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One Step at a Time: Evaluation of a Step-By-Step Recipe Tool Designed for People with Dementia

Yvon Ruitenburg, Gert Pasman, and Rens Brankaert

Abstract

Due to dementia, people lose the ability to deal with complex tasks such as cooking. We can support this group by designing new tools to keep them active and enhance their feeling of self-worth. Previous studies have focused on step-by-step guidance for people with dementia using innovative technology, which is often too complicated to learn and set up for the users. In this paper, we designed and evaluated an intuitive, non-intimidating, step-by-step recipe tool for people living with dementia. The tool is designed for collaboration to stimulate socialisation between people with dementia or with a caregiver. The design was evaluated in situ, with 36 individuals at varying stages of dementia. Participants were instructed to cook a dish using the recipe tool

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and reflect on its usability. The step-by-step approach of the tool appeared highly suitable for people with dementia, and added visuals helped with understanding the recipe. The level of initiative shown by the participants with dementia seemed to depend on the amount of trust shown by the caregiver. We found that collaboration between participants during cooking as facilitated by the tool was enjoyable and highly suited for both at-home and meeting centre settings. We offer several suggestions for designing step-by-step tools and encourage facilitating more collaborative, non-intimidating activities for people with dementia and their caregivers.

Keywords

Dementia · Cooking · Step-by-step

1 Introduction

Dementia is a syndrome in which a person's cognitive abilities deteriorate beyond what is expected to be caused by normal ageing [1]. Sixty per cent of risk factors for developing dementia are still unknown [2], only a few dementia cases can likely be prevented [3], and no cure is currently available [1]. Since we cannot cure or prevent dementia soon, we must find

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alternative strategies to support people living with dementia. This paper guides you through designing and evaluating a cooking aid tool specifically designed for people with dementia, also referred to as clients. Thereby we aim to add quality of life and a sense of agency to the years people with dementia still have ahead.

1.1 Complex Activities

As dementia progresses, people usually experience behavioural changes, difficulties recognising relatives and friends, difficulties walking and being unaware of time and place [4, 5]. However, dementia often starts with minor forgetfulness and struggling with more complex activities [5], such as driving a car, managing finances, and planning meals [6, 7]. Although these tasks used to be performed with ease because they are routine and familiar [8], Chevignard et al. found that errors occur more frequently as a person with dementia's cognition changes over time [9]. The tasks become too complex because they require coordinating multiple cognitive processes such as object selection, sequencing numerous steps, and perceptual-motor operations [9–11]. Therefore, people with dementia's changes in cognition prevent them from successfully executing their daily tasks [9].

This reduction in abilities is also known as *everyday action impairment* and is a severe challenge for persons with dementia. Clients require more help with daily tasks, which increases the caregiver burden [7]. Furthermore, their autonomy and self-esteem could be low-ered, causing a feeling of helplessness [7] or even depression [12]. In turn, depression can increase the development of functional disabilities [13]. We can potentially address some of these adverse outcomes by designing to support people with complex activities and contribute to their self-reliance and independence.

1.2 Cooking Challenges

One of the most challenging complex activities of daily living is cooking, as it requires planning, multitasking, and problem-solving [14]. As dementia progresses, people often stop cooking because it is experienced as tiring or frustrating. Furthermore, cooking may no longer be safe as people with dementia might get distracted easily [15], will not recognise particular objects [16], or are not aware of their limitations [17]. Nevertheless, it is essential that cooking is maintained as long as possible and desired by people with dementia themselves since it contributes to their autonomy, sense of purpose, and cognitive and motoric skills [15, 18].

1.3 Guidance Through Activities

Several researchers [11, 19, 20] have previously investigated how step-by-step technology can guide people with dementia through daily tasks.

Although these solutions present promising results, they all use technologies, such as VR glasses, tablets, and computer screens, that often feel unintuitive for people over the age of 65 [21] and are difficult to set up for family caregivers [22]. Moreover, as people with dementia often experience a reduced learning capacity [6, 17], it becomes extra challenging to learn how to use the technology. Thus, users may feel intimidated and hesitant to use it.

Furthermore, the studies [11, 19, 20] focused on increasing people with dementia's independence by letting them execute tasks by themselves. Although this increases autonomy and decreases caregiver burden, it does not contribute to the desire for social interaction by people with dementia [23]. People with dementia often withdraw from social interactions as they fear others will recognise their memory deficits [23, 24], leaving them feeling lonely and increasing their chances of further developing dementia [25]. As Fitzsimmons et al. suggest cooking is the most social of all activities of daily living [18], this task is highly suitable for socialisation purposes.

Therefore, this study aims to design an intuitive and unintimidating step-by-step cooking tool that offers guidance for people with dementia in collaboration with other people with dementia or their caregivers.

