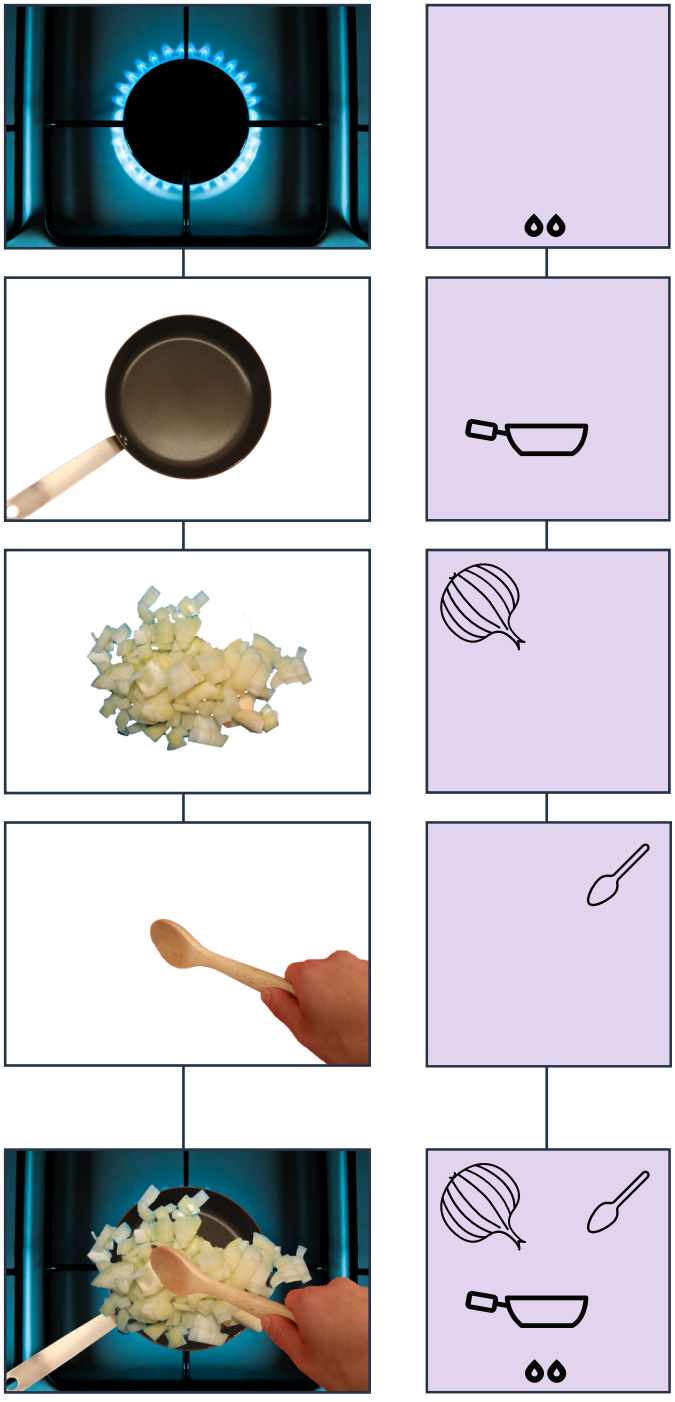


Figure 27: Prototype 4 – video recipe



"Add the onions to the frying pan on medium heat while stirring"

Figure 28: Prototype 6 – auto-generated images by layering multiple images (left) or icons (right) into a collage

AUTO-GENERATED IMAGES

Images could be generated automatically based on only the text instructions to make them less time-consuming to create. An application could use a natural language processing algorithm to understand the text instruction and use a set of pre-defined cooking images to combine into a coherent depiction of the text (Figure 28). A paper version of these auto-generated images was built in prototype 7 (Figure 29). The images helped a participant more quickly understand the steps and created a cohesive, calming look. However, one downside to the auto-generated images is that it would require an extensive database with cooking images which does not yet exist.

AUTO-GENERATED ICONS

A database for auto-generated icons would be easier to create as the icons can be taken from open sources and do not have the issues of different lighting, scaling, and angles. Furthermore, occupational therapists often already use icons in their step-by-step plans [23], [24] because they are straightforward and easy to find online. Participants quickly understood our auto-generated icons (Figure 28). Moreover, icons required less space on the page and were calmer on the eyes.

Figure 29: Prototype 7 - paper version of auto-generated images

5.5 MATERIALS

The guidance materials should fit the kitchen context and the desired interaction of PwDs, while also giving the necessary instructions.

SCREEN

Laptops can show moving images, create an interactive experience, and allow for quick adjustments to the recipe (Figure 30). However, participants seemed hesitant to touch the laptop, either because they did not know how to or were afraid of damaging it.

> *"I prefer not to have a step-by-step plan on the screen of a phone or laptop. I want nothing in the kitchen next to the stove that can break or be damaged." – Sanne, PwD prototype 10*

> *"The Ipad screen always goes black after a while, and my husband does not understand how to fix it" – Harriet, partner of PwD prototype 11*

Figure 30: Prototype 3 – video recipe presented on a laptop

PROJECTION

Projections can be shown directly on the kitchen counter, cannot get dirty, and create a more interactive experience (Figure 31). Unfortunately, hanging up the projector is challenging, the kitchen needs to be dark to see the projection, and turning on the projector is not easier than using a screen.

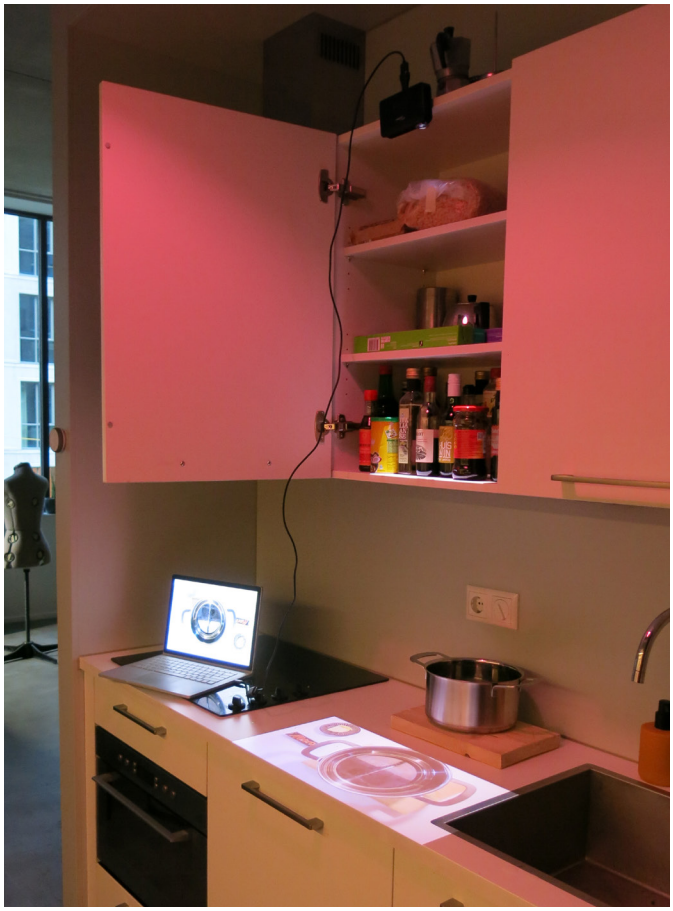


Figure 31: Prototype 5 - Projections onto the kitchen counter

Figure 32: Prototype 2 – PwD and designing baking cookies together using a paper recipe

PAPER ON WHITEBOARD

Participants were most comfortable with paper (Figure 32). They would interact with it without hesitation, could look at it from multiple angles, and could take it with them when moving around. Because paper can quickly get wet and takes up space on the countertop, a vertical whiteboard with a metal binder was built to hold the pages (Figure 33). Another downside was that a paper recipe could not easily be edited. Thus, pastel colours and whitespace were added so users could make adjustments with a pen.

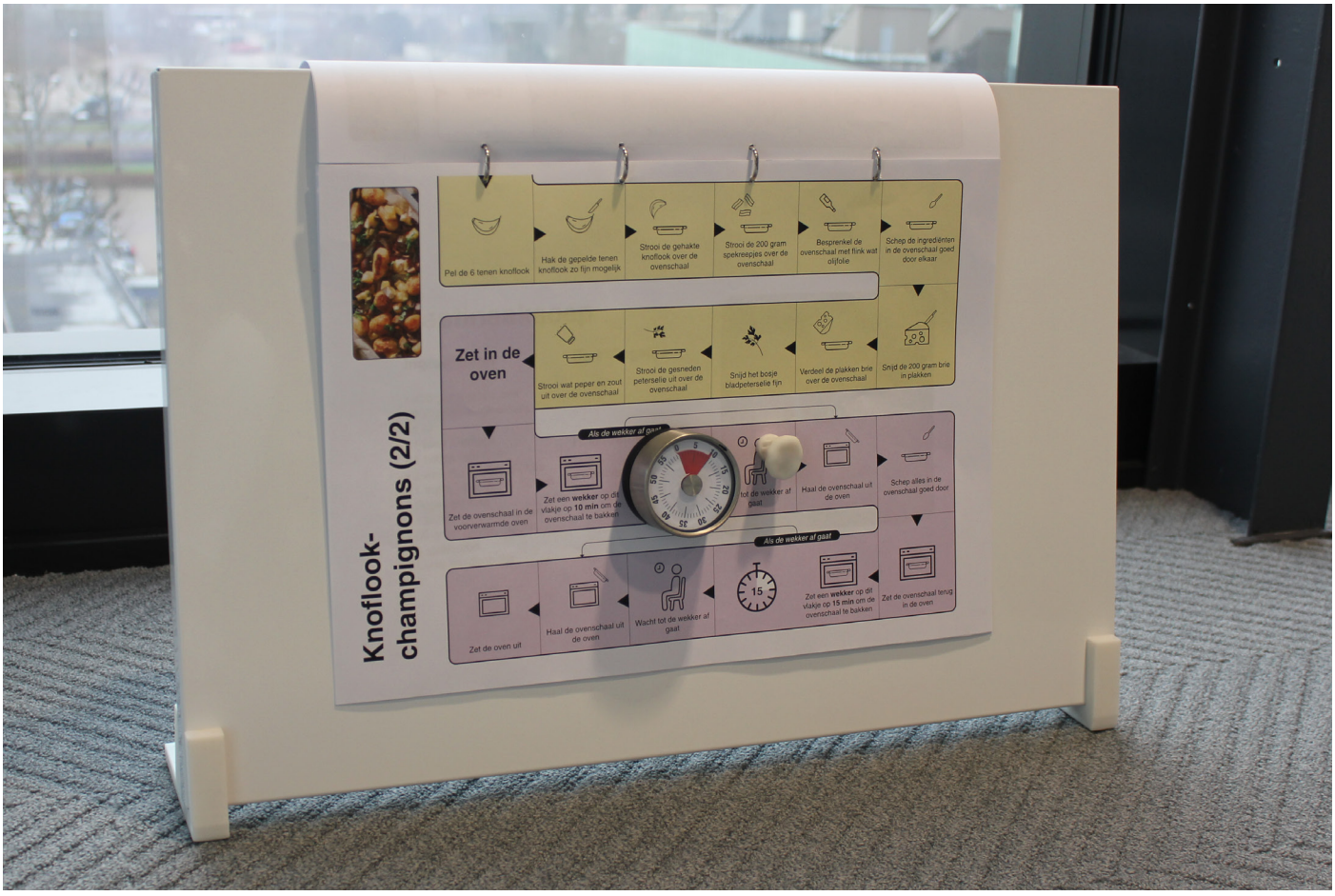


Figure 33: Vertical whiteboard presenting the paper recipe, magnetic pawn, and magnetic timer

5.6 NAVIGATION

The design should help PwDs remember which tasks they have already done as PwDs often struggle with their short-term memory. At the same time, the design should give PwDs an overview of the whole cooking process, so they know where they are in the activity.

LIST OF STEPS

The traditional way of listing the steps (Figure 34) appeared problematic, as one participant would forget which steps he had done and always return to the step on the top left of the page.

Figure 34: Prototype 2 – a list of steps with pictures and text

ONE STEP AT A TIME

Showing only one step at a time (Figure 35) prevented the participants from forgetting which step they were working on. However, participants lost overview of the cooking process and often asked what the next step would be. Moreover, it made it challenging for multiple people people to work together as they could only view one step at a time.

Figure 35: Prototype 4 – video recipe shows one step at a time

BOARDGAME LAYOUT

Showing multiple steps in boxes on a large piece of paper helped participants with the over-view. Numbering the steps (Figure 36) proved an insufficient way of navigation as participants of-ten lost their way in the recipe.

Figure 36: Prototype 10: A2 sized paper showing multiple numbered steps at once

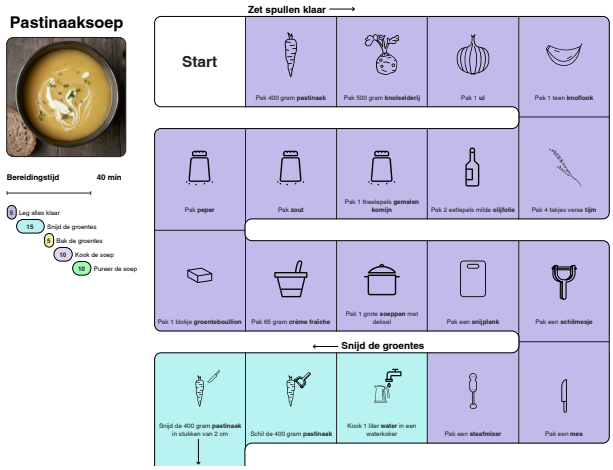


Figure 37: Prototype 11 – a paper recipe using a zig-zag navigation layout often used in board games.

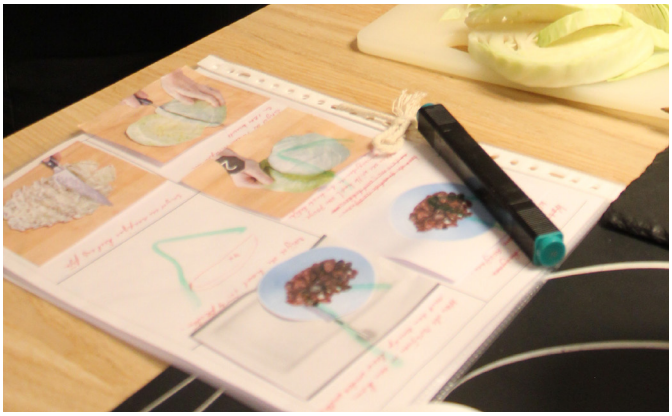


Figure 38: Prototype 7 – paper recipe inside a plastic folder with a marker to mark the steps

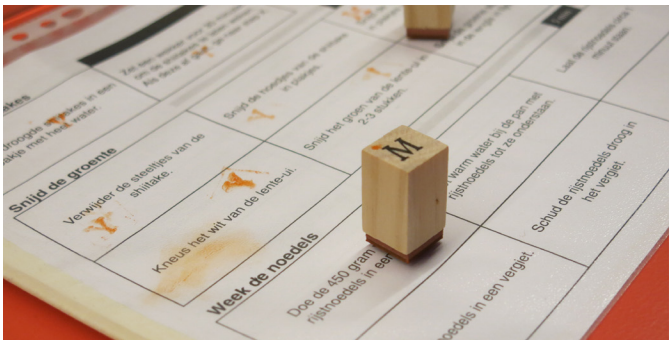


Figure 39: Prototype 8 – participants mark the steps with a stamp of their initials

Figure 40: Prototype 10 – participant uses the stamp as a pawn to move through the steps

A zig-zag layout where the navigation direction switches back and forth (Figure 37) made it easier for participants to move through the step. Nevertheless, moving from right to the left turned out challenging for PwDs as one participant kept trying to navigate from left to right.

MARKING THE STEPS

Placing the recipe in a plastic folder and marking the steps with a wipeable marker (Figure 38) helped the participant quickly see where she left off and not forget any steps. However, she often forgot to mark the steps and grabbing the marker, taking off the cap, and making the mark was too much effort to do after each step.

MOVING A PAWN

Having separate stamps with participants' initials (Figure 39) helped collaboration as it was clear who had completed which step and which steps still had to be done. Nevertheless, dabbing the stamp into the ink cushion every time was still cumbersome.

Using a pawn (Figure 40) felt more intuitive and faster to participants and helped indicate which step they were working on.

> *"Normally, this is the moment that I look through all the steps and see what I have to do, but now I have marked where I left off, so I do not have to read through all of it again." – Sanne, PwD prototype 10.*

5.7 WRITING THE RECIPE

Each client is unique in their cooking experience, routines, phase of dementia, and food preferences. Hence creating a cookbook with generalised recipes would not cater to their individual needs. The informal caregivers know the client's required level of detail, order of actions, and preferred recipes. All informal caregivers who participated in this study stated they would prefer to use their recipes. Thus, caregivers should have the ability to create personalised recipes themselves. The caregivers should adhere to the formulating step guidelines mentioned before. Furthermore, writing should allow for changes in the order of the steps and not take up too much time for the caregiver.

> *"We would rather have a good method to create my own recipes than a cookbook with predefined recipes. Everyone has different tastes and abilities change, so we would like to have the flexibility to do it ourselves." - Husband of PwD prototype 7*

LARGE GRID ON PAPER

A straightforward solution is to write down the recipe on paper, with each step separated in a large grid (Figure 41). A caregiver was asked to write down recipe steps on such paper while we added paper images matching these steps. His wife with dementia found it easy to follow his steps. The caregiver himself did not mind writing the recipe and offered to do it again. A downside to the paper is that the steps cannot be moved around, adjusted or deleted.

DIGITAL LIST

A digital list made on a computer (Figure 42) allowed participants more freedom to adjust steps and move them around. However, as it is not put in the intended layout and lacks visuals, it was challenging for the participant to check whether his recipe steps made sense.

Figure 41: Prototype 7 – caregiver wrote down the steps while we added 'auto-generated' images

Voorbereiding

1. Snipper 1 ui
2. Snijd 3 tenen knoflook fijn
3. Snijd 1 winterpeen in kleine blokjes
4. Snijd 750g tomaten, elke tomaat in vieren.
5. Ris de blaadjes van 1 takje verse tijm

Temp

6. Doe 1 eetlepel olie uit het potje gegrilde paprika in de soeppan.
7. Doe het vuur aan op lage temperatuur
8. **Zet een timer voor 6 min.**
9. Fruit de ui, knoflook en wortel.
10. **Als de timer gaat, reset de timer voor 3 minuten**
11. Voeg de geriste tijm en 70g tomatenpuree in de soeppan en bak mee.
12. **Als de timer gaat, reset de timer voor 11 minuten.**
13. Voeg de tomaten (in kwarten gesneden), 750ml water en 2 runderbouillontabletten aan de soeppan. Laat het zachtjes koken
14. **Als de timer gaat,** zet het vuur uit en breng de soeppan van het vuur.

