

Playful Design for Activation

Co-designing serious games for people with moderate to severe dementia to reduce apathy

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DOI

[10.4233/uuid:ebeef0fa-46fe-4947-86c1-c765a583770a](https://doi.org/10.4233/uuid:ebeef0fa-46fe-4947-86c1-c765a583770a)

Publication date

2017

Document Version

Final published version

Citation (APA)

Anderiesen, H. (2017). *Playful Design for Activation: Co-designing serious games for people with moderate to severe dementia to reduce apathy*. [Dissertation (TU Delft), Delft University of Technology].
<https://doi.org/10.4233/uuid:ebeef0fa-46fe-4947-86c1-c765a583770a>

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playful design for activation

Hester Anderiesen Le Riche

Playful Design for Activation

Co-designing serious games for people with moderate
to severe dementia to reduce apathy

Proefschrift

ter verkrijging van de graad van doctor
aan de Technische Universiteit Delft,
op gezag van de Rector Magnificus Prof. Ir.
K.Ch.A.M. Luyben;
voorzitter van het College voor Promoties,
in het openbaar te verdedigen op
maandag 24 april 2017 om 15:00 uur

door

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Prof. Dr. E.J.A. Scherder, as research mentor, and Dr. V.T. Visch, as
supervisor, have contributed significantly to the preparation of this
dissertation.

This research is for greater part funded within the Creative Industry
Scientific Program (CRISP), which is supported by the Dutch Ministry
of Education. An additional financial support was granted by the
'Woonzorgunie Veluwe'. We are grateful for the trust, enthusiasm and
commitment of the residents, relatives and carers that participated in
this project.

My grandma got several fentanyl patches to reduce the pain before she would drift away into her final sleep. She quirked “Oh now you have it, they stick all these postage stamps on me, but they forget to post me!” We laughed for her wittiness and realized that, although she was 91 years old, there was not a single sign of dementia. My choice of topic for this doctorate did not arise from personal experiences, but rather from gratitude for our older generations and my own passion for an active lifestyle. Unfortunately, dementia takes its toll now also in my closest environment by affecting my grandfather in law. The story is as the one of many and terribly sad. A doctor, an adventurer and an entrepreneur, now struggles to talk and to recognize grandma, who supported him during all their adventures for so many years. It is difficult to understand and hard to accept that such a brainy man is vulnerable for dementia. We all are. And we all share the responsibility for a meaningful time for our silver aged - with or without dementia.

For all my grandparents

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Introduction

1 Design for activation

There are several reasons why design innovations may be initiated, whether economical, functional, or societal. Despite these differences, design's common ground is to change current situations into preferred ones (Simon, 1969). Our daily lives are continuously 'improved' with everyday products that increase comfort, safety, efficiency, and thereby changing the way we live. Despite their good intentions, not all of these improvements prove beneficial for our health and well-being. Short-term improvements may be harmful on the long run. This phenomenon is extensively being explored by scholars in the field of design (Desmet & Pohlmeier, 2013) and has started to create awareness in the design field about the long-term impact design has on our lives. Designers are becoming aware of the dilemmas raised by conflicting values in short-term and long-term use (Ozkaramanli, Ozcan, & Desmet, 2014).

One of these conflicts can be found in the attitude towards physical activity in design. Comfort and efficiency in design seem to be maximized when physical activity is minimized. We use cars, remote controls, escalators, and washing machines, so we no longer have to walk to work, rise from our couch to change channels on our TV, take the stairs or do our laundry by hand (see Figure 1).



Figure 1. Examples of products that reduce physical activity (the two pictures from the left present: a Bang & Olufsen remote control and the Volkswagen Touareg)

However, while this trend is making our lives easier, on the long run, it also makes it more passive. The World Health Organization (n.d.) states that the most important reasons for physical inactivity are, among others, sedentary behaviour during occupational and domestic activities and 'passive' modes of transport.

The health consequences of this behavioural change are serious: physical inactivity is estimated to cause 3.2 million deaths worldwide each year (ibid.). A sedentary lifestyle can lead to overweight and obesity, and, over the last 35 years, the prevalence of obesity has more than doubled. People across all societal and demographic groups are obese, and nowadays, more people die from being overweight than from being underweight (World Health Organization, 2016). Besides having a negative impact on our physical health, physical inactivity also affects cognitive functioning and emotional well-being. People with an active life style are less subject to cognitive decline at a later age, and suffer less from depressions (Williams & Tappen, 2008).

It seems impossible to identify the cause for all this inactivity, as our level of physical activity is influenced by various personal, societal and environmental factors. However, design has arguably contributed to facilitate a more passive lifestyle. If our designed environment contributes to an undesired behavioural change such as physical inactivity, design should be able to create an environment where people become active again; design for activation. Design can only contribute to a more active lifestyle if society is susceptible for that change. Given the existing initiatives, presented in the next paragraph, to help people become more active, this seems to be the case. Design for Activation is therefore a supportive design vision, rather than an authoritarian one.

Current design initiatives based on this assumption are already being developed and implemented: the FitBit activity tracker motivates people to take the stairs rather than the escalator, the Pokemon Go game stimulates players to go outside to find their Pokemons, and finally the Spaac motorized bicycle allows people to still cycle when personal or environmental circumstances are challenging (see Figure 2).

Figure 2. Examples of products that increase physical activity (pictures present, from left to right: the Fitbit activity tracker, the Pokemon Go game, and the Spaac motorized bicycle)



The foundation of this thesis is the belief in the potential of design as an agency for positive activation. The aim is to research how product design can stimulate an active lifestyle, both for health purposes and to improve quality of life. Design for Activation is applicable to many different contexts and relevant for many different users. However, to take a first step and to explore the potential of Design for Activating as a thorough design approach, with the necessary insights, tools and methods, requires the definition of a specific context to work for. A societally relevant opportunity for this first step is the context of people with dementia living in a nursery home environment.

2. Design for activating people with dementia

An extreme case of physical inactivity is apathy: when a person does not show any interest or energy and is unwilling to take action. In literature, apathy is defined as ‘the absence or lack of feeling, emotion, interest or concern’ (Marin, 1996). In addition, Levy and Dubois (2006) defined the term apathy for observing purposes which is therefore used in this dissertation: “the quantitative reduction of self-generated voluntary and purposeful behaviours”.

Research suggest that 90% of nursing home residents with dementia suffers from apathy (Kolanowski, Litaker, & Buettner, 2005). Dementia has a degenerative nature and, over time, increasingly diminishes the person’s memory, thinking, behaviour and functioning. Lesions in the prefrontal cortex and basal ganglia, characteristic for several types of dementia, e.g frontotemporal dementia and Alzheimer’s disease (Levy & Dubois, 2006) reduce the capability to take initiative. Apathy is the most common behavioural change experienced by people with dementia. These findings are worrisome, as the absence of physical activity is related to the decline of physical health and cognitive capacities (Colcombe & Kramer, 2003). Apathy affects the older person’s physical flexibility, coordination and strength (Warburton, Nicol, & Bredin, 2006), whereas exercise (Heyn, Abreu, & Ottenbacher, 2004) and leisure activities (Verghese et al., 2003) are associated with improved physical, cognitive and emotional well-being of people with dementia (Lawton, Fulcomer, & Kleban, 2001).

Design for activation has the overall aim to improve health and quality of life, but what does this mean for people with dementia? Improving health in general may prolong one’s life, but people in the last stages of dementia typically experience severe deterioration in physical and cognitive function. Should our primary motivation be to stretch out that last phase of life? We think instead that stimulating people in the last stages of dementia should focus more on improving the quality of daily life, rather than on slowing the course of the disease. The term ‘Quality of Life’ (QoL) originates from philosophy and novelists, but is adopted by the psychometricians, health service researchers and policy makers (Kane, 2003). In mainstream psychology, the term ‘quality of life’ is defined as a conscious cognitive judgment of satisfaction with one’s life (Pavot & Diener, 1993).

Many studies suggest relations between physical activity and quality of life. Different mediating factors are studied and briefly discussed below: physical health, functional abilities and autonomy, depression, and sleep patterns (see Figure 3).

Figure 3: Relations between physical activity and quality of life, found in literature



Older person's quality of life is correlated to their independence. According to Galik and Resnick (2009), one way to improve residents' QoL is to maintain their functional abilities for as long as possible – which also decreases the caregivers' burden. Other research, by Stähelin (2009), describes the positive relation between functioning, physical activity, and mobility on older person's independence. Verdote-Robertson and Reddon (2000) too signal how older persons' level of mobility benefits their self-efficacy.

Quality of life and resident's functioning can also be improved by other means. Cutler (2007), for instance, discusses the field's need for research into how resident and environmental characteristics could interact to improve both quality of life and resident's functioning. The risk of disablement, for instance, is increased by tiredness, the result of restlessness at night (Avlund & Vass, 2003). Evidence suggests that sleeping problems are very common for residents of the nursing home environment. Resident's quality of sleep is affected by poor lighting conditions (lack of bright light during the day, but also lacking darkness at night), sleep hygiene and the disruptive nights in the nursing homes (Alessi & Schnelle, 2000).

But it is not just the environment. Aging has a negative effect on people's sleep quality, which is worsened by sleep disorders, some types of medication, dementia and depression. Depression is often related to: older persons, the last stages of our lives, the nursing home environment and especially with persons suffering from dementia (Barca, Selbaek,

Laks, & Engedal, 2008). Physical activity may provide an answer, as research shows a positive correlation between physical activity and the effect on various moods, such as depression (Williams & Tappen, 2008; Williams & Tappen, 2007). Another study suggests how physical activity, or individualized activities, can improve residents' sleep patterns (Richards & Beck, 2005).

The societal relevance of this target group is illustrated by the recent increase in attention for dementia across the fields of science, industry, government, and media. The group of dementia patients is growing; the number of dementia patients is expected to double worldwide every 20 years (see Figure 4).

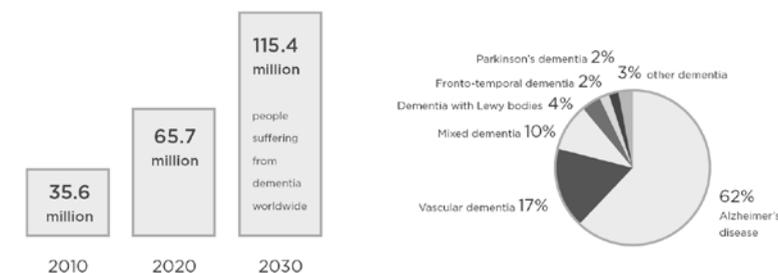


Figure 4. Dementia in numbers on a world scale

Because the neuropathology characteristic for dementia diminishes people's capability to initiate activities, they need external stimulation to remain active. The initiative to activate older persons living with dementia is thereby often transferred to the carers (professional and informal). Sadly, the trend to cut spending in dementia care, as witnessed in The Netherlands, reduces the time carers can spend on this task. Therefore, new solutions are needed that do not ask time and energy from the caregivers. This is the design aim of this dissertation.

To design an activating product for people with dementia within the nursing home environment, we conceptualized the context to explore their environment (illustrated in figure 5). This context consists of a social and a physical environment. The physical environment consists of the built environment and the products within it, such as furniture, appliances, decorations, and so on. The social environment is made up of the fellow residents and the formal and informal caretakers.

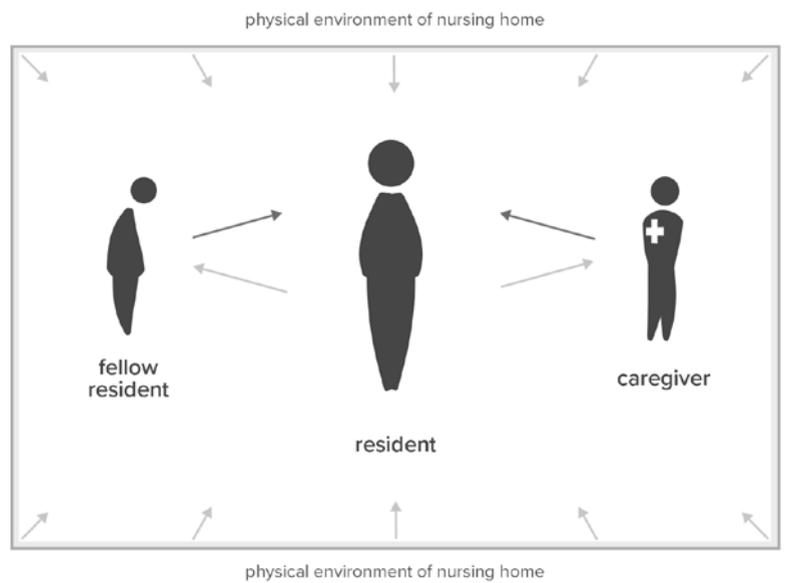


Figure 5. The physical and social context of people with dementia living in a nursing home

With the insights we gained during the course of this doctorate, we defined our target group more specifically. We chose to design a product for people in the three most advanced stages of dementia, i.e. 5-7 on the Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon, & Crook, 1982). Their severe cognitive decline makes it difficult for them to recognize people, are confused about time and place and cannot live without assistance anymore. We have several reasons to target this specific group with the design of our product; (1) typical for the degenerating process of the disease, they tend to become more passive the further the disease progresses, (2) products that are designed for the general public are hardly ever suitable for this group, even with support from a carer, and (3) the range of products that are specifically designed for this group is severely limited.

3. Playful experiences as a design perspective

This PhD project is part of the Creative Industry Scientific Programme (CRISP). CRISP stimulates collaboration between companies in the creative industries, industry at large, public sector organisations and knowledge institutes. CRISP aims to research and design complex product-service systems (PSS) that will benefit our society. This PhD is part of the sub-project ‘G-motiv’, which researches and applies new

design approaches for behavioural change based on motivation by using playful experiences. The G-motiv project consists of five researchers that explore the use of playful experiences in product design to change behaviour from three different perspectives: (1) social behaviour in the corporate environment (Vegt, Visch, de Ridder, & Vermeeren, 2015), (2) cognitive behaviour during addiction rehabilitation programmes (van der Kooij, Hogendoorn, Spijkermans, & Visch, 2014), and (3) physical behaviour in the dementia care context (this thesis).

Playfulness entails a far broader spectrum than just playing games; playfulness appears in many aspects of human culture (Huizinga, 1955). Korhonen, Montola, and Arrasvuori (2009) identified play experiences that were elicited by playing video games to understand the scope of playful user experiences that could be elicited by products. They categorized 21 play experiences: *captivation, challenge, competition, completion, control, discovery, eroticism, exploration, expression, fantasy, fellowship, humour, nurture, relaxation, sadism, sensation, simulation, subversion, suffering, sympathy, and thrill* (Korhonen et al., 2009). Play experiences are considered to be strong motivational factors in design aimed at behavioural change and there are several examples that product designers incorporate these play experiences into their designs. For example, the sensory experience of the Fun Theory Piano Stairs (Volkswagen, 2009), a rewarding smiley face if you drive under the speed limit, or the challenge of aiming for the ‘Blikvanger’ (Can Catcher in English) to prevent littering (see Figure 6). To embed play experiences into the user experience of a product seems to be a promising direction for designing for activation and is further explored in this doctorate.

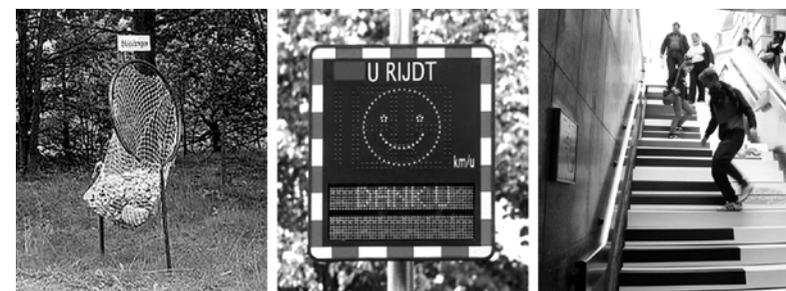


Figure 6. Examples of design for behavioural change that include play experiences (the right picture presents the Fun Theory Piano Stairs, an initiative by Volkswagen)

Finally, the implications of being part of CRISP is that the design outcome will not be a mere product (whether tangible or digital) but the product will be embedded in a product-service system (PSS). The approach of Gmotiv has two perspectives: first, the design context of dementia care is considered as a service, and the product should support this service in a coherent product-service system. In other words: the product is considered an enhancement of the existing care-service. Next, the design should not only provide a product, but the product itself should be designed with a service system. It is expected that products embedded in a solid product-service system create an increased value of experience and therefore to be expected to have a higher chance for a successful impact (Kuijken, Gemser, Wijnberg, & Erp, 2012). This perspective seems therefore a promising approach for Design for Activation.

4. Project-grounded research

The research presented in this thesis is design driven: the ultimate goal is to design a product that will activate the residents of nursing homes with dementia to reduce apathy. Also, the research questions formulated are grounded in the need to understand the users and their context. However, this thesis not only aims to contribute with its outcomes to the actual daily lives of people with dementia, but also to the field of design research itself, by exploring how one could design for activation, and more particularly for activation of people living with dementia. These more general research results may thereafter inform and inspire future projects with similar goals. The combination of a practical and a theoretical goal, such as design research projects offer, is referred to as project-grounded research, elaborated on by Chow (2010).

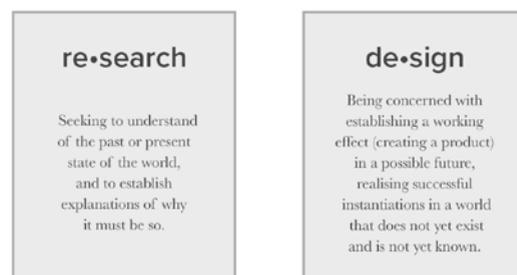


Figure 7. Definitions of 'research' and 'design' (Stappers, 2007)

Key to success is a user-centred approach with the ability to communicate with all specialists involved, and secondly, the retained focus on realising the product throughout the process (Stappers, 2007). Design and research find overlap in the aim of 'gaining knowledge': by absorbing, integrating and contextualising knowledge from different directions into a product design, we test new hypothesis and theories and gain new insights, new knowledge. By reflecting, generalising and documenting our newly gained (design) knowledge, we contribute to this 'middle ground' of design research (Stappers, 2007). Implication of this approach is that research will be done before designing, to formulate a refined design goal, a design vision and design directions, but research will go on during the design phase, through an iterative process where design and research are alternated and inform each other.

For this project-grounded research, the following initial research questions were formulated:

- 1.) Which factors in the physical and social environment of people with dementia, who are residing in nursing homes, influence their level of physical activity?
- 2.) Which play experiences can be expected in general to be suitable for persons in different stages of Alzheimer's disease?

During the design phase, the following design research questions were formulated:

- 3.) Which playful user-product interactions that stimulate people with moderate to severe dementia are suitable to reduce apathy?
- 4.) How can co-design contribute to the development of a new stimulating product for people with moderate to severe dementia?

Eventually, the designed prototype will be evaluated with the question whether the proposed design solution actually reduces of apathy, thereby contributing to quality of life of the people with dementia, envisioned as an increase in their subjective well-being.

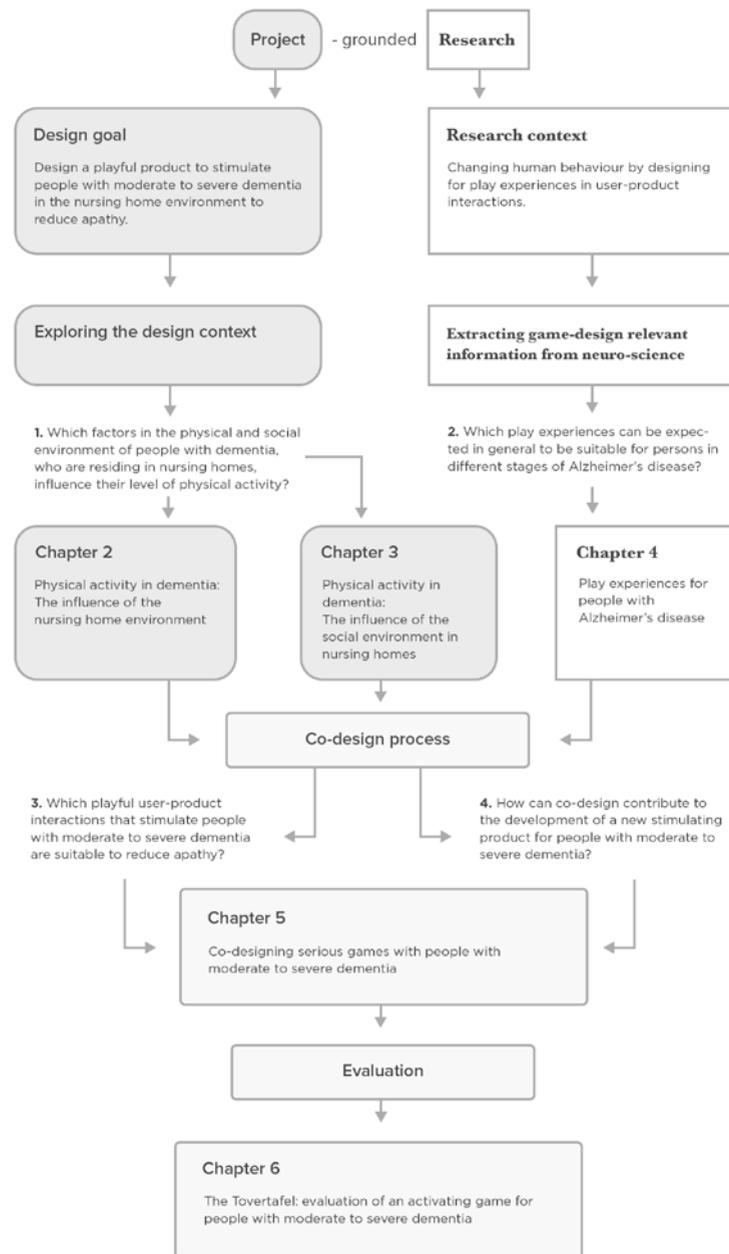


Figure 8. Structure of this thesis

5. Outline dissertation

The structure of this dissertation is based on the approach of project-grounded research; three preliminary studies (Chapters 2-4) present the research that informed the design, one study (Chapter 5) describes our novel design process and share our learnings, followed by a product presentation (Intermezzo) and thereafter an evaluation study of the product (Chapter 6). We will conclude with the general discussion and conclusion (Chapter 7). The structure of the thesis and the relation between the different chapters is presented in figure 8. The different chapters are based on accepted journal papers (Chapters 2 and 4), one paper that is submitted (Chapter 6), and two chapters that will be the basis of journal submissions after finalizing this dissertation (Chapters 3 and 5). The papers are not adapted but are included as they are in the thesis, creating some overlap in the texts. Each chapter is therefore preceded with a short introduction, to ensure a coherent and clear story line throughout the thesis.

Chapter 2. Physical activity in dementia: The influence of the nursing home environment

The chapter explores the stimulating and restricting experiences in the dementia care environment, through a systematic literature review of the influence of the physical nursing home environment on the level of physical activity of its residents. The review gives insights in the effectiveness of current environmental interventions, such as for example, bright light, music, building footprint and a homely interior. Although the variety of interventions found was somewhat limited, the review suggests a range of design directions, with the Multi-Sensory Environment as most promising.

Chapter 3. Physical activity in dementia: The influence of the social environment in nursing homes – a qualitative research journey

The chapter describes a qualitative research journey into the social environment of nursing home residents with dementia and its influences on their level of physical activity. Focus of the exploration is to understand how the interactions between peers, caregivers and relatives

may stimulate or demotivate physical activity. The social interaction in the dementia care context is a complex interplay of various enablers and inhibitors for its residents' physical activity. From our studies, we learnt that the carers play an important role with their strategies to stimulate their residents, but the residents influence its effect by their attitude. The social interaction between residents seems crucial in stimulating each other. These insights in the importance of social interaction for activation resulted in a stronger focus on the social aspects of our design.

Chapter 4. Play experiences for people with Alzheimer's disease

The chapter explores through a literature review which play experience are expected to be suitable for persons in different stages of Alzheimer's disease. The game literature provided twenty-two play experiences, to which reminiscence is added. The resulting play experiences are categorized into the neuropathology that is characteristic of the different stages of the disease. The chapter concludes on the 3 play experiences most suitable for people in later stage of Alzheimer disease. These play experiences are used as promising design directions for the development of the activating design.

Chapter 5. Co-designing games with people with moderate to severe dementia

The chapter describes the user-centred process that leads to the development of the Active Cues Tovertafel. It first describes the initial vision for the new product, based on the outcomes of chapters 2 to 4. Next, it describes the different iterations involving end-users and their immediate environment, with a co-designing approach. The process illustrates that although it initially seemed unlikely, co-design with people with moderate to severe dementia appeared to be valuable during the development of the new product; the Active Cues Tovertafel. The chapter concludes on the lessons learned regarding the interaction principles and the content of the Tovertafel.

Intermezzo. The Active Cues Tovertafel

This chapter is a product description of the final outcome of the design process. It starts with a brief summary of the goal and starting points of the project, followed by a description of the product, the product platform, and the provided product-services. The chapter illustrates the use of the product through user scenarios in context.

Chapter 6. The Tovertafel: evaluation of an activating game for people with moderate to severe dementia

The chapter describes an evaluation study of the Active Cues Tovertafel, executed in context with a real-life prototype. In a 5-day intervention, the impact of the Tovertafel was assessed through scores filled in by caregivers and interviews. The use of the Tovertafel was compared to two other situations: (1) the residents having coffee together at the dining table and (2) the residents sitting in their lounge area.

Chapter 7. General discussion and conclusions

This chapter concludes this thesis. It begins with a reflection on the entire process: the implications of the research approach, the design approach, and the CRISP context. Next, the chapter reflects on the design outcomes. The chapter ends with future perspectives on Design for Activation, first in particular, for people with dementia and next, in general, as a design approach: what are the lessons learned, the what questions that are raised, and the what could be future developments?



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Physical activity in dementia: The influence of the nursing home environment - *a systematic literature review*

A first step in understanding the context of residents in nursing homes, is to explore its physical environment: what factors are inhibiting or stimulating physical activity? This chapter presents a systematic literature review of empirical studies that measured the effects of the built environment on the level of physical activity of its residents. Positive results were found for music, a homelike environment and functional modifications. Predominantly positive results were found for the small-scale group living concepts. Mixed results were found for bright or timed light, the multisensory environment and differences in the building footprint.

The results of this chapter led to suggestions for improvements in different domains of design and policy. In particular, the results led to the insight that a Multi-Sensory Environment (MSE), which is also known as 'Snoezelen' is promising for the goal of this project. The MSE showed predominantly positive effects on the level of physical activity of people with dementia (Weert et al. 2005; Milev et al. 2008; Baker et al. 2001). However, the residents' exposure to the MSE is limited to the hours of treatment, whereas adapting multi-sensory elements into the communal areas could stimulate its residents throughout the day.

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Physical activity in dementia: The influence of the nursing home environment - *a systematic literature review*

1. Introduction

The design of our physical living environment influences our performances by supporting our abilities (Lawton, 1974). Especially for older persons with dementia, who have cognitive, physical and sensory limitations, the physical environment potentially supports or hinders a satisfactory life (Cohen-Mansfield & Werner, 1998). Thus, understanding the influences of the environment on their behaviour is of utmost importance for the teams that design nursing homes and comprise of architects, interior designers, care professionals and policymakers. In the literature, these environments are referred to as, for example, “healing environments” (Dijkstra, Pieterse, & Pruyn, 2006) or “therapeutically designed environments” (Day, Carreon, & Stump, 2000).

Many studies have investigated the health and behaviour-related effects of the nursing home environment on older persons with dementia (for reviews see: Day et al., 2000; Day & Calkins, 2002; Maslow & Ory, 2001; Calkins, 2009). The majority of these intervention studies aimed to moderate residents' disruptive behaviours (e.g. wandering, agitation or aggression) by reducing negative environmental stimuli (Mahoney, Volicer, Hurley, & Hurley, 2000). However, too little stimulation implies the stimulus deprivation of and little activity by older persons with dementia during the day (Cohen-Mansfield & Werner, 1998). Nearly half of the residents in nursing homes suffer from dementia-related diseases, for example, Alzheimer's, vascular dementia or Huntington's (Silverstein & Flaherty, 2003), and this group appears to be the least active: 90% of all nursing home residents with dementia suffer from passive behaviour (Kolanowski, Litaker, & Buettner, 2005).

The research interest has shifted from limiting disruptive behaviours by reducing negative environmental stimuli, towards providing enriched environments that elicit positive behaviours (Calkins, 2009). Moreover, recent studies have shown that stimulating older persons with dementia might actually reduce disruptive behaviours (Volicer, Simard, Heartquist Pupa, Medrek, & Riordan, 2006; Aman & Thomas, 2009). More specifically, the physical and mental activation of older persons living with dementia is important to prevent them from being bored, restless and apathetic (Morgan & Stewart, 1999; Lawton, 2001). In the literature, boredom and loneliness are associated with cognitive decline (Conroy, Golden, Jeffares, O'Neill, & McGee, 2010; Wilson et al., 2007).

There is also emerging evidence for the beneficial effects of physical activity on physical flexibility, coordination and strength (Warburton, Nicol, & Bredin, 2006), as well as on cognitive functioning, especially of older persons with and without cognitive impairment (Colcombe & Kramer, 2003).

Considering the growing consensus about the beneficial effects of physical activity on cognition, physical health, behaviour and older persons' mood, the goal of the present review was to address studies that measured the effects of environmental stimuli on the level of physical activity of older persons with dementia residing in a nursing home environment. Physical activity is defined as “any bodily movement produced by the contraction of skeletal muscles that results in a substantial increase over resting energy expenditure” (Pate et al., 1995). The recommended amount of physical activity for older persons is described in Text box 1.

As all non-apathetic behaviour is desirable, and possibly contributes to meeting the ACSM/AHA recommendations (Nelson et al., 2007), several physical activity outcomes were included in this review, that is, performance on (i)ADLs, attending leisure activities, total amount of daily activity and reducing apathy.

2. Method

2.1 Search strategy

We performed literature searches in five electronic databases: PubMed, PsycINFO, EMBASE, CINAHL and the Cochrane Library. For the searches, we used the following four sets of search terms: (1) dementia, (2) physical environmental stimuli, (3) physical activity and (4) nursing home environment. The search terms included medical subject headings (MeSH) in PubMed and controlled terms (EMtree) in EMBASE, and both were combined with free text terms.