1.4 Happje—A Step-By-Step Recipe Tool

We developed a new paper recipe tool called "*Happje*" ("bite" in Dutch) through an iterative design process. We completed thirteen cycles of building a prototype, evaluating it with the target group, and creating a redesign. At each iteration, the target group of people with dementia and caregivers was consulted to ensure the designed tool addressed the participants' needs, values, abilities, and everyday context [26].

People with dementia struggle with planning and figuring out the order of the cooking steps, not necessarily with executing them [27]. Yamaguchi et al. [21] found step-by-step guidance beneficial for improving the performance of people with dementia as it takes the challenges of the planning and order of steps out of their hands. Happje implements this approach by offering step-by-step instructions for recipes (Fig. 1). Each step only mentions a single task, as direct and short instructions are found to be most effective [28, 29]. Furthermore, as some people with dementia find it difficult to remember the details of the step they are working on [19], each step mentions the number of ingredients and where they should be added. Lastly, since the linguistic reading capabilities of people with dementia tend to decline over time [30], comprehending written instructions becomes challenging. For this reason, we developed an iconographic language to add visual instructions to the textual ones. These icons are a visual representation of each step's tools, actions, and ingredients.

We found that the elderly participants were often reluctant to use digital interfaces during our iterative design process, which could be because people over sixty-five often lack information technology skills [21]. All iterative paper prototypes were easy to use and non-intimidating for the participants; thus, Happje is presented on paper (Fig. 2). When participants of previous studies were only shown one step at a time, they often lost track of the overall cooking process. Therefore, Happje presents multiple steps on one page to ensure users can keep an overview of the entire sequence of tasks. Because seeing all the steps at once can be overwhelming, the steps are visually organised in coloured sub-groups. All pages show the recipe's title and photo to help users with faulty memory remember what they are cooking.

Due to the decline in short-term memory [31], people with dementia may also forget the actions

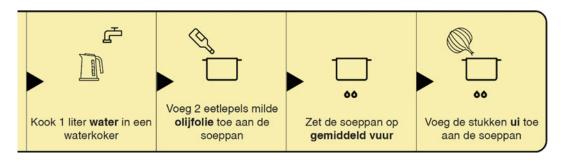


Fig. 1 Happje presents step-by-step cooking instructions with additional icons. Translated, the steps say: Cook 1 L of water in a boiler, Add 2 spoons of mild olive oil to the

soup pan, Put the soup pan on medium heat, Add the pieces of onion to the soup pan

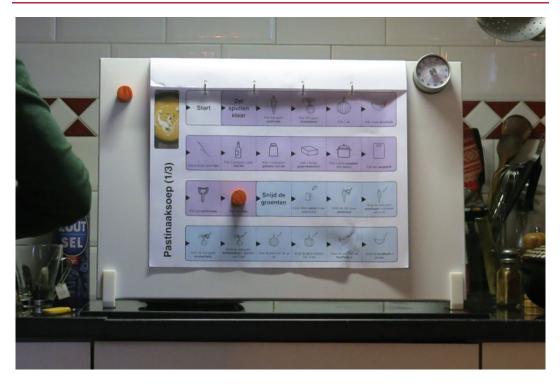


Fig. 2 Happje is presented on paper and shows multiple steps at once

they have just executed or why they have set a timer. For this reason, Happje includes a magnetic pawn (Fig. 3), which users use to mark the step they are currently working on and remember which actions they have completed. Caregivers can also look at the pawn to keep track of the progress. Additionally, for timed activities, a magnetic timer is placed on top of an allocated 'timer' step on the recipe to help users remember the reason for setting the timer.

1.5 Study Aim

This study evaluates whether Happje achieves its goal of guiding people with mild dementia through a cooking activity in collaboration with other persons with dementia or caregivers. Four research questions have been set up to guide the evaluation. (1) Does the design help people with dementia and their caregivers *understand* the cooking steps? (2) Does the design help people with dementia and their caregivers *navigate* the cooking steps? (3) How do people with dementia and their caregivers *collaborate* during the cooking process while using the design? (4) Does collaborative cooking with Happje generate a *desirable experience* for people with dementia and their caregivers?

2 Method

2.1 Participants and Environment

We conducted one pilot and eight evaluations with 36 Dutch participants (Table 1). The stages of dementia of the participants ranged from mild to moderate. The evaluation took place in two contexts (Fig. 4), which both reflected the intended contexts and were familiar to the participants to create a pleasant experience [26]. In the athome context, one person with dementia cooked together with an informal caregiver. In the meeting centres, groups of clients collaborated under the supervision of an informal caregiver.