15. Voeg 295g gegrilde rode paprika's uit pot aan de soeppan.
16. Breng de inhoud van de soeppan op smaak met peper.
17. Pureer de inhoud van de soeppan met een staafmixer.
18. Doe 2 eetlepels water bij 125g crème fraîche.
19. Roer de crème fraîche los met een lepel.
20. Verdeel de soep uit de pan over de kommen.
21. Teken iets leuks met de crème fraîche in elke kom met soep.
22. Serveer direct.

Figure 42: Prototype 12 – recipe's steps written by a participant in a bullet list in Word

TRAINING

An interactive training (Figure 43) with multiple-choice questions helped a participant (who had no prior experience with dementia) understand how the steps should be formulated. Adding visual correct and incorrect examples would increase a user's understanding of the information.

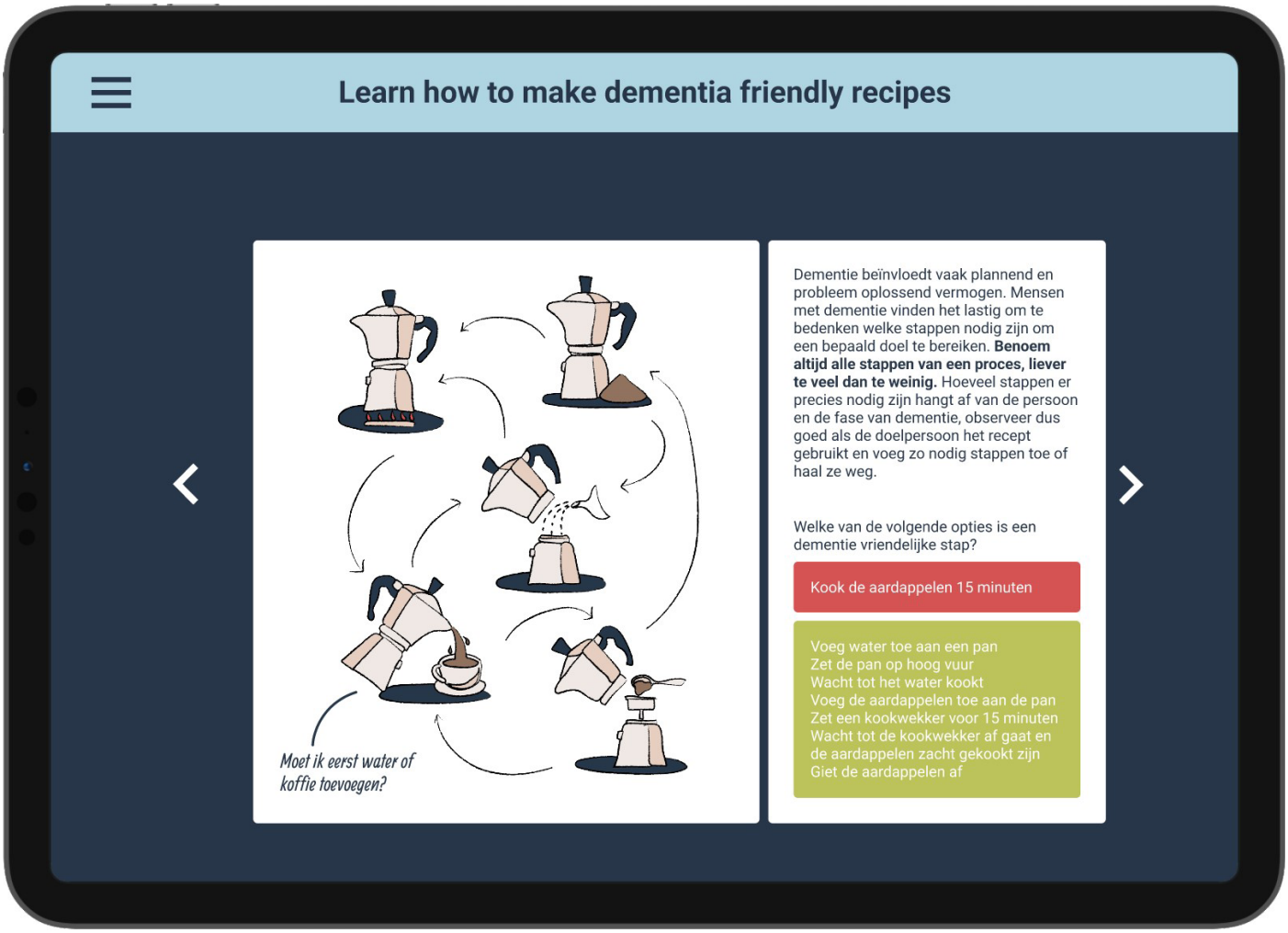


Figure 43: Prototype 12. Training for writing recipes

5.8 DISCUSSION

The first design challenge of this conceptualisation was to guide PwDs through a cooking process in a comfortable way. We found this can best be done by using a board game-like recipe that shows multiple steps on a large sheet of paper. By moving the pawn through the steps, the client no longer has to remember at which steps they left off. Furthermore, icons and a visual layout help the client keep an overview of the whole process, understand the direction of the steps, and not feel overwhelmed. A paper recipe seems to be most intuitive to use for people with dementia and thus adds to the level of comfort.

The second challenge was allowing multiple clients or clients and caregivers to collaborate and trust each other while cooking. A pawn can help PwDs and caregivers quickly spot the tasks at hand. If the client is given a task they do not fully understand, they can easily find additional visual information on the recipe. The caregiver can easily spot the task the client is working on and thus check in on the progress. The personal stamps with initials improved collaboration even further by actively marking the steps that have been executed, so collaborators could more autonomously work through the recipe. However, as stamping was too much effort, the design has settled on using a pawn. The scale of the recipe and its visual nature also help people collaborate, as multiple people can look at and understand the recipe simultaneously.

Lastly, the aim was to find how the design could be scalable yet fit each client's individual needs and desires. Caregivers can best write the recipes as they know the client's needs best. A digital interface can best support them by generating the layout and supporting icons. The interface should allow users to move, adjust, and delete the steps and offer training on how to formulate the steps.

LIMITATIONS

The iterative approach of the conceptualisation helped us better understand the needs and desires of the target group and let the target group have a say in the design development. Furthermore, through user testing, we could already add the feeling of autonomy, connection, and a sense of purpose to the client. Some participants had completely given up on cooking and felt inspired after the user tests to start cooking again.

As each prototype was only tested once in one setting with one target group, some design decisions may have been made too hastily. For instance, it was decided not to show one step at a time as the two prototypes that used this were not successful. However, other factors such as video and a laptop were also at play in these prototypes. Although the quick prototyping and single-user testing allowed the design to develop rapidly, it may also have given a skewed idea of the results.

Furthermore, the at-home and meeting centre locations could have given different insights as their observation levels differed. At the meeting centres, we often relied on the observation of other volunteers as we were mainly focused on organising the activity. The caregiver helped out more at home, so we had more time to observe the cooking session.

Chapter 6
DESIGN

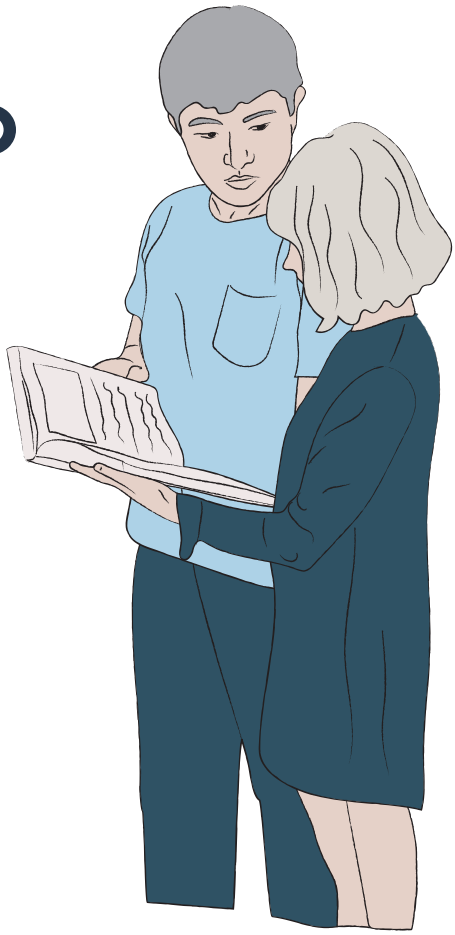
The iterative prototypes of the previous chapter provided us with many insights into how PwDs can be guided through and collaborate during the cooking process and how this guidance can be created in an individualised yet scalable manner. All insights are combined in this chapter into a recipe and application design. First, the usage scenario explains how the target group would interact with the designs. Then the new recipe format and the recipe writing application are described.

6.1 USAGE SCENARIO

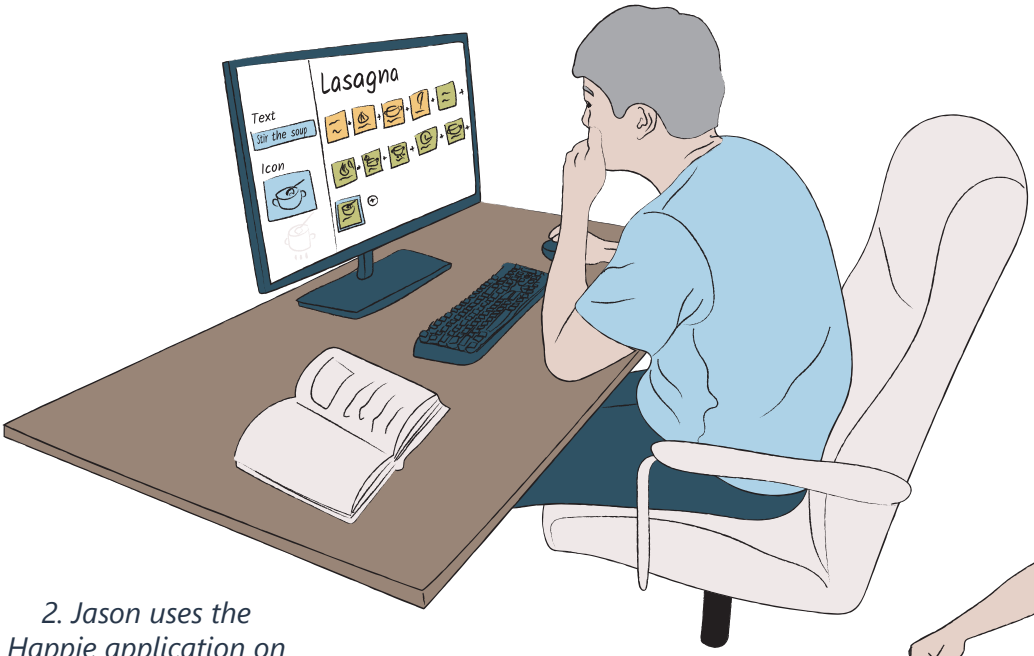
This user scenario shows the intended usage of the design.

Claire loves to cook, but because of her dementia, she now finds it more challenging.

Jason is her husband. He wants to spend time together and help Claire do what she loves for as long as possible.



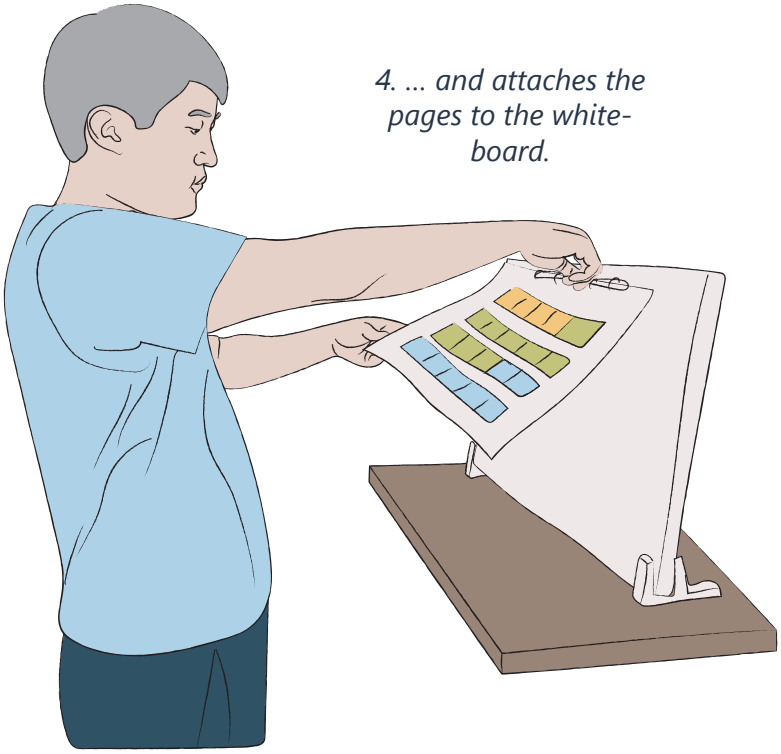
1. Claire and Jason pick out a recipe together. Tonight it will be their favourite lasagna.

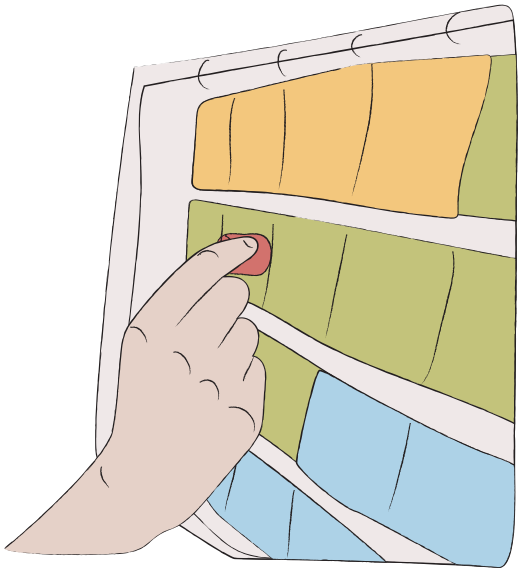


2. Jason uses the Happje application on the computer to rewrite the recipe, so it is easy for Claire to follow.

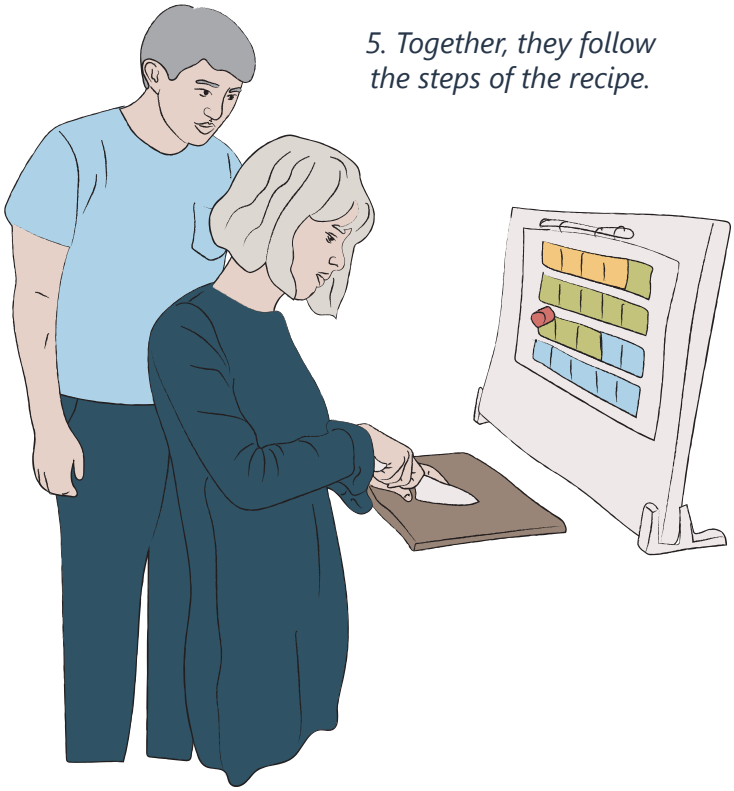
3. He prints out the pages of the recipe...

4. … and attaches the pages to the white-board.



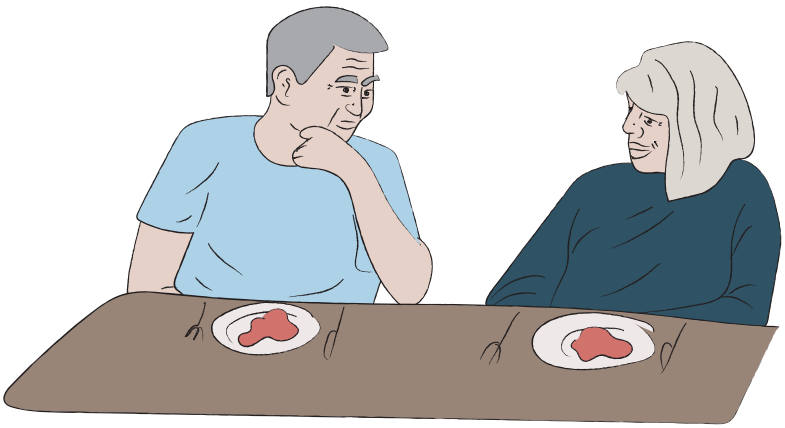


5. Together, they follow the steps of the recipe.



6. They use the pawn to mark the step they are working on.

7. And they end the night with a tasty homemade lasagna.



6.2 RECIPE DESIGN

The recipe is attached to the **whiteboard** with a metal binder. The **binder** keeps all pages together and allows users to flip through the pages.

A magnetic **timer** is placed next to the recipe to keep all cooking elements in one place.

The **whiteboard** helps the recipe stay clean and take up less space on the countertop.

The recipe is **large and visual**, so users can also read it from a distance in the kitchen.

Users navigate through the recipe by using a **magnetic pawn** to remember at which step they are.