The first set of terms consisted of *dementia* [MesH], *dement** and *Alzheimer**. The set of terms related to physical environmental stimuli included homelike, design, colour, light, sound, music, visual, auditory, olfactory, building layout, outdoor, interior, ambient, grid and pattern. The search terms related to physical activity included motor activity [MesH:NoExp], activities of daily living [MesH], activity level, functional ability, mobility, rest-activity, self-maintenance, sedentary, walking and self-efficacy. The last set of terms included residential facilities [Mesh], housing for the elderly [MesH], nursing home, SCU, assisted living, toilet, kitchen, resident room, activity area, wandering area and garden. The search covered studies published between January 1, 1993 and December 31, 2012. Upon request, the first author can provide the complete search strategy.

Physical activity for older adults

The recommended amount of physical activity for older adults (age≥65 year), as defined by the American College of Sports Medicine (ACSM) and the American Heart Association (AHA), is similar to the recommendations for adults, namely 30 min of moderate intensity at least 5 days a week, or 20 min of vigorous intensity aerobic activity at least 3 days a week (Nelson et al., 2007). For older adults, the recommendation differs on the definition of the aerobic intensity. Considering the low fitness levels of older adults, moderate intensity is defined as 'a 5 or 6 out of 10; produces noticeable increases in heart rate and breathing,' and vigorous intensity is 'a 7 or 8, and produces large increases in heart rate and breathing' (Nelson et al., 2007). The intensity of a particular activity depends on individual fitness levels, and these vary strongly amongst older adults. In addition, if older adults do not meet the recommended activity levels, they still benefit from reducing sedentary behaviour (Nelson et al., 2007).

Textbox 1

Inclusion criteria for studies relevant for this review were: (1) studies that involved patients who were diagnosed with dementia; (2) studies that exclusively intervened with a physical element in the architectural building layout, interior design or ambience of the nursing home environment; (3) studies that reported on outcome measures assessing performance on (i)ADLs, attending leisure activities, total amount of daily physical activity and reducing apathy; (4) studies with a pre- and post-test, (quasi) experimental, cross-sectional design and randomized controlled trials (RCTs); and (5) studies written in English and published in a peer-reviewed journal between January 1, 1993 and December 31, 2012. Due to the comparative nature of a systematic review, environmental stimuli that were evaluated by only one study were not included in this review. The severity of the patients' dementia was not a selection criterion, but it is reported in Tables 1e3 as follows: a Minimal Mental State Examination (MMSE) score of 20e27 is considered mild dementia, a score of 10e19 is considered moderate dementia and a score of 0e9 is considered severe dementia. Two researchers reviewed the abstracts independently to improve the objectivity and accuracy of evaluating the studies. The first author reviewed all of the abstracts, whereas two persons, for practical reasons, i.e. a PhD candidate and a senior researcher, have done the second review. Differences in opinion were discussed and in the case of doubt, the paper was selected as potentially relevant.

3. Results

3.1 Search results

The search revealed 3187 abstracts, of which 326 studies were selected as potentially relevant; of these, 24 met all the inclusion criteria. The structure of this review was based on the three dimensions of the physical environment described by Harris, McBride, Ross, & Curtis (2002): (1) ambient features (the least permanent features, such as music and lighting); (2) interior design features (the less permanent features of the building, such as the furnishings); and (3) architectural features (the relatively permanent features, such as the spatial layout of the building). Nine of the selected studies intervened with ambient features (see Table 1), seven with

Table 1), seven with interior design features (see Table 2) and eight with architectural features (see Table 3). The first two authors reviewed the 24 selected papers on their study designs as classified by the NHMRC evidence hierarchy (National Health and Medical Research Council, 2000) and appraised the methodological quality (Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009). These results are presented in Tables 1-3.

3.2 Ambient features

First author, year	Study type, N	NHMRC evidence hierarchy ^a	Estimated methodological quality ^b (%)	Control group Y/N, placebo	Severity of dementia ^c	Setting ^d	Intervention	Type of outcome	Measuring method(s)	Result
Light										
<i>Bright light</i>										
Riemersma-van der Lek et al. (2008)	RCT, 189	II	100	Y, (f) light (2) melatonin	2	AL	Four groups: whole day bright (± 1000 lux) or dim (± 300 lux) light combined with or without extra melatonin intake	Physical activity, ADL	Actigraphy, NI-ADL ^e	Increase of 1.8 points/yr (95% CI, 0.61-2.92; P = .003) on NI-ADL
Shochat et al. (2000)	Cross-sectional, 66	IV	67	N	0,1,2,3	NH	Lighting levels and sleepwake activities were measured for 3 days	Physical activity	Actilume ^f	No improvement on overall activity level, but association between acrophase of max illumination preceding peak activity
<i>Timed light</i>										
Ancoli-Israel et al. (2002)	RCT, 77	II	67	Y, dim light	2	NH	2 h evening bright light, 2 h morning bright light, 2 h evening dim light, or daytime sleep restriction; for 18 days	Physical activity	Actilume	Morning bright light delayed peak of activity rhythm and improved mean activity level
Ancoli-Israel et al. (2003)	RCT, 93	II	67	Y, dim light	3	NH	Morning bright light, morning dim red light or evening bright light	Physical activity	Actilume	No improvements in mean activity levels
Dowling et al. (2005)	RCT, 70	II	33	Y, usual indoor light	3	L-TC	Morning or afternoon 1 h bright light (≥ 2500 lux), mon-fri for 10 wks	Physical activity	Actigraphy	No improvements in mean activity levels
Dowling et al. (2007)	RCT, 70	II	33	Y, usual indoor light	3	L-TC	Morning bright light or afternoon bright light	Apathy	NPI-NH ^g	No significant improvements on apathy scores
Music										
Holmes et al. (2006)	Pseudo-randomised controlled trial, 32	III-1	67	Y, silence	2	RC, NH	Sequence of live music, recorded music, silence periods of 30min each, presented randomized	Activity engagement	DCM ^h	Engagement improved compared to baseline (12.5%) sig. to live music (69%) and positive but not sig. to recorded music (25%)
Gotell et al. (2008)	Non-randomised experimental study, 9	III-2	83	Y, usual care	3	NH	Two experimental groups: caregiver singing and background music	Activity engagement	Observation	Improved sense of vitality
Sixsmith & Gibson (2007)	Case series, 26	IV	83	N	u	Independent, RC	No intervention	ADL	Observation	Improved participation in activities that are stimulating and personally meaningful

Table 1
Ambient features

^a NHMRC (2000).

^b Pluye et al. (2009).

^c 0 = healthy, 1 = mild, 2 = moderate, 3 = severe, and u = unspecified.

^d RC = residential care, AC = assisted living, NH = nursing home, and L-TC = long-term care.

^e Nurse-informant adaptation.

^f Wrist mounted monitor which records both illumination and activity data.

^g Neuropsychiatric inventory-nursing home version.

^h Dementia care mapping.

3.2.1 Light

Six studies reported the effects of light on the residents' activity levels. Two of these studies intervened with extra bright light (Riemersma-van der Lek et al., 2008; Shochat, Martin, Marler, & Ancoli-Israel, 2000) and four with timed light, that is, bright light in the morning and dim light in the afternoon (Ancoli-Israel et al., 2003, Dowling, Graf, Hubbard, & Luxenberg, 2007; Dowling, Mastick, Hubbard, Luxenberg, & Burr, 2005). In the nursing home environment, the effects of light are generally associated with improved sleep—wake rhythms. As these circadian rhythms are commonly determined by monitoring physical activity, we considered the measured activity levels in the daytime.

3.2.1.1 Bright light

One of the two interventions with bright light used a melatonin prescription (Riemersma-van der Lek et al., 2008); for this review, we looked at the control group that was exposed to bright light only. Both intervention studies reported positive results of bright light, but differed in duration and outcome measures. A 15-month RCT (Riemersma-van der Lek et al., 2008) showed that exposure to bright light slowed down the decline in ADLs (activities of daily living) performance by 53% compared to residents exposed to dim light. During a cross-sectional study (Shochat et al., 2000), both the illumination and the activity levels were measured throughout the day. Although some influence was found, the results were less convincing. No overall improved physical activity was measured, but the study did show that the peak in light levels preceded the peak in activity levels. The authors suggest two explanations for this: the alerting effects of bright light enhanced the residents' activity levels, or the nursing home schedules of sitting outside followed by afternoon activities caused the positive relation (Shochat et al., 2000). Both studies conclude by suggesting that nursing homes should provide bright light throughout the day, and stating that this will have no long-term adverse effects.

3.2.1.2 Timed light

The effects of timed light on physical activity are reported in four studies.

Two studies, both RCTs (Ancoli-Israel et al., 2003; Ancoli-Israel, Martin, Kripke, Marler, & Klauber, 2002) with a similar setup, showed different results in the residents' mean activity levels. The authors suggested that the residents' MMSE score of 5.7 in the earlier study compared to the mean MMSE score of 12.8 in the later study, might be related to the absence of significant improvements in the first study (Ancoli-Israel et al., 2002). In line with this suggestion, two more RCT studies did not show significant improvements of timed light on mean activity levels (Dowling et al., 2005) or apathetic behaviour (Dowling et al., 2007) of residents in a severe stage of dementia. These results are not surprising: the severe impairment in patients' cognition could explain the lack of effect of bright light on physical activity.

3.2.2 Music

Three studies evaluated the effects of background and live music on the residents' level of physical activity and apathetic behaviour (Holmes, Knights, Dean, Hodkinson, & Hopkins, 2006; Götell, Brown, & Ekman, 2008; Sixsmith & Gibson, 2007). During an RCT, 30-min periods of either live or background music, or silent periods were randomly presented to subjects with moderate to severe dementia to reduce apathy (Holmes et al., 2006). During both musical periods, the subjects' engagement in a creative activity improved, but not significantly, whereas the results were the most promising for live music, during which the engagement improved significantly. Specific information about the nature of the creative activity was lacking. In line with these results, interviews with older persons with dementia revealed their appreciation for music and music-related activities in everyday life (Sixsmith & Gibson, 2007). According to the residents, music enables them to participate in enjoyable activities that are personally meaningful and support their ADLs (Sixsmith & Gibson, 2007). Music also appeared to contribute to the interaction between persons with dementia and the caregivers during morning care sessions in a quasi-experimental study (Götell et al., 2008). More specifically, background music or singing by the caregiver seemed to improve the residents' ADLs, and their interaction was characterized by the carers as “mutual vitality infused by playfulness” (Götell et al., 2008).

3.3 Interior design features

3.3.1 Homelike environment

Two studies evaluated residents' self-initiated activities and their attendance of group activities after implementing a homelike interior design (Morgan-Brown, Newton, & Ormerod, 2012; Cioffi, Fleming, Wilkes, Sinfield, & Miere, 2007). Studies that combined a homelike atmosphere with reducing the facility's scale are discussed in Section 3.4.1. The two studies discussed here did not change the size of the facilities, which accommodated 18 residents (Morgan-Brown et al.,

2012) and 21 residents (Cioffi et al., 2007), respectively. A qualitative study evaluated the redesigned facility, which now offers residents private rooms, bathrooms, the freedom to decorate, better garden access and layout, big windows and a multisensory room (Cioffi et al., 2007). The results of focus groups with staff and relatives revealed their appreciation of the environmental changes (both the staff and the relatives had also experienced the old units). Relatives and staff mentioned the unrestricted nature of the new facility and the ability to freely engage in activities. Unfortunately, possible changes in the residents' activity adherence were not measured (Cioffi et al., 2007). The second study also reported

First author, year	Study type, N	NHMRC evidence hierarchy ^a	Estimated methodological quality ^b (%)	Control group Y/N, placebo	Severity of dementia ^c	Setting ^d	Intervention	Type of outcome	Measuring method(s)	Result
Homelike environment										
Cioffi et al. (2007)	Pre-test/post-test, 19	IV	83	N	u	SCU	Dining room adjoined to kitchen, family pictures, decorating private room, unrestricted garden use, large windows, and multisensory room	ADL, Physical activity	Focus groups	Relatives mentioned the 'unrestricted nature' thus freedom to walk. The new layout contributes to the ability to freely engage in activities
Morgan-Brown et al. (2012)	Pre-test/post-test, 35/36	IV	67	N	u	NH	Conversion to a household environment; open plan design, functioning kitchen unit, supported by a homemaker role, and person-centred care	Activity engagement	ATOSE ^e	More interactive with their environment and did more activities for themselves
Multisensory environment										
van Weert et al. (2005)	Pseudorandomised controlled trial, 61	III-1	67	Y, usual care	2,3	NH	Individual 24 h snoezel program, based on family history and stimulus preference. Caregivers were trained.	Apathy	INTERACT	A significant improvement on the apathetic behaviour, and bored/inactive measure
Milev et al. (2008)	RCT, 21	II	100	Y, no treatment	3	LT-C	Two experimental groups; (1) 1 snoezelen/wk, (2) 3 snoezelen/wk	Apathy	DOS	There is a trend for better outcomes with the increase of sessions/week
Baker et al. (2001)	RCT, 50	II	67	Y, Activity group	2,3	Day care	Eight 30-min. sessions over a 4-wk period	Apathy	INTERACT	MSS group improved on (1) doing more from their own initiative, (2) enjoying themselves, more active and alert, and (3) less bored/inactive, but not more than controls
Functional modifications										
Connell et al. (2002)	Case series, 5	IV	67	N	1,2	NH	Pictures, magnified mirrors, coloured cups, consistent layout to support performance of oral care	ADL	AAI, Observation	Four participants were more independent in "in-the-mouth" oral care tasks
Chard et al. (2009)	Case series, 6	IV	67	N	Unspecified	AL	Labelling of drawers and closet doors, visible workstations, providing ADL equipment, removing distractions	ADL	AMPS	Significant changes in ADL process abilities for all participants and 2 participants also improved their ADL motor abilities.

Table 2
Homelike environment

^a NHMRC (2000).

^b Pluye et al. (2009).

^c 0 = healthy, 1 = mild, 2 = moderate, 3 = severe, and u = unspecified.

^d RC = residential care, AC = assisted living, NH = nursing home, and L-TC = long-term care.

^e Assessment tool for occupation and social engagement, daily observation scale, abilities assessment inventory, and assessment of motor and process skills.

improvements in residents' activity adherence after the conversion of a traditional nursing home into a more homelike environment (Morgan-Brown et al., 2012). The new design encouraged spontaneous interactions and self-initiated activities; both quantitative measures almost doubled. The residents spent more time in the communal areas, where they were more socially engaged, more interactive with their environment and did more activities for themselves.

3.3.2 Multisensory environment

Most intervention studies with a multisensory environment (MSE) measured its influence on the residents' agitated behaviour, whereas in this review we included only those studies that also reported on the level of physical activity or ADLs. Three studies reported on the effects of the MSE or 'Snoezelen' on the levels, or lack of physical activity of nursing home residents (van Weert et al., 2005; Milev et al., 2008; Baker et al., 2001). The MSE combines interior design features with ambient features to create a multisensory experience (Chung & Lai, 2009). Because these MSE rooms are placed permanently within the nursing home environment, we considered them an interior design concept. An RCT study among 50 patients who were diagnosed with moderate to severe dementia, compared a multisensory stimulation group (MSS group) with a control group that participated in puzzle activities (Baker et al., 2001).

Both groups improved on the outcome measures related to physical activity: initiating more activities, enjoying themselves, more active or alert, and less bored. However, the MSS group did not show significantly more improvements than the control group. In addition, no long-term effects were found: the improvements declined sharply during the one-month follow-up period. More promising results were found in another RCT study with 18 patients with severe dementia observed on either active or passive behaviour during a 24-week Snoezelen programme (Milev et al., 2008). Two treatment groups showed significant improvements on apathetic behaviour compared to the control group; they also showed more improvement when they were given three sessions per week rather than only one. The positive effects lasted for 12 additional weeks after

cessation of the multisensory treatment sessions. More positive effects on apathetic behaviour were found during a pre- and post-test quasi-experimental study among 61 patients with moderate to severe dementia (van Weert et al., 2005). The Snoezelen group showed less apathetic behaviour compared to the control group, which received the usual nursing home care.

3.3.3 Functional modifications

Two studies, both with a quasi-experimental design, investigated the effects of an environment that was modified to meet personal needs in order to support the residents' ability to perform ADLs (Connell et al., 2002; Chard, Liu, & Mulholland, 2009). In both studies, the intervention was a combination of environmental modifications and verbal cueing by the caregivers. In one study, five nursing home residents with dementia were helped to perform oral care independently (Connell et al., 2002). The environmental modifications were adjusted to the personal limitations of each of the five residents. The modifications included the provision of informative pictures, and the use of colour and contrast to improve concentration on the task. Four of the five residents showed improved independence on oral care tasks. In the second study, the emphasis of the intervention was on verbal cueing, supported by environmental modifications to improve residents' ADLs (Chard et al., 2009). The environmental modifications included the labelling of drawers and closet doors, workstations with visible items, providing ADL equipment and removing distractions. The interventions improved significantly the ADL process abilities (i.e. time management) of all five participants; in two participants, ADL motor abilities (i.e. pick up and hold objects) also improved.

3.4 Architectural features

3.4.1 Small-scale group living concepts

An emerging trend is the replacement of traditional large nursing homes, which typically have 100-120 beds, with small-scale living environments. Although there is not yet a consensus on the ideal number of residents for

First author, year	Study type, N	NHMRC Evidence Hierarchy ^a	Estimated methodological quality ^b	Control group Y/N, placebo	Severity of dementia ^c	Setting ^d	Intervention	Type of outcome	Measuring method(s)	Result
Small-scale/group living concepts										
Warren et al. (2001)	Two single arm, 54	III-3	100	Y, RC (N=36)	u	RC, SCU	Designed cluster environment (E-shape). Staff: emphasis on ADL and freedom, no physical restraints	ADL	FIM+FAM ^e	The functional decline over time did not differ. Scores on independence/choice was significant higher for RC. RC residents were more active than SCU residents.
Verbeek et al. (2010)	Non-randomised experimental trial, 124	III-2	67	Y, NH	2	Small-scale living facility	Six to eight residents, homelike character, emphasis on family situation, in group, staff is part of household, bottom-up influence	Apathy, ADL	NPI-NH	No significant differences
Schwarz et al. (2004)	Pre-test/post-test, unspecified	IV	67	N	u	Dementia care unit	Decentralized dining, bathing for smaller groups. Improved ambiance	Physical activity	Behavioral Mapping	More involvement in programmed activities, but did not meet the expectations.
De Rooij et al. (2012)	Pseudorandomised controlled trial, 179	III-1	100	Y, NH	3	Small-scale living facility	Small-scale group living concepts (not specified) in both The Netherlands and Belgium	Activity Engagement	QUALIDEM	Significant improvements in 'something to do' at the Dutch facility, not significant, but positive results for the Belgium facility.
Smit et al. (2012)	Pseudorandomised controlled trial, 1327	III-1	100	Y, NH	u	Small-scale living facility	Small-scale with: (1) living rooms with home-like atmosphere, (2) dinner is prepared in group-kitchen, (3) housekeeping is done by the staff, (4) freedom when to go out of bed	Activity Engagement	Activity Pursuit Patterns from the RAI-MDS	More involvement in overall and preferred activities.
Building footprint										
Zuidema et al. (2010)	Cross-sectional, unspecified	IV	100	N	2,3	NH	Walking circuit, number of patients/unit or living room (and staff/patient ratio and hours spent on direct care)	Apathy	NPI-NH	No changes in any of the NPI outcomes. Only apathy occurred less frequently when nurses spent more time on patient care
Milke et al. (2009)	Five single arm, unspecified	III-3	83	N	2	RC	Five homes, based on Woodside Place; differences in physical environment were measured with the TESS-2+	Physical activity, ADL	Activity behavior mapping	The differences in activity patterns were large and enduring. Between the sites, significant differences were found in the activities; ADLs, walking, and work.
McAllister & Silverman (1999)	Two single arm, 93	III-3	67	Y, NH	1,2,3	RC, NH	Visual and calming auditory stimulation, specialized rooms for activities and informal socializing	Physical activity, ADL	Observation	Improved "we-feeling" and ADLs

^a NHMRC (2000).

^b Pluye et al. (2009).

^c 0 = healthy, 1 = mild, 2 = moderate, 3 = severe, and u = unspecified.

^d RC = residential care, AC = assisted living, NH = nursing home, and L-TC = long-term care.

^e Functional independence measure + functional assessment measure.

a small-scale living cluster, the range is often 6-12 residents (Regnier & Denton, 2009; Warren et al., 2001; Schwarz, Chaudhury, & Tofle, 2004). Besides the restricted number of residents per group, the selected studies also reported on a more homelike atmosphere in which residents can personally decorate their private rooms, communal household facilities

and activities, and trained staff who provide resident-centred care. Five studies investigated the effects of small-scale living concepts on ADLs or involvement in other activities (Verbeek et al., 2010; Warren et al., 2001; Schwarz et al., 2004; De Rooij et al., 2012; Smit, de Lange, Willemse, & Pot, 2012).

A longitudinal quasi-experiment (Verbeek et al., 2010) found that residing in an 8-person small-scale living concept did not reduce apathetic behaviour compared to living in the traditional larger wards. However, two studies that reported on the effects of 12-person living concepts revealed more promising results (Warren et al., 2001; Schwarz et al., 2004). A quasi-experimental study compared a 12-person with a 6-person concept. The residents did not differ in functional decline, but were more active in the 12-person setting compared to that of 6 persons. Although the total number of falls was higher in the smaller setting, the number of falls with injuries was higher, but not significantly so, in the larger setting.

A pre-and post-test designed study evaluated the effects of modified facilities on quantitative and qualitative measures of residents' behaviour (Schwarz et al., 2004). Two floors of the facility were divided into three groups of 10-12 residents with a kitchen, dining area and living room. Place-centred behaviour mapping showed improved involvement in group activities, probably due to the easily accessible activity areas. The authors did not describe the programmed activities. The lack of consensus on the ideal number of members of a small-scale living group might be explained by the influences of also the environmental design, staff skills and institutional organization on residents' behaviour.

Two more recent studies selected the small-scale living concept not on the number of residents, but on the group living characteristics as discussed above. A quasi-experiment measured the residents' quality of life (QoL) with 'something to do' as one of the parameters (De Rooij et al., 2012). In this study, a Dutch and a Belgian facility were evaluated, and significant improvements in 'something to do' were found for the Dutch facility. The effects in the Belgian facility were not significant, as was the case for the long-lasting effects for both facilities. More promising results were found in a comprehensive cross-sectional study that included 136 long-term care facilities, accommodating a total of 1327 older persons with dementia, in the Netherlands (Smit et al., 2012). This study showed that residents living in facilities with more characteristics of group living

were more involved in overall and preferred activities. More specifically, the activities that were attended significantly more in the group living facilities were task-related activities, outdoor activities, leisure activities, physical exercise and interaction with others.

3.4.2 Building footprint

Three studies addressed the effects of the spatial layout of nursing homes on the residents' level of physical activity (Milke, Beck, Danes, & Leask, 2009; Zuidema, Jonghe, Verhey, & Koopmans, 2010; McAllister & Silverman, 1999). In these studies, the investigators changed the building footprint according to the architectural model of Woodside Place (DiMotta, Dubey, Høglund, & Luxenberg, 1993), or in a similar manner. Typical of this architectural design are several 12-resident clusters with an open floor plan to invite residents to walk around the entire facility without getting lost. One study that compared this clustered building footprint with a traditional nursing home showed promising results (McAllister & Silverman, 1999). Although they did not mention the Woodside Place building model, the building floor plan that was evaluated in this cross-sectional study was comparable. By observing the residents' activity patterns, they found higher participation in ADLs.

Two studies that compared several of these clustered building footprints reported remarkably contradictory results: whereas one concluded that small differences in designs could have large and long-term effects on residents' behaviour (Milke et al., 2009), the second study observed no effects on residents' behaviour of large differences in floor plans (Zuidema et al., 2010). It is difficult to explain these contradictory results. The first study compared residents' day-long activity patterns in five nursing homes, all built according to the Woodside Place model, but with small differences in specific design characteristics (Milke et al., 2009). The overall physical activity levels were surprisingly high compared to former studies (Ice, 2002; Bates-Jensen et al., 2004), and significant differences across the nursing homes were found in ADLs and walking (Milke et al., 2009). However, the causal relationship between specific design characteristics and the improved physical activity remains unclear.

With a cross-sectional cohort study, the effects of several environmental differences between 56 SCUs were evaluated on the residents' apathetic behaviour (Zuidema et al., 2010). Neither the presence of a walking circuit nor the number of residents correlated with apathy.

4. Conclusions

- ▶ Due to the limited number of studies that scored high on the NHMRC evidence hierarchy (National Health and Medical Research Council, 2000), we also included studies with less rigorous study designs. However, almost all studies scored relatively high on the quality assessment for mixed methods reviews by Pluye et al. (2009).
- ▶ Studies on the effects of timed bright light, and MSE on the levels of physical activity had the most rigorous study designs according to the NHMRC hierarchy (National Health and Medical Research Council, 2000), but the methodological quality differed, from 33% to 100% on the quality assessment of Pluye et al. (2009). The studies of music and small-scale living concepts covered almost all levels of the NHMRC evidence hierarchy, but scored overall high on methodological quality, from 67% to 100%. The two studies with whole-day bright light differed strongly in scientific rigor, i.e. a cross-sectional and RCT study, but both scored well on methodological quality, namely 67% and 100%. Studies that evaluated building footprint, functional modifications and the homelike environment scored in the lowest two levels of the NHMRC evidence hierarchy, whereas all studies scored relatively high on methodological quality, i.e. from 67% to 100%.
- ▶ The number of patients included in the studies varied strongly amongst the environmental elements. The qualitative studies that evaluated functional modifications included rather low numbers of residents ($N_{\text{total}} = 11$). Higher numbers of participants can be found for elements that are evaluated with both quantitative and qualitative studies: building footprint ($N_{\text{total}} = 93$; two studies that did not specify the number of participants), homelike environment ($N_{\text{total}} = 54$),

and music ($N_{\text{total}} = 67$). The highest numbers of participants can be found with the elements that were (predominantly) evaluated quantitatively: timed ($N_{\text{total}} = 310$) and all day bright light ($N_{\text{total}} = 257$), multisensory environment ($N_{\text{total}} = 132$), and small-scale living environments ($N_{\text{total}} = 1684$; one study did not specify the number of participants)

- ▶ As the search strategy shows, we search the databases on more environmental elements than are evaluated in this review. Physical elements of the nursing home environment that we searched but that were not studied (sufficiently) on its effect on physical activity are: colour, sound and noise (other than music), way finding and spatial orientation, visual and tactual stimuli, smell and fragrance, furnishing, outdoor and gardens, decoration and patterns. Future studies to the effects of these elements on the residents' level of physical activity would provide useful knowledge to make the nursing home environment more stimulating.
- ▶ It is remarkable that the known positive effects of timed bright light on, for example, physical activity have not resulted in improved lighting in nursing homes: the illumination levels in today's nursing homes are often low (Lepeleire, Bouwen, Coninck, & Buntinx, 2007). The studies that evaluated the MSE and small-scale living concepts also showed predominantly positive influences on the residents' level of physical activity; we therefore we recommend adapting these concepts to the nursing home environment.
- ▶ We should consider the results for music with caution, as the studies differed strongly in scientific rigor. However, as the results were unanimously positive, including background, or preferably live music in the daily care for residents might be advisable for physical activation.
- ▶ Because of the lack of evidence for the influence of the homelike environment, functional modifications and the building footprint on the residents' level of physical activity, we cannot provide design guidelines for these environmental characteristics.

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Physical activity and the social environment of dementia care - *a qualitative-research journey*

In exploring the environment of residents in nursing homes, the second step is to explore the effect social aspects have on their level of physical activity. The research set-up is a journey, which consists of 6 qualitative studies in nursing home environments, to explore the stimulating and inhibiting factors in the interaction between the residents and their carers. The care professionals who participated in this study appear to be strongly aware of the health benefits physical activity offers. This study identifies nine of the carers' strategies to stimulate residents to attend leisure activities and to actively engage in Activities of Daily Living (ADLs). These strategies vary from gentle (humour and optimism) to stronger approaches (being resolute about what carers expect from residents). However, the social interactions in the dementia care environment that influence residents' activities appeared to be more complex. There is an interplay between the attitudes of both the residents and caretakers. From this study, we derived three attitudes of carers, which gradually stimulate more independence: pro-active caring, supporting, and the wait-and-see attitude. Residents showed four different attitudes as a response to the stimulating strategies of the caretakers; (co)operative, compliant, hesitant, and resistant.

Finally, the social interactions between residents also seem to influence their level of physical activity. The direct interactions between residents are often poor in quality, which may be due from diversity in backgrounds or misunderstandings. However, interaction is necessary to stimulate each other, or to do activities together. From this insight, we concluded that the new product should have a social component that would facilitate social interaction. This component should be as simple as possible and recognizable, as to create a common ground between residents that differ in background, personality and capabilities.

Physical activity in dementia: The influence of the social environment in nursing homes — *a qualitative research journey*

1. Introduction

Physical and social activities in daily life benefit the health and well-being of older persons with dementia (Blondell, Hammersley-Mather, & Veerman, 2014; Heyn, Abreu, & Ottenbacher, 2004). However, they tend to suffer from apathy (Kolanowski, Litaker, & Buettner, 2005), because of their reduced ability to self-initiate activities, which is characteristic for several types of dementia, e.g. frontotemporal dementia and Alzheimer’s disease (Levy & Dubois, 2006). This apathy increases when they move to a nursing home environment. As expected, this passive lifestyle in nursing homes is harmful; apathy negatively influences their physical (Warburton, Nicol, & Bredin, 2006), cognitive (Colcombe & Kramer, 2003) and emotional well-being (Lawton, 2001).

Stimulating physical and social activities seems typically a task of professionals as well as informal caregivers. However, due to time restraints, caregivers are often unable to provide this service sufficiently. As carers also pointed out again and again in this study: “Everybody, even the interns feel the pressure. ‘Self-help’ is a beautiful concept, and we hear it often, but self-help requires time.” [FG-1/13] and “We have eight minutes to wash a resident, three minutes to provide dental care, and two minutes to give medicine. These times are predetermined. But when we get more residents, we just get fewer minutes per task. “Whether we can clean them sufficiently, I don’t know, but we just have to go faster” [FG-3/1] (for an explanation of the codes see Figure 2). As the minutes of care per resident decrease, there is a growing need for initiatives that stimulate activities that do not rely heavily on the caretaking staff. The design and research project ‘Active Cues’ aims to reduce apathy of people with moderate to severe dementia by designing a playful product, which

stimulates physical activity and social interactions within the nursing home context, without relying heavily on the carer’s time.

To achieve this design goal, and to assure that the product fits the context and meets the needs of both, the nursing home residents and their carers, we need a deeper understanding of the current context. Building on the user-product interaction model of Dirken (1997), we propose an interaction model of the nursing home physical and social environment (see Figure 1).