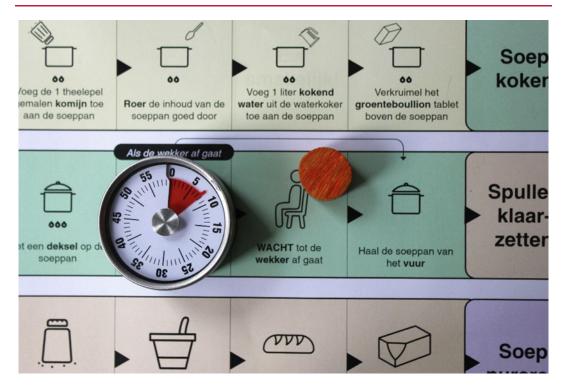


Fig. 3 A magnetic timer and pawn are placed on top of the recipe to help with navigating through the steps. Translated, the steps say: Put the lid on the soup pan, If

the timer rings, Wait until the timer rings, Remove the soup pan from the heat

Group*	Location	Clients (persons with dementia)	Caregivers	Volunteers	Participated in previous studies?
P1	At home	1	1		Yes
H1	At home	1	1		No
H2	At home	1	1		No
H3	At home	1	1		Yes
H4	At home	1	1		Yes
M1	Meeting centre	4	2		Yes
M2	Meeting centre	6	3		No
M3	Meeting centre	2	1	2	Yes
M4	Meeting centre	2	1	3	No

Table 1 Participants of evaluation

*P = Pilot, H = Home, M = Meeting centre



Fig. 4 One client and one caregiver are cooking at home (left). Multiple clients are cooking together at a meeting centre (right)

2.2 Prototype

A physical prototype with the same functionality and appearance as Happje was created for the evaluation. In most cases, the prototype was presented standing up against a whiteboard (Fig. 5). Five different recipes were designed to cater to the dietary preferences of the participants and ensure we tested the tool and not one specific recipe.



Fig. 5 The recipe presented on the whiteboard in the kitchen of one of the participants

2.3 Ethical Considerations

Ethical approval for the study was obtained from the Human Research Ethics Committee of the Delft University of Technology. All caregivers gave written consent. Clients were also asked for verbal or written consent [32] and observed for non-verbal cues during the study indicating they did not want to participate [33].

2.4 Procedure

Figure 6 presents the three phases of the session. The study was introduced in the first twenty minutes, and the participants gave informed consent. Furthermore, time was spent on small talk about a topic of the participants' desire to establish a relationship in which the participants felt comfortable expressing their opinions [34].

Next, the participants were presented with the prototype and given the following instructions "Please use this recipe for cooking the specified meal together. Each block in the recipe explains one step. Use the pawn to move through the steps." The researcher observed the interaction with the prototype and filled in the 'Researcher observation sheet' (Table 2). The sheet consisted of eleven usability elements and was rated on a three-point scale, ranging from always, sometimes, and never working as intended. Additional notes were taken to explain the rationale behind the observation.

The participants used the 'Participant selfreport sheet' (Table 2) to state whether they agreed or disagreed on a five-point scale on thirteen statements concerning their experience of using the prototype. All statements were written in positive statements to reduce the cognitive load of the participants. This section was audio-recorded, and the researcher asked participants additional questions to clarify why they agreed or disagreed.

2.5 Analysis

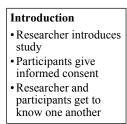
The quantitative data of the observation and selfreport sheets were digitised in a spreadsheet in Excel. All recordings of conversations with participants were transcribed. Quotes and observational notes related to the observation and selfreport elements were interpreted and linked to said data (Table 3). Interpretations were then clustered into themes concerning the usability and experience of the prototype.

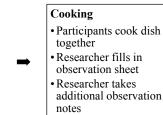
3 Results

The results are presented in the order of the study's four research questions. Group M4 did not fill in the self-report sheet; thus, we offer eight observations and seven self-reports.

3.1 Understanding the Cooking Steps

We observed that the clients from six out of eight groups perfectly understood the steps in the recipe and knew what to do after reading them (Fig. 7). One client (M4) did not look at the recipe, probably because she could no longer





Reflection • Participants fill in self-report sheet • Researcher asks additional questions • Conversation is audio-recorded

Fig. 6 The three phases of the evaluation sessions

Research question	Researcher observation sheet (Always, Sometimes, Never)	Participants self-report sheet (Completely agree, Agree, Neutral, Disagree, Completely disagree)
(1) Does the design help people with dementia and their caregivers <i>understand</i> the cooking steps?	Clients understand the steps and know what to do after reading them	"Every step was clearly formulated" "The icons helped with understanding the recipe"
(2) Does the design help people with dementia and their caregivers <i>navigate</i> the cooking steps?	Clients move through the steps in chronological order Clients move the pawn Clients look at the pawn to remember their progress Clients properly use the kitchen timer	"The recipe was easy to follow" "It was always clear what the next step was" "The pawn made it easy to remember where we left off" "Cooking in this way is easier than cooking with a normal recipe"
(3) How do people with dementia and their caregivers <i>collaborate</i> during the cooking process while using the design?	Clients initiate the steps themselves Participants trust each other to execute the tasks properly Collaboration between participants feels equal Clients execute actions safely	"We trusted each other to execute the steps correctly" "We felt safe while cooking"
(4) Does collaborative cooking with Happje generate a <i>desirable experience</i> for people with dementia and their caregivers?	Participants have a social experience Participants stay interested	"We enjoyed collaborating while cooking" "When we saw the recipe, we immediately felt like starting" "We all stayed interested while cooking" "We felt proud after cooking" "We would like to cook this way again"

Table 2 The two parts of data collection. The researcher filled in the observation sheet, and the participants the self-report sheet. The elements of the sheets were based on the four research questions posed in the introduction

read it. When asked what the next step was, she would guess instead of looking at the recipe.

