

Codesigning communication in dementia

Participatory encounters with people with dementia and their families towards personalised communication strategies

Rita Maldonado Branco

Faculdade de Belas Artes
Universidade do Porto
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FACULDADE DE BELAS ARTES
UNIVERSIDADE DO PORTO

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Participatory encounters with people with dementia and their families towards personalised communication strategies

Rita Maldonado Branco

Dissertação para obtenção do grau de doutoramento em Design

Orientação: Professora Doutora Joana Maria Ferreira Pacheco Quental
Co-orientação: Professor Doutor Óscar Manuel Soares Ribeiro

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Abstract

The journey through dementia affects not only the people diagnosed, but it also has a profound impact on those around them. Known ways of communicating progressively become unsatisfactory, leading to vicissitudes and challenges in the maintenance of social relationships, which are, in turn, considered vital to the well-being of people with dementia. Gradually, dementia, and particularly Alzheimer's disease, interferes with people's independence in everyday activities. Hence dementia care inevitably focuses on the daily necessities, such as feeding and hygiene, often leaving little space and energy for finding ways to communicate in alternative and meaningful ways. In familial contexts this is overloaded by the emotional charge of realising the changes in communication, and many times by the lack of sensitivity to deal with these changes.

This doctoral research addresses the difficulty of communicating with and relating to people living with dementia, and offers designed opportunities for connecting with them. It adopts a personalised approach that attends to the uniqueness and idiosyncrasies of people with dementia and their close social circle, who are involved in this research as participants, to explore how design can enable them to develop personalised strategies to communicate, with a special focus on leisure and entertainment. Strongly influenced by the person-centred dementia care values, the sensitivity and respect for personhood of people with dementia and the attention to the maintenance of communication and social relationships, this research uses design practice as the main form of inquiry, driven by ethical and aesthetic concerns and an emphasis on empathy as a way to relate to participants and discern their reality. Research activities employ ethnographic methods such as observation and interviews, as well as design interventions and participatory design events, to get a deeper comprehension of the experience of dementia, engage people with dementia and their families in the design process, and understand their experiences of participation and use.

The research initiated with a preliminary observational study that took place in two care institutions hosting people with dementia, and subsequently invited people with dementia and their families to take part in the research, with the support of healthcare professionals. As a result of this process, several artefacts, either personalised or designed from scratch, were produced and delivered to the participating families. In parallel, dementia care literature was interpreted from a designer perspective and transposed into the design field, which yielded a set of considerations to inform and inspire the work of design researchers and practitioners working for and with people with dementia. Posteriorly, family members and healthcare professionals were interviewed in order to evaluate the processes and products that emerged from their collaboration, disclosing significant learnings about the value of the participation of people with dementia and their families in the codesign process, the experiences of use of the artefacts both in familial and institutional contexts, and the relevance of personalisation.

Main findings revealed that it is possible to codesign with people with dementia and their families, through adapting the process and activities to their abilities, preferences and needs, and that this involvement can be satisfactory and beneficial. In addition, the designerly analysis of dementia care literature can be a valuable source of inspiration and scientific information for design to contribute to the well-being for the person with dementia. However, to ensure this positive experience it is crucial to provide more guidance on the personalisation process and use at home. Considerations and recommendations to address this issue are also outlined and discussed. In overall, there is space for design to serve people with dementia and their social circle, not only through designing for but also through designing with them.

Keywords

Participatory design; codesign; communication; dementia care; personalisation

Resumo

A experiência da demência afecta não só as pessoas diagnosticadas, como tem também um impacto profundo naqueles que as rodeiam. As formas conhecidas e comuns de comunicar vêem-se progressivamente comprometidas, resultando em desafios para a preservação e manutenção de relações sociais que, por sua vez, são consideradas vitais para o bem-estar destas pessoas. A demência compromete gradualmente a independência na execução de activitidades diárias e, por isso, os cuidados prestados às pessoas com demência centram-se inevitavelmente nas necessidades quotidianas mais elementares, como a alimentação e a higiene, deixando muitas vezes pouco espaço e energia para procurar formas alternativas de comunicar. As dificuldades estendem-se também, em contextos familiares, à falta de sensibilidade e, por vezes, de recursos emocionais para saber lidar com as mudanças que a doença implica.

Procurando conhecer e interpretar as dificuldades de comunicação e de relacionamento sentidas por aqueles que vivem com demência e os seus familiares, constitui-se como objetivo central desta tese identificar oportunidades de, pelo design, se desenharem novas aproximações. Para tal, adoptou-se uma abordagem personalizada, capaz de incluir a singularidade e as idiossincrasias das pessoas com demência e do seu círculo social – que são envolvidos neste projecto como participantes –, investigando formas de intervenção do design passíveis de os capacitar para o desenvolvimento de estratégias de comunicação, focando essencialmente momentos de lazer e entretenimento.

Este estudo tem o design como principal forma de indagação, assumindo preocupações éticas e estéticas, orientando-se pelos valores das práticas dos cuidados centrados na pessoa com demência, a sensibilidade e respeito pela sua individualidade, e valorizando a empatia como forma de aproximação aos contextos e experiências de vida dos participantes. Na prossecução destes objetivos, foram empregues métodos etnográficos (com recurso à observação e a entrevistas), a par do envolvimento em

eventos relacionados com o design participativo, no sentido de se ter uma compreensão mais realista da vivência da demência, procurando a melhor abordagem para envolver os participantes no processo de design e entender as suas experiências na utilização dos produtos desenvolvidos.

Partiu-se de uma observação preliminar, realizada em duas instituições que acolhem pessoas com demência. Subsequentemente, algumas das famílias foram convidadas a participar no estudo, com o apoio dos profissionais de saúde dessas mesmas instituições. Deste processo resultou a concepção de vários artefactos, personalizados ou desenhados de raiz, entregues às famílias para conhecer o seu potencial de uso. Paralelamente, a literatura relacionada com os cuidados prestados à pessoa com demência foi interpretada na perspectiva do designer e transposta para a sua prática, de forma a informar, enformar e inspirar o trabalho de investigadores e profissionais da área do design que trabalham para e com pessoas com demência. Os familiares e os profissionais de saúde envolvidos neste projecto foram posteriormente entrevistados para avaliar os processos e produtos decorrentes da sua colaboração – revelando aprendizagens importantes sobre o valor da participação das pessoas com demência e das suas famílias no processo de codesign, sobre as suas experiências na utilização dos artefactos (tanto em contextos familiares como em contextos institucionais) ou ainda sobre a pertinência da personalização.

Da investigação empreendida sobressai a possibilidade efectiva de se desenhar com pessoas com demência e com os seus familiares, adaptando o processo de design e actividades inerentes às suas capacidades, preferências e necessidades, daqui decorrendo um envolvimento que pode ser satisfatório e benéfico. O olhar do design, cientificado pela literatura sobre os cuidados prestados à pessoa com demência, pode constituir uma importante fonte de inspiração e de projeto, antecipando importantes contributos para o bem-estar destas pessoas. A participação e contributo do design estende-se, também, à orientação necessária ao processo de personalização e utilização dos artefactos em contexto familiar, propondo considerações e recomendações que são também apresentadas e discutidas. Em síntese, conclui-se haver espaço para o design servir a população com demência e o seu círculo social, não apenas desenhando para eles, mas também (e sobretudo) com eles.

Palavras-chave

Design participativo; codesign; comunicação; demência; personalização

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1 Introduction

This research emerges from a journey that started a while ago with my perplexity regarding the life changes brought by dementia, not only for those diagnosed but for the whole family. This inquietude comes from my first-hand experience with two grandparents diagnosed with dementia, my maternal grandmother and my paternal grandfather. Gradually, my grandparents ceased their usual activities which, for me, characterised them so much. My grandmother, a dedicated housewife who cooked devotedly and deliciously, became dependent on our help to eat while being very confused about where she was, even if she never left her home. My grandfather, a pharmacist by profession, but mainly dedicated to painting, ceramics, filmmaking and writing, left his passionate frenzy of being constantly creating and making new things, where we were all included, and passively sat down in a world that seemed to only belong to himself. Gradually, our common and known ways to communicate with each other became obsolete.

This puzzlement, this difficulty to reach who used to be so close, and the longing for making things together and communicating, impelled me to approach this issue from my professional perspective, with the aim to understand what design could do for dealing with this condition, and specifically to enhance the relationships between people with dementia and their families, or their close social circle. In parallel, the awareness about the epidemic scale of dementia, estimated to affect 46,8 million people all over the world (Prince et al., 2015), and the fact that it is considered to be the main cause of dependency among older people (World Health Organization, 2012), corroborated the relevance of working on this issue. Following this, during my MA, I worked on the representation of dementia—not only the information about it, but also using my personal experience to graphically interpret some of the symptoms observed in my grandparents in order to provoke reflection and convey empathy towards dementia—and developed artefacts to prompt communication and interaction, specifically for each of my grandparents, involving them and the rest of my family in this process. These artefacts



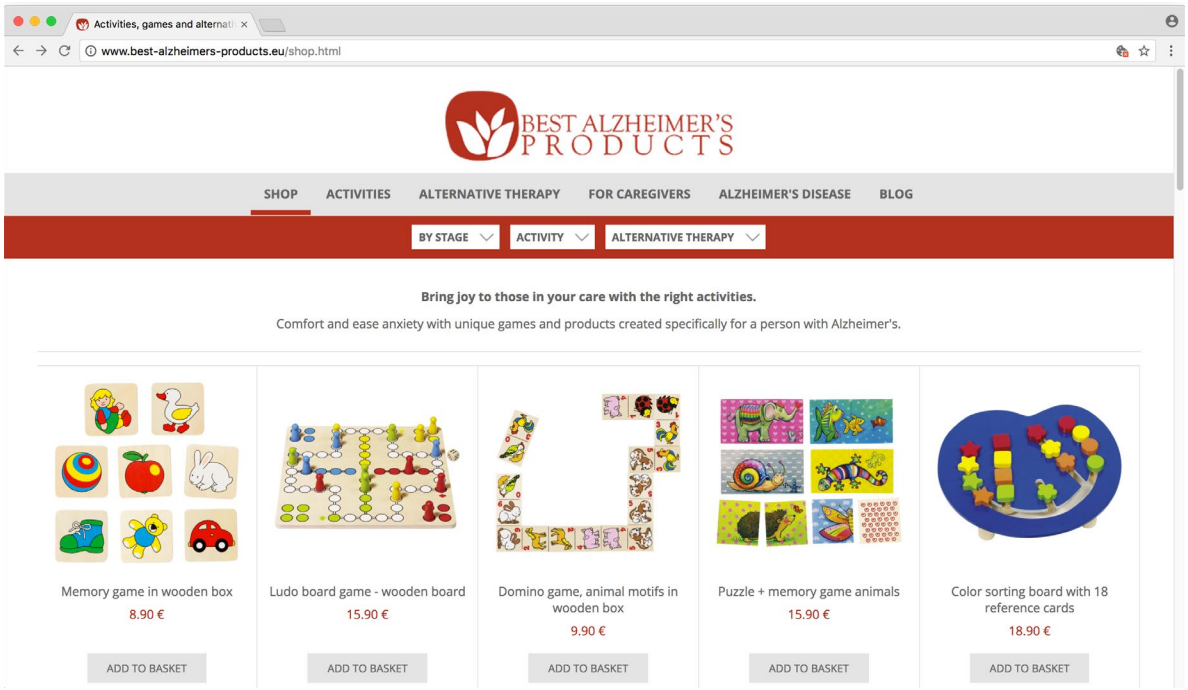


Figure 1.1 *The Alzheimer's Store* website (21.08.2017).

Figure 1.2 *Best Alzheimer's Products* website (21.08.2017).

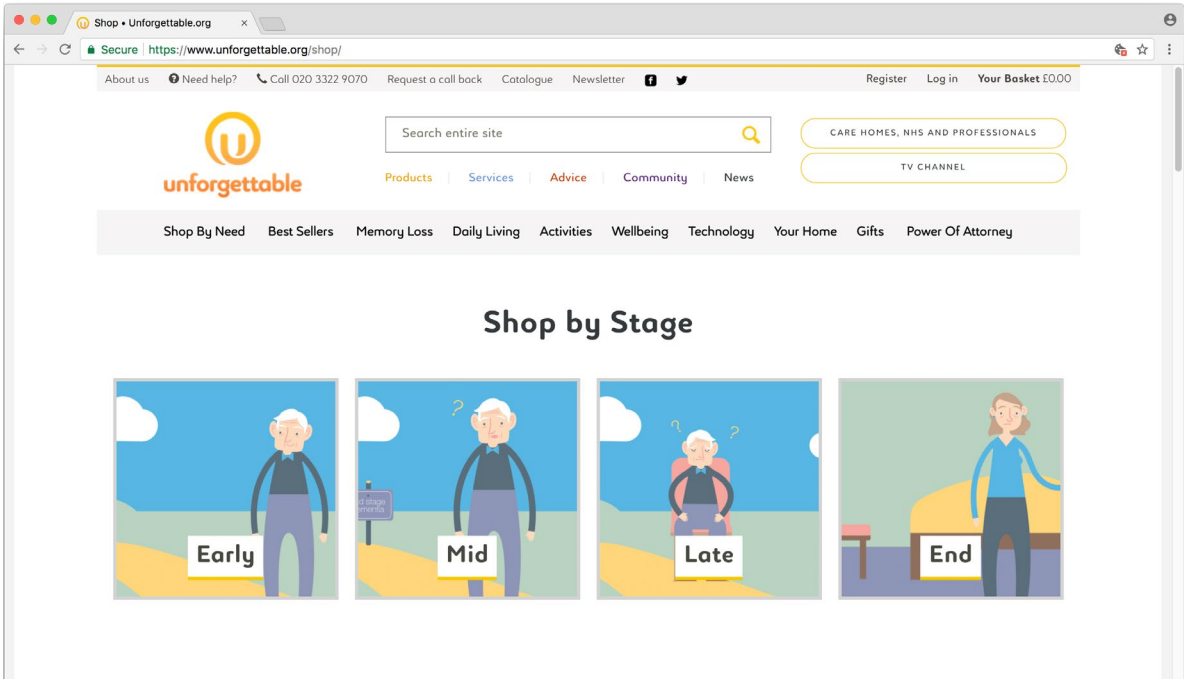
emerged very intuitively from the careful observation of their daily lives at that moment, our family needs and our knowledge about what could be appealing and engaging for them. The artefacts revealed to be adequate and interesting to my grandparents and, even if not for a long period of time, they became a means to speak and interact.

This experience, which was already the starting point for the current research, demonstrated the potential of design to mediate communication with people with dementia, namely if some degree of personalisation was incorporated—either through designing specially for a particular person, as I did for my grandparents, or through the envisaged possibility of having artefacts that are designed to allow families to personalise them. In this way, the current research revolves around communication (mainly related to its ludic, entertaining and social function), personalisation, and the essential involvement of people with dementia and their relatives to undertake this personalisation.

1.1 A brief journey through what is out there

When I started this project, back in my MA in 2011, it was not so easy to find specific products for people with dementia (and was even more difficult in Portugal). Essentially, these could be obtained from healthcare suppliers, sometimes not readily available or difficult to reach for individual families, and were mainly compensatory products (e.g. reminders, tracking and monitoring devices, etc) with a medical look[1]. The online information resource about assistive technology for people with dementia *AT Dementia* (www.atdementia.org.uk), or the *Alzheimer's Store* (www.alzstore.com) and *Best Alzheimer's Products* (www.best-alzheimers-products.eu) online shops were among the few that offered a selection of products for people with dementia. The latter had a stronger focus on activities for people with dementia, providing several products to support them. However, many of these were children's toys with an infantilising look. [Figures 1.1 & 1.2] In general, it seemed that there was little attention to the aesthetic attributes of such products, thus not very attractive and dignifying to my designer's and granddaughter's eye. Besides their unsatisfactory appearance, and in most cases their expensive cost, nearly all leisure products were foreign, thus using references (for instance in reminiscence materials) that were culturally unrelated to us. In addition, the type of products and activities seemed to be irrelevant and meaningless to the specific cases of my grandparents, not meeting their

1 By "medical look" I refer to artefacts that traditionally aim to enable and compensate for impairments in a very pragmatic way, without exploring as carefully the aesthetic and symbolic qualities of products, often camouflaging or hiding them. Pullin (2009) highlights this issue: "But is there a danger that this might send out a signal that disability is after all something to be ashamed of?" (p.15), and discusses the tension about discretion and fashion, typically concerned with projecting a positive image.



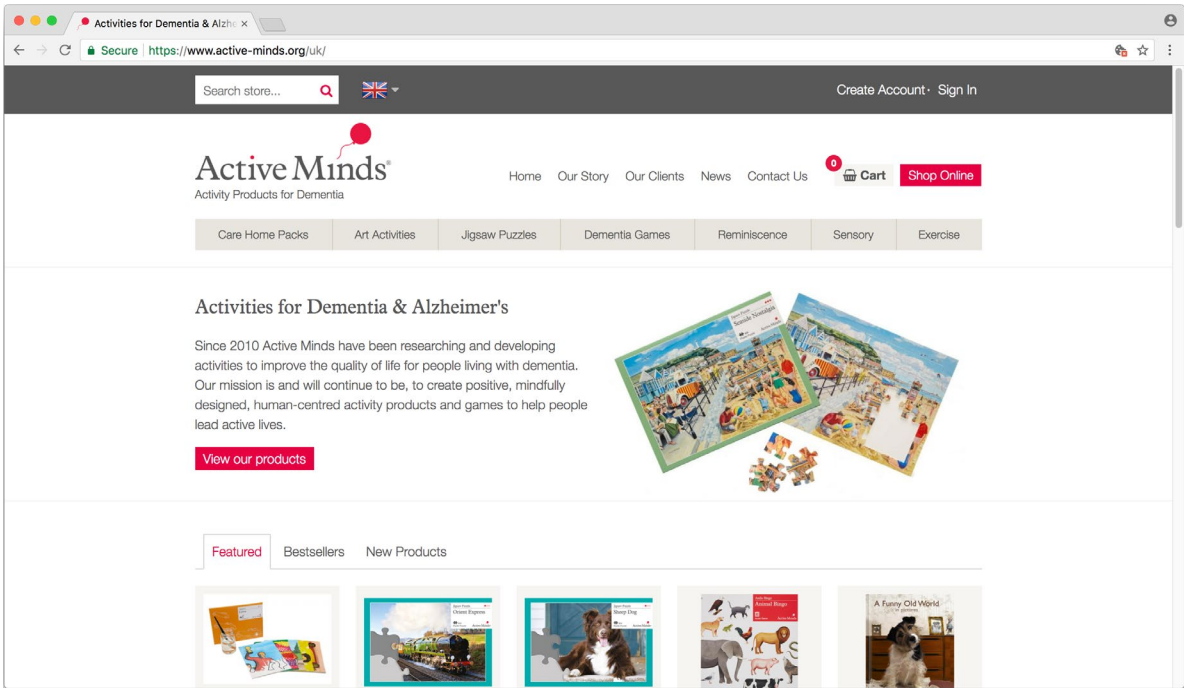


Figure 1.3
Unforgettable website (21.08.2017).

Figure 1.4 *Active Minds* website (21.08.2017).

preferences and idiosyncrasies, and did not respond to our needs as a family.

Nowadays, there is much more available. Generally, the awareness about dementia and its impact is much more widespread and publicly discussed. Specialised online shops multiplied, offering innumerous products for all aspects of care, and targeting families as much as institutions, like the *Alz Products* (www.alzproducts.co.uk), *Mind Start* (www.mind-start.com), *Active Minds* (www.active-minds.org), *Unforgettable* (www.unforgettable.org), and in Portugal, *Humanamente* (humana-mente.pt)[2], besides those already referred. Additionally, many of the Alzheimer's associations also have their own stores and, for instance, in the UK there are annual events like *The Alzheimer's Show* (alzheimersshow.co.uk), showcasing specialised products and services for people with dementia. However, most of the referred websites are repositories of the same products. Although more balanced today, there is still more supply of compensatory artefacts and the aesthetic qualities still seem to me dismissed in a great part of these products. Even the websites themselves are mostly not very inviting, confusing and difficult to navigate amidst the vast array of products they offer. Although there is more awareness about dementia, it seems that design and design research contributions are still scarce and not always accessible to people with dementia and their families. Exceptions are, for instance, the recently founded online shop *Unforgettable*, which presents the products in a more friendly way, and provides support material for families; and *Active Minds*, which not only sells but also designs mindful and positive activity materials for people living with dementia. [Figures 1.3 & 1.4]

Nevertheless, there is a need for more variety of careful designed products, and particularly those to engage people with dementia in communication and activities, so that it is possible to choose meaningful options that meet the uniqueness of each person. Although *Active Minds* started from a similar story of a designer who created adequate jigsaw puzzles for his grandfather with dementia, and offers an option of personalising a jigsaw puzzle with a personal picture, there still not much out there that allows the possibility of personalising and embedding idiosyncratic elements in the products available, so that they become more meaningful and pleasurable to use.

1.2 Previous work

As mentioned above, in previous research during my MA in Communication Design, I explored how communication design could contribute to dementia care. The outcomes of this research can be assembled into three groups: (1) an informative and (2) an empathic understanding about dementia;

2 These examples are conditioned by our search in Portuguese and English languages.



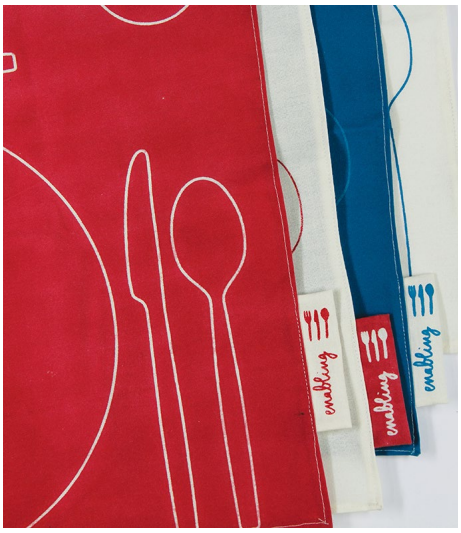


Figure 1.5 Laying the table with the help of the table cloth. [video—click on image to activate]

Figure 1.6 The table mats.

and (3) the mediation of interaction and communication[3]. The first group consists of visual representations of available written information about the prevalence, symptoms and causes of dementia. [Figure 3.13, p. 44]

The outcomes of the second group interpret dementia in a more experimental way, asking *what if graphic design had dementia?* This resulted in a set of artefacts, four books and one map, that were redesigned based on my personal experience with my grandparents, to embed graphic translations of dementia symptoms, inviting the reader to have an approximation to the experience of what it might be to have dementia: what if the structure and narrative of a book was affected by memory loss? What if typography experienced confusion? What if a map was disoriented? [Figures 2.1–5, pp. 20–21]

The third group of outcomes was inspired by specific challenges observed and experienced in the daily life with my two grandparents. Having been a housewife, my grandmother was still quite keen on helping out at home, even if she had difficulties performing the tasks. A tablecloth was designed to guide her in laying the table, by depicting the silhouettes of cutlery and crockery. She was able to make the connection between the visual representations and the objects, and managed to lay the table on her own. [Figure 1.5] The tablecloth was later redesigned as several table mats, to make it more flexible and accessible to a general public. [Figure 1.6]

In addition, in order to encourage conversation with my grandmother, I developed a set of cards about our family, which we knew was meaningful to her and thus a theme that could be captivating to talk about. Each card corresponds to a family member, showing a picture on one side and the name, a brief description and a question that can redirect to the other cards. Size, layout, typography and content were tested with my grandmother through

3 This work is described on Branco, R. M. (2014). How can communication design add value in the context of Alzheimer's disease? In A. Yoxall & K. Christer (Eds.), *Proceedings of the 2nd European Conference on Design 4 Health*. Sheffield: Sheffield Hallam University Art & Design Research Centre.

prototypes in an iterative process. She engaged with the cards, showing interest in the pictures and descriptions. They seemed to be a playful way to start a conversation, and to keep it going, while also allowing my grandmother to be entertained by just looking and reading them on her own. [Figure 1.7] Envisaging the possibility that similar cards could be used by other people, the layout was conceived as a template that could be personalised with what is important for a specific person, not only people but also places, objects, life events, etc, which we called the cards-about-what-matters. With a similar aim to facilitate communication about the family with my grandfather, but knowing that the cards format would not be engaging, I adapted this idea to a book. It was very difficult to start a conversation with him, since he was very withdrawn, but I observed that he spent a great part of his days reading, and thus I wondered whether we could reach him in this way. Family members were asked to write him letters that were compiled into a book, highlighting names and words that were important to him. My grandfather became very attached to the book, reading it several times a day. In addition, the book triggered some spontaneous verbal utterances about its content. He commented to a family member that the book *"is the portrait of our lives."* [Figure 1.8]



Figure 1.7 The cards-about-what-matters [more on chapter 7]

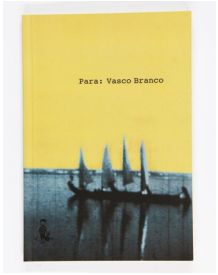


Figure 1.8 The book [more images on chapter 6]

1.3 Research Program

1.3.1 Foundations

While led by design practice, this research is grounded in dementia care literature that accounts for the deep respect for people with dementia and sensitivity to their *personhood*. The concept of personhood, proposed in the context of dementia care by Kitwood (1997), and emphasised by other authors that advocate the practice of person-centred dementia care, refers to a relational sense of self that is reinforced by others. Therefore, the maintenance of social relationships, through being in communication, constitutes a priority for dementia care (Killick & Allan, 2001), as well as the acknowledgement of each person's uniqueness and perspective of the world (Brooker, 2007). These resolutions became the main drivers for this research, exploring and interpreting them through design practice and the involvement of people with dementia and their families in the project. This supports our ethical stand, where people with dementia are not included as an object of study; instead, they are invited to participate, acknowledging and bringing their experiences and contributions to the core of the design process and practice (Cowdell, 2006).

Due to the aim to design *for* and *with* people with dementia, this research aligns both with inclusive views of design, such as inclusive design, and more dedicated approaches that embed the uniqueness of specific people, namely Pullin's (2009) views on designing for disability, along with participatory design and its democratic beliefs, as an opportunity

to involve people with dementia and their families in the research and design process. In addition, the approaches to design research that account for people's experiences and design for them, like experience design and design anthropology, are also pertinent to this research. Although I refer to design in a general way, encompassing examples and references from all kinds of design fields, I mainly use communication design practice in this research. This focus is related to my background studies in this area, namely print-based graphic design, but also to the main research purpose of designing for communication. Therefore, in this research, communication design is seen in a broad sense, where the aim is to generate artefacts that communicate with people and that mediate interpersonal communications, "the design of communicational situations" (Frascara, 2004)[4], where the role of the designer interchanges between designer, researcher, facilitator, and mediator.

1.3.2 Aims and questions

The overarching aim of this research is to design adequate and personalised strategies for ludic communication between people with dementia and those in their close social circle, inviting them to participate in this process. Therefore, the umbrella research question is

> How can design enable people with dementia and their social circle to develop personalised strategies to communicate?

This question was broken down into several objectives and research questions that consist of:

1. learning the values of person-centred care, based on respect and maintenance of personhood, and exploring how they can be used and reflected in the designed artefacts and in the configuration of the participatory design process:

   > How can artefacts be designed so that the personhood of people with dementia is maintained and respected?

2. exploring how codesign can be adapted to support participation regardless of the stage of dementia, respecting participants' abilities, needs and preferences and adapting the process accordingly, while promoting pleasurable moments for everyone involved, both during the design process and through the use of the artefacts developed:

   > How can participatory design be adapted to involve people with dementia and their social circle in finding and designing personalised strategies for communication and entertainment?

4 Although I align with the broad definition of visual communication design proposed by Frascara, in the sense that the designer creates communicational situations, I question some of the ideas presented by the author, namely the belief that design should be free of the personal presence of the designer.

3. using personalisation, meaning to design for a specific person, as a strategy to address the diversity inherent to dementia and respond to individual needs and preferences, but also as an invitation for people to engage in the codesign process; and understanding the relevance of this approach in the mediation of communication between people with dementia and those in their social circle

How does the personalisation of artefacts contribute to meaningful communication between people with dementia and their social circle?

The aim to deliver open artefacts and to provide means for families to personalise them, is associated with the recognition of the uniqueness of every person with dementia and the need to find proper ways to communicate meaningfully. In this way, we hope to contribute to maintain relationships and preserve the personhood of participants. We do not aim to have a medical contribution and do not expect to contribute to improve the cognitive condition of people with dementia. Being aware of the limitations that this kind of interventions has, our aim is to provide opportunities for communication, thus to be in relationship, and to so in a meaningful way, towards contributing to the subjective well-being of both people with dementia and those in their social circle.

1.3.3 Methodological approach

Committed to the aims exposed, design practice becomes the guidepost for all research activities, as a means to learn, inquire, make proposals and include participants. It is a practice-based project that takes a *research through design* approach (Gaver, 2012; Jonas, 2007), and draws on the *exemplary design research* proposed by Brandt, Redström, Eriksen, and Binder (2011). Accordingly, there is a dialogical relationship between the research questions and the research activities and experiments that, in this case, are driven by ethical and aesthetical concerns, the person-centred care values, the notion of personhood, and the quest for empathy, as a way to relate to participants and discern their reality. Research activities resorted to ethnographic methods such as observation and interviews, and experiments included both design interventions and participatory design events, to get a deeper comprehension of the experience of dementia, engage people with dementia and their families in the design process, and understand their experiences of participation and use. The core participatory design work was undertaken individually with each caregiving dyad, that was engaged in the personalisation of open artefacts or in the definition of a personalised design brief; as well as in the personalisation of their own participation, according to their availabilities, needs and preferences. This personalised participation was also characterised

by the effort to configure participatory activities as pleasurable moments of *conviviality*, involving participants in a respectful manner, attending and celebrating their uniqueness and personhood.

1.3.4 Context of research

This research is part of the Doctoral Program in Design, a partnership between the Faculty of Fine Arts of the University of Porto and the University of Aveiro, and the Research Institute for Design, Media and Culture (ID+).

The project was undertaken in collaboration with two different institutions in Porto Metropolitan Area, Portugal: the nursing home António Almeida Costa, in Gaia, that offers residential, day centre and home care services to older people, including some with dementia, with orientation from Dr. Ana Costa, who is also responsible for the project hOPENING Dementia; and the specialised dementia day centre S. João de Deus, in Porto, one of the few centres in the region dedicated to dementia, under coordination of Dr. Anabela Monteiro.

In addition, this research was enriched by spending nearly two months with the Center for Codesign Research, at The Royal Danish Academy of Fine Arts, Copenhagen, as a visiting researcher, as well as by the participation in several relevant workshops and conferences, where the work in progress was presented and discussed. Along with this, I participated in the organisation of three workshops about the involvement of people with cognitive impairments in design research, with the researchers Niels Hendriks (Social Spaces & Dementia Lab, LUCA School of Arts), Eva Brandt (Center for Codesign Research, at The Royal Danish Academy of Fine Arts, Copenhagen) and Karin Slegers (Meaningful Interactions Lab, University of Leuven), among others.

This research generated interest from several sources, mainly national, which resulted in some press articles, and the invitation to present the work in various contexts such as in Memory Cafes, on national television, in academic conferences of other research areas, and in 2016, as keynote speaker at the first Dementia Lab, an event dedicated to the discussion of designing for and together with persons with dementia.

1.4 Main research moments

Preliminary study: observation

Observation was undertaken in two care facilities and involved taking part in routine activities with older people with dementia. The design-led observation (Bichard & Gheerawo, 2010) drew upon the systematised data collection method of ethnographic participant observation, through the production

of extensive daily field notes (Angrosino, 2007; Calabrese, 2013; Fernandes, 2002) while keeping an intuitive and outcome-oriented glance of the designer described by Fulton Suri (2010) as *poetic observation*.

Preliminary study: board game development

Observed sessions inspired the development of a simple family board game, in response to the request of the day centre to develop a Christmas gift for their clients' families. The aim was to provide an opportunity for families to engage with their relative in a collective activity, through encouraging storytelling and affection, in parallel with simple challenges. This was an opportunity to put in practice what Gatt and Ingold (2013) called *anthropology-by-means-of-design*, a model of correspondence between anthropology and design, where new relationships are built through making things together. People with dementia and staff members contributed with ideas to include in the game, along with drawing and modelling of playing pieces. Additionally, the board game was adjusted to the intergenerational sessions in the nursing home.

Preliminary study: speculative exercise on materialising personhood

Starting from the *Positive Person Work* proposed by Kitwood (1997), a group of ten interactions that can enhance the well-being of people with dementia, and from the observation of these interactions during the fieldwork, we speculated on how to design for the experience of these specific interactions, taking into account different roles that artefacts can have in mediating them.

Participatory work with people with dementia and their families: trying and commenting on designed artefacts

Since some of the families had already received the board game, they were invited to play it for about 30min. The intention was to understand how participants played and interpreted the game, how they reacted to the several activities proposed and how they interacted with each other. Other families, that did not receive the board game, were asked to comment on three artefacts: the board game, a cards-about-what-matters (previously developed for my grandmother) and the family book (previously developed for my grandfather). All these artefacts were designed to be left open for personalisation, so that content is selected and adapted for and by the person with dementia and their family members.

Participatory work with people with dementia and their families: personalising an artefact or a design brief

Families were asked to contribute with content to adapt and personalise the chosen artefact. They were challenged to make it together with their relative with dementia and several family members, similarly to the group activities observed in the institutions. Alternatively, when families did not find any of the three artefacts appropriate for them, they were invited to engage in the definition of a design brief according to their needs and preferences.

In both cases (personalisation of an artefact or of the design brief) the process was also left open for participants to take control, adapting it to what was possible and reasonable for them to respond to the main aims of the project and suggested activities. Therefore, not only the artefacts were open for personalisation but also the process and the brief, which were defined, organised, and controlled by participants according to what suited them better, resulting in very different processes with each family.

From the eight participating families, two did not continue after the first meeting, four personalised the board game, one of whom also personalised the cards-about-what-matters and two others participated in the definition of a personalised design brief and subsequent prototype development, resulting in two new artefacts: the tactful things and the story-making card game. Depending on each family process, the development of most of these outputs also counted with the participation of healthcare professionals.

Evaluation

After prototypes were delivered and kept with participants for at least six months, a final evaluation was conducted, where family members and healthcare professionals involved in the research were interviewed.

1.5 Thesis structure

This thesis is composed of eight chapters, which can be grouped into two main parts. The first part makes an opening for the research undertaken, pointing to its relevance and advancing the main concepts and approaches. The second part describes, analyses and reflects on the research activities and experiments conducted throughout the doctoral journey, and presents its outcomes.

Chapters four and six are compilations of papers already published in academic journals and conferences, which are reproduced verbatim in this thesis[5]. This is a body of work that was already peer-reviewed and validated, hence the decision to include them in this way. Since each of these chapters comprise different papers that overlap each other in some aspects, we wrote an introduction to prepare the reader, highlighting the main differences and the focus of each of them. In order to make the rest of the thesis consistent with this decision, the other chapters were also written so that they can be read independently, even if the thesis structure follows the chronological occurrence of research activities and experiments.

Besides this introduction, chapter two presents the methodological approach, emphasising the fundamental values and concepts that underlie this

5 The images were not always included as in the published papers, since some of them were used repeatedly. To avoid using the same images, we either direct the reader to the page where the image was used before, or we substituted them with alternatives.

research, and explains further the research questions and main methods used. Since the chapters are independent, this was a way to assemble the core ideas that are important for what comes next.

Chapter three is a very short and entirely visual chapter, where the global impact of dementia is represented, and the symptoms and causes of dementia are visually interpreted.

Chapter four portrays the initial encounters with people with dementia during the observational study and the board game development while reflecting on the insights yielded from these activities, which became crucial in the configuration of the participatory process with people with dementia and their families.

Chapter five is a more conceptual chapter, that intertwines dementia care literature, and specifically the Positive Person Work interactions (Kitwood, 1997), with the observations from fieldwork and design strategising, to speculate about how to design for these ten interactions that are positive for people with dementia; thus exploring research question 1.

Chapter six describes the core experiments of this research, the participatory work with people with dementia and their families. It exposes the configuration of participatory moments and codesign activities, and explains the focus on personalisation as a strategy to include participants in the project. The processes of involving the different families are analysed (one of which is also described in detail). This led to the definition of a personalised approach to participation, where design, use and participation are open for personalisation according to the participants' availabilities, needs and preferences. Research question 2 is mainly addressed in this chapter.

Chapter seven brings all the experiments together in an evaluation of the project that focuses on the use and responses to the different artefacts, as well as on the participation and on the relevance of personalisation, thus reflecting on question 3. This chapter is grounded on interviews undertaken with family members and healthcare professionals that participated in this research and points to important considerations for designing for and with people with dementia.

The final chapter concludes with a summary of this research and its main findings and outcomes, and responds to the four research questions presented above. Finally, it ends by discussing possibilities for future research and implementation of this project.

2 Methodological approach

There are several approaches to design research according to the role and presence of design practice (Frankel & Racine, 2010). This PhD project uses design practice as the central form of inquiry: as a way of understanding dementia and the experience of dementia; interpreting dementia care literature and speculating about its applicability to design; creating tangible hypothesis and inviting people to participate (and facilitating participation) to collaboratively analyse and dwell on the proposals, towards generating adaptations, new possibilities, reflections and opportunities for intervention.

This designerly way of approaching research is commonly referred to as *research through design*. The term was originally proposed by Frayling (1993) and what it means and entails has been widely discussed in the design research community (Durrant, Vines, Wallace, & Yee, 2015; Gaver, 2012; Jonas, 2007; Koskinen, Zimmerman, Binder, Redström, & Wensveen, 2011; Zimmerman, Stolterman, & Forlizzi, 2010). In an interview conducted by the organisers of Research Through Design conference in 2015, Frayling states that "Research through design, as I see it, is taking design as a particular way of thinking and a particular approach to knowledge, which helps you to understand certain things that exist outside design" (Research Through Design Conference Series, 2015). Although there are distinct perspectives on research through design, Durrant et al. (2015) suggest that:

research *through* design

> it conveys, in a straightforward sense, how design may be understood as a knowledge-generating activity. This acknowledges that design provides a practice-based approach to raising questions about the world, and alternative perspectives and visions of the future, through making them tangible and relatable. (p. 9)

Contrary to the belief that research through design should be standardised (Zimmerman et al., 2010), Gaver (2012) emphasises the exploratory, speculative and prolific nature of research through design, and namely its capacity to produce outputs in the form of rich artefacts. Thus, methods, conceptual frameworks and theories that often emerge from research through

design are the result of the reflection on the designed artefacts that embody the designer's ways to address possibilities. Consequently, the same author suggests that design theory can be seen as an annotation of design practice, and introduces the concept of *annotated portfolios*: "An annotated portfolio, then, is a means for explicating design thinking that retains an intimate indexical connection with artefacts themselves while addressing broader concerns in the research community" (Gaver & Bowers, 2012, p. 44).

exemplary design research

These annotations can also be seen as the result of the constant dialectics between design experiments and the design program. Brandt et al. (2011) put forward the idea of *exemplary design research* driven by programs and experiments. A *design program* is a conceptual framing for the *design experiments*, which, in turn, will be *examples* of the possibilities of the program. The program is interpreted, explored and materialised through the experiments, and it is in the relationship between program and experiments that research questions are shaped and knowledge is obtained:

> Perhaps the most important difference between the design program and other constructs such as a hypothesis, is that while the hypothesis ideally should be quite precise and 'testable', a design program needs to be suggestive and open for the unexpected. ...it must at the same time be strong enough to maintain influence even when we are improvising, when spontaneous and intuitive (Brandt et al., 2011, p. 37; p. 41).

This PhD project draws from these design research approaches that are generative and open for exploration and spontaneity of design experiments while keeping a continuous and dynamic dialogue with the aims and research questions raised by the program interpretation. Although there is much emphasis on the methodological approach through an intense field and participatory work with people with dementia and their families, which was constantly being redefined and adapted to participants' needs and preferences, there is also much attention dedicated to the design qualities of artefacts and how people use them. In the remainder of this chapter, we present the design program, its main values and methodological choices and influences, and we outline the conducted design experiments.

2.1 Design program: mediating communication through design

> We must devote much greater energy to supporting the individual in remaining in communication, and therefore relationship, with those around them. (Killick & Allan, 2001, p. 20)

The starting point for this doctoral project, and overarching research question, is related with the aim to communicate and enhance social interactions and relationships between people with dementia and their families, exploring how design might facilitate and contribute to it:

> How can design enable people with dementia and their social circle to develop personalised strategies to communicate?

This question emerges from personal experience with close family members diagnosed with Alzheimer's disease. As a family carer, the need to communicate and relate to the relatives with dementia, and the experienced difficulty in finding ways to support it, motivated the interest to undertake this research. Additionally, dementia care literature highlights the cruciality of cultivating relationships and communication when caring for people with dementia (e.g. Allan & Killick, 2008; Brooker, 2007; Killick & Allan, 2001; Kitwood, 1997; Zeisel, 2009), constituting one of the essential elements of person-centred dementia care: "Recognising that all human life, including that of people with dementia, is grounded in relationships, and that people with dementia need an enriched social environment which both compensates for their impairment and fosters opportunities for personal growth" (Brooker, 2007, p. 12).

importance of communication and relationships when caring for people with dementia

Person-centred dementia care stresses the importance of all kinds of relationships and everyone's interdependence, including professional caregivers and family carers (Brooker, 2007; M. R. Nolan, Davies, Brown, Keady, & Nolan, 2004). In this research, although professional caregivers are involved and their collaboration is vital and invaluable, the main focus is on family relationships. This decision is related to the personal motivation but also justified by the immense impact that dementia has on family functioning and the fact that close family members are usually responsible for great part of the care delivered to their relatives with dementia (La Fontaine, Jutlla, Read, Brooker, & Evans, 2016; Whitlatch, 2014; S. H. Zarit & Zarit, 2008). La Fontaine et al. (2016) provide a comprehensive review about the experiences of people with dementia their family carers, and identify the need for individualised interventions for families, involving them and the person with dementia in the development of strategies to cope with dementia, to communicate and for meaningful occupation and activity, among other things. Moreover, since close family members and friends know the person well and have a history in common, Zeisel (2009) refers that the involvement of important others

focus on family relationships

is essential to read certain behaviours and to keep the person's narrative, providing meaningful content that might be useful to find ways to engage their relative with dementia. Therefore, this project aims to enable families to use the knowledge they already have, in order to include their relative with dementia in collective, entertaining and stimulating moments.