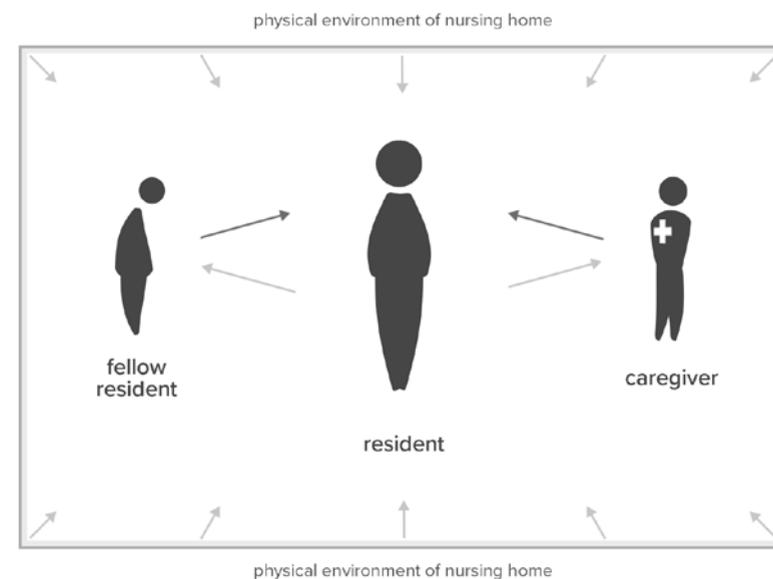


Figure 1: Physical and social interaction model of the nursing home environment

In the current study, we focus on the social environment, to reveal its enabling and inhibiting factors concerning the level of physical activity of the nursing home residents with dementia. By focussing on the social interactions, we do not consider the external factors of, for example, time restraints or the influence of relatives. Nor do we consider personal barriers and motivators, as they have been discussed in earlier studies (Schutzer & Graves, 2004). This study aims to answer the following research question: how do social interactions in nursing homes influence the physical activities of its residents, who are living with dementia?

This inductive field study explored the nursing home environment to identify the social interactions that influence the residents’ physical activities and to gain new insights from the observed data. To obtain

understanding into these social interactions, this study used several qualitative research methods, i.e. contextmapping techniques (Sleeswijk Visser, Stappers, Van der Lugt, & Sanders, 2005), focus groups, interviews, and observation methods (Ralph, Birks, & Chapman, 2014). The study consisted of several studies that emerged from our research question, but also from new insights, curiosities elicited along the way, and from unforeseen challenges. The sequence of these qualitative studies formed our research journey through the nursing home context.

In this chapter, we will first describe the various qualitative research methods that we used and a description of the six sub-studies of our journey. After presenting the results, we will conclude on how social interactions within the nursing home environment can either enable or inhibit physical activity of its residents with dementia. And lastly, we will discuss opportunities for designers, policy makers and carers to improve the stimulating character of the social aspects of the dementia care environment.

2. Methods

With a sequence of qualitative studies, we explored the dementia care context to identify its enabling and inhibiting factors. These consecutive sub-studies emerged during the course of the research (see Figure 2). Also, following an inductive research design, our data collection and analysis became more focused over time. With these studies, we unravelled the social interactions by exploring the environment from different perspectives and in various settings.

Figure 2: Overview of sub-studies

	Sub-study	Interaction	Research method(s)	Nursing home	Code
Consecutive sub-studies ↓	1	Meet the older persons with dementia	• Observations • Unstructured interviews	'Sint Jacob', Amsterdam	STJ-O
	2	Talking about physical activity and ADLs	• Structured interviews	'Sint Jacob', Amsterdam	STJ-CM
	3	Moving to a nursing home	• Structured interviews	'Het Nieuwe Feitenhof', Elburg	PP1-PP3
	4	The caregivers' point of view	• Focus group sessions	'Het Nieuwe Feitenhof', Elburg	FG-1-FG3
	5	Experiencing daily routines in large-scale care	• Observations • Unstructured interviews	'Het Nieuwe Feitenhof', Elburg	WZUV-O
	6	Experience small-scale care	• Observations • Unstructured interviews	'De Dierenriem', Hellevoetsluis	EXP

2.1 Research setting: nursing homes, their residents and carers

To achieve a broad perspective, we subsequently selected several nursing homes during the different studies, to obtain sufficient variation in our sample. The three Dutch nursing homes that participated in our studies differed in scale, environment and location in the Netherlands. They included both small-and large-scale nursing homes, in urban and rural areas, and positioned in the northwest, south and centre of the Netherlands. We included older persons with varying severities of dementia, carers, care managers and support staff to study the nursing home environment in all its aspects.

The first nursing home was 'St. Jacob' in the city centre of Amsterdam. This large-scale care facility has dedicated wards for residents living with dementia. Each ward consists of 18 private rooms, one communal lounge area, and one communal dining area. One of these wards participated in our study and all its residents were in moderate to severe stages of dementia. Also, two residents of a non-specific dementia ward participated, who were in an earlier stage of dementia.

Secondly, we studied the nursing home 'Het Nieuwe Feitenhof' of care group Woonzorg Unie Veluwe, in Elburg, a village centrally located in the Netherlands. The location holds 71 apartments, has two large communal activity and dining areas, and offers specific day care for residents living with dementia. The residents that participated in the study were cognitively healthy or in an early stage of dementia. Additionally, we included 6 older persons, who were on the waiting list of the nursing home, of which one with moderate dementia. In addition, a total of 25 care professionals with different occupations participated in the study.

Lastly, we observed the environment of 'De Dierenriem', which is a small-scale care facility located in the town Hellevoetsluis, in the southern coastal province of the Netherlands. This facility entails six groups in which six older persons live together. The residents have a private room and they share a communal area that both serves as the lounge and dining room. The facility also provides one large activity room for all its 36

residents. All residents are in the moderate to severe stages of dementia. Two groups participated in our studies and several care professionals were consulted for their expertise.

2.2 Data and analysis

The qualitative data was collected using context mapping, interviews, focus group sessions, and observations. The data was analysed using general coding procedures for qualitative research (Corbin & Strauss, 2008) and used to obtain new insights. The data was analysed inductively to gain a deeper understanding of the enabling and inhibiting factors of the social interactions within the nursing homes for its residents with dementia. Through iterative ‘in vivo coding’ and more structured coding (Corbin & Strauss, 2008), we developed our theoretical concepts. Through in vivo coding, we selected quotes from our interviews and snippets from our observation notes, which fuelled our understanding of the perspectives and actions of the carers and residents. Then, through more focused coding, we clustered these initial codings and developed the concepts, which will be illustrated with quotes.

2.3 Qualitative research journey

The following paragraphs describe the goals, research questions, and methods for the six consecutive sub-studies. To illustrate our journey, these paragraphs also discuss the newly gained curiosities and unforeseen challenges that induced the start of the next study.

Sub-study 1: Meeting the older persons with dementia

To become familiar with the nursing home environment, we engaged with its residents via unstructured interviews. To learn about the residents’ daily routines, we observed them in the communal living room and joined several classes, for example, sit-yoga and sit-dancing. We collected the data by writing observation notes. The interviews and observations gave rich insights in the daily lives of the residents and their social interactions, but the unstructured interviews did not seem suitable to steer the conversations to their motivations and barriers for physical activity.

Sub-study 2: Talking about physical activity and ADLs

To focus on the topic of physical activity during more in-depth interviews, we used context-mapping techniques. We used pre-printed posters with time lines and pictures to help the residents focus on the topic of physical activity and ADLs. With only one resident, who was in the early stage of dementia, the materials worked as we intended and we discussed in detail her daily activity routines. However, the other residents, who were in a more advanced stage of dementia, did not understand what to do with the cards, or forgot them while talking. All conversations were valuable to gain insights in the experiential world of the residents in the various stages of dementia. However, it is difficult to determine whether their stories reflect their current daily routines, or whether they are memories from previous phases in their lives.

Sub-study 3: Moving to a nursing home

To learn more about how their daily life routines had changed since moving to a nursing home, we included six older persons who were on the waiting list. Five of them were cognitively healthy, and one lady was in a moderate stage of dementia. We did structured interviews in their homes. Shortly after this study, one lady moved to the nursing home and we did a follow-up interview to discuss the differences in her daily life routine.

Sub-study 4: The carers’ point of view

In the first studies, we focussed on the residents themselves; in the subsequent studies, we focused on the carers’ perspective. We did several focus groups with a total of 25 care professionals, including care managers, kitchen staff, activity therapists, and carers. We used several context-mapping techniques: they made pictures during their working day to sensitize for the topic of physical activity (i.e. all illustrative pictures in this chapter are made by the care professionals). During the focus group sessions, the care professionals mapped their day on a time-line poster (see Picture 1), and answered different questions individually. We discussed their answers in the group and lively discussions revealed detailed and illustrative stories. To complement these verbal accounts of

the carers' daily care routines with the residents, we decided to observe these care routines directly by shadowing carers.



Picture 1. 'My day' timeline with sensitizing pictures of carer

Sub-study 5: Experiencing the nursing home environment

We observed the interaction with the carers from a residents' perspective to become more empathic with living in a nursing home. We also assisted the carers in their daily care routines and we observed residents when the carers were not around. We collected the data by writing observation notes. These experiences of "working" and "living" in a nursing home environment helped us interpret the stories of both the carers and the residents.

Sub-study 6: Daily routines in small-scale dementia care

The first studies gave insights about the time-efficient way of providing care in a large-scale nursing home setting. However, the current trend in dementia care is small groups of residents living together with a homelier approach. We were curious about the differences in providing care in these smaller settings and the influences on the interaction between carers and residents, and between residents. We did several observations and unstructured interviews with residents, carers and family members of the small-scale dementia care environment.

3. Results

From the data, we selected 218 quotes. The quotes were used to gain a deeper understanding of the social interactions and to generate theoretical concepts. The quotes are coded per sub-study: for example, the fifth quote of the third focus group sessions, is coded as [FG-3/5].

3.1 Nine strategies of carers to stimulate residents

The carers shared many strategies to stimulate their residents to attend leisure activities or to do activities of daily living (ADLs) (see Table 1). The first strategy we identified was 'humour and optimism', which was used by many[Sij-o/7][FG-1/23]. According to carers, the residents easily sense their mood[FG-3/45]. During our first sub-study, our own approach was still very careful and polite, whereas a surprising observation was a teacher's humorous way of creating a joyful and light hearted interaction with the residents attending her sit-dancing class[Sij-o/7]. The next strategy was that carers were 'raising awareness' by explaining and emphasizing the health benefits[FG-3/10]. They feel that the residents should be aware of their own responsibility in a healthy and active lifestyle. Moreover, care managers shared their ways to raise awareness in the carers of the importance of stimulating the residents, by for example discussing the topic during staff meetings[FG-3/39] and hanging notes with reminders in the staff rooms[FG-3/46]. The strategy 'stimulating self-efficacy' does not only stimulate the residents to do ADLs, but also strengthens their self-esteem. For example, carers show the residents that they can walk the short distance to the bathroom[FG-1/21], or they emphasize their expertise or experience in a certain activity[FG-1/24]. Moreover, stronger self-esteem may support the resident to be more independent in other activities as well. Some carers 'provided security' by reassuring the residents of their support whenever needed. Two strategies that seem contradictory are providing 'personal attention' and 'not now'; the extra attention in the first should stimulate the residents' positive mind-set and motivation[FG-3/40], whereas in the latter residents are temporarily given back their own responsibility to stimulate independence[FG-1/28].

A more rigorous strategy of stimulating residents is to be ‘resolute and firm’; the carers did not give room for the residents to argue or come up with excuses to refuse ADLs[FG-1/22][FG-1/20]. Although this strategy may sound harsh, according to the carers, it helped the residents to act without having second thoughts. A strategy that was highly appreciated by both the residents and carers is ‘emphasizing the teamwork’ [FG-2/23] [WZUV-O/17]; because it was also meaningful for their relationship. Lastly, a more controversial strategy was to ‘play along’ with the residents’ experiential world to stimulate their former active attitude[FG-2/34][FG-2/16]. Carers debated the ethical issues concerning this strategy, as some of them had the opinion that one should always be honest, also if that means confronting them with the reality of today.

Strategy Definition [Key quote]	Dutch (raw data)	English translation
1. Humour, optimism Stimulating enthusiasm by using humour and optimism. [FG-3/46]	"Als jij al met een mineur gezicht binnenkomt werkt dat natuurlijk alleen maar negatief. Ik zeg ook altijd bij een bewoner, ja, helaas ik ben er weer, we zullen weer in de benen moeten."	"Arriving moody has a negative effect. When I approach one of our residents I always say: Too bad! I am back again, we will have to get going!"
2. Raise awareness Explaining the health benefits of physical activity. [FG-3/10]	"Ze had aambeien. En ze zegt; hoe kan dit nu? Nou, ik zeg een goed voedingspatroon, en meer gaan bewegen, gaan lopen. Oh, en als ik dan ga lopen, gaat het dan over? Nee, dat zeg ik niet, maar meer beweging is wel goed. Nou, ze ging gewoon met me mee lopen."	"She had haemorrhoids. And she asks; how is this possible? I told her to improve her diet and do more physical activity. And if I walk more, will I get rid of them? That is not what I am saying, but physical activity is good for you. Well, she did come with me for a stroll."
3. Stimulating self-efficacy Emphasizing their strengths and capabilities. [FG-1/24]	"Ik zeg: 'U kunt dat goed.' En ze is aan het fröbelen gegaan en aan het eind van die twee bakjes zat ze met een glimlach om haar mond."	"I told her: 'You are so good at that.' And she started to decorate and after finishing two, she was sitting there, smiling proudly."
4. Providing security Securing them of support whenever they need. [PP-1/8]	"Dan komen ze je wassen en aankleden, maar dat kan ik zelf nog. En dat wil ik zelf zo lang mogelijk proberen door te doen. Maar die vrouw die zegt: 'Nou ja, als je niet meer kunt, moet je ogenblikkelijk aan de bel trekken, want dan krijg je hulp.'"	"They come to bath and dress you, but I can still do that myself, and I would like to do that as long as I can. And the lady says: 'If you can't cope anymore, let me know and we will help you.'"
5. Personal attention Providing personal attention. [FG-3/40]	"Als een mens zich heel erg lekker in z'n vel voelt door ons, en leuke activiteiten kan blijven doen, genoeg tijd en aandacht, dan blijven de cliënten ook actiever, dan zien ze alles ook vrolijker en dan zijn ze meer gemotiveerd om zichzelf te wassen en dingen zelf te blijven doen."	"If we give someone a good feeling by fun activities and by giving enough time and attention, they remain more active. They perceive everything with more fun and they are better motivated to bath themselves and do other activities independently."
6. Not now Assisting them only after some time. [FG-1/28]	"'s Ochtends ook wel bij het ontbijt, dat mensen toch verwachten dat jij het even brood smeert, terwijl ze eigenlijk wel zelf kan, maar ze is er gewoon wat langer mee bezig, maar ze kan het wel zelf. Dus ik zet de boel klaar en dan zeg ik: 'Nou, probeer het maar.' En dan ga ik weg, ja en meestal lukt het dan ook wel."	"People often expect that we will prepare their breakfast, whereas they can make their own toast, it will only take a bit longer. So, I put everything on the table and tell them; 'you can try it yourself' and when I leave they most often manage by themselves."
7. Resolute & firm Leaving no room for excuses or refusal by a resolute approach. [FG-1/22]	"Elke dag weer opnieuw bijna. Nu weet ze bij mij dat ze het dus niet voor elkaar krijgt om te blijven, dus ze komt al uit de stoel al 'pfff' zo. Dus nou ja, goed, zuster, nou ik kan hier toch wel blijven, bel de kok maar op. Ik zeg: 'Nee, dat doe ik dus niet', ik zeg: 'U gaat met mij mee.'"	"She tries it almost every day, but she knows that it won't work with me, so she already gets up from her chair 'pfff', OK like this? I can stay here right, you can phone the chef.' I tell her: 'No, I won't do that, you are coming with me.'"
8. Emphasize teamwork Initiating to do the activity together. [WZUV-O/17]	"Tijdens dat de verzorgster haar lichaam wast wast ze zelf haar gezicht, wat wel een gezellige bedrijvige sfeer geeft."	"While the carer is washing her body, she washes her own face, this give a pleasant and lively atmosphere"
9. Play along Play along with their experiential world to support activities that belong to their past.	"Wat moet ik nou met drie jassen? [waren haar eigen jassen] 'Is vast van een ander, maar die komen ze vast wel ophalen. Zullen we ze allemaal ophangen?' 'Ja, we gaan ze allemaal ophangen.'"	"What must I do with three coats? [were her own coats] 'They surely belong to someone else, but they will come and fetch them. Shall we hang them back?' Yes, let's put them all back."

Table 1. Illustrative quotes for the nine strategies of carers to stimulate residents in Dutch (raw data) and English (translated)

3.2 Complexity in the interaction between carers and residents

Although the carers' strategies to stimulate the residents for physical activity seem to describe the enabling characteristics of their interaction, reality is not so simple. We found several theoretical concepts in the interaction between the caregiver and resident that influence the activities of the resident (see Figure 3). In the following section, we unravel the interaction between carers and residents by expounding on these concepts.



Figure 3. Interaction between carer and resident

3.2.1 The carers' attitude

The amount of care that is provided by the carers obviously depends on the resident's physical and cognitive restraints, but seemed also influenced by the attitudes of both the carers [FG-2/4] [FG-2/20] and the residents [FG-1/7] [FG-1/19]. The residents became less independent when the carer provided more care (see Figure 4). We identified three attitudes of carers during the daily care routines: wait-and-see [FG-1/28] [FG-3/43], supportive [FG-2/37] [FG-2/38] [FG-3/40] [FG-1/30], and pro-active caring [FG-2/39] [FG-1/17] [FG-2/20].

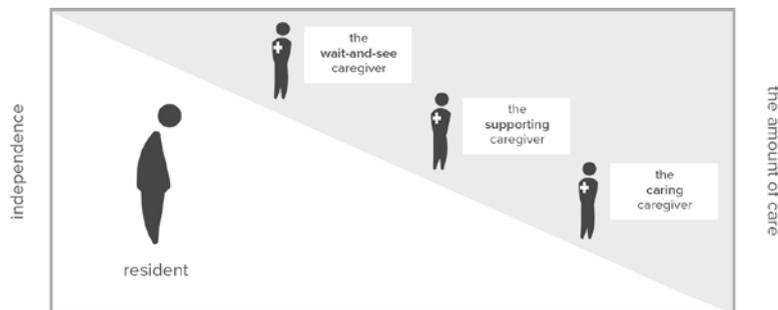


Figure 4. The influence of the carers' attitudes on the residents' independence

Carers that have a wait-and-see approach to the residents take a step back and give the residents the opportunity [FG-2/43] and encouragement [FG-1/28] to do daily activities themselves. The carer may also support the residents by partly taking over the activity; for example, letting the residents wash their own face while bathing them [FG-2/38]. And at last the pro-active caring approach, in which the carers completely take over the task for the residents; for example, the carer brings a prepared meal and cutlery to the resident's room, preferably with the meal pre-cut [FG-2/39] (see also Picture 2). This last attitude seemed to be most striking, as this caring approach was not always necessary due to the limitations of the residents according to the carers. We found several factors, both from the carers' and the residents' perspectives that strengthened this caring attitude. On the account of the carers; they have a natural urge to care which is rewarding to them [FG-2/20] [FG-2/4] [FG-2/20] [FG-2/36], they sometimes provide care out of routine [FG-1/30] [WZUV-O/9], or the lack of patience [FG-1/10] [FG-1/12] [FG-3/17], and some carers are scared for a negative response by the resident [FG-1/18], or worried about the resident's safety [FG-1/25] [FG-2/7] [FG-3/23] [WZUV-O/24].



Picture 2: Different carers' attitudes: (left) carer takes a step back and the resident returns to her room independently (the 'wait-and-see' attitude) and (right) carer takes over the resident's task of cutting bread (the 'pro-active' attitude)

3.2.2 The residents' attitude

The independence of the residents during care routines also depends on their own attitude. For example, residents stimulate a pro-active caring approach by their demanding attitude; residents expect carers to do certain activities for them [FG-1/29] [PP-3/3], and they respond disappointed [FG-1/7] or even agitated [FG-1/19] when the carer refuses. From observations and stories of the carers, we derived four attitudes: (co)operative [WZUV-O/17], compliant [WZUV-O/26], hesitant [FG-2/41], and resistant [FG-1/33].

Some residents bear up bravely, with a cooperative attitude, to engage in activities. We gained insights in two underlying factors; out of old habits[S_{tj}-CM/12] [PP-3/6], or intrinsic motivation[S_{tj}-CM/7] [S_{tj}-CM/8] [S_{tj}-CM/11]. Other residents might be less enthusiastic and intrinsically motivated, but join the carers in the activity without hesitation[WZUV-O/26]. We have seen residents who are grateful for the attention and care they receive, and therefore willing to do what is asked from them[WZUV-O/19]. Residents that are hesitant to engage in activities are more difficult to motivate for the carers[FG-2/41]. And at last, there are residents that resist doing any activities. For example, the lady that compared her energy level with an empty bottle; “you cannot refill mine, my energy is gone”[S_{tj}-O/10].

3.3 Interaction between nursing home residents

Nursing home residents also influence each other’s behaviour and attitude towards physical activity and ADLs. Residents can influence each other both positively and negatively, but the lack of interaction and the unused potential of being active together was a recurring topic. From our studies, we learnt that influences of their interaction could either be from direct and indirect interactions between peers. The direct interaction between the residents is the ‘exchange’ of communication, and the indirect interaction refers to the resulting atmosphere (see Figure 5). Both the exchange and the atmosphere can be stimulating or inhibiting their activities, and the following section expound on both theoretical concepts.

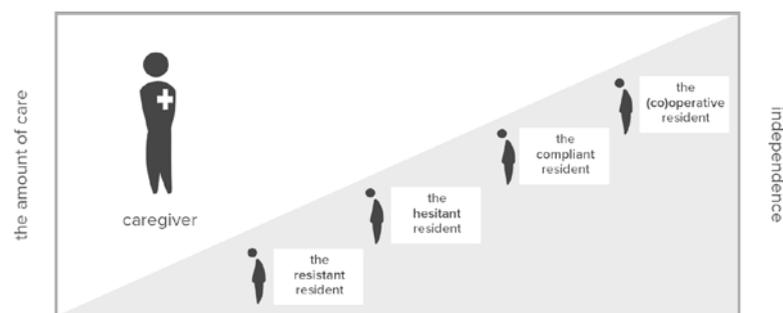


Figure 5. Interaction between residents that influence their activities

Attitude Definition [Key quote]	Dutch (raw data)	English translation
Three carers' attitudes		
1. Wait-and-see Carers take a step back to give the resident space and time to act independently. [FG-1/28]	"Ik zit op de wc, haal je me er even af? Ik zei: 'Nou, ik ben nu even bezig, dan zult u toch even een kwartiertje moeten wachten.' 'Zo lang? Dan doe ik het zelf wel' zegt ze."	"I am in the bathroom, will you come and fetch me? Well, I am busy at the moment, so you will have to wait for 15 minutes.' 'That long?' she says; 'Then I'd rather do it myself.'"
2. Supportive Carers partly take over a task to support the resident to do the remaining themselves. [FG-3/10]	"Ik (zorgmedewerkster) probeer toch altijd de mensen dat ze toch zichzelf in ieder geval het gezicht wassen, met heel de armen of het voorste gedeelte, als dat lukt, dat ze toch wat doen."	"I (carer) always try to make the people wash their own face, their arms; the front of their body. If they succeed, they did do something themselves."
3. Pro-active Caring Carers take over the task completely without room for the residents to act independently. [FG-2/39]	"Je brengt het eten. Misschien zijn we daartoe ook wel heel snel geneigd: je komt met het blad binnen, zet je op tafel, je pakt, trekt de keukenla open, mes, vork, lepel, alstublieft, eet smakelijk."	"You bring the food. Maybe we are too quickly to just: bring the food to their room, you put it on the table in front of the resident, open the drawer, knife, fork, spoon, there you go; enjoy your meal."
Four residents' attitudes		
1. (Co)operative The resident enthusiastically engages in the activity, and joins the carer in doing so. [WZUV-O/17]	"Tijdens dat de verzorgster haar lichaam wast ze zelf haar gezicht, wat wel een gezellige bedrijvige sfeer geeft."	"While the carer is washing her body, she washes her own face, this give a pleasant and lively atmosphere"
2. Compliant The resident is willing to engage in the activity, and joins the carer in doing so. [WZUV-O/26]	"Het is nog niet over hoor'. Ze is vorige week heel slecht geweest, maar ze is aan de betere hand. Ze lacht vriendelijke en heeft een rustige sfeer om zich heen. Je ziet dat alles haar moeite kost, maar ze is niet boos of onrustig."	"I am not feeling better yet'. She had been very frail last week, but she is slowly getting better. She smiles friendly with an easy-going attitude. One can see that everything is a struggle for her, but she isn't angry or agitated."
3. Hesitant The resident only engages in the activity after reinforcement of the carer. [FG-2/41]	"Maar er wordt ook niet iets geprobeerd, terwijl ze met zo'n speciale sta-op stoel iets omhoog kunnen, de afstandsbediening wordt nog niet gepakt."	"They don't even try, even though they have a special chair to support them in getting up. But they don't even reach for the remote control. "
4. Resistant The resident is not willing to do the activity. [FG-1/33]	"Goh, moet je toch eens kijken wat je kunt.' 'Ja, maar dat is helemaal niet nodig.' Ik zeg: 'Nee, maar u kunt nu wel gemakkelijk naar de keuken toe lopen.' Nouja, dan wordt ze echt heel boos op mij."	"Look what you are capable off!', 'Yes, but it is not necessary at all'. So, I tell her: 'no, but you can now easily walk to the kitchen'. Well, she really becomes very angry with me then."

3.3.1 Exchange between residents

The exchange between residents influences their activities in different ways. With ‘exchange’ we consider the ‘direct interaction’ between the residents. Exchange between residents is necessary for mutual support for activities or to do activities together; therefore the ‘lack of exchange’ [S_{tj}-CM/5] is an inhibitor for activities. We identified several reasons for the often poor direct interaction between the residents: reluctance due to differences in wealth[S_{tj}-CM/1], incomprehension for each other’s social behaviour[S_{tj}-CM/2], barriers due to (cognitive) decline of the residents[WZUV-O/16], unwillingness to identify with fellow residents[S_{tj}-O/20], and the fear of the unfamiliarity with their new social

environment[FG-2/28-30]. On the contrary, ‘mutual exchange’[StJ-O/12] potentially facilitates stimulating each other or doing activities together. Although there seem to be more obstacles for the residents to bond with each other, a similar background and shared interests[StJ-O/12] or the same religion[FG-2/19] can evoke a feeling of connectedness. Moreover, residents’ personal character also influences the extend of mutual exchange; there are simply more social and more private people[PP-1/18]. Lastly, activities can also be part of the exchange, by actively caring for one another[FG-2/18][WZUV-O/16]. Some residents have, and maintain, their natural urge to care for other people and they also do this for other residents in their nursing home. However, according to the carers, these caring residents are in the minority[FG-2/18].

3.3.2 The atmosphere created by the residents

A more indirect way of interaction between nursing home residents is via the atmosphere they create. We found three atmospheres that influenced either the stimulating or inhibiting character of their social environment. The ‘individual atmosphere’[StJ-CM/9] can give the residents the freedom to behave in their own way; they feel secure enough to participate in a group where nobody interferes in their activities. Whereas the experience of a ‘joined atmosphere’[FG-3/24] can either be stimulating or inhibiting activities; residents tend to give up their habits when they seem to deviate from the others’. The third atmosphere is defined by the nursing home’s ‘tolerant norms and values’[StJ-O/3], in which the residents are not criticized for subversive behaviours.

4. Conclusions and discussion

This qualitative study aimed to find out how social interactions in nursing homes influence the physical and social activities of its residents with dementia. The social interactions were investigated both from a client-based perspective and from a carer’s point of view. We included different types and locations of nursing homes; people with different severities of dementia, and nursing home staff from various disciplines.

The key finding of this study is that the social interaction in the dementia

Peers' interaction Definition [Key quote]	Dutch (raw data)	English translation
Exchange		
1. Lack of exchange Some residents do not interact with each other for various reasons. [StJ-CM/5]	“Op het moment dat wij (onderzoekers) een ruimte binnenkwamen was er een opleving in de activiteit. Je komt de woonkamer binnen, doodse stilte, maar de bewoners kletsen maar al te graag.”	“That we (researchers) entered the room caused a boost in activity. The moment you enter the room it is dead silent, but apparently, the residents love to talk.”
2. Mutual exchange Residents may bond with each other if they have something in common. [FG-3/10]	“Ze heeft een maatje hier, ook een docent geweest, waarmee zij op gepaste afstand een goede relatie onderhoud: ‘we begrijpen elkaar’. Ze sprak heel warm over deze meneer”	“She has a buddy here, he was also a teacher in his past career. With him, she had a good relationship at an appropriate distance: “we understand each other”. She spoke warmly about the man.”
3. Activity in exchange A few residents care for others. [FG-2/39]	“Er zijn echt van die zorgtypes. We hebben één buurvrouw, die woont hier al redelijk lang en die heeft al een aantal “vriendinnen” gehad waar ze altijd mee naar de koffie ging en waar ze altijd mee naar activiteiten ging en dergelijke. Maar die is geestelijk nog wel redelijk goed. Maar degenen met wie ze dan samen was, die kwamen te overlijden. Dus zij zoekt dan wel weer mensen op die bij haar passen. Maar dat zijn wel uitzonderingen, over het algemeen.”	“There are stereotypical ‘carers’. We have one lady, who has lived here for a considerable time and she has already had several “friends”, with whom she went for coffee or to group activities. She is rather strong still herself, but those friends past away. And then she just finds herself new friends. But these ‘carers’ are in the minority.”
Atmosphere		
1. Individual atmosphere Residents feel the freedom to act independently. [StJ-CM/9]	“Ik voel me daar een beetje thuis in die groep, ik vind het moeilijk om het uit te leggen, euhm, maar ik moet me een beetje veilig voelen, mensen die niet alsmat vragen stellen.”	“I feel quite comfortable in that group. And although I find it hard to explain why, but I must feel safe, with people who don’t ask me questions all the time.”
2. Joined atmosphere Residents feel forced to adjust to the group behaviour, which could either be active or passive. [FG-3/24]	“Ik denk dat het iets te maken heeft met het groepsgebeuren. Van het geheel; nu gaan we allemaal zo doen, niet te veel afwijken. (...) Er zijn hier echt mensen die zijn echt kerkelijk meelevend, altijd geweest, gingen twee keer per dag naar de kerk zondags, en nu niet meer, ze komen in een verzorgingshuis, en hier gaat bijna niemand meer naar de kerk.”	“I think it has to do something with the group’s behaviour. We all do it this way, and let’s not distance ourselves. (...) We have people here that were very much involved with the church their whole lives and went to the church twice every Sunday. The moment they come into the nursing home, they give that up, because almost no one here goes to the church anymore.”
3. Tolerant norms & values The norms and values of the nursing home environment give residents the freedom to be themselves. [StJ-O/3]	“Enerzijds had ik (onderzoeker) een medelijdend gevoel dat hij dat wat indolent onderuit in zijn stoel hing met zijn broek open, anderzijds keek helemaal niemand daarvan op, hier gelden andere regels, hier zijn andere dingen normaal.”	“I (researcher) felt sorry for a man that was sliding back somewhat hopelessly in his chair with his trousers open wide. But nobody seemed to notice, Other rules seem to apply here, there is a different normal.”

care context is a complex interplay of various enablers and inhibitors for its residents’ physical activity. From our studies, we have learnt that carers play an important role in their strategies to stimulate their residents. We identified nine strategies which carers frequently adopt to stimulate residents to attend physical and leisure activities. We also found that the interplay between attitudes of both the residents and carers influences the amount of support versus their independence. Furthermore, our results indicate that the social interaction between residents can be direct and indirect, which both seem to influence its stimulating character.