Pastinaaksoep (2/3)

Haal de blaadjes van de 4 takjes **tijm** af

Bak de groenten

Voeg 2 eetlepels milde **olijfolie** toe aan de soeppan

Roer de inhoud van de soeppan goed door

Voeg de stukken **pastinaak** toe aan de soeppan

Voeg de stukken **knolselderij** toe aan de soeppan

Voeg 1 liter **kokend water** uit de waterkoker toe aan de soeppan

Verkruimel het **groenteboullion** tablet boven de soeppan

Kook de soep

Als de wekker af gaat

Zet een **wekker** op dit vlakje op **10 min** om de soep te koken

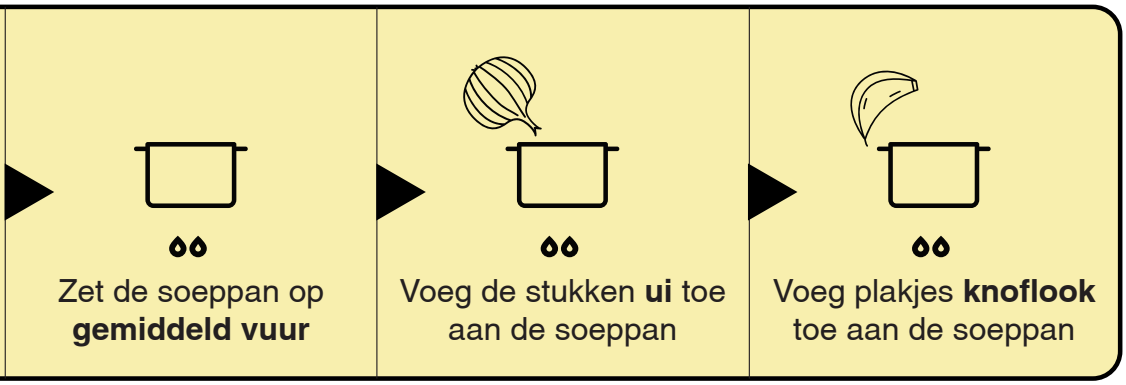
10

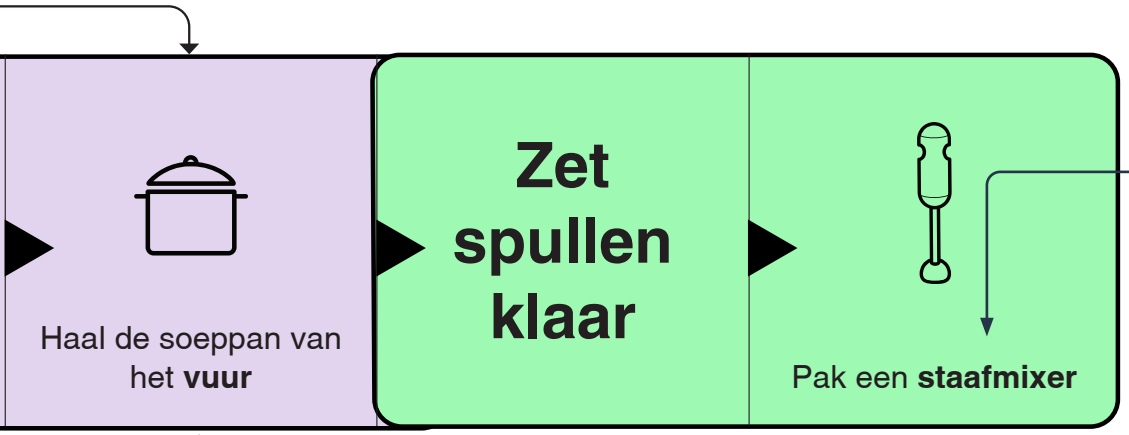
WACHT tot de **wekker** af gaat

Each page includes the **name and an image** of the recipe to help users remember what they are cooking.

The **magnetic timer** is placed on the step block in the recipe, so users remember what they set the timer for.

The **waiting step** tells users to relax, so they know they do not have to keep checking all the steps.





The **turn off the fire** step helps users remember to turn off the fire.

The steps are placed in **horizontal rows** with **arrows** in between to indicate how to navigate through them.

Each step mentions the **number and allocation of the ingredient**, so users do not have to remember information from previous steps.

Whitespace is left between the horizontal rows so users can make notes to adjust the steps.

Different sections of the recipe use different **colours** so users can quickly understand the recipe's order. Pastel colours maximise contrast for reading and allow users to make adjustments.

The **icons** give a visual overview of the recipe and help people with lesser reading capabilities understand the steps.

Each step only mentions **one action** so users can execute the task before forgetting it.

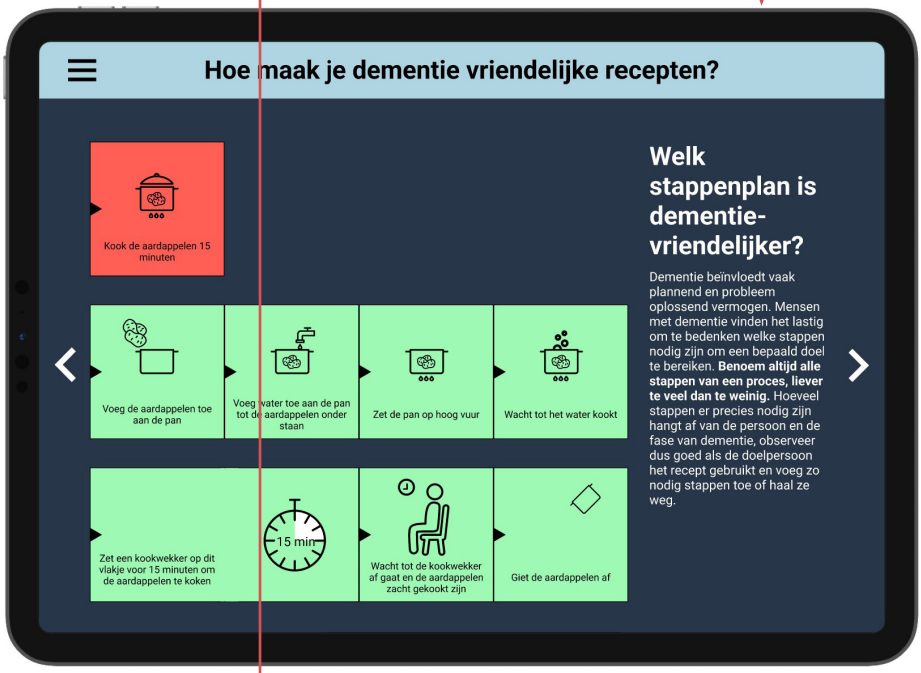
The most important word of the step is highlighted in **bold** to make it easier to understand the recipe.

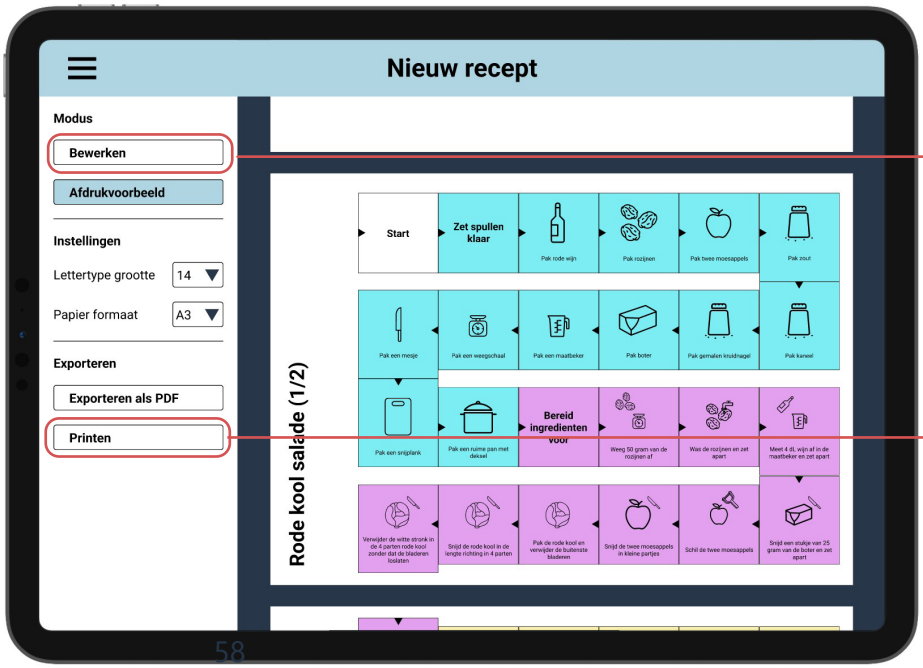
6.3 APPLICATION DESIGN (HAPPJE)

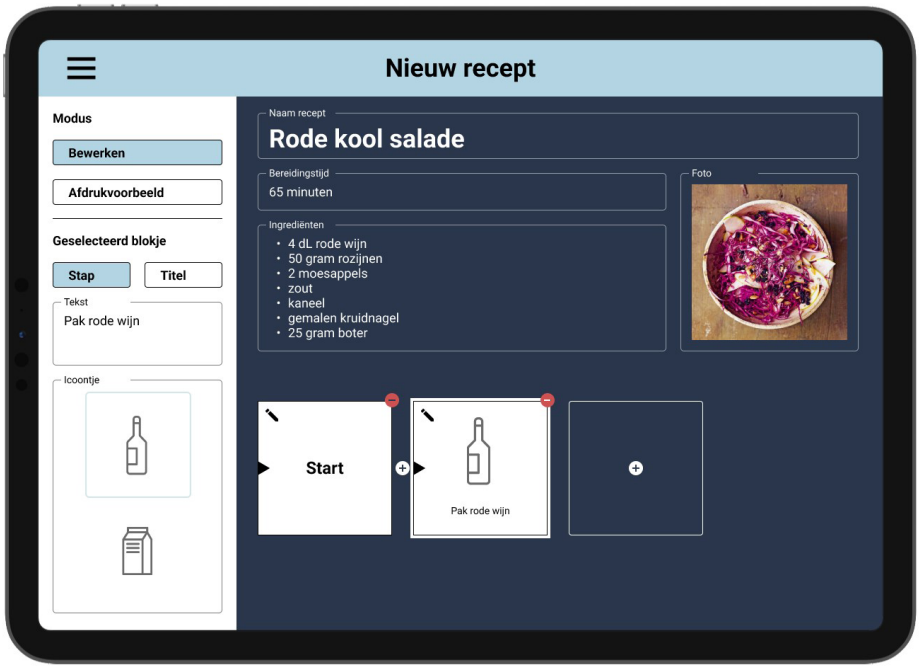
HOME PAGE: Choose whether you want to follow the training, create a new recipe, edit an existing recipe, or use one created by someone else.

TRAINING: Go through several multiple-choice questions to learn how to formulate the recipe's steps in a dementia-friendly manner. Each page includes a right and a wrong way to formulate the steps and explains why.

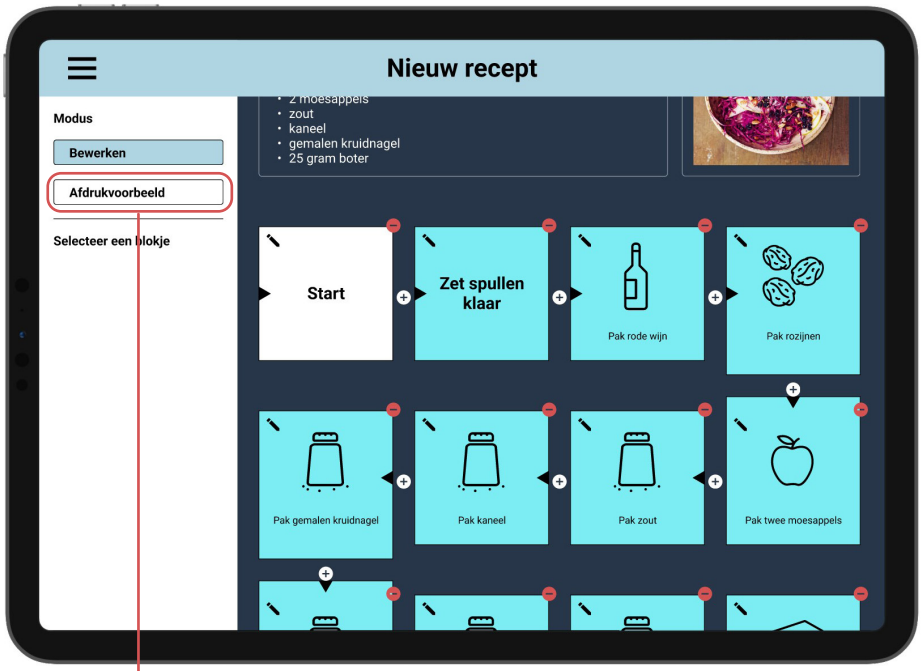
PREVIEW RECIPE: Look at the recipe preview and adjust the fonts, paper size, and colours. Export the recipe as PDF or print the recipe on paper.

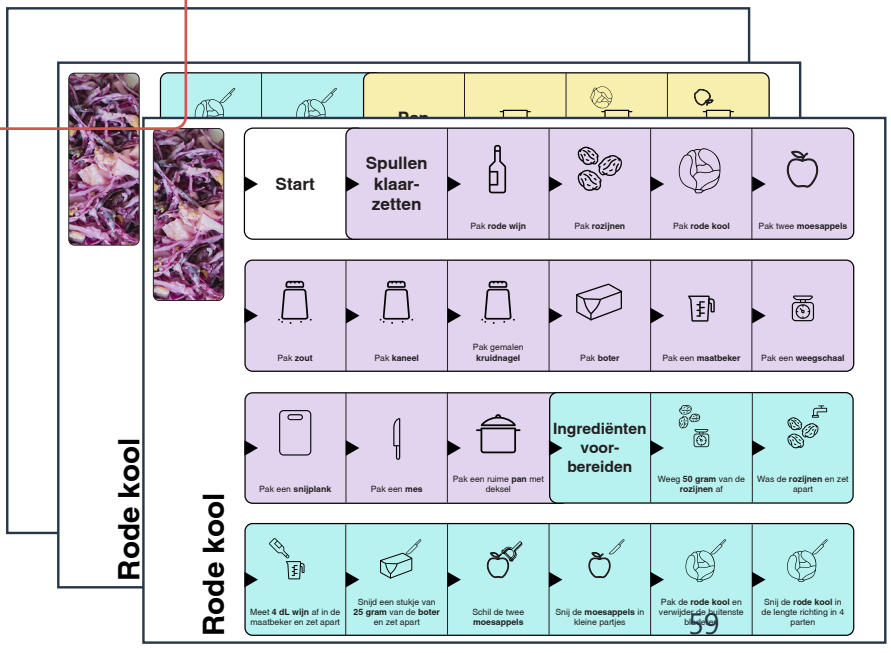






NEW RECIPE: Create a new recipe by adding its name and ingredients. Add a new block per step with textual instructions. The application automatically generates a corresponding icon. Blocks can be moved, adjusted, and deleted. Blocks can be steps or titles. All steps following a title will be rendered in the same colour.





PRINT RECIPE: Print the recipe on the desired paper size.

AUTO-GENERATED ICONS

The recipe uses icons to illustrate the cooking steps. Happje automatically generates these icons based on the input instruction text (Figure 44). Every cooking step can be analysed using a natural language processing algorithm to understand its meaning. The algorithm does so by tokenising every word of the sentence and deriving the root form of each token to understand its meaning. For example, 'stirring' and 'stirred' will all be pointed towards the root token 'stir.' With tokenisation, the total vocabulary used in the recipes can be reduced to a set of actions, ingredients, objects, and states. We create a database of base icons referring to each root token. So actions include mixing, cutting, and stirring icons, while ingredients include onion, bread, and milk icons. After tokenisation of the cooking step, an icon that fully illustrates the entire step can be generated from the base icons.

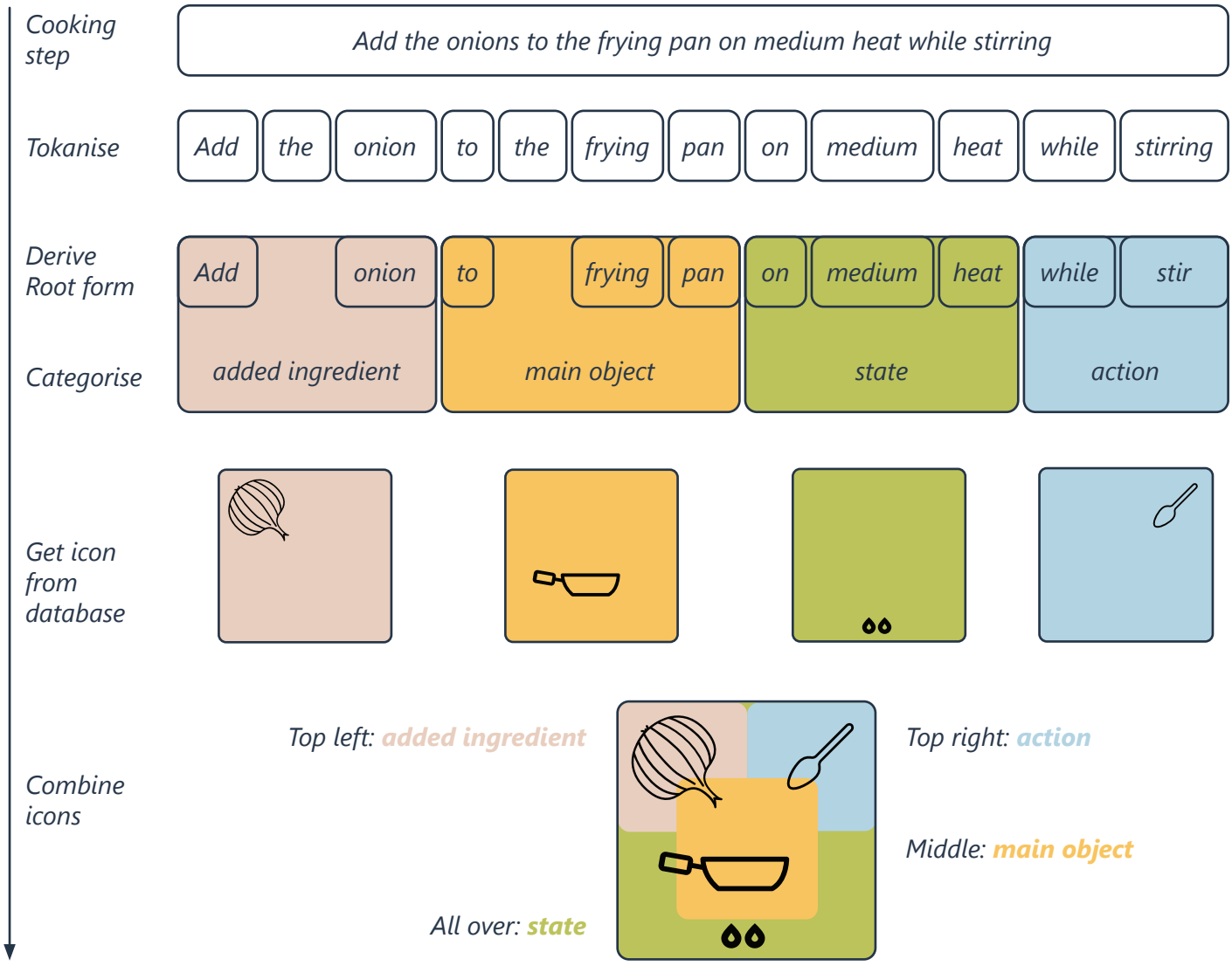


Figure 44: Process of auto-generating the icons

Chapter 7

EVALUATION RECIPE

This study aims to evaluate whether the designed recipe achieves its goal of helping guide people with mild dementia through a cooking activity in collaboration with other clients or caregivers.

Four research questions have been set up to guide the evaluation.

1. Does the design help PwDs and their caregivers understand the cooking steps?

2. Does the design help PwDs and their caregivers navigate through the cooking steps?

3. How do PwDs and their caregivers collaborate during the cooking process while using the design?

4. Which experience is elicited when PwDs and their caregivers use the design while cooking?

A working prototype of the designed recipe was developed and introduced to the intended target group of PwDs and their caregivers. The evaluation happens in the intended context of use, namely at home or dementia meeting centers. Participants receive the task of cooking a particular meal by following the steps on the prototype. By observing the prototype in the intended context with its intended target group participating in the intended activity, we can evaluate the design's usability, performance, and experience.