2.1.1 Personhood, ethics, aesthetics and empathy

This research is strongly influenced by person-centred dementia care values of respecting everyone as persons regardless of age and ability, esteeming and responding to their uniqueness through an individualised approach, understanding their perspective of the world and providing a rich social environment that supports personhood (Brooker, 2007). This approach to dementia care was originally advanced by Tom Kitwood (1997), who emphasised the importance of respecting and maintaining personhood of people with dementia through being in communication and relationship. Kitwood (1997) defines personhood as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (p. 8). These became the guiding values and the main drivers for the design experiments. The person-centred care values are interpreted from a design perspective, transposed to the design practice and in the involvement of people with dementia in the design process. These interpretations and translations are mainly described in chapter 5, but also in chapter 6 and 7. Like Wallace et al. (2013), our aim is to design for personhood: "An important distinction to emphasize is that we did not design for dementia we designed for personhood" (p. 2624).

personhood

ethics

This approach reflects an ethical position that does not view people with dementia merely as an object of study, but invites them to take part in the project and finds ways to support their participation, valuing their experiences, and bringing their voices to the core of the research. In addition, ethical concerns are present throughout the whole process, with an effort to respect and maintain personhood of people with dementia in the participatory activities, as well as in the designed artefacts. According to Cowdell (2006), including people with dementia in research requires sensitivity and flexibility, which are crucial to ensure participants' needs and wants are acknowledged, protecting them from anxiety and stress as well as being aware of potentially paternalistic attitudes. It is essential to build a respectful relationship with participants throughout the process, asking the researcher to develop a personal sensibility that will become key in enabling people with dementia to communicate and participate, a process that is commonly enjoyed by participants. In parallel with informed consent signed both by the participants

with dementia, whenever possible[1], and by the families, this mindful ethical attitude seeks continuous consent, and guides the research and design decisions, which were also informed and supported by the research team and healthcare professionals: providing information about the project to take home and introducing the project and the activities proposed at the beginning of the sessions; choosing an appropriate and friendly language both in the informational and activity materials, personal interactions and artefacts; being conscious about the possibility of confronting people with their difficulties, and with their condition[2]; focusing on the collective participatory activities, and taking into account participants' preferences and possibilities, and avoiding to speak about difficulties and dementia; welcoming everyone to participate despite their abilities and stage of dementia, constantly adapting the process so that participants contributed as they could and wished; designing materials and finding strategies to support their participation. Noteworthy decisions are presented and discussed throughout the thesis. The real names of participants have been replaced throughout the thesis to preserve anonymity.

aesthetics

Also important in this research is the notion of *aesthetics*, seen as a way to respect, dignify and value people through attractive and adequate artefacts, which become opportunities for aesthetic experiences as well as embodied and sensorial engagement. This is informed by our own design practice and values, as well as design and dementia literature, namely Pullin's (2009) call for attention to the importance of aesthetics to de-stigmatise artefacts for people with disabilities, Hassenzhal's (2010) definition of hedonic attributes as carriers on meaning, and Hughes' (2014) *aesthetic approach to people with dementia* that highlights the importance of sensorial and pleasing experiences to people with dementia, also as a means to communicate and interact in a holistic way, using the senses, gestures and actions.

empathy

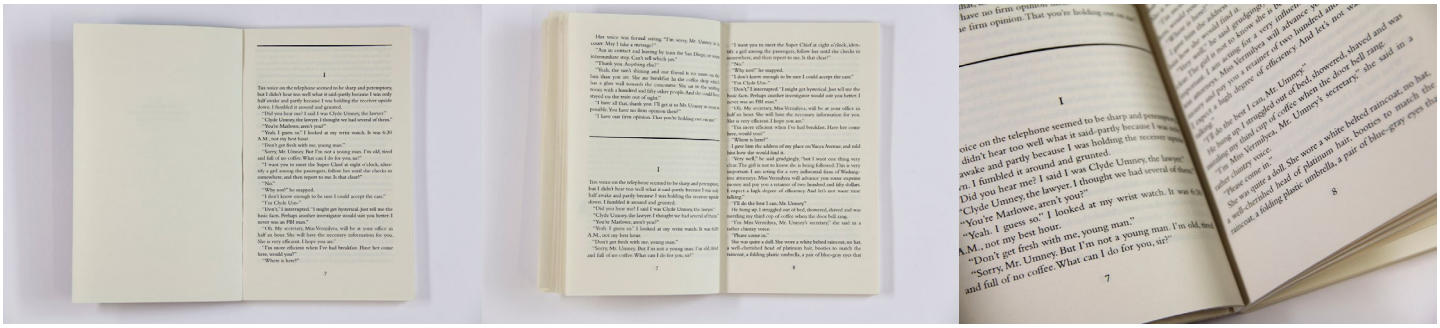
Similarly to other design researchers who designed for and involved people with dementia in design processes, this research emphasises the importance of developing *empathy* to understand people's experiences and build relationships (Hendriks, Slegers, & Duysburgh, 2015; Lazar, Edasis, & Piper, 2017a; Lindsay et al., 2012; Morrissey, McCarthy, & Pantidi, 2017;

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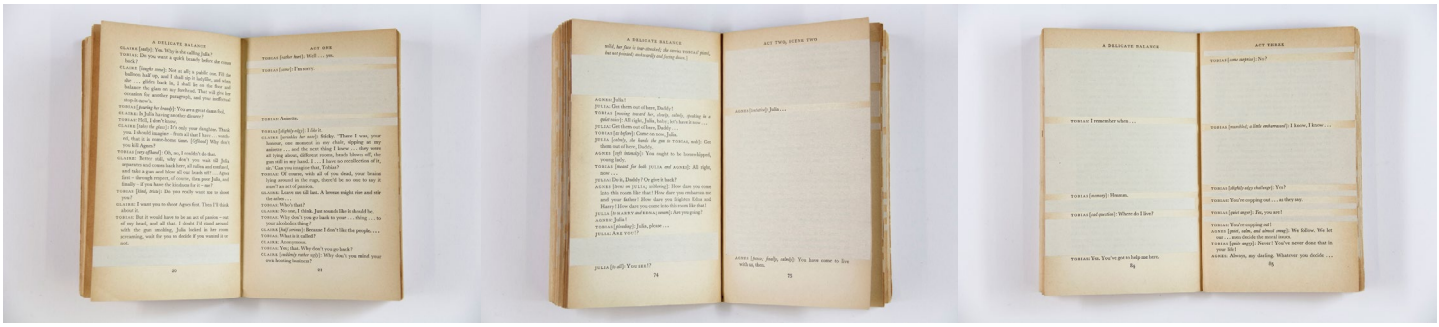
1 Some participants with dementia were unable to sign consent forms, either because the family members preferred them not to be present, or due to their stage of dementia. Instead, there was always an effort to explain the project as simple and clear as possible, adapting it to each person's communication, and seeking continuous consent through the ethical attitude described in the text. This is an inclusive way to approach consent, since the traditional informed consent becomes progressively irrelevant for people with dementia, and consequently preventing them to participate in research (Dewing, 2007).

2 Many people with dementia with whom we contacted did not know their diagnosis, either because their advanced stage makes it hard to understand if they are aware of it, or due to their family decision. Moreover, our commitment to not refer to dementia is not about hiding it or making it taboo, but to avoid that participants (namely family members) bring difficulties and issues into focus, and in that way, confronting the person with dementia. The idea was always to centre the attention on the positive aspects, on what can be done, and not so much on what cannot.

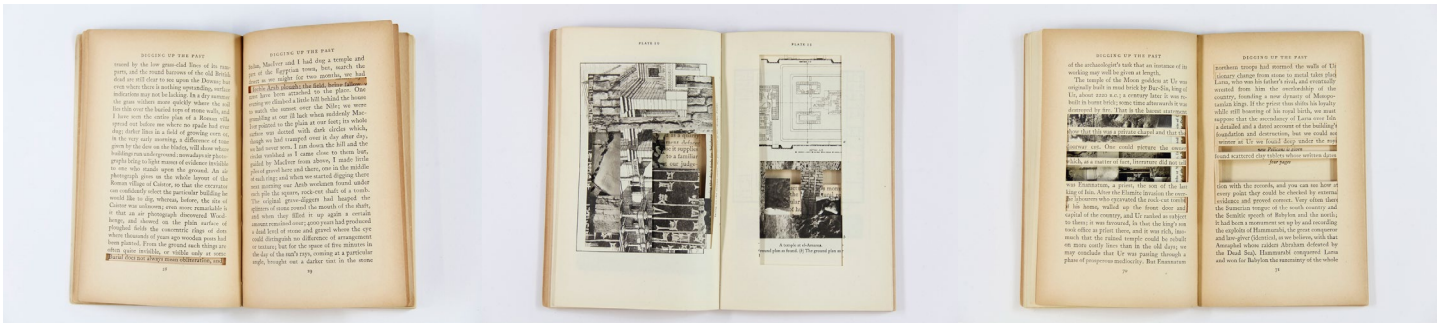
2.1



2.2



2.3



2.4



Figures 2.1–3 What if the structure and narrative of a book was affected by memory loss?

2.1 In *Playback*, the symptom of repetition was explored, through repeating its first pages until the end of the book.

2.2 *A Delicate Balance* is a play about a family and their friends. One of the characters was chosen to have Alzheimer's disease. This is represented by covering the other characters' speeches, as if the character with dementia progressively forgets about the others.

2.3 In book *Digging Up the Past*, parts of the text are gradually cut on every page throughout the book, resembling what happens with dementia, namely in Alzheimer's disease, which keeps 'digging' at the memories of those affected.

Figure 2.4 What if typography experienced confusion?

Four types of confusion were identified in my experience with my grandparents with dementia—regarding objects, places, people and time—and are represented by a system of four progressive typographic changes throughout the book.

[video—click on image to activate]

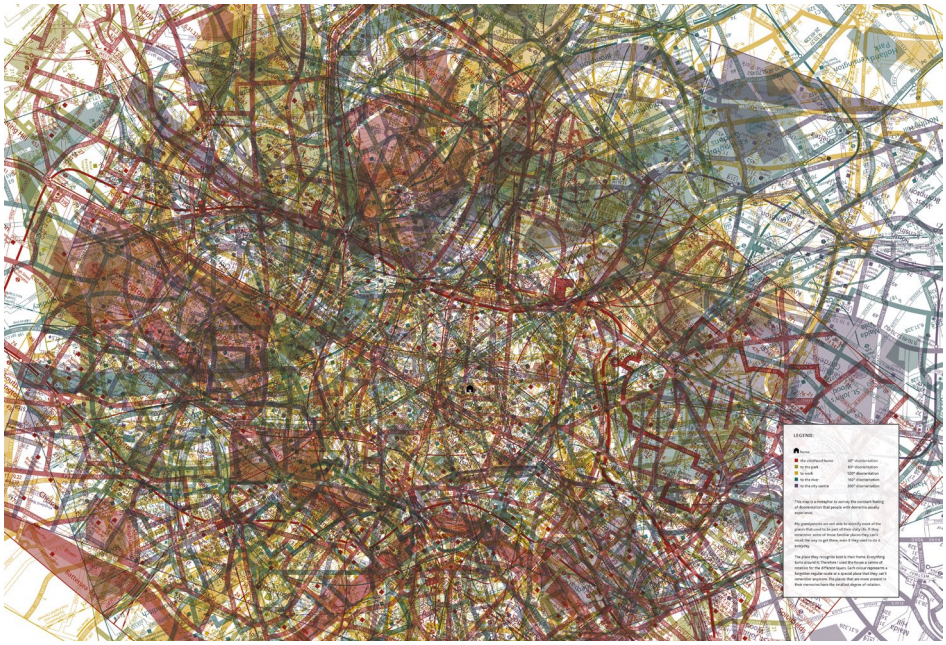


Figure 2.5 What if a map became disoriented?

In this map, home (a house) is the centre of rotation for layers that correspond to different other places. Usually, people with dementia recognise their home until later in their diagnosis. In addition, many people say recurrently that they want to go home.

Orpwood, 2009; Wallace et al., 2013), which is also convergent with person-centred care practices (Brooker, 2007; Killick & Allan, 2001; Kitwood, 1997). However, there are different views on empathy when designing for and with people with dementia. Brankaert (2016) asserts that it is not possible to gain an empathic understanding towards people with dementia, due to their distinct experience: "Because we design for people with dementia we cannot take their perspective through empathy. People with dementia have a cognitive impairment and are therefore too distant from our own perspective" (p. 18). Lazar, Cornejo, Edasis and Piper (2016) call attention to the fact that, many times, the effort to develop empathy for people with dementia results in sympathetic and diminishing attitudes, and highlights an approach to gain empathy, through acknowledging people's frame of reference, valuing and responding to their actions. McCarthy and Wright (2015) explain:

> Empathy is neither a feeling of sympathy nor an ability to identify with the other. It is an imaginative response to the other, an essential component of which is self-other differentiation, which moves along with them as they live out their experience, taking their perspective and anticipating where they are going. (p. 58)

This research subscribes to the latter view. The effort to develop empathy towards people with dementia was already present in previous work, where "empathy design exercises" were undertaken, seeking a more comprehensive understanding of the condition [Figures 2.1–5]. These were graphic interpretations of some of dementia symptoms that responded to the question *"what if graphic design had dementia?"* (Branco, 2014). Besides these exercises, and already during the doctoral project, the value of being in direct contact with people with dementia is highlighted for the whole process, enabling a continuous and symbiotic development of empathy as relationships are being built.
In chapter 4, the empathic process is described and the researcher's position, both as a designer and as a relative, is analysed, suggesting that this process is

non-linear and far more complex than the "Framework for Empathy in Design" proposed by Kouprie and Visser (2009).

2.1.2 Observation

design anthropology

In order to foster empathy and sensitivity to build relationships and work with people with dementia, as well as to understand their experience of the world, this research draws on Design Anthropology literature (Clarke, 2010; Gunn & Donovan, 2012; Gunn, Otto, & Smith, 2013; Smith et al., 2016) and uses hybrid methods that intertwine the tradition and subtlety of ethnographic research with a future-oriented and intuitive designerly way of looking.
In a preliminary phase, an observational study was conducted in two care institutions. The immersion in these contexts through observation combined the systematised production of extensive field notes from the ethnographic *participant-observation* (Fernandes, 2002; Angrosino, 2007; Calabrese, 2013), and what Fulton Suri (2010) calls *poetic observation*, a focused curiosity dependent on personal experience, imagination and intuition, that is strategic and generative, looking for opportunities and meaning for design decisions.

participant-observation

poetic observation

Still part of this initial study, but also an outcome of it, an artefact—the board game—was designed based on the activities with people with dementia observed in the two institutions. This artefact was both a way to materialise the observation findings and an opportunity to invite people with dementia and healthcare professionals within the institutions to participate in a codesign activity. The synergy between observation and making together was also informed by the *anthropology-by-means-of-design* model proposed by Gatt and Ingold (2013), that focuses on the relationships created with Besides being central to the preliminary phase of the doctoral project participants through making things together during fieldwork.

antropology-by-means-of-design

This initial study, described in detail in chapter 4, constituted a process of understanding by getting closer, sensing and empathising with people with dementia that influenced the structuring of the research project and the configuration of further participatory activities with people with dementia and their families. Besides being central to the preliminary phase of the doctoral project, the pursuit of understanding people's experiences, namely through observation, was maintained and found crucial in all moments of research.

2.1.3 Participation and codesign: a personalised approach based on conviviality

The choice of implementing a *participatory design* approach where people with dementia and their care partners are invited to collaborate is related to the aim of valuing their experiences and contributions, keeping their voices alive

in the project, which became crucial to the development of more adequate, meaningful and engaging artefacts. Robertson and Simonsen (2013) define participatory design as:

> a process of investigating, understanding, reflecting upon, establishing, developing, and supporting mutual learning between multiple participants in collective 'reflection-in-action'. The participants typically undertake the two principal roles of users and designers where the designers strive to learn the realities of the users' situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them. (p. 2)

Our participatory approach is tightly related to the practice of *codesign*, which Sanders and Stappers (2008) explain:

> By co-design we indicate collective creativity as it is applied across the whole span of a design process ... . We use co-design in a broader sense to refer to the creativity of designers and people not trained in design working together in the design development process. (p. 6)

participatory design and codesign in this research

In this research, participatory design is seen as an approach that configures and supports the participation of different stakeholders as partners in the project, which is put in practice through designing together—codesign. In this way, the terms participatory design and codesign are used in close association, with a subtle distinction that refers to participatory design as the general approach, and to codesign as the action through which the approach operates.

personalised participation

Our view of what constitutes participation is quite broad, valuing different forms of participation, including non-verbal, and responding to the participants' preferred ways of participating. As a result, similarly to the research of Wallace et al. (2013) and Hendriks et al. (2015), the work with each care dyad happened in a very individualised way, where personalisation was both an approach and a strategy to involve people with dementia and their families in a respectful manner, attending to their uniqueness and personhood. Besides the definition of their own participation, participants were engaged in personalising the design of leisure artefacts according to their individual needs, availabilities, preferences and stories, in two ways: as a starting point, they were invited to collaborate in personalising the content of open artefacts; alternatively, they were involved in defining a personalised brief for the development of new artefacts. Codesign activities ranged from the collective making of artefacts, the collective definition of design briefs and the collective personalisation of open artefacts, to the reactions to the use of props and artefacts and their incorporation in the iterative redesign of artefacts and the reflections on use that contributed to redefining design and use.

Related to the overall aim of the research project to promote communication and connectedness amongst family members, but also the understanding that people with dementia valued institutional activities for

conviviality

the collective aspect of making something together, we strived for making participatory activities as pleasurable moments of *conviviality*, where playing, sharing and making become ways to celebrate their personhood and what is meaningful to them.

Although observation and participatory design were founding methodological choices, research activities were not firmly structured from the beginning. Instead, they started gaining contours and were constantly being adapted as practice evolved, in an open and generative process that responded to the participants' idiosyncrasies.

2.1.4 Methodological influences of others who designed with people with dementia

Although referred to along the thesis, this sub-section highlights the work of other design researchers who designed with people with dementia that were influential to our approach.

involving people with dementia in the design process

Roger Orpwood (2009) was one of the first researchers to identify the relevance of including people with dementia in the design process, in order to gain an empathic comprehension: "There is a need to establish relationships with users, to immerse yourself in their world, if you are to have any chance of developing some empathy for their problems, and the implicit understanding of complex issues that goes with that" (p. 86). Following that, Lindsay et al. (2012) recognised the potential of using a participatory design approach to establish an empathic relationship with participants, so that the "enormous gulf of experience" (p. 521) between the experience of people with dementia and that of the designer/researcher can be bridged. Wallace et al. (2013) explored ways not only to understand the experience of dementia, but also the personhood of participants, through the development of bespoke design probes for empathy, which informed and led to the co-creation of digital jewellery pieces: "Understanding personhood is critical to any interaction design that mediates self for participants and the people who are important to them" (p. 2624). After seeking for guidelines (Hendriks, Truyen, & Duval, 2013) and recognising the challenges of doing participatory design with people with dementia (Hendriks, Huybrechts, Wilkinson, & Slegers, 2014), Hendriks et al. (2015) recognised importance of an individualised approach to codesign, that is adapted to each participant:

empathic relationships

understanding personhood

guidelines, challenges and the importance of designing for uniqueness

> Instead of searching for a dedicated approach for codesign with people living with cognitive or sensory impairments, we shifted to a view which focuses on cherishing the individual characteristics of every participant. ... When working with people with cognitive and sensory impairments, we are convinced that the approach in a design process should not only be adapted to the specific design situation at hand but to each individual participant as well. (p. 28)

Although not focused on research with people with dementia, McCarthy's and Wright's (2015) perspectives on *equality and difference:* "equality as the starting point and difference as the means, rather than inequality being the starting point and homogeneity being the endpoint" (p. 53); their notion of *dialogical relationships* as "mutually responsive relationships ... in which each party treats the other as differently placed centres of value, with different experience and expertise, people with feelings and values who can contribute to shaping their own and others' futures" (p. 9); as well as the value they attribute to a *sensible* dimension for configuring and undertaking participatory activities, where "*sensible* refers to what can be apprehended by the senses and therefore the idea that there is a distribution of the sensible draws attention to divisions between what is visible and invisible, sayable and unsayable, audible and inaudible, thinkable and unthinkable" (p. 41), were fundamental to this research. Morrissey et al. (2017) draw on this humanistic experience-centred design approach to work with people with dementia, understanding how people experience and feel the artefacts, and letting these experiences guide the research, finding ways to embed them in the design project. Despite the fact that this study was published after our participatory work was concluded, we believe it is important and shares similar values and *modus operandi*. Their approach works with specific people in their specific situation, in order to understand their specific reality, adapting to it rather than forcing participants into the research, and paying particular attention to the "embodied and sensual nature of experience" (Morrissey et al., 2017, p. 1332). In this way, artefacts can support communication in embodied ways, revealing not only how people use them but also providing them aesthetic experiences. These authors recognise that, although people with dementia do not interpret the future in the same way as people without dementia, they can contribute to the construction of future through their spontaneity, creativity and improvisation. Notions of empathy, ambiguity and enchantment are critical, as well as improvisational skills and the systematic documentation of the experiences. Morrissey et al. (2017) also stress the importance of "working with than against dementia" (p. 1334), meaning that although some compensatory artefacts can be useful, design should avoid 'fixing' people with dementia, which might be dehumanising in some situations. Instead, design should "explore the strengths of people with dementia – the remaining proficiencies, preferences, and passions – is not just ethical; it is likely to produce a design which is more in tune with their lives and likely to enrich their experiences" (Morrissey et al., 2017, p. 1334). Consequently, this approach allows a humanising and sensitive attention to participants' ways of communication, which are non-verbal, but very rich in other forms of expression (body movement, gesture, facial expression).

equality vs difference

dialogical relationships

redistributing the sensible

experience-centred design approach to work with people with dementia

Another important influence is the work of creative and arts practices in dementia care. This is strongly related to the initial observation study where the researcher helped with several activity sessions with people with

influence of arts and creative practices in dementia

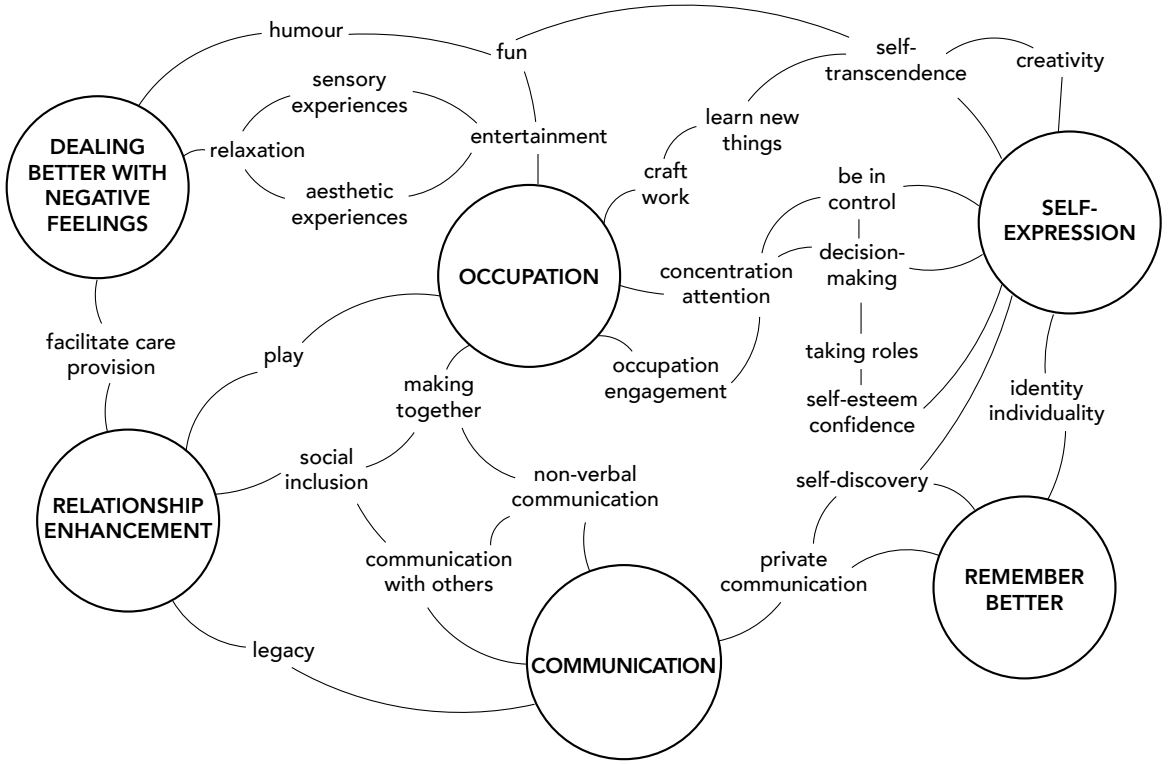


Figure 2.6 The value of arts in dementia care. Visual interpretation based on the book Creativity and Communication in Persons with Dementia, by Killick and Craig (2003).

dementia, understanding the attitude, types of exercises and structure, constituting an essential knowledge to configure participatory activities, as well as literature on the value of creative practice and the arts in dementia care, namely the work by Killick and Craig (Killick, 2012; Killick & Craig, 2011). Creative practice can become a meaningful occupation for people with dementia, making life more purposeful, helping to relax and to deal with the negative feelings inherent to dementia, making it easier to receive basic care from others, while being means for communication with themselves and with others and providing opportunities for making something together. Through creative practice, people with dementia can find a way for self-expression, for exercising control and decision-making, enhancing self-esteem and promoting self-discovery [Figure 2.6].

A recently published HCI study by Lazar et al. (2017a) also draws on art therapy practice in dementia care, as well as on person-centred care values. The authors' views on how design should work in a dementia care context and their position towards dementia (which they call *critical dementia*) highlight the fact that meaning-making relies on the context and on social and relational networks, without centring attention exclusively on the individual. Moreover, they stress the need to acknowledge people's non-cognitive forms of participation and their ability to communicate through physical and embodied interaction, focusing on what a person does instead of what she cannot do, and being able to interpret the meaning of those actions, even if resorting to others to do it (e.g. therapists, etc). This calls for a sensorial engagement that emphasises action and emotional understanding,

rather than rationalisation, recognising that people with dementia are able to express their emotions, even if they might do so differently. Therefore, the researcher should find ways to read bodily expressions and interactions in a detailed way. Similarly to Morrissey et al. (2017), the authors believe that cognitive impairment should not be something to compensate, but to work with, "pushes[ing] the boundaries of what constitutes participation and explores[ing] how diverse physical, sensorial, and emotional experiences opportunistically" (Lazar et al., 2017a, p. 2183).

2.2 Research questions, experiments and evaluation

After presenting the research program, its conceptual foundations and main methodological approaches, the derivative research questions and developed experiments are exposed.

As explained above, there is an interdependency and non-linear mutual influence between the definition of the research questions within the program and the configuration of experiments. The experiments are interpretations of the program, they are "exploratory probes into what the program may entail and how it can be expanded and sharpened" (Binder & Redström, 2006, p. 5). Among our experiments, we include design interventions, which mainly refer to the developed artefacts and their use, and participatory design events, which concern the instances where participants were involved in codesigning. Besides these experiments, the initial observational study and summative evaluation interviews were crucial research actions to prepare and configure experiments and to wrap them up. Participatory activities and artefacts' uses were constantly observed and reflected upon by the researcher and assessed by participants (including people with dementia, their families and healthcare professionals) throughout the whole project. However, to conclude this research we undertook a summative evaluation, to have a more comprehensive understanding of how participants viewed the research activities and outputs. Individual interviews with healthcare professionals and family members were conducted to find out about: their experiences of use; how artefacts, as well as the process, contributed to the promotion of meaningful communication; and how they interpreted and valued the artefacts, as well as reflecting on them taking into account person-centred care concepts. Moreover, they were asked about their experience of participating in the project, and about the relevance of personalisation. Chapter 7 describes the configuration of this evaluation moment in detail and analyses its results.

experiments: design interventions and participatory design events

evaluation

We already mentioned that the first and overarching aim of this research was the involvement of people with dementia and their close social circle in designing adequate and personalised strategies for ludic communication.

research questions

This main objective was partitioned into three research questions that frame and are explored through the experiments:

Q1: How can artefacts be designed so that the personhood of people with dementia is maintained and respected?

Q2: How can participatory design be adapted to involve people with dementia and their social circle in finding and designing personalised strategies for communication and entertainment?

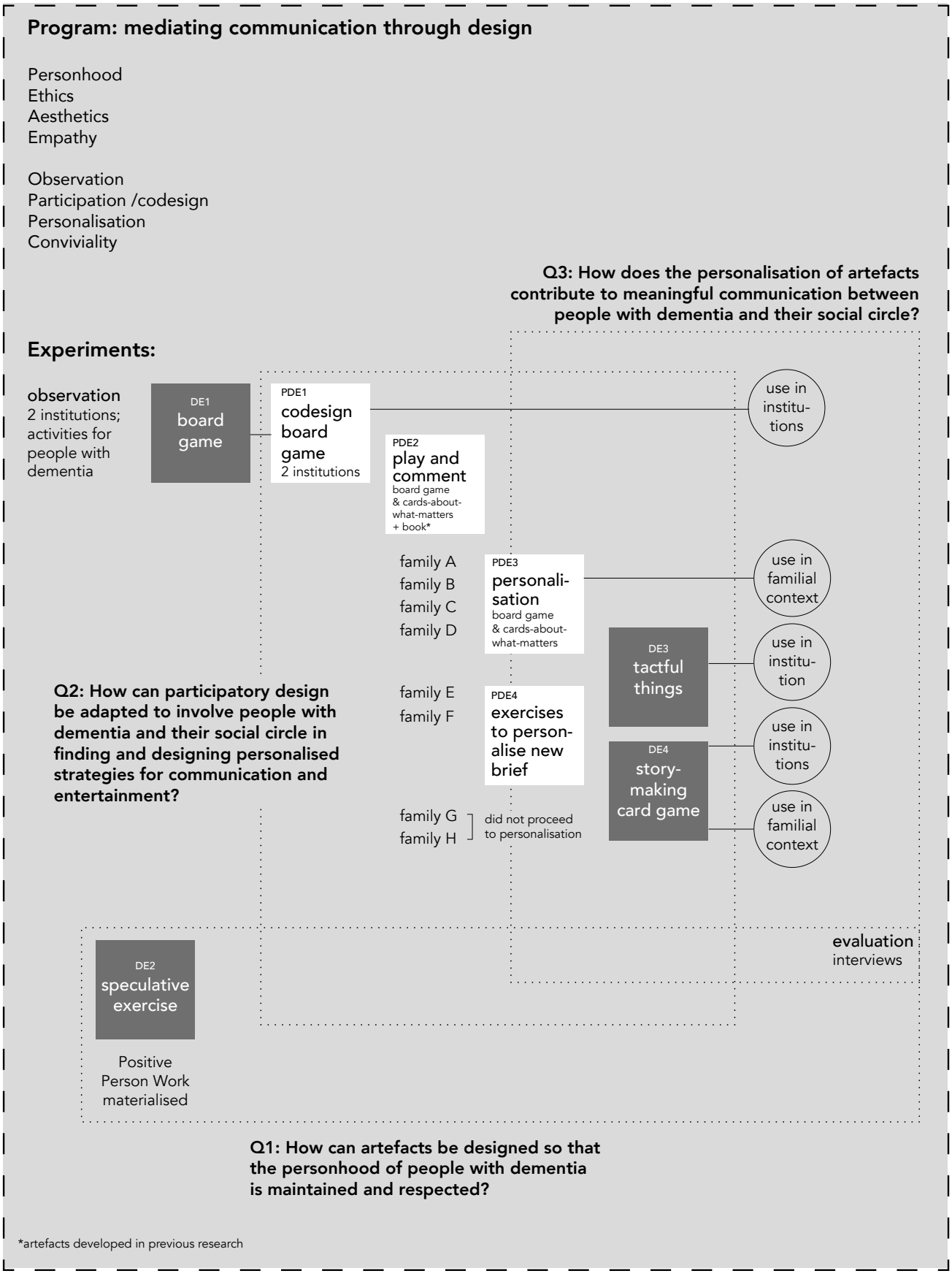
Q3: How does the personalisation of artefacts contribute to meaningful communication between people with dementia and their social circle?

relations between experiments and research questions

Most experiments address aspects of the three questions, although some are mainly related to a specific one. This thesis is structured around the main moments of research, which relate to these three questions. Main research moments and experiments comprise: (1) the preliminary observation-based study, and consequent design of the board game (Design Experiment [DE] 1) and involvement of people with dementia and staff of both institutions in defining and making it (Participatory Design Experiment [PDE] 1), which was the starting point for to reflect and define all research questions. In parallel, (2) another design experiment was being developed, consisting of a speculative exercise (DE2) about how to design for the ten Positive Person Work interactions that contribute to the well-being of people with dementia proposed by Kitwood (1997), thus exploring ways to answer Q1. The work proceeded with (3) the participatory work developed with families, which started by inviting them to play the board game and/or comment on this and other two artefacts developed in previous research, the cards-about-what-matters and the family book (PDE2). Eight families participated in this first meeting, but only six continued in the project. Four of them accepted the challenge to personalise one of the three open artefacts (PDE3). All four families chose the board game, and one family also personalised the cards-about-what-matters. The other two families, since they did not find any of the three artefacts suitable for them, were engaged in creating a personalised design brief (PDE4), resulting in two new artefacts, the tactful things (DE3) and the story-making card game (DE4). During this process, different ways of involving people with dementia and their families in a codesign process were tried and adapted to respond to participants needs and preferences, therefore working mainly on Q2. All artefacts were used by participants, who were then (4) asked to describe their experience and evaluate them, as well as their participation in the project. This evaluation moment was a way to learn and conclude about the work developed, and find answers to all questions, but especially for Q3. The following scheme aims to visually describe this process and relationships between experiments and questions as well as the chapter in which they are described in the thesis.

Figure 2.7 Map of design program, research questions and experiments—based on the diagram from XLab project (Brandt et al., 2011, p.24).

Question: How can design enable people with dementia and their social circle to develop personalised strategies to communicate?



3 About dementia

Dementia is a group of symptoms that gradually weakens cognitive functioning, affecting the ability to autonomously perform daily tasks and activities. It is the main cause of dependency among older people, thus also having consequences on the lives of those around them. It is considered a public health priority due to its epidemic scale and impact on health economics, and more importantly, due to its consequences on people's lives (World Health Organization, 2012).

This chapter presents a visual overview[1] of the global impact of dementia with the aim to demonstrate the relevance of working in this field, as well as a visual interpretation of how dementia is medically defined, the main diseases associated, and symptoms that constitute the basis for diagnosis. This visual description of dementia finishes with the positive notion which guides this research, that despite the difficulties that dementia entails, people living with this condition do not lose their personhood, and are unique and sensitive human beings, whose thoughts and emotions should be acknowledged.

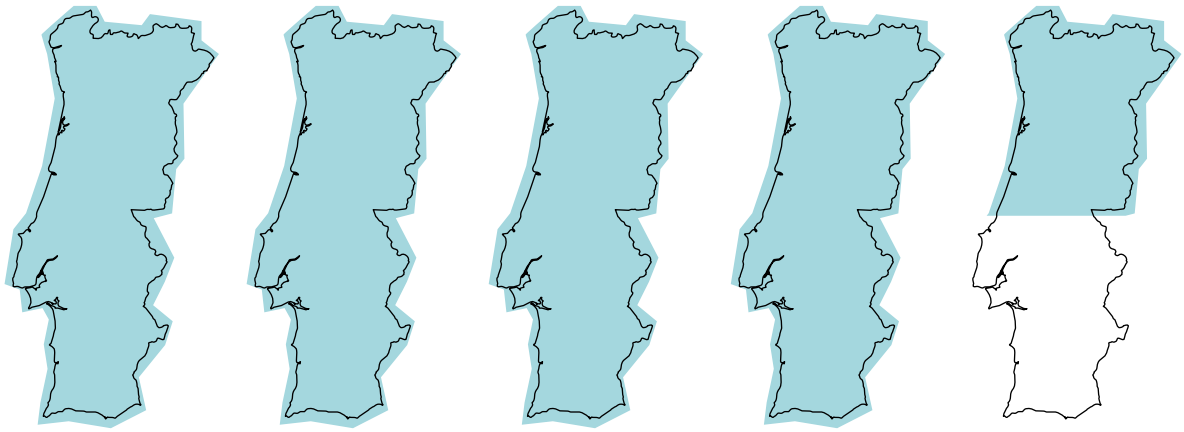
1 The standard information on the figures and facts about dementia was chosen to be presented visually because this is a thesis in design, thus making use of its visualisation tools to make data more eloquent.

3.1 The impact of dementia

3.1.1 Estimated number of people with dementia in the world

2015:

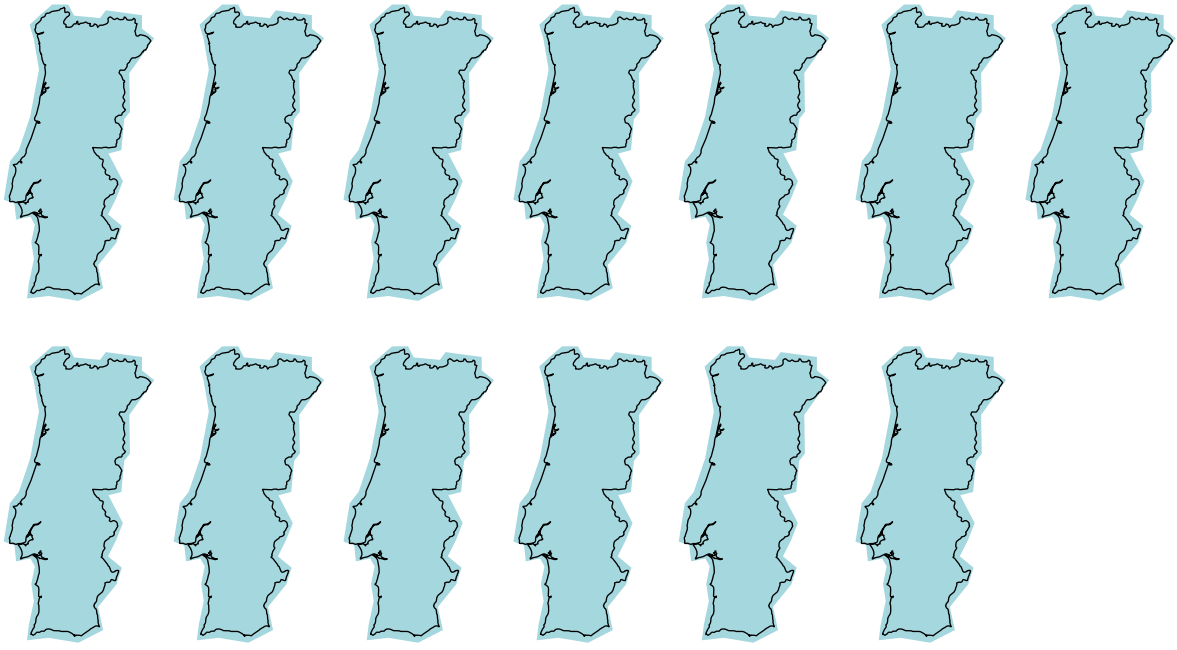
46 800 000 **people with dementia**



More than 4.5x Portugal's population (2015)

2050:

131 500 000 **people with dementia**

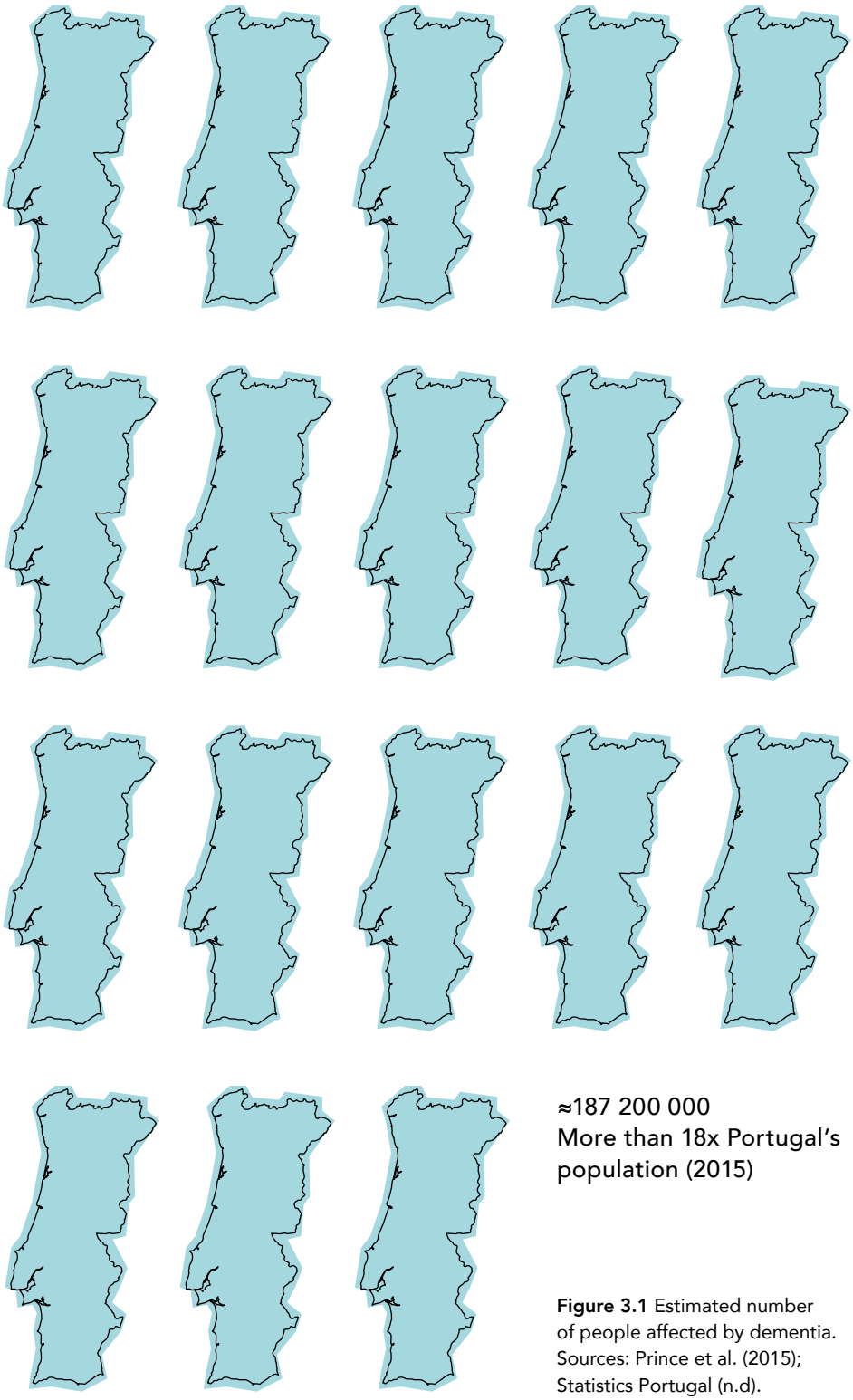


More than 13x Portugal's population (2015)

3.1.2 Impact on close social circle

Dementia not only affects those diagnosed, but also their close social circle, including family members:

46 800 000 x ≈4 relatives and carers

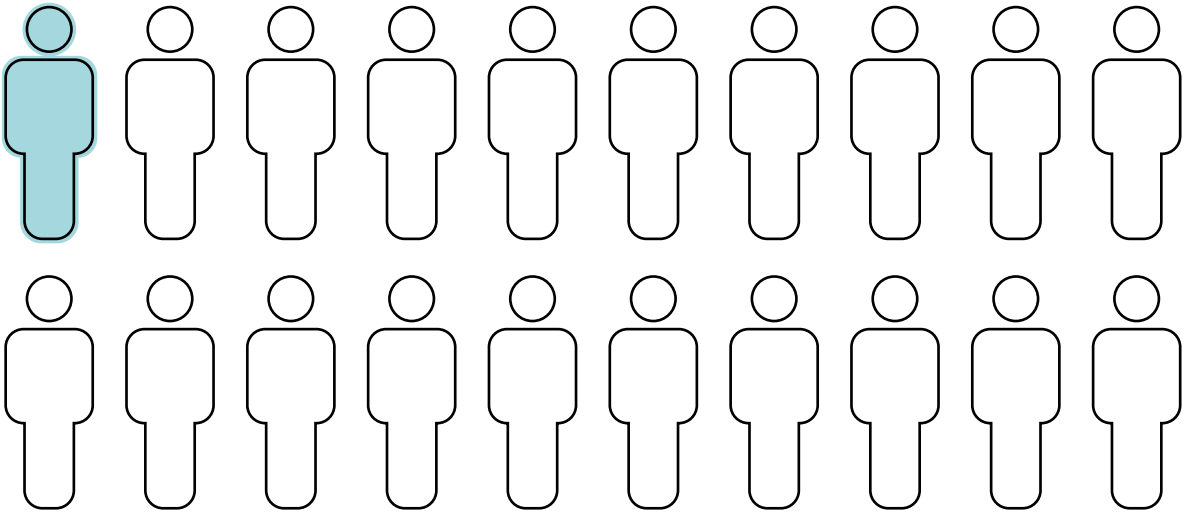


≈187 200 000
More than 18x Portugal's population (2015)

Figure 3.1 Estimated number of people affected by dementia. Sources: Prince et al. (2015); Statistics Portugal (n.d).

3.1.3 The prevalence of dementia

1 in 20 people with **60+** years old have dementia



2x more risk every 5 years after 65

Every five years after the age of 65 the risk of developing dementia doubles.

1 in 6 people with **80+** years old have dementia

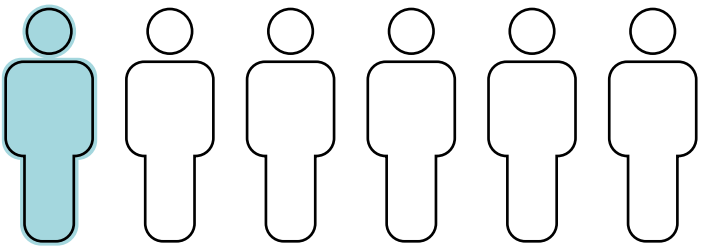
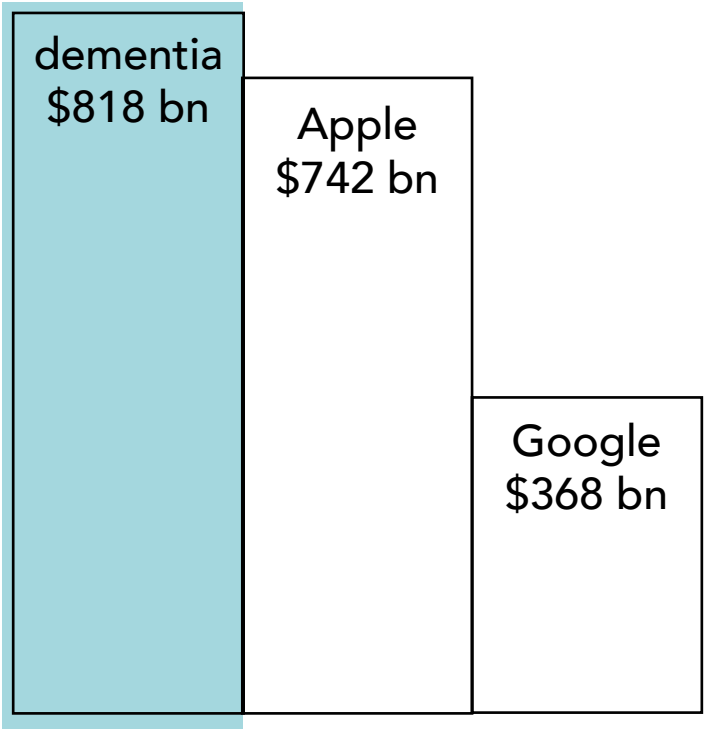


Figure 3.2 The prevalence of dementia. Sources: Prince et al. (2015); Alzheimer's Research UK (n.d.).

3.1.4 The economical impact of dementia

Estimated cost of dementia worldwide in 2015

$818 bn



The cost of dementia worldwide is higher than Apple's or Google's market value.

Figure 3.3
Estimated cost of dementia worldwide in 2015. Sources: Prince et al. (2015).