We identified nine strategies which carers frequently adopt to stimulate

residents to attend leisure activities and actively engage in Activities of Daily Living (ADLs). They often approach their residents with humour and optimism; they raise awareness by explaining the health benefits, or stimulate self-efficacy by emphasizing residents' capabilities. Also, carers provide security by the promise for support whenever residents are in need, and by giving personal attention, the carers stimulate residents' good mood and motivation. Firmer approaches are to take a step back for residents to do the activity independently, or by being resolute about what is expected from them. The last two strategies were either to team up with the resident or to play along in their reminiscence to stimulate their active behaviour from the past.

Several of the strategies we identified in our studies have been mentioned in previous research. One of these strategies was the carers raising the residents' awareness for the health benefits of physical activity. This finding is in line with the results of a systematic review that reported on the importance of support and guidance by caregivers for physical exercises among dementia patients (Van Alphen, Hortobágyi, & Van Heuvelen, 2016). Some of the other strategies seem to be in line with the principles of 'person-centred care', which is a working method in the care of people with dementia that has been widely implemented in long-term care facilities (Kim & Park, 2017), both in the Netherlands and abroad. Person-centred care for people with dementia has been found to be effective in improving residents' quality of life (Kim & Park, 2017). The overlapping strategies are humour and optimism; stimulating self-efficacy by emphasizing the strengths of the residents; and personal attention. Moreover, one of the other strategies we identified in this study was to play along with the experiential world of the residents to support activities that belong to the past. This strategy has also been acknowledged in the Netherlands as part of 'experience-centred care' (in Dutch: "Belevingsgerichte Zorg") in which caregivers focus on how the residents perceive the world (De Lange, 2004). Lastly, we identified a strategy to promote self-efficacy, by assisting the residents only after some time. Although we did not find this strategy to activate residents in the existing literature as such, the importance of self-efficacy from a

client-perspective has been suggested to be one of the 15 most important aspects in elderly care in the Netherlands (CMO Flevoland, 2011).

Our study identified two additional strategies adopted by carers to stimulate residents with dementia. As far as the authors know, these strategies have not yet been described in literature. These strategies include being firm towards the residents; and emphasizing teamwork with the carers to do the activity together. The overview of nine carers' strategies to stimulate nursing home residents with dementia as presented in the current study and the two newly identified strategies potentially enable the nursing staff to provide more activation in today's dementia care.

Another important finding of this study is that the residents influence the effect of the carers' strategies by their attitude. The interplay between attitudes of both the residents and carers influenced the extend of support versus their independence. When carers provided more care, residents seemed to become less independent. We derived three attitudes of carers, which gradually stimulated more independence: proactive caring, supporting, and the wait-and-see attitude. As a response to the stimulating strategies of the caregivers, residents showed and shared four different attitudes: (co)operative, compliant, hesitant, and resistant. Carers shared many underlying factors that influenced these attitudes. The wait-and-see attitude is strengthened by their awareness of the importance of physical activity. The proactive caring attitude can be prompted by several factors: lack of patience, the natural urge to care, out of routine, or fear of a negative response. From the resident perspective on the interaction with carers, we also found several differences in attitude in our studies.

Furthermore, we found that the lack of exchange between residents is an inhibitor for activities. Our results may suggest that stimulating exchange between residents could have a positive effect on their activities. However, exchange between the residents seemed to be hampered by the lack of commonalities in background; differences in lifestyle and social norms; uncertainties that come with a new environment; and the challenges for

interaction due to (cognitive) decline. Exchange between residents could potentially be improved by introducing a physical object or sight. An external stimulus could provide a linkage between people and prompt strangers to start interacting, according to Whyte's (1980) triangulation principle.

In addition, we found indications that the atmosphere that residents create in the nursing home environment can also be either stimulating or inhibiting. The freedom to be yourself should give the residents the confidence to do the activities they want, whereas a more group feeling can either be motivating or inhibiting when residents feel that they must adjust to the norm. Future research is necessary to gain a deeper understanding of the group dynamics between nursing home residents and its effect on their level of physical activity and independence.

This qualitative study aimed to identify the enabling and inhibiting elements for physical activity of nursing home residents with dementia in their social environment. We included different types and locations of nursing homes, people with different severities of dementia, and nursing home staff from most disciplines to study the social dementia care environment in all its complexity, to ensure a broad perspective. In the current study, we analysed the data inductively to gain a deeper understanding of the theoretical concepts. Future research could validate our insights, find missing concepts, and could give weight to these concepts. Future effect studies could contribute to the implementation of the current results into the practice of nursing.

6. Implications for (design)solutions

The complexity in the dementia care environment challenges the understanding of designers and care professionals, but also gives many opportunities for designers, carers and policy makers to improve its stimulating character, as will be elaborated on in the following section.

By exploring this social context from a designer's perspective, we learnt about its enabling and inhibiting influences on the residents' activities.

We distinguished the social interaction between the residents and their carers, and between the residents. In our studies, we transformed these interactions into several underlying theoretical concepts that all seem to influence each other. Design products, or product-service systems, could aim to improve or facilitate one, or more, of these concepts.

- ▶ In the interaction between the carer and the resident: a new product or service could support the carers to share, learn and practice their strategies. The nine strategies of carers to stimulate residents were collected from the stories of many and these could be insightful and inspiring for others to implement into their own care routines.
- ▶ In the interaction between the carer and the resident: The attitudes of both play a role in the stimulating character of their interaction, new products or services could for example aim to strengthen carers that have a more wait-and-see or supporting attitude. Or new products could empower the resident to be able to be more (co) operative or compliant.
- ▶ In the interaction between residents: as it seems difficult for nursing home residents to mingle naturally, new products could help residents to communicate their personality and find other residents with similar interests.
- ▶ In the interaction between residents: the atmosphere that is created by the residents also influences their own activities; a new product, service, or for example architectural design could give enough privacy for the residents to do it their own way.

The social interactions within the dementia care environment foster a wide range of design opportunities to improve its stimulating character. However, designers should be sensitive for this complexity, to design products that fit within this context. Considering the passive lifestyle most of the dementia patients currently have, this study hopefully informs and inspires fellow designers and policy makers to develop more products that motivate nursing home residents with dementia for physical and social activities.

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Play experiences for people with Alzheimer's disease - *a literature review*

The cognitive decline, which is typical for dementia, influences a person's cognitive, behavioural and emotional functioning. One may expect that reduced brain functioning also influences the experience of play. We explored the possibilities to assess which play experiences are still possible to elicit for people in the different stages of dementia. However, this appeared to be difficult due to the differences in the neuropathology between different types of dementia. As Alzheimer's Disease (AD) is the most common subtype of dementia, with 65 to 80 percent of all cases (Alzheimer's Association, 2016), it seemed most relevant to study the experience of play for people with Alzheimer's disease. Moreover, the sequence of brain areas that are affected by the disease is similar for every person with Alzheimer's. On the contrary the neuropathology for people with vascular dementia, the second largest group, is different from person to person. Vascular dementia occurs due to bleeding in the brain or due to strokes. Therefore, the location, size and number of brain injuries depends on the stroke. As a result, the physical and cognitive changes will differ strongly between people with vascular dementia, which makes it very difficult, if not impossible, to assess the suitability of play experiences for people with vascular dementia. Although we focused this literature study on people with Alzheimer's disease, we included nursing home residents with moderate to severe dementia, irrespectively of the type of dementia during the development and evaluation of the product (later in this thesis). This has two reasons; we design a product for the dementia care context and we do not want to exclude any resident beforehand. Also, the type of dementia can only be determined with autopsy for 100% certainty, which makes it impossible to include only people with Alzheimer's disease.

Play experiences for people with Alzheimer's disease - *a literature review*

1. Introduction

The interest of older persons in playing games is shown by various studies from the mid-1970s and 1980s (Whitcomb, 1990). Although the actual number of gamers over 65 years of age is unknown (Ijsselsteijn, Nap, de Kort, & Poels, 2007), the group is growing as our society is aging (Sharkey & Sharkey, 2011). This aging of society also results in a growing segment of older persons with dementia (Qiu, de Ronchi, & Fratiglioni, 2007), most of whom have Alzheimer's disease (AD) (Brunnström, Gustafson, Passant, & Englund, 2009). The body of evidence is growing for the therapeutic value of playing games for older persons (Griffiths, 2005). Playing games can for example slow down the deterioration of, or might even improve, memory, hand-eye coordination, reaction times, and self-esteem (Griffiths, 2005). Also, people with AD often have a sedentary lifestyle (Scherder, Bogen, Eggermont, Hamers, & Swaab, 2010), and we argue that playing games can be an opportunity to stimulate them to more physical and social activity. Unfortunately, knowledge on how to design games that match the capacities of this target group is still in its infancy.

The majority of commercial games involve fast interactions, high tones, and small typography (Whitcomb, 1990), and rarely meet the interests of older gamers (Ijsselsteijn et al., 2007). However, the number of studies concerning game design for elderly people is growing rapidly and, although at a less mature level, also for people with dementia. McCallum and Boletis (2013) reviewed serious games for dementia, and reported mostly positive health effects and successful implementation. However, the majority of studies only included persons with mild cognitive impairment (MCI) and mild AD, whereas no studies reported on people with moderate to severe dementia. Elderly care professionals

To define the foundations for the design project, a literature review is conducted to determine which play experiences can be expected to be suitable for persons in different stages of Alzheimer's disease (AD). Twenty-two play experiences were related to the neuropathology that is characteristic of the different stages of dementia: earliest, mild-to-moderate, and severe. This literature overview is based on neuroimaging, neuropathological, and clinical studies. We found that for all older persons with AD, regardless of disease severity, the play experiences sensation, relaxation, and reminiscence are likely to be suitable. The play experiences *nurture, sympathy, fellowship, expression, humour, eroticism, subversion, and challenge* may be appropriate only for those in the earliest and mild-to-moderate stages of AD. The play experience exploration is most likely not suitable, irrespective of the stage of AD. For the remaining play experiences we did not find sufficient evidence to draw conclusions. We conclude that the choice of play experiences in game design for older persons with AD is dependent on the stage of the disease. Current recommendations may contribute to tailor-made games that are suitable for different persons with AD. Because the target group consists of people with moderate to severe dementia we incorporate the play experiences sensory stimulation, relaxation and reminiscence into the design vision. Also, we gained insights in the importance of avoiding play experiences that are not suitable for this group, such as exploration, because they will not be understood and might cause frustration.

Anderiesen, H., Scherder, E. J. A., Goossens, R. H. M., Visch, V. T., & Eggermont, L. H. P. (2015). Play experiences for people with Alzheimer's disease. *International Journal of Design*, 9(2), 155-165.

acknowledge the potential of serious games in the care of people with dementia, but emphasize the importance of designing them specially for this group (Robert et al., 2014). Bouchard, Imbeault, Bouzouane, and Menelas (2012) addressed the fact that most of the existing games were not suitable for the perceptual and interaction needs of persons with AD, especially in the more advanced stages of the disease, and they presented specific guidelines for designing serious games for people with dementia. Fua, Gupta, Pautler, and Farber (2013) assessed gameplay mechanics, Ijsselsteijn et al. (2007) evaluated digital game interfaces as to their suitability for cognitively impaired older gamers, and Cherniack (2011) and Lewis and Rosie (2012) reviewed literature considering the application of virtual reality in games and rehabilitation for older persons with cognitive disorders. In addition to the existing literature, the present literature overview focuses on the experience of persons with AD when playing games, rather than game design elements, and includes all severities of the disease. Moreover, the play experiences discussed in this paper are not restricted to digital or video games, but also include tabletop games, outdoor games, and serious games. Therefore, we use the term game for all of these subtypes of games.

A person's cognitive, behavioural, and emotional functioning is closely related to the pathology in the brain (neuropathology) that is characteristic of AD (Samanta, Wilson, Santhi, Kumar, & Suresh, 2006), and may also affect the experiences of persons with AD while playing games. Moreover, their ability to experience play may change during the course of the disease. A wide array of play experiences can be found in literature, such as competition, exploration, fellowship, challenge, thrill, and so forth (Korhonen, Montola, & Arrasvuori, 2009). As far as the authors know, there is no literature describing which play experiences may still be experienced by people with AD over the course of the disease (see Figure 1).

In this paper, we address the question of which play experiences can be expected to be suitable for persons in different stages of AD. We used neuroimaging, neuropathological, and clinical studies to review play

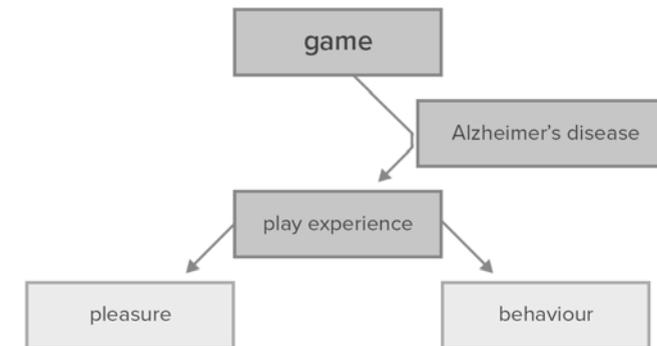


Figure 1. The play experience of games by people with Alzheimer's disease.

experiences of persons with AD. Answering this question is important for several reasons: Firstly, play experiences that rely too much on brain structures that are severely affected by the disease could be experienced by the person with AD to be meaningless and may lead to frustration (Lucero, Kijek, Malone, Santos, & Hendrix, 2000). Secondly, play experiences that are cognitively challenging for the person with AD may be more beneficial from a healthcare perspective than play experiences that are not challenging (Fratiglioni, Paillard-Borg, & Winblad, 2004). Thirdly, play experiences that are cognitively challenging will be most enjoyable (Flores et al., 2008). Finally, appropriate leisure products for persons with AD are scarce, but may enhance their quality of life and may support caregivers in providing good-quality care (Lucero et al., 2000).

We will first provide background knowledge from the game design field, followed by relevant insights from the neuropathology of AD. Subsequently, we will review 22 play experiences, 21 as defined by Korhonen et al. (2009) and an additional one proposed by ourselves, on their appropriateness for older persons in the different stages of AD.

2. Knowledge from both worlds games and play

2.1 Games and play

The historian Johan Huizinga (Huizinga, 1955) influenced thinking about the value of play with his classic definition: “a free activity standing

quite consciously outside ‘ordinary’ life as being ‘not serious’ but at the same time absorbing the player intensely and utterly.” Although we tend to associate the absorbing experience of play with children running around the schoolyard, we play throughout our entire lifespan. Caillois (2001) defined two different forms of play: “*ludus*,” referring to a “game” entailing rule-structured playing and often including competitive behaviour; and “*paidia*,” representing “play” as a more free-form and improvisational playful behaviour. Whether play is more ludus- or more paidia-like depends on the game design, but even more on the player’s behaviour and experience: a ludus-like chess game can be played exploratively and a paidia dance party can be played competitively. Korhonen et al. (2009) systemically collected and defined all *play experiences* between ludus and paidia. Their categorization of 21 playful experiences identifies: captivation, challenge, competition, completion, control, discovery, eroticism, exploration, expression, fantasy, fellowship, humour, nurture, relaxation, sadism, sensation, simulation, subversion, suffering, sympathy, and thrill (see Table 1 for definitions). In addition, we propose a complementary play experience, especially for the older generation: reminiscence. In literature, games for older people often appeal to the sentiment of the past and elicit a reminiscing experience, as for example the game “The Chitchatters” (Van Rijn, van Hoof, & Stappers, 2010). Reminiscence, i.e., the act or process of recollecting past experiences or events (Cotelli, Manenti, & Zanetti, 2012) can be compared to fantasy, but in a different computation of time. To understand which of these experiences can be potentially elicited in people with AD we should take the AD neuropathology into account.

2.2 AD neuropathology

A detailed description of the neuropathology of AD is beyond the scope of this review. At a more global level, the neuropathology of AD includes, among other things, amyloid plaques (accumulation of amyloid, a protein, between neurons), neurofibrillary tangles (twisted masses of protein fibers within neurons), and atrophy (shrinkage of neurons) (Nelson et al., 2011), leading to a marked decrease in neuronal activity (Kern & Behl, 2009). In AD, shrinkage of neurons and lesions of

the pathways connecting different brain areas (i.e., white matter lesions) increase during the disease process (Kester & Scheltens, 2009). Although the speed of the process and the clinical symptoms may vary between persons, the distinct AD neuropathology follows a similar course (Braak & Braak, 1991; Villemagne & Rowe, 2013). In the earliest stage of AD, neuropathology develops in the medial temporal lobe, particularly in the hippocampus (Braak & Braak, 1991; Bastos Leite, Scheltens, & Barkhof, 2004; Ewers et al., 2011). This neuropathology, further developing throughout the mild-to-moderate stage, disrupts important networks connecting the medial temporal lobe and the frontal lobe (Bastos Leite et al., 2004; Scherder, Eggermont, Visscher, Scheltens, & Swaab, 2011), and additional cortical thinning of the temporal and posterior parietal lobes is seen (Ewers et al., 2011). In the most advanced stage, according to both post-mortem research (Braak & Braak, 1991; Swaab, Dubelaar, Scherder, van Someren, & Verwer, 2003) and neuroimaging studies (Ewers et al., 2011), the primary somatosensory cortex shows least AD-related degeneration.

Consequences of Alzheimer’s disease in daily life

Earliest stage: A person has difficulty concentrating, has a decreased memory of recent events, and experiences difficulties in financial management or in travelling alone to new locations. This interferes with daily activities. Socialization may become difficult and the person may therefore start to withdraw from family or friends.

Mild-to-moderate stage: A person in this stage has more profound memory deficiencies. Assistance will be needed to complete daily activities such as dressing oneself. Memory loss may include major relevant aspects of current life, such as confusion about time and location. The person will lack good judgment, will have great difficulty handling problems, and will have few interests.

Advanced stage: A person in the advanced stage of AD requires extensive assistance during daily activities. They cannot take part in community affairs outside the home and close family members may not be recognized. The person may remember only some details of earlier life. Incontinence, personality changes, delusions, repetitive behaviours such as wandering, and agitation may occur.

Based on the Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982) and Clinical Dementia Rating (Morris, 1993).

Textbox 1

3. Merging knowledge from both worlds

In our recommendation as to whether to facilitate certain play experiences in games for persons with AD we used the following requirements: It is appropriate to design for play experiences in games when the brain areas required for these experiences: 1) are still relatively intact; and 2) are slightly affected, but may still be able to respond to an external stimulus. Due to the progressive course of AD, brain areas become more and more affected (Braak & Braak, 1991; Scherder et al., 2011). We included neuroimaging studies (studies that use scanning instruments to interpret damage to and remaining activity of the brain) and neuropathological studies (studies that examine brains post mortem) to review which brain areas relevant for the 22 play experiences are still relatively intact in the different stages of the disease. However, it is difficult to conclude from these studies when there is a change from “experiences being affected” to “an inability to experience.” We therefore also included clinical studies (studies that evaluate those behaviours of persons with AD that reflect certain play experiences, for instance studies that report the presence of a play experience in persons with AD, such as humour). In view of the different neuropathological stages of AD (Braak & Braak, 1991), we divide persons into those at the earliest stage, those at a mild-to-moderate stage, and those at an advanced stage of AD, as has been done previously (Scherder et al., 2011). Of note is that the six neuropathological stages according to Braak and Braak (1991) do not easily overlap with the three clinical stages generally used (see Textbox 1 for a clinical description of the consequences of different AD stages for daily life). Brain areas that are involved in the different play experiences are presented in Table 1.

3.1 Search strategy

Literature searches were performed in the databases MEDLINE, Pubmed, and PsychInfo. With respect to neuropathology in persons with AD we looked for both neuropathological studies (using the following search terms: Alzheimer’s disease, neuropathology, staging, stages, mild, moderate, severe) and neuroimaging studies (using the following search terms: Alzheimer’s disease, magnetic resonance imaging, neuroimaging, brain areas, mild, moderate, severe, temporal, parietal, frontal, occipital).

Play Experience	Definition (Korhonen et al., 2009)	Involved brain area(s)
Relaxation	Experience of unwinding, relaxation or stress relief. Calmness during play	Primary somatosensory cortex (Kastrup et al., 2008)
Sensation	Meaningful sensory experience	Primary somatosensory cortex (Kastrup et al., 2008)
Reminiscence	Recollecting past experiences or events (Cotelli et al., 2012)	Widely distributed (Detour, Danion, Gounot, Marrer, & Foucher, 2011; Watanabe et al., 2012)
Nurture	Experience of nurturing, grooming, or caretaking	Orbitofrontal cortex, striatum (Rilling, 2013; Roelofs, Minelli, Mars, van Peer, & Toni, 2009)
Simulation	Experience of perceiving a representation of everyday life	Various brain areas (Szpunar, Jacques, Robbins, Wig, & Schacter, 2013)
Captivation	Experience of forgetting one’s surroundings	Orbitofrontal cortex, striatum (Rosenberg, Dick, O’Hearn, & Sweeney, 1997; Viskontas, Possin, & Miller, 2007)
Eroticism	Experience of sexual pleasure or arousal	Orbitofrontal cortex, dorsolateral prefrontal cortex, amygdala (Henderson et al., 2012; Kagerer et al., 2011; Kühn & Gallinat, 2011)
Expression	Experience of creating something or expressing oneself in a creative fashion	Right prefrontal, posterior temporal, and parietal cortices (Palmiero, Di Giacomo, & Passafiume, 2012)
Fellowship	Experience of friendship, fellowship, communality or intimacy	Orbitofrontal cortex (Roelofs et al., 2009)
Humour	Fun, joy, amusement, jokes, gags (Lucero & Arrasvuori, 2010)	Nucleus accumbens, caudate, putamen (Franklin & Adams, 2011; Mobbs, Greicius, Abdel-Azim, Menon, & Reiss, 2003)
Challenge	Experience of having to develop and exercise skills in a challenging situation	Dorsolateral prefrontal cortex, anterior cingulate cortex (Declerck, Boone, & De Brabander, 2006)
Competition	Experience of victory-oriented competition against oneself, opponent or system	Inferior parietal and medial prefrontal cortices (Decety, Jackson, Sommerville, Chaminade, & Meltzoff, 2004)
Subversion	Experience of breaking social roles, rules, and norms	Orbitofrontal cortex (Baumgartner, Götte, Gügler, & Fehr, 2012; Morey et al., 2012; Zaki, Schirmer, & Mitchell, 2011)
Sympathy	Experience of sharing emotional feelings	Orbitofrontal cortex (Roelofs et al., 2009)
Completion	Experience of completion, finishing and closure, in relation to an earlier task or tension	Prefrontal and parietal areas (Kayser, Buchsbaum, Erickson, & D’Esposito, 2010)
Control	Experience of power, mastery, control, or virtuosity	Temporoparietal, frontal and cingulate cortices (Falkenberg, Specht, & Westerhausen, 2011)
Discovery	Experience of discovering a new solution, place, or property	Dorsolateral prefrontal cortex (Farias et al., 2013)
Exploration	Experience of exploring or investigating a world, affordance, puzzle, or situation	Hippocampus (Johnson, Varberg, Benhardus, Maahs, & Schrater, 2012), prefrontal brain areas (Declerck et al., 2006)
Fantasy	Experience of make-believe involving fantastical narratives, worlds, or characters	Frontal and temporal areas (Mason et al., 2007)
Sadism	Experience of destruction and exerting power over others	Frontotemporal brain areas including the amygdala (Harenski, Thornton, Harenski, Decety, & Kiehl, 2012)
Suffering	Experience of frustration, anger, boredom and disappointment typical to playing	Anterior insula, amygdala (Abler, Walter, & Erk, 2005; Mohr, Biele, & Heekeren, 2010; Reuter, Weber, Fiebach, Elger, & Montag, 2009)
Thrill	Experience of thrill derived from an actual or perceived danger or risk	Orbitofrontal cortex, anterior cingulate cortex (Joseph, Liu, Jiang, Lynam, & Kelly, 2009)

Table 1: Play experiences as defined by Korhonen et al. (2009) and involved brain areas

With respect to studies investigating different play experiences and specific brain areas we searched for the 22 play experiences separately combining each specific experience with the search terms: magnetic resonance imaging, neuroimaging, brain areas, temporal, parietal, frontal, occipital. Finally, for the clinical studies we searched for the 22 play experiences

separately in combination with the term: Alzheimer's disease. We will first discuss our recommendations regarding the play experiences based on neuropathology and clinical studies and then our recommendations for the play experiences based on clinical studies alone.

3.2 Appropriate play experiences for persons with AD based on neuropathology and clinical studies

A detailed description of our findings is presented below and a graphical presentation is given in Figure 3 in the discussion section. All brain areas that are involved in play experiences are to some degree affected in the earliest stage of AD, except for the primary somatosensory cortex (Scherder et al., 2011; Braak & Braak, 1991; De Jong et al., 2011; Gili et al., 2011; Madsen et al., 2010; McEvoy et al., 2009; Rabinovici et al., 2007; Tondelli et al., 2012). Some areas required for play experiences, i.e., the hippocampus (Apostolova et al., 2012; Braak & Braak, 1991) and the amygdala (Roh et al., 2011; Vasconcelos et al., 2011), are affected earlier in the disease process than other areas, such as the striatum (Scherder et al., 2011; Ginsberg et al., 2010) and anterior cingulate cortex (McDonald et al., 2009; Richards et al., 2009). For an overview of these brain areas affected by AD neuropathology see Figure 2.

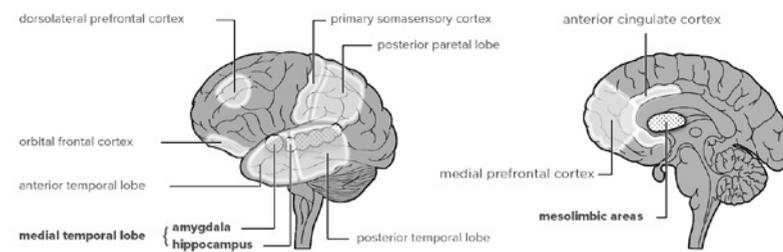


Figure 2. Relevant brain areas affected in Alzheimer's disease. Graphics are based on the artwork of Patrick J. Lynch and C. Carl Jaffe (Lynch, 2006), under Creative Commons Attribution 2.5 License

Exploration

Active exploration of the environment is a process in which the hippocampus plays a pivotal role (Johnson, Varberg, Benhardus, Maahs, & Schrater, 2012), and this is an area affected already very early in AD (Apostolova et al., 2012). Exploration also requires executive functions (Collins & Koechlin, 2012) mediated in part by prefrontal brain areas

(Declerck, Boone, & De Brabander, 2006), areas that are vulnerable in AD (Rabinovici et al., 2007). Clinical studies show that the ability to take initiative is reduced in persons with AD, which is reflected in higher levels of apathy (Esposito et al., 2010; Ready, Ott, Grace, & Cahn-Weiner, 2003). We therefore recommend that game designers should not include exploratory elements appealing solely to a player's own initiative in games for all persons with AD.

Relaxation

Sensory stimulation can lead to a state of relaxation (Poza, Gómez, Gutiérrez, Mendoza, & Hornero, 2013). Clinical studies in persons with AD generally investigate the association between sensory stimulation and measures that promote reduced agitation, rather than investigating measures that induce a feeling of relaxation. In order to reduce agitation, several sensory stimulating activities have been suggested, including massage and multisensory stimulation (Rowe & Alfred, 1999; Staal, 2012). Relaxation by sensory stimulation is therefore a recommended strategy for nonpharmacological interventions in persons with AD (Ward-Smith, Llanque, & Curran, 2009). We therefore strongly encourage inclusion of elements of sensation and relaxation in games for all people with AD, including those in an advanced stage of dementia.

Reminiscence

It is generally assumed that during reminiscence, patterns of brain activity resembling the areas that were activated during the corresponding experience are reactivated (McNaughton, 1998). Reminiscence therapy in dementia is based on the assumption that remote memory remains intact until more advanced stages of the disease (Cotelli et al., 2012). Brain areas involved in remote memory include both the posterior and anterior temporal lobes and the prefrontal lobe areas (Detour et al., 2011; Watanabe et al., 2012). In view of the widely distributed storage of elements of remote memory, people with AD appear to have relatively intact remote memory (Bayley et al., 2005).

Although remote memory deficits are present in persons with mild to moderate AD (Dorrego et al., 1999; Meeter et al., 2006) remote memory indeed seems more intact than more recently stored memories, even in those with AD in an advanced stage (Sartori et al., 2004). Reminiscence as a therapy is often applied to nursing home residents with dementia (Cotelli et al., 2012). We recommend including elements of reminiscence with a personal content in the design of games for persons with AD, regardless of the stage of severity.

Sensation

The primary somatosensory cortex, the area remaining spared the longest from AD neuropathology (Braak & Braak, 1991; Jacobs et al., 2011), mediates an important play experience: sensation (Blatow et al., 2007; Kastrup et al., 2008). Clinical studies show that sensory systems appear to be relatively intact in persons with AD (Başar et al., 2010). Sensory stimulation is therefore a widely recommended strategy for non-pharmacological interventions in persons with AD (Swaab et al., 2003; Briones, 2006).