7.1 METHOD

PILOT

One pilot study was conducted with two participants (one informal caregiver and one person with dementia). The pilot was done remotely, as corona cases were spiking. The participants received the printed recipe materials and questionnaires. They executed all tasks, sent the filled-in questionnaires through email, and were interviewed through a phone call. The evaluation setup was then changed based on their feedback and the intended results.

PARTICIPANTS AND ENVIRONMENT

We conducted one pilot and seven evaluations with 34 participants (19 persons with mild dementia, 11 formal/informal caregivers, 4 designers) (see Table 6). The evaluation took place in two contexts; at-home and dementia meeting centres. Both contexts reflect the intended contexts and are familiar to the participants. PwDs cooked together with their informal caregiver in the at-home setting (see Figure 45). At the meeting centres, PwDs cooked together, sometimes with the supervision of formal caregivers (see Figure 46).

Code	Location	# PwDs	# Caregivers	# Volunteers	# Designers	Written recipe themselves?	Participated in previous studies?
H1	At home	1	1			No	No
H2	At home	1	1			No	No
H3	At home	1	1			Yes	Yes
H4	At home	1	1			Yes	Yes
M1	Meeting centre	4	2			No	Yes
M2	Meeting centre	6	3			No	No
M3	Meeting centre	2	1	1	1	No	Yes
M4	Meeting centre	2	1	2	1	No	No

Table 6: Participants of using the recipe evaluation

Figure 45: Participants in the at-home setting

Figure 46: Participants in the meeting centre setting

PROTOTYPE

The prototype was a full physical prototype of the design. All functions were possible and the aesthetics reflected those of the concept. The recipe pages were printed on several A3 papers and presented on a standing whiteboard with magnetic pawn and timer (see Figure 47). In three cases, due to lack of space or materials, the recipe was presented flat on the table without the whiteboard (see Figure 48).

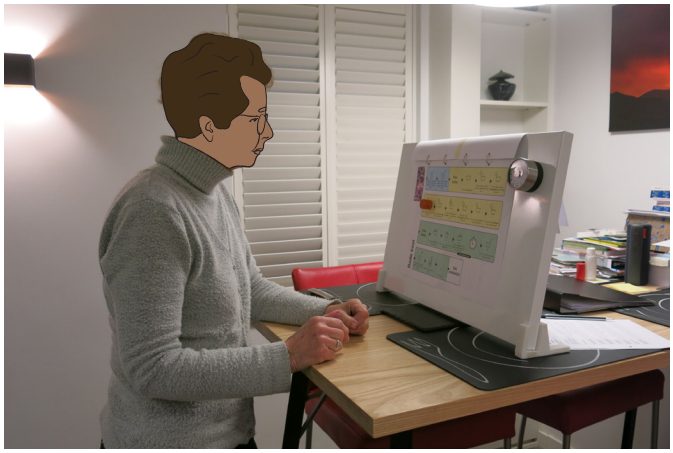


Figure 47: Using the recipe prototype with a whiteboard

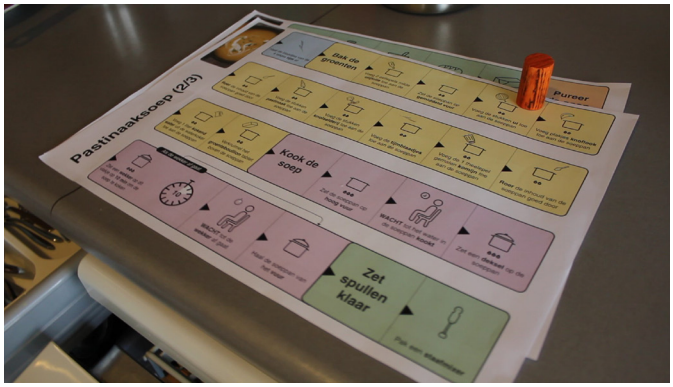


Figure 48: Using the recipe prototype without a whiteboard

MEASUREMENTS

A triangulation of measurements was used to increase the credibility and validity of the research findings. The researcher observed participants during their interaction with the prototype and evaluated eleven design usability elements on a three-point scale. Participants self-reported the experience by filling in a five-point scale on whether they agreed or disagreed with thirteen statements. All statements were written in positive statements to reduce the cognitive load. The observation elements and self-reporting statements were based on the four research questions. All conversations were audio-recorded to add meaning to the previously mentioned quantitative data.

PROCEDURE

Participants of the evaluation were given a choice in the recipe used to cater to every participant's dietary preferences. In two cases, recipes were used based on a prior rewritten recipe of the participants themselves.

The first ten minutes of the study were used to introduce the study and for everyone involved to get comfortable with each other. The PwD and the caregiver filled in the consent form in the at-home setting. In the meeting centres, only the formal caregiver filled in the consent form and the PwDs gave verbal consent. The consent form (see Appendix D: Consent form evaluation) was written in easy language, used a large font, and did not mention the word dementia to prevent unnecessarily upsetting the participants.

Participants were given the following instruction. "Please use this recipe to cook the specified meal together. Each block in the recipe explains one step. Use the pawn to move through the steps."

While they executed the task, we filled in the observation sheet. After the tasks, participants collaboratively filled in the self-reporting sheet. All conversations throughout the evaluation were recorded.

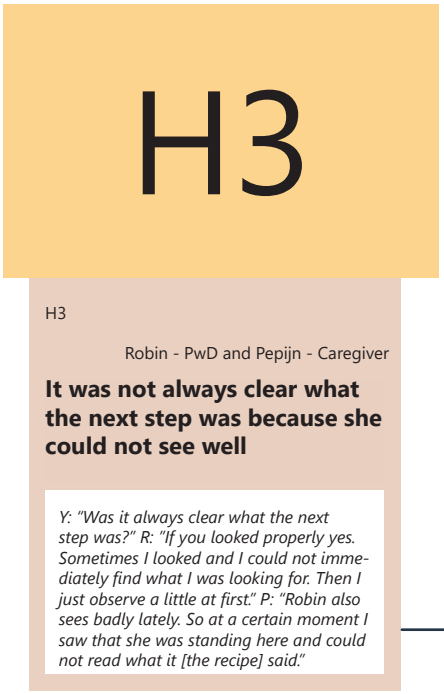


Figure 49: Statement card describes why group H3 was neutral (yellow) about the statement 'it was always clear what the next step was.'

ANALYSIS

The quantitative data of the observations and self-reporting were digitised in a spreadsheet in Excel. All recordings of conversations were transcribed and turned into statement cards. These statement cards were linked to the corresponding quantitative data (Figure 49). Four clusters (understanding the cooking steps, navigating through the cooking steps, collaboration, experience) were formed based on the four research questions by combining the relevant data. Next, sub-groups (Figure 50) based on the topic were formed within the clusters by combining related observations, self-reporting, and interview statements to triangulate data.

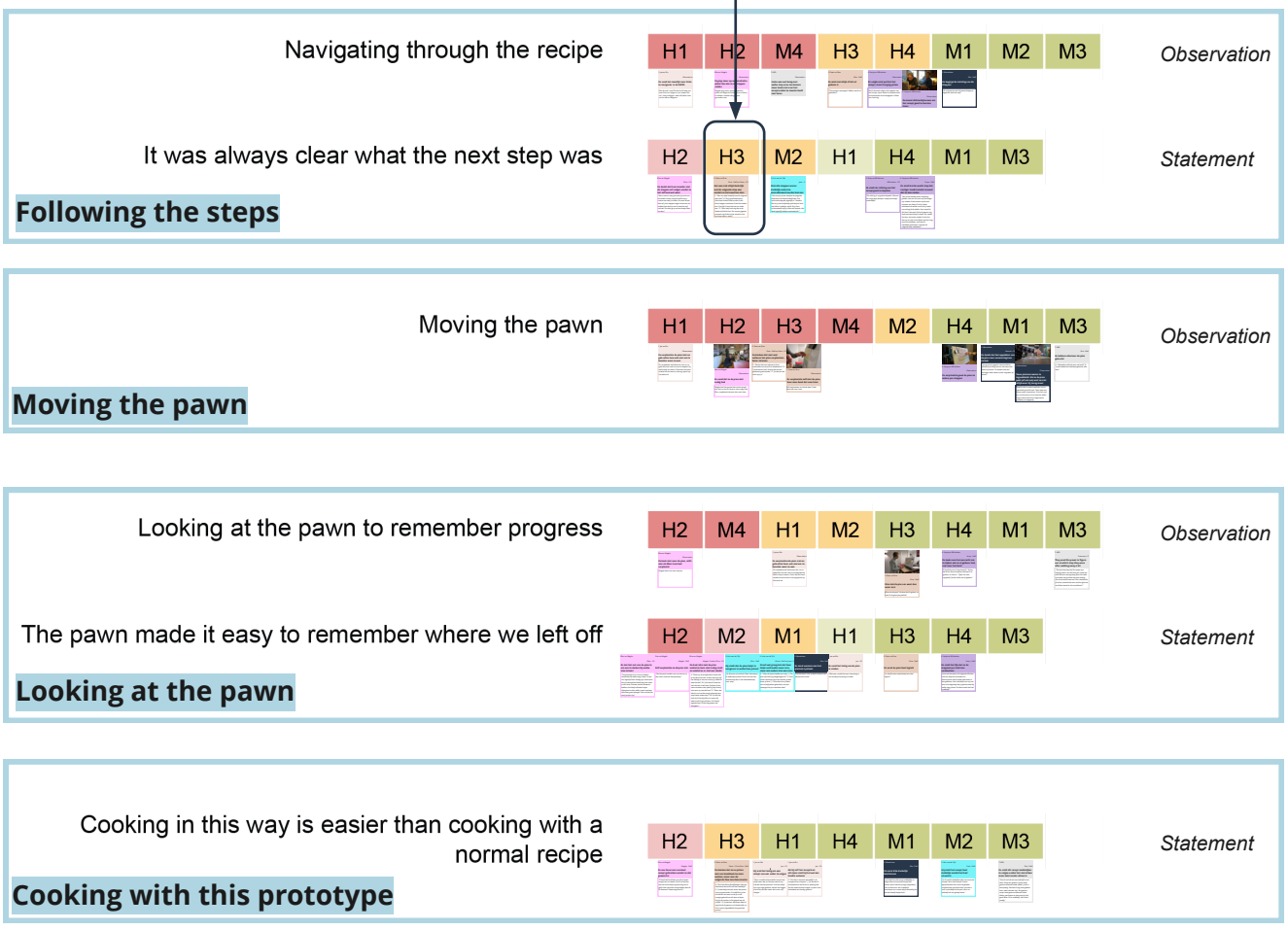


Figure 50: Sub-groups of the cluster ' navigating through the cooking steps' . Each sub-group aims to contain observations, self-reporting, and interview data

7.2 RESULTS

UNDERSTANDING THE COOKING STEPS

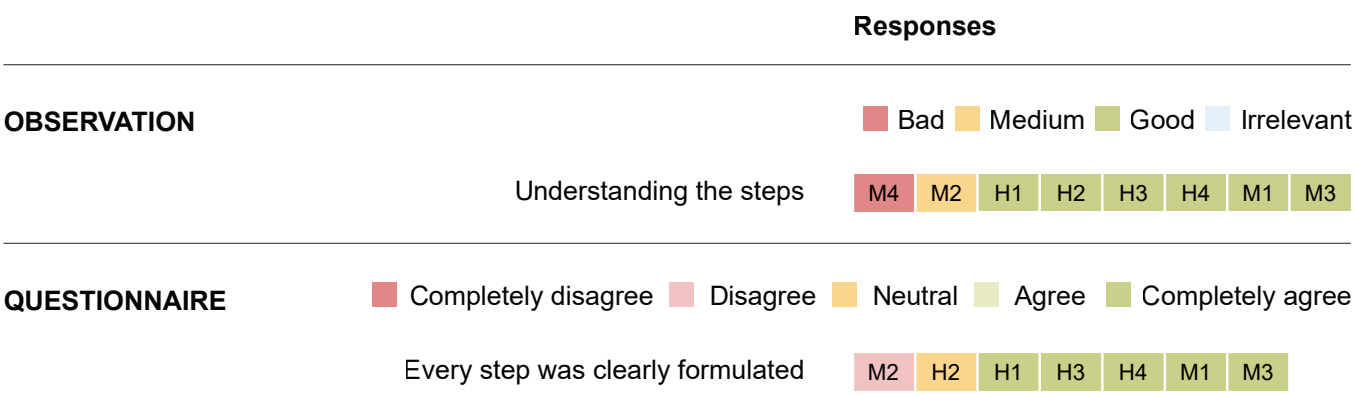


Figure 51: Results – formulation of steps

FORMULATION OF STEPS

We observed that six out of eight groups perfectly understood all the steps and knew what to do after reading them (Figure 51).

PwDs M2 sometimes relied on the caregiver's explanation to understand a step. It was not always clear where they should add an ingredient, so they disagreed that every step was clearly formulated.

> *"I noticed it was asked three times, all of them asked if it [the mushrooms] should go on top of [the oven dish] or in a new oven dish." – Paula, caregiver (M2 b wse).*

Furthermore, group M2 automatically combined some steps ('peel the garlic' and 'chop the garlic'), so they thought it was confusing that these steps were mentioned separately. We also observed this behaviour in other participants.

One PwD from M4 could not read and thus did not understand any of the steps independently. PwDs from H3 and H4 were observed to move closer towards the prototype and putting on reading glasses to read the steps (Figure 53). Some participants could thus not understand the steps from afar.

Figure 53: Participant (H4) has to get closer and take off her glasses to read the recipe

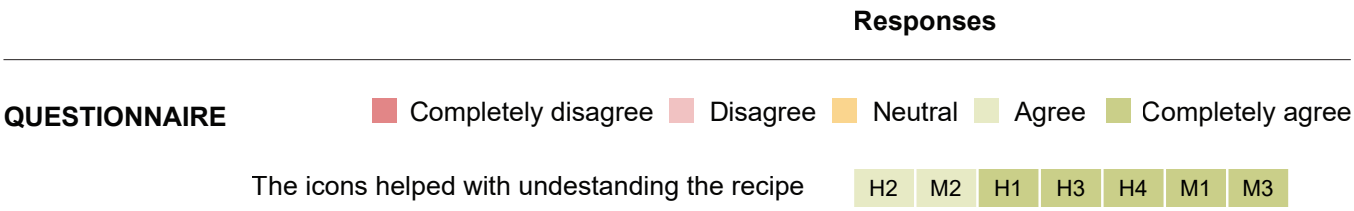


Figure 54: Results - icons

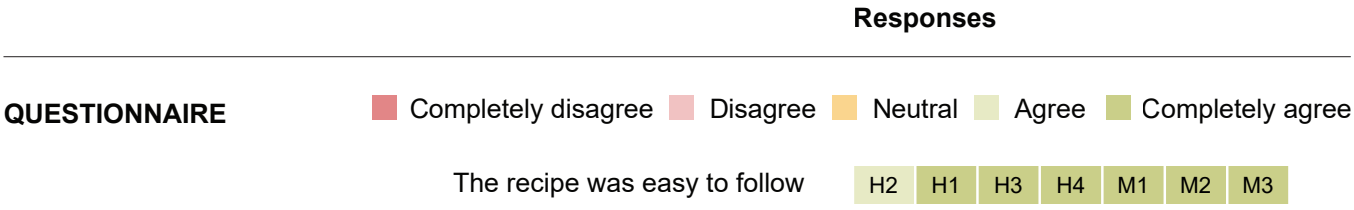


Figure 55: Results - following the steps

ICONS

All participants stated that the recipe iconography helped with understanding the steps (Figure 54). A PwD (H4) said that the icons made the recipe feel calmer.

> *"I notice that this recipe looks very calm, and that is nice. It is clear because all the icons are added, so you can see what it has to be." – Sanne, PwD (H4).*

Another PwD (M2) that she barely looked at the icons but would miss them when they were gone.

> *"The weird thing is that if you would leave out the icons you would miss them. But if they are there you look at them more fleetingly." – Corrie, PwD (M2).*

FOLLOWING THE RECIPE

All participants agreed that the recipe was easy to follow (Figure 55). One PwD (H4) felt it was beneficial that all tasks were mentioned step-by-step.

> *"The fact that it is made step by step, image for image, may seem unnecessary for some. But for me, it is not unnecessary." – Sanne, PwD (H4).*

Another PwD (M2) said the step-by-step approach helped him not feel nervous.

> *"It is indeed very simple and very much step, step, step, which prevents you from feeling nervous. That is the thing with cooking; it makes you super nervous. And we are not getting nervous from this." – Josef, PwD (M2).*

A PwD (M3) found it pleasant and easier to understand because the recipe did not use a list.

> *"A normal recipe lists everything underneath each other, and then you have to read really carefully. This is easy; it is very pleasant." – Rosalie, PwD (M3).*

Lastly, group H4 felt the whiteboard helped organise the pages and cooking supplies and thus made it easier to follow the recipe.