3.2 Neurocognitive Disorders (NCD)

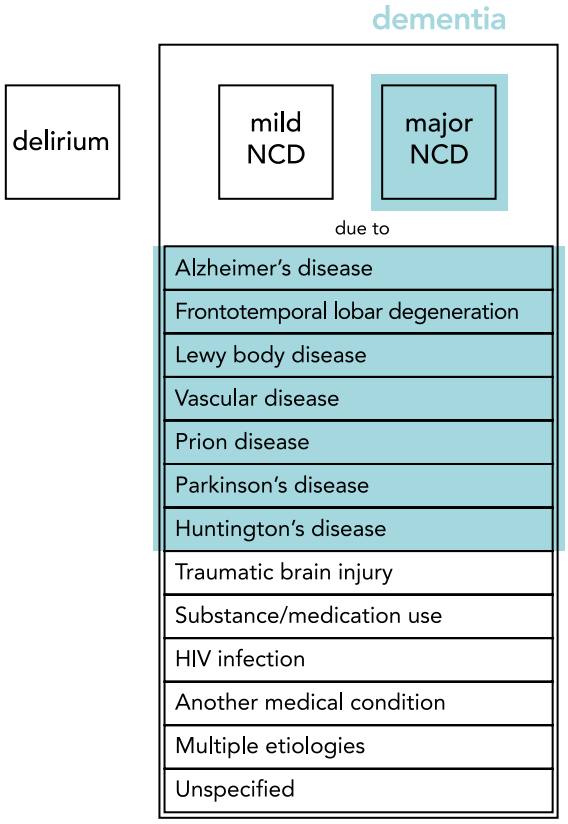


Figure 3.4 What are neurocognitive disorders (NCDs), and how they are organised according to severity. Source: America Psychiatric Association (2013).

Mild vs. Major NCD

mild NCD

Modest cognitive decline in one or more cognitive domains

Cognitive deficits **do not interfere with independence** in everyday activities

major NCD

Significant cognitive decline in one or more cognitive domains

Cognitive deficits **interfere with independence** in everyday activities

Major NCD stages

mild	moderate	severe
Difficulties with **instrumental activities** of daily living (e.g., housework, managing money).	Difficulties with **basic activities** of daily living (e.g., feeding, dressing).	**Fully dependent.**

Incidence rates of dementia subtypes

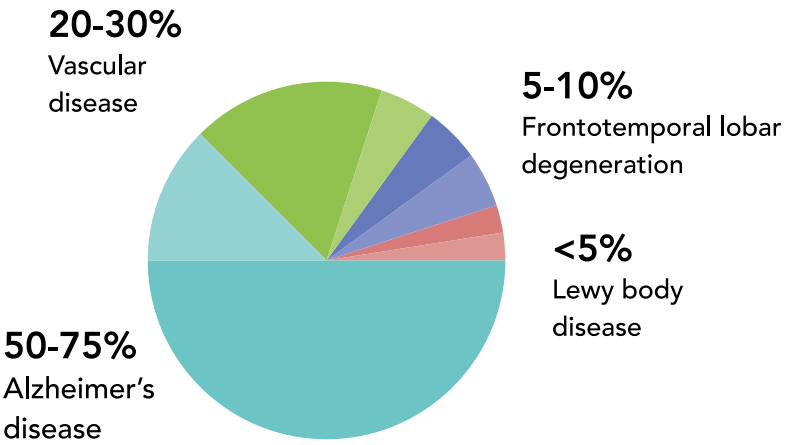


Figure 3.5 Incidence rates of proportion subtypes. Source: Prince et al. (2015).

Table 3.6 Neurocognitive domains and associated symptoms. Source: America Psychiatric Association (2013).

3.2.1 Neurocognitive domains and associated symptoms

	mild NCD	major NCD
complex attention	Normal tasks take longer than previously. Begins to find errors in routine tasks. Work needs more double-checking. Thinking is easier when not competing with other things.	Increased difficulty in environments with multiple stimuli. Is easily distracted by competing events in the environment. Difficulty holding new information . Unable to perform mental calculations. All thinking takes longer than usual. Components to be processed must be simplified to one or a few.
executive function	Increased effort required to complete multistage projects. Increased difficulty multitasking. Difficulty resuming a task if interrupted. Extra effort to organize, plan, and make decisions. Extra effort to follow shifting conversations.	Abandons complex projects. Needs to focus on one task at a time. Relies on others to plan daily activities or make decisions.
learning and memory	Occasionally may repeat self over a few weeks to the same person. Difficulty recalling recent events. Needs occasional reminders or re-reading to keep track of characters in a movie or novel. Loses track of whether bills have already been paid.	Repeats self in conversation. Cannot keep track of short list of items when shopping or plans for the day. Requires frequent reminders to orient the task at hand. Except in severe forms, semantic, autobiographical, and implicit memory are relatively preserved.
language	Noticeable word-finding difficulty. May substitute general for specific terms. May avoid use of specific names of acquaintances. Grammatical errors involve subtle omission or incorrect use of articles, prepositions, auxiliary verbs, etc.	Has significant difficulties with expressive or receptive language. Uses general-use phrases such as “that thing” and “you know what I mean” Prefers general pronouns rather than names. With severe impairment might not even recall names of closer friends and family.
perceptual -motor	May need to rely more on maps or others for directions, or to get to a new place. May find self lost or turned around when not concentrating on task. Is less precise in parking. Needs to expend greater effort for spatial tasks (e.g. carpentry, assembly, sewing, knitting).	Has significant difficulties with previously familiar activities (using tools, driving motor vehicle). Has significant difficulties with navigating in familiar environments. Is often more confused at dusk, when shadows and lowering levels of light change perception.
social cognition	Has subtle changes in behaviour or attitude, such as: · less ability to recognise social cues or to read facial expressions, · decreased empathy, · increased extraversion or introversion, · descreased inhibition, · subtle or episodic apathy or restlessness.	Behaviour clearly out of acceptable social range. Shows insensitivity to social standards of modesty in dress or of political, religious, or sexual topics of conversation. Focuses excessively on a topic despite groups’ disinterest or direct feedback. Behavioural intention without regard to others. Makes decisions without regard to safety. Typically, has little insight into these changes.

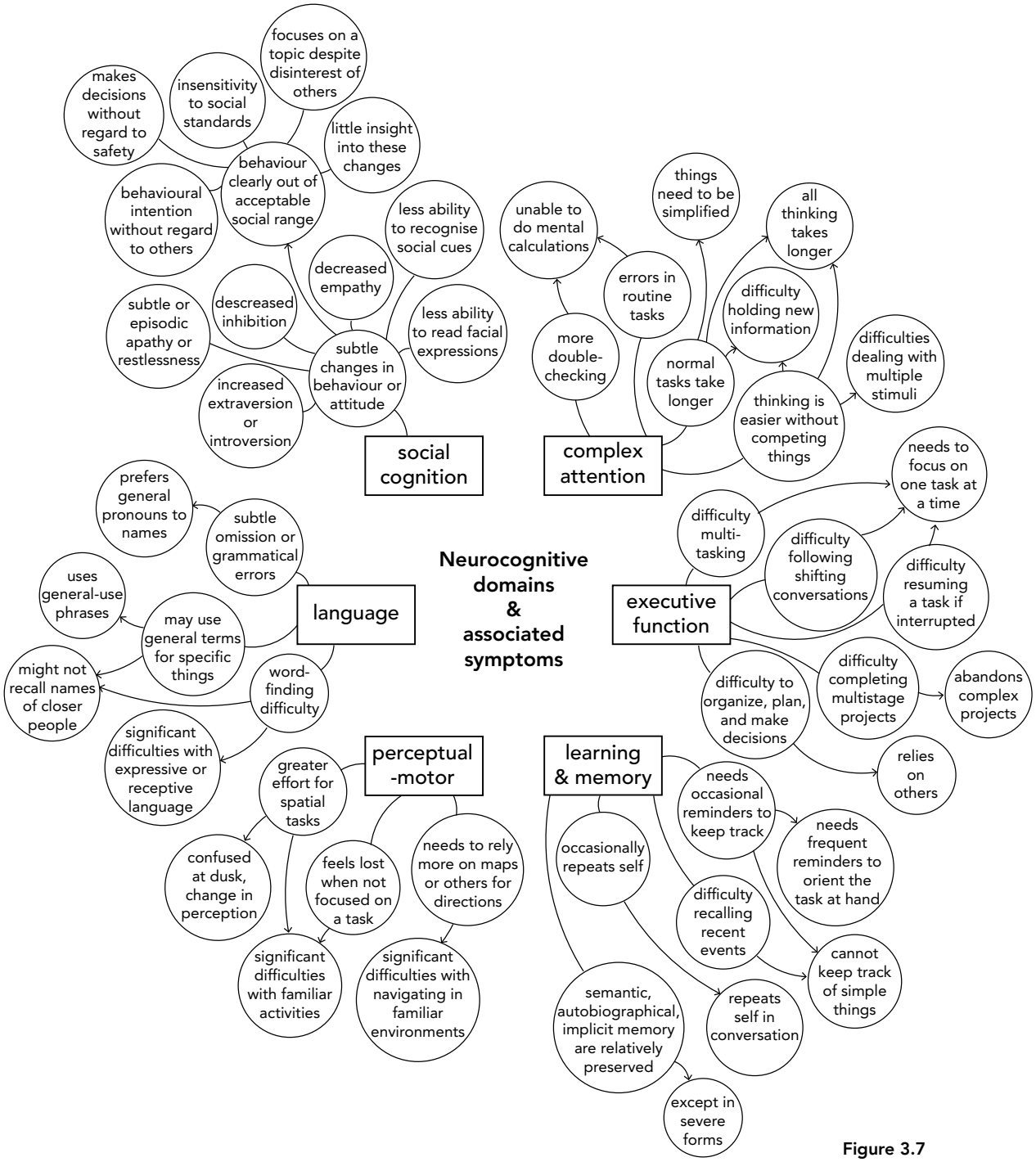


Figure 3.7
Neurocognitive domains and associated symptoms diagram. Source: America Psychiatric Association (2013).

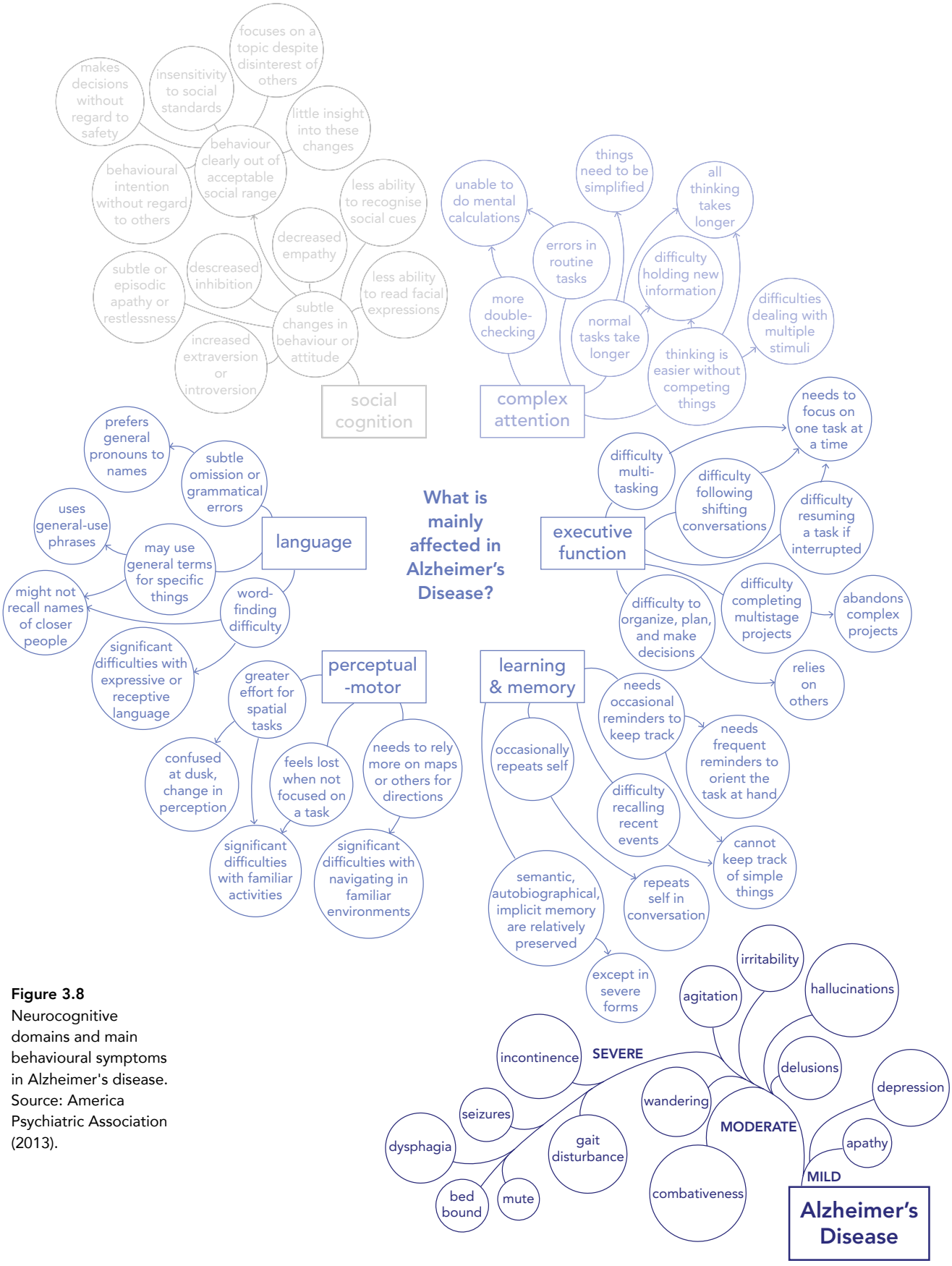


Figure 3.8
Neurocognitive domains and main behavioural symptoms in Alzheimer's disease. Source: America Psychiatric Association (2013).

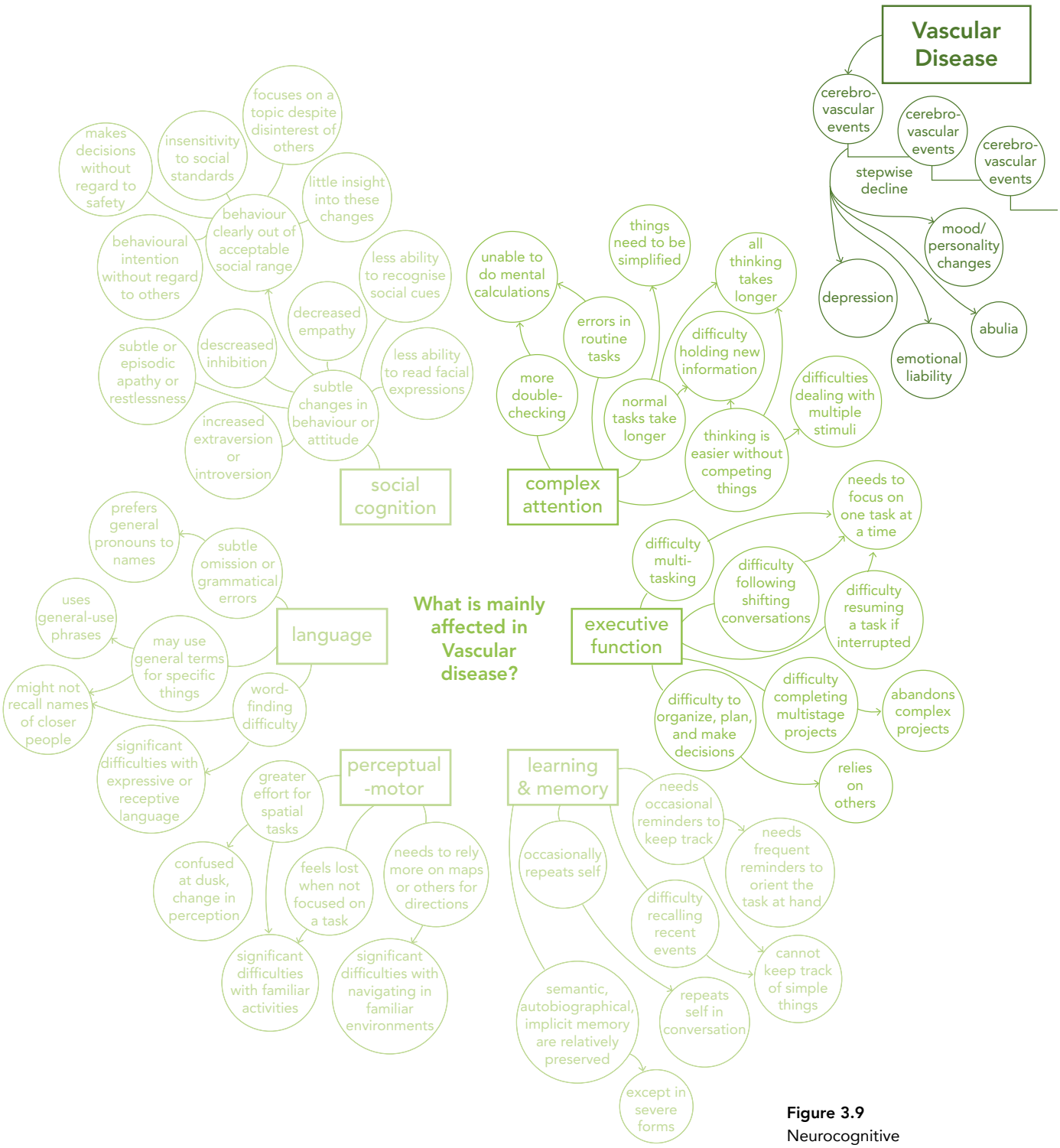


Figure 3.9
Neurocognitive domains and main behavioural symptoms in Vascular disease. Source: America Psychiatric Association (2013).

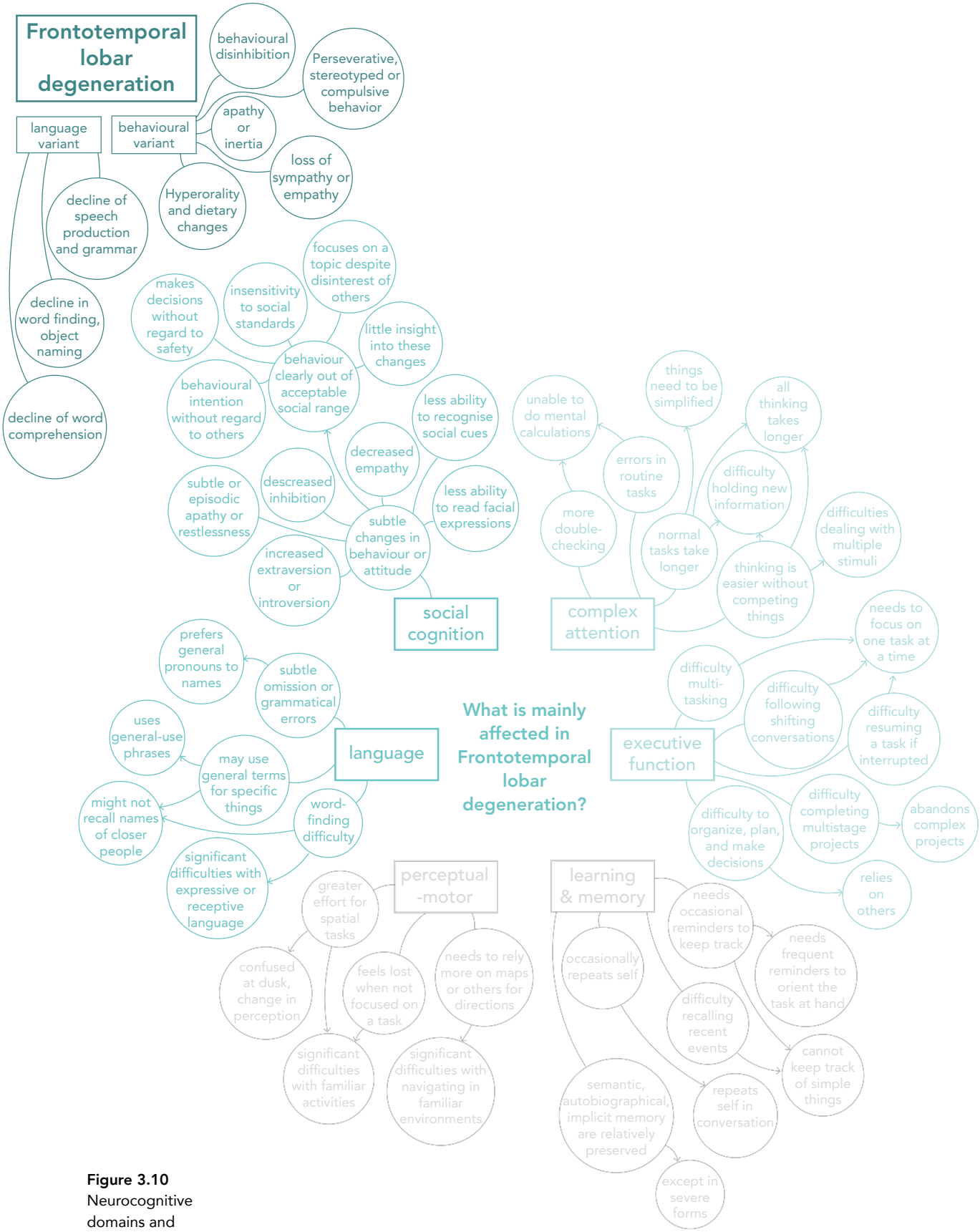


Figure 3.10
Neurocognitive domains and main behavioural symptoms in Frontotemporal lobar degeneration. Source: America Psychiatric Association (2013).

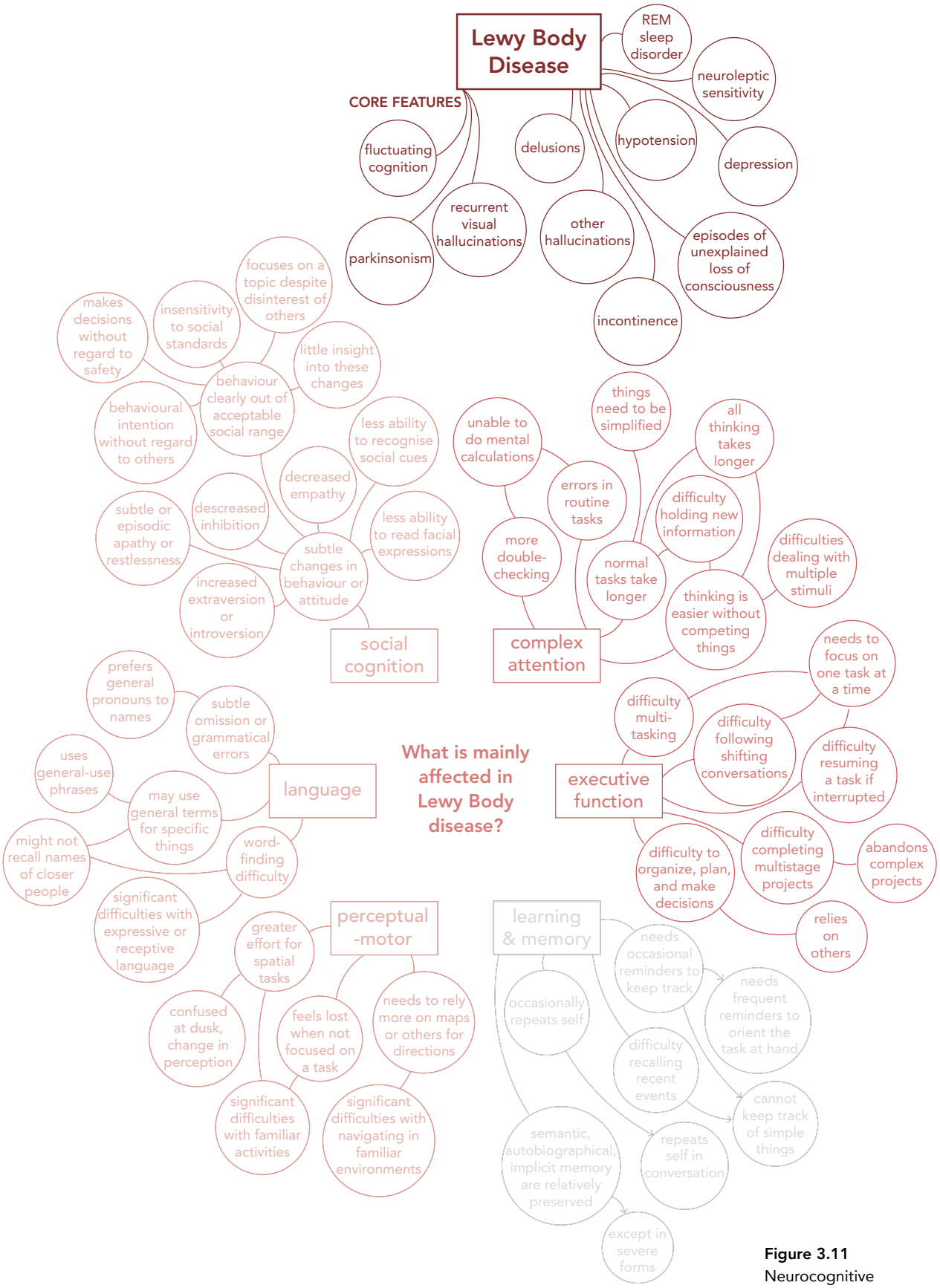


Figure 3.11
Neurocognitive domains and main behavioural symptoms in Lewy Body disease. Source: America Psychiatric Association (2013).

3.2.3 What cognitive functions are mainly affected?

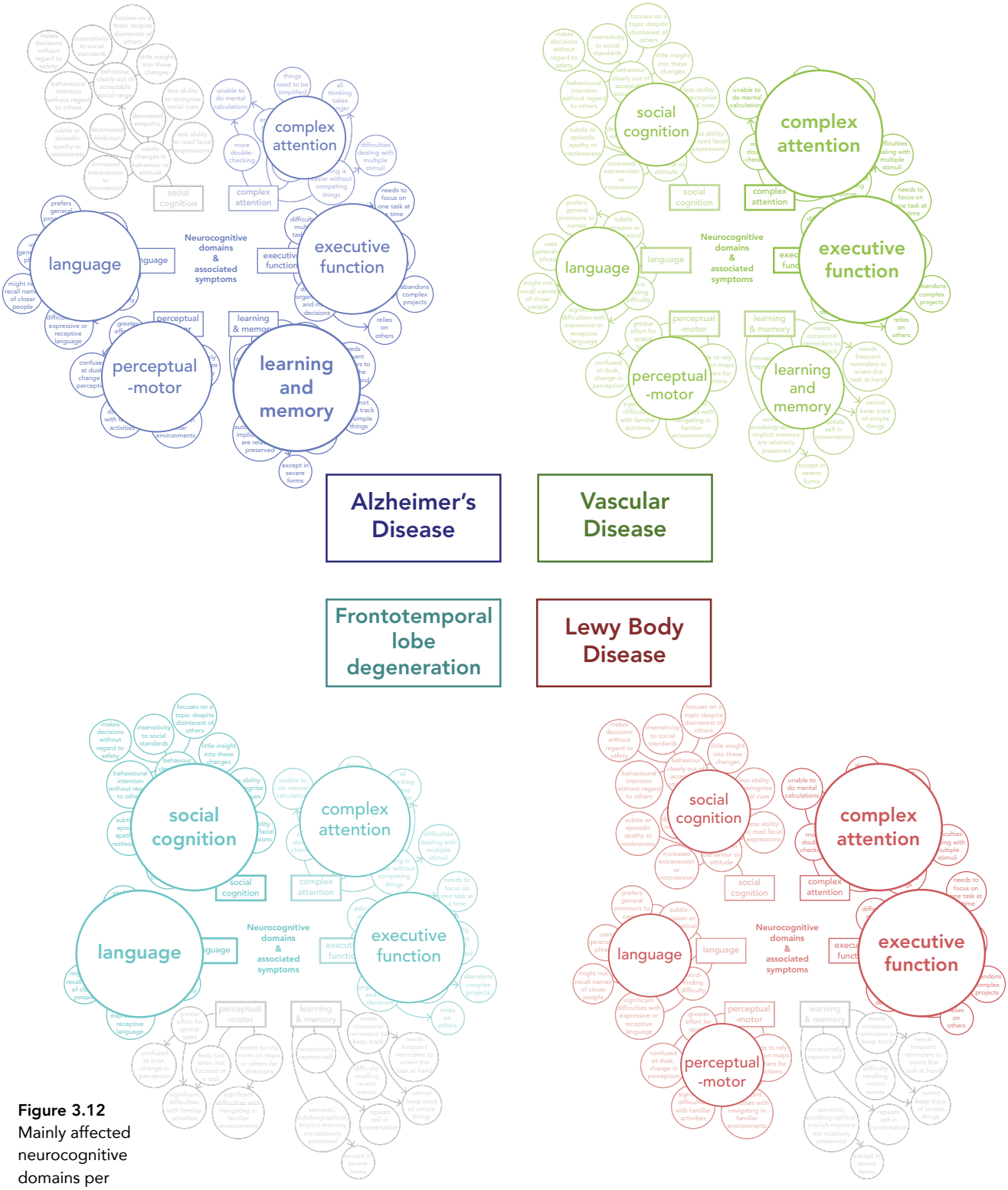


Figure 3.12
Mainly affected neurocognitive domains per disease. Source: America Psychiatric Association (2013).

3.2.4 Main dementia symptoms vs. what is part of normal ageing

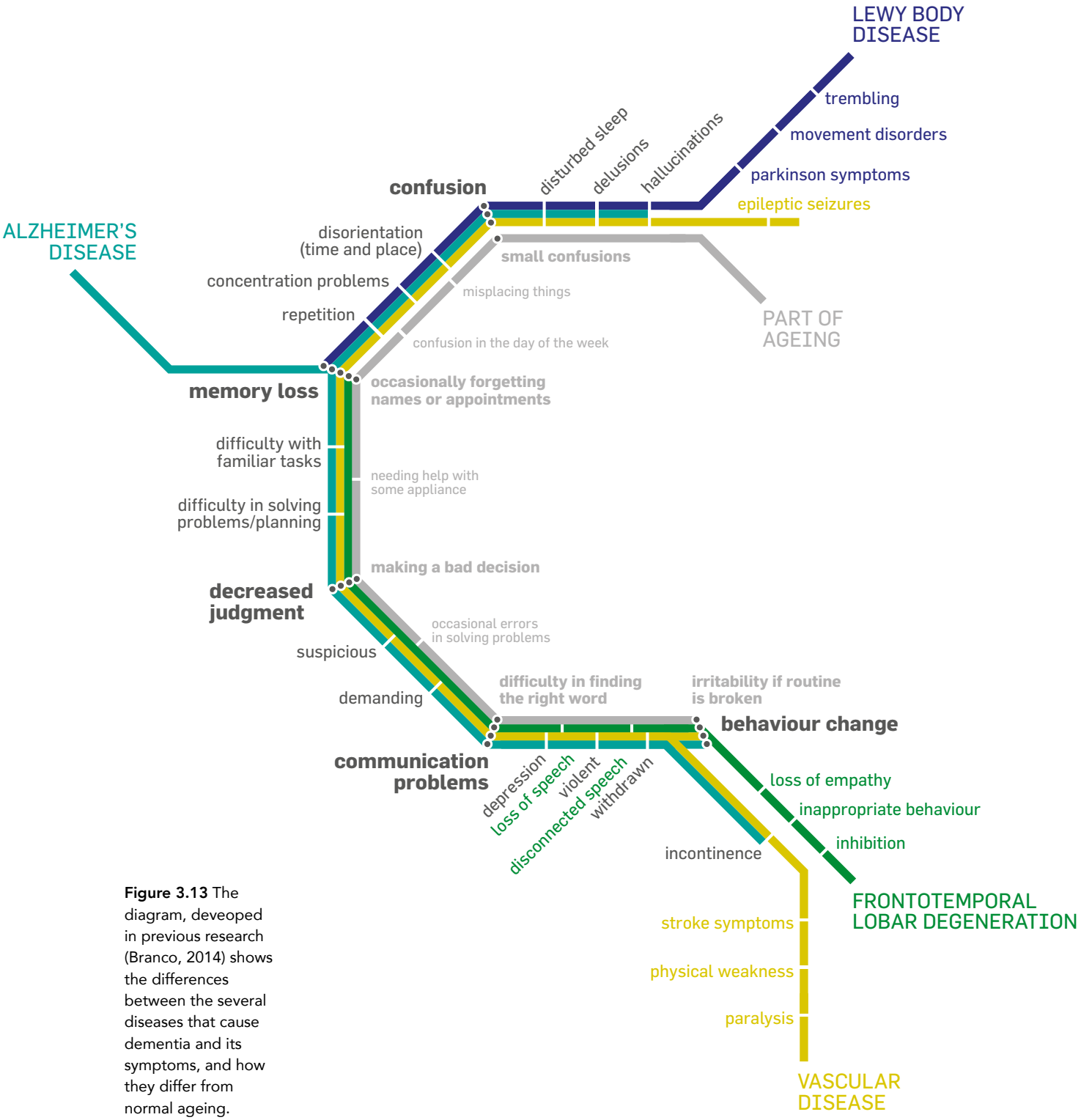


Figure 3.13 The diagram, deveoped in previous research (Branco, 2014) shows the differences between the several diseases that cause dementia and its symptoms, and how they differ from normal ageing.

3.2.5 What is always preserved?

the person

Having dementia does not, in itself, entail a loss of personhood."

—Kitwood, 1997, p.13

Figure 3.14
The person, and her/his uniqueness, are maintained, despite the diagnosis of dementia.

4 Initial encounters with people with dementia

This chapter focuses on the initial encounters with different people with dementia during the preliminary field work, which consisted of an observational study. For this purpose, the researcher became a volunteer in two care institutions that offered different contexts and options of care, resources and social dynamics, and facilitated access to various cases of people with dementia in a social environment. The volunteering work happened during three months, around three hours every week, in each institution. In this way, the researcher adopted a *participant-as-observer* approach (Angrosino, 2007), participating in the normal life of the institution and helping with what was needed: chatting, helping with preparing and participating in activities for people with dementia and clearing away. The observation focused primarily on these activity sessions, carefully noticing people's reactions to stimuli and different materials, interactions with peers, behaviour, communication and attention.

When allowed and feasible, sessions were documented with photographs and/or short videos. Quick handwritten notes were made right after the field work to support extensive field notes, that were also produced as soon as possible, drawing on the participant-observation approach to note-making. The field notes' structure and organisation were adapted from Fernandes (2002), and included content suggestions by Angrosino (2007). These consist of the chronological description of events as close as possible to what happens, supported by photo and/or video documentation; descriptions of the settings (physical, routines, special events) and people; personal hunches and feelings; comments on the progress, doubts and difficulties of fieldwork; in addition, in order to meet the needs of the design process, we also included the registration of ideas for future product development, and aspects to take into account in designing for people with dementia, that emerged from specific observed episodes.

This chapter is composed of two papers published in 2015, that are replicated verbatim. Since both articles are about this specific research

moment, they overlap in several points but have different foci. The first paper, presented at the Design4Health Conference, introduces the observation-based study, and the design intervention that it generated—the board game and the subsequent involvement of people with dementia and staff at both institutions to make it—and discusses the learnings gained, namely regarding the characteristics of the activity sessions observed, and how they could be transposed to participatory design events.

The second paper, published in the Interaction Design and Architecture(s) Journal (IxD&A) in focus section on Design Anthropology in Participatory Design, contains a more comprehensive description and analysis of this preliminary study. It presents the two institutions in more detail, and describes two specific experiences with two different people with dementia, based on our observation. Following that, it meticulously explains the rationale behind the board game development, disclosing the relations between the observed events and the design decisions, suggesting that the findings of observation were materialised in this artefact. In addition, it reflects on the whole process of approaching people with dementia and staff from institutions, the development of empathy and understanding, including the growth of ethical awareness and sensitivity, already pointing to next research steps.

4.1 "I'm always well when we are together"

Observation of institutional activities with people with dementia and its implications for a co-design research project[1]

4.1.1 Introduction

dementia

Dementia is a condition that weakens cognitive functions, and compromises the ability to perform daily activities. It is one of the main causes of dependency among older people worldwide, and has a direct impact on their families and caregivers. Dementia is considered a public health priority due to its epidemic scale and impact on national health economies and, more importantly, its consequences on people's lives (World Health Organization, 2012).

This paper describes an observation based preliminary study within a PhD research project exploring ways for design to enable people with dementia and their families to co-design personalised strategies for communication. With the support of dementia care specialists, the research draws upon ethnographic and participatory methods to get a deeper understanding of the experience of dementia and engage those diagnosed, in the design process.

4.1.2 Personhood, communication and creativity in dementia

personhood and the importance of relationships and communication

Despite the difficulties that dementia entails, people with dementia are equally unique and sensitive human beings, whose thoughts and emotions should be acknowledged. As opposed to more traditional accounts based on the dehumanisation and stigmatisation of dementia, Kitwood (1997) claims that people with dementia do not lose their personhood, and that maintaining a relational sense of self that is conveyed by others, should be a priority of dementia care. This is reinforced by Zeisel (2009) who refers to social relationships as "a treatment that reduces Alzheimer's symptoms" (p. 152). Communication plays a major role in strengthening relationships and therefore reinforcing personhood (Allan & Killick, 2008). In addition, good communication is also important to help understand needs of people with dementia and facilitate caregiving. On the other hand, dementia affects communication in several ways, which has adverse impact on relationships.

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1 This section was previously published as: Branco, R. M., Quental, J., & Ribeiro, Ó. (2015b). "I'm always well when we are together": Observation of institutional activities with people with dementia and its implications for a co-design research project. In K. Christer (Ed.), *Proceedings of the 3rd European Conference on Design 4 Health*. Sheffield: Sheffield Hallam University Art & Design Research Centre.

communication in dementia

Difficulties with communication include struggling to find the right word, confusing and ambiguous speech, repetition, difficulty following a conversation and making non-verbal sounds, towards a gradual reduction of language use. Despite these difficulties, people with dementia are often resourceful and inventive in the use of language and demonstrate a heightened sensibility for nonverbal communication, such as facial expression, tone of voice, gesture, touch and eye contact, whose combination brings meaning to the communication and becomes essential in establishing rapport with others (Killick & Allan, 2001).

creativity and the arts as a means of communication

The arts can be a vehicle of communication for people with dementia. Creative practice enables self-expression, exercises control, enhances self-esteem, promotes self-discovery and constitutes an opportunity for making something together, thus nurturing relationships (Killick & Craig, 2011). Playfulness also contributes to alleviate some difficulties and humour can be a way to cope with, and resolve challenging situations, thus enhancing relationships (Killick, 2012).

4.1.3 Inclusion of people with dementia in research

It is possible and recommended to include people with dementia in research (Cowdell, 2008). Instead of being regarded only as an object of study, placing people with dementia in the centre of the research process and hearing their voices is a tribute to their personhood by recognising the value of their experiences. However, it is imperative to take ethical principles into account to guarantee that personhood is preserved in research. This demands sensitivity and flexibility in respecting the needs of the individuals, being mindful of paternalistic attitudes and ensuring their protection from anxiety or stress. It requires building a respectful and trustful relationship with the participants at every stage of the process, thereby also enriching the research with more profound interactions. The personal approach and sensibility of the researcher is crucial in enabling people with dementia to communicate their thoughts and feelings, a process that is usually enjoyed by the participants (Cowdell, 2006).

ethics

4.1.4 Inclusion of people with dementia in the design research process

brief literature review on including people with dementia in the design process

Designing for and with people with dementia is a significant design challenge and requires an extensive comprehension and empathic understanding of their life experiences (Hendriks et al., 2013; Lindsay et al., 2012; Wallace, Thieme, Wood, Schofield, & Olivier, 2012). The use of participatory methods allow the design process to concentrate on the contributions of people with dementia instead of focusing on their impairments, thus designing for

personhood rather than dementia (Wallace et al., 2013). In order to build a good relationship, reciprocity and flexibility are essential, as well as a sympathetic and uncritical attitude, to make individuals express themselves comfortably, without a need to justify. It is also necessary to be conscious of not following assumptions, and making inaccurate interpretations of expressed needs (Hendriks et al., 2013; Hendriks et al., 2014; Lindsay et al., 2012; Wallace et al., 2012). People with dementia have difficulties with abstract thinking, understanding visual and imaginary items, keeping focused on a task, and making choices, thus rendering participatory design too demanding (Hendriks et al., 2014). Traditional participatory techniques need to be adapted to find a common ground, and to create strategies that enable and motivate people to participate despite their difficulties (Hendriks et al., 2013; Lindsay et al., 2012; Wallace et al., 2013).

4.1.5 Preliminary study: Observation

observation study and approach

During the period of study, observation was undertaken in two different care facilities; a nursing home for older people; and a specialised dementia care day centre; and involved taking part in activities with older people with dementia. These activities included arts and craft, music, cognitive and sensory stimulation, and reminiscence. In the nursing home, the artistic activities were energised by the presence of small children. This *design-led observation* (Bichard & Gheerawo, 2010) draws upon the systematised data collection method of ethnographic *participant-observation*, through the production of extensive daily field notes (Angrosino, 2007; Calabrese, 2013), while keeping an intuitive and outcome-oriented glance of the designer, described by Fulton Suri (2010) as *poetic observation*.

development of the board game

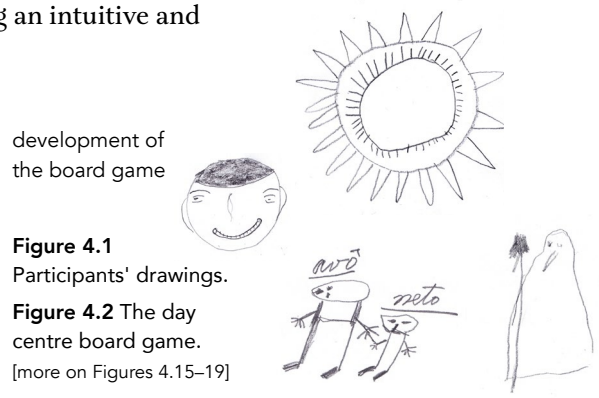


Figure 4.1
Participants' drawings.

Figure 4.2 The day centre board game.
[more on Figures 4.15–19]



Observed sessions inspired the development of a simple family board game, in response to the request of the day care centre to develop a Christmas gift for their clients' families. The aim was to provide an opportunity for families to engage with their relative in a collective activity, through encouraging storytelling and affection, in parallel with simple challenges. The traditional "goose game" was adapted to incorporate some of the sessions' characteristics, activities and tasks, and organised according to the calendar year, where annual events act as triggers to share stories. This was an opportunity to put in practice what Gatt and Ingold (2013) call *anthropology-by-means-of-design*, a model of correspondence between anthropology and design, where in new relationships are built through making things together. People with

dementia and staff members contributed with ideas to include in the game, along with drawing and modelling of playing pieces [Figure 4.1–2]. Additionally, the board game was adjusted to the intergenerational sessions in the nursing home. In order to increase levels of participation, annual events were discussed and listed together with participants before drawing.[2]

4.1.6 Discussion of preliminary findings

To reiterate, this preliminary study followed the guidelines of participant observation, which were influenced and adjusted by a design lens and intuition. Writing the field notes was an essential task that encouraged paying attention to various details of communication, that otherwise could have been missed. The development of the board game and the observation process were mutually influential. The participation of people with dementia and the staff in developing the board game helped bring emotional value to the final outcome, and strengthened the relationship with the researcher (Gatt & Ingold, 2013). Besides in-depth learning about the experience of dementia, initial findings revealed further possible approaches to the inclusion of people with dementia in participatory design. The findings include:

Learning about people with dementia

Direct contact with a diverse group of people with dementia was critical to become aware of the different levels of comprehension, communication, interaction and participation. It was crucial to understand in real situations some aspects of communication that are mentioned in literature, namely the difficulties with language and its inventive use, the heightened sensibility to emotions and actions of others, the role of humour, and the importance of non-verbal communication mainly with people in more advanced stages of dementia (Killick & Allan, 2001). This experience fostered empathy and sensibility, building a trusting relationship with users and staff of both institutions. It was also important to understand the social dynamics of the institutions, and the interactions, companionship, and hostilities between people with dementia and others.

Considerations for design ideation

The participant-observation of activity sessions facilitated learning how different people with dementia engage in various activities and react to a range of distinct stimuli, which yielded workable ideas for design. It became apparent that regardless of personal preference, most people valued the activities as moments of meaningful occupation and togetherness, and this

[2 A more detailed and systematised description about the design decisions, use and evaluation of the board game is provided in chapter 7]

could prove relevant in defining the aims for design outcomes. Additionally, the study raised insights on visual perception, mainly regarding colour, image quality and characteristics.

Considerations for participatory design process

structure of activity sessions

There is a common *structure* to the sessions observed, usually taking an hour, and including invitation, introduction, activity, closure and return, which resembles the model for creative activities proposed by Killick and Craig (2011). The invitation to participate, and the welcoming moment, set a warm and informal tone for the session. Usually there is a minute for temporal and spatial orientation before the activity is explained and exemplified. Staff members have a reassuring role, guiding the exercise and stimulating participation. [Figure 4.6] The activity concludes with a celebration of what was accomplished, the acknowledgment of everyone's participation, and at times a feedback moment, before dispersing. It was common for participants to stay a little longer, sharing experiences and stories.

environment of activity sessions

The *environment* is relaxed, non-judgmental and convivial, providing a safe space for self-expression, and where people enjoy being together. The empathic attitude of staff and friendship among participants was essential to this atmosphere, an aspect that was also pointed out by Lindsay et al. (2012) and Hendriks et al. (2013). Activities usually involve small groups of 6 to 10 people to ensure that everyone gets enough attention and accompaniment from the staff. The sessions occur in a separate quiet room, where everyone sits around a table.

type of activities

The *activities* observed can be divided into 4 main groups, which were often combined in the same session: *conversation*, often with the help of visual, physical or olfactory prompts [Figure 4.3]; *games*, pre-existing, adapted or created by staff members; *creative tasks* that consist of making something, individually or together, towards achieving a final outcome, using different mediums and materials that work simultaneously as visual, tactile or olfactory stimulus [Figures 4.4–11]; and *music*, listening, singing along and producing sounds. [Figures 4.12–13] Regardless of the type of activity, exercises are usually simple, without many constraints, and respect everyone's self-expression.