Five out of seven groups completely agreed that every step was clearly formulated, and most clients were observed to be able to execute the tasks before forgetting them. One group (M2) felt it was sometimes unclear where each ingredient should go and felt some steps could be combined.

All groups agreed that the icons helped them understand the recipe. Participants did not solely look at the icons to understand the steps but glancing over them while reading the textual instructions helped provide context. "*The weird thing is that if you left out the icons, you would miss them. But if they are there, you look at them more fleetingly.*"—client (M4). Furthermore, the icons made the recipe look calmer as participants

Data type	Statement	Group	Response	Quote/observation	Interpretation
Researcher observation	"Client navigates through the steps in chronological	Н3	Always	[10 min after the client sliced the apple.] Client: "The finely chopped apple, have we already cut those?"	Client followed the steps in the intended order but sometimes forgot which steps she had already completed
	order."	H4	Sometimes	Client first chopped the parsley and then the mushroom, while the recipe stated these steps the other way around	The client moved around the order of some steps but did complete all steps in the end
Participant self-report	"It was always clear what the next step was"	H3	Neutral	Client: "If you looked properly, then yes. But sometimes, I would look at it and not immediately find what I was looking for." Partner: "She also sees badly lately, so at a certain moment, I saw her standing there and not being able to read what it said."	The client could not always find the next step quickly because she could not see them correctly
		H4	Completely agree	Client: "Also, because you can move [the pawn] one square every time and push it forward, I always know where I left off."	The client feels the pawn helped her remember where she left off

Table 3 Examples of two researcher observation- and two participant self-report responses. Additional quotes and observations were interpreted and linked to the corresponding responses data to add meaning to the quantitative data

		Res	pons	es					
Researcher observation	Not evaluated	Ne	ver		Some	etime	s	Alw	ays
	Clients understand the steps.	M4	M2	HI	H2	H3	H4	M1	M3
Participant self-report	Completely Disagree disagree	N	eutral		Agro	ee 📕	Cor agr	mplet ee	ely
	"Every step was clearly formulated."	M2	H2	H1	H3	H4	M1	M3	
"The ico	ns helped with undestanding the recipe."	H2	M2	H1	H3	H4	M1	M3	

Fig. 7 Results understanding cooking steps

could get a feel for the recipe without reading all the text. "I notice that this recipe looks very calm, which is nice. It is clear because all the icons are added, so you can see what it [the step] should actually be."—client (H4).

3.2 Navigating the Cooking Steps

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All participants stated the recipe was easy to follow (Fig. 8). Participants mentioned they enjoyed the step-by-step approach, as it helped

		Res	pons	es					
Researcher observation	Not evaluated	Ne	ever		Some	etime	s	Alv	ways
Clients move throught	the steps in chronological order.	HI	H2	M4	H3	H4	M1	M2	M3
	Clients move the pawn.	H1	H2	H3	M4	M2	H4	M1	M3
Clients look at the pa	awn to remember their progress.	H2	M4	H1	M2	H3	H4	M1	M3
Client	s properly use the kitchen timer.	H3	Hl	H2	H4	Ml	M2	M3	M4
Participant self-report	Completely Disagree	N	eutra	1 🔳	Agr	ee 📕	Cor agr	mple ee	tely
•	'The recipe was easy to follow."	H2	Hl	H3	H4	M1	M2	M3	1
"It was alway	vs clear what the next step was."	H2	H3	M2	H1	H4	Ml	M3	ĺ.
"The pawn made it easy	to remember where we left off."	H2	M2	M1	H1	H3	H4	M3	
"Cooking in this way is easier than	cooking with a normal recipe."	H2	H3	Hl	H4	M1	M2	M3	

Fig. 8 Results navigating cooking steps

guide them through the process and made them feel calmer. "The fact that it is made step by step, image for image, may seem unnecessary for some. But it is not unnecessary for me."—client (H4). "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."—client (M2).