> *"It [whiteboard] is indeed a lot clearer. You can flip over a page, and you do not have to spread everything out at once on the table." - Wilma, friend (H4). "It works indeed that you also have the timer on hand because now you just have one image [to pay attention to]." - Sanne, PwD (H4).*

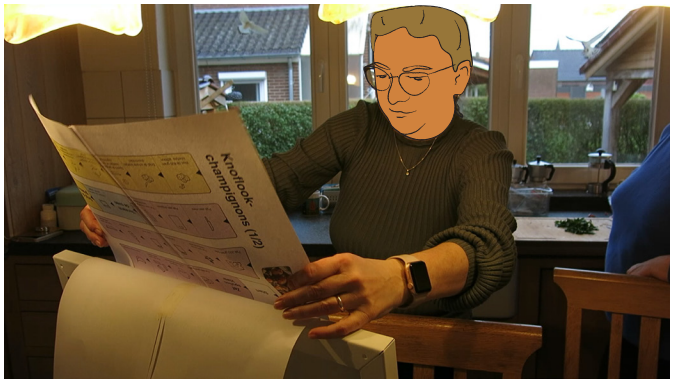


Figure 56: Participant (H4) flipping through the recipe

NAVIGATING THROUGH THE COOKING STEPS

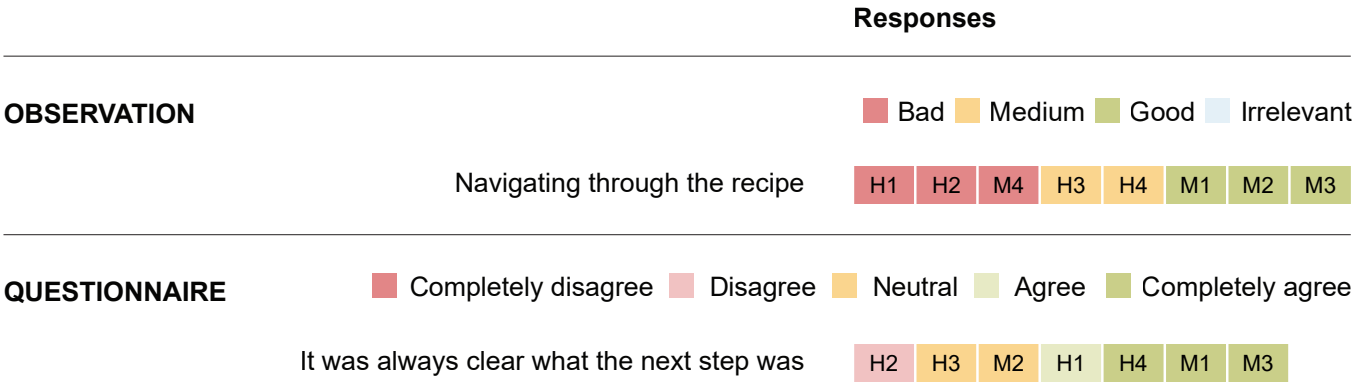


Figure 57: Results - following the steps

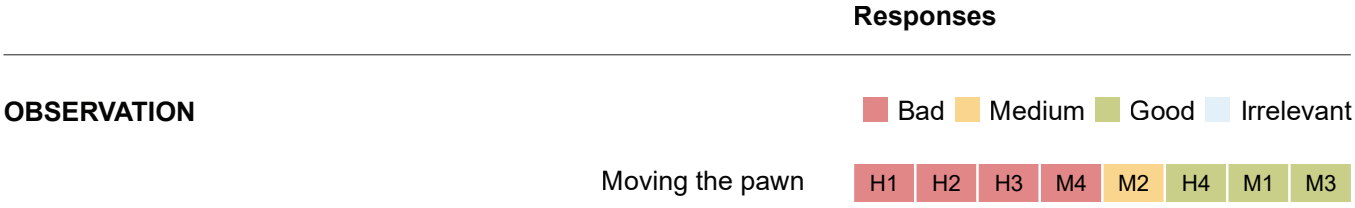


Figure 58: Results - moving the pawn

FOLLOWING THE STEPS

We observed that only three groups perfectly moved through the cooking steps in chronological order (Figure 57).

Two groups (H3, H4) did not always remember whether a task had been completed and sometimes accidentally changed the order.

> *"Thin slices of apple, have we already cut those?" – Robin, PwD (H3).*

Furthermore, one PwD (H3) felt she had to search for the right step. Her husband accounted this to her worsening eyesight.

Another PwD (M4) could not read, so she did not navigate through the recipe.

Group H2 disagreed with it always being clear what the next step was. The PwD was observed to switch around the recipe's steps as she saw fit and would bake the garlic before all the vegetables were cut because she felt it would be more efficient. Her daughter thought her mother thought she did not need the recipe.

> *"What I notice is that you always, also with a different recipe, fall back onto the routines that you already know. So, on the one hand, you want to follow the [recipe] steps, but on the other hand, you think you already know it." – Edith, daughter of PwD H2.*

Lastly, one caregiver (H1) found it challenging to follow a recipe that was not his own.

> *"I am always just doing whatever, and with this [recipe], I have to stick to the protocol. I have always been a free bird, that does not mean I cannot do it [follow this recipe], but it is more difficult for me." – Johan, partner of PwD (H1).*

MOVING THE PAWN

In five out of eight groups, the PwD did not move the pawn consistently (Figure 58). Their caregiver would move the pawn for them. One PwD (H3) felt that she could learn to move the pawn with practice.

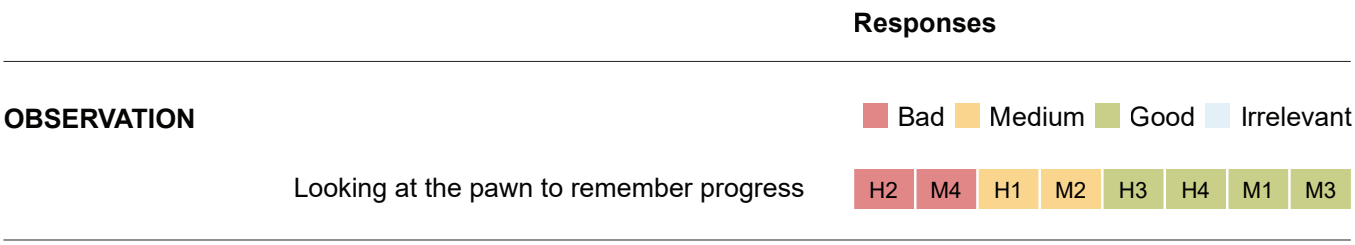


Figure 60: Results - looking at the pawn

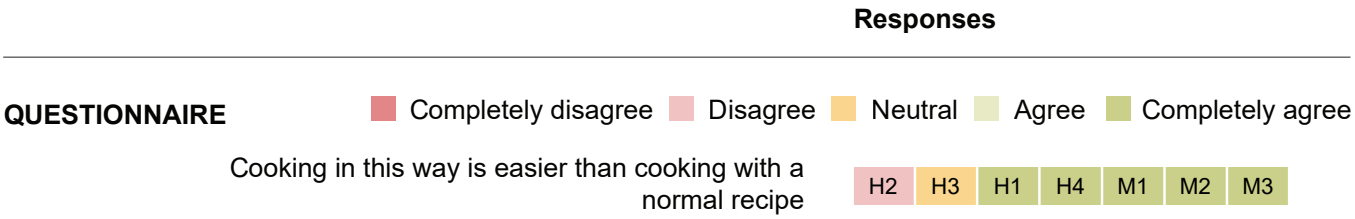


Figure 61: Results - cooking with this prototype

"Yes, I think [with practicing, I can remember moving the pawn]. I think it will simply become a habit." – Robin, PwD (H3).

Some participants were seen struggling to remember where to place back the pawn after picking it up (Figure 59). A caregiver confirmed seeing this.

"At a certain moment, I saw that she [PwD] took the pawn away and no longer knew where it belonged. She has to move it but does she then still remember where it was before?" – Mila, Caregiver (M1).

LOOKING AT THE PAWN

Although not all PwDs moved the pawn, half of the groups did look for the pawn to see their place in the recipe (Figure 60).

"[Robin sees pawn on recipe] Oh, I have done this one, so now I have to grab the large pan." – Robin, PwD (H3).

Four groups also agreed that the pawn made it easy to remember where they left off.

"Because you can move the magnet [pawn] one step every time, so I always know where I left off. That makes it very easy." – Sanne, PwD (H4).

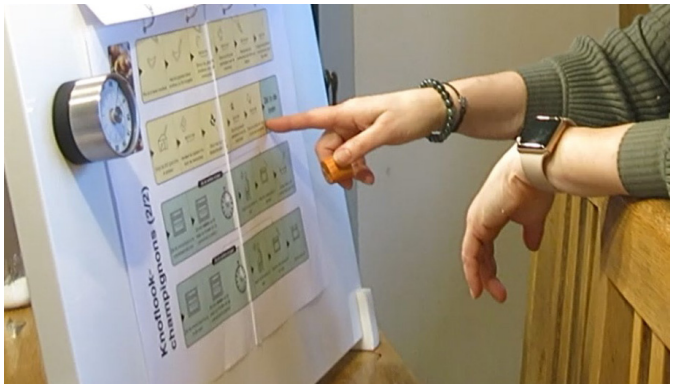


Figure 59: Participant holds pawn in hand while moving

One caregiver (H1) thought his wife had difficulty seeing the pawn and thus often looked over it.

One PwD (M1) felt she had to get used to using the pawn. And indeed, during the evaluation, she was observed to get more consistent in moving and looking at it.

"The [pawn] is a system you have to get used to." – Renee, PwD (M1).

Another group (M2) felt something to remember where you are would be valuable but were not convinced of the pawn.

J: "The pawn did not really catch on, right?" C: "No, but maybe still something so you know where you are." – Jane, caregiver, and Corrie, PwD (M2).

One PwD (M2) fully disagreed that the pawn made it easy to remember where they left off because she did not see the point in moving it.

> *"I like it when I see you [moving and using the pawn], but for myself, I think well, I will just continue. And I do not actually consciously think it; I just continue." – Melany, PwD (H2).*

Her daughter thought the pawn could be valuable but was not convinced it would work for her mother.

> *"The pawn is there to help indicate at which step you are. And that would be very valuable because sometimes you completely lose track of where you are. But for some reason you do not do it [use the pawn]." – Edith, daughter of Pwd (H2).*

COOKING WITH THIS PROTOTYPE

Five out of seven groups completely agreed that cooking with this prototype was easier than cooking with a normal recipe (Figure 61). Participants thought the prototype was clearer (M1, M3) and more visual (M2).

One participant (H2) disagreed because she thought the recipe was too fixed, and she preferred to use familiar recipes.

> *"I think that [cooking with the prototype or a normal one] does not make a difference. If I would do it on my own, with a normal recipe or yours, I would immediately go for the normal thing, I think. Why? Because I am used to it, I think." – Melany, PwD (H2).*

Another participant (H3) was neutral because she felt she could still cook with her old cookbooks.

> *"If I have those little books from Blue Band, that is also really easy. If I just have one of those little booklets, and it is not too complicated, then it goes fine." – Robin, PwD (H3).*

COLLABORATION

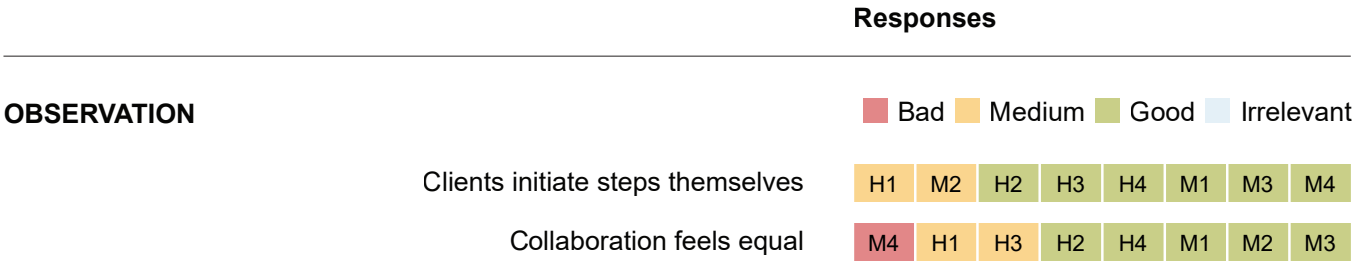


Figure 62: Results - equal collaboration

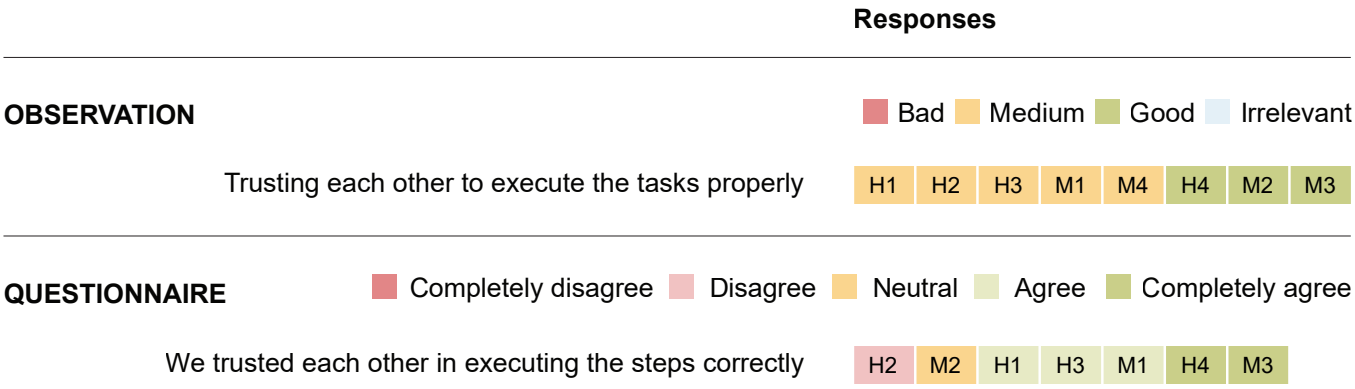


Figure 63: Results - trust

EQUAL COLLABORATION

PwDs of six out of eight groups initiated steps themselves (Figure 62). Two PwDs (M1, M2) were observed to hand out tasks to others, which pleasantly surprised a caregiver.

> *"I thought it was great [that she was handing out the tasks instead of me], better even. Because their brains will be stimulated again by doing an activity. It is good to be aware of that because it sometimes sneaks in always to take over things [as a caregiver] while they [visitors] are capable of doing a lot themselves." – Mila, caregiver at meeting centre (M1).*

In two groups (H1, M2), the PwDs mainly followed instructions from the caregiver. One PwD (H3) started passive, but initiated tasks herself once stimulated by her caregiver.

In all groups without a formal caregiver or partner (H2, H4, M1, M3), the collaboration felt equal, with participants giving each other helpful tips, listening to one another, and dividing the tasks.

> *S: "Sprinkle the parsley... oh we have already done that. Then sprinkle some pepper and salt over the oven dish." W: "I think you have forgotten something Sanne." S: "Yes? Sprinkle the parsley over the oven dish. Oh yes, hahaha!" – Sanne, PwD, and Wilma, friend (H4).*

However, the collaboration between two groups with partners (H1, H3) seemed unequal as the partner mainly handed out the tasks and took over if it did not go to their satisfaction.

TRUST

Five groups stated they trusted each other to execute the steps correctly (Figure 63). This trust was not wholly reflected in the observation, as participants in these groups kept checking the progress and taking over if they felt it was not going right (Figure 64).

> *[Rianne is cutting a vegetable] "If you cut it this way... yes, no, like this." [Johan shows how to cut it in his way] – Rianne, PwD, and Johan, partner (H1).*

One participant (H2) disagreed with trusting her mother and said she always felt she had to check her mother's actions. She would walk to the recipe and compare the steps with her mother's doing.

> *"Yes, I was indeed checking a little bit. Whether everything was going in at the right moment and that the fire was at some point still on without any oil in the pan. And also checking a little if she was doing it according to the steps." – Edith, daughter (H2).*

Figure 64: Partner showing PwD how she should cut the garlic

Figure 65: Results - interest

Figure 66: Results - socialising

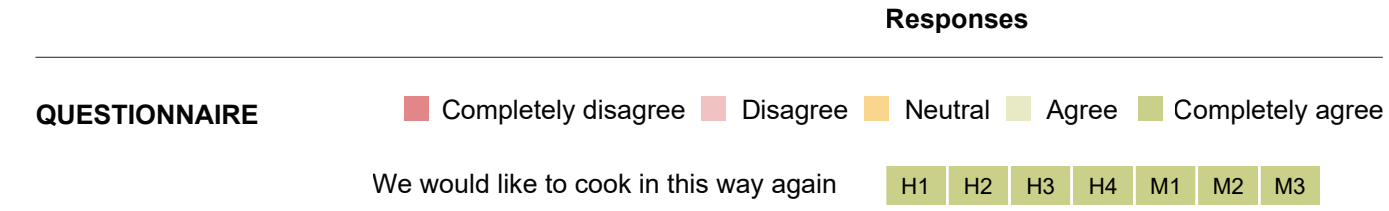


Figure 67: Results – cooking again

INTEREST

All participants said they stayed interested throughout the cooking activity (Figure 65). Likewise, we observed only one PwD (M4) that got distracted and wandered off with her thoughts.

The others all stayed involved in the activity, and one group (M3) even asked if they could help another group when they were finished.

> *"Are they [another group] still not done? Ours are already in the oven!" [She proceeds to walk to the other table to help] – Rose, PwD (M3).*

Six out of eight groups also immediately felt like starting when presented with the prototype.

> *"Yes, I did [feel like starting]! I thought gosh, fun. Especially because I am bad at cooking." – Corrie, PwD (M2).*

SOCIALISING

All groups stated they enjoyed collaborating while cooking, and seven out of eight groups were also observed to chitchat and have social experiences together (Figure 66). Participants (H3, M3) said they always like doing things together.

COOKING AGAIN

All participants completely agreed with wanting to cook this way again (Figure 67). Three groups (H2, H3, M1) highly enjoyed the sociable experience.

> *P: "Oh, I can do that [cooking this way] more often." R: "Yes, I think it is very cosy this way." – Pepijn, partner, and Robin, PwD (H3).*

One PwD (M2) said she wants a cookbook with recipes like these.

> *"I do [want to cook this way again]. I simply want a cookbook like this." – Corrie, PwD (M2).*

Another (M1) said she thought this cooking experience was an excellent way to keep all visitors involved.

> *"Yes [we would like to cook this way again]. Because it is a good way to keep everyone engaged, so they can learn something new because you are not just doing it for you, but also for each other." – Renee, PwD (M1).*

7.3 DISCUSSION

This evaluation looked into whether the designed recipe helps people with dementia and their caregivers cook collaboratively. The recipe's layout, iconography, colours, step formulation, and presentation helped most participants understand the cooking tasks easily. People without reading capabilities could not use the current recipe. Minor improvements for the prototype would be combining related steps and increasing the text's contrast.

Navigating through the recipe still proved difficult for some. The pawn element was trickier to get used to as participants often forgot to move the pawn, and some would not look at the pawn to find their place in the recipe. However, having something to mark the current step or the past executed steps did help participants with navigating through the recipe. PwDs can (re)learn skills using errorless learning [40]. With this method, participants keep doing the same tasks and are prevented from making mistakes to form a fixed routine. Perhaps with much practice, PwDs would thus be able to learn moving and looking at the pawn. Additionally, the pawn should be redesigned to be more visible and inviting to move across the recipe.

All participants stayed interested throughout the entire activity, which contrasts with the passivity and lack of incentives generally mentioned about PwDs [32], [41]. Potentially, the prototype appeared inviting and intimidating and the setting was sociable that all participants felt inclined to join.

The prototype helped with collaboration as all participants could see all steps and the step they were currently working on. The collaboration could be improved by allowing participants to work on multiple tasks simultaneously. In collaborations between multiple PwDs, the interaction was light and fun, so using this prototype within a meeting centre context is highly suitable. Although the prototype also suited the at-home contexts, the collaboration between PwDs and their partner was less patient and more controlling. We believe this is because the caregivers have lost trust in the perception of the PwD and have learned to take over household tasks. Potentially, the trust could come back with practice, and the interaction could become as light and fun as those between multiple PwDs.

LIMITATIONS

The evaluation's context, participants, tasks, and prototype are representative of the intended context, users, tasks, and design. Thus, no user scenario was used for this study as the prototype could be tested in its intended use. Furthermore, as the evaluation contained eight cases with 34 participants, we believe the study gives insight into various users and contexts.

However, the quantitative data could not have been entirely objective as the self-reporting questionnaire for the participants was filled out by the participant groups collaboratively, meaning the opinions of the PwDs and caregivers were merged. PwDs tended to have a more positive view of the prototype and experience, while the caregivers were more critical. Also, the caregivers may not have felt entirely comfortable being too critical as the PwD was in the room with them. Therefore, having the caregiver and PwDs collaboratively fill in the questionnaire could have led to less accurate results.