Independent of the kind of activity and final outcomes, most people seem to enjoy and benefit from being included in a shared moment, whether *participating* actively or passively. While some people were more forthcoming, others needed constant stimulus to continue, and a selective few in advanced stages of dementia, despite not actively participating, showed non-verbal signs of enjoyment at being present. During feedback, participants often referred to the importance of spending time doing something together.

Participatory development of the board game

The board game development was included in these sessions and followed

4.3



4.4



Figure 4.3 *Conversation*: reminiscence activity session, using visual prompt cards [13.11.2014]

Figure 4.4 *Creative task*: modelling dough and using pine twings to create little sculptures. [08.10.2014]

Figure 4.5 *Creative task*: painting together with little children in intergenerational sessions. [10.12.2014]

4.5



4.6



Figure 4.6 Staff members have a reassuring role [19.11.2014]

Figure 4.7 *Creative task:* composition with orange tree twigs [12.11.2014]

4.7



4.8

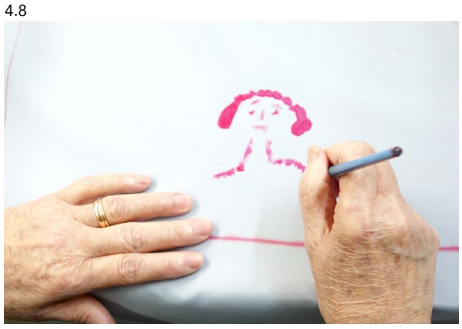


Figure 4.8 *Creative task:* drawing and painting [17.12.2014]

4.9



4.10



Figure 4.9 *Creative task:* drawing to the sound of music [19.11.2014]

Figure 4.10 Intergenerational interaction [22.10.2014]

4.11



Figure 4.11 *Creative task:* making an "autumn garden" with leaves and flowers [22.10.2014]

4.12



4.13



Figure 4.12 *Music*: listening to a student choir. [03.11.2014]

Figure 4.13 *Music*: singing along and playing handmade instruments [17.11.2014]

the same structure, so that it would not interfere with what people are used to. Staff members were also present and helped in conducting the sessions. This activity was aimed at creating personalised versions of an existing artefact, and a collaboration from the beginning of the design process to create new artefacts will be explored later in the project. Overall the activity received satisfactory review in both institutions, and at the end of the exercise, everyone was happy to see the outcome to which they were contributing individually, but it raised some critical questions. It is difficult to find a balance between giving freedom for self-expression—that may compromise the comprehension of the outcomes—and constraining too much or imposing—which is questionable and may lead to situations of frustration. Also, the fact that people were given different tasks generated some levels of confusion. Additionally, although there was an effort to raise the level of participation in the second institution, the amount of discussion and activity could have been managed better.

4.1.7 Conclusion

In this study it was observed that, in general, people enjoy and benefit from institutional activities. Participation can be passive and yet revealing, but some people are keen and able to actively and creatively participate despite cognitive impairments.

Participatory design can borrow the structure and environment from these activities, learning from their variety of different exercises and proposing new ones. It can engage people with dementia in more meaningful activities, which do not overwhelm or harm them, and may even provide well-being. However, in institutional activities there is no pressure of achieving results as in a design or research context, therefore the designer needs to be realistic about the possible outcomes. Although the individual involvement of people with dementia and their caregivers allows more intimacy and seems to facilitate the design process (Hendriks et al., 2013; Lindsay et al., 2012; Wallace et al., 2013), drawing on these institutional activities might be a possible approach for doing participatory design with a group of people with dementia.

The data gathered in the field notes is being analysed with more depth, towards seeking participation patterns and profiles, and to understand how personhood is preserved and reinforced in these sessions.

The teaming of individuals with dementia and people in their close social circle in doing activities together appears to be a practicable way of preserving personhood for both, while providing a ludic moment. This idea justifies the importance of a participatory design approach and will be further explored throughout the research.

The current scope of the research deals with finding avenues to implement the learning from institutional activities, in familial setups.

4.2 Getting closer, empathising and understanding

Setting the stage for a codesign project with people with dementia[3]

4.2.1 Introduction

design antropology

Design Anthropology merges future-oriented collaborative design practices and their interventions that aim to transform social reality, with anthropological attributes, including cultural and theoretical interpretations and contextualisation, considering the role of the past in contributing to future-making, and developing a *unique sensitivity* to the perspectives and values of those who will be addressed by the design intervention (Otto & Smith, 2013). This paper presents the preliminary work of a research project involving people with dementia in a codesign process, where this unique sensitivity is particularly important to develop an appropriate approach that is based on empathy and understanding of the participants' experience, recognising challenges, and being aware of possible risks of stigmatisation or stress.

dementia

Dementia is a group of symptoms that progressively diminishes the performance of cognitive functioning such as reasoning, memory and communication, and compromises the ability to conduct daily tasks. Dementia is one of main causes of dependency among older people, therefore it also affects those around them. It is considered a public health priority due to its epidemic scale and impact on national health economies, and more importantly, its consequences on people's lives (World Health Organization, 2012).

personhood and communication in dementia

Respecting and preserving *personhood* is one of the core values in person-centred dementia care (Brooker, 2007). Kitwood (1997) defines personhood as a relational sense of self that is conveyed by others. Therefore, being in vivid social environments and having significant relationships based on respect, recognition and trust, openness and tenderness, is crucial for people with dementia. Good communication is central to reinforcing social relationships and contributing to the maintenance of personhood. Furthermore, it is important to help understand specific needs of people with dementia and to facilitate care provision (Allan & Killick, 2008). However, dementia weakens the ability to use language and communication in several ways, such as difficulty in finding the right words, confusing and repetitive speech, struggling to follow a conversation, and making non-verbal sounds, towards a gradual decrease of overall verbal communication, thus impacting

3 This section was previously published as: Branco, R. M., Quental, J., & Ribeiro, Ó. (2015a). Getting closer, empathising and understanding: Setting the stage for a codesign project with people with dementia. *Interaction Design and Architecture(s) Journal – IxD&A*, 26, 114–131.

relationships adversely. Consequently, non-verbal communication becomes extremely important to create meaning and establish rapport with others (Killick & Allan, 2001).

The present research focuses on the relationship between people with dementia and their close social circle, and how design can help maintain and build relationships through offering opportunities for communication.

research through design

The project takes a *research through design* approach as defined by Jonas (2007): "The idea of RTD [research through design] is based upon a concept of domains of knowing and a generic structure of learning/designing, which has been derived from practice" (p. 202), resulting in artefacts that incorporate *designerly ways* of addressing possibilities and problems, as well as in methods, conceptual frameworks and theories (Gaver, 2012). Drawing upon ethnographic methods and participatory approaches to get a deeper understanding of the experience of dementia and engage with those diagnosed in the design process, the research project explores how communication design can enable people with dementia and their social circle to develop personalised strategies to communicate.

The preliminary phase of this doctoral research consists of an observation period in two care institutions that deal with people with dementia, and a design intervention with them. It reflects on how these exercises were undertaken—approaching institutions and individuals, developing empathy and understanding—and how they influenced and helped shape participation for the next stages of the research.

4.2.2 The observation study

> To cognise certain dimensions of the society, it is necessary to have a reasonably continued contact and exposure to it, since there are aspects of a culture and society that are not made explicit or do not appear on the surface, and a more substantial and detailed effort through observation and empathy is required.[4] (Velho, 1987, p. 123)

reasons for observation study

Observation was chosen as the primary method for this preliminary study for several reasons. Firstly, the experience of dementia is complex and perplexing, therefore 'it requires a more substantial and detailed effort'. Thus direct contact is considered crucial to grow an understanding and develop sensibility towards working with people with dementia. Namely in situations where verbal communication is compromised, learning people's reactions and behaviours through observation becomes critical. Secondly,

4 Author's free translation from the Portuguese: "para conhecer certas dimensões da sociedade é necessário um contato, uma vivência durante um período de tempo razoavelmente longo, pois existem aspectos de uma cultura e de uma sociedade que não são explicitados, que não aparecem à superfície e que exigem um esforço maior, mais detalhado e aprofundado de observação e empatia."

through participating in institutional activities with people with dementia, this study aspired to learn how healthcare professionals include and engage this population in various ways, what different stimuli they use, and how the participants act in and enjoy these sessions. In this way, the observation aimed to provide insights on how to configure a participatory project that involves people with dementia, and to find inspiration for the development of design ideas for communicating with people with dementia, thereby drawing attention to aspects which are to be taken into consideration.

observation approach

This design-led observation (Bichard & Gheerawo, 2010) followed guidelines of ethnographic *participant observation* (Angrosino, 2007; Calabrese, 2013) and systematised data collection through the production of extensive daily field notes (Fernandes, 2002), while keeping the intuitive and strategic *poetic observation* of design (Suri, 2010).

The following sections contextualise the study through describing the institutions, synthesising the observed activity sessions, and demonstrating distinguished experiences of dementia, introducing two women that frequently participated in the observed sessions.

Context: Two elderly care institutions

description of the two institutions

The study takes place in two institutions dealing with people with dementia in Porto Metropolitan Area, Portugal. These offer different contexts and options of care, resources and social dynamics.

The nursing home António Almeida Costa offers different care options such as a residential home, day centre and home care services. Approximately 100 people live there, and about 30 clients attend the day centre. It is a part of a bigger social complex that includes a preschool and a kindergarten, which encourages intergenerational encounters. Despite scarce resources (both human and material), the institution provides several weekly activities, including some specific for people with dementia, which are organised by the psychology service, with the help of volunteers.

The specialised dementia day centre S. João de Deus is a part of a Conde Ferreira psychiatric hospital in Porto, and thus can take advantage of their medical and therapy staff. They have a maximum capacity of 30 clients. There is a weekly plan with different activities everyday in both the morning and the afternoon, with substantial material resources.

Institutional activities

description of structure, environment and activities observed in institutional sessions

Observed sessions included cognitive stimulation, reminiscence activities, music, and arts and crafts in the day centre S. João de Deus. In the nursing home António Almeida Costa, music and intergenerational sessions were observed, consisting mainly of arts and crafts and sensory stimulation activities.

Independent of the session, observed activities can be categorised into four main types: conversation, games, creative tasks and music. These were

frequently combined in the same session. Conversations were often prompted by the other types of exercises. The activities were simple and, when necessary, supported by the staff. Most sessions observed lasted an hour, and in agreement with Killick and Craig (2011), had a common structure. This structure consists of (1) the invitation to participate; (2) an introductory moment to greet and introduce everyone (if people do not know each other), inform about the date, and speak about recent events; (3) the activity; (4) a closing moment where participants are asked for feedback about the session and their participation is acknowledged; and finally, (5) helping participants return to their individual routines. This structure promotes a welcoming, relaxed, non-judgemental and convivial environment. The participation of little children in the intergenerational sessions at the nursing home naturally contribute to a more vivid and joyful atmosphere. Sessions usually involve small groups of 6 to 10 people and occur in a separate room, where everyone sits around a table. The rooms are well-lit and quiet, in order to help participants to stay focused (otherwise they can easily get distracted with too much noise).

Regardless of the kind of exercise or outcomes, most people seem to enjoy and be satisfied at being included in a collective activity. While some people participate promptly and creatively, others need constant stimulus to perform a task, and a few others in more advanced stages of dementia show non-verbal signs of enjoyment of being present in the sessions, even if not actively participating. During feedback, participants often referred to the importance of spending time doing something together.

Meet Mrs Evans and Mrs Martin[5]

description of the experience with two different people with dementia

Mrs Evans attends the day centre. Although she often presents an apathetic and alienated expression, it is very easy to verbally communicate with her, as she does not demonstrate much cognitive impairment or memory lapses:

> *Mrs Evans communicated easily, without any effort. However, as soon as we stopped speaking, she got back to her usual apathetic facial expression.* (Fieldnotes, 04.11.2014)

She always attends and engages in all kinds of activities provided by the day centre. Her participation is usually shy, but attentive, without much difficulty in understanding a game, or following a conversation or exercise. She speaks quietly and uses short sentences, without adding too much to what was asked:

> *Mrs Evans' participation was short but wise. It was clear that she was paying attention.* (Fieldnotes, 13.11.2014)

In visual arts activities, she draws with light strokes and colours and shows concern about the quality of her work:

> *Mrs Evans makes slightly wavy lines, very light, making the light colours she selected almost unnoticeable.* (Fieldnotes, 19.11.2014)

5 The real names of participants have been replaced to preserve anonimity.

She sometimes demonstrates some insecurity, but says she enjoys these activities:

> *Mrs Evans seemed to have little self-esteem in the drawing exercise. She was saying that she doesn't know how to do it, and was asking help from the therapist.* (Fieldnotes, 10.12.2014)

It is difficult to ascertain whether she has any preference for a specific kind of activity or stimulus, as she is not very expressive and does not smile very often.

Mrs Martin uses the day centre service of the nursery home, together with her husband Mr Martin, her main carer. Her verbal language is very impaired, restricted to a few words such as *"Look", "Yeah"* and *"Yes",* which are also not used often. Instead, she frequently repeats the same loud sound *"Nanananana"*, which is at times disturbing to others:

> *"She shouldn't come... You only make noise. You bother everyone." Says Mrs Green.* (Fieldnotes, 15.10.2014)

She demonstrates a heightened use of non-verbal communication through facial expressions, gestures and body posture. Her facial expression is usually serious, and at times even aggressive:

> *Her facial expression seems to be always very unforthcoming, aggressive. She reacted to certain situations ..., with sounds "nanananananana" or banging the table.* (Fieldnotes, 15.10.2014)

However, Mrs Martin is very sensitive to the expressions of others, and returns a smile when people smile at her. She shows sign of well-being through smiles and other demonstrations of affection:

> *On the other side of the table, a little girl starts crying. I notice that Mrs Martin is looking at her, and her face changes to a painful expression, almost mirroring the child distress. The teacher comes to comfort the girl who leaves the table. Some minutes after, Mrs Martin looks at a little boy next her. He is in a really good mood, enjoying the activity, and Mrs Martin smiles tenderly at him.* [Fieldnotes, 15.10.2014]

> *Mrs Martin looks happy. She smiles and kindly caresses Mr Martin, showing her affection for him.* (Fieldnotes, 29.10.2014)

Mrs Martin attends most of the intergenerational sessions in the nursery home. She does not actively participate, but it can be observed that she clearly benefits from the sessions. She seems to relax, she smiles and expresses emotion and tenderness when she sees the children, and sometimes even demonstrates the will to interact with them:

> *Mrs Martin was not in a good mood before the session, and initially demonstrated some resistance to go to the activity. During the session, she was in a good mood, smiling, and said "nananana" less than usual. She said "Look" several times to some of the children and even said "Look, so pretty!" to a little girl.* (Fieldnotes, 03.12.2014)

She never engages in the tasks proposed, even when there is an effort from staff to do it with her. However, she reacts very well to olfactory stimuli, and shows great enthusiasm for musical activities. She laughs, hums sounds and songs, tapping her feet and hands:

As they sing, Mrs Martin enthuses. She laughs and hums the songs. (Fieldnotes, 15.10.2014)

When Mrs Martin grabs other people's hands, she presses the hands and each finger, which can also be seen as a tactile stimulus:

She holds me both hands. I feel that she is squeezing my fingers, one by one, and then the whole hand. (Fieldnotes, 03.11.2014)

4.2.3 From institutional activities to codesign

Materialising findings of observation: the board game

description of board game concept in more detail, based on observation study

After two months of observation, the day centre S. João de Deus requested the researcher to develop a Christmas gift for their clients' families. In order to comply with the research objectives of maintaining the relationships between people with dementia and their relatives, it was proposed to the day centre that the gift should provide an opportunity for families to engage with their relative in a collective activity, by bringing home some of the exercises delivered in the institutions, and making it easy for families to conduct them.

Games involve social interaction and promote a sense of togetherness, enhancing the interaction between different generations, family members and friends (Kayali et al., 2013). Taking into account the Christmas family time, when different generations come together, and since playing games or adopting a game-based approach to an activity was something common in the observed sessions, the development of a game seemed appropriate.

During this period, while conducting observation, special attention was paid to deliberating on exercises that could be included, and episodes that could inspire new activities for this game. All sessions observed were reviewed and deconstructed, considering the general engagement and enjoyment levels of the participants, as well as the practical aspects of replicating them at home. Additionally, since this game was to be distributed to all the users of the day centre, the different stages of dementia and the various ways in which people communicate and participate were also taken into account. Other elements that were not specific to the activities, such as the importance of affection and non-verbal communication, and the fact that passive participation can also be valuable and beneficial, were key aspects to make sure that the game included a variety of activities that tried to suit the range of the different possible players.

Following the analysis of the observed sessions, certain activities were selected for the game, consisting of small challenges, singing, gestures and storytelling. Small challenges included, for instance, drawing for others to guess and speaking about colours, as observed in arts and crafts sessions; simple calculations used to advance or return stops, counting through the act of rolling the dice and moving the playing pieces, and matching similar images, as in cognitive stimulation sessions; mimicking, which was used in

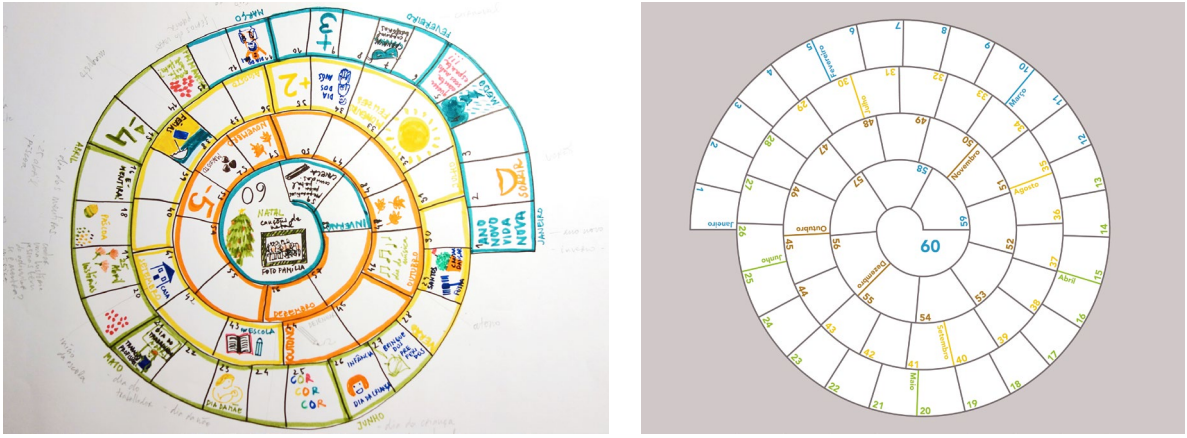


Figure 4.14 Early sketch of game idea and board game frame [this frame was posteriorly redesigned: colours were removed and space was added in between "spiral rows" to facilitate comprehension].

a few sessions where people had to act out for others to guess. Singing was included in several stops, since most people in both institutions demonstrated signs of great enjoyment in activities that involved music, even in later stages of dementia:

> *The group was focused. You could see the joy in their faces. They were leaving the room with a smile.* (Fieldnotes, 17.11.2014)

Also taking into account people whose participation might be more restricted, the importance of non-verbal communication and physical touch (Killick & Allan, 2001) led to the inclusion of activities that encourage gestures of affection such as smiling to each other, hugging, shaking hands and greeting people.

Since conversation and sharing personal stories were stimulated in most sessions and seemed to be appreciated by most participants, storytelling was also included in the game. Specific sessions observed, such as reminiscence, focused mainly on this aspect, whereas in others, materials and themes of the activity became the triggers for conversations and discussions. Moreover, sharing personal occurrences was very common during or after the activities, at times stimulated by the staff and at times initiated by the participants:

> *Many times, irrespective of the presence of children, some of those ladies end up sharing personal stories and their feelings, and in general, people look happy to be there. It feels that they see the space and the activity moment as joyful and safe for sharing.* (Fieldnotes, 17.11.2014)

This storytelling component was given priority to in the game, considering the fact that telling and sharing personal stories is crucial to build and preserve relationships within families and social groups (Fels & Astell, 2011). In a study that explored the potential of storytelling as a model for conversation with people with dementia, Fels and Astell (2011) put forward that people with dementia retain the ability to tell personal stories, even in advanced stages, with the aid of prompts and careful listeners, who are crucial to support, show interest, and give control and ownership of the narrative to the person with dementia, without judging how or what is being said. Accordingly, the game rules were also created in order to make the person with dementia feel

included and at ease, and to help other family members support storytelling.

The structure and organisation of the game also draws on aspects of the observed sessions, and responds to the concept and activities defined. Inspired from a reminiscence session about toys, the traditional "goose game" was adopted to be the basis of the proposed game. This classic board game, whose structure is composed by several successively numbered stops (commonly 63) laid out in a spiral, was chosen for its simplicity, capacity to accommodate several different activities and for the reminiscence value that it could have for some people. Following that, considering the introductory part of the observed sessions, which included temporal orientation, a small conversation about the current season and, at times, upcoming annual events, the stops were organised according to the calendar year. In this way, several annual events, ranging from national holidays, religious celebrations, commemorative days, and season dates were distributed throughout the game, acting as prompts for storytelling and conversations. [Figure 4.14]

The game rules and list of activities for each stop try to set a friendly, flexible and inclusive tone, in order to promote a corresponding atmosphere as experienced in the institutional sessions. It starts with an introductory text demonstrating the value of doing something together, as quoted by a user of the day centre after an activity session:

> *"I am always well when we are together."* [Fieldnotes, 19.11.2014]

It encourages the inclusion of people in more advanced stages of dementia, even if through passive participation: *observing and listening are also ways to participate*. Furthermore, the game's rules suggest forming intergenerational teams, and urges everyone to participate. Activities can be done collectively or individually, helping each other within the team if necessary. Some activities are done by the whole group in order to stimulate a sense of togetherness. The list of activities suggests questions and approaches to the several exercises within the game.

Codesigning the game

more detailed description of board game development in the day centre

Even though the fundamentals of the game were pre-devised, staff and users of the day centre collaborated in the making and finalisation. They were asked to comment upon, and suggest activities or themes to be included in the game. There was still no prototype, therefore the game was presented to some users abstractly, only using a classic goose game board as reference. The users did not reveal much enthusiasm for the idea, but it was perceivably difficult to imagine the game in such a non-concrete way. However, when they were asked about events and activities that they would like to see included, they suggested events and other small challenges, such as the completion of proverbs and saying words starting with a specific letter, which were then added to the list of activities. In addition, all these users agreed to participate in the making of the game. On the following week, a prolonged art activity was organised with

4.15

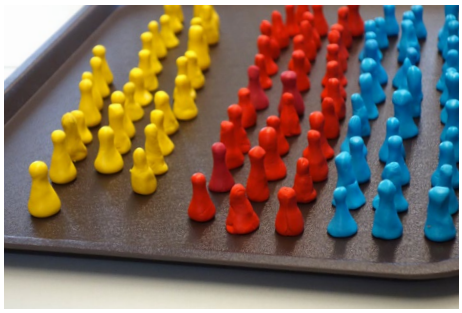




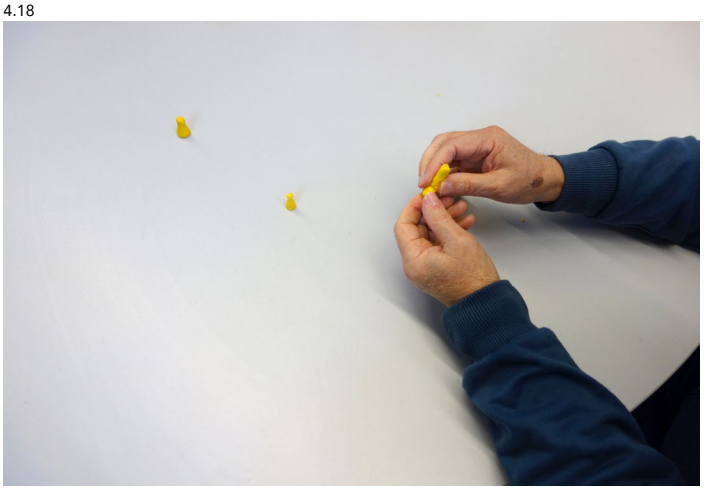
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4.17



4.18



4.19



Figure 4.15–19 Board game developement at the day centre.

Figure 4.15 Drawing illustrations for the game stops.

Figure 4.16 The dice.

Figure 4.17–18 Playing pieces modelled by participants.

Figure 4.19 Final outcome.



the therapist to draw images for the board. Following the reconfigured list of activities, some users drew with pencils and no colour was added in order to keep the process as simple as possible. [Figure 4.15] Later, colour and some missing details were digitally added and the drawings were combined in the board game frame. [Figure 4.19] Two more art sessions were organised by the therapist for modelling the playing pieces. [Figure 4.17—18] Dice and bags for carrying the game materials were produced internally in the hospital, as well as the printing of the board. The game was offered to the families during a Christmas party organised by the day centre.

adaptation of the board game making to nursing home

The activity of making this board game together was adapted to the intergenerational sessions of the nursing home António Almeida Costa. Since there was no aim to offer it to the families, a bigger board was created to be played in the institution. A big blank board frame was previously printed and used to help present the game idea. In order to increase the level of participation in codesigning the game, annual events were discussed and selected together with the participants. [Figure 4.20] Cut-outs of each individual stop were prepared earlier so that participants could draw directly on them. [Figure 4.21] These were pasted on the board at the end, so that the participants could have a more tangible sense of the development of the game. [Figure 4.22] During two sessions, people with dementia and little children taking part in the sessions contributed with drawings according to the list of activities, but with no constraints about the use of colour. In a third session, participants were asked to paint the playing pieces (wooden blocks). [Figures 4.23–24]

The two main changes in adapting the board game to the nursing home were: (1) the discussion of the annual events which was an activity by itself; and (2) making the development of the game more tangible, by showing the board to help explain the game better, and paste the drawings directly on the board, so that everyone could see what was achieved. While some people were enthusiastic about discussing what happens in each month every year, for others it was difficult to participate, and it was seemingly boring for the children. Acknowledging that, we did only a part of it at the beginning of the session and started drawing immediately from what we had already. The list of events was then completed with interested participants, after the children left. Although handling the cut-outs of individual stops was quite complicated, it was important for most people to see the game taking shape, and to identify their contributions to the board.

In both institutions, these codesign activities of making the game together took place during normal activity sessions with the help of staff, and drew from the structure, environment and exercises observed previously.

4.20

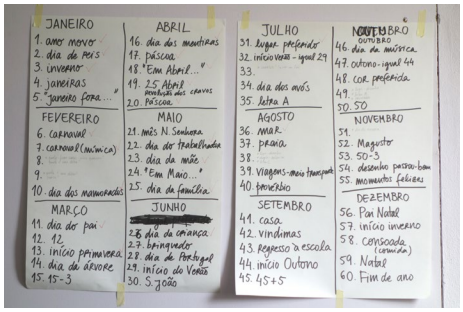


Figure 4.20–25 Board game developement at the nursing home.

Figure 4.20 List of game stops defined together with participants.



4.21



4.22



4.23



4.24



Figure 4.21 Drawing illustrations for the game stops.

Figure 4.22 Showing the work in progress board to participants.

Figure 4.23–24 Painting wooden blocks to serve as playing pieces.



Figure 4.25 Final outcome.

4.25



4.2.4 Discussion: Towards an understanding for configuring participation with people with dementia

Observation and immersion in real situations informs and inspires the designer to make sense of how people they are designing for experience the world, responding to their real needs and making it culturally relevant (Bichard & Gheerawo, 2010; Suri, 2010). Inviting people to collaborate in a participatory design process takes this preposition further, democratising the project by giving voice to the ones who will ultimately benefit from it, and consequently "sharing control, sharing expertise and inspiring change" (Vines, Clarke, Wright, McCarthy, & Olivier, 2013, p. 2).

challenges in involving people with dementia in the design process

Designing for people with dementia raises a number of challenges, due to the big difference between the experiences of the designer and those living with the condition. These challenges double when trying to involve them in a participatory design process which uses tools and techniques that presuppose that participants are cognitively able (Hendriks et al., 2014; Lindsay et al., 2012). Similarly to Lindsay et al. (2012) and Wallace et al. (2013), this research tries to bridge this gap in experience and ability through an empathic approach, where people with dementia are seen as "*differently placed equals*" (McCarthy & Wright, 2015). This positioning aligns with the principles of person-centred dementia care of valuing people as individuals, recognising their uniqueness regardless of age or ability, being able step in their frame of reference and understand their perspective, respecting and supporting their personhood through meaningful relationships and rich social environments (Brooker, 2007), and perceives equality, as McCarthy and Wright (2015) put it, "as the starting point and difference as the means, rather than inequality being the starting point and homogeneity being the endpoint" (p. 53).

empathy

influences from person-centred care values

ethics

This approach also reflects the researchers' ethical stand, regarding people with dementia not only as an object of study, but also inviting them to the centre of the design research process and acknowledging the value of their experiences. On the other hand, including people with dementia in research raises several ethical questions: it requires sensitivity and flexibility, making sure that the needs of the individuals are respected, and that they are protected from anxiety or stress. Additionally, it demands a respectful relationship with the participants at every stage of the process, being aware of potentially paternalistic attitudes. It asks the researcher to develop a sensibility and personal approach that becomes crucial in enabling people with dementia to participate (Cowdell, 2006).

Getting closer

importance of observation to get closer and start building relationships

The first objective of this project was to develop this sensibility, to gain empathy and a greater understanding about the experiences of people with dementia, in order to get insights for both design ideation and possible ways to configure participation with this group. Consequently, contacts were

established with elderly care institutions rather than, for instance, home care services or private families, for two main reasons: to involve, have support, and learn from healthcare professionals, to have a facilitated access, and to be immersed in a social environment where people know each other, with several individuals living with dementia, in different stages of progression of the condition. The initial observational study was therefore a starting point to get closer to the unfamiliar contexts of institutional care and to a multitude of experiences of dementia, and start building relationships with the staff from the institutions and possible future participants. The research and aims of the observational study were explained to the staff of both institutions, and the researcher became a volunteer, helping out with what was needed, mainly during the occupational activities. Although clear for staff, the role of the researcher was not disclosed with the institutions' users, unless they asked directly, for several reasons. On one hand, staff would present the researcher as a volunteer, which was in fact much easier to understand, avoiding lengthy or complex explanations, that could cause confusion: the word design is a recent neologism in the Portuguese vocabulary, thus often not understood among older people; and there was some concern that revealing the role as a researcher could provoke suspiciousness. On the other hand, not everyone with dementia is aware of their diagnosis, either due to family decisions or simply because dementia allowed them to forget about it. Being conscious of this fact, explaining the project openly could confront the users with their diagnosis, which could also be unethical. Since the research was at its early stages, the observational study was also a good starting point to reflect upon and learn how to address ethical issues in later phases, for instance dealing with informed consent. Nonetheless, the researcher's main intention was to be known as someone who was there occasionally to accompany and help spend a pleasant time together during the activities. This initial approach allowed the researcher to build relationships within the institution, being trusted by the staff and recognised as a comfortable presence by the users.

ethical decisions

Although the experience of dementia and designing for people with this condition was already well-known to the researcher through personal experience with relatives, the encounters with other individuals with dementia and observing the work of healthcare professionals became an invaluable learning. This lead to a process of questioning assumptions and being exposed to different realities, in a mixed process of estrangement and familiarisation (Halse, Brandt, Clark, & Binder, 2010).

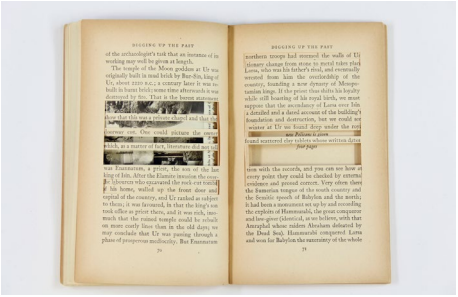
Empathising

The empathic approach is fundamental to this research, not only for design ideation but, equally or even more, for the exercise of involving people with dementia in the design process. The personal experience and previously developed work makes the empathising process more complex and non-linear,

reflection on Kouprie and Visser (2009) "Framework for empathy in design"

where the roles of relative and designer overlap, hence differing from the framework for empathy adapted to the design practice by Kouprie and Visser (Kouprie & Visser, 2009), which comprises of four sequential phases—*discovery, immersion, connection* and *detachment*. Being a relative of people with dementia, *immersion* was immediate and always present. It was due to the consternation of dealing very closely with this condition and its progression that the other phases of empathy emerged. The *discovery*—described as the initial contact, primary or secondary—happened through studying, as a way to look for means to understand and cope with the situation, and later deepened, as a designer. The *connection* phase involves emotional resonance, which in the case of dementia is quite challenging due to the inherent cognitive impairments and, consequently, the big difference in experience it represents. It was through being a designer that, also as a relative, this phase of empathic understanding was achieved. A set of graphic interpretations of the main symptoms of dementia, as if graphic design had dementia, was developed for this purpose [Figure 4.6]. Similarly, the *detachment* phase happened by means of designing, distancing in order to ideate, and developing tools for communication with the people with dementia (Branco, 2014).

Figure 4.26 What if the structure and narrative of a book was affected by memory loss? [more on Figures 2.1–5, pp. 20–21]



developing empathy through codesigning / codesigning for empathy

Being a relative deeply influenced and motivated the design work, but on the other hand, the design work also helped the researcher to understand and deal with the situation, and eventually become a better carer. This insight lead to the set up of the current research, exploring the potential of design and codesign to develop tools for providing opportunities for communication between people with dementia and their family. Additionally, empathy and understanding can emerge for the relatives through this process, possibly constituting a positive moment, and alleviating feelings of helplessness.

empathy towards family members

So far, the empathic process was described with regard to people with dementia, however since the current research does not focus exclusively on the individuals with dementia, but also on their families and close social circle, empathy is also to be developed towards them. Having a similar experience, it is instantaneous to *connect* to this user-group, but not always easy to *detach* from it. The observational study described in this paper helped the researcher embark on a new and different process of gaining empathy, seeking to separate the roles of the designer and the relative, in order to embrace other experiences concerning both people with dementia and their families, and staff, on a *dialogical perspective*: "not about fusing with another into a single entity; rather, it is about being able to understand how the other sees the world and to respond to that understanding from one's own subjective position" (McCarthy & Wright, 2015, p. 20). During the observation period, the four phases of empathy were constantly intertwined: *immersion times*, during fieldwork, were followed by *connection* moments, through doing field

notes and reflecting on what was observed. Both phases were running in parallel with *discovery,* mainly through literature, and *detachment,* in order to look for directions and making decisions on next steps of research. However, in a macro perspective, we can see this observation period as the *immersion* and *connection* phase due to the weekly direct contact with people with dementia, which was followed by *detachment*, where the direct contact became less frequent, all running in parallel with *discovery*.

Understanding

different types of knowledge in the creative understanding through direct contact with participants

In her doctoral thesis, van Rijn describes how encounters with users are a cogent means to achieve a *creative understanding* of their experiences, which she explains as "the combination of a deep, cognitive and affective understanding of the other, and the ability to translate this understanding into product concepts and services" (Van Rijn, 2012, p. 48). According to van Rijn, the three types of knowledge that help designers to attain *creative understanding* are propositional, personal and procedural knowledge. Propositional knowledge is easily accessible through literature or documentaries, and is highly informative but often too abstract to provide a deeper comprehension of the user experience. Personal knowledge is obtained through direct encounter and observation of users. It is tacit and subjective, and open to individual influence (by having some degree of control, for instance, through asking questions) and interpretation. It is particularly informative, but also very inspiring and empathic. Lastly, procedural knowledge is acquired through making—in this case, through interacting with users. Direct interaction with others opens the possibility for building *dialogical relationships* defined by McCarthy and Wright (2015) as "mutually responsive relationships. ... in which each party treats the other as differently placed centres of value, with different experience and expertise, people with feelings and values who can contribute to shaping their own and others' futures" (p. 9). Encountering different others puts different perspectives in place and allows potential to be seen from the outside, encouraging learning from and with each other, and generating a *creative understanding* that can outline future experiences for both.

Following this, the observational study described in this paper complemented propositional knowledge from literature, enriching personal and procedural knowledge about dementia through learning from how professional caregivers work, and through direct contact with different experiences of dementia. However, in this empathic process, although it seems possible to isolate and identify these three types of knowing, they not only complement each other, but more than that, they are more fluid and their boundaries are tenuous, overlapping and influencing one another. Personal and procedural knowledge appear to be particularly entangled, since the procedure here is to relate to people, thus calling for more affective,

sensible dimension of understanding

emotional and *sensible* qualities. The concept of *sensible* "refers to what can be apprehended by the senses ... draws attention to divisions between what is visible and invisible, sayable and unsayable, audible and inaudible, thinkable and unthinkable" as explicated by McCarthy and Wright (2015, p. 41) based on the ideas of Rancière. This *sensible* dimension seems to be even more relevant when dealing with people with dementia, due to the importance and heightened use of non-verbal communication (Allan & Killick, 2008) and, since their cognitive capacities may be weakened they may depend even more on emotion (Killick & Craig, 2011). This ongoing process of knowing and understanding through relating with others alters and widens the perception of the researcher (as a researcher, designer and a person).

The observational study made possible to meet and hear individuals, such as the two women introduced earlier, and to relate to their uniqueness: how they communicate and connect with others, how they engage in activities, what they enjoy and what makes them smile and have fun, and also what triggers a negative reaction or what should be avoided. These people not only became an inspiration for design ideation, but provided some insights on how they act as participants in collective activity sessions (Branco, Quental, & Ribeiro, 2015). Following that, a more strategic aim of this study was to look for ways to, similarly to Hendriks et al. (2015), configure participation, drawing from individualised knowledge about participants, specifically how they can be involved and what artefacts can help mediate participation. Parts of these aspects were also apprehended by observing how the institutions' staff organised the activity sessions and made them engaging and entertaining, the type of exercises and different stimuli they used, and their open attitude and flexibility—many times individually adapting the activities.

sensitivity to people's uniqueness in the configuration of an individualised approach to participation

new understanding gained from board game development

The development of the game added another level of understanding to the observation. The board game was directly inspired from the combination of personal and procedural knowledge obtained during the observation, and it was a way of synthesising and materialising this learning. In the game, these two types of knowledge take form in the included range of activities, and seem to be reflected on the acquired sensitivity to select these activities and create an appropriate tone for the game and its instructions. Although strongly informed by dementia care literature—thus propositional knowledge—this sensitivity is very intuitive and difficult to make sense of, and is still being achieved through the practice of being in direct contact with people with dementia. The setup for the game, the concept of joining together a collection of activities undertaken in the institutions in a board game, is an outcome of the experience of taking part in group sessions involving people with dementia. This practical and strategic but also intuitive way of observing, and retrospectively transposing it to a tangible artefact seems to resemble what Fulton Suri (2010) describes as *poetic observation*. This often brings 'emotional relevance' to the design outcome, as it might reflect a recognised

situation. Likewise, since the board game was intended to be a Christmas gift from the institution to the families of their clients, the purpose was also to make something that the staff could identify with, and to acknowledge their work, as well as having activities that at least some people are used to doing and can easily relate to.

The production of the board game was seen as an opportunity to invite people with dementia to participate. Although the concept of the game was previously ideated and based on the researcher's observational study, it was intentionally left open for participation. The list of activities was only finalised after consulting and hearing the suggestions of the users and staff of the institutions, and the graphic frame for the activity stops on the board game was left blank to include the participant's drawings. In addition, with the help from staff of the institutions, the learning obtained from the structure, environment and type of exercises from sessions observed was applied to organising these sessions of making the board game together. This was a first attempt to *make participation sensible* (McCarthy & Wright, 2015), and bring people with dementia and staff together to negotiate and collaborate in the project. Being included in developing the game together added emotional value to the final outcome, and helped strengthen the bond between the researcher and the users, as well as developing a more trustful relationship with the staff. These participatory sessions developed in parallel with the observation, also draws on *anthropology-by-means-of-design*, a model developed by Gatt and Ingold (2013) which focuses on the relationships created with participants through making things together during fieldwork. This vision changes the way participant observation is traditionally approached, to become an *observant participation.* In fact, this intervention also revealed more about the participants, like the will to help and to collaborate on achieving a task together, and in some cases their joy in seeing the final outcome of their own contributions; and yielded new insights on how to configure participation. Although many aspects of the activity sessions observed can be borrowed to configure participatory design sessions, including the appreciation of the collective process rather than the final outcome, in a design research setting there is more pressure of achieving results. This pressure was not imposed or revealed to the participants, but made the researcher more aware of the need to be realistic regarding several factors such as time, or what to expect from individual participations, and adapt exercises accordingly.

Configuring participation

importance of observation before starting participation

The observational study and the development of the board game were crucial to establish relationships and gain empathy, meeting individuals and dealing with their experiences, and to understand how participation might be configured involving these people. Halse (2010) defends the importance

and effectiveness of understanding through participation: "understanding as we intervene" (p. 36). Likewise, McCarthy and Wright (2015) describe "understanding the other by making participation sensible" (p. 58). However, in this research, it was necessary and extremely valuable to allow some time to get closer and immersed in the institutional context before trying to involve people in activities straight away. The first-hand contact with people with dementia and staff from the institutions contributed to an improved sensibility and understanding, in parallel and related to a continuous ethical growth and enhanced awareness. Ethical concerns have been present throughout this research, but it was mainly through this observational study and the empathic approach undertaken that the ethical contours became apparent. This regards not only the more conventional and specific issues of addressing consent, but also ensuring that the participatory moments are consistent with values of recognition, respect and dignity, preserving people's personhood, maintaining social relationships and promoting pleasurable moments. In the next stages of the research, participation is configured by taking into consideration practical learnings, such as the characteristics of observed sessions to organise the encounters and develop materials to facilitate the participation, and sensible learnings such as the flexible, positive and warm attitude. Moreover, it also takes into account that, independent of the activity, people often enjoy the sessions because they are making something together, even if everyone has different rhythms or does not participate actively.

ethical, practical and sensible learnings from the observation study that were carried to the configuration of participation

The next step in the research is to bring people with dementia together with some of their family members or friends, to create a *dialogical space* for mutual understanding (McCarthy & Wright, 2015), through codesigning strategies for communication. The board game, which was distributed to the families, is the starting point for a series of encounters. It is simultaneously a material for family entertainment to be analysed in order to understand the experience of playing, and a research tool to get closer and mutually learn about each other, since the game has a strong component of storytelling. Participants are then invited to think how they would personalise the game and make it their own. In this way, similar to what Halse (2013) describes as *ethnographies of the possible*, the game becomes open for exploration and collaboration, enabling "participants to revitalize their pasts, reflect upon the present, and extrapolate into possible futures" (p. 194). In this research, these codesign sessions with persons with dementia and their dear ones are also the outcome as much as the process since, like the observed sessions, they are trying to promote warm and pleasurable moments by bringing people together to make things, and potentially add some emotional and affective value to their relationships.

reference to next steps of research: codesign work with families

4.5 Conclusions

The ethnographic exercise of being immersed in two institutional contexts allowed the designer to get closer, build relationships based on empathy, and to know and understand better different experiences of dementia. This consisted of encounters with different ways of thinking, feeling and experiencing the world due to dementia diagnosis and generational difference, that were apprehended, as well as sensed, through the researcher's own experience and intuition, as a designer and as a person. This preliminary observational study was enriched with the subsequent design intervention, the board game, which consolidated learnings from what was observed, and transposed them into a material artefact. Furthermore, it constituted the first opportunity to invite people to participate in codesigning, which in itself, added emotional value to the outcome and provided the researcher a more refined sensibility regarding the involvement of people dementia in this participatory research.

This way of understanding by getting closer, sensing and empathising with the other, in parallel with more rational ways of knowing like literature, influenced the directions and structuring of this research project. Consequently, both the configuration of participation and the design ideation try to reflect the values and theoretical frameworks of person-centred care, and include not only the needs and culture, but also the way of thinking and feeling of participants, aiming to "keeping their experiences alive in the project" (McCarthy & Wright, 2015, p. 65).

In this project, there is reciprocal correspondence between Design Anthropology and Participatory Design, where Design Anthropology is an essential approach to develop a *unique sensitivity* using the ethnographic method, and drawing on theoretical interpretations—necessary to understand the other, generate design concepts, and frame and configure participation. On the other hand, once participation is *made sensibl*e, Participatory Design events become the means through which the work of understanding and developing sensitivity continues.

5 Materialising personhood

a design approach to respect and maintain the personhood in people with dementia

Based on the premise that the main effort of dementia care should be to respect and maintain the personhood of people with dementia (Brooker, 2007; Kitwood, 1997), this paper reflects on how this purpose can be achieved through design. Personhood is described by Kitwood (1997) as a relational sense of self which is conveyed by others, stressing the importance of social relationships for people living with dementia. In order to address the basic psychological needs of people with dementia (inclusion, occupation, identity, attachment, comfort and love), Kitwood (1997) puts forward the idea of *Positive Person Work*, which consists of ten interactions and behaviours towards people with dementia that are recommended to preserve their personhood.