However, only four out of seven groups felt it was always clear what the next step was, and only three out of eight groups were observed to move through the steps chronologically. Some clients (H3, H4) could not remember whether an action had been completed. For instance, a client (H3) asked, "Thin slices of apple, have we already cut those?" only a few minutes after slicing the apple. Furthermore, some clients could not immediately find the step they were looking for on the large paper recipe. One client (H3) would stare at the recipe for a few seconds before finding the step she was looking for. "If you looked properly [it was always clear what the next step was]. Sometimes I would look and not immediately find the thing I was looking for. Then I would just wait and see for a little bit." client (H3). Also, some participants (H1, H2, H4) would stray off the recipe, start improvising, and

then find it difficult to find their way back to the steps. They found it difficult to follow the stepby-step plan as it did not allow for any improvisation. "I've noticed that you always, also with other recipes, want to fall back on the routines you already know. On the one hand, you want to follow the steps, but on the other hand, you think you know it better yourself."—daughter (H3).

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The orange pawn was designed to help participants keep track of the steps they had completed and quickly find the next step on the paper recipe. Four out of seven groups found the pawn helped them remember where they left off. "Especially also because you can move the magnet [pawn] one square and push it forward every time. I always know where I left off. Because of that magnet, it is clear to me at which step I am. That makes it very easy."-client (H4). The other three groups did not feel the pawn was in remembering beneficial the current step. Clients of five out of eight groups did not move the pawn after every step. Two clients (H3, M1) felt they would have to practice more to get used to using the pawn. "Yes, I think [with practising, I can remember moving the pawn]. I think it will simply become a habit."-client (H3). Clients also seemed to overlook the pawn as four groups did not refer to the pawn to remember their progress in the recipe. Although not all groups consistently used the pawn, several participants still felt something to keep track of the current step would be valuable. "*The pawn is there to help indicate at which step you are. And that would be valuable because sometimes you* [mother] completely lose track of where you are. But for some reason, you do not [use the pawn]."—daughter (H2).

In three cases (M2, M3, M4), participants did not use the magnetic timer because the researcher took care of it. One group (H3) required help to figure out how to set the timer. The others showed a perfect understanding of setting the timer and remembered what to do after the timer rung.

Even though the navigation was challenging, five out of eight groups completely agreed that cooking this way (with this prototype) was easier than cooking with a standard recipe. The two who disagreed (H2, H3) felt they could still easily use their standard recipes. "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."—client (H3).

3.3 Collaboration While Cooking

The nature of the collaboration seemed to differ based on whether a caregiver (either the partner or formal caregiver) was present. Caregivers appeared to be less trusting towards the perception and execution of tasks of the client. All groups without caregivers (M1, H4, M3) agreed they trusted each other to execute the steps correctly (Fig. 9). Only half of the groups with a caregiver stated the same. We also observed less trust in groups with caregivers than in groups without. Formal caregivers or partners would continuously check whether the client executed the steps correctly. "Yes, I was indeed checking a little bit [...] whether she was doing it according to the steps."-daughter (H2). "I often walked towards the board [recipe] to check how far she was."-partner (H3). Or sometimes, when the caregiver disagreed with the actions, they would take over the task without being asked. For instance, when a client (H1) was cutting a vegetable, her partner took over to show her how to do it. "If you cut it this way ... yes, no, like this."—partner (H1).

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		Res	pons	ses						
Researcher observation	Not evaluated	Ne	ever	Sometimes Al						
		•	Vith	care	egive	er		itho regiv		
Participants trust each o	ther to execute the tasks properly.	H1	H2	H3	M4	M2	M1	H4	M3	
Collaboration	n between participants feels equal.	M4	HI	H3	H2	M2	H4	M1	M3	
	Clients initiate steps themselves	H1	H3	M2	M4	H2	H4	M1	M3	
	Clients execute actions safely.	H2	M2	H1	H2	H3	M1	H4	M3	
Participant self-report	Completely Disagree	N	eutra	1	Agro	ee 📕	Con agr	mple ee	tely	
"We trusted each oth	her to execute the steps correctly."	H2	M2	H1	H3		M1	H4	M3	
	"We felt safe while cooking."	M2	Hl	H2	H3		H4	M1	M3	



We observed much autonomy in groups without a caregiver present. Here, all clients initiated the steps themselves. In two of these groups (M1, M2), a client took charge and handed out the tasks to other clients. In four out of five groups with caregivers, the clients only sometimes initiated steps themselves. These clients would wait for instructions from the caregiver and only take the initiative when prompted by the caregiver. Clients would also often look at the caregiver for insights on whether they were doing it correctly. However, over time, two caregivers showed an increasing trust in the clients and encouraged them to figure out the steps themselves. "I thought it was great [that the client was handing out the tasks instead of me], better even. It is good to be aware of that because it sometimes sneaks in to take over things [as a caregiver] while [the visitors] can do a lot themselves."—formal caregiver (M1).