The quantitative questionnaire only consisted of positive statements to suit the cognitive abilities of the PwDs. Although these positive statements made it easier for participants to fill in the questionnaire, perhaps it made them look less critically at each statement and more inclined to agree with statements fully.

Furthermore, while observing the meeting centres, the researcher was also organising the activity. Thus, she could not pay full attention to the observation task. The observation and analysis were also solely done by the researcher, meaning the outcomes may not be entirely objective.

Lastly, the study only evaluates the use of this design and does not compare it to ordinary recipes. Therefore we cannot with complete certainty state that this design is more accessible to cook with than an ordinary design.

Overall, the study gives insight into which elements were helpful and which did not in guiding people with dementia through an activity. Further research could be done with the study's insights to improve how we guide people with dementia and thus help make them more independent.

Chapter 8

EVALUATION APPLICATION

The second evaluation aims to understand whether the application Happje achieves its goal of helping caregivers create dementia-friendly recipes for their PwD. As this application does not yet fully work, and only a Figma prototype exists, the evaluation focusses the following three research questions:

1. Can caregivers write recipes according to the guidelines after following a training on these guidelines?

2. Are caregivers motivated enough to write recipes more often?

8.1 METHOD

PARTICIPANTS AND CONTEXT

Four caregiving participants were part of the study (Table 7). Three had participated in previous studies of this project; all had participated in evaluating using the recipe. The study was held at their homes.

Code	Relation to PwD	Participated in previous studies?
H1	Partner	Yes
H2	Daughter	No
H3	Partner	Yes
H4	Friend	Yes

Table 7: Participants of writing the recipe evaluation

PROTOTYPE

A paper prototype of the application was developed (Figure 68) to simulate the experience of writing the recipe without the need for a fully working prototype. A paper booklet trained participants in writing steps. A paper 'normal' recipe of mashed potatoes with kale was provided as an example, and post-its were used to simulate writing the steps in Happje.

PROCEDURE

The study was done after the evaluation of 7. Evaluation recipe and thus made use of the same consent form (Appendix D: Consent form evaluation). Participants were given the following instruction. "Please read through the tips for writing the recipe in this booklet. Then use the ordinary recipe for mashed potatoes with kale as a guide to writing your recipe while keeping the tips in mind. Write each step on a separate post-it."

The researcher observed whether the written recipe adhered to the guidelines given in the training. Participants self-reported their experience in a questionnaire and conversations were recorded by audio.

MEASUREMENT AND ANALYSIS

The same measurement and analysis methods were used as in the previous study 7. Evaluation recipe.

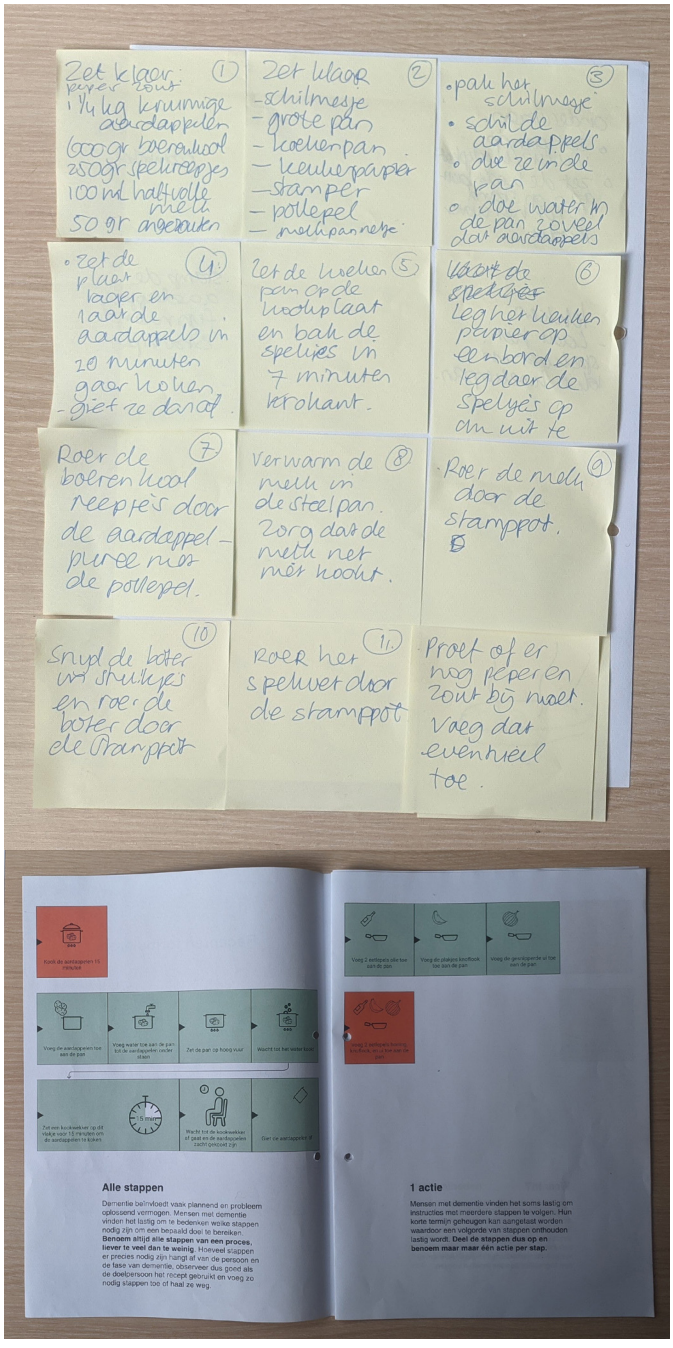


Figure 68: Paper prototype for writing the recipe. Post-its (top) and training booklet (bottom)

8.2 RESULTS

Three out of four participants followed the study according to the procedure. One participant (H4) did not follow the training and reported on her previous experience of writing a recipe.

CAPABILITY

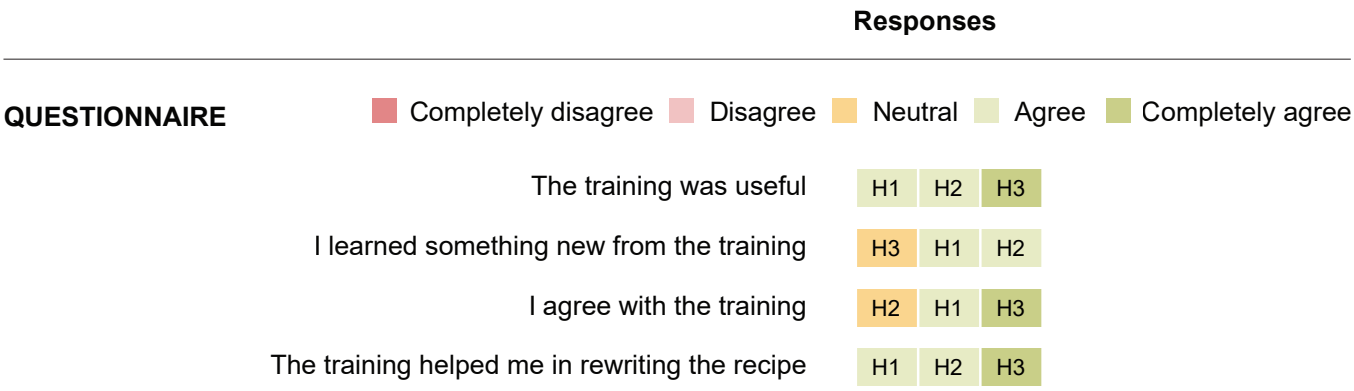


Figure 69: Results - training

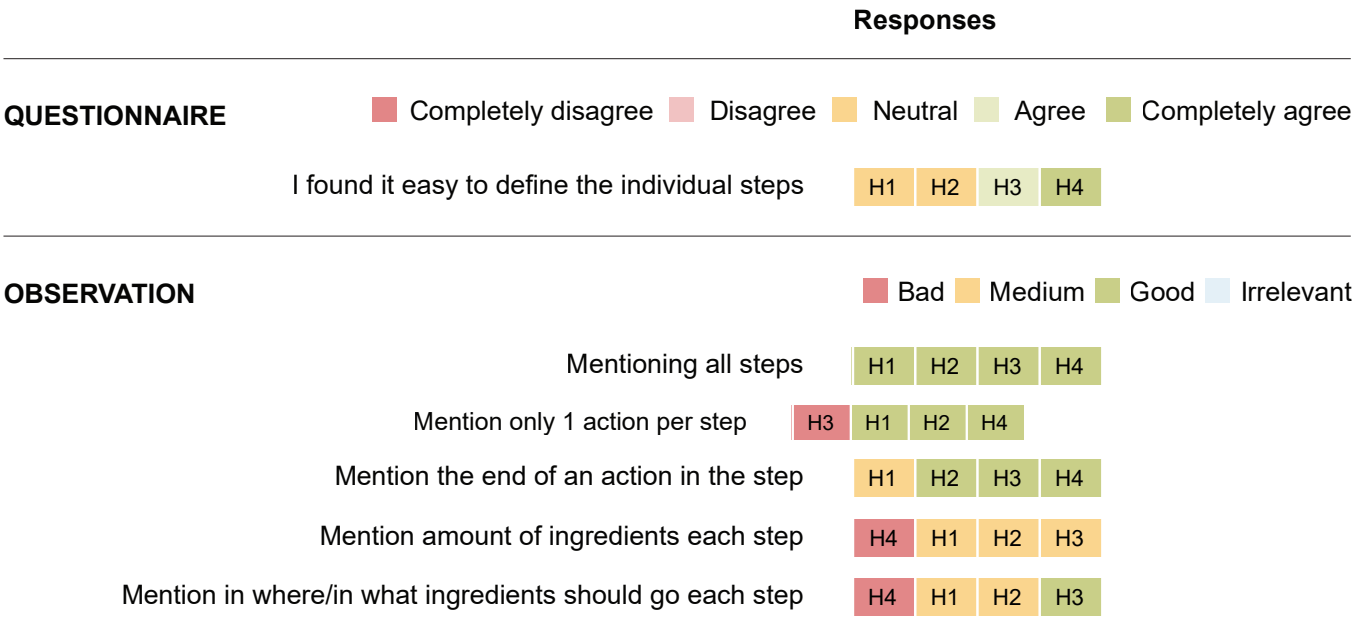


Figure 70: Results - formulating the steps

TRAINING

All participants agreed that the training was useful and felt it helped them write the recipe (Figure 69). One participant (H3) was neutral about learning something new from the training as he had already written recipes twice before and thus was already aware of the guidelines. One participant (H2) was neutral about agreeing with the training as she doubted whether they worked for her mother.

> *"It is not that I disagree, it is more that I am wondering whether these things will work for her [her mother]" – Edith, caregiver and daughter (H2).*

FORMULATING THE STEPS

We observed all participants succeeded in including all the steps (Figure 70). However, two participants (H1, H2) were neutral about finding it easy to define the steps. Participants H3 and H4 found it challenging to determine whether their PwD would understand their defined steps.

> *"Yes [defining the steps] did require some thinking. I know it [the steps] but another person?" – Pepijn, partner of PwD (H3).*

> *"Well, I did have to think carefully about that [defining the steps], whether I had added all the steps correctly. I am always a bit of a doubter. Because I know what I want to bring across, but I do not know, because you are not face to face, how that will translate to another person." – Wilma, friend of PwD (H4).*

Three participants adhered to mentioning only one action per step. Furthermore, three participants mentioned when an action should end. Only one participant (H3) mentioned where ingredients should go in each step, and none of them mentioned the number of ingredients in each step.

ORDERING THE STEPS

All participants succeeded in putting the steps in chronological order, and three participants (H2, H3, H4) agreed it was easy to do so (Figure 71). All also used the first steps to grab the ingredients and materials necessary to cook. Three participants also grouped the steps.

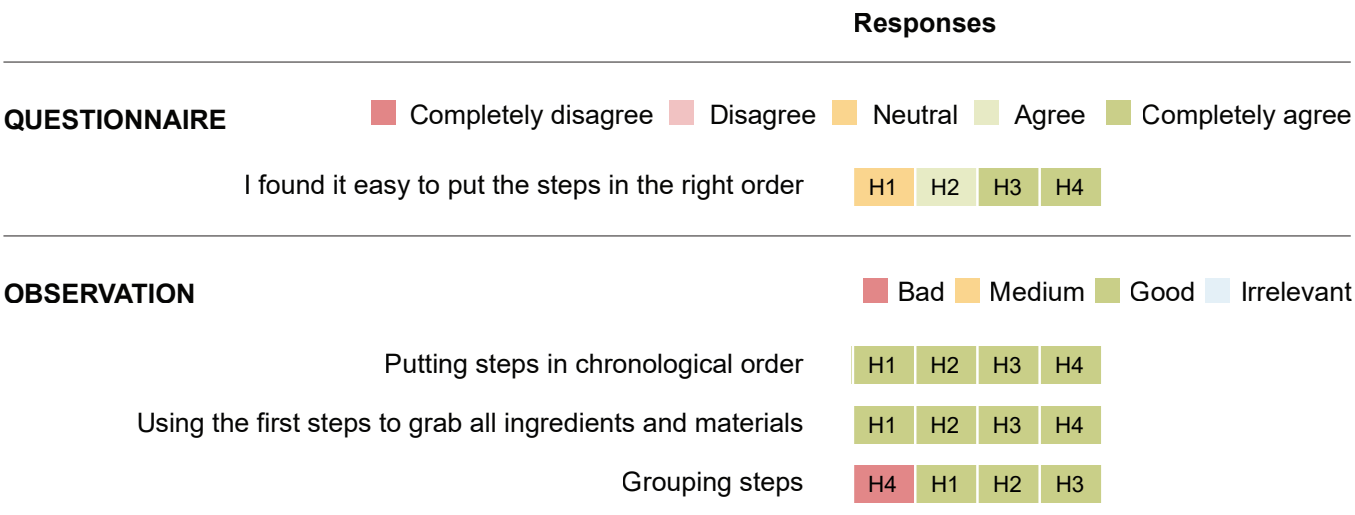


Figure 71: Results - ordering the steps

MOTIVATION

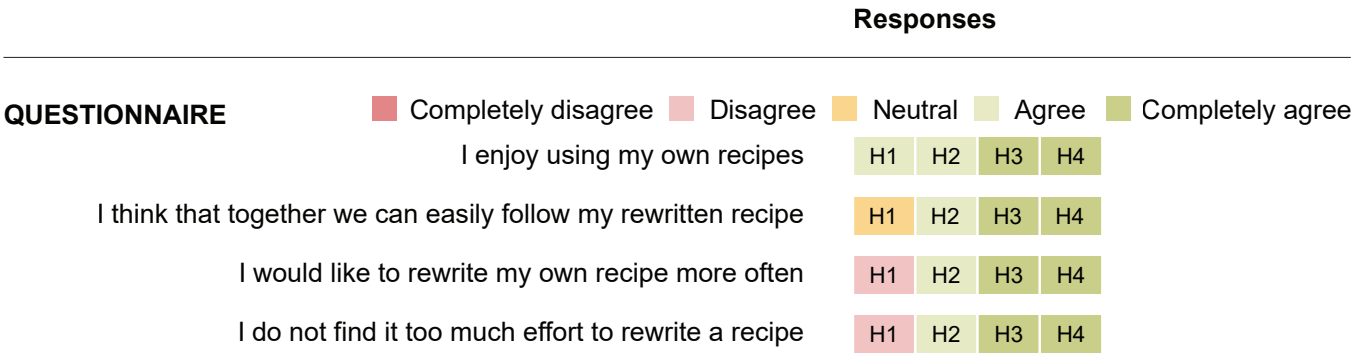


Figure 72: Results - motivation

All participants stated they enjoy using their own recipes while cooking (Figure 72). The three participants that thought they could easily follow their rewritten recipe (H2, H3, H4) also do not think it is too much effort to rewrite a recipe and would like to rewrite recipes more often. One participant (H4) feels the effort is worth it to help her friend.

> *"It was definitely worth it. It is also for a good cause, right. I also enjoy it if I notice it helps Sanne so much and that she can then just to it [cooking] and that it [the steps] is clear." – Wilma, friend (H4).*

The participant who disagreed (H1) thought it was too much effort to rewrite a recipe and preferred using existing ones.

8.3 DISCUSSION

As all participants managed to mention all steps in chronological order, we conclude they are capable of writing recipes. However, they were less consistent in mentioning the number of ingredients and where they should be added in every step. This inconsistency could be accounted to the study taking place between cooking and eating a meal. Thus, participants may have rushed writing the recipe to start dinner. Furthermore, writing with pen on paper is often slow and takes much effort, decreasing the participant's willingness to write down many details. Either way, we suggest letting Happje offer suggestions on which information is lacking in every step.

Most participants were motivated to write recipes for their PwD. For the ones that are less motivated, Happje should also offer a database with existing recipe for caregivers without the time or motivation to write their own.

LIMITATIONS

The evaluation was done with participants in a context with a task that reflects the intended target group, context, and activity. However, the prototype was a low-fi paper version of the intended application and thus was limited in evaluating the complete design. The low-fi prototype has maybe influenced the participants' capability of writing recipes. Nevertheless, conclusions about caregivers' motivation most likely still hold. If they are motivated to write the recipe using the low-fi prototype, they will likely still be motivated with the more efficient and aesthetical Happje application.

As this study was executed after the previous study, participants may have felt a reduced focus and motivation. Furthermore, as they had already worked with a recipe, they had pre-existing knowledge on how a recipe could be written.

Chapter 9

DISCUSSION AND RECOMMENDATIONS

This chapter discusses whether the design meets the needs, desires, and challenges of PwD while cooking. Furthermore, recommendations for the design and further research are stated.

9.1 DISCUSSION

This thesis has described the challenges, needs, and desires of cooking with dementia and developed a design to tackle these challenges. This section discusses whether the design has been successful in doing so. An overview is presented in Table 8.

Chapter 2.3 described the effect of cooking by listing two needs that were harmed and five that could be fulfilled. Our design made cooking more **comfortable** by reducing the complexity of cooking. The **safety** has slightly increased as the PwD cooks with someone who can pay attention to any safety hazards. However, besides the collaboration, no other security measures were introduced. The recipe helps PwDs execute cooking tasks more **autonomously** and helps them feel more in control in the kitchen. However, PwDs still have to rely on caregivers to write their recipes. The studies did not evaluate the feelings of competency, purpose, recognition, or relatedness.

In Chapter 2.4 we describe the challenges PwDs face when cooking. The design certainly helps PwD with **planning tasks** as the PwD no longer has to think of the tasks themselves and is guided through the steps. The cooking activities were placed in an interactive social setting which kept everyone **interested** and not distracted throughout the activity. The design assisted PwDs in **remembering information** as it enabled them to quickly find the step they were working on and provided them with all necessary information in every step. We did not evaluate what happens if PwDs use the same recipe multiple times. Thus, we cannot state whether it helped to **learn new routines**. When multiple PwDs collaborated, they took much initiative in taking on cooking tasks and laughed about the errors that they made. There seemed to be more judgment and less patience in the at-home setting, where PwDs took less initiative. Thus, the **fear of making mistakes** at the meeting centres was much less compared to the at-home setting. The design did not address the challenges of **fine motor skills** and **identifying objects** as these occurred in later stages of dementia.