We analyse and explore each of the proposed Positive Person Work interactions from a design perspective, which is complemented by the empirical experience of the observational study in two institutions caring for people with dementia. We speculate how we might design for the experience of such interactions, how to promote them through the use of artefacts or embed these attitudes in formal aspects of artefacts. We also reflect on how these interactions can be taken into consideration in a participatory design process involving people with dementia. This reflection does not intend to be prescriptive or to find 'one way' of designing for and with people with dementia. Instead, it aims to look into Kitwood's ideas of person-centred care and Positive Person Work from a design point of view, in order to translate these values, inform and inspire the work of design researchers and practitioners dealing with people with dementia.

5.1 A brief review of inclusive design and design for disability

Traditionally, aids and products for people with disabilities have been mainly looked at from a technical and physical point of view, and many times are

brief historical account on designing for people with disabilities

seen as stigmatising. In the 60s, designers and architects started considering accessibility for disabled people in the built environment, such as Selwyn Goldsmith in the UK and Ron Mace in the US, both wheelchair users (Clarkson & Coleman, 2015; Myerson, 2007). In the 70s, Papanek (1984) challenged the current commercial practice of design and highlighted that design for disability was a neglected area that should be looked at with the same industrial approaches as mainstream design. From 1979 to 1982, Patricia Moore went around North America acting and looking like an old woman, with artificial restrictions to her joints, hearing and vision, a revealing exercise that pioneered the use of empathic research to understand users' needs (Myerson, 2007).

The term *inclusive design* was coined in 1994 by Roger Coleman, at the time director of DesignAge, an action research programme at the Royal College of Arts, which gave origin to the Helen Hamlyn Centre, in 1999. With the aim of improving older people's lives through design, the Helen Hamlyn Centre challenged the idea of the older and the disabled as groups with special needs, but rather including them in a broader group of users, and bringing the perspective of "designing for our future selves". The Helen Hamlyn Centre, together with the Engineering Design Centre at the University of Cambridge, Brunel University, Bath Institute of Medical Engineering, Sheffield Hallam University, Dundee University and commercial companies such as IDEO, Ergonomidesign (now Veryday), among others, have been developing comprehensive practice and research on the field of Inclusive Design and Design for Disability (Clarkson & Coleman, 2015; Myerson, 2007).

inclusive design vs design for disability

Inclusive design, also called universal design in the US, aims to make design accessible for all ranges of ability and age, whereas *design for disability* focuses on designing particularly for people's special needs. In his book, *Design Meets Disability,* Pullin (2009) discusses the differences between both approaches. He points out the need to take people's cultural diversity into account, as much as their abilities, which might be more difficult to meet when trying to design for everyone:

> Bringing a richer sense of identity into design for disability would involve more than just introducing design ethnography, however. And its implications would be more profound and contentious: understanding for whom we are designing acknowledges that we are not designing for everybody at once. (Pullin, 2009, p. 90)

However, design for disability also risks resulting in bespoke design, which is also commercially less viable.

In this research project, both approaches are considered and combined. On one hand, the effort to understand the specific persons we are designing for, by including them in the process and designing with them, is at the core of this project. On the other hand, these products are designed for people with dementia as well as for their social circle, thus, also taking them

into consideration. In addition, to think about designing for a wider group of people might result in less stigmatising and more attractive products than those that focus exclusively on people's impairments. In fact, Pullin (2009) suggests that design for disability should embrace more experimentation and playfulness, and consider the aesthetic values of mainstream design, to reduce discomfort or shame of using aids and medical devices.

5.1.1 Design for people with dementia

In the forward of *Design for Dementia* report by Timlin and Rysenbry (2010), Clive Bowman refers that design is still an "underexplored aspect of the care and support of people with dementia" (p. 4). Pullin (2009) argues that this is due to the difficulty for designers to put themselves in the shoes of someone with cognitive impairment, resulting in limited design solutions in this area. However, in last two decades, and especially in the last years, there has been a growing interest in designing for people with dementia, towards the amelioration of their quality of life. Contributions come mainly from research on the built-environment and HCI, with particular emphasis on maintaining independence, such as compensating memory problems and assisting daily activities safely (e.g. Holbø, Bøthun, & Dahl, 2013; M. L. Lee & Dey, 2007; Lindsay et al., 2012; Pham, Hooper, Lindsay, Jackson, & Shearer, 2012); and on reinforcing connectedness both with others, through the support of communication and participation in conversation and joint activities (e.g Gowans et al., 2007; Huldtgren, Mertl, Vormann, & Geiger, 2015; Morrissey, Wood, Green, Pantidi, & McCarthy, 2016), and with oneself, through the effort to attend to their personhood (e.g. Wallace et al., 2013; Zeisel, 2013). Although these projects address the communication with others, there are only a few that are specifically directed to family carers, such as the research of McNaney et al. (2017) that focuses on supporting young people to deal and communicate with their relatives with dementia.

contributions of design research for people with dementia: maintaining independence and reinforcing connectedness

Besides the focus on the outputs, the involvement of people with dementia in the design process also became a concern for many design researchers (e.g. Hendriks et al., 2014; Hendriks et al., 2015; Hendriks et al., 2013; Lindsay et al., 2012; Orpwood, 2009; Wallace et al., 2013), as well as possible epistemological views and approaches regarding dementia and design (Lazar et al., 2017a; Morrissey et al., 2017).

design research on the involvement of people with dementia in the design process and epistemological views

Other projects emerged, related to raising awareness and encouraging designers to work for and with dementia contexts, such as the *Living Well with Dementia Challenge*, organised by the Design Council and the Department of Health to encourage collaborations between design and healthcare organisations to develop products or services that would improve certain aspects in the lives of people with dementia (Design Council, 2012b); the *Stanford Centre on Longevity Design Challenge*, an annual challenge for university students,

projects that raised awareness on the importance of designing for people with dementia

which started in 2013 with the focus on "Maximizing Independence for those with Cognitive Impairment" (Stanford Center on Longevity Design Challenge, n.d.); or the *Dementia Lab* project, which initiated in 2013 with a research project focusing on the involvement of people with dementia in participatory design processes, and evolved into a more educational project, consisting of an annual student design module at LUCA School of Arts, and several workshops taught in other design schools, and an international conference on the topic, having its second edition in 2017 (Hendriks & Wilkinson, n.d.).

5.2 Design for subjective well-being

Design approaches that are deliberately concerned with designing products that conduce to subjective well-being are related to design research on the experiences elicited while interacting with products, as well as how products can be designed to contribute to a desired positive experience (Desmet & Pohlmeyer, 2013; Desmet, Pohlmeyer, & Forlizzi, 2013; Desmet & Hekkert, 2007; Hassenzahl, 2010; Hassenzahl et al., 2013; Pohlmeyer, 2013). Desmet and Hekkert (2007) proposed a framework for understanding product experience, consisting of three levels: the aesthetic experience, related to product's ability to please the senses; the experience of meaning, regarding the significance attributed to products; and the emotional experience, concerning the feelings and emotions induced by the appraised use of products. Each level of experience can activate or be activated by the others, demonstrating the complex nature of product experience. Hassenzahl (2010) researched further the possibilities of designing for an experience, claiming that in order to so, there is a need to understand what an experience is, and to script it first, before thinking about the practical and aesthetic aspects of an artefact:

framework for understanding product experience

designing for experience

> An experience is an episode, a chunk of time that one went through—with sights and sounds, feelings and thoughts, motives and actions; they are closely knitted together, stored in memory, labelled, relived and communicated to others. An experience is a story, emerging from the dialogue of a person with her or his world through action. (p. 8)

Accordingly, the same author proposed an experience design model based on a hierarchy of goals: *be-goals*, *do-goals* and *motor-goals*. While *be-goals* concern the meaning, motivation and emotion of an activity (the why), *do-goals* and *motor-goals* are related to operational and instrumental parts of an activity (the what and how). To design for an experience requires that all types of goals are considered and addressed, starting with *be-goals* and, only after, thinking how *do-* and *motor-goals* can support the achievement of *be-goals*. Although there is a focus on designing experience, the product should not be underestimated, since it is through both pragmatic and hedonic attributes that experiences can

be mediated. Pragmatic attributes are related to *do-goals* and *motor-goals*, they enable the product to be used, and in this way permit or block, experiences to happen. On the other hand, "hedonic quality summarises the product's perceived ability to support the achievement of be-goals" (Hassenzahl, 2010, p. 49). This is what makes people become attached to a certain product, through its relation to need fulfilment and the creation of meaning. Hassenzhal (2010) argues that psychological needs can be used as starting point to design and to categorise positive experiences since the fulfilment of needs is related to positive emotions.

framework for Positive Design

Desmet and Pohlmeyer (2013) brought together this experiential design approach and the study of positive psychology, towards a framework for *Positive Design*. This framework is based on the main elements for well-being, or human flourishing—to be happy with one's life, to live at full capacity, to have meaning in life. Therefore, Positive Design's core ingredients are design for virtue, design for pleasure, and design for personal significance, which should be equally considered, since human flourishing emerges from their combination. Even if one of these aspects might be emphasised, it should never undermine the others. These ingredients should guide the design process, and it is this intentionality that distinguishes this from other approaches. Additionally, Positive Design should have several characteristics: "Positive design should be possibility-driven, it should strive for balance, it should accommodate a personal fit, it should promote active user involvement, and it should offer the means for long-term impact" (Desmet & Pohlmeyer, 2013, p. 11). Possibility-driven refers to the focus on possibilities, rather than addressing negative factors or improving efficiency. Balance concerns the effort to combine all three ingredients, even if one might be highlighted, so that personal conflicts can be harmonised, e.g. the desire of pleasure in the moment and the need to achieve a long-term goal. Human idiosyncrasies should also be taken into account, thus recognising the importance of design in a way that allows for a personal fit, as well as the long-term use and impact of the designed products. Desmet and Pohlmeyer (Desmet & Pohlmeyer, 2013) also highlighted some of the current challenges that this kind of approaches faces: the lack of empirical evidence, assessment tools and design methods, and the need for reflection about consumer behaviour and ethical issues.

These approaches to design for well-being also require the designer to reflect on and make explicit the values behind the design of products (Desmet et al., 2013; Hassenzahl, 2010):

> Each product is a proposition, and we cannot escape the fact that it has the power to change how people feel, think, and act. To do this consciously is important. The more, the better we fulfil our goal to design deep, meaningful experiences. (Hassenzahl, 2010, p. 63)

roles of design in promoting happiness

In addition, Pohlmeyer (2013) analyses possible roles design can have in promoting happiness: (1) artefacts as *direct sources* of happiness; (2) artefacts

as *enablers* of an activity that contributes to well-being; (3) artefacts as *symbolic representations* of something valuable to people; (4) artefacts as *support and encouragement* to motivate and guide people to happiness-enhancing activities.[1]

Likewise, in order to design for people with dementia, we have reviewed the best practices in dementia care to identify guiding principles and values both for design and for the inclusion of people with dementia in the design process. If the maintenance of personhood should be the main effort of dementia care (Kitwood, 1997), and the basis for person-centred care, then our aim is to reflect and understand how design can contribute to support this kind of experiences.

5.3 Personhood and person-centred dementia care

person-centred care and personhood

Person-centred care was introduced in the context of dementia by Tom Kitwood (1997), who called attention to the importance of maintaining the personhood of people with dementia. This became a fundamental concept for person-centred dementia care, which recognises the person beyond her or his diagnosis, and emphasises relationships and communication. Subsequently, Brooker (2007) outlined the core values of person-centred dementia care, consisting of (1) valuing each person, irrespective of age and ability, (2) delivering a personalised approach that acknowledges the uniqueness of each person, (3) understanding the person's perspective of the world, and (4) promoting a rich social environment, to balance the losses that dementia brings, supporting personhood and meeting psychological needs (Brooker, 2007). The psychological needs of people with dementia identified by Kitwood (1997) are comfort, attachment, inclusion, occupation, and identity, which are part of an overall need for love. The need for *comfort* is related the frequent feelings of pain, sorrow, anxiety, therefore it is important to provide warmth, tenderness, soothing, reducing unease and promoting a feeling of security. The need for *attachment* is caused by the uncertainty provoked by memory loss and disorientation, and it is compensated with bonding and connecting, and providing a safety net that is reassuring for the person with dementia. Due to the difficulty in performing tasks and communicating, people with dementia often become isolated and excluded, leading to attention seeking behaviour, depression and apathy. *Inclusion* is about sharing and engaging socially, making people feel they are welcomed

psychological needs of people with dementia

1 The relations between humans and material objects are described by Verbeek (2012) as mediation. In his view, "material objects play a role in the relations between humans and their world, helping to give shape to the nature of their experiences and activities" (P. 167), and that "an intervention in the material world is always an intervention in the human world" (p. 172). In addition, Niedderer (2007) points out the potential artefacts can have in mediating social interaction, suggesting a triangular relation of interaction. The author speaks about performative objects since they can influence behaviour, through contributing to make the user aware of what is doing, mediating social interaction and being instrumental to behaviour change.

and they belong to a group. *Occupation* is crucial to maintain abilities and control, to have a sense of agency and to feel that one can have an impact on the others and in the world, and it is about being engaged in activities that are meaningful. Failing to meet this need can lead to boredom, apathy, lack of self-esteem. *Identity* refers to the knowledge and feeling of who one is, as well as a sense of continuity with the past. As dementia progresses, this might become increasingly blurred, thus it is important that others remember. Identity is also related to the recognition of one's uniqueness, and the sensibility and empathy to respond to it (Brooker, 2007; Kitwood, 1997).

Positive Person Work

Additionally, Kitwood (1997) described ten types of interaction towards people with dementia that address these psychological needs, preserve personhood and enhance well-being, which he called Positive Person Work, as opposed to Malignant Social Psychology, a group of 17 interactions that threat personhood. Positive Person Work includes recognition, negotiation, collaboration, play, timalation (sensorial stimulation), celebration, relaxation, validation, holding and facilitation. In fact, Kitwood (1997) mentioned two more interactions: creation and giving. While the other ten are initiated by the carer, thus seeing the person with dementia as a receiver, these two arise spontaneously from the person with dementia, to whom the carer should respond in an empathic and encouraging way. In this chapter, we focus on the initial ten interactions since we are mainly considering how artefacts can mediate them, supporting the carer to initiate Positive Person Work. The idea of Positive Person Work was further researched and developed by other authors, such as Van Weert et al. (2006), who analysed these interactions in specifically in hygiene moments and mealtimes; and Brooker (2007), who expanded this list of positive interactions to 17 and named them Personal Enhancers: warmth, holding, relaxed pace, respect, acceptance, celebration, acknowledgement, genuineness, validation, empowerment, facilitation, enabling, collaboration, recognition, including, belonging, fun.

others who researched Positive Person Work

decision to work with original proposal of Positive Person Work

In this research, we have opted to use Kitwood's Positive Person Work proposal for several reasons. On one hand, the differences between some of the 17 Personal Enhancers become very subtle, which are significant on interpersonal interactions but become too nuanced for an analysis from a design perspective. On the other hand, Positive Person Work includes interactions like timalation and play, where design might be able to contribute in an interesting way. In order to empirically understand these interactions, we have looked for them during the preliminary observation study [chapter 4]. Fieldnotes were taken after all the sessions observed, which were posteriorly analysed taking the Positive Person Work interactions into account. This analysis will be presented in the following section. The reviewed literature and the observational study and analysis became the basis for a reflection on these interactions from a design perspective.

5.4 Designing for Positive Person Work

description of speculative exercise

In this section, we describe and explore each of the Positive Person Work interactions, reflecting on how they can be used as design considerations, and how to design for them. In order to do this, we did a speculative exercise consisting of four parts:

1. identifying existing artefacts that could be metaphors for the interaction, without thinking about the context of dementia;
2. identifying characteristics that could correspond and symbolically suggest the values and attitudes inherent to these interactions—the artefact as a *symbol*;
3. imagining artefacts that could provide a similar interaction directly with the person with dementia—the artefact as *catalyst*;
4. imagining artefacts that could mediate the interaction between the person with dementia and others—the artefact as *support*.

general analysis of results from speculative exercise

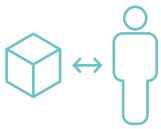
This exercise helped us to understand different ways in which design can support these interactions, which we used to illustrate the reflections on each Positive Person Work below. The first part was a way of getting started and thinking how these interpersonal interactions could be translated or represented by products. The second part refers to a more *symbolic* dimension, related to how these interactions can be reflected in the formal aspects of artefacts. Both pragmatic and mainly hedonic attributes are considered, so that person-centred care values can also be visually embedded, and hopefully result in more respectful, dignifying and non-stigmatising artefacts.



symbol

products as *symbol*:
· pragmatic and hedonic attributes that reflect the Positive Person Work interactions

The third and fourth parts regard the interaction with the product. Since Positive Person Work refers to interactions between the person with dementia and others, and emphasises relationship building and maintenance, we also try to reinforce this aspect through considering both person-product interactions, and the interpersonal interactions mediated by a product.



catalyst

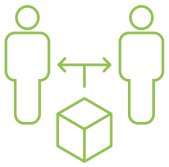
products as *catalysts*:
· enablers of pleasurable activities, self-expression, creativity, and daily tasks
· prompts and cues for action
· comfortable artefacts
· 'messages' for the person with dementia

In a more general analysis, and drawing on the roles that design can play in contributing to subjective well-being proposed by Pohlmeyer (2013), the third exercise referring to person-product interactions, suggested that artefacts that can be direct sources or enablers of the desired interactions. Although this is not a comprehensive list of possibilities, and it varies according to the interaction, we have identified that most of the ideas consist of products that are enablers of pleasurable activities, self-expression, creativity, and daily tasks (mainly through redesigns that facilitate use), as well as prompts and cues for action. Besides this, another group of ideas focused on evoking the desired interaction through comfortable artefacts, and through leaving pleasurable, tender or fun 'messages', that can take any form (visual, written, audio, etc). Therefore, since the person with dementia

becomes a 'recipient' of these messages, we have considered these artefacts as direct sources of Positive Person Work. These are very much associated to the symbolic value mentioned before, and can also be related with the fourth exercise, if these messages are personalised, or left by important people for the person with dementia. We chose the term *catalyst* to refer this more direct experience between the person with dementia and an artefact, including both roles of source and enabler.

The fourth part focuses on the interpersonal interactions mediated through artefacts. This is the kind of experience we are more interested in, given the aim to create opportunities to communicate through design and looking at relationships. Many times, artefacts become a vehicle for communication, they become things to speak through (Wallace et al., 2013). They are used as triggers to start a conversation and as cues to keep it going. Sometimes, through an artefact people with dementia can convey meaning to an interaction. Most ideas emerging from this exercise are related to the potential of artefacts to be boundary objects (Star, 2010), mediating interaction that involves verbal and non-verbal communication. In these cases, artefacts are also enablers as well as a support and encouragement for the carers to make those interactions happen. Another group of ideas aimed directly, and sometimes only, at carers. Some consist of activity suggestions that can be done with the person with dementia, and others are tools and exercises to develop empathy and encourage understanding, which might support the carer in delivering the interactions, and possibly contributing to deal and relate better with the person. We will use *support* to designate this experience of an artefact as mediator of interpersonal interactions.

All Positive Person Work interactions are analysed, reflecting on how to design for the experience of those interactions—as a *symbol*, as a *catalyst* and as *support*—, and re-defining them as considerations and strategies to design for people with dementia. To illustrate this, we have used a selected number of artefacts designed specifically for people with dementia (unless stated otherwise), by design practitioners, researchers and students, as well as some products developed in healthcare contexts. In this review, we have mainly focused on tangible products, rather than digital. Architecture, interior design, medical devices and screen-based products were also consulted, but not extensively reviewed. Although we refer to many products that have a more practical function in supporting daily activities, we have mostly covered those that have a ludic function and promote connectedness. We have also included some artefacts that aim to raise awareness and empathy towards people with dementia. Along with the descriptions of each Positive Person Work interaction we will highlight some of these projects that we considered exemplary.



support

products as *support* for interpersonal interactions:
· products as vehicles for communication
· products aimed directly at carers: activity suggestions; empathy and understanding exercises.

5.4.1 Recognition

Recognition observed

On the day centre anniversary, they organised an event for everyone to participate (staff, users and their families). All participants were invited to comment on and make suggestions regarding the day centre, based on a previously prepared set of cards with written words.
Fieldnotes 27.10.2014

"Mr. B, please stay here with us! You don't need to participate if you don't feel like. You can see what we are doing. If you feel like you are very welcome to join us, if not you can just observe and you can leave whenever you want."
Fieldnotes 13.04.2015

"Here ***a man or a woman who has dementia is being acknowledged as a person***, ***known by name***, ***affirmed in his or her own uniqueness***. Recognition may be achieved in ***a simple act of greeting***, or in ***careful listening*** over a long period... Recognition, though, it is never purely verbal, and it need not involve words at all. One of the profoundest acts of recognition is simply the ***direct contact of the eyes***".
—Kitwood, 1997, p. 90

In an activity with children, a lady with advanced dementia was making some unusual sounds. Observing that some children found the lady's behaviour strange, the psycologist explained to them that these sounds were her way of communicating.
Fieldnotes 29.10.2015

"Meeting the participant in his or her own uniqueness, ***bringing an open and unprejudiced attitude***".
—Brooker, 2007, p. 94

Before starting the activity, the therapist greeted everyone individually by their names and asked them about the weekend. Fieldnotes 15.09.2014

"This is Mrs. O!' The children greeted the lady and she smiled." Fieldnotes 08.10.2014

I sat next to Mrs C. We spoke for about 30 minutes. A told me several things about her life. After a while, when she noticed the time, she apologised:
"I talk so much, I am so sorry".
"No worries, Mrs A, I enjoyed listening you very much".
Fieldnotes 13.10.2014

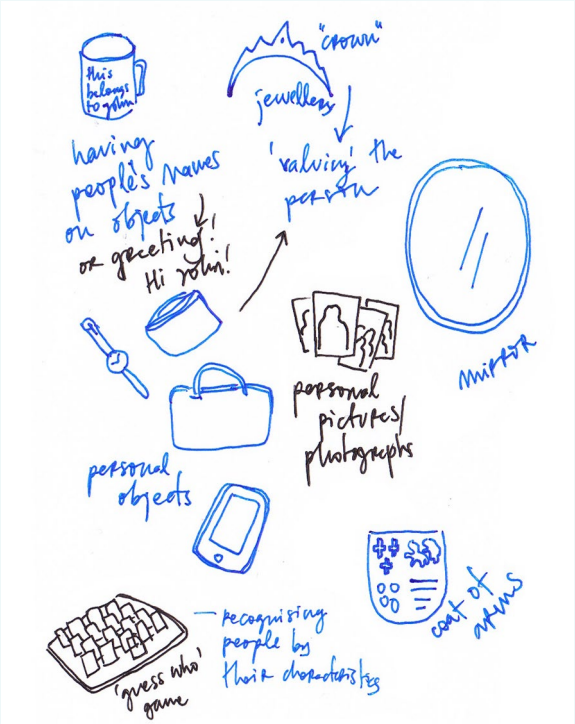
In the music activity, Mrs. L sings along, tapping her foot and her hand on her knee. The volunteer seated next to Mrs L accompanies her, looking her in the eyes and smiling at her, and Mrs. L smiles back.
Fieldnotes 17.11.2015



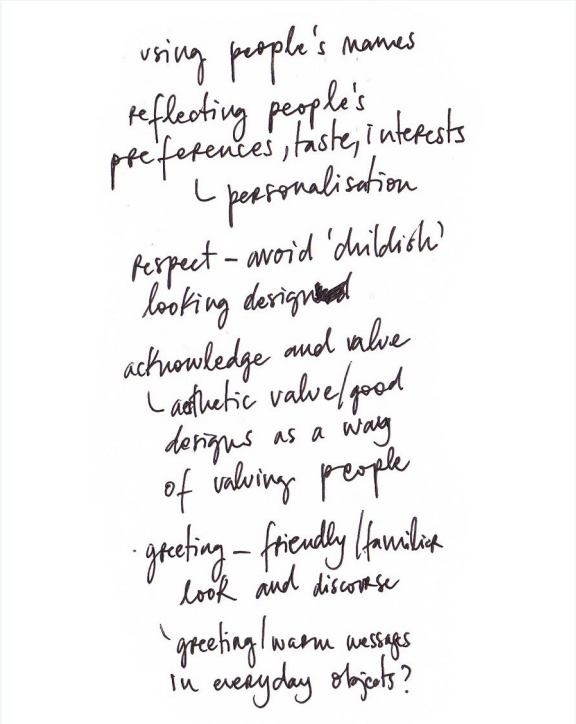
Figure 5.1 Recognition observed at activity sessions with people with dementia.

Designing for recognition?

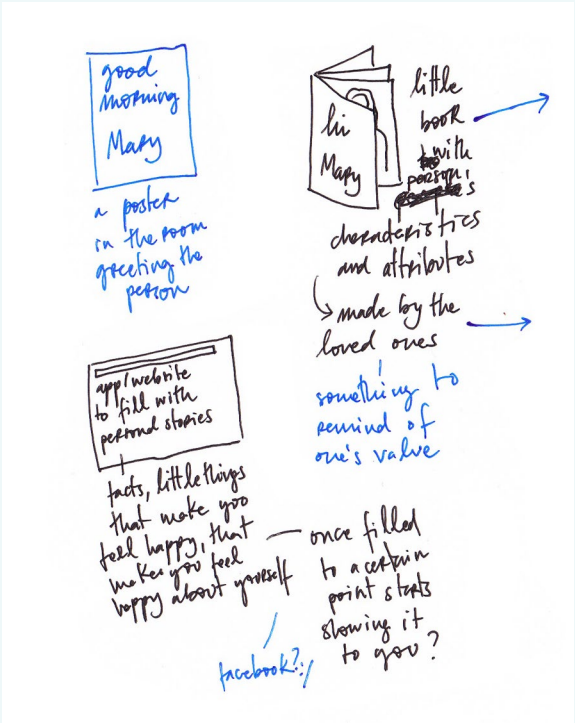
1. What could be a **recognition** object?



2. How does something look **recognition**?



3. How could an artifact **"acknowledge someone as a person..."**?



4. How could an artifact trigger interactions of **recognition**?

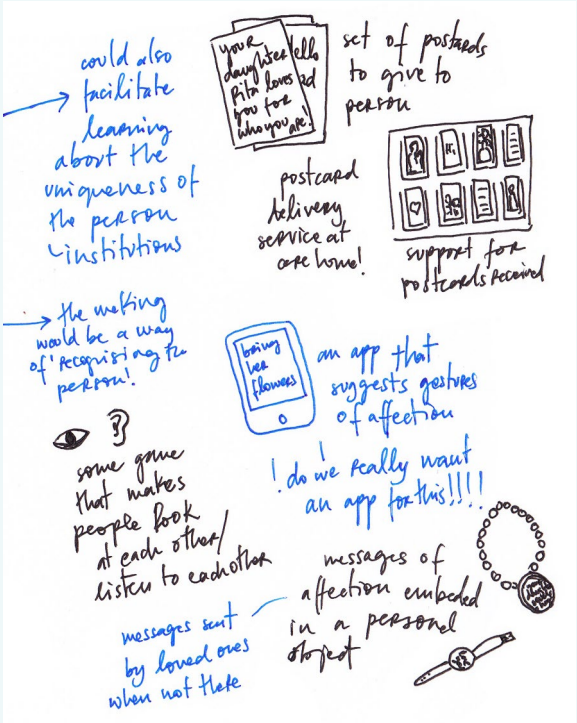


Figure 5.2 Speculative exercise about how **recognition** could be used in design.

respect and dignity both in function and aesthetics

Recognition refers to the acknowledgement of the person with dementia as a person, and the affirmation of her or his own uniqueness (Brooker, 2007; Kitwood, 1997; Van Weert et al., 2006). Designing for **recognition** implies that what is designed demonstrates respect and dignity for the person, both in the proposed use and mediated interactions, but also conveyed aesthetically. The aesthetic qualities of artefacts are often left behind the functionality when designing for people with impairments. As Pullin (2009) suggests, this comes from the fact that artefacts for people with disabilities have been traditionally developed in medical contexts, favouring efficiency and often resulting in stigmatising artefacts. We believe that making an effort to design aesthetically pleasing artefacts, symbolically respects and valorises who we are designing for. *Vigour* is a cardigan with embedded stretch sensors and an associated iPad application developed to encourage older adults to keep active and to help physiotherapists and family members to understand the progress of their exercises, by monitoring the movements and giving sound feedback, which was found relevant for people with dementia. [Figure 5.3] The designers put special emphasis on designing a normal, comfortable and appealing cardigan that can be worn all day so that it would be easily accepted by older people and their families:



Figure 5.3 Vigour. From Martijn ten Bhömer – photo 1 by Joe Hammond; photo 2 by Wetzer and Berends (https://www.mtbhomer.com/portfolio/vigour/)

> Family and caregivers do not like the stigma of a patient that a garment with a strong medical look puts on the wearer. It is important that the person wants to wear it, first of all because it is comfortable and also fits their identity and is beautiful, and additionally has the other features you expect from a smart garment. (Bhömer, 2016, p. 53)



Figure 5.4 Ten design probes to learn about personhood. From "A Design-led Inquiry into Personhood in Dementia," by J. Wallace et al., 2013, p. 2619.

In addition, **recognition** can be used as a design strategy to support one's identity and value one's uniqueness. Wallace et al. (2013) developed a set of ten design probes to explore and understand several aspects of the participant's sense of self, relationships and life history. Although these were not the final artefacts, this exploration into a person's personhood through the use of probes is a rich example of how artefacts can be triggers to reflect and talk about one's identity. [Figure 5.4] This process led to the design of personalised jewellery, aiming to support important aspects of the participant's identity, throughout the progression of dementia.

support identity

Personalisation, through bespoke artefacts or artefacts that invite and allow personalisation (e.g. including people's names, emphasising characteristics and virtues, using known references to meaningful people, places, events, etc), seems to be a way to design for **recognition**. For example, in the Helen Hamlyn Centre project *Design for Dementia*, Timlin & Rysenbry (2010) proposed a personalisation system for the walls of residents' bedrooms in care homes, making space for personal objects and decoration and enabling the arrangement of the room according to the resident's preference. [Figure 5.5]

personalisation

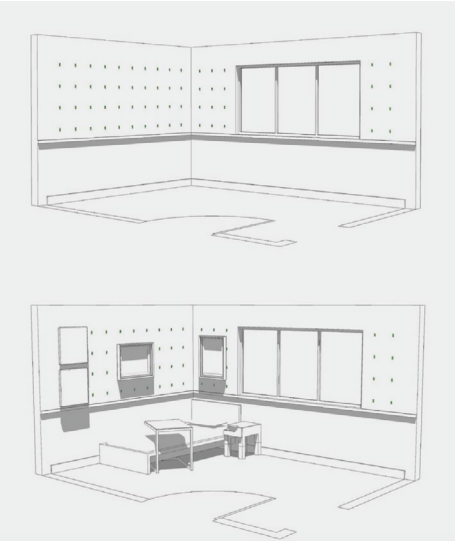


Figure 5.5 Personalisation system for the walls of residents' bedrooms. From *Design for Dementia: Improving dining and bedroom environments in care homes* (p. 75) by G. Timlin and N. Rysenbry, 2010.

Also related to **recognition** due to its focus on personal life history, the use of references (from one's past, but also from popular culture) to elicit autobiographical memories is a frequent strategy in designing for people with dementia, especially if the aim is the engagement in activities and conversation. *Reminiscence* "is the voluntary or involuntary action of recollecting memories from one's past" (Afonso, Selva, & Postigo, 2016, p.2), and it is often used therapeutically by healthcare professionals. Although the value of these interventions was already identified, it is necessary to be aware that remembering the past can also generate emotions that might be negative, thus possibly having an adverse impact (Afonso et al., 2016). Reminiscence work should consist in "making deliberate attempts to trigger memories of the past and use them as a vehicle for communication in the present. Reminiscence work provides opportunities for people to communicate about their memories in their own way" (Bruce & Schweitzer, 2008, p. 170). This intervention regularly uses products (personal or general) as a stimulus to start conversations and trigger memories, thus making it "natural" for design to explore it.

reminiscence



Figure 5.6 Memory Music Box. From Studio Meineck (http://www.studiomeineck.com/music-memory-box/).

The *Music Memory Box* is an example of a product designed to be used in reminiscence work, using objects, music and audio. The box is personalised with the person's favourite objects that, when placed at the centre, make personal music or audio content play (Meineck, n.d.). [Figure 5.6]

Recognition can be taken into account and mediated by design in several ways, corresponding to the three roles described before: (1) *symbolically*, artefacts should be respectful and dignifying, through an appropriate and pleasurable appearance. In order to support the person's uniqueness, artefacts can also include personalised elements, such as the person's name or personal references. Regarding the (2) artefact as a *catalyst* for the direct interaction of the people with dementia with the artefact, these personalised elements can act as 'messages' that greet and valorise the person, using their preferences and telling them about their value, their important people, their life history. However, as pointed by Bruce and Schweitzer (2008), it is essential that these messages regarding life history, are told in ways that help the person to have a "sense of ownership of her/his story", trying to check with the person, understanding how the person recalls and feels about it, and accepting and respecting her/his account of the story. Although it is important to involve the person with dementia in this process of personalisation as much as possible, part of it can also count with the participation of family members and formal carers. This is already related to the (3) artefact as *support* to the interaction between the person with dementia and the carer. Products and services that consider this possibility can bring benefits both for the person with dementia and their carers: it can constitute an opportunity to make something together, which is important to build and maintain relationships; it supports the identity of the person with dementia, through self-expression and through the work with life stories, crucial for several aspects such as keeping

use of personal references

the personalisation process as opportunity for interaction between people with dementia and their families

autobiographical memories and leaving a legacy for younger generations (Bruce & Schweitzer, 2008); it is also an opportunity for the carers to perceive the person differently, beyond the diagnosis, which influences the relationship with the person with dementia. Although **recognition**, and personalisation, can involve more than reminiscence work, Bruce and Schweitzer (2008) affirm that revisiting and knowing the life history of the person being cared for, can contribute to an enhanced understanding and to give meaning to the relationship, as well as providing cues about certain behaviours and themes that can be used to stimulate communication.

5.4.2 Facilitation

Facilitation observed

Mrs F kept holding a brush for a while, without doing anything. She was only staring at the little girl next to her. I approached her and invited her to paint. She seemed not to know what and how to do it. I suggested her to start around the line that Dr M drew [at the beginning of the session, on a big paper covering all the table, as a starting point for participants to draw and paint]. Fieldnotes 10.12.2014

"At its simplest this means **enabling a person to do what otherwise her or she would not be able to do, by providing those parts of the action – and only those – that are missing**. ... The task of facilitation now is to **enable interaction to get started, to amplify it and to help the person gradually to fill it out with meaning**. When this is done well there is a **great sensitivity to the possible meanings in a person's movements**, and interaction proceeds at a speed that is slow enough to allow meaning to develop". —Kitwood, 1997, p. 91

Her fine motor skills do not allow her to hold a brush to paint. Therefore, Dr J brought her a sponge. She started painting with the sponge, making regular shapes side by side, almost like a pattern.
Fieldnotes 17.12.2014

Mrs N grabs a piece of fabric that does not have enough width to make the bag. However, I see that she liked the fabric pattern, she put it next to her blouse, almost as if she was trying it. Since it had enough length, I put it around her neck, suggesting it is a new scarf, and I pick another piece of fabric for making the bag.
Fieldnotes 03.12.2014

Mrs T has a serious facial expression, but smiles from time to time, the volunteer shows her the flowers and leaves and makes a drawing for her to see. Mrs T smiles. From time to time, we bring her the rosemary, to smell.
Fieldnotes 22.10.2014

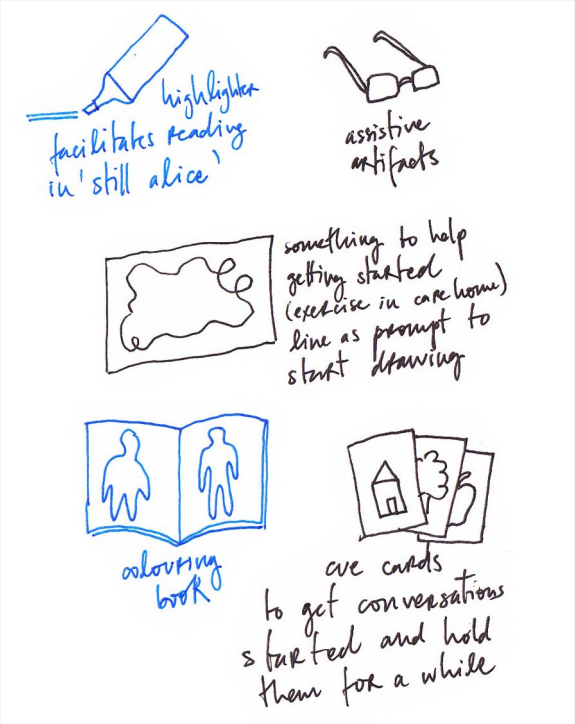
"enabling: **recognising and encouraging a participant's level of engagement within a frame of reference**".
—Brooker, 2007, p. 93



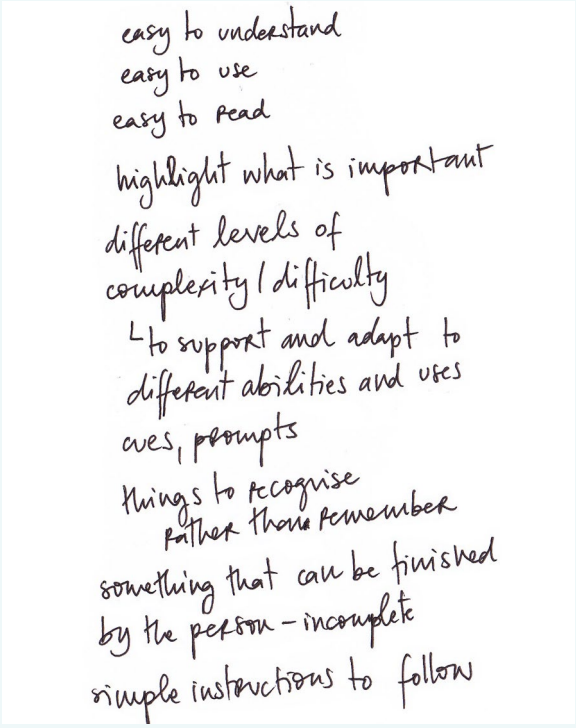
Figure 5.7 Facilitation observed at activity sessions with people with dementia.

Designing for facilitation?

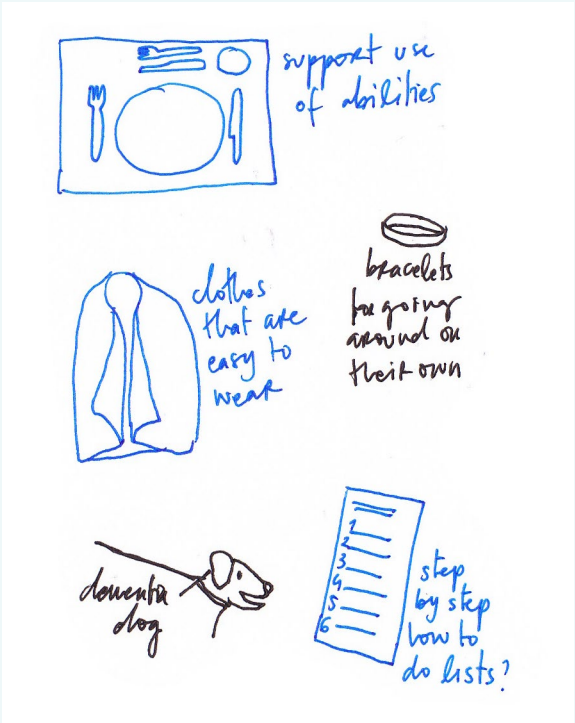
1. What could be a **facilitation** object?



2. How does something look **facilitation**?



3. How could an artefact **"enable interaction to get started, encourage engagement and assist on using abilities & skills"?**



4. How could an artifact trigger interactions of **facilitation**?

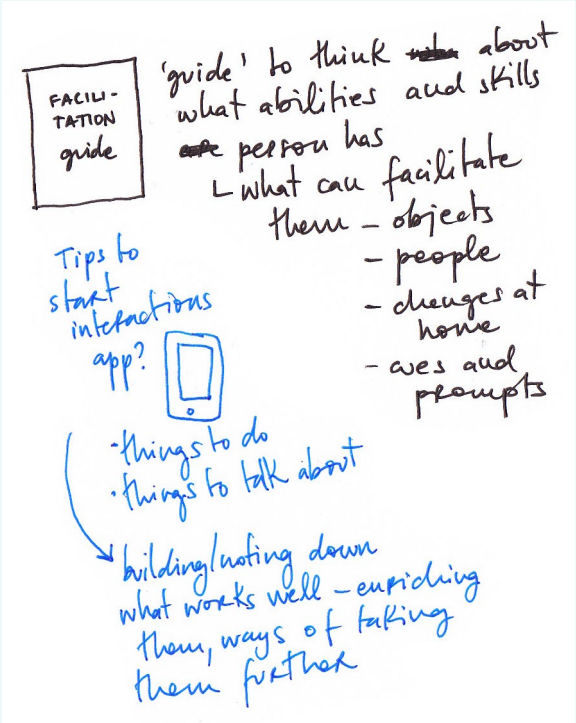


Figure 5.8 Speculative exercise about how facilitation could be used in design.

Facilitation is about enabling action by assisting with what is missing, and supporting people to perform activities that otherwise would be difficult to achieve (Brooker, 2007; Kitwood, 1997). To provide this kind of interaction is relevant to enhance and maintain people's abilities, to keep independence and to create a sense of agency. Although not the focus of this study, assistive technology is typically aimed at having an enabling role. There is wide variety of assistive technologies developed specifically for people with dementia, ranging from devices to improve safety at home (fall sensors, flood, gas, smoke detectors, automatic lighting, water isolation and shut-off devices), to help with safe-walking outside (tracking devices, monitoring systems and alarms), reminders and automated prompts (clocks and calendars, item locators, medication reminders and dispensers, voice recorders and memo minders), communication aids (intercoms, telephones), telecare, and devices to support leisure moments (radios, TVs, electronic games and apps, puzzles, sensory and mental stimulation) (Lindsay, 2011; Trent Dementia Services Development Centre, n.d.). While these are important examples and contributions to be aware of, we would like to focus on a more sensitive perspective to **facilitation**. Kitwood (1997) described **facilitation** in the context of interpersonal interaction, emphasising the importance of not only allowing interaction to start and continue, but also to develop a "sensitivity to the possible meanings in a person's movements" so that they can "gradually to fill it out [the action] with meaning" (p.91). Accordingly, is it possible develop *sensitive* artefacts that *facilitate* people with dementia to fill their actions with *meaning*? Although this might be an ambitious question to answer, we believe that there are some design considerations that may be used as starting points.

assistive technology

a sensitive and meaningful view of facilitation

Artefacts can be enhanced to facilitate physical, cognitive and cultural accessibility, making products easier to understand and use. Unnecessary complexity should be avoided and products should be reduced to the essential. Aesthetic decisions can support functionality and prompt use: a familiar and recognisable look; contrasting colours to help to distinguish different elements; consistency among different elements; emphasis on the essential functions and features (Gowans et al., 2007; Pullin, 2009; Timlin & Rysenbry, 2010; Zeisel, 2013). The tableware designed by Timlin and Rysenbry (2010) for the project *Design for Dementia* take these aspects into account, and it is a good example of how a careful observation of how people use and manoeuvre artefacts can be translated into the understanding of how to shape artefacts that **facilitate** and encourage use. Moreover, the different designed tableware sets also take into account distinct levels of autonomy (Timlin & Rysenbry, 2010). [Figure 5.9] When designing for people with dementia, it is important to envisage possibilities of use that support different abilities, across the progression of dementia. This is also related to **recognition**, the interaction discussed before. While a person in more severe stages of dementia might need a specific artefact to undertake a certain

aesthetic qualities to support product's physical, cognitive and cultural accessibility

considering the progression of dementia

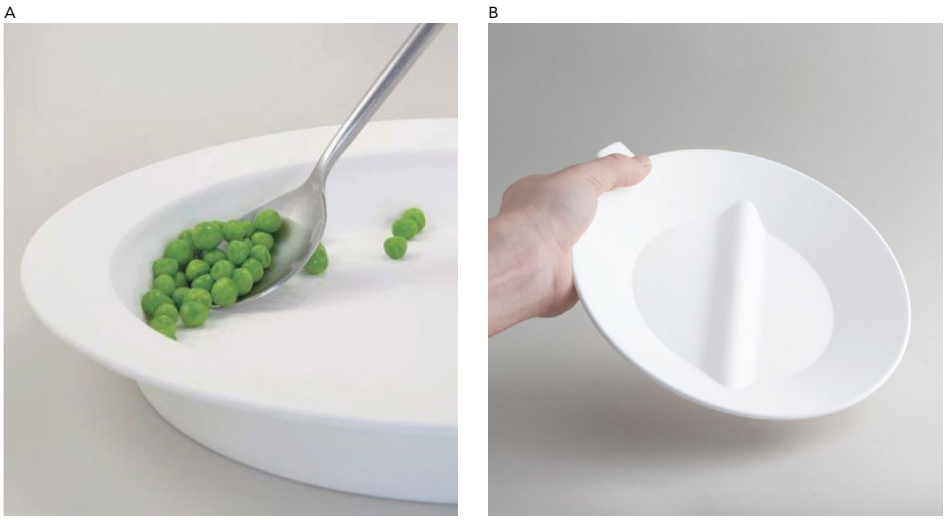


Figure 5.9
A) Tableware to reduce complexity. **B)** Tableware for assistance. From *Design for Dementia: Improving dining and bedroom environments in care homes* (p. 54; p. 60) by G. Timlin and N. Rysenbry, 2010.

activity, someone in early stages might find diminishing to use the same artefact. Responding to this might require the design of separate solutions or products that can adapt to these changes. In either case, it is important that artefacts are appealing and not stigmatising. The *Dementia Dog* project, which emerged from the challenge *Living Well with Dementia* organised by the Design Council, responds to these issues in a very subtle and non-stigmatising manner. *Dementia Dog* is a service that brings dogs into the lives of people with dementia, to support daily routine and provide orientation. Dogs are taught to act as reminders for the several quotidian tasks while being naturally good companions (Design Council, 2012a). [Figure 5.10]

reminders and cues

Reminders, as well as visual, verbal and environmental cues, are also frequent design solutions for people with dementia. Also in these cases, there is the need to be sensitive to what can be helpful and enabling, or confronting and diminishing. Again, enhancing aesthetic qualities of artefacts can be ways to de-stigmatise this kind of products. These might

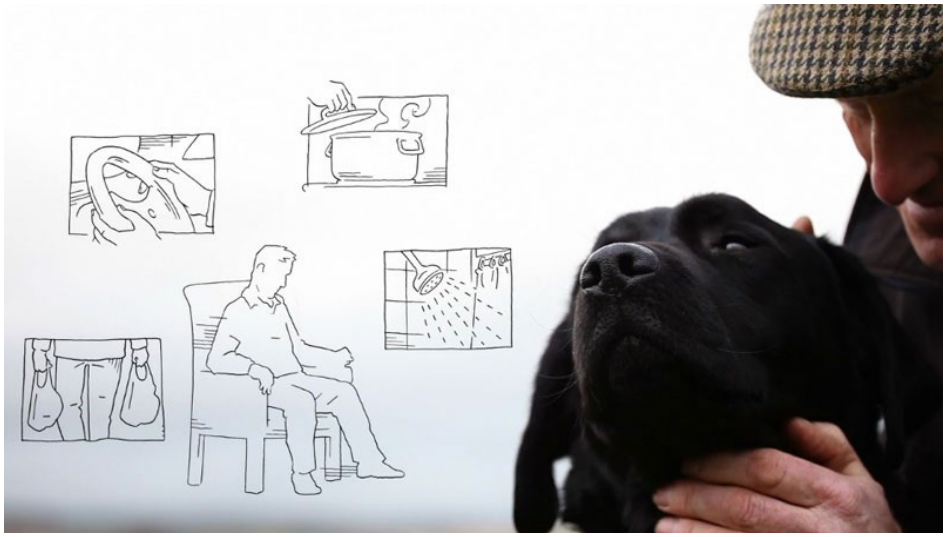


Figure 5.10
Dementia Dog. Frame from video "Dementia Dog Case Study", by Design Council, 2011 (http://www.designcouncil.org.uk/resources/case-study/dementia-dog).