3.3 Appropriate play experiences for persons with AD based on clinical studies alone

Challenge

A task can be considered challenging when it is uncertain whether a person believes him- or herself to have sufficient ability and capacity to accomplish the task, which in turn depends on self-efficacy (Tsang, Hui, & Law, 2012). Although there are plenty of studies examining self-efficacy in caregivers of people with AD (Gallagher et al., 2011; Semiatin & O'Connor, 2012), hardly any studies focus on persons with AD themselves. As far as we know, there are no studies really describing self-efficacy measures in persons with AD, but reduced levels of self-awareness of their own memory deficits have been reported (Mimura, 2008). Elements of challenge to stimulate self-efficacy are recommended in games for persons in the earliest and mild-to-moderate stages of AD.

Eroticism

We did not find any clinical studies that examined experiences of eroticism in persons with AD, but sexual intimacy and interactions are still reported in persons with AD in a mild-to-moderate stage of the disease (Davies, Sridhar, Newkirk, Beaudreau, & O'Hara, 2012; Harris, Adams, Zubatsky, & White, 2011). Game designers can therefore consider incorporating erotic elements into games for persons in the earliest and mild-to-moderate stages of AD.

Expression

There is anecdotal evidence of clinical studies reporting expression and creativity in people with mild to moderate AD (Cummings, Miller, Christensen, & Cherry, 2008). More specifically, although persons with AD may be unable to copy images correctly or make realistic drawings, they may still be able to produce art by using colour or composition (Cummings et al., 2008). In addition, in view of communication problems often present in persons with AD (Müller & Guendouzi, 2005), a creative game may offer the possibility of expressing burdensome feelings (Przybylski, Weinstein, Murayama, Lynch, & Ryan, 2012). We recommend games that appeal to the players to express themselves for persons in the earliest and mild-to-moderate stages of AD.

Fantasy

No studies looked at the ability to fantasize in persons with AD. People with mild to moderate AD, however, are often confused about their own orientation in time and place (De Vriendt, Gorus, Bautmans, & Mets, 2012). It is therefore unclear whether the use of elements of fantasy should be recommended for persons with AD, regardless of disease stage.

Humour

There is anecdotal evidence that people with AD in a mild-to-moderate stage of the disease still have a sense of humour (Hawkins & Graff-Radford, 2007), and humour can actually help them to cope with the disease (Macrae, 2008). We therefore recommend humoristic games for persons in the earliest stage of AD, and with mild to moderate AD.

Nurturing, fellowship, and sympathy

Clinical studies reveal that persons with mild to moderate AD show responsiveness towards pets (Cohen-Mansfield, Marx, Thein, & Dakheel-Ali, 2010). Also, studies report friendship (Spector & Orrell, 2006) and emotional intimacy between people with mild to moderate AD (Davies et al., 2012; Harris et al., 2011). Anecdotal evidence reports that persons with mild to moderate AD can still show emotional responsiveness (Cohen-Mansfield et al., 2010). Based on these findings, we recommend games that evoke the experiences of nurture, fellowship, and sympathy for persons in the earliest and mild-to-moderate stages of AD.

Simulation

Creating a simulation of everyday life has been applied to persons with AD in the earliest and mild-to-moderate stages and was well appreciated (Hofmann et al., 2003; Pengas et al., 2012). We therefore recommend including elements of simulation for persons in the earliest and mild-to-moderate stages of AD.

Subversion

If one has knowledge concerning social norms, one might be tempted to undermine them. Persons with AD in the earliest stage have been reported to still be as capable of making decisions involving basic social norms and preferences as their age-matched counterparts (Bosch-Domènech, Nagel, & Sánchez-Andrés, 2010). We recommend games that suggest the subversion of norms for persons in the earliest stage of AD.

Suffering and sadism

No clinical studies have been performed examining the experience of suffering or sadism in people with AD. However, due to the higher levels of anxiety (Wadsworth et al., 2012), suffering and sadism may not be suitable experiences in games for this group. Moreover, people with AD are at risk of being unable to grasp the distinction between play and real-life experience, due to their confusion about orientation in time and place (De Vriendt et al., 2012), which may cause negative or even traumatic experiences. We are therefore reluctant to recommend including elements

of suffering and sadism in games for people with AD.

Thrill

No clinical studies have been performed examining thrill seeking or sensitivity to risk in people with AD. However, in general, people with AD do reveal higher levels of anxiety (Wadsworth et al., 2012). This may indirectly imply that people with AD may be less inclined to take risks. We are therefore somewhat reluctant to recommend including elements of thrill seeking in games for people with AD.

Remaining play experiences

No clinical studies were found examining the presence of the following experiences in persons with AD: captivation, competition, completion, control, and discovery.

4. Discussion

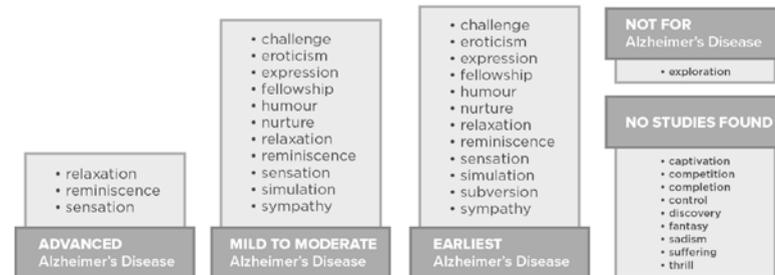
The neuropathology of AD influences a person's capacity for and experience of playing games. To design suitable games for persons with AD, designers should know the stage of the disease and the related neuropathology, and choose the appropriate play experiences (see Figure 3). Suitable play experiences for older persons in the most advanced stage of AD are: relaxation, reminiscence, and sensation. Those with mild to moderate AD may also experience challenge, eroticism, expression, fellowship, humour, nurture, simulation, and sympathy. And those in the earliest stage of AD may also experience subversion. The play experience exploration is most likely not suitable for any older person suffering from AD. For the remaining play experiences we did not find enough evidence to draw conclusions. For design guidelines concerning play experiences for people with AD, see Textbox 2.

The results of this review support the design of games that specifically target older persons in different stages of AD. An interesting existing example is the MINWii game (Benveniste, Jouvelot, & Péquignot, 2012), which is in accordance with the conclusions of our review. The MINWii game was specifically designed for—and tested with—older persons with AD and



was evaluated by seven hospitalized people, all in the mild-to-moderate stage of AD (Benveniste et al., 2012). The MINWii study reported the subjects' play behaviour while playing two different modes of the game: (1) the Improvisation Mode, based on exploration, and (2) the Challenge Mode, based on challenge and reminiscence. The disappointing findings for the Improvisation Mode are not surprising, as "exploration" relies on brain structures that are already affected in an early stage of the disease: "None of them were willing to explore the system in depth on their own, let alone improvise . . . and never even tried to click random notes" (Benveniste et al., 2012, p. 8). However, challenging the patients to copy songs of the past with the Challenge Mode was more successful: "They clearly were more comfortable following the highlighted notes than trying to create something on their own. . . patients would now clap, sing and start reminiscing more and more often" (p. 8).

Figure 3. Play experiences for people with AD.



It is difficult to match the affected neuronal circuits that are responsible for eliciting play experiences to the different stages of the disease, due to the complex neuropathology of AD. However, this review represents a step in understanding the consequences of the disease for the design of games that match the cognitive abilities of people with AD. Future experimental studies, examining the play experience of people with AD in a game context, would strengthen the current theoretical knowledge from neuroimaging and neuropathology studies with more practical insights for game designers (and other designers) targeting people with dementia.

The present literature review provides game developers with evidence-based insights to design games that are suitable for persons in different stages of AD. We advise game developers to define their target group according to the level of AD because the experience of playing varies widely along the course of the disease. As we have shown in our paper, a broad variety of play experiences can potentially be successfully elicited in persons with AD. In addition, stimulating affected brain areas possibly slows down the neuropathology in that particular area according to the "use it or lose it" principle (Swaab et al., 2003). We strongly encourage game developers to design games for persons with AD that contribute to a meaningful and fun way of spending their time. To design games that match the players' cognitive abilities, but are also challenging and stimulating, could best be achieved through collaboration between game developers and AD specialists.

Guidelines for the experience of play with Alzheimer's Disease (AD)

- ▶ The severity of AD should be taken into account while designing games for people with AD, because the experience of play varies widely over the course of the disease.
- ▶ The play experience exploration is most likely not suitable for persons with AD, because the responsible brain areas are already affected in the earliest stages of AD.
- ▶ Games for people with early AD may facilitate the play experiences challenge, eroticism, expression, fellowship, humour, nurture, relaxation, reminiscence, sensation, simulation, subversion, and sympathy.
- ▶ Games for people with mild to moderate AD may facilitate the play experiences challenge, eroticism, expression, fellowship, humour, nurture, relaxation, reminiscence, sensation, simulation, and sympathy.
- ▶ Games for persons with advanced AD may facilitate the play experiences relaxation, reminiscence, and sensation.
- ▶ The play experience sensory stimulation is suitable for all severities of AD and therefore suitable to be incorporated into all games for people with AD.

Textbox 2

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Co-designing games with moderate to severe dementia – *a case study*

This chapter presents the design process of the Tovertafel. The three preceding studies (Chapters 2-4), which explored the environment and the appropriateness of play experiences, were the starting point for the design project. Through several design iterations the final concept of the Tovertafel and its interaction principles were developed. With a 'Wizard of Oz' prototype we tested the initial design vision. The prototype served as a tool to initiate a user test with the residents and their carers. Contrary to what was initially expected, the nursing home residents with moderate to severe dementia did take up a participatory role during the Active Cues design process. Due to the more co-design approach that we chose during the design project, we collaboratively changed the initial design vision; from stimulating ADLs to stimulate play.

Designers, residents, their relatives and caretakers collaboratively developed six games for the Tovertafel that stimulate physical activity and social interaction. The participation of people with moderate to severe dementia and their immediate environment during our creative process was successful. It requires a realistic prototype with room for experimentation. From the designers, it requires sensitivity to the families' strenuous situation, empathy and thorough communication skills to build a trustful relationship, and an open mind to new ideas and insights.

Co-designing games with people with moderate to severe dementia

— a case study

1 Introduction

Co-design methods involve the end users in the design process so that they inform and inspire the designers (Sanders & Stappers, 2008). These collaborative design methods require both, from the designers and end-users, reflection, imagination (Dawe, 2007), and creativity (Sanders & Stappers, 2008). For people with a cognitive impairment these cognitive processes are challenging and therefore participation in a design development process is difficult (Dawe, 2007; Muller, 2002). Also, the cognitive processes that are required to express creativity (Müller & Guendouzi, 2005) are too challenging for most people with dementia and confronting them to do so may evoke burdensome feelings (Przybylski, Weinstein, Murayama, Lynch, & Ryan, 2012).

However, including future users into the design process is important to take into account the experiential consequences of a new product, especially the ones with very different life experiences compared to the designers themselves (Lindsay et al., 2012). Therefore, the research interest in the involvement of ‘hard-to-reach target groups’ into design processes is growing. For example, several studies included children with autism during design processes (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012; Frauenberger, Good, & Keay-Bright, 2011; Van Rijn, 2012). Also, people with dementia have been included in studies that developed and refined specific co-design methods (Branco, Quental, & Ribeiro, 2015; Hendriks, Truyen, & Duval, 2013; Lindsay et al., 2012; Mayer & Zach, 2013; Rodgers, 2017; Van Rijn, van Hoof, & Stappers, 2010). However, to the best of our knowledge does the existing research either include people in the early to moderate stages of dementia or the severity of dementia is not specified in the publications, which is in accordance with earlier results of Span, Hettinga, Vernooij-Dassen,

Eefsting, and Smits (2013). With this study we want to contribute to this growing body of knowledge to share insights of a co-design process with people with moderate to severe dementia.

Dementia is responsible for a degeneration of the brain and evolves over time. Although the progression of the degeneration may differ between people, they all go through the different stages of dementia. With our design project, we targeted people in the three most advanced stages, i.e. 5-7, of dementia, according to the Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon, & Crook, 1982), who are residing in the nursing home environment. People with moderately severe cognitive decline, in stage five, cannot live without assistance, cannot recall major events of their current live, are confused about time and place and experience difficulties in recognizing close family members. People with severe cognitive decline, in stage six, are entirely dependent on their spouse, of whom they often forget the name, are unaware of recent events, and only have a sketchy recollection of major past experiences, are unaware of their surroundings, year or season, may become incontinent and need assistance in many activities of daily living, as for example travelling, but some may still be able to travel to familiar places. In the last stage, seven, people have a very severe cognitive decline and lose the ability to speak, walk and eat and become incontinent (Reisberg et al., 1982).

The research in this study is carried out to design a playful product that stimulates people with moderate to severe dementia to reduce apathy. We initially chose a user-centred design approach by doing several preceding studies to our future users and testing our preliminary design concepts with them in an early stage of the project. However, testing our design concepts did not only change our design concept, but also changed our approach from designing for our future users to designing with our future users. In this chapter we describe how we discovered the abilities of people with advanced dementia to participate creatively during a design process, using co-design methods.

The aim of this paper is to inform designers and design researchers on what we have learnt from a co-design process including people with moderate to severe dementia. We gained insights on various levels and will reflect on the co-design tools that were used, the role of designers that were involved, and on the design insights that were gained into designing a product that activates this group prone to apathy. In this paper, we aim to answer the research question: “How can co-design contribute to the development of a stimulating product for people with moderate to severe dementia?”

2. User centred design approach

We worked with the principles of user centred design as defined by ‘The International Usability Standard’ (ISO DIS 13407): “(1) the design is based upon an explicit understanding of users, tasks and environments, (2) users are involved throughout design and development, (3) the design is driven and refined by user-centred evaluation, (4) the process is iterative, (5) the design addresses the whole user experience, and (6) the design team includes multidisciplinary skills and perspectives.”

3 . The initial design direction

In three preceding studies we researched the older persons with moderate to severe dementia, their carers and relatives in the physical and social context of the nursing home environment prior to the design process. The newly gained knowledge inspired and informed the initial design direction:

The new product for the nursing home environment will stimulate people with moderate to severe dementia to engage in activities of daily living (ADLs) to reduce apathy. The interaction with the product will elicit the playful experiences of sensory stimulation and reminiscence to intrinsically motivate the older persons to change their behaviour. The product will initiate the start of the activity by providing unobtrusive triggers that are sensory based. Also, the product will support the older persons to prolong their engagement with the activity by providing additional triggers whenever their attention drifts away from the task. Finally, the product will stimulate activities that are familiar and

meaningful to people with dementia, to strengthen their self-efficacy and hopefully reduce their confusion about time and place.

3.1 Foundations for the design direction

This section describes the foundations for our initial design direction and consists of both existing literature and newly gained knowledge concerning games, motivation and behavioural change, the experience of people with Alzheimer’s disease (AD) while playing games, and the stimulating effects of the current physical and social environment within nursing homes.

3.1.1 Designing for behavioural change

The designer can try to intentionally change the users’ behaviour or attitude by the design of persuasive technologies (Fogg, 2002). The Fogg Behaviour Model (FBM) (Fogg, 2009), has three principal factors to understand human behaviour: motivation, ability (simplicity) and triggers. We applied the FBM principles as follows: the motivation for physical activity of people with dementia can be expected to be low, because they lack the ability to self-initiate actions (Esposito et al., 2010; Levy & Dubois, 2005; Ready, Ott, Grace, & Cahn-Weiner, 2003). To motivate the people with dementia, we aim to design pleasant and fun interactions, which Fogg (2009) regards as core motivators. Secondly, ability (simplicity) should be considered with caution for people with dementia, considering their age-related deficiencies, for example reduced mobility (Pahor et al., 2014) and reduced eyesight and hearing (Freedman, Martin, & Schoeni, 2002). Therefore, we also aim to simplify the interactions by ensuring a low demand on physical and cognitive effort. Lastly, the character and the timing of the trigger are important to stimulate the intended behaviour. For people with dementia, it is important to give multiple motivating triggers because of their diminished short-term memory and short attention spans (Reisberg et al., 1982). We investigated which play experiences are suitable for people with moderate to severe dementia (see the next section 3.1.2).

3.1.2 Alzheimer's disease and the experience of play

The experience of gamers while playing is referred to as 'play experiences' (Korhonen, Montola, & Arrasvuori, 2009), for example exploration, challenge, fellowship and sensation. We reviewed all twenty-two play experiences on its suitability for people in the different stages of Alzheimer's disease (AD) (Anderiesen, Scherder, Goossens, Visch, & Eggermont, 2015), the most common subtype of dementia (Brunnström, Gustafson, Passant, & Englund, 2009). AD influences a person's cognitive, behavioural and emotional functioning (Samanta, Wilson, Santhi, Sampath Kumar, & Suresh, 2006). Consequently, this may affect the experiences of persons with AD while playing games. Due to the degenerative character of the disease, the number of play experiences that can be successfully elicited most likely decreases as the disease progresses. The play experiences that are most suitable for the target group of the Active Cues project – namely people in the moderate to severe stage – are sensation (Başar, Güntekin, Tülay, & Yener, 2010), relaxation (Ward-Smith, Llanque, & Curran, 2009), and reminiscence (Cotelli, Manenti, & Zanetti, 2012). Sensation is defined as meaningful sensory experience (Korhonen et al., 2009); relaxation is the experience of unwinding, stress relief, and calmness during play (Korhonen et al., 2009); reminiscence is the act or process of recollecting past experiences or events (Cotelli et al., 2012). We therefore included sensation and reminiscence into our concept design.

3.1.3 Physical environment of people with dementia

Insights into the stimulating character of the current nursing home environment are important if one is to design a product that is contributory. We have systematically reviewed the studies into the relation between the physical environment and the level of physical activity of its residents with dementia (Anderiesen, Scherder, Goossens, & Sonneveld, 2014). The multi-sensory environment (MSE), which in the Netherlands is also known as 'Snoezelen', showed predominantly positive effects on the level of physical activity of people with dementia (Baker et al., 2001; Milev et al., 2008; Van Weert, van Dulmen, Spreuwenberg, Ribbe, & Bensing, 2005). However, the residents' exposure to the MSE is limited

to the hours of treatment, whereas adapting multi-sensory elements into the communal areas could stimulate its residents throughout the day (Anderiesen et al., 2014).

3.1.4 Social environment of people with dementia

We entailed a qualitative exploration into the stimulating and inhibiting factors in the social interaction between carers and nursing home residents (to be submitted). We interviewed and observed residents and dementia-care professionals attended our focus group sessions. The care professionals emphasized the health benefits of physical activity and shared their strategies to stimulate their residents to attend leisure activities and to engage in Activities of Daily Living (ADLs). However, the social interactions between carers and residents showed more complexity by interplay of their attitudes. Some carers have a more 'pro-active' attitude, whereas others have a more 'wait-and-see' attitude towards the residents. On the residents' behalfs, their attitudes vary from resistant to more (co)operative. Also, peers influence each other's activities, and their social interaction in itself would prevent them from apathy. Sadly, social interaction between residents appeared to be often poor for various reasons: the lack of commonalities in background, differences in lifestyle and social norms, but also the residents' uncertainties that come with a new environment, and the challenges for interaction due to their (cognitive) decline. Interestingly, certain factors appeared to be stimulating for the one resident and inhibiting for the other. For example: an invitation for a group activity could be either experienced as motivating to join, or experienced as pressurizing and elicited a more resistant reaction. For these reasons, we found the freedom of choice to join the activities important in our concept design and we aimed to stimulate activities in the communal areas of nursing homes to facilitate social interaction between its residents.

3.2 Concept design: Active Cues

The Active Cues concept is a playful product that stimulates older persons with moderate to severe dementia to start- and continue the act of drinking coffee. Interactive light projections, on the existing dining table

in the nursing home environment, nudge the residents to take sips of their cup of coffee. The concept registers whether the residents are actively drinking or whether they became passive. Whenever their attention drifts away, Active Cues gives a light cue to remind them. The light projections attract their attention and guides it back to the activity. The projections are unobtrusive to prevent the residents for overstimulation and ideally the product provides the residents with support without them noticing to strengthen their self-efficacy.

3.3 Field testing the Active Cues concept

3.3.1 Prototyping the Active Cues concept

The prototype consisted of a 2800-lumen BenQ MX618ST DLP Projector that was mounted from the ceiling and beamed light projections on the table (see Figure 1). With an Acer Aspire V3 laptop we controlled the light projections on the existing dining table of the nursing home.

For the first two field tests we developed a so-called ‘Wizard of Oz prototype’ to test our initial design ideas, i.e. the prototype was manually operated by the designers to nudge the residents whenever they saw the residents losing attention for their coffee drinking activity. We could give the computer mouse different shapes, for example: dots, circles, twinkling speckles and words.

The Active Cues prototype was further developed during the iterations of the third and fourth field tests. The third field test was explorative in nature and we used the Wizard of Oz prototype, whereas the prototype was automatically operating during the fourth field test. Two Microsoft Kinect motion sensing devices to detected arm- and hand-movements of the residents around the dining table (see Figure 1). The Kinect depth-sensing cameras provided a grayscale image, detailing the perceived difference in height on the surface of the table. The two Kinects cameras in conjunction with each other, produced consistent readouts with differences as small as one centimeter. This data automatically operated the light projections on the table.

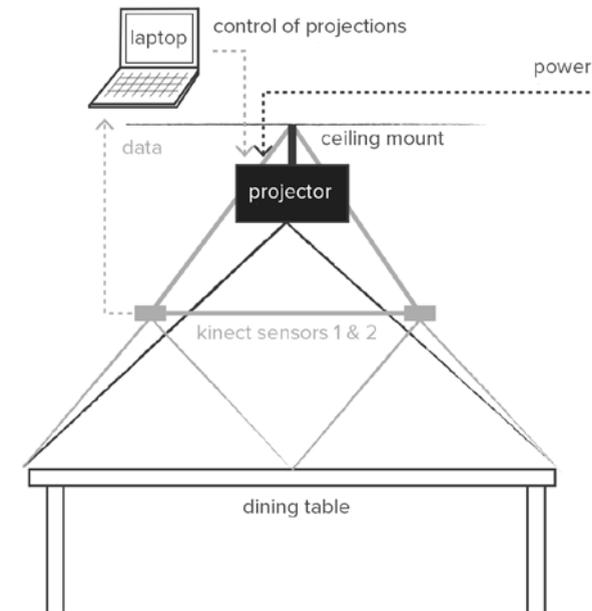


Figure 1. The Active Cues prototype during field tests 3 and 4

3.3.2 Procedure of field testing

Prior to testing our initial design concept, we presented our design ideas and procedure to the residents’ relatives and carers to inform them and to obtain their permission for the residents to participate. Gatherings with the residents’ relatives and carers lasted for 90 minutes: 30 minutes were spent presenting the results, 30 minutes were devoted to questions, remarks and suggestions, and 30 minutes were dedicated to introducing the next step. All study procedures were approved by the Ethical committee from Delft University of Technology and VU Medical Ethical Committee. The people with dementia (verbal) and their relatives (written) provided informed consent. During the testing, a team of two designers and one

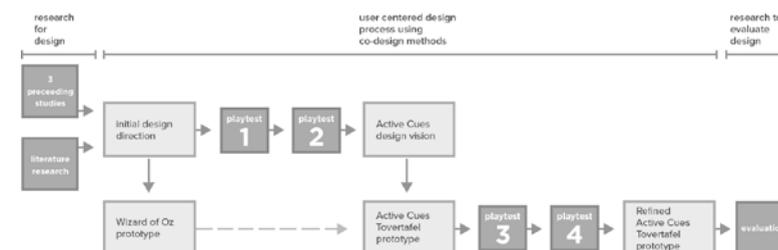


Figure 2. Research, design and evaluation process of the Active Cues Tovertafel

researcher made notes. We used video recordings to look back at certain situations and to communicate our findings to the residents' relatives and carers. The current study describes the four iterations that entailed the interactive research through design process (see Figure 2).

3.3 Design insights

The core of the initial Active Cues concept design – namely that the product substitutes for the residents' initiative during activities by sensory triggers – proved to be valuable and was not changed during the process. Other elements, however, underwent radical changes as a result of the insights gained from playing with the prototypes. The design insights are described in the following sections.

3.3.1 From stimulating ADLs to playing games

Our initial concept design stimulated the residents to continue with the ADL of drinking coffee by projecting 'light cues' whenever they stopped drinking for a considerable period of time. We tried light cues with differing intensities, sizes, shapes and behaviours (twinkling, moving or static). We tried abstract as well as more literal cues, for example projecting the words 'Are you thirsty?'. None of these light cues made the residents take another sip of their coffee. However, the residents seemed to be intrigued by the 'magically' moving lights on the table, and responded positively and playfully to the projections. For example, one of the ladies did not drink her coffee for a while and when we projected a circle of light round her cup, she picked it up and set it aside to play with the light (see Figure 3A). We realised that our moving and interactive light projections, although meant to stimulate ADLs, have a playful character in itself and we started the development of games based on 'playing with light'.



Figure 3. Residents with dementia testing initial design ideas

3.3.2 Initiative remains with the product

Although the residents' activity that is stimulated by Active Cues changed (see previous paragraph), the product still substitutes for the initiative of the residents to start the activity, whether that is drinking coffee or playing a game. Because, the light projections successfully captured the attention of the residents, who engaged naturally in the interaction by reaching for and touching the projections. However, the user-product interaction changed in nature: in the initial concept the product starts with monitoring the behaviour of the resident and provide triggers whenever they have lost their attention to the task. In the redesigned concept the product provides triggers (light projection) initially and responds to the reaction of the residents; the interactive light projections change graphically or behavioural if the residents touch them and the product provides more triggers if the residents do not react.

3.3.3 Triggers remain sensory based

Active Cues visually stimulated the residents through the projection of light. The lights were directly noticed by the residents and successfully triggered a reaction. We also experimented with auditory stimulation, but the residents soon became irritated by the repetitive sound triggers. The products' triggers will therefore remain only visual.

3.3.4 From unobtrusive to surprising projections

We first provided the least obtrusive light projections and gradually amplified them, to avoid over-stimulating the residents. We only increased the intensity if the residents did not see them, or did not react to them, and would stop if they would show agitation. However, none of the projections triggered negative reactions. Instead, the residents appreciated the more intense and surprising projections. We therefore intensified the design of the light projections and added surprising elements in the games (see Figure 3B).

3.3.5 From a private to a shared experiential world

Changing the purpose of Active Cues from stimulating an individual ADL to stimulating a group game, changed the residents' experiential

world accordingly. Social interactions arose naturally due to the light projections on the table in between the residents. These lively social interactions were remarkable, because people with dementia often show little interest in their peers (Brod, Stewart, Sands, & Walton, 1999). We fostered the social interactions in developing the games, as interacting with each other also reduces apathy. Even more so, the residents stimulated each other to join in (see Figure 3C). We want to preserve this unforeseen mutual encouragement in the design of the games.

3.4 Methodological insights

While testing various light projections to stimulate the residents to continue drinking coffee we realised that none of these encouraged them to actually take another sip. However, they were clearly aware of the projections and responded enthusiastically to the light projections on the table. The residents promptly became aware of its playful character. The Wizard of Oz prototype enabled us to respond ad-hoc to their behaviour and we played along. Only moments later, all residents, carers, and designers were ‘throwing’ light dots from one person to the other. This unexpected event did not only change our design direction, but also changed our design method; from testing our design concept we started a co-design process to explore new ways of playing with light together with the residents and the carers.

4. Co-design approach

4.1 Exploring new ways of playing

The freedom in use of the Wizard of Oz prototype allowed us to respond ad-hoc to the residents’ behaviour and we could explore different ways of playing. We used the different shapes of light projections in our prototype; we intuitively responded to the behaviour of the residents, and closely listened to their reactions and suggestions. Also the carers contributed to the exploration of playing by showing the designers how they anticipated to the residents. While playing together with the light projections we extracted several elements that seemed to appeal to the residents: they enjoyed the interactive behaviour of the projections,

they enjoyed the surprise of unexpected events, they could relate to the projections that were familiar to them, they enjoyed reading out loud words and sentences, and they enjoyed to engage with each other.

4.2 Co-designing six games

In close collaboration with the residents, their family members, carers and the designers we further developed our playful ideas into six games: (1) Little Fishes, (2) Fluttering Butterflies, (3) Sweeping Leaves, (4) Throw that Ball, (5) Amazed by Flowers, and (6) Guess the Sayings (see Figure 4). Most playful interactions were based on real-life objects and natural phenomena. Each of the following paragraphs contains a game description and its tailoring to the residents’ preferences and abilities.



Figure 4. Adjustments to Active Cues game concept

4.2.1 Experimenting with colour and intensifying the stimulating character of the Little Fishes game

The Little Fishes game is a group of schooling fish that swim round the table (see Figure 4A). The movement of the fish triggers the residents to reach out for them. The fish respond to their arm movement by circling round their hands. When another resident also moves her hand, the fish swim over to her.

Because the residents showed their appreciation for coloured projections, we experimented with several colours for the fish. However, due to the higher contrast with the wooden table, white fish appeared to be the most

visible to the residents. Because the fish could cluster round one person, we also included a 'pioneering fish' that breaks away from the school of fish and swims to someone who is not yet involved in the game. Since the residents sometimes played with the fish for more than 15 minutes, which left the other residents waiting, we increased the number of fish. Lastly, a fish disappearing off the edge of the table evoked negative concern in the residents: 'The fish has gone!' or 'The fish fell on the ground!' We took this into account and made fish turn around before they got to the edge of the table.

4.2.2 Detailing the graphics and improving the behaviour of the Fluttering Butterflies game

The Fluttering Butterflies game is similar to Little Fishes: the butterflies attract the attention of the residents by flying over the table (see Figure 4B). When a resident reaches for them, the whole group of butterflies settle round the resident's hands.

We tried different graphic designs and improved the butterflies' behaviour. Because detailed graphics were more appreciated than abstract graphics, we made the butterflies more detailed, but the primary colour remained white to preserve the high contrast. We also improved the visibility of the individual butterflies by scattering them enough to prevent them becoming a large, blurry projection. Similar to the case of the Little Fishes game, we incorporated a pioneering butterfly and increased the number of butterflies to increase the stimulation.

4.2.3 Adding a trigger to the Sweeping Leaves game

In the Sweeping Leaves game, the table is completely covered by leaves (see Figure 4C). The leaves are reactive to arm movements: when an arm moves over the table, the leaves swirl away. Several beetles are walking underneath the leaves, and they appear when the leaves are swept away. We realised that this game did not fit our design vision by not initiating the interaction. As people with dementia are not able to take the initiative, they did not start sweeping away the leaves. However, the residents were surprised by the appearance of the leaves and found them the most

beautiful. We adjusted the game and projected beetles above the leaves to trigger the residents to start sweeping. The walking beetles captured their attention, and by reaching for the beetles the residents discovered that the leaves reacted to their hands. They enjoyed the reactivity of the leaves and continued sweeping enthusiastically for a considerable period of time. In the final version, we used ladybirds rather than beetles, because the former have a more friendly appearance.