We looked into alternative solutions in Chapter 3.1 and concluded the design should be scalable yet personalised. The caregiver can fully **personalise** the recipe by picking the dish, defining the steps, and choosing the order. Thus the recipes can be adjusted to every client's needs and desires. The application Happje makes personalised recipes more **scalable** by help the caregivers to do this in an efficient and effective way by generating corresponding icons, putting the steps in the right layout, and helping with exporting and printing.

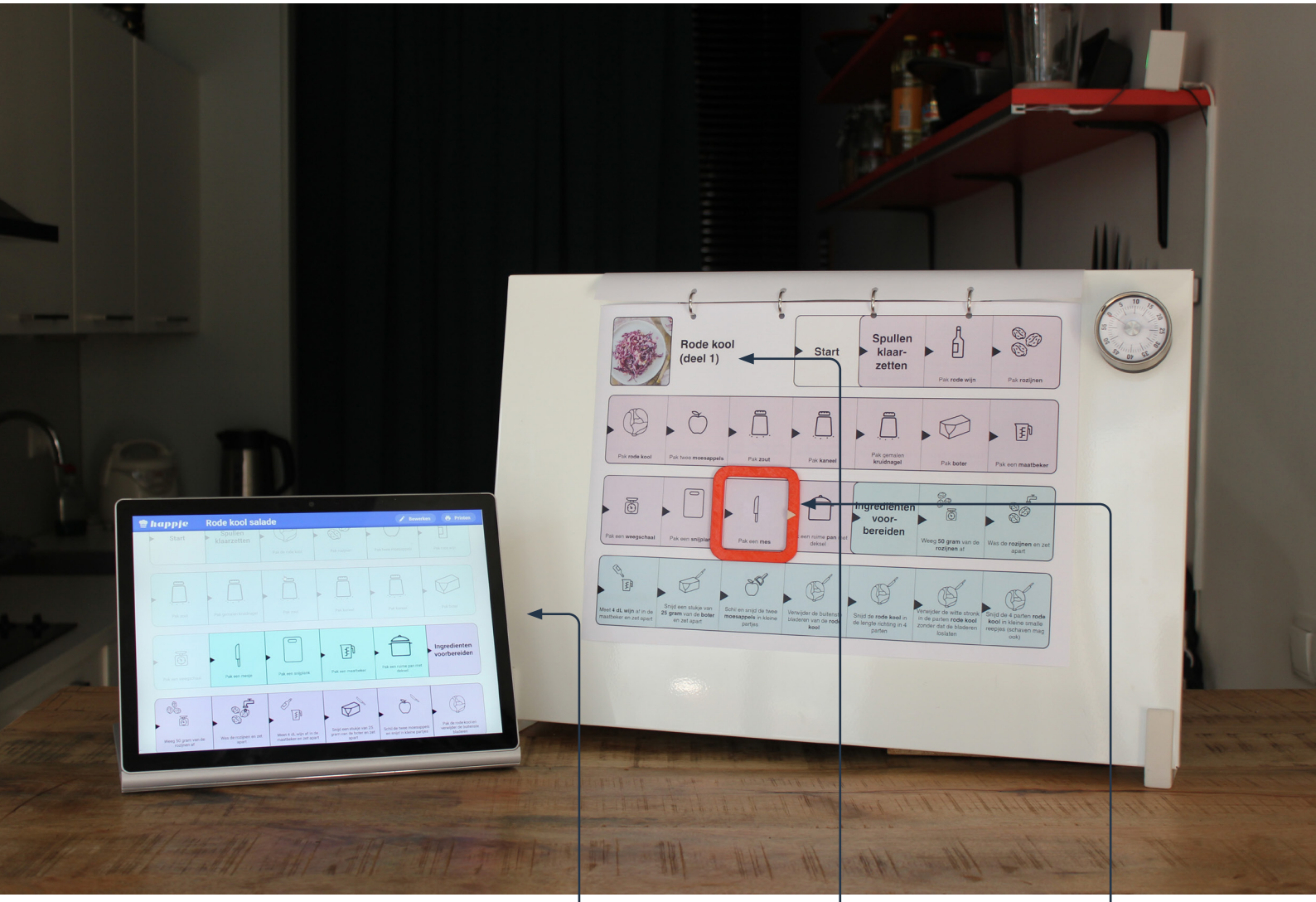
Chapter	Topic	Improved through design?
Effect of cooking	Comfort	Yes
	Safety	Slightly
	Autonomy	Slightly
	Competence	Not evaluated
	Purpose	Not evaluated
	Recognition	Not evaluated
	Relatedness	Not evaluated
Cooking challenges	Planning tasks	Yes
	Staying interested	Yes
	Remembering information	Yes
	Learning new routines	Not evaluated
	Fearing making mistakes	Slightly
	Fine motor skills	No
	Identifying objects	No
Current solutions	Scalable	Yes
	Personalised	Yes
Interaction vision	Comfortable	Yes
	Guiding	Yes
	Collaborative	Slightly
	Trustworthy	Slightly

Table 8: Overview of how successful the design has been in addressing the needs, desires, and challenges of cooking with dementia

Four interaction qualities of a interaction vision were defined in Chapter 4.2. The cooking activity's familiar setting and familiar people made the PwDs feel **comfortable**. The design feels **guiding** as it takes PwDs through the whole cooking process step-by-step. The design slightly helped improve **collaboration** as it allowed multiple people to see the steps simultaneously and quickly see the task at hand. Unfortunately, the collaboration does not yet feel as fluent as our interaction vision of dancing salsa with a partner. The design did not necessarily increase the **trust** between parties during the cooking activity. It did, however, allow caregivers to check the tasks of the PwD as they could clearly see the steps and the progress. Potentially, the trust between parties could increase through multiple uses of the design, but this was not evaluated in this thesis.

9.2 DESIGN RECOMMENDATIONS

Based on the two evaluations, we recommend the following changes to the design.



Steps that are automatically combined are **merged** in one step to make the recipe more efficient and improve readability.

Happje includes a **digital cooking mode** in which users can mark the steps they have completed. This mode could make clients less likely to forget steps as they have to click all steps to mark them as done. Furthermore, it could support collaboration as steps do not have to be marked chronologically.

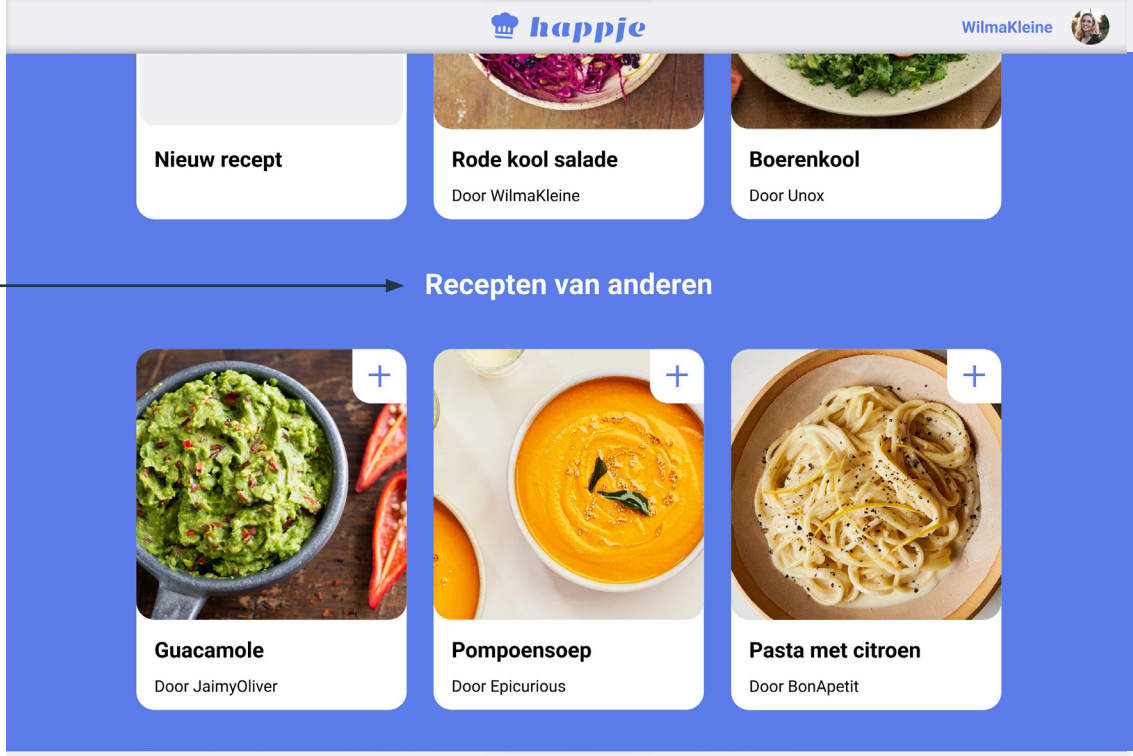
All text is put **horizontally** to make it easier to read.

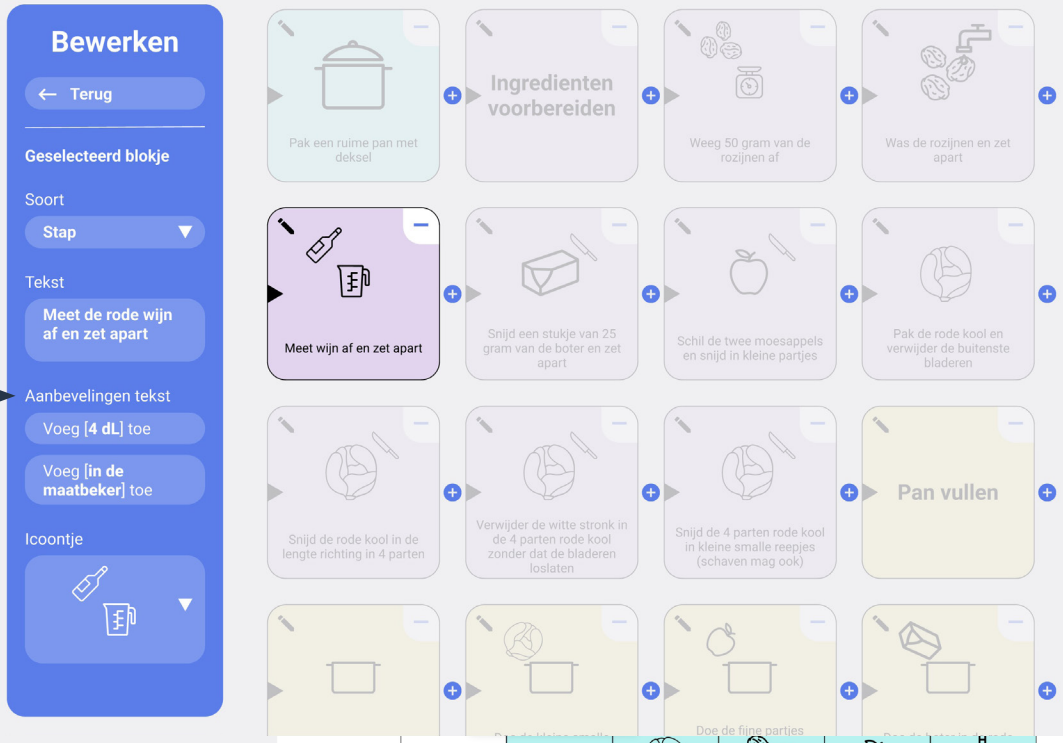
The **pawn** is redesigned into the shape of a frame that fits around the blocks so users can still read the steps. Furthermore, it partly blocks the next step, encouraging users to move the pawn. The orange emphasises the pawn, so the user is more likely to see it. The added arrow helps indicate the step direction.

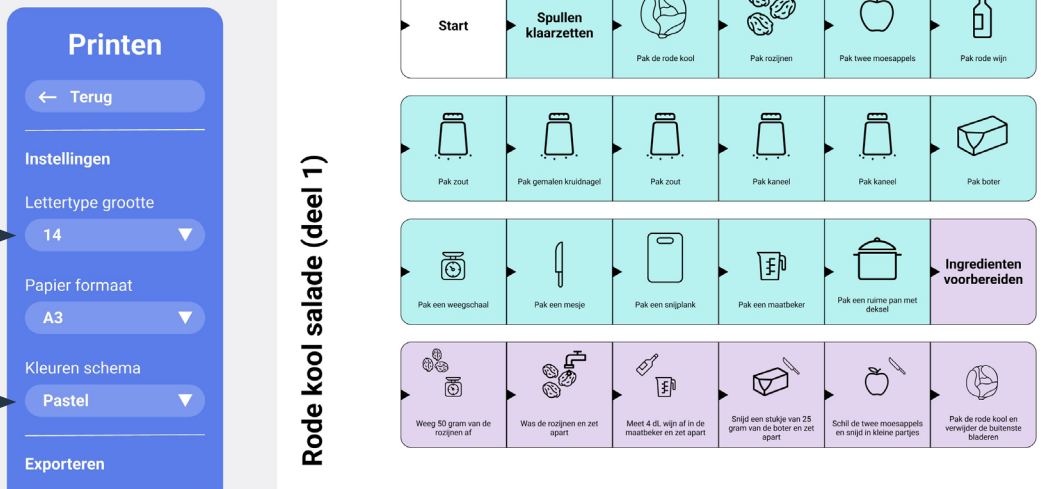
Happpje should include a **database** of recipes created by others for users without the time or motivation to write their own.

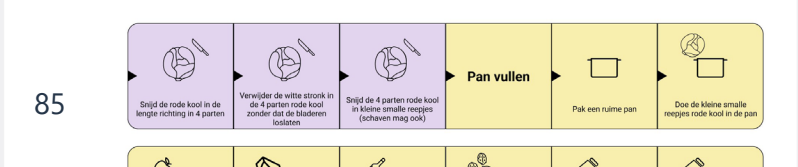
The writing part of Happje should **automatically add** the number of ingredients and where it should be added based on the ingredients stated at the beginning and the previous steps.

The print mode of Happje should contain settings for the **font size** and the **colour scheme** so users who desire it can increase the contrast.









9.3 RESEARCH RECOMMENDATIONS

We suggest the following topics for further research. Firstly, we suggest elaborating on the application Happje. We only tested whether caregivers have the motivation and capability to write recipes, but not whether the application helps them in doing so. The Figma prototype of the application should be tested on usability, and software should be written to explore how the iconography is generated.

Moreover, the redesign of the pawn and digital cooking version in Happje should be tested with the target group to see if they improve navigating through the cooking steps.

Also, we suggest evaluating what happens if PwDs and caregivers use this recipe format or even the same recipe multiple times. Such a study could answer if PwDs can learn to move the pawn with more practice. Furthermore, it could evaluate whether, with practice, the trust between PwDs and caregivers can be improved.

Finally, additional studies should be done on how the design can further enable collaboration. The present design helps multiple people understand the task and quickly see the current step but does not aid two people working together and executing different steps simultaneously. Therefore, we recommend researching how the cooking collaboration can feel as collaborative and intuitive as our interaction vision of dancing salsa with a partner.

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APPENDIX

A: CONSENT FORM CONTEXT RESEARCH

Onderzoek naar koken met dementie

U bent uitgenodigd om deel te nemen aan het onderzoek Koken met Dementie. Dit onderzoek wordt gehouden door Yvon Ruitenburg van de TU Delft.

Het doel van dit onderzoek is om inzicht te krijgen in de ervaring van mensen met dementie met koken en zal ongeveer 60 minuten duren om uit te voeren. De data zal gebruikt worden om een ontwerpdoel op te stellen voor het project. Het project gaat over mensen met dementie helpen om langer zelfstandig te kunnen koken.

Uw deelname in dit onderzoek is geheel vrijwillig en u kunt u op ieder moment terugtrekken. U bent vrij om eventuele vragen niet te beantwoorden.

Ik geloof dat er geen risico's verbonden zijn aan dit onderzoek. Tijdens het onderzoek zal ik meerdere rustmomenten aanbieden als u daar behoefte aan heeft. Ook zal ik de data anonimiseren.

Alvast heel erg bedankt voor uw deelname aan dit onderzoek.

Yvon Ruitenburg

Toestemmingsformulier voor onderzoek naar koken met dementie

Markeer a.u.b. de passende vakjes

	Ja	Nee
Deelnemen aan het onderzoek		
Ik heb informatie over het onderzoek gelezen (of het is voorgelezen) en begrepen. Ik heb vragen kunnen stellen over het onderzoek en mijn vragen zijn naar voldoening beantwoord.	☐	☐
Ik geef toestemming om vrijwillig een deelnemer te zijn van dit onderzoek en begrijp dat ik kan weigeren om vragen te beantwoorden en ik mij ieder moment kan terugtrekken, zonder dat ik een reden hoef te geven.	☐	☐
Ik begrijp dat het deelnemen aan het onderzoek een audio-opgenomen interview, foto's en een video-opname inhoudt. De audio zal worden gebruikt om het gesprek uit te typen. De foto's en video worden gebruikt om de context en kookactiviteiten weer te geven. Personen in foto's en video's zullen worden geanonimiseerd.	☐	☐

Gebruik van de informatie in het onderzoek

Ik begrijp dat de informatie die ik geef gebruikt gaat worden in verslagen en presentaties voor Yvon's master aan de TU Delft. Ik zal hier anoniem worden behandeld; mijn naam zal veranderd worden en mijn gezicht vervaagd.	☐	☐
Ik begrijp dat persoonlijke informatie dat van mij verzameld is waarin je mij duidelijk kunt identificeren, zoals mijn naam of videobeelden, niet buiten mijn studie groep verspreid zullen worden.	☐	☐
Ik geef toestemming voor het gebruiken van citaten die ik heb gezegd in het interview in onderzoek resultaten. Ook hier zal mijn naam veranderd worden voor privacy.	☐	☐

Handtekening

_____	_____	_____
Naam van deelnemer	Handtekening	Datum

_____	_____	_____
Naam van verzorger/partner	Handtekening	Datum

Ik heb nauwkeurig de informatie voorgelezen aan de potentiële deelnemer en, naar mijn beste vermogen, ervoor gezorgd dat de deelnemer begrijpt waarmee hij vrijelijk instemt.