Figure 5.11
See What I Mean iPad app. From See What I Mean (http://seewhatimean.co.uk/).

also benefit from a more positive, possibility-oriented approach aiming at positive experiences and *human flourishing* (Desmet & Pohlmeyer, 2013; Hassenzahl, 2010), rather than the more common problem-driven proposals. For instance, *See What I Mean* is an app that translates what is being said into images. [Figure 5.11] The immediate response of the app to people's words helps people with dementia to follow a conversation while having reminiscence value, thus facilitating engagement and communication with others (See What I Mean, n.d.). With a more creative aim, and without focusing on reminiscence, the intervention program *Timeslips*, founded by the artist and scholar Anne D. Bastings, uses photographs to engage people with dementia in group storytelling, encouraging people to contribute to the creation of a story, in their own terms (Fritsch et al., 2009).

To summarise, we look at **facilitation** not only from the perspective of creating assistive artefacts, but also to make an effort to enable the creation of *meaning*. The attention to aesthetic qualities, as a means to enhance function and ease of use, while making artefacts culturally and personally relevant and less stigmatising, seem to be ways to balance pragmatic and hedonic attributes. Although the pragmatic aspects are crucial, the creation of meaning lies in the hedonic characteristics of an artefact (attractiveness, capacity to stimulate and to communicate one's identity) (Hassenzahl, 2010). This might be even more important in the case of people with dementia:

> The head of BIME, Roger Orpwood, explains that dementia is often accompanied by a heightened artistic appreciation and emotional response. So it is likely that the beauty of objects around individuals with dementia, both everyday objects and those designed for them, could play a part in people's experiences of living with this condition. (Pullin, 2009, p. 83)

aesthetic approach to people with dementia

In fact, Hughes (2014) describes people with dementia as "aesthetic beings", referring to the embodied engagement with all the dimensions of the world, not only through our understanding but also through the senses. The same author highlights the importance of aesthetic experiences for people with dementia, also affirmed and described by Killick and Craig (2011), and proposes an *aesthetic approach to people with dementia*, where openness, receptivity and humility, as well as intuition and imagination, are required to learn about the person through their gestures and actions, and to interact and communicate in a holistic manner, using the senses (Hughes, 2014). In this way, designing for people with dementia also constitute opportunities for aesthetic experiences and for supporting this aesthetic approach.

If we consider artefacts as *catalysts* of activities or actions, thus regarding the direct interaction between people with dementia and the artefact, cues and memory aids have revealed to be important in the daily lives of people with dementia (M. L. Lee & Dey, 2007). Most of these reminders and cues focus on compensating the memory difficulties of people with dementia to enable daily tasks to be performed independently. However, it is also important to design prompts for positive experiences, namely meaningful occupation, related with aesthetic and pleasurable activities. In all kinds of proposals, it is important to consider the progression of dementia in a sensitive way, and this also involves the inclusion of carers into the equation, namely in later stages of dementia. Therefore, products that assist care, support the carer in identifying possibilities and engaging with the person with dementia in activities, or provide occupation for the person with dementia to be entertained, also allowing the carer can have some piece of mind, might also fit into this strategy.

reminders and cues for positive experiences (not only for practical functions)

5.4.3 Negotiation

Negotiation observed

"Good morning Mrs. R, how are you doing?" Mrs. R replies with an unhappy facial expression.
"Would you like to join us in the activity session?"
"Not today. My belly hurts."
"Oh I am sorry to hear. I hope you get well soon. Will you join us next week?"
"Yes, I will join".
Fieldnotes 22.10.2014

Mr. C asks the psychologist how to go home.
"Mr. C, the driver will take you home. He will call you when he arrives. But it will still take a while, in some hours".
"I am afraid of not knowing when to go".
"You don't need to worry, Mr. C. We will find you and the driver takes you to your wife".
Fieldnotes 13.10.2014

Mrs J was insecure about initiating the exercise [molding dough as they wished]. The psychologist helped her starting and she continued with enthusiasm, even if constantly asking about how she was doing. In the end, she was happy with the exercise and asked the psychologist when the next activity session was happening. Fieldnotes 08.10.2014

"The characteristic feauture of this type of interaction is that people who have dementia are **being consulted about their preferences**, **desires** and **needs**, rather than being comformed to other's assumptions. ... Skilled negotiation **takes into account the anxieties and insecurities** that often pervade the lives of people with dementia, and the slower rate at which they handle information. Negotiaton **gives even highly dependent people some degree of control** over the care that they receive, and puts power back into their hands". —Kitwood, 1997, p. 90

"Empowerment: letting go of control and **assisting the participant to discover or employ abilities and skills**".
—Brooker, 2007, p. 93

"What are your favourite activities, Mr. P?"
"I prefer being quiet, not doing anything". Fieldnotes 27.10.2014

Mrs. F was writing something and stopped. I asked her if she wanted to change colour. She denied and I asked her if she would like to add anything else to what she was doing. She tells me she finished and preferred to look at what the others were doing.
Fieldnotes 10.12.2014

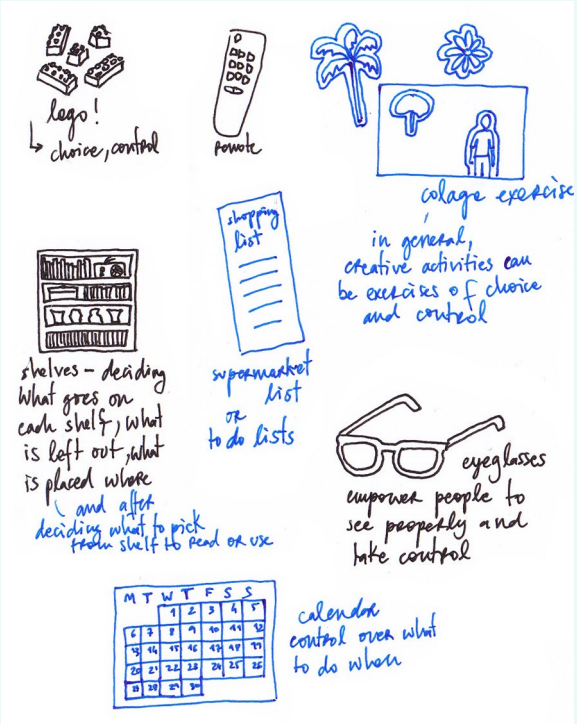
"I am not being able to finish this."
"How can I help Mrs T?"
"I would like to put it all around."
"Ok. So should I put this one here?"
"No, that one is too big."
"Should I cut it, then?"
"Yes! That is looking good. Put another one there."
"Is it ok like this?"
"Just one more at the top... That's it!" Fieldnotes 08.10.2014



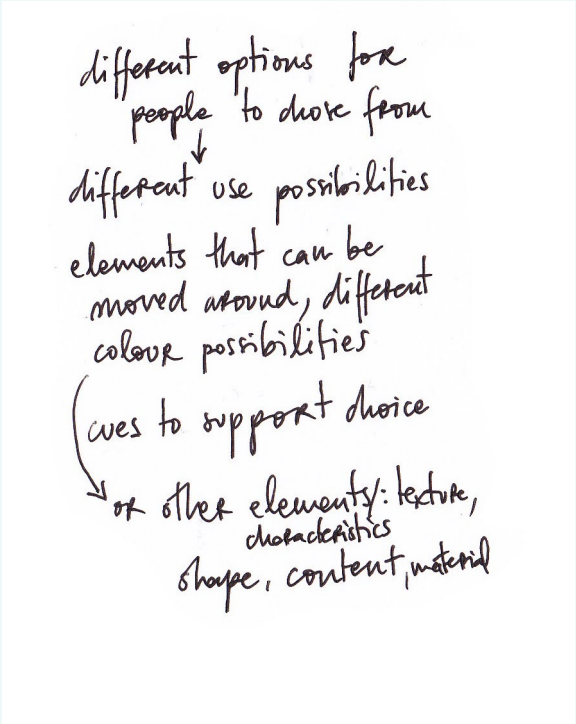
Figure 5.12 Negotiation observed at activity sessions with people with dementia.

Designing for negotiation?

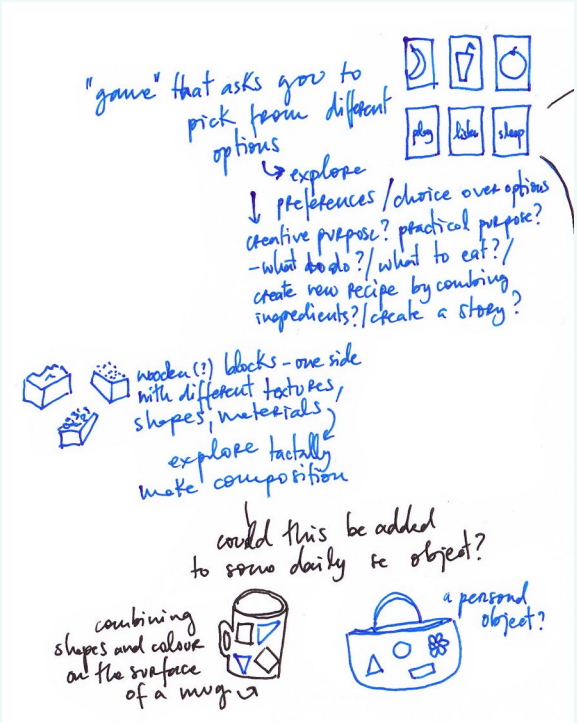
1. What could be a **negotiation** object?



2. How does something look **negotiation**?



3. How could an artefact
"give some degree of control"?



4. How could an artifact trigger
interactions of **negotiation**?

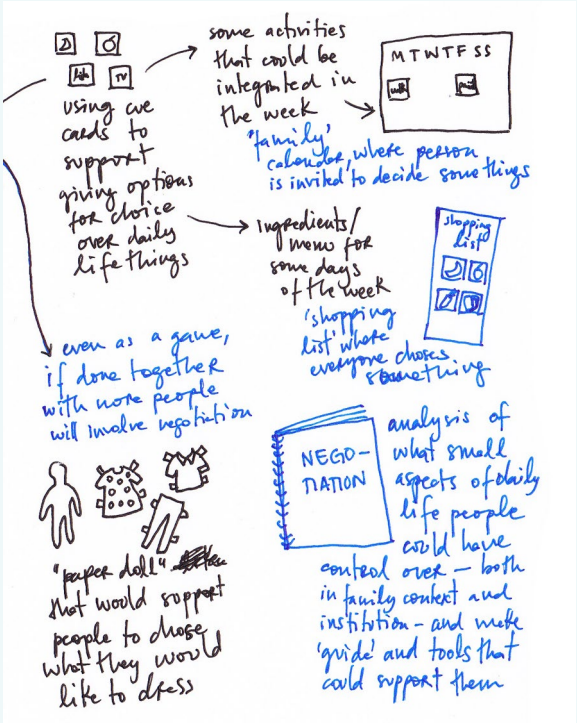


Figure 5.13 Speculative exercise about how negotiation could be used in design.

Negotiation consists in providing opportunities for exercising control and choice. As dementia progresses, people with dementia increasingly become dependent and have less control over their lives. Thus, there should be an effort to find ways to enable people with dementia to be in control, through being consulted about their needs and preferences or stimulating more creative and personal expression. In this way, supporting negotiation becomes a way of acknowledging people's choices so that they feel respected.

> It appears then that providing the types of starting point which enable the person to pursue their own interpretations of material, and have maximum control over what they say or otherwise express, are the most likely to be successful. Ideally the experience of success could derive both from meaningful information being communicated, and the person with dementia feeling that the interaction has respected their individuality and dignity, and boosted their confidence regarding further such encounters. (Allan, 2001, p. 103)

artefacts to support consultation

It was already mentioned that artefacts can play a role in triggering conversation and reminiscence, and that sometimes they can be used as dialogue (Wallace et al., 2013). Likewise, artefacts might support and encourage the person with dementia to be consulted about their preferences, wishes and needs, despite the difficulties in communicating verbally, understanding and remembering. Sabat (2014) distinguishes the ability to remember, recall and recognise:

remember, recall and recognise

> one should not assume that a person's failure to recall information means that the person cannot remember that information. Recall and remembering are not the same things. Recall is one way to remember, but there are other ways to do so, including recognition. (p. 109)

multiple-choice

Therefore, the ability to recognise, which is based on a multiple-choice format, is often less compromised and easier for people with dementia (Sabat, 2014). From a design perspective, this implies that artefacts have several options and possibilities, allowing people to choose. For instance, an artefact can be designed to have different elements to be moved around according to preferences, different aesthetic possibilities (e.g colour), or different possibilities of use.

Artefacts can be designed as *catalysts* of choice. *Talking Mats*, a tool developed by Speech and Language therapists at Stirling University to support people with communication difficulties to express themselves, is an example of a product based on multiple-choice. It was not designed specifically for people with dementia, but it has been widely used in this context, proving to be very effective. It consists of pictures representing the topic, the possible options and a scale with different feelings about the topic or options, and a space (a mat or

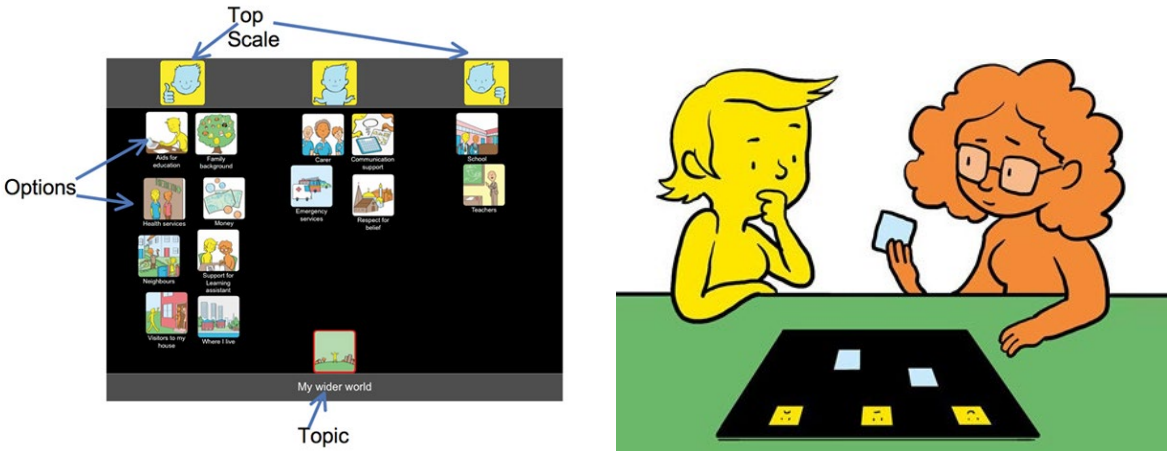


Figure 5.14
Talking Mats. From Talking Mats (http://www.talkingmats.com/).

a digital app) where to move these pictures. This helps people to decide over more practical aspects of their daily lives or care and supports conversation and the expression of preferences or feelings (Talking Mats, n.d.). [Figure 5.14]

creativity and self-expression

Another way of designing for people with dementia to exercise control is to stimulate creativity and self-expression. Killick and Craig (2011) have comprehensively demonstrated the value of creative practice and arts in dementia care. Although artistic activities are probably more complete at all levels, we can try to find ways to design artefacts to either leave space for creative self-expression, or that encourage and facilitate artistic activities.

supporting carers to consult and encourage the person with dementia to exercise control

Like *Talking Mats*, artefacts can also prompt and enable **negotiation** interactions between people with dementia and their carers. For instance, tools to support simple everyday life decision making, such as what to dress, what to eat or what to do. Another example of how an artefact can support carers to enable **negotiation** is *Moments*, a system for digital sharing of art work developed in an art therapy context. People with dementia are encouraged to document and share their art work through the manipulation of several physical objects that are used to encourage and support decision and meaning-making (Lazar, Edasis, & Piper, 2017b). In addition, it could be important to develop tools to help to reflect and guide carers on how to consult the person with dementia about aspects of daily life that they could have control over, and what might be needed to support it.

5.4.4 Collaboration

Collaboration observed

Mr. V interacted a lot with the little kid next to him, helping him in his drawings and composition. Fieldnotes 22.10.2014

"I would like to ask you something! We are already thinking on our Christmas party. What do you think about declaiming some Christmas poems?"
"It sounds good", replies Mrs. U
Mr. S starts singing.
"Can I count on you Mr. S?"
"Yes, you can", replies Mr. S.
"What do you think, Mrs. E?"
"Sure, but I would like to read from a paper".
"Of course, with a paper. What about you Mr. F?"
"With the paper I can do it".
"This is great! We will have a beautiful party!"
Fieldnotes 19.11.2014

"Here we gain a glimpse of **two or more people aligned on a shared task, with a definite aim in view. The true meaning of collaboration is 'working together'**, and this may be literally the case... The hallmark of collaboration is that care is not something that is 'done to' a person who is cast into a passive role; it is a process in which **their own initiative and abilities are involved**".
—Kitwood, 1997, p. 90

"Collaboration: **treating the participant as a full and equal partner** in what is happening, consulting and working with them".
—Brooker, 2007, p. 94

[In an arts and crafts activity, participants were encouraged to draw to the sound of music, as if they were 'dancing on the paper'.]
"Mr. H, can I take you to 'dance'?" asks the therapist.
Mr. H smiles with a surprised expression.
"You can place your hand on the top of my hand". Mr. H does so, but puts a lot of pressure.
"Mr. H, can you please loose a little bit, without making so much pressure, so I can also move."
Together, they 'dance' [draw together] a little bit on the paper. Fieldnotes 19.11.2014

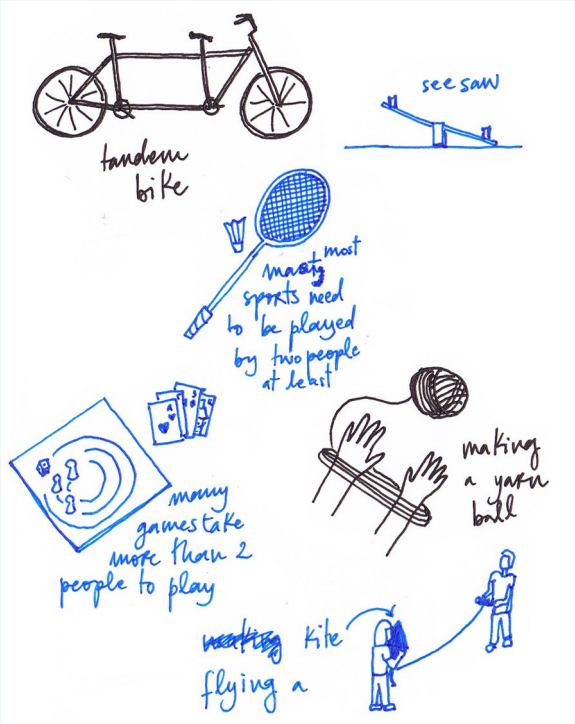
"Can you show me how it works?" [referring to a slingshot]
Mr. F explains: "You hold it like this, you pull it here, you aim at the target and the you release it". Fieldnotes 23.10.2014



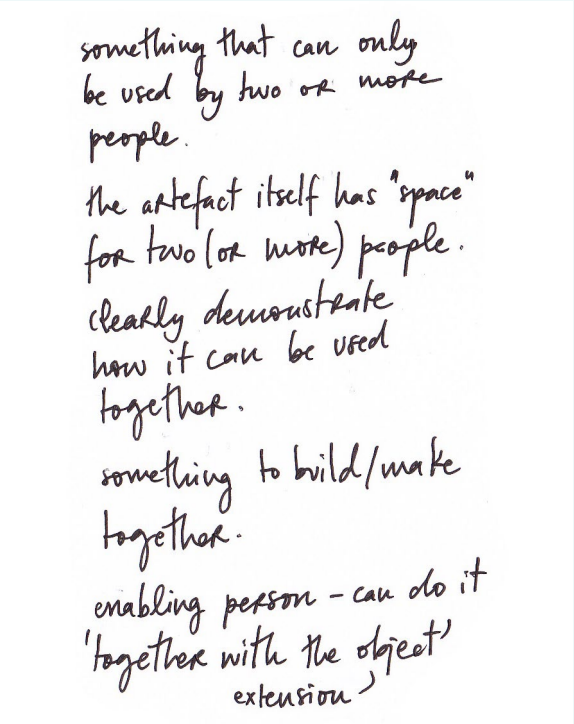
Figure 5.15 Collaboration observed at activity sessions with people with dementia.

Designing for collaboration?

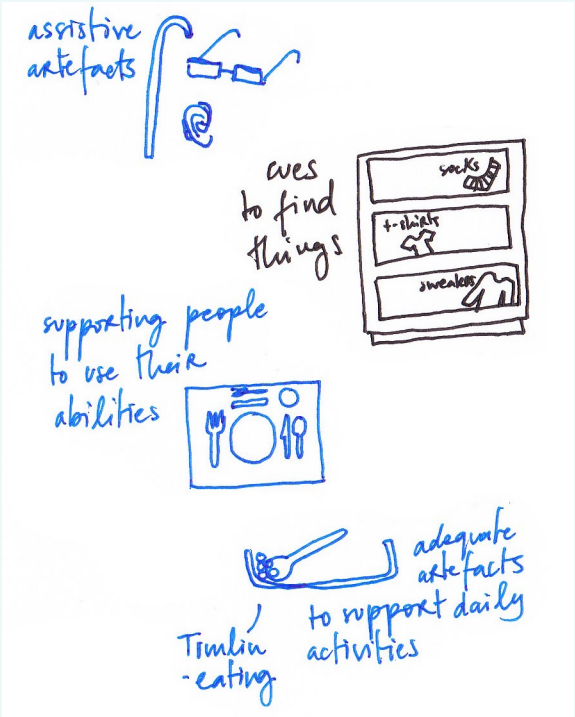
1. What could be a **collaboration** object?



2. How does something look **collaboration**?



3. How could an artefact **"work together"?**



4. How could an artifact trigger interactions of **collaboration**?

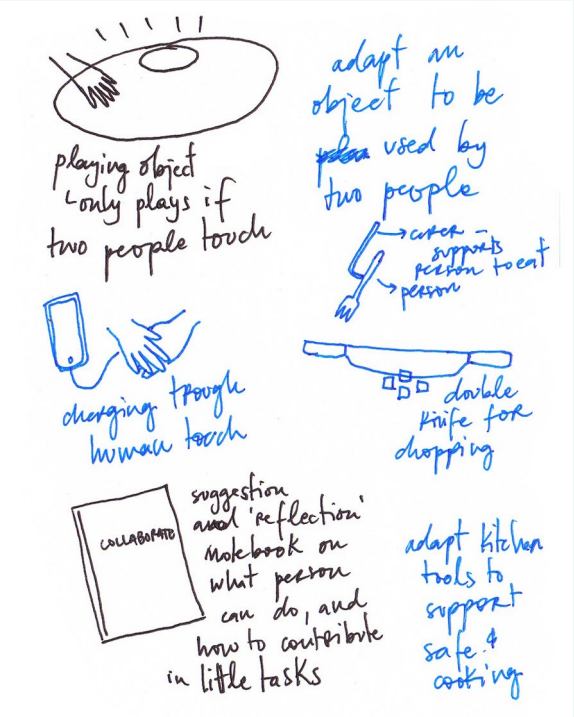


Figure 5.16 Speculative exercise about how collaboration could be used in design.

collaboration vs. facilitation

Collaboration means to work together, involving the person with dementia "as full as equal partner" (Brooker, 2007, p. 94). Here, we focus on artefacts that promote and enable collective activities and moments of togetherness, important to address inclusion and attachment needs. In the original definition by Kitwood (1997), **facilitation** and **collaboration** are interrelated, and when doing the speculative exercise about both, this relation became obvious since some of the ideas crossed over. We opted to distinguish them, by emphasising the enablement of people with dementia to undertake actions in **facilitation** and highlighting the promotion of connectedness and joint actions, in **collaboration**. Therefore, in this case, we will centre the attention on the interaction between a person with dementia with others, and how artefacts can mediate in this interaction.

supporting people with dementia to participate in shared activities

Still very much associated with **facilitation**, artefacts should be designed to be easier and safer to use, not only to promote autonomy and independence but also to enable the person with dementia to participate in shared activities. This can refer to more practical daily tasks, enabling the person with dementia to take part instead of being a passive receiver of care, or to leisure activities. *Tuin aan Tafel* is a project that aims to engage people with dementia in garden activities, by bringing nature into care facilities. Developed by a multidisciplinary team of designers, architects and care workers, and involving residents and staff in the process, several products were created to enable and encourage people to participate in shared garden activities: a room in the care facility was refurbished for this purpose, a mobile cart to store tools and garden material, a dedicated garden table, oval and big to promote socialisation during garden activities, a radio with birdsongs, and crates for vases to enable flower arrangement to be made on the lap (Tuin aan Tafel, n.d.). [Figure 5.17]





Figure 5.17 Tuin aan Tafel crates, room and table. From Tuin aan Tafel (http://www.tuinaantafel.nl/).

Slightly different from this approach, artefacts' main aim can also be the promotion of social activities. Games, namely board games, are good examples of products that prompt social interaction and sense of togetherness, across different generations (Wildevuur et al., 2013). While innapropriate game experiences and game elements (which sometimes might be too challenging and competitive) may lead to frustration, adequate games are considered to have the potential to improve the quality of life of people with dementia (Anderiesen, Scherder, Goossens, Visch, & Eggermont, 2015). In a study about elements of play that contribute to the health of older adults, Kayali et al. (2013) highlight, among others, the social benefits of playing games in enhancing interaction with others and decreasing isolation, referring that the social aspect is the most valued by older people. On the other hand, besides promoting social interaction, **collaboration** can also be embedded in the game experience. Owusu (2012) researched how to elicit pride in people with dementia through human-product interaction, leading to the design of *Recordis*, a record deck and simultaneously a social game that consists of matching record pieces so that they could listen to them. In order to evoke pride, the product aimed to provide opportunities to share personal memories, related to the personally meaningful songs played, and where people were encouraged to collaborate, by helping each other to find the matching record pieces. [Figure 5.18]

promotion of social activities: games



Figure 5.18 Recordis. From *Design for Pride: Study on Elicitation of Pride in Human-Product Interaction for People with Dementia* (p. 154) by I. Owusu, 2012.

Another identified approach to promote **collaboration** interactions using artefacts is *interdependence*. This means that an artefact requires more than one person to be used, for instance flying a kite or playing on a seesaw, or that an element of a product, or the product itself, needs more than one person to be activated. *CRDL*, a product that explores that transforms touch into sounds, is activated by the contact between two people or more. It stimulates people to playfully communicate on a different level, through physical contact, connecting and providing moments of joy (CRDL Contact Door Aanraking, n.d.). [Figure 5.19]

interdependence



Figure 5.19 CRDL. From CRDL Contact Door Aanraking (https://crdlt.com/).

Symbolically, an artefact can also be designed to clearly demonstrate that it should be used in group or by two people, like a tandem bike for instance.

5.4.5 Play

Play observed

Mr. H, on my right side, draws energetically, filling the whole sheet. Mr. B on my left side is staring at his sheet and leaves two very shy traces. Next to him, Mr. D draws little figures, that look naïve and very beautiful. Fieldnotes 15.09.2014

"Whereas work is directed towards a goal, play in its purest form has no goal that lies outside the activity itself. It is simply an exercise in **spontaneity** and **self-expression**, an experience that has value in itself. Because of the sheer pressures of survival, and disciplines of work, many adults have only poorly developed abilities in this area. **A good care environment is one which allows these abilities to grow**".

—Kitwood, 1997, p. 90

"Can I say a poem?" Asks Mr. N again. Mr. N says the poem and everyone applauded at the end. Fieldnotes 27.10.2014

We put flour, salt and water at the centre of each table. Rapidly, several hands, little and big ones, start mixing and kneading the dough. Others were more hesitant and Dr. S encourages them to get their hands dirty. Everyone seems to be entertained with the activity. The flour, salt and water become a consistent dough which is then split and worked on individually. Everyone has their own dough and start modelling it into new shapes. Fieldnotes 08.10.2014

"Fun: **accessing a free, creative way of being** and using and responding to the use of **fun and humour**".

—Brooker, 2007, p. 95

At the end of the session, Mrs. M thanks Dr. L, as well as Mrs. O: "I was even a little unwell [before coming], but I always like coming to the activities. Thank you all for spending these moments with us". Fieldnotes 03.12.2014

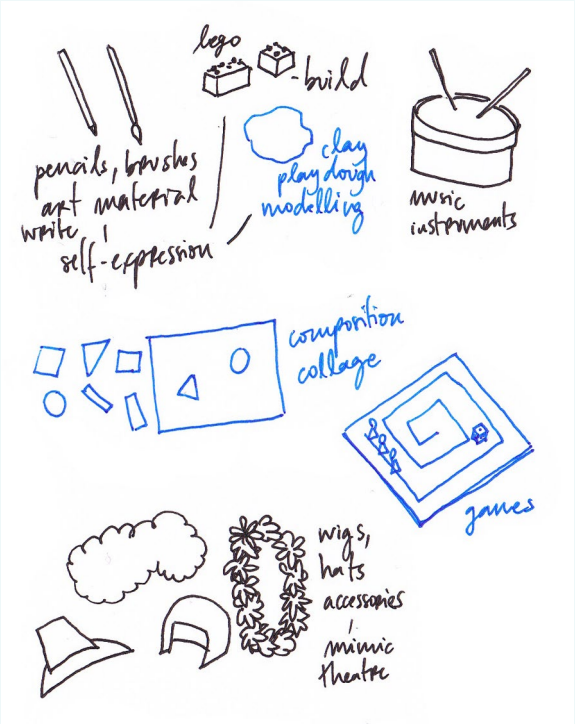
Dr. E starts asking everyone's name. Mrs. L responds and makes jokes about her own name. Fieldnotes 03.12.2014



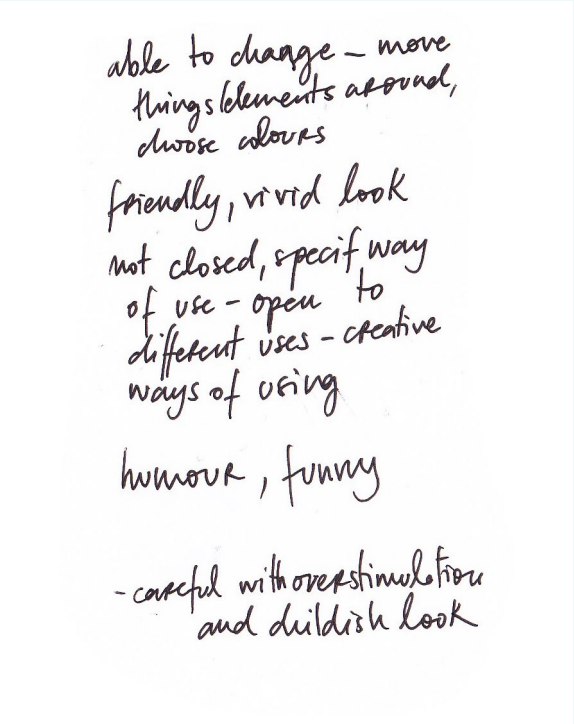
Figure 5.20 Play observed at activity sessions with people with dementia.

Designing for play?

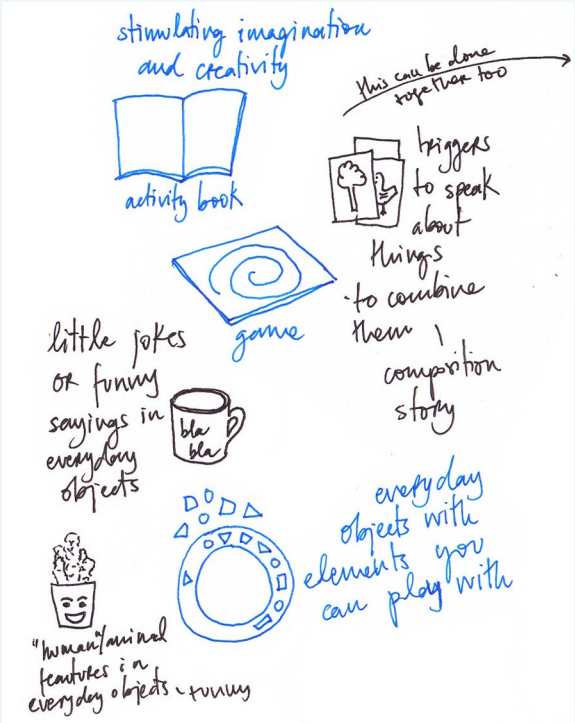
1. What could be a **play** object?



2. How does something look **play**?



3. How could an artefact **promote "spontaneity and self-expression", use "fun and humour"**?



4. How could an artifact trigger interactions of **play**?

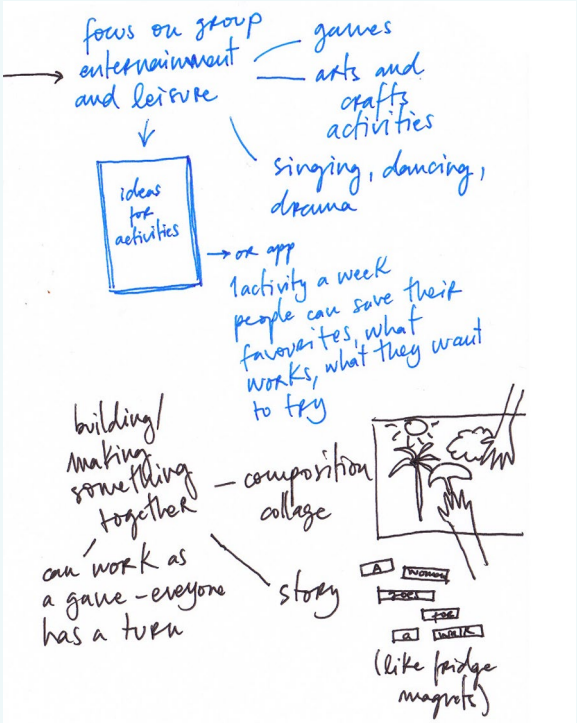


Figure 5.21 Speculative exercise about how play could be used in design.

Play refers to spontaneity and self-expression. It "has no goal that lies outside the activity itself" (Kitwood, 1997, p. 90), and it is related to creativity, fun and humour (Brooker, 2007). On his book about *Playfulness and Dementia*, Killick (2012) reinforces the human need to play at all ages: to learn about the world and the self, to energise body and mind, to stimulate imagination, positive enjoyment and active engagement, while promoting connectedness and bonding with others. For people with dementia and their carers, play, as well as humour, often have an important role in solving difficult times and dealing with the adversities of dementia.

designing for Homo Ludens

In order to design for play, we believe to be pertinent to consider Gaver's (2009) proposal of *Designing for Homo Ludens*[2], where the idea of free, spontaneous and satisfactory play is emphasised, as opposed to competitive play. This approach often resulted in ambiguous and suggestive artefacts that foster curiosity and speculation through uncommon use, and that are open for people to add their interpretation and stories (Gaver, 2009). Although this view challenges some of what was mentioned in **facilitation**, we believe that some of these aspects can probably be balanced with the previous considerations. While it is important that artefacts have a familiar and recognisable look to facilitate understanding and use, ambiguous and versatile artefacts might trigger curiosity and have a non-judgemental attitude, since they do not imply a right or wrong way to use. For instance, *Nuts on Circles* is a set of ambiguous modular objects made of different materials and textures that can be twisted and combined, stimulating the senses (Gähwiler, 2013). [Figure 5.22] However, ambiguous artefacts might also provoke anxiety

ambiguity and versatility



Figure 5.22 Nuts on Circles. From Nuts on Circles (http://www.nuts-on-circles.com/).

2 Homo Ludens is an idea borrowed by Huizinga (1949), referring to people as playful beings.

and frustration if people cannot understand its use, therefore it is important to be careful and find a balance, which also depends on the artefact's intended function. Moreover, deliberately designing an artefact that makes space for appropriation can be a means to add personalised, idiosyncratic elements that can become relevant and meaningful for the person with dementia.

So far, we have focused only on a spontaneous, unstructured play. Caillois (1961) distinguishes this type of play – *paidia*, from a more structured, game-like kind of play – *ludus*. As referred before, although competitive game aspects might be inadequate for people with dementia, the structure, rules and material elements might also be important to prompt **play**. For instance, simple operational rules can guide action and challenge people to participate; turn-taking can level participation in a collective activity, supporting more passive players to contribute; behavioural rules can encourage a playful and open attitude, as well as role-playing; game materials can be *things-to-think-with*, taking a role of boundary objects (Star, 2010), where the same piece can be understood and mean something to different people, helping to bridge gaps in communication (Brandt, 2011). Game materials can also act as cues to trigger playful activities, moments of sharing, and creative self-expression. Therefore, a combination of both approaches to play might be fruitful.

game characteristics can prompt play

The play experiences of people with dementia are also important to consider. In a study focused on game design for people with dementia, Anderiesen et al. (2015) reviewed neuropathology and clinical studies regarding twenty-two play experiences for people with Alzheimer's Disease. Their findings reveal that sensation, relaxation, and reminiscence are appropriate for people in all stages of Alzheimer's Disease, whereas nurture, sympathy, fellowship, expression, humour, eroticism, subversion and challenge might be suitable only for people in mild to moderate stages. Exploration was found to be inadequate for people with Alzheimer's Disease. Although this is a valuable and important starting point, the literature reviewed on dementia care and our empirical experience point to a few diverse conclusions. For instance, exploration can be appropriate if concerning the senses, e.g. exploring different textures through touch; and humour, expression, fellowship and sympathy can be experienced at all stages.

play experiences of people with dementia

In short, drawing on the presented definitions of **play** as Positive Person Work in the context of dementia (Brooker, 2007; Kitwood, 1997), we distinguish two broad sub-strategies to design for **play**, even if they complement each other and often overlap: those centred on *self-expression* and those that do not have this aim, but make more use of *fun and humour* (many times, in parallel with other goals, such as cognitive stimulation, social interaction or physical activity). *Active Cues* is an example of a playful product that promotes fun, without explicitly inducing self-expression. It is a game based on interactive projections onto a table, that react when the person "touches" the projection, offering different types of playful animations,

play centred on self-expression vs. play centred on fun and humour



Figure 5.23 Active Cues. From Active Cues (https://tovertafel.com/games/dementia/).



Figure 5.24 Paper Street View. From Tommy Dylan (http://tommydylan.co.uk/portfolio/items/paperstreetview/).

designed to promote physical and social activity (Active Cues, n.d.). [Figure 5.23] Regarding self-expression, we also differentiate between a more *creative self-expression*, related with the arts (already mentioned in **negotiation**), and a self-expression that consists of sharing stories, opinions, interpretations, feelings, etc. *Paper Street View* is a social activity for people with dementia, designed by Tommy Dylan, to stimulate sharing about special places, using a tangible map and objects to navigate on *Google Maps Street View* (Dylan, n.d.). [Figure 5.24]

The described approaches embrace both *catalyst* and *support* roles of artefacts in the mediation of **play** since many of these activities are collective. In addition, although it is necessary to be careful about overstimulation, artefacts can also be visually playful, through a friendly and vivid appearance, and the use of fun and humour. The series *Family Follows Fiction*, by the Italian design company Alessi, is a representative example of this, where artefacts become "ludic tools, telling little tales, giving captivating twists to everyday uses, suggesting a mediation with playfulness" (Alessi, 1998, p. 101).

artefacts can be visually playful

5.4.6 Timalation

Timalation observed

Dr. C starts distributing rosemary twigs to everyone and asks them to smell.
Fieldnotes 15.10.2014

We sang "Oliveira da Serra" [traditional Portuguese song] a few times more. Mrs. R got up two or three times to dance. Mrs. V also got up and sat down in another part of the room. She keeps singing and tapping her foot on the floor, and her hand on her shoulder. The volunteer P keeps accompanying her, smiling to her, and Mrs. V smiles back.
Fieldnotes 17.11.2014

"This term refers to **forms of interaction in which the prime modality is sensuous or sensual**; for example through aromatherapy and massage. The word itself is a neologism, derived from the Greek word timao (I honour, and hence I do not violate personal or moral boundaries) and stimulation (with connotations of sensory arousal). The significance of this kind of interaction is that it can **provide contact, reassurance and pleasure, while making very few demands**. It is thus **particularly valuable when cognitive impairment is severe**".
—Kitwood, 1997, p. 90

After singing in the main common living room at the nursing home, the student choir went to the ward. There was a bedridden woman that seems to not understand what is happening. The nurse raises her bed a little bit, so she can see what is going on. Dr. D is next to her.
"What is it?" asks the lady.
"It is a serenade. They are singing for you!"
The lady asks the same thing a couple of times more. She has an emotional expression.
"Did you enjoy Mrs. G?"
"I did. Thank you. Who are you?"
"My name is D."
"Is it raining?"
"It is... But these musicians brought you a little bit of sun, didn't they?"
"They did! Thank you."

They sang two more songs in the ward living room, where several people were already having lunch. There, one lady had a big smile. She was visibly content. In another armchair, a man was also smiling. At the table, Mrs J was apathetic. She continued eating as if nothing different was going on in that room. On the second song, she stops eating and looking around, noticing the musicians. The other ladies at the table had already stopped eating. They looked happy and applauded at the end.
Fieldnotes 03.11.2014



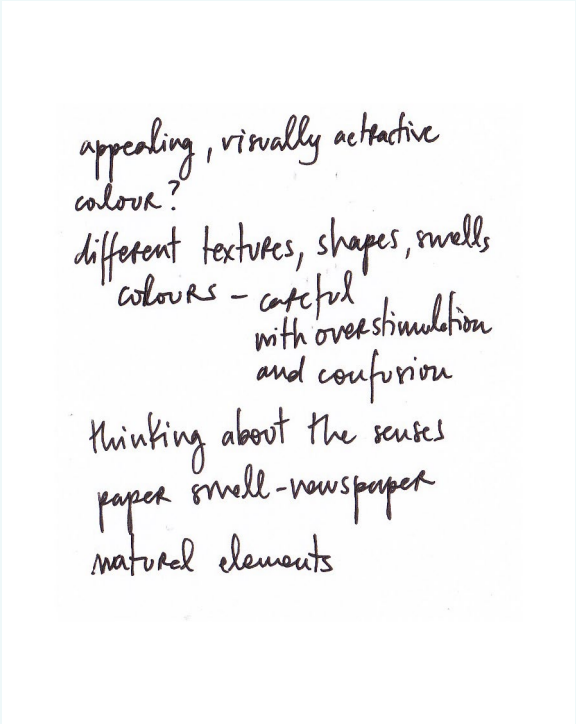
Figure 5.25 Timalation observed at activity sessions with people with dementia.

Designing for timalation?