4.2.4 Changing the graphics and improving the responsiveness of the Throw that Ball game

The Throw that Ball game was inspired by the reaction of the residents to the light projections in the first two playtests (see Figure 4D). Whether we projected a dot, a ring or a flower, the residents naturally threw or waved the projection to one another. The projection moves over the table, and when the residents reach for the projection, or when the projection reaches the edge of the table, it bounces in a different direction.

The first projection was a flower, which stimulated the residents to reach for it, but it did not occur to them to throw it around. However, because the flowers were highly appreciated for their shapes and colours, this concept was developed into two games: Throw that Ball and Amazed by Flowers. For Throw that Ball, we changed the graphic to a traditional beach ball as a natural representation of something that we do toss around. We also improved the responsiveness of the ball to the residents' arm movements, as their attention soon drifted off when the reaction of the ball was delayed or its direction was not logical.

4.2.5 Adding a new game: Amazed by Flowers

The Amazed by Flowers game was derived from the flowers used in the earlier version of Throw that Ball. As mentioned, the residents highly appreciated the projections of the rotating and expanding colourful flowers. In Amazed by Flowers, several flowers float over the table, and whenever a resident touch a flower something unexpected happens to surprise her. The rotating flowers can grow in size or change colour (see Figure 4E).

4.2.6 Adjusting the behaviour of the trigger of Guess the Sayings

The Guess the Sayings game is based on reminiscence and the joy of reading out loud the sentences that were projected during playtest 2 ('Are you thirsty?'). When a resident reaches for the dot, the first part of a saying is projected on to the table. The traditional sayings refer to their long-term memory. The residents can guess the second half of the saying, and by touching the dot again the remaining text appears (see Figure 4F). The game is designed to stimulate conversation between the residents by discussing the sayings.

The speed of the dot influenced the reaction of the residents. When the dot moved too fast, some of the residents were unable to reach it in time. However, when the speed of the dot was slow, the residents became distracted before the dot was within reach. In the final design, the dot accelerates when it crosses the table and slows down when it is within reach of the residents. The font, size and duration of the projected sayings were sufficient.

In conclusion, it can be said that the older persons with moderate to severe dementia played a pivotal role in the design and redesign of the six Active Cues Tovertafel. The collaboration between the designers, carers, relatives and the residents entailed exploration of new ways of playing with interactive light projections as well as detailing the designs to truly match their abilities, challenges and preferences.

6. Discussion

Existing literature and several preceding studies were the groundwork for the design of the Active Cues Tovertafel. During the design iterations, we gained insights into how people with moderate to severe dementia reacted to the design and how their behaviour changed. The Fogg Behaviour Model (FBM) (Fogg, 2009) ensured considering the three principle factors that may have contributed to activation of the residents. In retrospect, we observed another phenomenon that reduced the residents' apathy; the introduction of a new product in the nursing home environment elicited social interaction between the residents. This observation is in line with the

triangulation theory of Whyte (1980), which argues that "some external stimulus provides a linkage between people and prompts strangers to talk to each other as though they were not." Several design characteristics of the Active Cues Tovertafel seemed to contribute to this triangulation process; creating a shared experience may draw its members together, revealing shared interests can work as conversation openers, and each other's reactions can be the most entertaining, which is referred to as the 'amphitheatre effect' (Whyte, 1980). From literature, we expected that the play experiences 'sensory stimulation' and 'reminiscence' would be suitable for people with moderate to severe dementia (Anderiesen et al., 2015) and the current study seems to confirm our expectations.

The residents noticed and were positively surprised by the moving and coloured light projections. Also, recognizable projections were favoured over abstract images and evoked conversations about the past, which convincingly showed the suitability of reminiscence. Within the scope of this study we designed a game with these two play experiences for people in the most severe stages of dementia. Future design studies that incorporate other play experiences for people in earlier stages of dementia would contribute to the understanding of designing play experiences for people in the different stages of dementia. Existing literature that present games, which are specifically designed for people with dementia target people in the earlier stages (Cohen, Firth, Biddle, Lewis, & Simmens, 2009; Van Rijn et al., 2010). However, as expected the design concepts that were developed during these studies showed profound differences with the Tovertafel design. Future design and research projects that develop games specifically for people with moderate to severe dementia would be valuable to gain deeper understanding in specific game design principles for this sub-group.

During our studies the role of the people with dementia as being the future users changed: from being the focus of our design activities they became part of our design team. The residents were initially approached as the focus of our work; we observed them, designed for them and tested our design ideas with them. Later on in the project the design approach



shifted (see Figure 5) and they took up a participatory role. The older persons with dementia, the carers and the designers were now exploring ways of playing together, and co-created the Active Cues games.

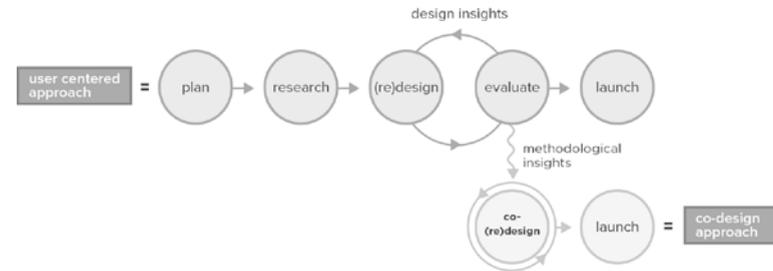


Figure 5. Changing design approach during Active Cues project

Literature describes various challenges for people with severe cognitive decline to participate in a creative process; they tend to struggle with abstract thinking, focusing on a task, and making choices (Hendriks, Huybrechts, Wilkinson, & Slegers, 2014), with imagination (Mayer & Zach, 2013) and they experience difficulties expressing themselves (Müller & Guendouzi, 2005), which may evoke burdensome feelings (Przybylski et al., 2012). However, this study shows that people with moderate to severe dementia contributed to the development of a new product. Although this study was limited to our evaluation of the value of the residents' and carers' contribution, we want to argue that their participation was crucial to the design of the Active Cues games.

Typically for a co-design approach is that future users and designers together create possible design solutions represented with low-fi prototypes. As it is difficult for people with severe dementia to imagine the use and functionality of a new product, which are resembled by paper prototypes (Mayer & Zach, 2013), realistic tools seem to be more suitable. Realistic prototypes in the early stages of the design process are often costly and time-consuming, however, these are most likely the only way to explore design concepts. Although the Active Cues prototype was a high-fi prototype, the 'Wizard of Oz' prototyping concept allowed room for experimentation. The people with dementia could explore new ways of playing with the interactive light projections and the designers

could both, initiate interactions and react ad-hoc to their responses and behaviour.

This freedom in exploration and interaction by the people with dementia, the carers, and the designers was essential to collaboratively design the Active Cues Tovertafel.

In this research, the design method changed from user centred design to co-design and we have learnt how this influenced the design of the Active Cues Tovertafel. Research for design, which is characteristic for a user centred design process (ISO DIS 13407), implies preceding studies or analyses of the target group and its context. We found that these studies were useful to gain knowledge about the neuropathology of dementia and its complexity and how that could influence the older people's experience of the context, including products. Also, the understanding that we gained of the nursing home environment gave us insights in the role of stakeholders. The initial design concept was based on this newly gained knowledge and understanding. However, due to the participation of the target group during the co-design process the design changed radically; the reactions and behaviour of both the older persons with dementia and their carers guided the redesign. Drastically changing a design concept requires several characteristics from the designer; among them are sensitivity and honesty to acknowledge that the initial concept might not have been the right direction, open-mindedness and creativity to see the new opportunity and flexibility and courage to make radical changes. Nevertheless, we want to argue that the knowledge and understanding that we gained during our preceding studies helped us to interpret the reactions and behaviour of the people with dementia and their carers during the co-design sessions and enabled us to redesign our concept based on both, knowledge gained by research and experience with the target group.

Our studies showed that people with moderate to severe dementia are able to play a participatory role in the creative process of designing the Active Cues games. However, the studies preceding the concept

generation were not involving the residents according using co-design methods. Rather, more traditional research methods were involved. These observations raise two questions for future consideration: first, would it be possible to involve people with moderate to severe dementia even earlier on in the design research process? For example, during the exploration of the context of use? Second, would it be possible to involve residents with moderate to severe dementia in co-design processes in other design domains, such as for example sanitary, interior decoration, meals and so on. And if so, what would such a co-design process in these domains look like? Based on our experiences, a preliminary answer in both cases would be positive. Crucial for success would be that the residents are approached in relation to their social context, so involving the carers and relatives into the process. Both carers and relatives proved to play an important intermediate role and as such, could become active participants in the whole process.

5. Conclusions

In this section, we share our insights during a co-design process with people with moderate to severe dementia and their immediate environment. This research gave insights on various levels of the design process: we further developed our concept design based on the appreciation of the residents, who inspired us to develop the six games of our final concept design. Also, we gained insights into interaction principles that seem to stimulate people with moderate to severe dementia to engage with the games. And we gained insights about the co-design tools that we used and our collaboration with the residents, their carers and relatives.

5.1 The participation of people with moderate to severe dementia in a design process

We learnt that including people with moderate to severe dementia and their immediate environment in a design process requires a deliberate preparation with sensitivity to their situation. Namely, both the people with dementia and their family members are in an emotionally intense and demanding situation. From our experiences, a thorough communication with the relatives and paying them, and their difficult situation, careful

attention seemed to be key to build a relationship of trust. Moreover, the relatives helped us to interpret the residents' emotions and behaviours.

The carers were of great value in the design process: as moderators between the residents and us, as experts of daily living with dementia and as experts to interpret their emotions and behaviours. However, also for the carers it appeared to be important to receive a detailed explanation of our intentions and methods, because we interfered with their daily routines and operated in their working environment.

Although building a continuing relationship with people with dementia is difficult due to their memory problems, working with the same people throughout the process benefits the collaboration. Mayer and Zach (2013) mentioned these difficulties for people in the early stages of the disease and these are even more profound for people in more severe stages of dementia. However, we found that it is still valuable to pay multiple visits to the same group of residents, because the designers themselves became more empathic, more receptive, and more competent at getting along with them. As the designers became more at ease working with the people with dementia, the residents seemed to be more confident in trying the new and unfamiliar.

In conclusion, people with moderate to severe dementia contributed to the creative process of developing the Active Cues games. The realistic prototype with room for experimentation was important for the people with dementia to participate in the process and express their creativity. However, sensitivity to the strenuous situation of the people with dementia and their relatives was important in terms of trust. Openness to the relatives and care professionals benefits the understanding of the designers. And a confident and empathetic attitude from the designers is crucial for a successful collaboration with people with moderate to severe dementia during a co-design process.

Considerations for co-designing with people with moderate to severe dementia

- ▶ Make use of realistic prototypes that leave room for experimentation
- ▶ Provide relatives and carers with detailed information about the process
- ▶ Give frequent and deliberate room for relatives and carers to express their ideas, opinions and fears
- ▶ Involve the relatives and carers as moderators and experts to learn from them
- ▶ Be sensitive to the people with dementia, to their relatives and to their strenuous situation to build a relation of trust
- ▶ Pay multiple visits to become more empathic, receptive and competent in working with people with moderate to severe dementia

Textbox 2

5.2 Interaction principles that stimulate people with moderate to severe dementia

The design aim of this project was to design a playful product that reduces apathy of people with moderate to severe dementia by stimulating physical activity and social interaction. During the multiple design iterations, we gained insights into which product characteristics elicited a reaction from the residents. In this section, we give an overview.

- ▶ A product can stimulate people with moderate to severe dementia by initiating the interaction.
- ▶ A product can support people with moderate to severe dementia to lengthen their time engaged with an activity by providing triggers whenever their attention drifts away.
- ▶ Sensory triggers can stimulate people with moderate to severe dementia to interact with a product. However, visual triggers seemed to be preferable over auditory triggers.
- ▶ The detailed, colourful, unexpected and accelerating visuals seemed to be more activating than the subtle and unobtrusive ones, without causing sensory overstimulation. However, one must be cautious and additional research is important to study the most stimulating intensity of triggers with minimal risk for overstimulation.

- ▶ Interactions that cannot go wrong emphasise their abilities and create a safe environment for people with moderate to severe dementia to interact freely with the product.
- ▶ A so-called 'layered' design, i.e. a product that is suitable for persons with varying severities of dementia, seems to have a bonding effect and therefore stimulates social interaction and mutual encouragement to join in.

Our concept design consisted of interactive and animated light projections on the dining tables in the communal area of a dementia care environment. The residents interacted successfully with the projections, and moreover, they expressed their amazement and appreciation of these 'wonderful lights'. We therefore think that stimulation with visual triggers is a promising design direction for people with dementia and the following are our design insights:

- ▶ The familiarity of the projections made them easy to recognise and intuitive to interact with. Colourful and detailed projections were preferred; however, the contrast should be high and the graphics fairly simple in order to preserve the visibility.
- ▶ The behaviour of the light projections comprises their speed, interaction dynamics and responsiveness. Light projections were stimulating when the speed was fast enough to attract attention, but allowed enough time for the people to react. Our solution to accomplish both was to accelerate the projections while they were crossing the table, and to slow them down when they were within reach of the residents. The interaction dynamics include the 'pioneering' behaviour of the light projections to invite the residents, who are not yet, or who have stopped, interacting with the product; these consecutive reminders successfully stimulated to start/continue playing. The residents were intrigued by the reaction of the projections to their arm movements. However, when the responsiveness of the interactions was not logical, delayed or non-existent, interest was soon lost.

The choreography of the projections comprises the number and distribution of the projections over the surface. To prevent the residents from losing interest in the game, enough projections should be provided at the same time. To stimulate a group of six, sitting round the dining table, three or four (groups of) light projections create a lively atmosphere. These projections should be spread evenly over the table to include all residents. Of course, for games with a different game concept – for example the group game of throwing a ball to each other – only requires one projection of a ball.

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Intermezzo: Active Cues

Tovertafel - *a product description*

This project-grounded research entailed the development of the Active Cues Tovertafel; a collection of six serious games for people with moderate to severe dementia. The research chapters in this dissertation describe the knowledge that we gained prior to developing the product, the insights that we gained while developing the product, and the evaluation study of the product. However, this intermezzo describes the product as is. For those interested in the actual design of the Active Cues Tovertafel, we elaborate on the design aim, the concept design, the platform, the design of the games, the interaction design, the user scenarios and how the product is embedded in a product-service system.

1. DESIGN AIM

The behaviour of people with dementia often lacks interest and energy and they show an unwillingness, or incapacity, to take action. This behaviour is referred to as “apathy”. This apathy has detrimental health consequences for people with dementia. Apathy diminishes their physical flexibility, coordination and strength, and their cognitive functioning is at risk, especially for older persons who are already vulnerable for (more) cognitive decline. The Tovertafel’s main objective is to stimulate physical and cognitive activity and social interaction for people with moderate to severe dementia, who reside in the nursing homes environment. The product also aims to facilitate a fun activity that contributes to their quality of life.

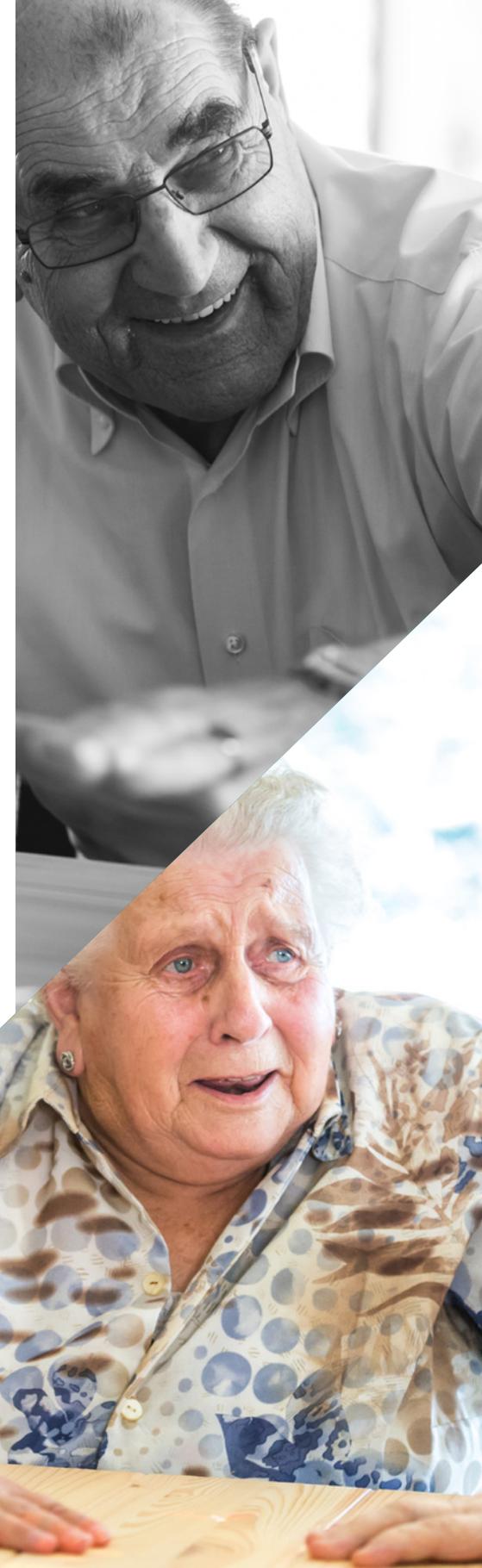
The Tovertafel aims to contribute to the quality of care in the dementia care context. The new product should improve the carer’s enjoyment in their work by equipping them with an enjoyable activity for their residents. At

the same time, the residents should be able to enjoy the activity independently or with minor support to unburden the carers, who so often lack time to fulfil their wide range of responsibilities. The Tovertafel should facilitate pleasurable activities and meaningful conversations between informal carers, relatives, and their loved ones. It is emotionally strenuous for family members to witness the declining capabilities of their father, mother, or spouse. It may also be their first encounter with dementia, which may cause them to feel insecure and makes it difficult for them to provide the loving support they would like to give. During these challenging times, the Tovertafel contributes to these relationships in families or between friends.

In conclusion, the Tovertafel aims to contribute to the care eco system: by contributing to the residents’ health and well-being, by improving the quality of life of the residents, carers and family members, and by supporting the carers efficiency.

2. COLLABORATIVE DESIGN PROCESS

The Active Cues Tovertafel was developed in collaboration between the stakeholders of this project. The different parties contributed to the development process within their expertise. The design brief, design vision and concept design ‘Active Cues’ were created and developed by the first author, individually. The materialisation for building the prototype was the result of a brainstorm including the companies that participated in this project; Monobanda, Novay and Careyn. Thereafter, the software for the prototype was developed by Monobanda. They programmed the various software versions that the first author required during her design iterations; from the Wizard of Oz prototype to realising her ideas for the final 6 games, which she renamed later as the ‘Tovertafel’.



3. PRODUCT DESIGN

3.1 The Tovertafel concept

The Tovertafel is a playful product that consists of a collection of interactive games that are projected on the dining table. These interactive light animations connect the nursing home residents whilst playfully stimulating physical and cognitive activity and social interaction. The light animations invite the players to reach for them and respond to their hand and arm movements. These interactive light animations allow the residents to 'play with light', for example, by throwing a ball to each other or sweeping away autumn leaves. The Tovertafel games are based on familiar projections to make the interactions recognizable and for the residents to reminisce about past

“het is een Tovertafel”

experiences and personal stories. It is essential for the interactions between the people with dementia and the light animations that they are intuitive and accurate. Also, it is impossible to make 'mistakes' while playing the game; all interactions are successful and therefore emphasize the older person's capabilities instead of the challenges they face due to their dementia. The name 'Tovertafel', which means 'Magic Table' in English, arose during one of our co-design sessions during the development of the games. A Dutch male resident, participating in our sessions, had difficulties with his speech due to aphasia. However, while he was playing with one of the games, he whispered softly, but clearly: "het is een Tovertafel" (in English: "it is a magic table").



3.2 Tovertafel platform

The final Tovertafel platform consists of a device which is suspended from the ceiling, containing a high-quality projector, infrared sensors, a speaker, a processor, a memory card and a Wi-Fi antenna. The infrared sensors detect the hand and arm movement, the processor controls the games and the projector projects the interactive light animations onto the table. The Tovertafel can be used with the dining tables already present in the nursing homes and is mounted, out of sight, on the ceiling. The Tovertafel was developed in this unobtrusive way to prevent participants from feeling uneasy by having unfamiliar elements in their environment. The Tovertafel can be connected to the internet, providing software updates and new games, thereby ensuring the improvement of the existing games' quality and to enrich the overall experience with new games.



Sweeping Leaves



A gust of wind covers the table in autumn leaves. The older persons instinctively sweep the leaves away by moving their hands over the table. The very sensitive, responsive nature of the leaves has a remarkable effect on the participants, enticing them to swipe again. The table does not stay 'clean' for long, as the leaves start settling back on the table again. When the players have not interacted for a while, a light breeze shuffles the leaves to draw their attention back to the game.

Amazed by Flowers



Beautiful flowers in different colours and shapes float across the table. Their movement encourages the players to reach out to them and, when they do, they receive a wonderful surprise! A magical animation appears, inspiring conversations about what each person's flower just did. Deeper conversations start to blossom about the players' personal favourite flower, or the ones they used to have in their gardens.

Little Fish



Colourful, small fish swim among water lilies across the table, which create a calming, but dynamic, atmosphere. The fish swim often to the edges of the table to invite all players to interact with the game. When someone reaches for a fish, it swims away. But a fun challenge is to try to keep the fish swimming on top of your hand! Even though this game challenges players to reach across the table, it is not too physically demanding, because the Tovertafel also responds to the smallest of finger movements.

Throw that Ball



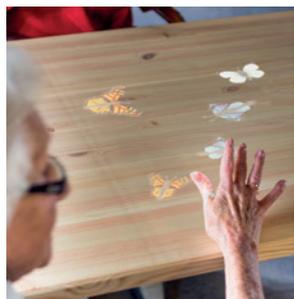
A physical and social game that is fun and recognizable. We all threw balls to each other as children, and throwing a ball successfully is just as satisfying for the older persons. They also encourage each other to throw the ball back. The ball never drops off the table as it bounces back off the edge. The game contains one ball so all players have the same focus, increasing social interaction and the feeling of togetherness.

Guess the Sayings



White 'rings' float across the table. When touched, the rings reveal the first part of a saying. The rings disappear to give the players time to read the sentence out loud and to complete the saying. As soon as the rings reappear, the completed saying can be revealed by touching another ring. This game relies strongly on reminiscence; the players naturally and almost 'without thinking' finish the saying. It creates a dynamic, interactive experience and players have different 'roles'; some participants enjoy catching the rings; others prefer reading out loud or finishing the sayings.

Fluttering Butterflies



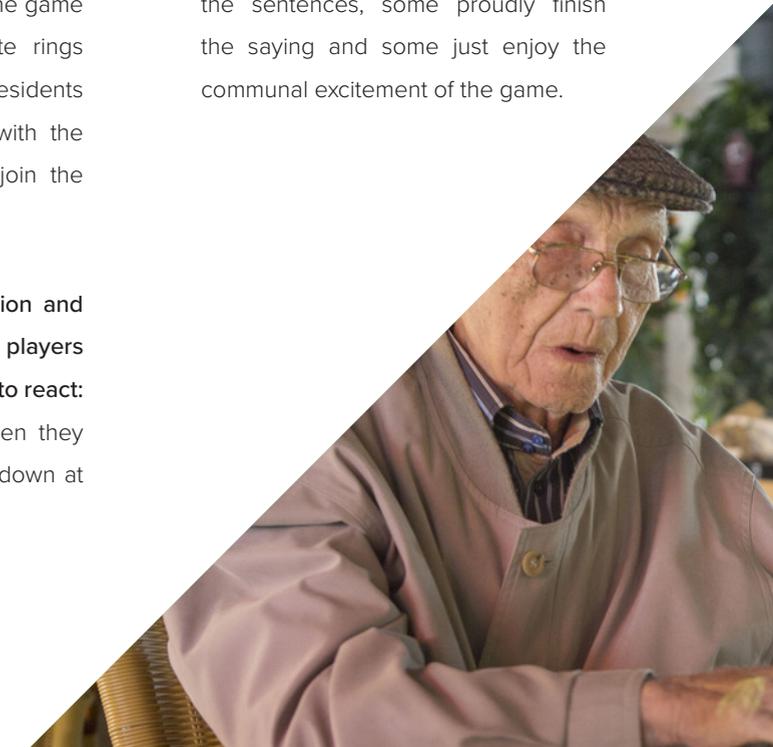
This game creates a tranquil and relaxing atmosphere, even while the fluttering behaviour of the butterflies can unexpectedly cause surprise and lead to giggling. Not only do the older people find the butterflies beautiful, the butterflies also have a social effect on the players. As soon as a player reaches for one, it flies to a different person on the table, linking the players. The butterflies' beautiful colours are often a topic of conversation and fun to enjoy together.



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- 1.) **The product initiates the interaction:** the beach ball moves across the table which starts the game 'Throw that Ball'; the ball's movement provokes a reaction from the player.
 - 2.) **The games use sensory triggers:** in the game 'Sweeping Leaves', the table is covered with brightly coloured projections of leaves, creating a vibrant visual stimulation.
 - 3.) **The games contain colourful, unexpected and accelerating visuals:** the graphics of the butterflies in the game 'Fluttering Butterflies' clearly show the beautiful colours of their wings and their fluttering movement across the table surprises the players from unexpected angles.

- 4.) **The games are based on familiar elements:** the graphics of the fish in the game 'Little Fish' are realistic and their behaviour is recognizable from real life. This facilitates the joy of recognition and contributes to an intuitive interaction.
- 5.) **The contrast of projections is high and the graphics are fairly simple.** While the graphics of the fish are realistic, we simplified the images and preserved high contrast by using bright colours that are visible on different table tops.
- 6.) **The product gives triggers frequently:** the butterflies that flutter to the edges of the table reactivate people with dementia whenever their attention drifts away.
- 7.) **The pioneering projection:** in the game 'Guess the Sayings', the white rings purposefully move to the residents that have not yet interacted with the projections to invite them to join the game too.
- 8.) **Fast projections attract attention and slow down within reach of the players to allow enough time for them to react:** the white rings accelerate when they cross the table and they slow down at arms-length of the players.

- 9.) **Behaviour of projections are flawless and logical:** the flowers in the game 'Amazed by Flowers' always respond to a hand touching them; some grow in size when you rub them and others change colour when you reach out for them.
- 10.) **The games never 'go wrong':** whether a player successfully touches the beach ball or not, it will never drop from the table, because it also bounces from the edges of the table.
- 11.) **The design of the games is 'layered':** the game 'Guess the Sayings' allows for players with different strengths and challenges; some players are mostly involved with touching the white rings, others enjoy reading out the sentences, some proudly finish the saying and some just enjoy the communal excitement of the game.



5. USE SCENARIOS

The Tovertafel allows the nursing home residents to play at different moments of the day with different people. Although a carer must turn on the Tovertafel, residents can play the games independently. They do not necessarily need support from the carers, which may contribute to their self-efficacy and allows carers to attend other matters. Also, carers can play the games as a fun communal afternoon activity where everyone can join at their own level and pace. Activity

therapists and physiotherapists can use the games in groups, or individually, to focus on physical and cognitive stimulation. Informal carers, friends and family can also play with their loved one, enjoy each other's company and reminisce about past experiences. We have seen that residents enjoyed playing with their great-grandchildren, whose vibrant energy contributes to the residents' stimulation and the two generations, who seem worlds apart, intuitively spend quality time together.





6. PRODUCT-SERVICE SYSTEM

The Tovertafel was developed during the Creative Industry Scientific Programme (CRISP) of the Dutch national funding program NWO. CRISP studied complex product-service systems that benefit society. Our approach was to develop and study a product to support an existing complex service: dementia care. However, for carers to familiarize themselves with a new technology and to adapt a new activity in their day-to-day routines takes time, which is so precious in the dementia care context.

Therefore, we also developed a dedicated service to complement the Tovertafel, which supports all stakeholders in the dementia care context to implement the new product.

The Tovertafel-service is based on three elements that we believe will increase the likelihood that the product will be used to its full potential:

- ▶ Awareness: everyone supporting a person with late stage dementia should be aware of the benefits of physical activity, cognitive stimulation, and social interaction.
- ▶ Enthusiasm: everyone should be excited to use the new tool that is available in their nursing home.
- ▶ Responsibility: everyone should feel the responsibility and empowered to actually turn on the Tovertafel.
- ▶ The Tovertafel-service consists of several elements to raise awareness, to enthuse and to involve all stakeholders in the dementia care context:
 - ▶ Having installed the Tovertafel, the technician gives an instruction to the staff that is present on how to use the Tovertafel.
 - ▶ A few weeks after the installation, a gathering is organized for the staff, family and carers, to show the possibilities of the Tovertafel, and how playful and stimulating activities may improve the life of people with dementia.
- ▶ During the first three months, a 'Tovertafel Buddy' visits the nursing home weekly and inspires the staff and management to use the Tovertafel in their care routine, as well as friends and family who visit. Also, the Tovertafel Buddies collect experiences, feedback and new game ideas in the nursing home to feed further development to improve the games.
- ▶ A personal technical service supports the carers over the phone in case of a defect. If necessary, the Tovertafel will be repaired or replaced within three working days to minimize the hassle for the carers and safeguard their enthusiasm for the product.
- ▶ In 2017, an online environment "My Tovertafel" will be launched, that gives the staff and management insights in the use of their Tovertafels, new developments and enables direct communication for requests, feedback, complaints, and ideas.



The Tovertafel: evaluation of an activating game for people with moderate to severe dementia

- a small-scale intervention study

This chapter describes a small-scale evaluation study to the effects of the Tovertafel on the apathetic behaviour of nursing home residents with moderate to severe dementia. The Tovertafel was compared to two other situations: to the organised coffee drinking activity and to sitting in the lounge area without an organised activity.

The 5-day small-scale evaluation study (n=6) shows that, according to the nursing home carers, the Tovertafel reduces apathy of older persons with moderate to severe dementia by increasing their physical activity and reducing sadness. Moreover, the results also indicate improvements in happiness, and reduction of anger and fear. In sum, the present study shows that co-designed games can play a beneficial role in the dementia care context.

Although conclusions on the general effects of the Tovertafel are difficult to draw from this small-scale evaluation study, the results are promising and in line with the experiences of the nursing homes who have acquired the Tovertafel for their residents.

Le Riche, H., Visch, V. T., Sonneveld, M. H., Goossens, R. H. M. (2017). The Tovertafel: evaluation of an activating game for people with moderate to severe dementia (submitted to *Dementia, The International journal of social research and practice*).