3.4 Experience While Cooking

All participants stated they enjoyed collaborating while cooking and would like to cook this way again (Fig. 10). Seven out of eight groups were also observed to have a pleasant social experience. Participants thought the collaborative cooking with the prototype was an enjoyable social experience (H2, H3, M1), an excellent way to keep everyone engaged (M1), and an easy way to cook (M2). "I do [want to cook this way again]. I simply want a cookbook like this."—client (M2).

All participants, except M4, who could not read, stayed interested and involved throughout the entire activity. Furthermore, six out of seven groups stated they immediately wanted to start when they saw the prototype, indicating that the prototype felt inviting and non-intimidating to use.

Lastly, five out of seven groups felt proud after cooking. "Well, I definitely do [feel proud]! Because I have had so many times that I just could not get [the cooking] done. And then I thought, why can I no longer get it done? Why can I no longer do it? And if it does work, wow!"—client (H4). However, one caregiver said cooking is too much of a daily routine to say he was feeling proud about it. "Proud, well, I think that is a heavy word. I would say it is just such a daily routine."—partner (H3).

		Resp	pons	es					
Researcher observatio	n Not evaluated	Ne	ver		Some	etime	s	Alw	ays
	Participants have a social experience.	M4	H1	H2	H3	H4	M1	M2	M3
	Participants stay interested.	M4	H1	H2	H3	H4	M1	M2	M3
Participant self-report	Completely Disagree	Ne Ne	eutra	1	Agr	ee 📕	Con	mplet ee	ely
	"We enjoyed collaborating while cooking."	H1	H2	H3	H4	M1	M2	M3	
	"We would like to cook in this way again."	HI	H2	H3	H4	M1	M2	M3	
	"We all stayed interested while cooking."	HI	H2	H3	H4	M1	M2	M3	
"When we saw	the recipe we immediately felt like starting."	H2	H1	H3	H4	M1	M2	M3	
	"We felt proud after cooking."	H2	H3	H1	M1	H4	M2	M3	

Fig. 10 Results experience while cooking

4 Discussion

This evaluation investigated whether people with dementia could be supported in cooking using a specifically designed recipe concept, which includes a step-by-step guide.

First, we conclude that breaking up the cooking process into step-by-step increments makes recipes easier to understand and follow for people with dementia. The size of the steps can be adjusted to suit the cognition level of the client. As the text per instruction is short, the tasks are easier to understand and remember. Furthermore, the additional icons make the recipe look less overwhelming and help people with dementia with linguistic difficulties [31] comprehend the steps more easily. As the icons were only shown in combination with textual descriptions, further research could investigate the understanding of people with dementia of standalone icons.

A minor downside to the step-by-step approach is that it does not allow much for improvisation. Like Wolf et al. [20], we found some participants tended to change the order of the steps and improvise steps as they saw fit and then struggled to find their way back to the fixed order of the recipe. Therefore, we suggest investigating how a step-by-step guide can clearly describe a process while allowing for improvisation.

A pawn was introduced to the prototype so users could keep track of their current place in the recipe. The pawn helped half of the participants quickly find the next step in the recipe. However, as the learning ability of people with dementia tends to decline [6], not everyone seems to be able to learn to move or look for the pawn. Without it, due to their decline in shortterm memory [31], clients could not always remember which steps they had already completed or quickly find the current step on the page with multiple steps. People with dementia are still able to (re)learn [6, 11], so future research could assess if the person with dementia's pawn use can be improved through practice. Another approach could be using an automated interface that only shows one step at a time [11, 19, 20] but making it highly intuitive for people with dementia and integrating a way to see the overview of the entire process.

We found that caregivers and partners significantly influence conveying agency and trust to people with dementia. Like Wijngaarden et al. [23], we found that caregivers and partners often lacked trust in the perception of the person with dementia and would check or take over tasks without being asked to. This behaviour influenced the behaviour of the people with dementia, as those in groups with a caregiver or partner took less initiative. However, the results of our study do suggest that the caregiver and partner's trust can improve with practice. We recommend conducting further research in which people with dementia and caregivers collaborate, for example, with this cooking tool to understand and enhance trust.

We also found that collaborative cooking is an enjoyable and suitable activity for people with dementia and their caregivers, both at home and at meeting centres. Although many people with dementia often stop doing activities they are still capable of to avoid challenging situations [28], all participants of this study were excited to start cooking. Stanyon et al. and Fitzsimmons et al. suggest giving direct short instructions [29] and introducing collaborative cooking activities [18] can increase the involvement and initiative of people with dementia. Thus, we recommend using intuitive and inviting tools such as Happje to counter the apathy [35] often seen in people with dementia.

Like Fitzsimmons et al. [18], we found that participants with dementia highly enjoyed collaboratively cooking with other people with the same condition. Brataas et al. and Wijngaarden et al. [23, 24] suggest this is because people with dementia feel more like 'equals' when interacting with one another and feel they do not have to hide their symptoms. Therefore, we suggest introducing more activities to the lives of people with dementia where they can create together.