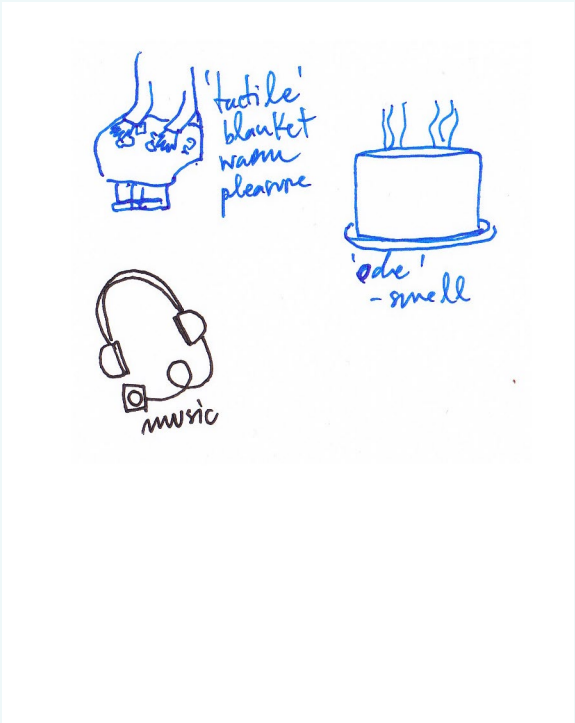
1. What could be a **timalation** object?



2. How does something look **timalation**?



3. How could an artefact **"provide sensory stimuli or sensual information"**?



4. How could an artifact trigger interactions of **timalation**?

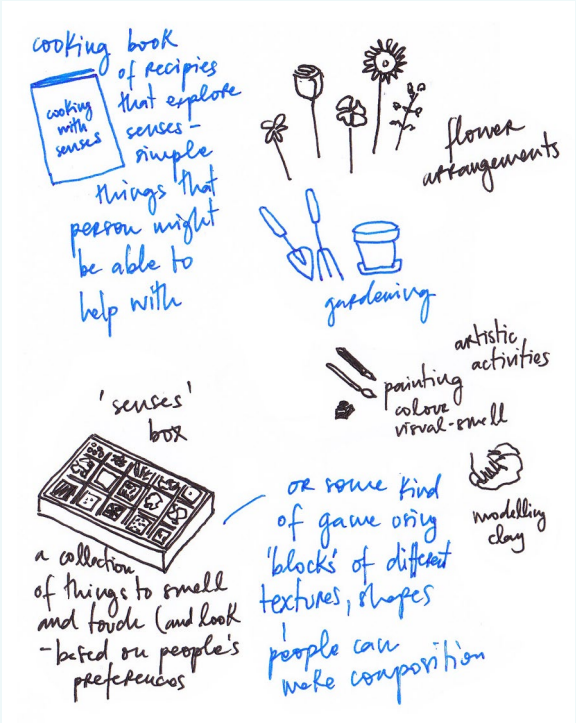


Figure 5.26 Speculative exercise about how **timalation** could be used in design.

aesthetic approach to people with dementia

Timalation is a term coined by Kitwood (1997) which involves the provision of sensuous and sensory stimulation, without requiring intellectual understanding: "The significance of this kind of interaction is that it can provide contact, reassurance and pleasure, while making very few demands" (Kitwood, 1997, p. 91); hence, especially important for people in advanced stages of dementia. As mentioned above, Hughes (2014) reinforces this idea, by discussing the value of regarding people with dementia as *aesthetic beings* and approaching them aesthetically, making use of the senses: "Really seeing the person, hearing her, communicating by touch, explaining something by smell, engaging in a manner that is holistic, such would constitute aspects of the aesthetic approach" (Hughes, 2014, p. 1409).

sensorial aspects of products as a means to communicate non-verbally

Designing artefacts for people with dementia constitute an opportunity to explore this sensuous approach, emphasising the sensorial aspects of products, and using them as a means to communicate. For instance, *Ode*, another project resultant from the Design Council's Living Well with Dementia challenge, is a product that uses smell to stimulate appetite, acting as a reminder of mealtimes (Ode, n.d.). [Figure 5.27] *Tactile Dialogues*, a textile object with incorporated vibration elements, promotes dialogue and physical communication through touch (Bhömer, 2016). [Figure 5.28] Or *CRDL*, already referred, encourages playful communication through touch and sound (CRDL Contact Door Aanraking, n.d.). [Figure 5.19] All these examples emphasise and make use of the senses to interact with the person with dementia or mediate interactions between people. This type of artefacts is also important to help carers to develop a sensitivity to communicate and connect non-verbally.



Figure 5.27 Ode. From Ode (http://www.myode.org/)



Figure 5.28 Tactile Dialogues. Designed by Martijn ten Bhömer, Borre Akkersdijk and Oscar Tomico (https://www.mtbhomer.com/portfolio/tactile-dialogues/). Image from "Interactie tussen dementerenden & verzorgers door dit kussen", by Gimmii, 2016 (https://www.gimmii.nl/blog/dutch-design/kussen-tactile-dialogues-martijn-ten-bohmer/).

Treadaway et al. (2015) studied the effects of personalised textile objects with integrated sensors on the subjective well-being of people with late-stage dementia. The authors found that the textiles supported communication and connection, bringing together things that matter and have some reminiscence value to the person. The physicality of the artefacts, as well as the enhanced sensory aspects achieved through technology, was found to be engaging and to bring pleasure for people with dementia. Moreover, whereas in some cases, and situations, the textiles promoted movement and exercise, in others, they were distracting and relaxing. These variations can be taken into account when designing so that sensorial elements can be adjusted to provide a more active and energetic stimulation or a calmer moment, helping to slow down and relax.

All the mentioned examples are *catalysts* of sensory stimulation to the person and simultaneously *support* the interaction between the person with dementia and carers, through the senses. Another possible strategy is to design products that support the interaction with elements that are stimulating to the senses, such as plants or spices, such as the already mentioned *Tuin aan Tafel* project (Tuin aan Tafel, n.d.). [Figure 5.17] In addition, although overstimulation needs to be considered, it is also possible to think about the senses in all kinds of products, putting attention on the textures and smell of materials, possible sounds arising from the use of the artefact, as well as the visual elements, so that artefacts can have rich sensory qualities, despite their function. During her MA, the designer Adriana Machado designed a collection of rosaries for her grandmother with advanced stage Alzheimer's disease, who was still able to use them for praying. In the rosaries, texture, size and colour were explored using different materials, providing sensory richness to a meaningful object (Machado, n.d.). In this case, the artefacts also play a role in supporting an *embodied selfhood*, "the idea that bodily habits, gestures, and actions support and convey humanness and individuality" (Kontos, 2014, p. 123). [Figure 5.29]

support interactions with sensorial stimuli

attention to sensory qualities of products

support embodied selfhood



Figure 5.29 Remember this feeling. From Adriana Machado (http://cargocollective.com/adrimachado/Remember-This-Feeling).

5.4.7 Celebration

Celebration observed

Mrs. L also seemed content to be in that environment, enjoying the company of the children. She was smiling. However, she seems to prefer looking around than to actively participate in the exercises of the activity session. Fieldnotes 12.11.2014

In general, these [music] sessions are very joyful. The group is focused, it is noticeable that they are enjoying it. Mrs. F got up three or four times to dance, despite her mobility difficulties. Fieldnotes 17.11.2014

Mrs. K is making her drawing on a fabric. I pass by and I comment that it is looking very beautiful. She thanks and gives me a kiss. Fieldnotes 10.12.2014

"The **ambience here is expansive and convivial**. It is not simply a matter of special occasions, but **any moment at which life is experienced as intrinsically joyful**. **Many people who have dementia, despite their suffering, retain the capacity to celebrate; perharps it is even enhanced** as the burdens of responsibility disappear. Celebration is the form of interaction in which the the division between caregiver and cared-for comes nearest to vanishing completely; **all are taken up to a similar mood**".

—Kitwood, 1997, p. 90

"Celebration: **recognising, supporting and taking delight in the skills and achievements of the participant**".

—Brooker, 2007, p. 92

It seems that there is a celebration spirit. Every activity session is like a party. They sing, they share and they do things together. Fieldnotes 26.11.2014

Everyone in the nursing home seems to like the student choir. The clap, sing along, raise their hands to the sound of music. The trainees suggest some movements and clapping. At the back of the room, some people gather to dance, as if it was a ball. Fieldnotes 03.11.2014



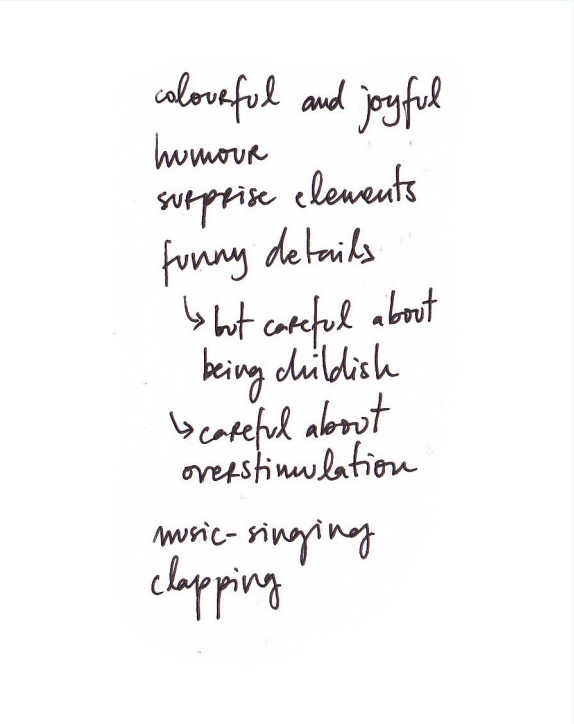
Figure 5.30 Celebration observed at activity sessions with people with dementia.

Designing for celebration?

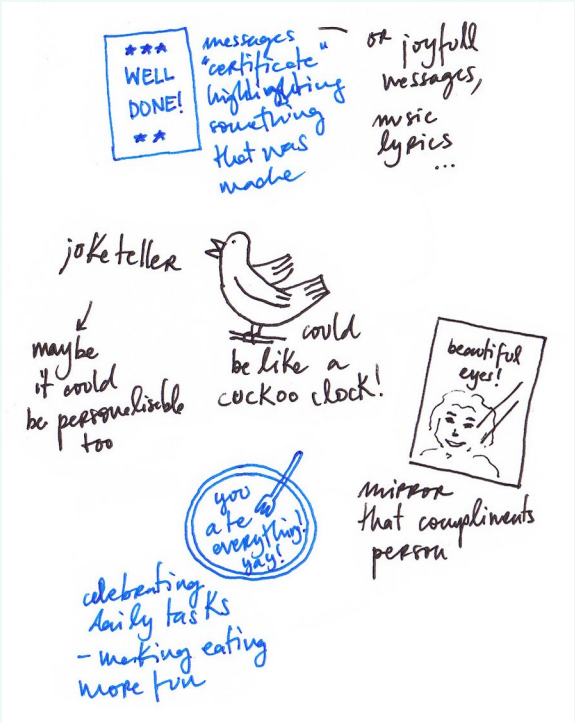
1. What could be a **celebration** object?



2. How does something look **celebration**?



3. How could an artefact **"celebrate"**?



4. How could an artifact trigger interactions of **celebration**?

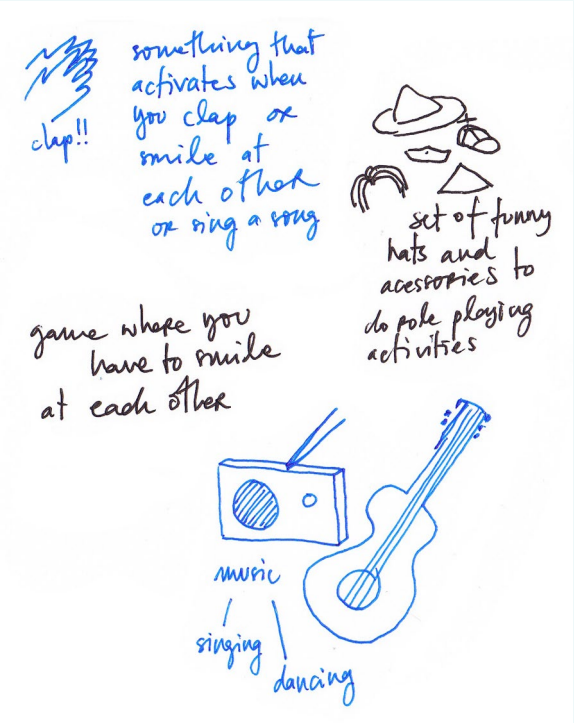


Figure 5.31 Speculative exercise about how celebration could be used in design.

Celebration does not only regard special occasions but the experience of joy at any moment in life, through promoting a friendly atmosphere. This is, according to Kitwood (1997), a form of interaction where the differences between people with or without a diagnosis become less noticeable. Brooker (2007) adds another dimension to celebration, which is about "recognising, supporting and taking delight in the skills and achievements of the participant" (p. 92).

Taking this into account in the design of artefacts means to try to embed this feeling of joy and celebration into the artefacts themselves, to design artefacts that enhance celebration moments or to focus on celebrating a person and what is meaningful to her/him, as well as her/his achievements. Using humour, surprise, fun, music, all can be possibilities to make products more celebratory. In the project *Drumming Out Dementia*, the designer Tom Maisey incorporated musical elements in everyday objects to encourage people with dementia to participate in musical activities, since musical instruments are many times unfamiliar and intimidating (Drumming out dementia, n.d.). [Figure 5.32] Also related to music, *SwaytheBand* is an interactive system that controls light and colour of connected batons according to the music beat. It was designed to enhance sharing and connecting during music sessions, by encouraging people with dementia to sway the batons together (Morrissey et al., 2016). [Figure 5.33] The *Cloud Watcher* is an artefact inspired by the person it was designed for. It is a necklace that gives shape to the person's love for watching the clouds while celebrating the person's sense of humour, fun, and delight in looking at beautiful things (Wallace et al., 2013). [Figure 5.34]

use of humour, surprise, fun, music

celebrating people's uniqueness





Figure 5.32 Rhythm Sticks.
From Drumming Out Dementia, 2013
(https://drummingoutdementia.com/)



Figure 5.33 SwaytheBand. From "'I'm a rambler, I'm a gambler, I'm a long way from home': The Place of Props, Music, and Design in Dementia Care," by K. Morrissey et al., 2016, p. 1014.

Figure 5.34 The Cloud Watcher. From "A Design-led Inquiry into Personhood in Dementia," by J. Wallace et al., 2013, p. 2622.



5.4.8 Relaxation

Relaxation observed

Mrs. O smiles several times at the children in front of her. She seems to be calmer than usual. Fieldnotes 12.11.2014

"Of all forms of interaction, this is the one that has the lowest level of intensity, and probably also the slowest pace. It is possible, of course, to relax in solitude, but **many people with dementia, with their particularly strong social needs, are only able to relax when others are near them**, or in actual **bodily contact**".

—Kitwood, 1997, p. 91

The nursing assistants hold her hands and she seems to relax a little bit. Fieldnotes 22.09.2014

Mrs. T was much quieter today. She didn't speak as much and she seemed to be listening to the nursing assistants' conversation next to her. When the nursing assistants got up, it seemed that she became a little bit restless and started holding the blanket from the couch. Maybe she feels 'safer' to have people next to her? When others arrived to the living room from the activity, there was more agitation in the room, and she got up. Fieldnotes 13.10.2014

"Relaxed pace: **recognising the importance of helping to create a relaxed atmosphere**".

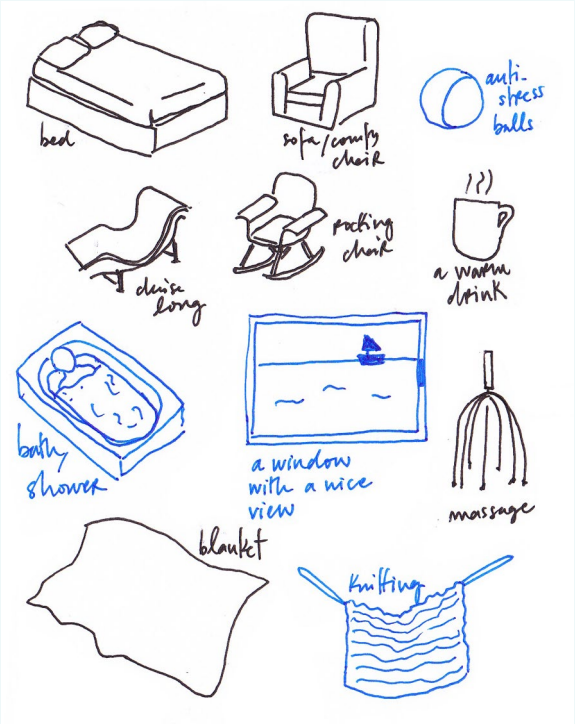
—Brooker, 2007, p. 91



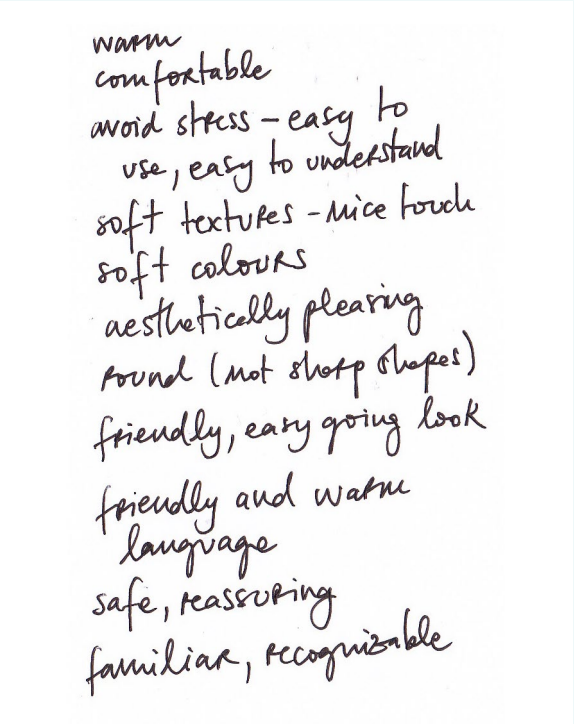
Figure 5.35 Relaxation observed at activity sessions with people with dementia.

Designing for relaxation?

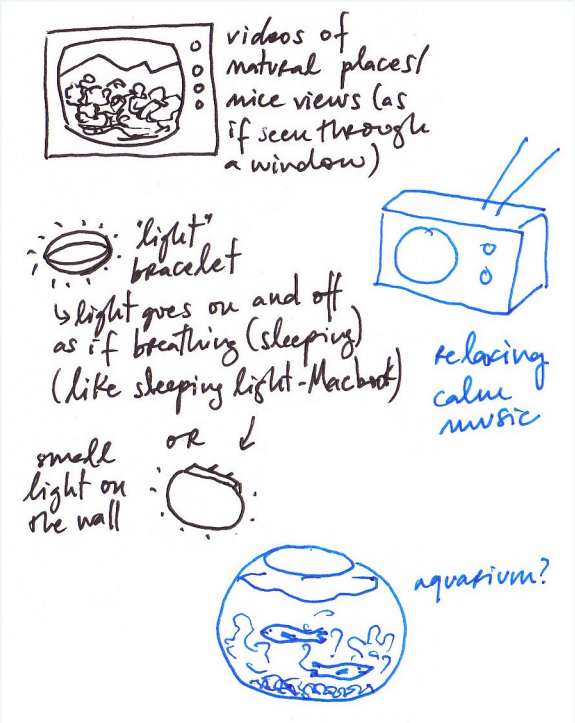
1. What could be a **relaxation** object?



2. How does something look **relaxation**?



3. How could an artefact **"help to relax"** or **"create a relaxed atmosphere"**?



4. How could an artifact trigger interactions of **relaxation**?

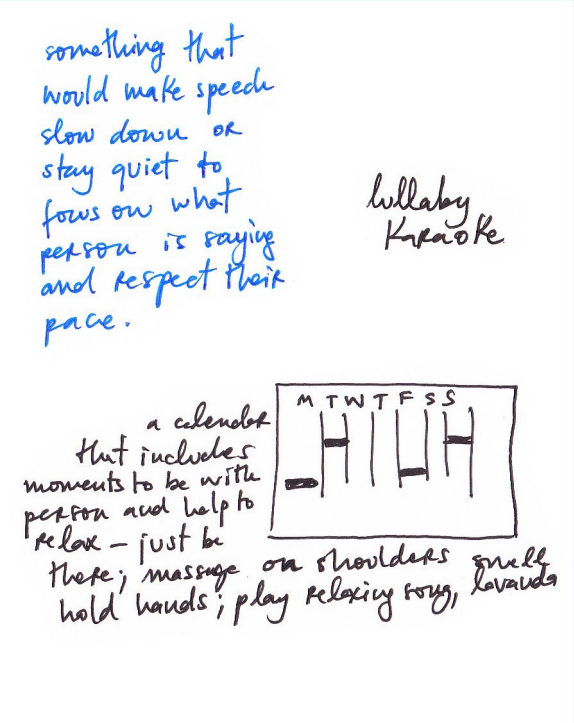


Figure 5.36 Speculative exercise about how **relaxation** could be used in design.

Relaxation consists in slowing down and creating a calm atmosphere (Brooker, 2007; Kitwood, 1997). Dementia symptoms can generate a lot of anxiety and agitation (Zeisel, 2009), therefore people might need help to relax. Kitwood (1997) points out that some people with dementia are only able to relax when near others, due to their high social needs.

comfort and warmness; friendly and familiar looking artefacts

Artefacts can play a crucial role in **relaxation**, mainly through providing comfort and warmness. Friendly and familiar looking artefacts can avoid stress, and a choice of soft tones and textures, pleasing to touch, or setting an appropriate light can promote a relaxed environment. Biamonti et al. (2014) redesigned an environment to be used for train therapy, a therapy that simulates a train journey, used for reminiscence and socialisation, as well as to promote relaxation. The space, previously an arranged living room with four armchairs and a monitor displaying movies from train journeys, was redesigned to look like a familiar train compartment, which proved to be more acceptable and effective among residents with dementia. [Figure 5.37]

relaxing entertainment

Additionally, artefacts can also encourage to slow down, while being entertaining. The *Resonant Interface Rocking Chair*, designed within the *Tangible Memories* research project, is a rocking chair that starts playing sounds (music, poetry, nature sounds) when someone sits on it, having a strong reminiscence value. This product is a result of the authors' vision on designing technology for people with dementia which is not intimidating, but motivating and engaging to use, and that can be easily updated with novel material, towards the *Resonant Home*: "a calming environment that provides gentle stimulus through music, memories and spoken word, subtly augmenting the care home through a series of peripheral and liminal interactions based on oscillatory movement and motion" (Bennett, Hinder, & Cater, 2016, p. 2025). [Figure 5.38]

supporting carers to encourage relaxation

The described artefacts focus more on the direct interaction with the person with dementia. However, artefacts can also support carers to provide **relaxation**: by inducing a calm atmosphere, artefacts might also suggest carers to slow down to people's time and pace; moreover, even if relaxing is not the primary aim, the fact that people are engaged in other activities might assist in distracting from obsessive thoughts or behaviours, thus keeping them entertained, comfortable and at ease.



Figure 5.37
Therapeutic Train. From "A design experience for the enhancement of the quality of life for people with Alzheimer's disease", by A. Biamonti et al., 2014, p. 294.



Figure 5.38 Resonant Interface Rocking Chair. From "Robots, Research & Rocking Chairs: Computer-Human Interaction Conference 2016," by Tangible Memories, 2016 (http://tangible-memories.com/robots-research-and-rocking-chairs/).

5.4.9 Holding

Holding observed

I feel that in these activity sessions (with or without the kids) people seem to see it as a joyful safe space for sharing. Namely some of the ladies end up sharing feelings, stories, life events. It is, in general, a space and a moment where everyone is well. Fieldnotes 17.12.2014

"To hold, in a psychological sense, means to **provide a safe psycological space**, a 'container'; here hidden trauma and conflict can be brought out; areas of extreme vulnerability exposed. When holding is secure a person can know, in experience, that devastating emotions such as abject terror or overwhelming grief will pass, and not cause the psyche to desintegrate. ... As in the case of childcare, psychological holding in any context **may involve physical holding too**". —Kitwood, 1997, p. 91

On the way to the activity room, and then at the activity table, Mr. H grabs the intern's hand and holds it until the end of the session. Fieldnotes 13.11.2014

Prompted by the activity they were doing, Dr. G asked about situations in which they felt happy. Mrs. J said she was happy in the activity sessions with children. Mrs. V said she was happy on that very moment. Mrs. O said she was happy when they were all together. Fieldnotes 26.11.2014

"Holding: **providing safety, security and comfort** to a participant".
—Brooker, 2007, p. 91

Mrs. T went to the activity session despite feeling a bit unwell. However, she abandoned it before it finished. She wasn't feeling good with herself and did not feel like being there. Fieldnotes 13.04.2015

"Empathize: **accepting the feelings and emotions of a resident** and **showing warmth and affection to cover the needs of a resident**".
—van Weert et al., 2004, p. 662

"I feel lost..!" Mr. E said to Dr. F. Dr. F holds his hands:"Oh Mr. E you felt unconfortable for having had lunch in a different place, away from the people you are used to eat with, wasn't it? I am so sorry. I warned the caregivers already, it won't happen again Mr. E" Fieldnotes 13.10.2014



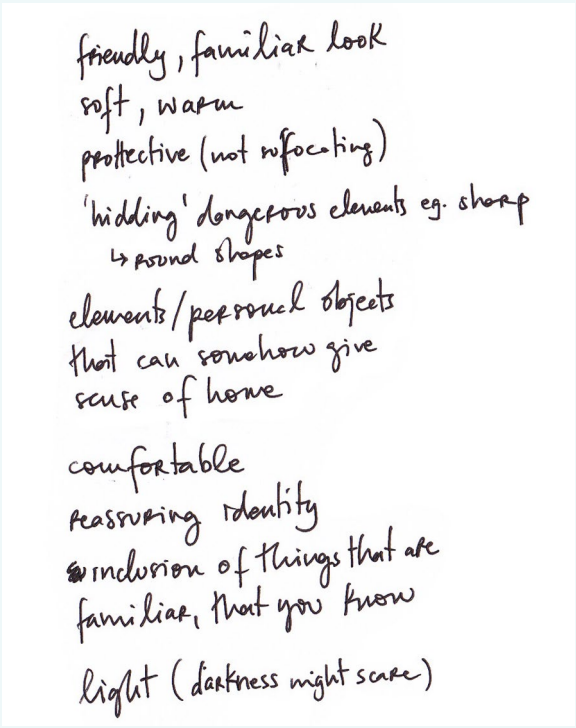
Figure 5.39 Holding observed at activity sessions with people with dementia.

Designing for holding?

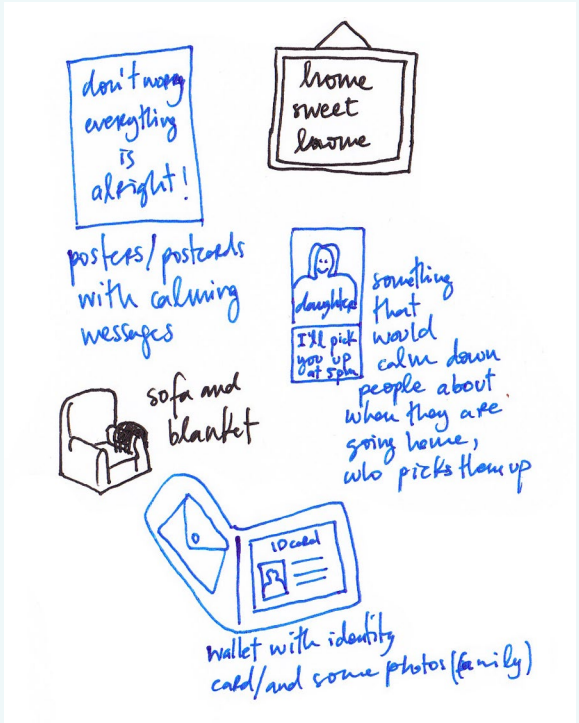
1. What could be a **holding** object?



2. How does something look **holding**?



3. How could an artefact **"provide safety, security and control"**?



4. How could an artifact trigger interactions of **holding**?

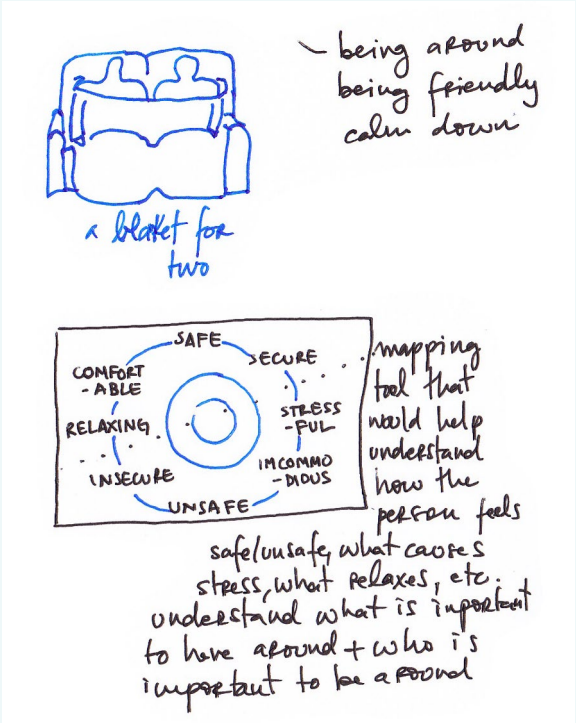


Figure 5.40 Speculative exercise about how holding could be used in design.

Holding "means to provide a safe psychological space, a 'container'; here hidden trauma and conflict can be brought out" (Kitwood, 1997, p. 91). Van Weert et al. (2006) adds empathy to the definition of **holding** so that the feelings of the person are accepted and responded to, with warmth and affection, and Brooker (2007) includes the provision of security and comfort as part of this kind of interaction.

inducing feeling of safety: comfort, familiarity, personal belongings

While promoting a relaxed environment, familiar and comfortable objects that look warm and friendly might foster a feeling of safety. Cues or calming messages might be possibilities to make the person reduce anxiety and feel secure. Personal belongings can be reassuring too. The *Locket* is another personalised jewellery piece, designed by Wallace et al. (2013), to allow personal pictures to be loaded. Every time the locket is opened it shows one of these pictures randomly so that it becomes motivating to open it again. This piece was inspired by the way the participant with dementia and her carer value photographs, considering them "a source of great pleasure and sanctuary" (p. 2621). The aim was to offer an alternative way to provide contact with these pictures over time, acting as a refuge and as an enjoyable activity for the participant with dementia, as well as a trigger for the family to add new pictures of experiences over time. [Figure 5.41]

support carers to provide holding

However, even if artefacts can be designed to promote a safe and comforting environment, **holding** is essentially a human interaction, which cannot be substituted by artefacts. Therefore, it might be more relevant to design artefacts to support carers to provide this secure and comfortable environment, either through developing tools that help understanding and analysing what causes the person to feel safe or unsafe, relaxed or stressed, to reflect on why it might happen, and what, or who, is important to be around the person; or through prompting a collective activity that is adequate and pleasurable for the person, encouraging her to feel included, and valorising her contributions, which might be even more meaningful if occurring with those in her/his close social circle.



Figure 5.41 Locket. From "A Design-led Inquiry into Personhood in Dementia," by J. Wallace et al., 2013, p. 2621.

5.4.10 Validation

Validation observed

"I remember you. You stayed with me. But it was a while ago" —this is what I understand from her very confused speech.
"That's right Mrs. K."
"I can't speak. I can't. It's because of this here" (she points to her head)
"But it is getting better Mrs. K. I can notice it."
Fieldnotes 08.10.2014

"The literal meaning is to make strong or robust; to validate the experience of another is to **accept the reality and power of that experience, and hence its 'subjective truth'**. The heart of the matter is **acknowledging the reality of a person's emotions and feelings, and giving a response on the feeling level**. Validation involves a high degree of empathy, **attempting to understand a person's entire entire frame of reference**, even if it is chaotic or paranoid, or filled with hallucinations. When our experience is validated we feel more alive, more connected, more real; there is every ground for supposing that this is true in dementia as well".
—Kitwood, 1997, p. 91

Everyone was drawing and one of the volunteers noticed that Mrs. D was not participating. She approaches the lady who tells her she didn't know what to draw. Mrs.D starts speaking about some past life events. The volunteer listens to it carefully. When Mrs. D finishes, the volunteer suggests her to do a drawing inspired on what she just told. Fieldnotes 17.12.2014

Mrs. R seems to be more agitated today. She said her "nananana" more repeatedly. The little kids next to her, look at her suspiciously. Dr. T decides to explain: "Mrs. R makes these sounds, but it is not for bad reasons. She does this because she likes you and wants to communicate. Mrs R lost her capacity to speak as we do, with words. So she makes these sounds".
Fieldnotes 29.10.2014

"Validation: recognising and supporting the reality of the participant. **Sensitivity to feeling and emotion take priority**."
—Brooker, 2007, p. 93

Meanwhile, we see Mr. L worried and disoriented. He is looking for his wife. B goes with him, to look for Mrs. L. When they see each other in the living room, Mrs. L gets up and walks to Mr. L. Both smile and are happy to see each other, almost as if they didn't see each other for days!
Fieldnotes 29.10.2014

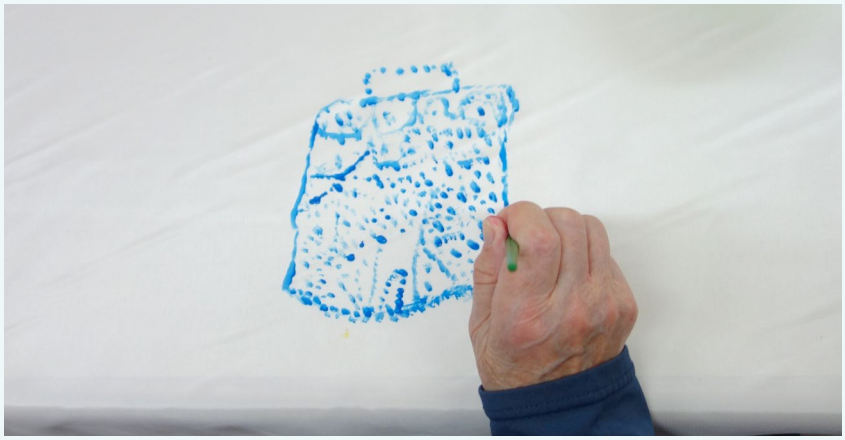
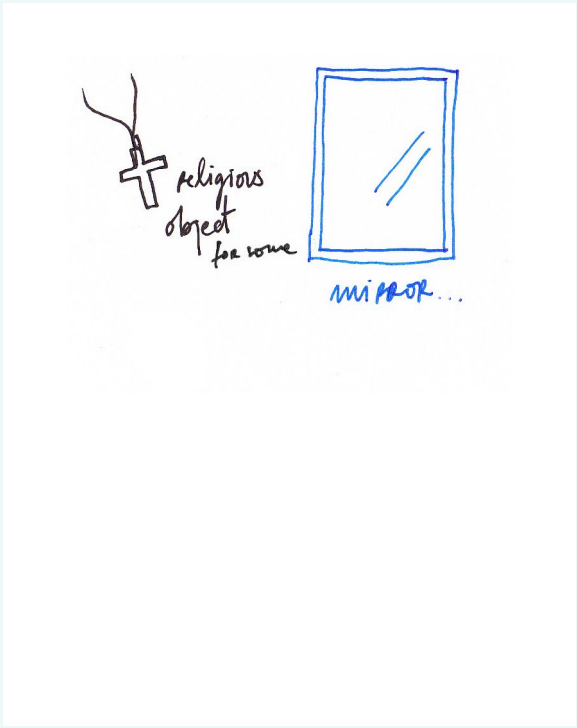


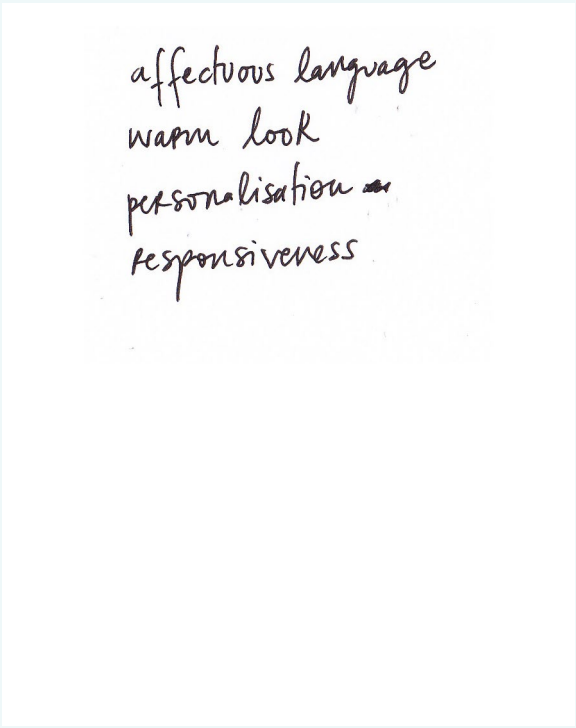
Figure 5.42 Validation observed at activity sessions with people with dementia.

Designing for validation?

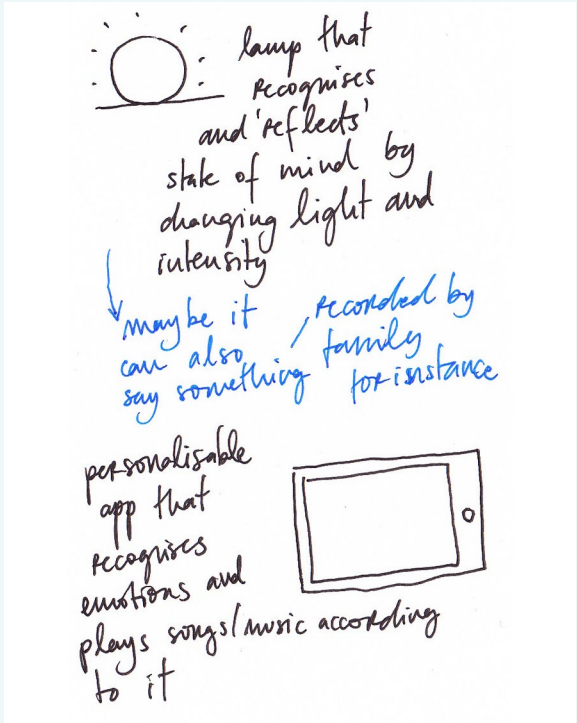
1. What could be a **validation** object?



2. How does something look **validation**?



3. How could an artefact **"acknowledge, support and be sensitive to the reality of a person's emotions"**?



4. How could an artifact trigger interactions of **validation**?

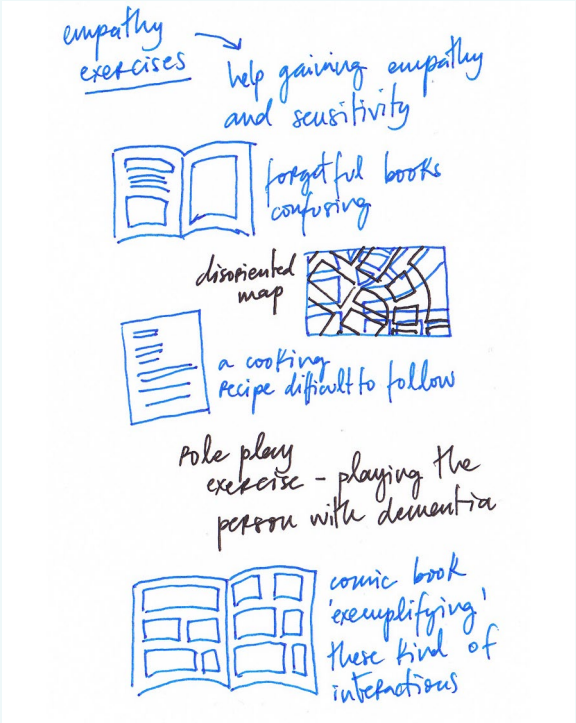


Figure 5.43 Speculative exercise about how validation could be used in design.

Validation refers to the acknowledgement and sensitivity to the experience, emotions, and 'subjective truth' of the other, and to respond accordingly, on the feeling level. It requires empathy to seek an understanding of the person's frame of reference (Brooker, 2007; Kitwood, 1997).

Similarly to **holding**, and perhaps even more, **validation** is a highly psychological and human interaction. An artefact can have a tender, affectionate look and language, can be personalised and might even be responsive, but for this kind of interaction, people are needed. If artefacts create opportunities for people to be included in an activity, encouraging them to participate in their own time and way, this might encourage other to listen and respect their contributions, relate to and validate them. The *Disruptive Dementia Tartan* project, which took place in Scotland, involved several people in different stages of dementia to design their own tartan pattern. From all the designed patterns, a jury chose one to become the Alzheimer's Scotland tartan. The main aim of the project was to raise awareness and show that people with dementia are still able to contribute to society despite the diagnosis, through demonstrating how they were able to participate in codesigning a mass-produced object (Rodgers, 2017). [Figure 5.44]

encourage others to validate person through enabling her/him to be included

Another approach consists of supporting an empathic and emotional understanding of the reality of the person with dementia. *A Walk Through Dementia* is a mobile app developed by Alzheimer's Research UK to raise awareness about the experience of having dementia. Using virtual reality, it puts people in the shoes of someone with dementia in various situations, at home, on the road and at the supermarket, to perceive how complex everyday tasks can be due to dementia symptoms (Alzheimer's Research UK, 2016). [Figure 5.45] The *Open Dementia Project* was designed by the HKDI Desis Lab to raise awareness about dementia, through the experience with tangible objects. Thinking about how a city would be if it had dementia was the starting point for the development of "dementia experience tools", aiming at generating empathy (Y. Lee & Tsang, 2016). [Figure 5.46]

supporting empathic and emotional understanding



Figure 5.44 Disruptive Dementia Tartan. From *Designing with people with living with dementia* (p. 8), by P. Rodgers, 2016Newcastle: Northumbria University.



Figure 5.45 A Walk Through Dementia. Frame from "A Walk Through Dementia – at home", by Alzheimer's Research UK (https://www.youtube.com/watch?v=9GBXEjw3iHw).



Figure 5.46 Open Dementia City. From Open Design in Action (p. 126), by Y. Lee and A. Tsang (eds.), 2016, Hong Kong: Hong Kong Design Institute.

5.5 Codesigning with Positive Person Work

We have also reflected on the implications of considering the Positive Person Work interactions in a codesign process including people with dementia. Since the original proposal by Kitwood (1997) refers to interpersonal interactions, they can serve as an ethical guide to involve people in the project, protecting them from anxiety and stressful situations, respecting their needs, and being aware of potential paternalistic attitudes, while promoting activities that might induce well-being for the person with dementia. To include people with dementia as active participants in the design process, instead of regarding them as an object of study, is already a way of recognising the value and celebrating people's contributions. Embedding the Positive Person Work interactions in this process might enrich further these encounters. These reflections also take into account previous research on how to include people with dementia in the design process (Hendriks et al., 2013; Hendriks et al., 2014; Lindsay et al., 2012; Orpwood, 2009; Wallace et al., 2013; Wallace et al., 2012; Wilkinson & Hendriks, 2015), as well as studies on the involvement of people with dementia in research (Cowdell, 2006; Cowdell, 2008; Dewing, 2007), and on the communication with people with dementia (Killick & Allan, 2001; Downs & Collins, 2015).

considering Positive Person Work in participatory design

To show respect, to greet participants by their name, to be sensitive to how they communicate, observing, listening carefully and non-judgementally, are ways of taking **recognition** into account. Additionally, being open for people to participate as they feel comfortable with and as they wish, thus including people's needs and preferences, which might result in a more engaged participation that recognises the uniqueness of participants. Likewise, it is important to find ways to **facilitate** participation: adapting the process to participants, setting up meetings that are not too long, having warm and open attitude, avoiding activities that require abstract thinking, bringing good quality prototypes to try, redesigning tools and materials to support participation.

Activities and materials can also be designed to promote **negotiation**, encouraging the exercise of choice through providing options for recognising rather than recalling. The **collaboration** of family members and formal caregivers is also important to encourage participation, however ensuring that people with dementia still have space to contribute by themselves. Participatory design events can be seen as opportunities for joint activities where people with dementia and their social circle do something together, which might also stimulate bonding.

Codesign activities can constitute moments of fun and self-expression, thus embedding **play**, which might result in a more engaged participation. Even if the meeting does not yield the planned outcomes, or outputs do not work as expected, if we provide participants an enjoyable

time as a consequence of their participation, this is already a valuable outcome. **Timalation** might be the best and possible way of connecting with and including people in advanced stages of dementia. This involves giving stimuli to people and observing carefully their reactions and non-verbal communication. Although this is particularly relevant to people with advanced dementia, it is also important to pay attention to non-verbal gestures and expressions with everyone, since they provide extra information of how a person might be feeling or thinking.

Codesign activities should also focus on and **celebrate** participants' abilities, as well as their life history and the demonstration of a genuine interest in it. It is important to congratulate and value participants' contributions and avoid situations that might be confrontational. Although codesign meetings might be more active and stimulating moments, it is important to ensure a **relaxed** and easy-going atmosphere, respecting the pace of participants.