The Tovertafel: evaluation of an activating game for people with moderate to severe dementia - a small-scale intervention study

1 Introduction

Older persons, especially those living with dementia, often engage in very little physical and social activity (Kolanowski, Litaker, & Buettner, 2005). In this group, apathy is a common behaviour due to lesions in the prefrontal cortex and basal ganglia, which are characteristic of several types of dementia (Levy & Dubois, 2006). Apathy can be specified into three underlying processes: (1) emotional-affective processing, (2) cognitive processing and (3) auto-activation processing (ibid.). The absence of regular physical activity negatively influences the older persons' physical flexibility, coordination and strength (Warburton, Nicol, & Bredin, 2006), but also affects cognitive functioning. This applies especially to older persons, who are already vulnerable to more cognitive decline (Colcombe & Kramer, 2003). In addition, exercise (Heyn, Abreu, & Ottenbacher, 2004) and leisure activities (Verghese et al., 2003) are associated with improved physical, cognitive and emotional wellbeing of people with dementia.

Despite the positive effects of physical and social activity for people with dementia, nursing homes experience difficulties in activating their residents due to various reasons, e.g. challenges in the communication between staff and residents, understaffing due to financial cuts, and so on. The present Tovertafel project aims to overcome these difficulties by designing an interactive and playful product that activate people with moderate to severe dementia with minimal support of the carers.

Games can play a stimulating role in designing for behavioural change with the purpose to benefit one's health (Thompson et al., 2010; Desmet et al., 2014). Most existing games have been developed for people in the earlier stages of dementia (Hendriks, Truyen, & Duval, 2013; Lindsay et

al., 2012; Van Rijn, Hoof, & Stappers, 2008). As far as the authors know, there are no activating games developed for people in the more advanced stages of dementia, yet this subgroup seems most in need of activity stimulation due to their increased apathy. We therefore chose to target our design for people in the three most advanced stages of dementia, i.e. stage 5-7 according to the Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon, & Crook, 1982).

In our earlier study (Anderiesen, Scherder, Goossens, Visch, & Eggermont, 2015) combining neuroscience and game literature, we investigated which of the 22 game experiences (Korhonen, Montola, & Arrasvuori, 2009) could potentially be elicited in people with various stages of Alzheimer's disease. For instance, due to decline in the hippocampus and prefrontal brain areas already in the early stages of the disease (Apostolova et al., 2012), the game experience exploration would be very difficult for everyone with dementia. In contrast, the play experiences *sensory stimulation*, *relaxation* and *reminiscence* are still suitable for people in the more severe stages of dementia (Anderiesen et al., 2015). We used these three play experiences as the starting point for the design process of the Tovertafel.

2. The Tovertafel prototype

Our designed Tovertafel projects interactive light animations on the dining table for nursing home residents to trigger play activity - see Figure 1. The prototype consists of a 2800-lumen BenQ MX618ST DLP Projector that is mounted on the ceiling and beams the light projections on the table. Two Microsoft Kinect motion sensing devices detect arm- and hand-movements of the players. An Acer Aspire V3 laptop uses this data as input for the interactive games. The product applies the light projections to trigger the people with dementia for interactive play.

For the Tovertafel, we designed the following six games that vary automatically every 5 minutes: (1) Little Fish (the players can interact with the projected fish by moving their hands), (2) Fluttering Butterflies (similar to the previous game but with groups of butterflies), (3) Sweeping Leaves (the table is covered with windblown leaves- the players can swipe

the leaves away), (4) Throw that Ball (the players can throw and catch a projected beach ball to each other), (5) Amazed by Flowers (small rotating flowers travel slowly around the table, upon touching them they grow or change in colour, and (6) Guess the Sayings (the first half of traditional textual proverbs are projected, upon touching them the remaining part appears). The Tovertafel is designed to be played individually, with fellow patients, care professionals or visiting family members.

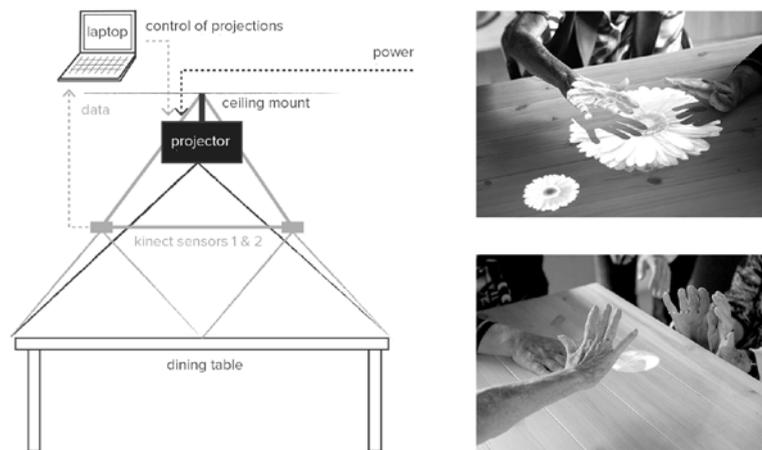


Figure 1. Tovertafel prototype set up and two games (Amazed by Flowers, Throw that Ball).

3. Method: setting, participants, measurement and procedure

For the evaluation a small-scale Dutch dementia care facility participated having six units, each accommodating six residents. Every resident has a private room and in each unit the residents share an open-plan lounge room, i.e. a living and dining room with kitchen. The daily routine of the units consists of eating together and various group activities. The personal routines of the residents include therapies, organised individual activities and visits from relatives. During late morning and afternoon the residents drink coffee and tea together in the lounge room, either at the dining table or in the sitting area.

Six older persons with dementia participated in the study, all of whom needed intensive assistance in their daily living. Five of the six residents

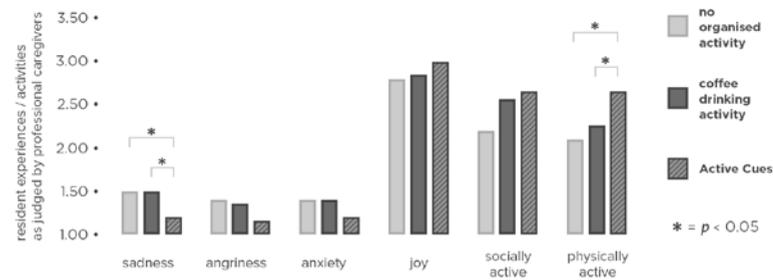
were female. The care professionals assessed the residents' stage of the dementia according to the GDS (Reisberg et al., 1982). At the time of this study, two of the residents had moderate cognitive decline (stage 5: moderate dementia), two had severe cognitive decline (stage 6: moderately severe dementia) and two had very severe cognitive decline (stage 7: severe dementia). All study procedures were approved by the VUmc Medical Ethical Committee and the TU Delft Ethical committee. Informed consent was agreed upon by the people with dementia (verbally) and by their relatives (written).

The evaluation lasted five days (Monday to Friday) and was set up as a within-subject design involving measurement of three succeeding 30-minute conditions per day: 1) baseline measurement of the group of participants sitting in the lounge area without any activity, 2) baseline measure of the group sitting round the dining table engaged in the coffee drinking activity, and 3) intervention measure of the group sitting round the dining table drinking coffee with the interactive Tovertafel projection active. The involvement of carers was based on the usual daily routine during the three conditions; 1) no carer's involvement, 2) one carer poured the coffee and tea and facilitated group conversations, and 3) no carer's involvement to evaluate the stimulating effects of the games itself. The targeted effect of the Tovertafel design was to reduce apathy by stimulating physical activity of people with moderate to severe dementia. Since negative emotions and social interaction are also strongly tied to apathy (Levy & Dubois, 2006) and were expected to be influenced by engaging play activities as well, we measured the participants' emotions along with their behaviour, i.e. their social interactions and physical activity.

Due to the moderate and several dementia stage of the participants, we were unable to ask them directly about their evaluation of the Tovertafel. Instead, we asked the professional care-providers to observe the participants during all three conditions (2 baseline, 1 intervention) and fill in a brief paper questionnaire about the observed experience of each participant and the end of each of the conditions. All observations

on one day were done by the same carer. However, due to the carers' working schedules, the observations were done by different carers between the days. The questionnaire consisted of six 5-point Likert scales (1 = not at all 5 = very much) on the observed a) social engagement of a participant with the group, b) physical activity of the participant, c) sadness of the participant, d) anger of the participant, e) fear of the participant, and f) happiness of the participants. Additionally, to gain more explorative outcomes, the care professionals were asked in open questions to describe in their own words the social interaction of the group. All three 30-minute conditions on the 5 days were audiovideo-recorded. For the test a level of significance $\alpha = 0.05$ was used.

Figure 2. Residents' experiences and behaviour as judged on a 5-point Likert scale (1 = not at all; 5 = very much)



4. Results

Due to the variability in the residents' care needs, not all six residents could attend all three moments of measurement for the five days. Also, the variability among the residents with regard to their play and interaction capacities was expected to be large. Therefore, only those residents who were described by the care-givers at three moments on at least one day were included in the analysis. Two residents were observed and measured three times on all five days, two residents on four days, one on three days and one on none of the days. This resulted in a total of 21 measurements, observed in three conditions (no organised activity, organised coffee drinking activity, Tovertafel activity) and on six dependent variables measuring 'experience', i.e. emotions (sadness, anger, fear, happiness) and behaviour (physically active, socially active). An SPSS repeated measurement analysis (Visch & Tan, 2007) showed that the sphericity assumption was violated for condition ($\chi^2(2) = 12.93$,

$p < .001$) and experience ($\chi^2(14) = 72.69$, $p < .001$). To correct for this violation, we applied Greenhouse-Geisser estimates of sphericity in our analysis. In line with our prediction, the repeated measures within-subject analysis showed a significant interaction of experience *condition ($F(3.77, 71.55) = 4.21$, $p = .005$, $\eta^2 = .18$) with an observed power of 0.90. Figure 3 presenting the means shows that the Tovertafel condition seems to decrease the residents' negative emotions (sadness, anger, fear), increase their positive emotion (happiness), and increase their engagement (socially active, physically active). Due to the limited number of participants and the large in-group variance, not all effects are significant. However, a detailed repeated measurement contrast analysis on each of the dependent variables, represented in Figure 2, showed that the sadness of the residents as judged by the caregivers was significantly less in the Tovertafel condition than in the organised coffee drinking activity condition ($F(2, 20) = 7.00$, $p < .02$, $\eta^2 = .26$) and the no organised activity condition ($F(2, 20) = 7.00$, $p < .02$, $\eta^2 = .26$). Moreover, the Tovertafel condition led to significantly more physical activity compared to the organised coffee drinking activity condition ($F(2, 20) = 7.68$, $p < .02$, $\eta^2 = .28$) and to the no organised activity condition ($F(2, 20) = 5.53$, $p < .03$, $\eta^2 = .22$).

In the open questions, the care-providers reported differences in the social interaction between the residents with and without the Tovertafel. The residents were mostly sleeping, dozing or staring when there was no organised activity. They barely talked to each other and communication occurred only if the carer took the initiative. They enjoyed watching a music DVD but did not comment on it or discuss it with each other. During the organised coffee drinking activity, the social interaction was still poor. Again, the only, and brief, communication was in response to the care-provider or to a visitor. In contrast, the residents' response to the Tovertafel was one of joy and surprise: they laughed together and pointed out to each other what was projected on the table. Characteristic of their communication is that the periods of talking were still relatively short, but when the projections changed they started to chat again. Not all residents were involved in the conversation; some remained silent, but

they did seem to be aware of the rest playing with the Tovertafel. All of the chatting was about the projections themselves, or about a topic that was inspired by a projection.

5. Discussion

The 5-day small-scale evaluation study shows that, according to the dementia carers, the Tovertafel reduces apathy of older persons with moderate to severe dementia. According to our results, the residents were significantly more physically active and less sad when playing with the Tovertafel in comparison to the organised coffee drinking activity or in comparison to no organised activity. Our evaluation also shows indications of improvements in social activity, although this was not measured in the Likert scales, happiness, and reduction of anger and fear. These results should be interpreted as an indication of the beneficial effects of the Tovertafel, because of the limited scale of this evaluation study. Also, future studies would benefit from an objective and quantitative measurement tool for the residents' hand and arm movements on the table. Additional research involving larger populations is necessary to gain more insights into the effects of the Tovertafel on the emotions and behaviour of people with dementia. However, it should be noted that setting up large validation studies, e.g. RCTs, for serious games is complicated for various reasons such as the difficulty to create comparison groups (see Van der Kooij, Hoogendoorn, Spijkerman, & Visch, 2015 for a discussion on this topic). Also, evaluation studies on the use of activities for people with dementia encounter several methodological difficulties (Marshall & Hutchinson, 2001). It might even be debated if and for whom large-scale validation studies are needed for a successful dissemination or understanding. Apparently, this small-scale study showing indications of the (health) benefits of the game, together with the appealing design of the product convinced many care institutes of its added value. Also, new Tovertafel games have been developed to motivate other user groups for interaction, i.e. children with autism spectrum disorders and people with severe learning difficulties. In sum, the present project showed that serious games have the potential to play a beneficial role in the dementia care context.

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General discussion and conclusions

1 Introduction

This research began on the assumption that design innovations may facilitate a more passive lifestyle with detrimental health consequences for society. But a well-designed environment can also stimulate a more active lifestyle, referred to as '*design for activation*'. Design for activation is the research topic and design aim for this doctorate.

The design mission that encouraged this project-grounded research was to stimulate people with dementia for physical activity, as this group of people is particularly inclined to become passive. This research explored how playful design can contribute to a more active lifestyle, thereby contributing to people's health and well-being. The results give insights into the stimulating character of the current physical and social environment in dementia care and in insight into which playful user experiences are suitable for people during the course of Alzheimer's disease.

This thesis also resulted in the design of the Active Cues Tovertafel; a series of animated and interactive light projections on the dining table, which stimulates the residents cognitively and invites them to become physically and socially active. The implementation of the Tovertafel in different home situations has been well received and in addition, its positive effect has been validated in a small-scale study.

This doctorate was part of the Creative Industry Scientific Programme (CRISP) and its sub-project G-motiv. CRISP aimed to design and research complex product-service systems (PSS) that benefit society. G-motiv researched and applied new design approaches for behavioural change based on motivation by using playful experiences.

In this chapter, we will first reflect on CRISP as the research and design

context for this project. Thereafter, we will discuss our lessons learned and the limitations and future perspectives for research and design. The chapter concludes with reflections on the design mission of 'design for activation'. Again, we will reflect on the lessons learned and on the position of *design for activation* in the design practice: should we create awareness in all design activities, or should *design for activation* be a dedicated design approach for specific design projects?

2 Reflection on CRISP and G-motiv as design and research context

2.1 Collaboration between creative industry, universities and application domain

In this PhD project, scientific research and product innovation played an equally important role. Combining scientific research and innovation in one project seems to be rare and so we experienced several challenges during the process, but also evidential advantages. Within CRISP, we collaborated with two universities, three nursing homes, an innovative consultancy agency, and a game development company. The difference in 'timing' appeared to be challenging in the collaboration with both creative and research partners. There was little mutual understanding of each other's time frame to execute tasks in the project. The literature reviews and the extensive qualitative study took more than two years to accomplish, whereas the game developers were inclined to start designing and testing from the start. One of the lessons that we have learnt is to start collaborations with different partners to suit their time frame and that excellent communication is essential to raise awareness of each other's working methods. Also, 'the unknown', inherent in an innovation project, complicated our collaborations with both the secondary university and the creative industry. For example; the collaborating group of Clinical Neuropsychology at the VU University of Amsterdam expected a research proposal and detailed project planning at the very beginning, which is known as the "fuzzy front-end" phase at our design faculty, with many unknowns concerning research methods and timing. Another example is how difficult it is to start collaborations with creative

companies without knowing what kind of product we would develop during this research. In this project, Monobanda appeared to be a great partner to collaboratively develop our prototype, whereas the expertise of Novay was not used to its full potential due to changes in the research methods during this project.

However, despite the challenges, this collaboration strongly benefitted the research on and design of the Active Cues Tovertafel. Together with the group of Clinical Neuropsychology, we extracted design relevant knowledge from their field of neuroscience. We, as design researchers, became acquainted with literature and research methods that contributed to the understanding of our target group and rigour of our studies. Also, the collaboration with the creative industry inspired the materialization of the Active Cues Tovertafel and their practical skills enabled us to develop a prototype during this doctorate to evaluate the design.

Despite the complexity and challenges in the collaboration between these three different worlds, the broad spectrum of knowledge and skills was of great value and worthwhile to seek out in future developments.

2.2 The value of product-service systems

Being part of CRISP made us aware of the importance of developing products within the context of an existing service, and at the same time developing a product-service system (PSS) itself.

Firstly, the value of considering a product as a supportive asset to a service (such as dementia care) is that it emphasises the importance of the contextual research before one starts designing. The question became: “what does the environment of people with dementia look like, as the context of the care that is provided?”. Therefore, we include the carers (formal and informal) in our research, and the insights derived from these studies were crucial for the development of the Active Cues Tovertafel: it is not only designed for the residents, but it is also designed to fit within the care service that is provided to benefit all stakeholders in the service of dementia care.

Next, our contextual research gave insights into the challenges of the carer in nursing homes to adapt new products, or activities, into their existing routines. This, and other insights inspired the design of a service to complement the Active Cues Tovertafel to support its implementation. The results of the design iterations were a valuable starting point for the development of the Tovertafel-service. Future evaluation studies of de Active Cues Tovertafel as a product-service system will give insights into the added value of the service.

2.3 The value of designing for play experiences

As part of G-motiv, the project took play experiences as a promising starting point to design for activation. The choice proved to be successful, and became leading for the final design. Initially, it was expected that adding play experiences to ‘everyday life’ activities would motivate people to do them. However, the play experiences in themselves were so attractive, that they became the activity. It is intriguing to envision how the quality of daily life of people with moderate to severe dementia could be enhanced, by taking this insight to other domains of their daily life. Existing examples of play experiences show the potential of this approach, such as the design of a virtual beach, where one experiences the sensations for a day at the beach (“De Zon-Zeesnoezelruimte” in nursing home ‘De Vreugdehof’ in Amsterdam, The Netherlands), or the art project of a virtual train compartment where landscapes passing by on the wall suggest that the train is moving (“De Coupé”, designed by Y. Dröge-Wendel and L. Hellings for nursing home ‘De Bieslandhof’ in Delft, The Netherlands).

3. Reflection on a project-grounded research

3.1 The value of research as input for design

The overlap between design and research is ‘gaining knowledge’. It is evident that science created an immense body of knowledge that could benefit designers. However, the differences in language and platforms can be an obstacle for designers to use scientific research throughout their design process. During this project, the design was evidently fuelled

by research. The systematic review on the current physical environment and its relation to the level of physical activity of its residents with dementia gave us an accurate insight into the existing knowledge on the topic and it prevented us from making the wrong assumptions. Two years of several qualitative studies within the dementia care environment gave us rich insights into this complex service system and strengthened our empathy for the residents with dementia, but also everyone supporting them. These two studies were essential to design a product that fits into the dementia care context and support all stakeholders that are involved in the care service. Finally, the literature review to the suitability of play experiences for people in different stages of Alzheimer's disease helped us understand their brain functioning which guided our design process into the very last details of the games.

3.2 The value of validation of the design

The design aim for this project grounded research was to develop a playful product that stimulates people with moderate to severe dementia to reduce apathy. The resulting design concept is the 'Active Cues Tovertafel', which was evaluated with a small-scale study on its effects on the older persons' level of physical activity, social interaction and emotion. Despite the small scale of the current evaluation study, the results were positive and significant. However, a larger scale study would contribute to a more solid validation of how the Tovertafel benefits residents in nursing homes. Also, during this research and design project several secondary design goals elicited (for an overview see the Intermezzo) and future studies would contribute to a more integral understanding of the effects of the Tovertafel as a product-service system on the many stakeholders involved.

3.3 The limitations of the research

A systematic review gives an overview of the interventions in the nursing home environment that have been studied and published in peer-reviewed journals. This review is relevant for the research community and may inspire fellow researchers to do more intervention studies on environmental elements, as a stimulating environment is important

for the well-being of nursing home residents. Also, understanding the effect, often limited, of interventions in the nursing home environment is relevant for designers and may contribute to a critical view on their own design work. However, there are many more products available in the field of dementia care, but they were not subject of a scientific study and therefore are not part of our systematic overview. For this reason, our literature review does not give a complete overview of the products that are available for this group and gives a rather limited view on the scope of dementia-friendly products and environments.

The qualitative journey into the social context of residents in nursing homes, on the contrary, offered a broad pallet of insights that were valuable as starting points for our design phase. For time's sake, the study was limited to the residents and their caretakers. It is expected that a broader perspective, which includes family and friends, may enrich the insights that were collected even more.

3.4 Future perspectives

This research aimed to answer several research questions. We found many answers and new phenomena. Future studies in the following directions would benefit the dementia care domain:

- ▶ Evaluation studies of activating products in the dementia care context to learn more about the activating elements in the designs, but also raise awareness of its benefits in the dementia care context.
- ▶ Validation studies of the theoretical concepts that we distinguished during our qualitative studies to stimulating elements in the social environment of nursing home residents with dementia.
- ▶ Experimental studies to examine the results of our literature-based acquisition of suitable play experiences for people in different stages of Alzheimer's disease. Testing the different play experiences in the context of playing games could validate our findings and will give a better understanding of how these play experiences can be elicited.
- ▶ Design-research studies on co-design processes involving groups with

different cognitive challenges to learn more about group-specific requirements of co-design methods and tools and the role of the designer.

- ▶ Design studies of games that are specifically designed for people with moderate to severe dementia to gain a deeper understanding of the specific game design principles for this group.

4. Reflection on designing for and with people with moderate to severe dementia

In this section, we will reflect on the lessons learned while designing for and with people with moderate to severe dementia, both on a process level as on a content level.

4.1 Designing specifically for activating people with dementia

The motivation for design for activation is the insight that increasing one's level of physical activity increases one's health and one's overall quality of life. This project shows that this general insight needs to be fine-tuned to the specific user group one is designing for. The first step is defining the level of physical activity one is striving for. This might differ significantly for high-school students, pregnant women, or people with dementia.

In this project, the goal was not to activate residents 'as much as possible'. On the contrary, to contribute to the quality of their lives the aim became to reduce apathy. However, this had to be discovered during the research phase of the project: the initial goal was to stimulate people to walk more, a goal that would exclude nursing home residents who are unable to walk. During our research, we realised that reducing apathy is most relevant for people with dementia, and that this can be achieved in several ways, without excluding anyone, but rather with a bonding activity for the residents.

The project showed that when designing for activation, one needs to be sensitive to the relevance for and level of fitness of the target group.

One can easily be too ambitious, setting the goals too high, thereby inviting frustration. This sensitivity for the right amount of activation is developed in close relation with the group one designs for, as happened in the case of the Active Cues Tovertafel. In addition, the empathic skills of designers are needed to ensure that the level of activity one aims for are embedded in positive experiences.

4.2 The value of a co-design process

During the design process, an important shift occurred from designing *for*, to designing *with* people with moderate to severe dementia. This shift occurred while the first design proposals were tested with the residents in a small-scale nursing home: the residents took over and started playing, which led to a vivid co-creation session in which the Active Cues Tovertafel was developed. This co-creation process was not only crucial for the success of the design, it also created a genuine social atmosphere which was valuable for all participants involved in what was initially framed as 'testing'.

Being able to co-create with people with moderate to severe dementia was a surprise, and confronted us with our prejudices regarding co-creation: that one needs to be able to communicate and express their creative thoughts to be able to be a participant in a co-creation process. Also, the lesson learned is that in design for people with dementia, with the right tools and techniques, co-creation should not be set aside too easily as 'not-possible'.

4.3 The value of prototyping

The design process of the Tovertafel consisted of different design iterations, and all iterations were supported by prototypes, from Wizard of Oz style at the start to more advanced, high-fidelity versions in the later stages. These prototypes were essential for all parties involved in the iterations: it is through the (at times unexpected) interactions with the prototypes that the Tovertafel games were developed, and that the interaction principles were discovered. Also, the use of the prototypes allowed all participants in the co-designing process to participate in an equal way.

4.4 The limitations of the design

The research and design were executed in the Netherlands, which may explain why the design fits these countries. Simultaneously, this may also be a limitation of the design. For future developments, it is interesting to extend the research to other cultures and other contexts: what would a Tovertafel look like if it were to be used in Japan? Or in China? And what would be essential for the service that comes with it? For every new context of use, the Tovertafel will have to fit not only the new users, but also the new context of care. To achieve this match, the same sensitivity to what is needed applies as was developed during the development of this first Tovertafel.

4.5 Future perspectives on designing for people with dementia

This project aimed to improve the quality of life of people with dementia who live in nursing homes. This raises the question of how we envision quality of life in this later stage of life? Throughout the project, we became more and more aware that the quality of life does not lie in the attempt to lengthen its day. On the contrary, to cite Dame Cicely Sanders, “it is not about adding days to your life, but about adding life to your days.” This insight became the core motivation for activation of the people with dementia, as will serve as our drive for future developments. In addition, a different mind-set is needed from designers: it is not about designing games to add to the environment, which may make the environment only more confusing, but about making the environment playful by design.

5. Reflections on design for activation

This thesis started with the observation that our designed world tends to lead us towards an inactive lifestyle, hence the mission to explore the possibilities of designing for activation. The case of designing for the activation of people with moderate to severe dementia showed us that this mission can be achieved successfully, and in the previous chapter we reflected on some lessons learned that we believe can be taken into other design domains. The question is: what is design for activation, how can it be positioned in the design practice, in design education and in design research? We propose a twofold approach to design for activation:

the creation of general awareness in any design project and dedicated objectives in specific design projects.

5.1 Creating awareness for the possibly (de)activating impact of design

We envision that in any given design project, designers should be aware of the possible impact of their design on the physical activity of their intended and unintended users, and develop a vision on how to address the topic in their project. Such a mind-set should be present in all designers, no matter the design goal and context. To take the possibility of activation into account when designing, or at least to avoid unintended deactivation, designers should take responsibility and make a well-informed decision regarding the impact of their design on (de)activation of the end user. For this, the topic should be part of design education, just like sustainability and other social topics. Also, design for activation should be part of future design research agendas to ensure that designers can be informed sufficiently. To achieve the latter, we recommend collaborating with scientist from the field of human movement science, behavioural sciences, neuroscience, and other related fields is recommended, as occurred during our project.

5.2 Activation as dedicated objective in design (in specific design cases)

Besides advocating for general awareness in design for its (de)activating potential, we favour initiating specific design projects with the dedicated goal to create activating environments. This perspective puts activation at the core of design, as the main objective of a design project, fostering an active lifestyle. This perspective will open up the vast space of design opportunities to design for activation, given the fact that there is so much potential in our world to design for. The perspective is promising because it does not tell the end-user he/she should be more active (should go to the gym, should take the stairs, should take my bike, and so on), but it is based on enticing people to become active.

This perspective will create several cases that will serve as inspiration for the previously described awareness in design, and will create a design research space where research can be developed to inform design.

6. Conclusions

We conclude this thesis by answering the research questions that were formulated for this project-grounded research:

1. Which factors in the physical and social environment of people with dementia, who are residing in nursing homes, influence their level of physical activity?

Through a systematic literature review (Chapter 2), we found evidence that elements in the physical environment of people with dementia, who are residing in the nursing home environment affect their level of physical activity. Positive results on the residents' levels of physical activity were found for music, a homelike environment, and functional modifications. Predominantly positive results were also found for the small-scale group living concepts. Mixed results were found for bright or timed lights, the multisensory environment and differences in the building footprint.

Through researching the nursing home environment qualitatively (Chapter 3), we elicited several elements in the social environment that may influence the residents' level of physical activity. The social interaction in the dementia care context appeared to be a complex interplay of various enablers and inhibitors for its residents' physical activity. Carers play an important role by their strategies to stimulate their residents, but their efforts are affected by the residents' attitudes. Between residents, too, social interaction seems to be crucial to be able to stimulate each other.

2. Which play experiences can be expected in general to be suitable for persons in different stages of Alzheimer's disease?

With a literature overview (Chapter 4) that was based on neuroimaging, neuropathological, and clinical studies, we identified which play experiences seem to be suitable for people in different stages of Alzheimer's disease (AD). We found that for all older persons with AD, regardless of disease severity, the play experiences sensation, relaxation, and reminiscence are likely to be suitable. The play experiences *nurture*, *sympathy*, *fellowship*, *expression*, *humour*, *eroticism*, *subversion*, and *challenge* may be appropriate only for those in the earliest and mild-to-moderate stages

of AD. The play experience exploration is most likely not suitable, irrespective of the stage of AD. For the remaining play experiences, we did not find sufficient evidence to draw conclusions.

3. Which playful user-product interactions that stimulate people with moderate to severe dementia are suitable to reduce apathy?

During a case study (Chapter 5), we co-designed six games (Intermezzo) with people with moderate to severe dementia, which have shown to be stimulating during a small-scale evaluation study (Chapter 6). During our design process, we identified several interaction principles that seem to contribute to the stimulating character of the product:

- ▶ A product can stimulate people with moderate to severe dementia by initiating the interaction.
- ▶ A product can support people with moderate to severe dementia to lengthen their time engaged with an activity by providing triggers whenever their attention drifts away.
- ▶ Sensory triggers can stimulate people with moderate to severe dementia to interact with a product.
- ▶ The detailed, colourful, unexpected and accelerating visuals seemed to be more activating than the subtle and unobtrusive ones, without causing sensory overstimulation.
- ▶ Interactions that cannot go wrong emphasise residents' abilities and create a safe environment for people with moderate to severe dementia to interact freely with the product.
- ▶ A so-called 'layered' design, i.e. a product that is suitable for persons with varying severities of dementia, seems to have a bonding effect and therefore stimulates social interaction and mutual encouragement to join in.

4. How can co-design contribute to the development of a new stimulating product for people with moderate to severe dementia?

During the design iterations in which we used co-design methods (Chapter

5), we learnt specific requirements to both the designers and the tools that we used to include people with moderate to severe dementia into the creative process of game development. The realistic prototype with room for experimentation was important for the people with dementia to participate in the process and express their creativity. However, the designer's sensitivity to the strenuous situation of the people with dementia and their relatives was important in terms of trust. Openness to the relatives and care professionals benefits the understanding of the designers. And a confident and empathic attitude from the designers is crucial for a successful collaboration with people with moderate to severe dementia during a co-design process.

Summary

Research finds that 90% of nursing home residents with dementia suffer from apathy (Kolanowski, Litaker, & Buettner, 2005). Dementia has a degenerative nature and diminishes people's memory, thinking, behaviour and functioning more and more over time. Lesions in the prefrontal cortex and basal ganglia, which are characteristic for several types of dementia, e.g. frontotemporal dementia and Alzheimer's disease (Levy & Dubois, 2006) reduce the ability to take initiative. Apathy is the most common behavioural change experienced by people with dementia. These findings are worrisome, as the absence of physical activity is related to the decline of physical health and cognitive capacities (Colcombe & Kramer, 2003). Apathy affects the older persons' physical flexibility, coordination and strength (Warburton, Nicol, & Bredin, 2006). On the other hand, exercise (Heyn, Abreu, & Ottenbacher, 2004) and leisure activities (Verghese et al., 2003) are associated with improved physical, cognitive and emotional well-being of people with dementia.