4.1 Limitations

The evaluation's context, participants, tasks, and prototype are representative of the intended context, users, tasks, and design. Furthermore, as the evaluation contained eight cases with 36 participants, we believe the study gives valid insights into various users and contexts.

However, the data may have been biased as the caregivers and clients collaboratively filled in the self-reporting questionnaire. The caregivers could have overpowered the conversation, clients may have had a too optimistic view of the situation, and both parties may have felt reluctant to be critical of each other's performance. Furthermore, the self-reporting questionnaire only consisted of positive statements to suit the participants' cognitive abilities, which perhaps made participants look less critically at each statement and feel inclined to agree with all of them. Also, the analysis mainly focused on what was said by participants, which is challenging for those with linguistic difficulties [34]. Lastly, the observation and analysis were done by one researcher, meaning some observations may have been missed or the analysis was biased.

5 Conclusion

This paper presents a novel cooking tool called Happje to support people with dementia in cooking activities in collaboration with other people with dementia or caregivers. Our recipe tool uses a step-by-step approach, which helped people with dementia understand the steps more easily. A pawn was introduced to help users remember their place in the recipe. However, navigating through the steps still proved challenging as half of the clients struggled with learning to move and look for the pawn. The caregiver's trust significantly impacts the clients' agency and confidence in their perception and capabilities. Collaborative cooking with the cooking tool is an excellent activity to introduce at homes and meeting centres for people with dementia as it is not intimidating and stimulates socialisation.

The pawn should be further iterated on to become so intuitive that users no longer need to learn how to use it. Furthermore, a more extended study using the recipe tool could evaluate whether the caregiver's trust in the client can increase over time. We also suggest designing more intuitive and collaborative activities such as facilitated by Happje for people with dementia to reduce apathy and loneliness. Future studies around the experience of people with dementia should not just focus on what people write and say but also on how they behave during the experience. Moreover, clients and caregivers should be interviewed separately to ensure they both get to express their opinions.

References

- World Health Organisation (2021) Dementia. September 02. https://www.who.int/news-room/factsheets/detail/dementia. Accessed 27 January 2022
- Livingston G et al (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet commission. Lancet London England 396(10248):413–446. https://doi.org/10.1016/S0140-6736(20)30367-6
- de Bruijn RF et al (2015) The potential for prevention of dementia across two decades: the prospective, population-based Rotterdam Study. BMC Med 13 (1):132. https://doi.org/10.1186/s12916-015-0377-5
- Dementia Care Central (2020) Seven stages of dementia Symptoms, progression & durations, April 24. https:// www.dementiacarecentral.com/aboutdementia/facts/ stages/. Accessed 27 January 2022
- Brankaert R (2016) Design for dementia : a designdriven living lab approach to involve people with dementia and their context, Phd Thesis 1. Research TU/e/Graduation TU/e), Technische Universiteit Eindhoven, Eindhoven
- Dechamps A et al (2011) Effects of different learning methods for instrumental activities of daily living in patients with Alzheimer's dementia: a pilot study. Am J Alzheimers Dis Other Demen 26(4):273–281. https://doi.org/10.1177/1533317511404394
- Desai AK, Grossberg GT, Sheth DN (2004) Activities of daily living in patients with dementia. CNS Drugs 18(13):853–875. https://doi.org/10.2165/ 00023210-200418130-00003
- Giovannetti T, Bettcher BM, Libon DJ, Brennan L, Sestito N, Kessler RK (2007) Environmental

adaptations improve everyday action performance in Alzheimer's disease: empirical support from performance-based assessment. Neuropsychology 21 (4):448. https://doi.org/10.1037/0894-4105.21.4.448