_____	_____	_____
Naam van onderzoeker	Handtekening	Datum

B: PARTICIPANTS CONCEPTUALISATION

Code	Prototype	Location	# PwD	# Caregivers	# Volunteers	# Designers
Prototype 1	Steps to make tea					
Prototype 2	Booklet recipe with pictures (cookies)	Meeting centre	3	2	2	1
Prototype 3	Video recipe (cappuccino)	Meeting centre	3	2		
Prototype 4	Video recipe (bonbons)	Meeting centre	4	2	4	1
Prototype 5	Projections	At home			1	
Prototype 6	Auto-generated images					
Prototype 7	Recipe with auto-generated images (cabbage salad)	At home	1	1		
Prototype 8	Boardgame recipe (noodles)	At home			1	1
Prototype 9	Flow chart recipe (hutspot)	At home	1	1		1
Prototype 10	Boardgame recipe with photos (hutspot)	At home	1	1		
Prototype 11	Zigzag boardgame (parsnip soup)	At home	1	1		
Prototype 12	Training for writing recipes	At home			1	
Prototype 13	Interface to write recipes					

Table 9: Participants of each prototype of the conceptualisation phase

C: CONSENT FORM CONCEPTUALISATION

Onderzoek naar koken met dementie

Doel project: Mensen met dementie helpen om langer te kunnen koken.

Doel vandaag:

Onderzoeker: Yvon Ruitenburg van de TU Delft.

Alvast hartelijk dank voor uw deelname aan dit onderzoek.

Toestemmingsformulier

Markeer a.u.b. de passende vakjes	Ja	Nee
Deelnemen aan het onderzoek		
Ik doe vrijwillig mee aan dit onderzoek.	☐	☐
Ik begrijp dat ik mij ieder moment kan terugtrekken, zonder dat ik een reden hoef te geven.	☐	☐
Ik begrijp dat ik kan weigeren om vragen te beantwoorden.	☐	☐
Ik begrijp dat ik kan weigeren om een taak uit te voeren	☐	☐
Gebruik van de informatie in het onderzoek		
Ik geef toestemming om foto's en video's van mij te maken. Deze zullen geanonimiseerd worden.	☐	☐
Ik begrip dat de informatie die ik geef gebruikt wordt in verslagen en presentaties van Yvon. Ik wordt hier anoniem behandeld.	☐	☐
Ik geef toestemming voor het gebruiken van citaten die ik zeg.	☐	☐

Handtekening

_____	_____	_____
Naam van deelnemer	Handtekening	Datum

Ik heb nauwkeurig de informatie voorgelezen aan de potentiële deelnemer en, naar mijn beste vermogen, ervoor gezorgd dat de deelnemer begrijpt waarmee hij vrijelijk instemt.

_____	_____	_____
Naam van onderzoeker	Handtekening	Datum

D: CONSENT FORM EVALUATION

Onderzoek naar koken

Het doel van het project is recepten makkelijker te volgen maken. Vandaag gaan we een recept gebruiken om een gerecht te koken. Vervolgens evalueren we het ontwerp van het recept. Dit duurt ongeveer 1 a 2 uur. Het wordt uitgevoerd door Yvon Ruitenburg van de TU Delft. Alvast hartelijk dank voor uw deelname aan dit onderzoek.

Yvon Ruitenburg

Toestemmingsformulier

Markeer a.u.b. de passende vakjes	Ja	Nee
Corona maatregelen		
Ik voel mij comfortabel met de **corona maatregelen** die de onderzoeker heeft genomen.	☐	☐
Deelnemen aan het onderzoek		
Ik **begrijp** waar dit onderzoek voor is.	☐	☐
Ik doe **vrijwillig** mee aan dit onderzoek.	☐	☐
Ik begrijp dat ik mij ieder moment kan **terugtrekken**, zonder dat ik een reden hoef te geven.	☐	☐
Ik begrijp dat ik kan weigeren om **vragen** te beantwoorden.	☐	☐
Ik begrijp dat ik kan weigeren om een **taak** uit te voeren.	☐	☐
Ik begrijp dat ik tijdens het onderzoek een **recept** ga gebruiken om iets te **koken**.	☐	☐
Gebruik van de informatie in het onderzoek		
Ik geef toestemming om **foto's en video's** van mij te maken. Deze zullen **geanonimiseerd** worden.	☐	☐

	Ja	Nee
Ik geef toestemming om de **audio** op te nemen van het interview. Deze zal gebruikt worden om het interview uit te schrijven.	☐	☐
Ik geef toestemming voor het gebruiken van **citaten** die ik zeg in de onderzoek resultaten.	☐	☐
Ik begrijp dat de informatie die ik geef gebruikt wordt in **verslagen en presentaties** van Yvon. Ik wordt hier **anoniem** behandeld.	☐	☐
Ik begrijp dat **persoonlijke informatie** (naam, adres, email) niet gedeeld wordt buiten het onderzoeksteam.	☐	☐
Ik geef toestemming om **gefilmd** te worden tijdens het uitvoeren van de taken en het interview. Deze beelden worden **niet geanonimiseerd** en worden gebruikt om de resultaten van het onderzoek te laten zien.	☐	☐

Begeleiding

	Ja	Nee
Ik, als begeleider, geef aan **welke taken** (snijden, koken, etc.) door de deelnemer uitgevoerd kunnen worden. Ik let hierbij op of het veilig uitgevoerd kan worden.	☐	☐

Handtekening

_____	_____	_____
Naam van begeleider	Handtekening	Datum

Ik heb nauwkeurig de informatie voorgelezen aan de potentiële deelnemer en, naar mijn beste vermogen, ervoor gezorgd dat de deelnemer begrijpt waarmee hij vrijelijk instemt.

_____	_____	_____
Naam van onderzoeker	Handtekening	Datum

DESIGN FOR our future

TU Delft

E: GRADUATION PROJECT BRIEF

IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT
Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME

Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy".
Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !

family name: Ruitenburg
initials: Y given name: Yvon
student number: 4553063
street & no.:
zipcode & city:
country:
phone:
email:

Your master programme (only select the options that apply to you):

IDE master(s): ( ) IPD (★) DfI ( ) SPD
2nd non-IDE master:
individual programme: - - (give date of approval)
honours programme: ( ) Honours Programme Master
specialisation / annotation: ( ) Medisign
( ) Tech. in Sustainable Design
(★) Entrepeneurship

SUPERVISORY TEAM **

Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair: Gert Pasman dept. / section: TUD IDE/user centered
** mentor: Rens Brankaert dept. / section: TU/e ID/healthy ageing
2nd mentor:
organisation:
city: country:

comments (optional)

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..

Second mentor only applies in case the assignment is hosted by an external organisation.

Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.

APPROVAL PROJECT BRIEF

To be filled in by the chair of the supervisory team.

chair Gert Pasman date - - signature

CHECK STUDY PROGRESS

To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair.
The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: _____ EC

Of which, taking the conditional requirements into account, can be part of the exam programme _____ EC

List of electives obtained before the third semester without approval of the BoE

YES all 1st year master courses passed

NO missing 1st year master courses are:

name date - - signature

FORMAL APPROVAL GRADUATION PROJECT

To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **.
Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: APPROVED NOT APPROVED

Procedure: APPROVED NOT APPROVED

comments

name date - - signature

introduction (continued): space for images

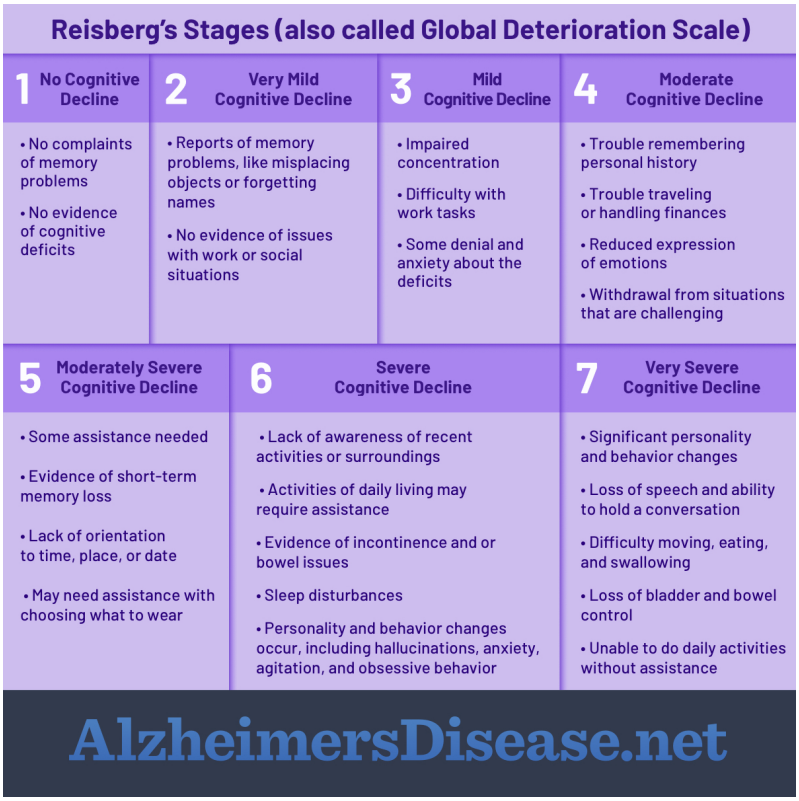

image / figure 1: Seven stages of dementia (AlzheimersDisease, 2019)

TO PLACE YOUR IMAGE IN THIS AREA:

- **SAVE THIS DOCUMENT TO YOUR COMPUTER AND OPEN IT IN ADOBE READER**
- **CLICK AREA TO PLACE IMAGE / FIGURE**

PLEASE NOTE:

- **IMAGE WILL SCALE TO FIT AUTOMATICALLY**
- **NATIVE IMAGE RATIO IS 16:10**
- **IF YOU EXPERIENCE PROBLEMS IN UPLOADING, COVERT IMAGE TO PDF AND TRY AGAIN**

image / figure 2:

Cooking with dementia

project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 06 - 09 - 2021

04 - 02 - 2022 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

Dementia is an illness that does not just impact memory, but also language, behaviour, mood, reasoning, and problem solving. The illness comes in seven phases (Reisberg, 1982; see figure next page), and while people living with dementia can remain living independently up to phase four (the early stage), they require much care and assisted living as the illness progresses (Dementia Care Central, 2020). As there currently is no cure for dementia, and only a limited number of cases can likely be prevented (de Bruijn et al. 2015), we should focus on improving the experience and coping mechanisms of both individuals living with dementia and their caregivers.

In the early stage of dementia, patients may already show difficulty with planning, organising, comprehending instructions, and problem solving (Dementia Care Central, 2020). They have difficulty going from a thought ("I want to make a cup of coffee"), to how they would actually do it. Everyday tasks that used to be easy to do for the person with dementia, are now almost impossible because they make multiple errors and do not know how to get to their goal (Chevignard, 2008).

Through this action impairment, they lose their sense of security, autonomy, and being an active member of society (Steeman, de Casterle, Godderis, & Grypdonck, 2006). Caregivers tend to take over the tasks, and while it is often with the best intentions, it sometimes leaves the patient feeling patronised, like they are no longer taken seriously and no longer treated as 'complete human beings' (van Wijngaarden, Alma, & The, 2019). Furthermore, it shifts the dynamic people with dementia have with their significant others as one becomes the carer and the other the care receiver. People with dementia become the one's solely being cared for and may end up feeling like a burden (van Wijngaarden, Alma, & The, 2019). Although friends or family often step up to be the caregiver, they find the experience stressful and frustrating (Butcher, Holkup, & Buckwalter, 2001).

Sources:
- Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. The American journal of psychiatry.
- Dementia Care Central. (2020, April 24). Stages of Alzheimer's & Dementia: Durations & Scales Used to Measure Progression (GDS, FAST & CDR). Retrieved 1 September 2021, from https://www.dementiacarecentral.com/aboutdementia/facts/stages/
- de Bruijn, R. F., Bos, M. J., Portegies, M. L., Hofman, A., Franco, O. H., Koudstaal, P. J., & Ikram, M. A. (2015). The potential for prevention of dementia across two decades: the prospective, population-based Rotterdam Study. BMC medicine, 13(1), 1-8.
- Chevignard, M. P., Taillefer, C., Picq, C., Poncet, F., Noulhiane, M., & Pradat-Diehl, P. (2008). Ecological assessment of the dysexecutive syndrome using execution of a cooking task. Neuropsychological Rehabilitation, 18(4), 461-485.
Steeman, E., de Casterle, B. D., Godderis, J., & Grypdonck, M. (2006). Living with early-stage dementia: a review of qualitative studies. Journal of Advanced Nursing, 54(6), 722–738. https://doi.org/10.1111/j.1365-2648.2006.03874.x
- Steeman, E., de Casterle, B. D., Godderis, J., & Grypdonck, M. (2006). Living with early-stage dementia: a review of qualitative studies. Journal of Advanced Nursing, 54(6), 722–738. https://doi.org/10.1111/j.1365-2648.2006.03874.x
- Butcher, Howard Karl, Patricia A. Holkup, and Kathleen Coen Buckwalter. "The experience of caring for a family member with Alzheimer's disease." Western journal of nursing research 23.1 (2001): 33-55.

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PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

Cooking is one of such everyday tasks people with early dementia may struggle with. Preparing even a simple meal requires using (and understanding) multiple tools, keeping track of the time, remembering and sequencing multiple steps, and multitasking (Chevignard, 2008). Thus cooking often becomes a problem for people with early dementia (Giovennetti, 2002; Chevignard, 2008).

Besides these physical and mental challenges, people with dementia also face social challenges concerning these everyday tasks. As they often fear being scrutinised and attempt to avoid disapproval (van Wijngaarden, Alma, & The, 2019), they withdraw from the activity altogether to avoid making mistakes.

Helping people living with dementia prepare their own meals or drinks again will help increase their level of dependence. It may help in them feeling meaningful, as they can take care of their own and other's needs. Furthermore, it might relieve caregiver burden, as their task load will decrease and they can be 'cared for' again by the person living with dementia.

A small intervention may already be powerful. For instance, allowing someone to make a cup of coffee again allows them the freedom to drink coffee whenever they want, as well as show appreciation and care for others by offering them a hot beverage.

Chevignard, M. P., Taillefer, C., Picq, C., Poncet, F., Noulhiane, M., & Pradat-Diehl, P. (2008). Ecological assessment of the dysexecutive syndrome using execution of a cooking task. Neuropsychological Rehabilitation, 18(4), 461-485.
van Wijngaarden, E., Alma, M., & The, A. M. (2019). 'The eyes of others' are what really matters: The experience of living with dementia from an insider perspective. PLOS ONE, 14(4), e0214724. https://doi.org/10.1371/journal.pone.0214724

ASSIGNMENT **

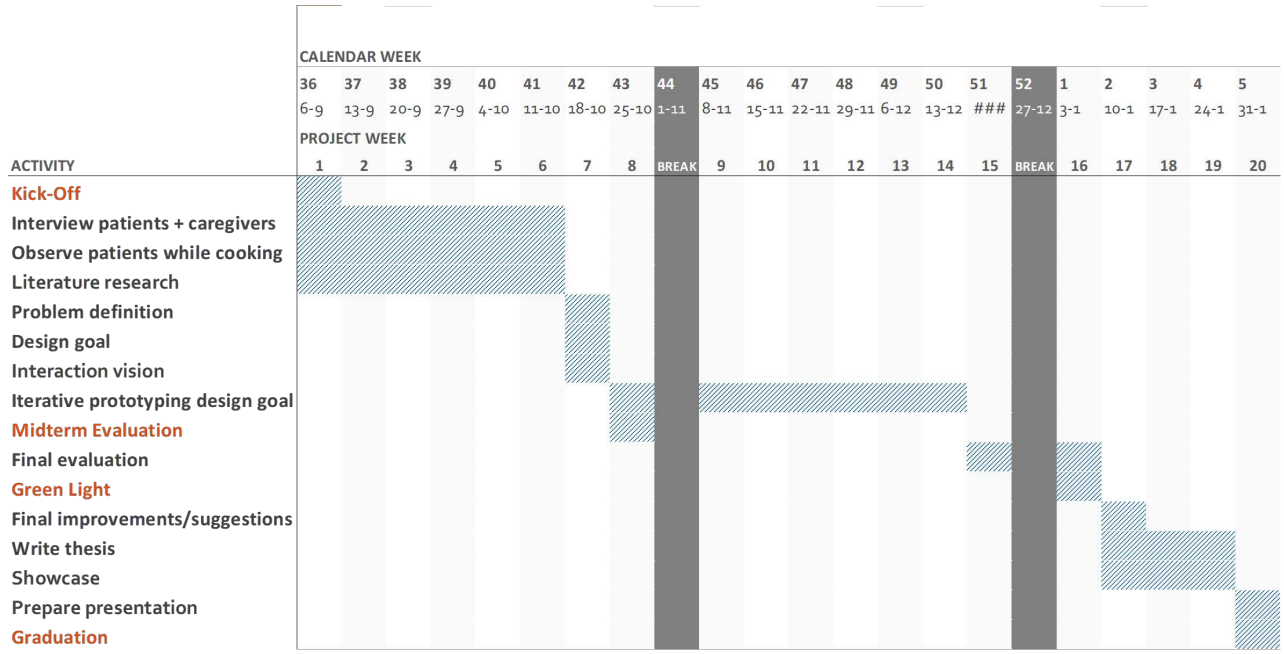
State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

I will research how people with early dementia and their caregivers currently experience preparing food and drinks, and what their needs and wishes are. The goal is to develop and evaluate a product or service (or combination) for people with early dementia to safely enjoy cooking again.

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 6 - 9 - 2021 4 - 2 - 2022 end date



The proposed project consists of three phases; 1) What is the problem, 2) How can it be solved, 3) Does it work?

In the first phase, I will interview patients and caregivers and observe them while they are in the kitchen. In the literature research I will look into the experience of people with dementia, learning methods, and cooking. Combined, this will help me understand the context I am designing for and lead to a problem definition. This phase will shed light on the current situation and the needs and wishes of the stakeholders.

In the second phase, I will explore how I can solve the problem. I will set up a design goal and interaction vision to determine the effect and feel of the solution. Next, I will use iterative prototyping and intermediate user testing to test and develop a working concept. User testing will be done with both people in my intermediate surroundings (to get out the first usability bugs) and with people within context.

In the last phase, I will evaluate whether the designed concept actually solves the problem defined in phase 1. I will simulate the context of use and ask patients and caregivers to interact with my concept. They will evaluate it and test whether it improves their experience. Based on this evaluation, I will make some improvements and write recommendations.

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, ... Stick to no more than five ambitions.

After reading into dementia, I was struck by how this illness impacts every aspect of the person and their caregiver's lives. That it does not just mean forgetting information from the past, but also not being able to do things in the future. The things you used to love doing over time become too complicated and impossible. And as there is no cure, I want to help in at least improving the experience of this mental decline. To help people enjoy the things they love doing (which in my case is cooking) for as long as possible.

During the project, I aim to learn as much as I can about dementia, its symptoms, and its care. I want to learn how technology (the small impactful ones) can be used to positively impact the experience of dementia. Furthermore, I am eager to learn about how to design with and for dementia. I hope to learn new methods and tools to increase my research skills in interviewing and observation. I also want to dive deeper into co-creation, as I believe this is a valuable tool to let users express their needs and wishes. Lastly, I want to focus on sharing my knowledge with others. I expect to gain many insights into what it is like to prepare meals and drinks when living with dementia, and I believe this information could be valuable to other designers and caregivers as well. I want to help others understand this illness, so more people can start looking for solutions.

FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

March 2022