Designing for activation of people with dementia demands an articulation of the overall aim to improve health and quality of life. Improving health in general may be perceived as resulting in prolonging one's life. However, considering the severe deterioration in physical and cognitive functioning, typical for people in the last stages of dementia, we should question whether stretching the last phase of life is indeed the primal motivation. In this case, the motivation to activate is therefore more focussed on the improvement of the quality of daily life, rather than on slowing down the course of the disease.

The goal of the research and design described in this thesis is to develop a product-service system that stimulates nursing homes residents, living with moderate to severe dementia, to reduce their apathy.

A first step in understanding the context of residents in nursing homes was to explore the physical environment: what factors inhibit or stimulate physical activity? A systematic literature review addressed empirical

studies that measured the effects of environmental stimuli on the physical activity of nursing home residents living with dementia, addressing the effect of the built environment on the level of physical activity of its residents.

Positive results on the residents' levels of physical activity were found for music, a homelike environment and functional modifications. Predominantly positive results were found for the small-scale group living concepts. Mixed results were found for bright or timed light, the multisensory environment and differences in the building footprint.

The results of this chapter suggested improvements in different domains of design and policy. In particular, the results led to the insight that a Multi-Sensory Environment (MSE), which is also known as 'Snoezelen' is promising for the goal of this project. The MSE showed predominantly positive effects on the level of physical activity of people with dementia (Van Weert, Dulmen, Spreeuwenberg, Ribbe, & Bensing, 2005; Milev et al., 2008; Baker et al., 2001). However, the residents' exposure to the MSE is limited to the hours of treatment, whereas adapting multi-sensory elements into the communal areas could stimulate its residents throughout the day.

The second step into the exploration of the environment of residents in nursing home was to explore the effect of the social aspects on the level of physical activity. The research set-up is a journey consisting of 6 qualitative studies in nursing home environments, to explore the stimulating and inhibiting factors in the interaction between the residents and their carers.

The care professionals who participated in this study appear to be strongly aware of the health benefits physical activity offers. Also, the carers developed nine strategies to stimulate their residents to attend leisure activities and to actively engage in Activities of Daily Living (ADLs). These strategies vary from gentle (humour and optimism) to stronger approaches (being resolute about what is expected from them).

However, the social interactions in the dementia care environment that influence the activities of its residents appeared to be more complex. The interplay between attitudes of both the residents and caretakers are of influence. From this study, we derived three attitudes of carers, which gradually stimulate more independence: pro-active caring, supporting, and the wait-and-see attitude. Residents showed four different attitudes as a response to the stimulating strategies of the caretakers; (co)operative, compliant, hesitant, and resistant.

The social interactions between residents also seemed to have a strong influence on their level of physical activity. The direct interactions between residents are often poor, and may derive from diversity in backgrounds or misunderstandings. However, exchange is necessary to stimulate each other, or to do activities together. This insight led to the conclusion that the new product should have a social component that would facilitate social interaction. This component should be as simple as possible, recognizable, to be able to create a common ground.

The cognitive decline, which is typical for dementia, influences a person's cognitive, behavioural and emotional functioning. One may expect that reduced brain functioning also influences the experience of play. We explored the possibilities to assess which play experiences are still possible to elicit from people in the different stages of dementia. However, this appeared to be difficult due to the differences in the neuropathology between different types of dementia. As Alzheimer's disease (AD) is the most common subtype of dementia, with 65 to 80 percent of all cases (Alzheimer's Association, 2016), it seemed most relevant to study the experience of play for people with Alzheimer's disease. Moreover, the sequence of brain areas that are affected by the disease is similar for every person with Alzheimer's. In contrast, the neuropathology for people with vascular dementia, the second largest group, is different from person to person. Although we focused this study on people with Alzheimer's disease, during the development and evaluation of the product, we included nursing home residents with moderate to severe dementia, irrespective of the type of dementia. This has two reasons;

we design a product for the dementia care context and we do not want to exclude residents out of hand. Also, only by autopsy can the type of dementia be determined with 100% certainty, which makes it impossible to include only people with Alzheimer's disease.

The third step was a literature review to determine which play experiences can be expected to be suitable for persons in different stages of Alzheimer's disease (AD). Twenty-two play experiences were related to the neuropathology that is characteristic of the different stages of dementia: earliest, mild-to-moderate, and severe. This literature overview is based on neuroimaging, neuropathological, and clinical studies. We found that for all older persons with AD, regardless of disease severity, the play experiences sensation, relaxation, and reminiscence are likely to be suitable. The play experiences *nurture*, *sympathy*, *fellowship*, *expression*, *humour*, *eroticism*, *subversion*, and *challenge* may be appropriate only for those in the earliest and mild-to-moderate stages of AD. The play experience exploration is most likely not suitable, irrespective of the stage of AD. For the remaining play experiences, we did not find sufficient evidence to draw conclusions. We conclude that the choice of play experiences in game design for older persons with AD is dependent on the stage of the disease. Current recommendations may contribute to tailor-made games that are suitable for different persons with AD. Because the target group consists of people with moderate to severe dementia, we incorporate the play experiences sensory stimulation, relaxation, and reminiscence into the design vision. Also, we gained insights in the importance of avoiding play experiences that are not suitable for this group, such as exploration, because they will not be understood and might lead to frustration.

The three studies to explore the environment and the appropriateness of play experiences were the starting point for the design project. Several design iterations led to the final concept of the Tovertafel and its interaction principles. With a 'Wizard of Oz' prototype, we tested the initial design vision. The prototype served as a tool to initiate a user test with the residents and their carers. Contrary to what was initially expected, the nursing home residents with moderate to severe dementia

took up a participatory role during the Active Cues design process. Due to the more co-design approach that we chose during the design project, we collaboratively changed the initial design vision; from stimulating ADLs to stimulating play.

The Active Cues Tovertafel, developed during this PhD-project, is a playful product that consists of a collection of interactive games that are projected on a dining table. These interactive light animations connect the nursing home residents whilst playfully stimulating physical and cognitive activity and social interaction. Players are invited to reach for the light animations and they respond to players' hand and arm movements. These interactive light animations allow the players to 'play with light', as for example by throwing a ball to each other or sweeping away autumn leaves. Essential for the interactions between the people with dementia and the light animations is that they are intuitive and accurate. Also, all Tovertafel games are based on familiar projections to make the interactions recognizable and for the residents to reminisce about past experiences and personal stories.

Designers, residents, their relatives, and caretakers collaboratively developed six games for the Tovertafel that stimulate physical activity and social interaction. The participation of people with moderate to severe dementia and their immediate environment during our creative process was successful. It requires a realistic prototype with room for experimentation. From the designers, it requires sensitivity to the families' strenuous situation, empathy and well-developed communication skills to build a relationship of trust, and an open mind to new ideas and insights. The different iterations led to a final design of the Active Cues Tovertafel. Next, the thesis describes a small-scale evaluation study to the effects of the Tovertafel on the apathetic behaviour of nursing home residents with moderate to severe dementia. The Tovertafel was compared to two other situations: to the organised coffee drinking activity and to sitting in the lounge area without an organised activity. The 5-day small-scale evaluation study (n=6) shows that, according to the nursing home carers, the Tovertafel reduces apathy of older persons with moderate to severe

dementia by increasing their physical activity and social interaction. Moreover, the results also indicate improvements in happiness, and reduction of anger, fear and sadness. In sum, the present study shows that co-designed games can play a beneficial role in the dementia care context.

Although it is difficult to draw conclusions on the general effects of the Tovertafel from this small-scale evaluation study, the results are promising and in line with the experiences of the nursing homes who have acquired a Tovertafel for their residents.

Samenvatting

In zorginstellingen lijdt 90 procent van de bewoners met dementie aan apathie (Kolanowsky, 2005). Dementie is een progressieve degeneratieve aandoening en reduceert steeds meer het geheugen, de cognitieve vaardigheden en het functioneren. Aantasting van de prefrontale cortex en de basale ganglia, kenmerkend voor verschillende vormen van dementie (Levy & Dubois, 2006), verminderen het vermogen om initiatief te nemen. Apathie is daarom een van de meest voorkomende gedragsveranderingen bij mensen met dementie. Dit fenomeen is verontrustend aangezien een gebrek aan fysieke activiteit leidt tot een vermindering van lichamelijke gezondheid en cognitieve vermogens (Colcombe & Kramer, 2003). Beïnvloedt apathie de fysieke mobiliteit, de coördinatie en de spierkracht (Warburton et al., 2006); lichamelijke oefening (Heyn, Abreu, & Ottenbacher, 2004) en recreatieve activiteiten (Verghese et al., 2003) hebben daarentegen een positief effect op het lichamenlijk, cognitief en emotioneel welzijn van mensen met dementie.

Ontwerpen voor een actieve levensstijl voor mensen met dementie vraagt om een genuanceerde aanpak om gezondheid en kwaliteit van leven te verbeteren. Over het algemeen zal het verbeteren van de lichamenlijke gezondheid worden ervaren als een poging om het leven te verlengen. Echter, gezien de ernstige verslechtering van het fysieke en cognitieve functioneren, kenmerkend voor mensen in de laatste fasen van dementie, moeten we ons afvragen of het verlengen van de laatste fase van het leven inderdaad de primaire motivatie moet zijn. In dit proefschrift is de motivatie om mensen te activeren daarom vooral gericht op het verbeteren van de kwaliteit van hun dagelijks leven, meer dan op het vertragen van het verloop van de ziekte.

Het doel van dit onderzoek en ontwerpproject is om een product-servicesysteem te ontwikkelen om bewoners van zorginstellingen in de midden- tot late fasen van dementie te stimuleren om apathie te verminderen.

Een eerste stap was het in kaart brengen van de fysieke omgeving van mensen met dementie in zorginstellingen en met name: de factoren die lichamelijke activiteit remmen of stimuleren. Dit is onderzocht aan de hand van een systematisch literatuuronderzoek van empirische studies die meten wat de effecten zijn van prikkels uit de omgeving op de lichamelijke activiteit van mensen met dementie die in zorginstellingen wonen. Positieve effecten op de lichamelijke activiteit van bewoners werden gevonden bij het luisteren naar muziek, een huiselijk ingerichte omgeving en specifieke functionele aanpassingen. Overwegend positieve resultaten werden ook gevonden voor de kleinschalige woongroepen. Gemengde resultaten werden gevonden voor het effect van licht, een multisensorische omgeving en verschillen in de plattegrond van het gebouw.

De resultaten van dit onderzoek hebben geleid tot suggesties voor verbeteringen in verschillende domeinen, van zowel ontwerp als van beleid. Met name hebben de resultaten geleid tot het inzicht dat een multisensorische omgeving, ook wel bekend als een 'snoezelruimte' veelbelovend is voor het doel van dit project en gaf daardoor richting aan ons ontwerpproces. Deze ruimtes toonden overwegend positieve effecten op de lichamelijke activiteit van mensen met dementie (Van Weert, Dulmen, Spreuwenberg, Ribbe, & Bensing, 2005; ; Milev et al., 2008; Baker et al., 2001). Echter, de aanwezigheid van de bewoners in de snoezelruimte is beperkt tot de uren van de behandeling, terwijl multizintuiglijke elementen in de gemeenschappelijke ruimtes de bewoners de hele dag zouden kunnen stimuleren.

De tweede stap in de verkenning van de zorgomgeving van de bewoners met dementie is het onderzoeken van het effect van sociale aspecten op de lichamelijke activiteit. De onderzoeksopzet is een exploratie bestaande uit 6 kwalitatieve studies in diverse zorginstellingen, waarbij de stimulerende en remmende factoren worden verkend in de interactie tussen de bewoners en hun verzorgers.

De deelnemende zorgmedewerkers aan deze studie bleken zich sterk

bewust te zijn van de voordelen van lichamelijke activiteit voor de gezondheid van hen bewoners. Het zorgpersoneel deelde negen strategieën om hun inwoners te stimuleren om recreatieve activiteiten bij te wonen en om actief deel te nemen aan activiteiten van het dagelijks leven (ADL). Deze strategieën variëren van een zachte aanpak (humor en optimisme) tot een strengere aanpak (vastberaden laten weten wat er van hen wordt verwacht). Echter, de invloed van de strategieën op de bewoners bleek afhankelijk van meerdere sociale aspecten. Namelijk de wisselwerking tussen de attitudes van bewoners en verzorgers bleken van invloed te zijn op het succes van de strategieën. Uit deze studie hebben we drie attitudes van de mantelzorgers afgeleid, die geleidelijk meer autonomie van de bewoners stimuleren: de handeling uit handen nemen door het leveren van proactieve zorg, de bewoner ondersteunen bij handelingen, en tot slot, de handen-op-de-rugattitude en de bewoner zelfstandig de handeling laten doen. Bewoners toonden vier verschillende attitudes als reactie op de stimulerende strategieën van de verzorgers; meewerkend, gehoorzaamend, aarzelend, en met weerstand.

Tenslotte heeft de sociale interactie tussen de bewoners onderling een sterke invloed op het niveau van hun lichamelijke activiteit. Het aantal directe interacties tussen bewoners onderling is vaak beperkt, deels door diversiteit in achtergrond en deels door misverstanden. Echter, sociale interacties zijn een noodzakelijke voorwaarde om elkaar te stimuleren activiteiten samen te doen. Dit inzicht heeft geleid tot de conclusie dat een sociale component in het nieuwe product sociale interacties zou kunnen bevorderen en dus ook zou kunnen bijdragen aan het reduceren van apathie. Deze component moet dan wel herkenbaar zijn voor alle bewoners om zo een gemeenschappelijke ervaring te kunnen creëren.

De cognitieve achteruitgang, die kenmerkend is voor dementie, beïnvloedt cognitief gedrag en emotioneel functioneren van een persoon. Het is daarom te verwachten dat de verminderde werking van de hersenen ook de ervaring tijdens het spelen van spellen beïnvloedt. Het is van belang om te beoordelen welke spelervaringen nog mogelijk zijn in de verschillende stadia van dementie. Echter, dit bleek moeilijk

vast te stellen, vanwege de verschillen in de neuropathologie tussen de verschillende soorten dementie. De ziekte van Alzheimer (ZvA) is de meest voorkomende subtype van dementie: 65 tot 80 procent van alle gevallen (Alzheimer's Association, 2016). Het is daarom het meest voor de hand liggend om de spelervaring van mensen met de ziekte van Alzheimer te bestuderen. Daarnaast is de volgorde van de hersengebieden die worden aangetast door de ziekte van Alzheimer bij iedereen nagenoeg hetzelfde, in tegenstelling tot de neuropathologie die typerend is voor vasculaire dementie, de op een na grootste groep. Voor die groep verschilt de volgorde van hersengebieden die worden aangetast wel sterk. Ondanks dat we in deze literatuurstudie vooral de neuropathologie van de ziekte van Alzheimer hebben bestudeerd, hebben we wel ouderen met verschillende typen dementie geïnccludeerd in de ontwikkeling en evaluatie van het nieuwe product. De belangrijkste reden hiervoor zijn dat we in dit promotieonderzoek we een nieuw product voor de dementiezorg omgeving wilden ontwikkelen en daarmee geen bewoners willen uitsluiten. Daarnaast, is het enkel met autopsie mogelijk om de ziekte van Alzheimer met 100 procent zekerheid vast te stellen. Dat maakt het onmogelijk om de diagnose als inclusiecriteria te gebruiken.

De derde stap was een literatuuronderzoek om in kaart te brengen welke spelervaringen er nog geschikt zijn voor mensen in de verschillende fasen van de ziekte van Alzheimer. Tweeëntwintig spelervaringen zijn in verband gebracht met de neuropathologie van drie verschillende stadia in de ziekte: beginnende, midden-, en late dementie. Dit literatuuronderzoek heeft neuro-beeldvormende studies, neuropathologische studies en klinische studies geïnccludeerd. We hebben gevonden dat alle mensen met ZvA, dus onafhankelijk van de stadia waar van hun ziekte, de spelervaringen sensatie, ontspanning en herinnering hoogstwaarschijnlijk nog kunnen ervaren. De spelervaringen koesteren, kameraadschap, expressie, humor, erotiek, subversie en uitdaging zijn waarschijnlijk geschikt voor mensen in de vroege en middenfase van de ZvA. Exploratie is een spelervaring die waarschijnlijk voor niemand met de ZvA geschikt is. Voor de resterende spelervaringen hebben we onvoldoende bewijs gevonden om conclusies te trekken. Duidelijk is wel dat de keuze van de spelervaringen

die je als ontwerper wilt bieden gebaseerd zou moeten worden op van het stadium van de mensen met de ZvA waar je de spellen voor ontwerpt. De aanbevelingen uit dit onderzoek kunnen daarom bijdragen tot het op maat maken van spellen die geschikt zijn voor mensen in verschillende fasen van de ZvA.

In dit proefschrift ontwerpen we een nieuw speels product voor mensen met een zwaardere vorm van dementie en richten ons daarom op de ontwikkeling van het product gebaseerd op de spelervaringen sensorische stimulatie, ontspanning en herinnering. Inzicht in de spelervaringen die niet worden begrepen, en mogelijk zelfs leiden tot frustratie, helpen ons indirect ook in de ontwikkeling van een product dat geschikt is voor deze groep.

Deze drie studies waren het vertrekpunt van het ontwerpproject. Middels verschillende ontwerpiteraties hebben we het uiteindelijke concept van de Active Cues Tovertafel ontwikkeld. Met een 'Wizard of Oz'-prototype hebben we onze initiële ontwerpvisie getest. Het prototype is gebruikt om gebruikerstesten te doen met de bewoners van zorginstellingen en het zorgpersoneel. In tegenstelling tot wat wij voor mogelijk hielden speelden de bewoners zelf een hele interessante participerende rol in de ontwikkeling van het product. Hierdoor hebben we onze aanpak verschoven naar een co-designproces en zodoende gezamenlijk de ontwerpvisie veranderd van het stimuleren van activiteiten in het dagelijks leven naar het stimuleren van het spel.

De Active Cues Tovertafel, die is ontwikkeld tijdens dit promotietraject, is een speels product dat bestaat uit verschillende interactieve spellen die worden geprojecteerd op de eettafel. Deze interactieve lichtanimaties verbinden de bewoners in zorginstellingen met elkaar door op speelse wijze fysieke en cognitieve activiteit en sociale interactie te stimuleren. De lichtanimaties nodigen de spelers uit om te reiken met hun armen of te bewegen met hun handen, waar de animaties weer op reageren. De interactieve projecties maken het mogelijk dat de bewoners kunnen 'spelen met licht', door bijvoorbeeld een bal naar elkaar te gooien, of

door herfstbladeren van tafel te vegen. Essentieel voor de interacties tussen de mensen met dementie en de lichtprojecties is dat ze intuïtief en accuraat zijn. Anders verliezen ze snel hun aandacht. Daarnaast zijn alle Tovertafelspellen gebaseerd op herkenbare projecties om de interacties vertrouwd te maken en mogelijkheden te bieden dat de bewoners kunnen reminisceren over ervaringen en persoonlijke verhalen uit hun verleden. Ontwerpers, bewoners van de zorginstelling, hun naasten en het zorgpersoneel hebben gezamenlijk zes spellen ontwikkeld die fysieke activiteit en sociale interactie stimuleren. De deelname van de mensen in de midden- tot late fasen van dementie was succesvol tijdens de ontwikkeling van de spellen. Een realistisch prototype waarmee we konden experimenteren was daarvoor een vereiste. Van de ontwerpers werd verlangd dat zij sensitief en empathisch zijn voor de moeilijke situatie van de families en van uitstekende communicatieve vaardigheden zijn voorzien om een vertrouwensrelatie op te bouwen en open te staan voor nieuwe inzichten en ideeën.

De ontwerpiteraties hebben geleid tot het uiteindelijke ontwerp van de Active Cues Tovertafel. Tot slot beschrijft dit proefschrift een kleine interventiestudie waarin de effecten van de Tovertafel op het gedrag van de bewoners wordt geëvalueerd. We hebben de Tovertafel vergeleken met twee andere situaties: koffiedrinken aan tafel en ontspannen in de zitkamer van de zorginstelling. De evaluatiestudie van 5 dagen (n=6) laat zien dat volgens het zorgpersoneel de Tovertafel apathie kan reduceren voor mensen in de midden- tot late fase van dementie door fysieke activiteit en sociale interactie te stimuleren. Daarnaast laten de resultaten zien dat er tevens verbeteringen waren te zien in plezier, boosheid, angst en verdriet. We concluderen dat deze korte studie laat zien dat spellen die door middel van co-designmethoden zijn ontwikkeld potentie hebben om bij te dragen aan de dementiezorg.

Conclusies over de effecten van de Tovertafel zijn uiteraard moeilijk te trekken op basis van deze studie op kleine schaal, maar de resultaten zijn veelbelovend en komen overeen met de ervaringen van de zorginstellingen die reeds met de Tovertafel werken.

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Acknowledgements

Richard, in our first meeting about this project, you gave me the confidence that we could succeed. Although I stretched this project with a few extra years, I never doubted that the day would come that ‘memodemo’ would be successfully completed. You have taught me so much about applied research, product design, (project) management and challenged me to form my own research point-of-view. Your ambition, optimism and approach to life are an inspiration to me. And whether we write a few books-for-dummies, or map out life paths, as long as we have a good bottle of wine by our side, I am looking forward to it!

Marieke, I have often told people that you are much more than just my co-promotor. For almost a decade, you have been more of a life coach to me. With your trust, enthusiasm, critical questions and ethical dilemmas, you guided me to become the designer, researcher, and person that I am today. Because of you, I now understand what the word ‘sensitive’ means and it will always be one of the values to strive after in work and in life. Writing together always took place in beautiful places, alternated by long walks and good conversation. Although this dissertation is finished now, I hope that our week spent writing in Cape Town was not our last.

Erik, you are the inspiration for this dissertation. Passionate and encouraging as you are, you convinced me in less than an hour that it is crucial for people with dementia to become more active and that we can do something about it. You made me review thousands of abstracts, but have broadened my knowledge about research and taught me the neuro-lingo.

Thank you, Valentijn, for adopting me in the G-motiv team and introducing playful elements into my project, it became more fun! The CRISP-collaboration was crucial for the development of the Tovertafel and you helped me a lot with the evaluation.

My PhD journey became significantly less lonely when I found some fellow-travellers on the way. G-motiv, gmotiv or g•motiv, you were a feast

to work with! Thank you, Ellis, Niko, Katinka, Alessia, and Susana for the fun that we had and for inspiring me with all your different backgrounds and beautiful projects. And thank you, Michaël, Huib and Arnold for the informative conversations and discussions!

When I finished my masters, I expected to feel excited to explore the world outside of the IDE-walls. Instead, I felt somewhat sad leaving this faculty, which was still full of knowledge and people to learn from. Luckily, I could stay a few more years and I enjoyed my time in idStudiolab and being part of the AED section and Medisign group. There are countless people to mention and inevitable to forget some of you (sorry), but thank you Lyé, Armagan, Stella, Tischa, Henri, Daan, Anton, Jasper, Henk, Marian, Marijke, Johan, Suzanne, Iemkje, Peter, Annemieke, Pieter, Steven, Elmer, Paul, Elif, Nynke, Thomas, Fenne, Mathieu, Aadjan, Janneke, Marc, David, Ingrid, Gert, Natalia, Froukje, Pieter Jan, Onno, Reinier, Rob, Helma, Irene, Fien, Rene, Elisa, Jeroen, Jie, Sylvia, Marco, Alex, Maarten, Monique, Daphne, Amanda en Charleyne. And thank you, Ena for your enthusiasm and support.

In collaborating with the department of Clinical Neuropsychology, I could also explore the world inside the very-concrete walls of the VU University of Amsterdam. You gave this strange creature from Delft a very warm welcome into the team! Obviously, I spent many Fridays working in Amsterdam to not miss out on the Basket-afternoons. Thank you, Hester, Marjolein, Astrid, Karlijn, Gerdine, Hanneke, Tieme, Annabeth, Nanda, et al.

Thank you, St. Jacob (Amsterdam), Het Feitenhof (Elburg), and De Dierenriem (Hellevoetsluis) for your enthusiasm for the project. The collaborations were crucial for the development of the Tovertafel. I worked with many of your dedicated staff, but I would like to personally thank Carian, Marja, and Ingrid. Also, the residents and their family were incredibly important for this project. It would like to thank you for your trust and courage to do the unknown in challenging times. Besides the nursing homes, Monobanda and Novay also contributed to this

project. I want to thank Simon, Nikki, Rajiv, Sjoerd and Mathijs for their inspiration, long road trips to Hellevoetsluis and determination to get that prototype to work!

My paranymphs! Fleur, I wouldn't know what to do without you! Whatever question I have, about pretty much any topic, you have an answer. And your answers are evidence-based, always. I remember vividly your enthusiasm about one of my papers after I lost faith; your passion for research is contagious and although I leave that academic career to you, you inspired me during this PhD journey! Laura, we met each other between those concrete walls in Amsterdam, but you brought colour to our room. I learnt so much from you, brainy! Together we merged our fields into one study, which undoubtedly was challenging at times, but it brought us to Copenhagen (and the chapter with the most references in this dissertation). As I am writing this, I am wearing a snake-print top, just for you!

A couple of years ago, I named my design vision 'Active Cues'. Little did I know that Active Cues would now stand for a driven and capable team, who share my love for our target groups and fulfil our mission with boundless energy. I am so proud of what we do, and you inspire me daily to do what we do. 9.988.000 'geluksmomenten' to go...let's do it!

During the last weeks of finishing this dissertation, I received great help from several Active Cue-ers and I would like to thank you for the amazing work that you did (besides the other 99 to-dos on your lists). Thank you especially Yvonne, Thom, and Janna but also Rajiv, Judith, Claudia, Nanne, and Hannah for standing by me during these last exhilarating weeks! All credit for the layout and cover design goes to Yvonne, thank you.

I want to thank my friends who listened to my PhD-struggles, celebrated my PhD-victories, and supported me during this journey and in starting a new chapter. I am not sure how many Tovertafel-movies you must have seen by now, but your everlasting enthusiasm for my work often inspires me to forge ahead.

Thank you Yuna and Loe for warming my lap during the many hours writing this dissertation.

Thank you Reho, Laura, Nicholas, and Quarta for welcoming me as a family member. Your love and support make me feel at home, so far away from home. It is extraordinary that you travelled from the Karoo to The Netherlands for my defence and I hope for an unforgettable trip with not too much rain.

Lieve familie, pap, mam, Thom en Eef, dank jullie wel. Voor alles eigenlijk. In een aantal regels beschrijving wat jullie voor me betekenen lijkt een ondoenlijke taak. Maar of ik nou wilde leren schaatsen, mijn kamer geel-paars verven, in Delft studeren, een promotieonderzoek doen, worldcup windsurfen, naar Kaapstad verhuizen of een bedrijf starten, jullie zijn er altijd voor me en ik had het niet gekund zonder jullie.

Peter, my love. Thank you for being the thrilling person you are. We live our life at full intensity and you give me the energy to achieve the many dreams we share. I am excited about all that is still to come and I cannot wait for our next little adventure, who is on his way!



Curriculum vitae

Hester Anderiesen Le Riche was born in Amsterdam in 1982. After receiving her VWO diploma at the Fons Vitae Lyceum in Amsterdam and travelling through South-East Asia for a year, she moved to Delft in 2002 to study Industrial Design Engineering. After finishing her bachelor degree, she did a six-month internship in Cape Town, South Africa. During her master, Design for Interaction she participated in the Vehicle Design Summit that was initiated by MIT - Massachusetts Institute of Technology. In collaboration with many universities around the world she contributed to the design of an affordable city car for Bangalore in India.

Although she was inspired by the cross-cultural collaboration during the project, Hester found her passion during design projects that contributed to people's (social) behaviour and health. During her graduation project, she designed a product 'Scattered Connected' to support elderly of the future to stay connected and provide informal care amongst friends.

The topic of this dissertation 'Playful Design for Activation' was a natural next step after her studies. She is fascinated by how people experience the world, and how this influences their behaviour, and the use of products. She is passionate about research and design that benefit people with dementia, other groups with (cognitive) challenges and the people around them.

Hester founded her company 'Active Cues B.V' in 2015 with one of the CRISP partners, Monobanda Digital. Her vision for the company heavily relies on the work that is done during this dissertation and the values and principles of the CRISP project. With her company, she aims to establish 10 million 'moments of joy' per day in the care-ecosystem by developing playful products that enlighten people's daily life, but also contribute to their health and personal development. Following a co-design approach, she works in close collaboration with the target groups, their relatives, professionals and researchers to develop serious games that match their

specific requirements and wishes. The company shares their experiences and new insights, derived from these co-design projects, to inform and inspire other designers in the field. Active Cues launched three products; the Tovertafel Original for people with moderate to severe dementia, the Tovertafel UP for people with severe learning disabilities, and the Tovertafel Unique for children on the spectrum of autism.

Publications

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Prizes

New Venture winner for most innovative Dutch start-up company, awarded by the Ministry of Economic Affairs and consultant firm McKinsey & Company (2015).

Dutch Game Design Award for the Best Serious Game (2015).

Boer & Croon Co-generation Award for strategically collaborating with different generations and showing the added value of combined leadership skills and young talent (2016).

Research finds that 90% of nursing home residents with dementia suffer from apathy, which negatively influences their physical, cognitive, and emotional well-being. The goal of this project-grounded research is to develop a product-service system that stimulates nursing homes residents, living with moderate to severe dementia, to reduce their apathy. This thesis entails three preceding studies to inform the design project. A systematic literature review that addressed empirical studies that measured the effects of environmental stimuli on the level of physical activity of nursing home residents living with dementia. A qualitative exploration of the social environment of residents in nursing homes to explore the effect of the social aspects on their participation in daily and leisure activities. And a literature review to determine which play experiences can be expected to be suitable for persons in different stages of Alzheimer's disease. During a co-design process the Active Cues Tovertafel was designed together with the people with dementia, their relatives and carers making use of a 'Wizard of Oz' prototype. We developed six serious games for the Tovertafel, which projects playful interactive light animations on existing dining tables in the nursing home environment. The games were evaluated on their effect on the apathy of the residents with moderate to severe dementia during a small-scale study and the results show significant improvement in physical activity. Moreover, the results also indicate improvements in social interaction, happiness, and reduction of anger, fear and sadness. In sum, the present study shows that co-designed serious games can play a beneficial role in the dementia care context.