- Chevignard MP, Taillefer C, Picq C, Poncet F, Noulhiane M, Pradat-Diehl P (2008) Ecological assessment of the dysexecutive syndrome using execution of a cooking task. Neuropsychol Rehabil 18(4):461–485. https://doi.org/10.1080/096020107 01643472
- Giovannetti T, Libon DJ, Buxbaum LJ, Schwartz MF (2002) Naturalistic action impairments in dementia. Neuropsychologia 40(8):1220–1232. https://doi.org/ 10.1016/S0028-3932(01)00229-9
- Mis R, Giovannetti T (2020) Decline in everyday functioning in MCI and dementia: a neuropsychological perspective. In: Vascular disease, Alzheimer's disease, and mild cognitive impairment: advancing an integrated approach. Oxford University Press, New York, NY, US, pp 102–128. https://doi.org/10. 1093/oso/9780190634230.003.0006
- Espiritu DAV, Rashid H, Mast BT, Fitzgerald J, Steinberg J, Lichtenberg PA (2001) Depression, cognitive impairment and function in Alzheimer's disease. Int J Geriatr Psychiatry 16(11):1098–1103. https://doi.org/10.1002/gps.476
- Hargrave R, Reed B, Mungas D (2000) Depressive syndromes and functional disability in dementia. J Geriatr Psychiatry Neurol 13(2):72–77. https://doi. org/10.1177/089198870001300205
- Scheltens P (2017) Ik wil Alzheimer genezen, NRC. January 27. https://www.nrc.nl/nieuws/2017/ 01/27/ik-wil-alzheimer-genezen-6428125-a1543134
- Balota D, Faust M (2001) Attention in dementia of the Alzheimer's type. Handb Neuropsychol 6:51–80
- Bauer RM (2006) The agnosias. In: Clinical neuropsychology: a pocket handbook for assessment, 2nd edn. American Psychological Association, Washington, DC, US, pp 508–533. https://doi.org/ 10.1037/11299-020
- Rosen HJ (2011) Anosognosia in neurodegenerative disease. Neurocase 17(3):231–241. https://doi.org/ 10.1080/13554794.2010.522588
- Fitzsimmons S, Buettner LL (2003) A therapeutic cooking program for older adults with dementia: effects on agitation and apathy. Am J Recreat Ther 2:23–33
- Mihailidis A, Boger JN, Craig T, Hoey J (2008) The COACH prompting system to assist older adults with dementia through handwashing: an efficacy study. BMC Geriatr 8(1):28. https://doi.org/10.1186/ 1471-2318-8-28
- 20. Wolf D, Besserer D, Sejunaite K, Riepe M, Rukzio E (2018) cARe: an augmented reality support system for dementia patients. In: The 31st annual ACM symposium on user interface software and

technology adjunct proceedings, New York, NY, USA, October 2018, pp 42–44. https://doi.org/10. 1145/3266037.3266095

- Yamaguchi T, Foloppe DA, Richard P, Richard E, Allain P (2012) A dual-modal virtual reality kitchen for (Re)learning of everyday cooking activities in Alzheimer's disease. Presence 21(1):43–57. https:// doi.org/10.1162/PRES_a_00080
- Lazar A, Thompson H, Demiris G (2014) A systematic review of the use of technology for reminiscence therapy. Health Educ Behav 41(1_suppl):51S-61S, Oct. https://doi.org/10.1177/1090198114537067
- 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
- Brataas HV, Bjugan H, Wille T, Hellzen O (2010) Experiences of day care and collaboration among people with mild dementia. J Clin Nurs 19(19– 20):2839–2848. https://doi.org/10.1111/j.1365-2702. 2010.03270.x
- Fratiglioni L, Wang H-X, Ericsson K, Maytan M, Winblad B (2000) Influence of social network on occurrence of dementia: a community-based longitudinal study. The Lancet 355(9212):1315–1319. https://doi.org/10.1016/S0140-6736(00)02113-9
- Houben M, Brankaert R, Kenning G, Bongers I, Eggen B (2022) Designing for everyday sounds at home with people with dementia and their partners. In: CHI conference on human factors in computing systems, New York, NY, USA, April, pp 1–15. https://doi.org/10.1145/3491102.3501993
- Dirkse R, Kessels R, Hoogeveen F, van Dixhoorn I (2011) (Op)nieuw geleerd, oud gedaan: over het lerend vermogen van mensen met dementie. Bohn Stafleu van Loghum (BSL)
- Gillies BA (2000) A memory like clockwork: accounts of living through dementia. Aging Ment Health 4(4):366–374. https://doi.org/10.1080/ 713649961
- Stanyon M, Thomas S, Gordon A, Griffiths A (2019) Effects of care assistant communication style on communicative behaviours of residents with dementia: a systematic multiple case study. Scand J Caring Sci 33(1):207–214. https://doi.org/10.1111/scs. 12622
- Cummings JL, Houlihan JP, Hill MA (1986) The pattern of reading deterioration in dementia of the Alzheimer type: observations and implications. Brain Lang 29(2):315–323. https://doi.org/10.1016/0093-934X(86)90051-9
- Memory loss and dementia | Alzheimer's Society. https://www.alzheimers.org.uk/about-dementia/sym ptoms-and-diagnosis/symptoms/memory-loss. Accessed 19 May 2022

- Dewing J (2008) Process consent and research with older persons living with dementia. Res Ethics 4 (2):59–64. https://doi.org/10.1177/174701610800 400205.
- Berghmans RLP, Meulen RHJT (1995) Ethical issues in research with dementia patients. Int J Geriatr Psychiatry 10(8):647–651. https://doi.org/10.1002/ gps.930100803
- Communicating and dementia | Alzheimer's Society. https://www.alzheimers.org.uk/about-dementia/ symptoms-and-diagnosis/symptoms/communicatingand-dementia. Accessed 19 May 2022
- Mega MS, Cummings JL, Fiorello T, Gornbein J (1996) The spectrum of behavioral changes in Alzheimer's disease. Neurology 46(1):130–135. https://doi.org/10.1212/WNL.46.1.130