Holding asks that we sincerely care about the people we are working with. The relevance of creating a comfortable, non-judgemental and friendly environment, as already referred, is also a way of encouraging the person to feel secure to participate. The researcher conducting the participatory activities can also play a crucial role in encouraging the person to feel at ease and safe, observing, trying to understand how the person is feeling and responding to it, avoiding confrontational situations. Unexpected reactions and feelings can be brought out in all kinds of situations, and it is important to deal with them with a caring and comforting attitude. This is also supported by **Validation**, which demands an empathic attitude at several moments: when planning, to understand if what is being asked from participants is appropriate and does not put them in uncomfortable situations, consulting family or formal carers about topics that might confront or elicit negative emotions; during the meetings, to respond to participants' reactions and feelings, paying attention to signs of tiredness, anxiety or frustration; being open to stop a meeting if the person wishes to, even if not all the goals for that sessions are fulfilled, or to postpone the meeting if it is not a good day.

person-centred care values transposed to participatory design

The person-centred care values (Brooker, 2007) presented above can also be taken into consideration in participatory design with people with dementia, by welcoming everyone to participate, independently of the person's capacities and progression of dementia; by including people with different experiences of dementia and adjusting the process accordingly, analysing and reflecting on the adapted participatory processes; by having an open attitude and flexible strategy to accommodate people's perspectives, needs, and preferences; by supporting different forms of participation; and by focusing on the creation of value for participants, making sure that participation is enjoyed and has some benefit for all involved in the process.

5.6 Discussion

These reflections on personhood, person-centred dementia care, and specifically on Kitwood's (1997) Positive Person Work, combined the study of literature with the empirical exercise of identifying these interactions in two institutional contexts, and a designerly way of speculating about them. This consisted of a brainstorming about how these interpersonal interactions could be represented metaphorically and symbolically, thinking about function, aesthetics, language, and considering how artefacts could be designed for the experience of such interactions.

These interactions do not correspond to any specific type of artefacts, but we believe they can be 'embedded' in the design of artefacts in two main ways: as an attitude or value represented *symbolically*, e.g. respect and dignity through a non-stigmatising appearance in **recognition**, or as a strategy for engagement, in which we distinguished the artefact as direct *catalyst* of person-product interaction, and the artefact as *support* of interpersonal interactions e.g. personalisation or reminiscence.

combining and overlapping different interactions

In each artefact, these values and strategies corresponding to each interaction can be combined and overlapped, in a complex web of relations between them. However, this does not mean that all artefacts should include all interactions. For instance, although sometimes **play** can be **relaxing**, these two interactions correspond to different forms of engaging, one more active and stimulating, the other one calmer and tranquillising, so it might be difficult to combine them. Nevertheless, similar strategies can be used to reach different goals. For example, **timalation** can support both playful and relaxing interactions.

Although we consider all interactions equally important, some seem to have more potential to be addressed by design. Consequently, we chose to present them in a specific order, different from that presented by Kitwood (1997), to reflect this. In this way, we believe that the values and strategies inherent to **recognition**, **facilitation**, **negotiation** and **collaboration** could be transversal to most artefacts. Despite the main function of the artefact, the respect for the person should be explicit (**recognition**), supported by the ease of use and the possibility to encourage the create meaning (**facilitation**), and by the exercise of choice and control (**negotiaton**). Since the effort for maintaining relationships is crucial, and due to the level of dependency that gradually increases, artefacts should also consider how to encourage the inclusion of the person with dementia in all kinds of joint activities (**collaboration**). **Play**, **timalation**, **celebration** and **relaxation**, serve already more specific moments and goals, which might be more relevant at different stages of the progression of dementia. Self-expression and fun (**play**) can be important to promote **celebration** moments (as well as the experience of **negotiation** and **recognition**). Sensory stimulation (**timalation**) can be used

to promote playful moments and reminiscence, as well as being important in assisting **relaxation** moments, and becomes particularly important when abilities are more compromised. At the end of the list, we have **holding** and **validation**, which Kitwood also identified as more psychotherapeutic interactions. Due to this nature, artefacts are less likely to be direct *catalysts* of these interactions, which are essentially human and demand the presence of people. However, an artefact might *support* indirectly these interactions, through helping carers to understand, reflect and empathise with their relatives living with dementia, so that they gain the necessary sensitivity to respond and put in practice these interactions; and through the promotion of collective activities that stimulate a warm and non-judgemental environment, where space is made for the person with dementia to be listened and acknowledged.

It is also important to note that, although artefacts might have the potential to promote these interactions and thus positive experiences for people with dementia and those taking part in the interaction, they also depend on how each individual person perceives and uses the artefact: "Experience is not a property of the product but the outcome of human-product interaction, and therefore dependent on what temporal and dispositional characteristics the user brings into the interaction" (Desmet & Hekkert, 2007, p. 7).

experience of interactions depend on how each individual perceives and uses the artefact

Additionally, this research also considers on how to put Positive Person Work and person-centred dementia care values in practice when involving people with dementia in a codesign process. The process also becomes an opportunity to design for the experience of these interactions, which might be equally, or even more important, than the final outputs.

These exercises and subsequent reflections are not extensive and do not intend to be prescriptive. They constitute a starting point to understand dementia care from a design perspective and the effects that artefacts might have on the experience of dementia, in an effort to support a more conscious, ethical and aesthetic approach to designing for people with dementia and their carers.

	designing for Positive Person Work	*codesigning with Positive Person Work*
Recognition	The artefact respects and dignifies the person, and it is not stigmatising. The artefact supports and values her or his uniqueness and identity. respect and dignity both in function and aesthetics; personalisation; reminiscence; use of personal references.	Showing respect. Greeting participants by their name. Listening carefully and non-judgementally. Being sensitive to how participants communicate. Attending to participants' uniqueness by being open to share control about the process and accept their preferences of participation.
Facilitation	The artefact enables action, providing the necessary support. The artefact encourages the creation of meaning. sense of agency and autonomy; physical, cognitive and cultural accessibility; simplicity; aesthetics to support functionality; considering progression of dementia; prompts, cues, reminders; products that assist care.	Adapting the process to participants. Attention to duration of meetings. Having warm and open attitude. Avoiding activities with abstract thinking. Bringing tangible things to try. (Re)designing tools and materials to support participation.
Negotiation	The artefact provides opportunities for control and choice. support consultation; multiple-choice; stimulate creativity and self-expression.	Designing activities and materials that encourage the exercise of choice. Providing options for recognising rather than recalling.
Collaboration	The artefact promotes inclusive joint activities. support participation in shared activities (daily tasks or social activities); promotion of collective activities (e.g. games); interdependence.	Including family members and/or formal caregivers can be important to encourage participation (but ensuring that people with dementia have space to contribute by themselves). Setting participatory design events as opportunities for joint activities.
Play	The artefact stimulates self-expression.The artefact makes use of humour and provides enjoyable moments. spontaneity; self-expression (sharing stories or more artistic); creativity; fun; humour; ambiguity and versatility; friendly, vivid appearance; attention to overstimulation; game structure materials as cues for participation.	Planning codesign activities as moments of fun and self-expression. Providing participants an enjoyable time as a consequence of their participation. Valuing particitation in codesign activities as an outcome, even if it does not yield expected outputs.

Figure 5.47 Synthesis of main reflections on designing for and with Positive Person Work.

designing for Positive Person Work	*codesigning with Positive Person Work*	
The artefact provides and emphasises sensorial experiences. using senses to communicate; energising or relaxing activities; pleasurable aesthetic experiences; support participation in activities that stimulate the senses; support embodied selfhood; attention to sensorial aspects of products (textures, materials, etc).	Important to include and connect with people with advanced dementia. Giving stimuli and carefully observing their reactions and non-verbal communication. Also relevant in earlier stages of dementia.	**Timalation**
The artefact contributes to create a convivial and joyful atmosphere. The artefact supports and celebrates personal abilities and achievements. convey joy; enhance celebration moments, celebrate the person and what is important to her/him; humour; surprise; fun; music.	Focusing on participants' abilities. Celebrating participant's uniqueness. Congratulating and valuing participants' contributions. Avoiding situations that might be confrontational.	**Celebration**
The artefact promotes relaxation and/or a relaxing environment. comfort; warmness; easy-going; relaxed entertainment; familiar and friendly look; soft and pleasing tones and textures; helping carers to slow down.	Ensuring a relaxed and easy-going atmosphere. Respecting the pace of participants.	**Relaxation**
The artefact helps to create feelings of safety, security, reassurance. relaxed, familiar, comfortable environment; use of personal belongings or references; calming messages or cues; support carers to provide holding.	Creating a comfortable, non-judgemental and friendly environment. Encouraging the person to feel secure and at ease to participate. Avoiding activities with abstract thinking. Observing, trying to understand how the person is feeling and responding to it. Avoiding confrontational situations	**Holding**
The artefact encourages the development of empathy and sensitivity. tender and affectionate look and language; personalisation and responsiveness; encourage listening and acknowledging people's contributions; empathy exercises.	Empathic attitude throughout the whole process. Understanding if what is being asked is appropriate and comfortable for participants. Consulting family or formal carers about topics that might confront or elicit negative emotions. Responding to participants' reactions and feelings. Paying attention to signs of tiredness, anxiety or frustration.	**Validation**

6 Codesigning with people living with dementia and their families

personalised artefacts, brief and process

The observational study [chapter 4] and the conceptual reflection on the dementia care references from a design perspective [chapter 5] led to the core experiments of this doctoral research. These comprise the engagement of people with dementia and their families in codesigning ludic artefacts, where artefacts, brief and the participatory process were open to being personalised by participants. This chapter is dedicated to this research moment. It explains this approach based on personalisation, describes how participation was configured and posteriorly negotiated and readjusted with the six families involved, and presents the outcomes of these processes.

This chapter is a compilation of three published papers, reproduced verbatim. The first article, a full-paper presented at the Participatory Design Conference in 2016, is the most comprehensive of the three. It introduces why personalisation was chosen as a crucial idea in this research, based on person-centred dementia care literature, it exposes different perspectives on the meaning of personalisation, makes reference to associated notions of openness, appropriation, the definition of use through use and infrastructuring. In this paper, the participatory activities with the several families, the tools created and used, and the participants' responses are exhaustively described. In addition, the paper discusses how artefacts, design brief, and participatory design process were left open to make participation happen and share control with participants, analysing its influence on participation with some specific examples.

The second paper, a pictorial[1] presented at the Conference on Design and Emotion, also in 2016, details the collaboration with a particular family with whom a new brief was defined and new artefacts designed. It depicts the careful process of involving a person with advanced dementia with no verbal communication, and how her non-verbal reactions were embedded in the design of the artefacts.

1 A format with a predominant use of pictures.

Finally, the last paper in this chapter was an invitation from the Participatory Design Conference chairs to rewrite the first paper to integrate a special issue on the CoDesign journal. Consequently, this paper has much in common with the first one, such as the description of the participatory work with families (although with fewer examples). Nevertheless, it introduces the two new artefacts created in collaboration with two families, discusses the constant negotiation of use, design and participation throughout the project, and presents a more consolidated view on our personalised approach to personalisation.

6.1 Playing with personalisation and openness in a codesign project involving people with dementia[2]

6.1.1 Introduction

This paper describes and discusses the configuration of participation and first results of an on-going participatory design research project involving people with dementia. Dementia is a group of symptoms that gradually weakens cognitive functions, having an effect on the ability to perform daily tasks and living independently. In this research, people with dementia are not considered an object of study, but instead, there is an effort to include them and facilitate their participation so that their voice is present within the design process and outcomes.

dementia

This research explores how design can enable people with dementia and their social circle to codesign personalised strategies to communicate, with a special focus on leisure and entertainment, as a means to build and maintain social relationships. It is a practice-based project that follows a *research through design* approach (Jonas, 2007) using design practice as a method of inquiry, and draws from the *exemplary design research* proposed by Brandt et al. (2011). In this research, participatory design is guided by *person-centred care* values, and explores the concept of openness, through the personalisation of several aspects of the design project.

methodological approach

6.1.2 Why personalisation?

The aim to deliver open artefacts and provide means for families to personalise them, is associated with recognising the uniqueness of each person with dementia and the need to find proper ways to communicate meaningfully, so that social relationships are maintained.

The importance of cultivating relationships with people with dementia is central to person-centred dementia care and it is explained and linked to the concept of *personhood*, defined by Kitwood (1997) as "... a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (p. 8), which is not lost with a dementia diagnosis. Likewise, Zeisel (2009) emphasises this idea, claiming that people with dementia can remember themselves through the presence of important others "When

personhood and the importance of relationships

2 This section was previously published as: Branco, R. M., Quental, J., & Ribeiro, Ó. (2016). Playing with personalisation and openness in a codesign project involving people with dementia. In C. Bossen, R. C. Smith, A. M. Kanstrup, J. McDonnell, M. Teli, & K. Bødker (Eds.), *PDC '16 Proceedings of the 14th Participatory Design Conference* (pp. 61–70). New York: ACM. http://doi.org/10.1145/2940299.2940309

family members are present, she knows who each person is and remembers herself—even if she may not be able every time to remember a name or specific relationship" (Zeisel, 2009, p. 11), and believes that social relationships can ameliorate dementia symptoms. This is also reinforced by Brooker (2007) "As the sense of self breaks down, it becomes increasingly important that the sense of self is held within the relationships that the person with dementia experiences" (p. 84). Therefore, preserving this sense of self conveyed by social relationships becomes the main aim of dementia care. It implies addressing the central psychological needs of people with dementia: comfort, attachment, inclusion, occupation and identity, and an overall need for love, which are fundamentally achieved through finding ways to communicate (Brooker, 2007; Kitwood, 1997).

psycologicall needs of people with dementia

Several aspects of communication and the use of language are likely to be affected by dementia—not being able to find the right word, having difficulties following a conversation, speaking in a confusing and repetitive manner. This progressively diminishes the capacity to verbally communicate and has an unfavourable impact on relationships (Allan & Killick, 2008). Meaningful communication is possible, even with people in later stages of dementia, but it requires empathy, understanding, and respect for their individuality, as well as being resourceful to recognise alternative means to communicate with each person (Allan, 2001).

how dementia affects language and communication

Dementia affects people differently. In addition, the huge differences between individuals (with or without a diagnosis), due to their personality and life events, influences how each person experiences the condition and accepts care (Allan, 2001; Kitwood, 1997). This heterogeneity calls for individualised care, a characteristic of person-centred care practices which recognises the person as a whole and appreciates her uniqueness, not only focusing on her condition. Person-centred dementia care "...encompasses all those ways of working that consider men and women with all their individual strengths and vulnerabilities, and sees their dementia as part of that picture rather than defining their identity" (Brooker, 2007, p. 47).

uniqueness

In this research, personalisation is seen as a way of dealing with the diversity inherent to dementia and providing opportunities for meaningful communication. On one hand, designed artefacts are left open to be completed with content that is of matter, or is related to the person with dementia and their social circle, with the hope of making it more engaging. Conversely, the act of selecting content and finalising an artefact can constitute opportunities for the person with dementia to exercise control and choice, and/or for family members to reflect upon and understand their relative, while engaging in a collective activity. The focus on family relationships is pertinent due to the huge impact dementia has, not only on the life of persons diagnosed but also on that of their relatives, affecting family functioning in different ways. Close family members are usually responsible

reasons for personalisation

focus on family relationships

for providing a great part of the needed care, which becomes a challenge on several levels (S. H. Zarit & Zarit, 2008). Moreover, all families are also unique and have their own characteristics, strengths, issues, and needs, which become a part of one's sense of self. Family members and close friends are usually the ones who know the person better, and with whom they have shared their lives. Therefore, their involvement is crucial to read and provide cues about certain behaviours, as well as to keep the person's narrative and provide valuable content that might be helpful in engaging with their loved one (Zeisel, 2009). This project aims to enable families to use the knowledge they already have, in order to include their relative with dementia in collective, entertaining and stimulating moments.

6.1.3 On personalisation and openness

The terms *personalisation* and *to personalise* are used very differently across several fields of practice and research. In dementia care, personalisation means "figuring out how people can have as much choice and control as possible in their day-to-day life" (Bailey & Sanderson, 2013). This approach, focused on the provision of dementia care services, draws on person-centred care practices and uses a set of tools for gathering information about each person, such as what is important to them and how they wish to be supported in their daily lives.

different meanings of term personalisation > this part is not included in 6.2 section

Fan & Poole (2006) reviewed the concepts of personalisation used in different areas of knowledge, such as computer science, information science, e-commerce and marketing, architecture and social sciences. The definitions vary according to what is personalised (content, functionality, interface), to whom is personalisation done (individual or categorical), who personalises (the user—explicit personalisation; or done automatically by the system—implicit personalisation), as well as the motivation and goals for personalisation. Based on this analysis, the authors identify four main approaches to personalisation: *architectural*, related with incorporating needs and preferences of users in the design of the built environment and using a strategy based on individuality; *instrumental*, focusing on usability and functionality; *relational*, concerned with the mediation of social relationships; and *commercial*, referring to the differentiation of commercial content to increase loyalty and sales. Kuksa and Fisher (2014) reflected upon the current ubiquity of personalisation, which is mainly commercially driven, and point out to potential implications and threats that it might imply both for users and designers.

In this research, the term personalisation does not completely fit into any of the definitions presented above. Instead, it is used in a broader sense, as in the dictionary definition "to change or design (something) for a particular person" (Merriam-Webster, n.d.). Although the motivation

t personalise, as explained before, is related to and influenced by dementia care and person-centred practices, the goals are not related to the delivery of dementia care services, but with the development of adequate and meaningful artefacts to promote engaging leisure moments for people with dementia and their relatives. In order to accomplish this goal, participants are invited to collaborate in personalising the content of the previously designed 'incomplete artefacts', as well as in defining a personalised brief for the development of new artefacts or communication strategies.

openness

In this way, both artefacts and briefs are left *open* so that participants can contribute to the results. Eco (1989) put forward the idea of *open work* which is "characterized by the invitation to make the work together with the author". An open work can be: a *suggestive work*, meaning that every work of art is open to multiple interpretations, thus being able to be read differently by different people; and a *work in movement*, where in the work is intentionally left open to be completed by others, in a process which is organised and oriented by the author and which eventually leads to unforeseen results. McCarthy and Wright (2015) use Eco's concept of open work to reflect on the openness of different participatory projects, which can be broadly grouped into three configurations of openness: (1) projects where the author has more presence and participants are given components to combine or complete, co-creating content, structure, or behaviour; (2) relationship-based projects in which the relationship between researcher and participants determines the process and work; and (3) participatory publics where the presence and voice of authors and participants become more complex, with their roles overlapping simultaneously.

'definitions of use through use'

Considering that "designers create not only shapes of things but also forms of use" (Redström, 2008, p. 412), and that *use* refers to who uses, Redström suggests that opening the design process in Participatory Design is a way of anticipating use, and exploring 'definitions of use through use' by including various perspectives as means to divulge new opportunities for design. Redström calls this kind of approaches '*use' before use*, where use is tried, tested, and opened up for definition during the design process, ahead of real use. However, actual 'definitions of use through use' happen only when there is something to be used, thus *after design*. In this way, another possibility to bring in 'definitions of use through use' to design is to leave artefacts open, unfinished and undetermined, so that it allows different possibilities for use to be defined and developed through use, giving origin to a new design, which Redström (2008) names as *'design' after design*. A similar idea is proposed by Wright and McCarthy (2005), who consider *design-in-use* as the result of appropriation of an artefact into use, into one's life, by giving meaning to the artefact and adapting it to one's uses.

appropriation

Ehn (2008) builds on these concepts of '*design' after design* and *appropriation*, "seeing every use situation as a potential design situation" (p. 96),

and reflecting on how design can support appropriation. Dix (2007) had previously explored this topic, advancing that, in order to design for appropriation it is necessary to allow different interpretations, make functioning easy to understand, supporting instead of controlling, giving different components that can be configured in different ways, making clear that appropriation can happen, encouraging sharing, and learning from how people appropriate. Ehn (2008) relates the mediation between acts of design and acts of use, inherent to appropriation and to design for appropriation, to the notion of *infrastructuring* as put forward by Leigh Star, seen as a relational "socio-material public thing", a flexible and open structure that supports many uses without the need to be reinvented all the time. Ehn (2008) discusses several infrastructuring strategies, such as the use of protocols and formats; the provisioning of "means for *configuring*" through assembling and arranging components; the recognition and articulation of patterns; and the development of ontologies. Although '*use' before use* approaches of Participatory Design and '*design*' *after design* strategies seem to be opposite perspectives of 'defining use through use', Ehn (2008) claims that they can actually be complementary.

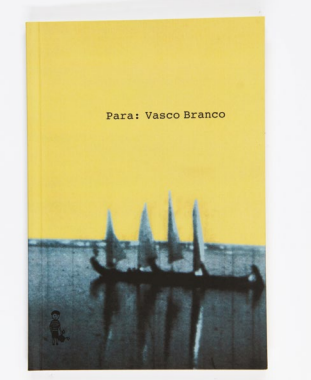
infrastructuring

6.1.4 Configuration of participation

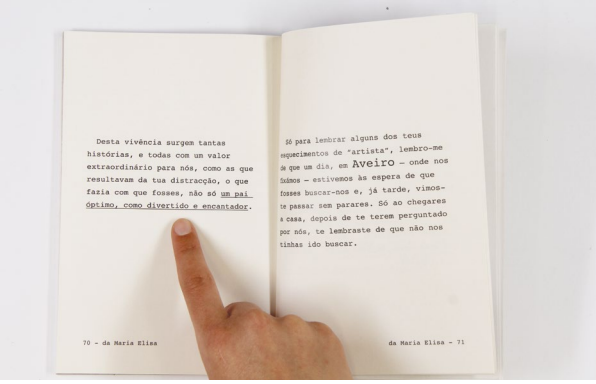
Being aware of the challenges of including people with dementia in a participatory design process (Hendriks et al., 2014), this research uses an empathic attitude, similarly to Lindsay et al. (2012) and Wallace et al. (2013), in order to manage the experiential differences between those living with the condition and their families, and the design researcher, who is also a relative of two persons diagnosed. This requires an individualised approach with each family (Hendriks et al., 2015; Wallace et al., 2013), with a view to embed the values of person-centred dementia care which regard people with dementia as individuals and appreciate their uniqueness while making an effort to understand their perspective of the world, and promote a vivid social environment based on building meaningful relationships (Brooker, 2007). Furthermore, it takes into consideration ethical principles to ensure that the personhood of people with dementia is maintained in research (Cowdell, 2006), protecting them from anxiety and stressful situations, respecting their needs, and being aware of potential paternalistic attitudes. This demands a sensibility which was gained and strengthened during direct contact with people with dementia in the preliminary phase of this project in the form of an observational study in two care institutions. These values, centred on the person and their relationships, became the main drivers for configuring participation (Iversen, Halskov, & Leong, 2012), and were translated into practice as (1) everyone can participate, regardless of ability,

empathy, person-centred care values, ethics

6.1



6.2



6.3



Figure 6.1–6.2 Family book. Letters written by family members were compiled into a book as a way of communicating through an activity (reading) that was still very engaging to the researcher's grandfather.

Figure 6.3 Card game [cards-about-what-matters]: Personalised set of cards with visual and written cues to facilitate conversation about what was important to the researcher's grandmother.
[more about this artefact on chapter 7]

about board game developed during observation

and the process can be adapted accordingly; (2) openness and flexibility to accommodate people's needs and preferences, within the aims of the project; (3) creating value for participants, making sure that participation is enjoyed and has some benefit for all involved in the process.

Preliminary work

Former research generated three tools for communication and interaction that arose from the researcher's first-hand experience with two grandparents diagnosed with Alzheimer's disease (Branco, 2014). Although these were highly customised artefacts adapted to the persons' and families' preferences and needs, two of these tools pointed out the possibility of developing open artefacts that can be personalised by and for others. These were a book personalised for the researcher's grandfather and a set of cards personalised for the researcher's grandmother. [Figures 6.1–6.3]

Subsequently, the preliminary observational study of the current research culminated in the development of a board game in collaboration with one of the institutions where the observation took place. [chapter 4] People with dementia participated in the making of the game, which was later offered to their families. This game uses a spiral structure similar to the classic *goose game* and incorporates characteristics, activities, and tasks of the observed institutional sessions. Each stop corresponds to an activity, organised according to the calendar year, where annual events act as triggers to share stories. In this way, the aim of the game is to take home some of the activities undertaken in the institutions, providing an opportunity for the families to involve their relative with dementia in a collective moment based on storytelling (about personal preferences and life events), affection (through smiling, hugging, shaking hands) and simple challenges (such as singing, completing proverbs, drawing for others to guess...) (Branco, Quental, & Ribeiro, 2015a). Although only one general board game was developed at this point, it was also intended to be customisable. [Figure 6.4]

The referred observational study also provided important practical and sensible learnings which were included in the setup and development of participatory activities. These considerations were related to the structure of

institutional activity sessions, the exercises, the materials used to facilitate participation in such activities, and the flexible, positive and warm attitude [of healthcare professionals] (Branco, Quental, & Ribeiro, 2015b). Moreover, the preliminary study contributed to an enhanced understanding and sensibility to the difference in experiences of people with dementia, and a growth in the awareness of ethical values consistent with those advocated by person-centred dementia care practices (Branco, Quental, & Ribeiro, 2015a). Another significant insight was that, despite everyone's different rhythm and active or passive participation, people with dementia often seemed to enjoy being included in institutional activities mainly because they felt occupied and were engaged in making things together.



Figure 6.4 Board game. [more about this artefact on chapters 4 and 7]

Initial configuration

Drawing on preliminary work, participation was configured to involve persons with dementia and their families to explore this project in two ways. Firstly, participants were asked to personalise the already developed artefacts (the card game [cards-about-what-matters], the family book and/or the board game) [Figures 6.1–6.4] in order to experiment with these ideas involving more people, and to understand whether they can be generalised if they are consequently able to be personalised to a certain degree, acting as an *infrastructure*. This invitation to personalise an existing artefact was also seen as a good starting point to include people in the project since there was something tangible that participants could already engage in, comment and react to, rather than to start by discussing abstract ideas. The board game was given precedence over the other artefacts, considering that some families had already received it. Secondly, participants were invited to take part in a codesign process for devising communication strategies together, emerging from their specific needs and preferences.

personalisation strategies

In order to facilitate family involvement and gradually build up participation, the initial work plan was divided into three main moments: (1) a feedback moment to try and/or comment on the artefacts; (2) the personalisation of an artefact and (3) the codesign of a new personalised communication strategy. The feedback moment consisted of two possible alternatives. Since one of the institutions distributed the board game to the families of their clients, this was used as the starting point to meet. These families were invited to play the game with the researcher and to comment on this experience. Following that, they were asked to reflect on how they could personalise the game (the content and type of activities) for their family. Alternatively, the researcher presented the three different artefacts developed

description of participatory activities as originally planned

feedback moment

earlier to the other families, unrelated to the institution that distributed the game, and asked them whether they would consider using the artefacts or not, and why. They were then solicited to choose one or more artefacts and think how they could personalise their content. For the personalisation moment, families were asked to take into account their thoughts about what to change in the artefact in order to personalise and make it. After this, the process depended on the artefact chosen to be personalised and on the families' preferences (e.g. drawing, collage, painting). In the codesign moment[3], families were asked to engage in a codesign process where new personalised strategies to communicate would be developed together according to their needs and preferences, similarly to the researcher's experience designing for and with her grandparents and other family members.

personalisation moment

codesign moment

This process, consisting of several moments where persons with dementia and their families are brought together to collaboratively make something, is also an outcome of this project since it is trying to provide warm and pleasurable moments of togetherness, and eventually adding emotional and affective value to the artefacts.

participation as outcome of research

The meetings were planned and adapted according to the structure of the observed activity sessions (Branco, Quental, & Ribeiro, 2015b). Drawing on these activities but also on participatory design tools and techniques (Brandt, Binder, & Sanders, 2012), namely the exploratory design games (Brandt, 2011), specific materials were designed to motivate, support and facilitate the participation of people with dementia, focusing on what they are able to do. As suggested by Binder (2010) "in each design laboratory, these tools and methods have to be shaped and sharpened by the issues and concerns of the participants" (p. 21). In this case, since people with dementia have problems with abstract thinking, memory, understanding visual and imaginary items, following conversations and discussions, keeping focused, making decisions, and some have difficulties communicating verbally, traditional participatory design tools are too demanding (Hendriks et al., 2014). The decision to use already designed tangible artefacts (good quality prototypes) that could be tried and commented on by participants, was also a strategy to deal with these difficulties, avoiding the discussion of concepts and abstract ideas. The presentation of rough prototypes to people with dementia can provoke anxiety since these might be unclear and difficult for one to understand and use (Orpwood, 2009). Questions were focused on people's experiences and views, and were always formulated to avoid participants with dementia feeling they were being tested. In order to facilitate sharing their experiences, some exercises used words

participatory tools to engage people with dementia in codesign

[3 This is called 'codesign moment' because families are invited to collaborate throughout the design process (from defining a brief until the development of final prototypes). However, we also consider personalising as a codesign activity.]

and images as cues to help identifying and recognising possible answers, or to serve as prompts for answers, detouring situations that can confront or frustrate the person with dementia for not remembering or not being able to find the right words. Since most meetings involved families, relatives were encouraged to support the participation of the person with dementia, which would also be done by the researcher. Exercises observed in the institutional activities, such as drawing or collage, were also favoured. Legibility and accessibility were taken into account in all the materials, ensuring that language was simple and clear to understand, as well as written in a friendly manner. In the same way, graphic details were considered to facilitate reading and convey an affable look, like type size and font, graphic layout, contrast and choice of colours.

6.1.5 Responses to participatory activities

recruiting

The families invited to participate were suggested and initially approached by clinicians of the two institutions, based on families' possible interest and availability in taking part in such project, and on how they could benefit from it. The stages of progression were not a factor for selection to participate, but instead, the intention was to include people with varied experiences of dementia and to adapt the process accordingly. Later on, some families voluntarily showed interest in participating, after a presentation of the project at a local *Memory Cafe*. Even though we have only approached the families that revealed some interest in participating and authorised being contacted, people were not readily available to take part in the project. Fourteen families were invited to participate, from which six did not follow up. Some never replied, others stated that they preferred not to participate due to several reasons such as lack of availability, lack of support of other family members or the fragile health of the relative with dementia.

Introducing the research project and participatory activities to participants

ethical decisions: friendly accessible presentation of project and consent

In the first meeting, the main aims of the project were briefly presented in a simple way without the reference to the words *Alzheimer's disease* or *dementia*. The decision to do so is based on the ethical intention not to confront people with their difficulties and diagnosis, and to focus on the shared abilities rather than on the problems. The explanation of the project focused on the main aim to contribute to the communication and relationships between different generations within a family, through the development of personalised leisure artefacts. The first two moments, feedback and personalisation, were also delineated and exposed. This information was described in the consent form given to every participant to sign (unless this was too difficult), and on a small booklet handed over to every family. The booklet was specifically





Figure 6.5
Introductory booklet.

produced for the families to keep and consult at any time. It has more detailed information about the project and the research team, as well as about previous related work and the collaboration with the two institutions. It was carefully written and designed in a simple and friendly way, so that it could also be accessible for (at least some) people with dementia. [Figure 6.5] The decision not to mention *dementia* when presenting the project seem to have left participants at ease and centred the attention on the collective activity rather than on the difficulties inherent to the condition.

Feedback moment

Families were asked either to play the board game (if they have received it previously) and to reflect on this experience; or to consider the three artefacts (the personalised book, the personalised card game and the board game) and comment on them.

Playing and commenting the board game



Figure 6.6 Meetings started by playing the game for around 30 minutes.

After introducing the project and the board game, participants were solicited to play for around 30 minutes. The intention was to understand how participants played and interpreted the game, how they reacted to the several activities proposed and how they interacted with each other. The researcher would also play if the family agreed. Since the board game activities ask about personal preferences and life events, this was also seen as an opportunity for researcher and family to getting to know each other. [Figure 6.6]

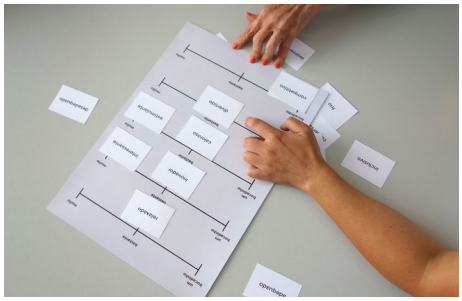


Figure 6.7
Redesigned semantic differential to characterise the experience of playing the game.

Afterwards, participants were questioned about several aspects of the experience of playing, and about the game. Firstly, people were enquired about how they felt while playing the game and were asked to characterise this experience by using a redesigned semantic differential. This consisted of several cards with adjectives (positive and negative). Participants were required to choose the ones they would associate with the game (minimum 5) and to place them on a scale of intensity, ranging from "a little bit", "rather" or "very". All participants with dementia, including a person in a moderate to advanced stage of progression, were able to understand the exercise, contribute with at least one adjective, and choose its intensity. [Figure 6.7]

Participants were then questioned about their preferences for the different activities and overall opinion about the game. Comments on preferred and disliked activities, as well as the positives and negatives of

general aspects were written in purpose-made cards. Participants were also enquired about the game elements (board, instructions, dice, playing pieces), which had the contribution of people attending the day centre, and were asked to write down their thoughts next to the photograph of each element. [Figure 6.8] Comparing to the semantic differential, these exercises seemed more demanding for the persons with dementia, although all of them contributed with their thoughts with the help of the family member(s). Based on their written comments, participants were finally questioned about what they would change in the game (e.g eliminating or adding more instances of a specific activity) and what personal interests, themes, stories or important events could be included to make it "their" game, which were also written on specific cards.

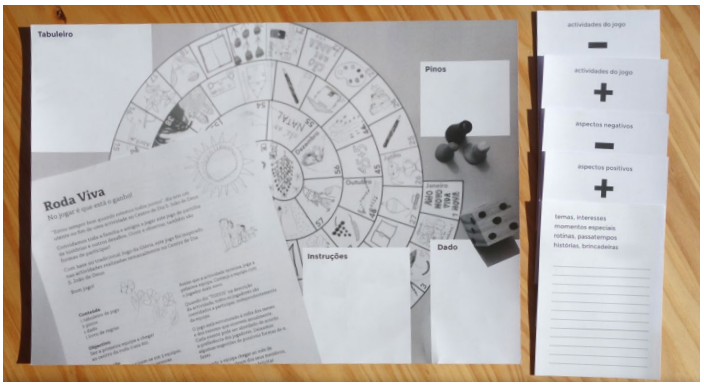


Figure 6.8 Other materials for feedback about: game elements, activities, overall positive and negative aspects, and possible themes, interests, special moments for personalising the game.

Commenting the three artefacts

With the families who had not received the game previously, the set up was different. After a similar introduction of the project and signing of consent forms, the three artefacts—book, card game [cards-about-what-matters], and board game—were shown and explained to the participants. The participants were asked to comment and write down their views for each artefact and whether they would use them or not and why. [Figure 6.9]

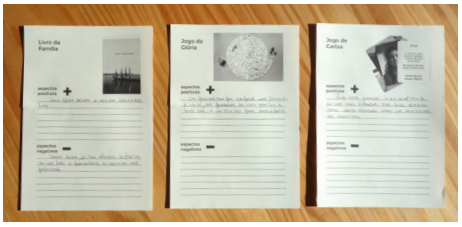


Figure 6.9 Materials for feedback on the three artefacts: positive and negative aspects of each artefact and why they would use it or not.

People were then invited to choose one or more artefacts and think how they could be personalised to their family. Since in this instance, there was not a follow up from having received the game earlier, this approach was considered the best way to give the opportunity of selecting the preferred and more appropriate artefact.

Although the intention was to listen to both the people with dementia and their family members about these artefacts, this set up seemed inadequate for people with dementia. On one hand, despite the fact that the artefacts were physically shown and demonstrated, there was still the need for imagining its use, which might have made it difficult to comment on them. On the other hand, since it was also asked to justify why they would use the artefacts or not, this ended up, at times, highlighting and confronting the person with dementia with some of her difficulties. For this reason, this set up was abandoned if the person with dementia was present. In three cases, the meeting happened only with the family members without dementia (because it was either according to their preference, or it was not feasible to meet with

showing and commenting on an artefact, without using, was found inadequate for person with dementia—better to play/make something during participatory design activities





Figures 6.10–13 Personalised board games.

Figure 6.10 This board belongs to the family that personalised the 60 stops. The family member preferred to work directly on a blank board. Since it was the first family to personalise the game, the frame is exactly the same as used earlier in the institutions. Later the board was redesigned to make the spiral rows more clear.

Figures 6.11 This family opted to keep the appearance of the original board game developed in the institutions, and changed only a few stops, which they asked the researcher to illustrate.

the relative diagnosed) and it did not raise any issues. Instead, it actually generated important insights about the three artefacts, and in one case, the card game [cards-about-what-matters] was also chosen to be personalised.

Personalisation moment

personalisation of the board game

As a result of the second moment, five artefacts (four board games and one set of cards [cards-about-what-matters]) were personalised by four families. In order to personalise the board game, it was suggested that the game structure could be seen as a blank space for families to personalise according to their preferences. However, only one family redefined all the 60 activities.[4] In this case, the organisation of activities related to annual events was abandoned, adopting a more dynamic game strategy, with quick-answer activities, also leaving behind the component of storytelling. [Figure 6.10] The other families maintained most of the activities proposed in the original version, unless they were inadequate or disliked, and added mainly personal elements such as important dates, people and other activities known as engaging to the person with dementia. [Figure 6.11–13]

personalisation of the cards-about-what-matters

The card game [cards-about-what-matters] was initially created as a set of personal images and corresponding descriptions, without specific playing rules, to facilitate conversation about what is important (people, places, moments, objects, etc) and possibly more engaging to the person with dementia. One family chose the card game [cards-about-what-matters] to personalise, for its

[4 Personalising the 60 activities was too demanding for most families (probably overwhelming too). Thus, as meetings with families progressed we also started to present different options and levels of personalisation, to leave families at ease to chose according to the time and effort they wanted to invest in this process.]

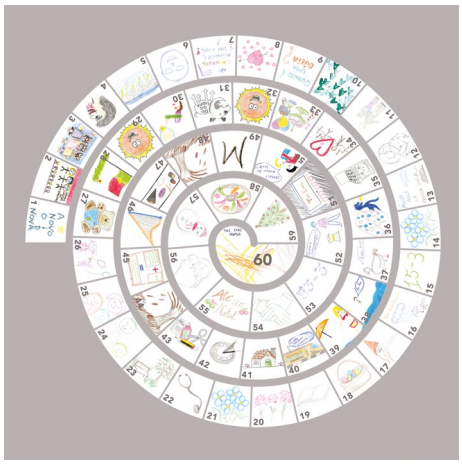


Figure 6.12 All drawings on the board were made in a collective session at home with several family members and their relative with dementia. Although all the stops look differently, most activities are the same as in the original version.

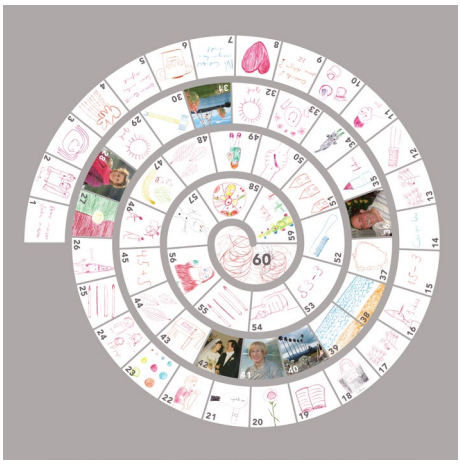


Figure 6.13 All drawings on the board were made by the person with dementia, supported by the researcher and an art therapist. The family member adapted and suggested several new activities to make it more adequate for her relative, but was not involved in the making.

simplicity and because they found it stimulating and relevant for their relative in early stages of dementia, who was always keen on playing cards. Due to this fact, a new game dynamics was created, with rules and goals, so that the cards could be played as much as functioning as a trigger for conversations.

importance of openness and flexibility to make participation happen

As stated earlier, in order to better include people with different experiences of dementia, we envisaged some aspects of the process to be adapted along the way. However, every family somehow defined their participation in the design process. As soon as we became aware of the complexity of people's availabilities and preferences (mainly due to the logistics of caring for someone with dementia, busy lives with work and children, and emotional reasons), an effort was made to set the process as open as possible and let participants take control of it, while maintaining the main aims of the project and its planned activities [5].

Codesign moment

inadequacy of presented artefacts

In the first moment, two families did not find any of the three artefacts adequate for them. For one of the families, the book did not correspond to the habits of the relative with dementia, the cards [cards-about-what-matters] seemed too easy or too basic and the game did not suit the family routines for being too lengthy and was found inappropriate due to the lack of common interests among the different generations of the family. The other family did

[5 Although the two first families that participated in the feedback moment showed interest in personalising the game, they did not follow up. This was also a reason to reconsider the initial plan, leading to the understanding that being more flexible and open to negotiate participation with families and simplify the process was crucial to make it happen.]

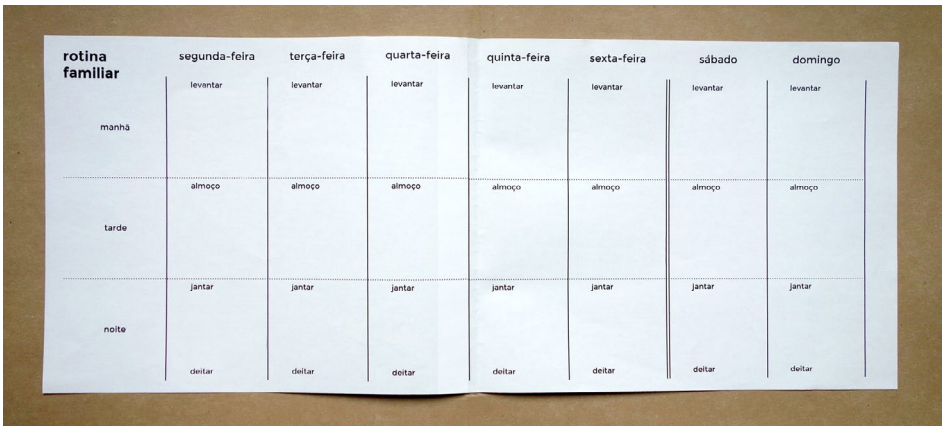


Figure 6.14 Weekly routine exercise.

not find any of the outcomes adequate due to the advanced stage of dementia and severely limited verbal communication ability of their relative.

codesign moment as an alternative to personalisation

Given these facts, the two families were invited to take part directly in the codesign moment, which consisted of designing a communication strategy for entertainment for and with them. In this way, the codesign moment became an alternative for the personalisation moment, rather than coming after it. Considering the general lack of availability of most family members, this unforeseen adjustment was considered more appropriate than the original plan which would have been too lengthy and exigent for the families. For the same reason, this codesign moment, which was originally planned to include more steps and tools such as cultural probes, was simplified. Drawing on the *person-centred thinking tools* (Bailey & Sanderson, 2013) used by dementia services to gather information to deliver individualised care, two exercises were created to support the personalisation of the design brief: (1) about the weekly routine of the person with dementia and their close family, so that plausible opportunities of use could be identified; and (2) about how a good day and a bad day would be like for both the person diagnosed and the main family carer, in order to understand what is important for both (things they like and dislike doing, interests and preferences) and should be taken into consideration in the design ideation.

tools to define a personalised design brief

weekly routine exercise

The weekly routine exercise consisted of a grid with the week days and different moments in the day to be filled in. In both cases, it was responded only by the family members. Namely in one of the cases, this simple exercise prompted the family member to speak about the behaviour of the relative with dementia and some of the difficulties in dealing and entertaining her, sharing some episodes, which was also important to understand the family perspective [Figure 6.14].

good/bad day exercise

The good/bad day exercise was more comprehensive. Participants were questioned about several aspects in order to create their day: (1) how is the weather? (2) what do I do? (3) with whom? (4) where am I? (5) what do I see? (6) what do I eat? (7) how do I feel? For the two first questions, small cards with various drawn and written responses were created to work as

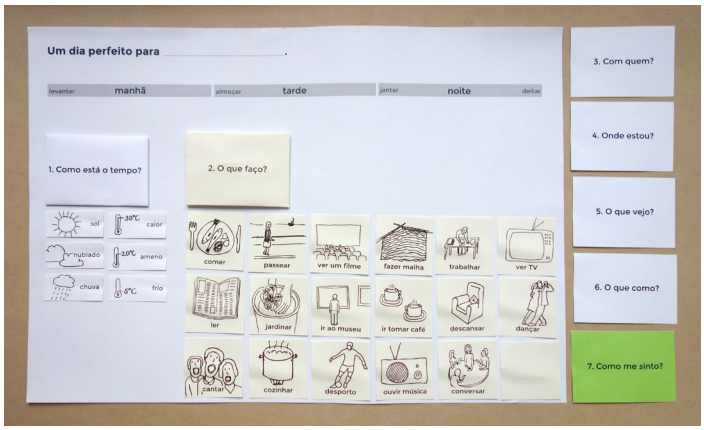


Figure 6.15
Good day exercise: question and cue cards.

cues for people to relate with. There were also blank cards so that people could add what they wished. The answers were placed in a blank page and arranged according to the daily periods. Due to the difficulties with verbal communication of the person with advanced dementia, the family member responded for both, sometimes asking her to see how she reacted non-verbally. The good day exercise was individually conducted with the other person with dementia. In both cases, the exercise ran smoothly and both mentioned their enjoyment in being given the opportunity to speak about what they like to do. The several questions were very helpful to guide the exercise, equally for the participants and the researcher. The cue-cards were relevant to facilitate responding to the questions, mainly for the person with dementia. She mentioned that is was easier to go through these options, identifying and selecting what she preferred. It was also important to have the blank cards since both participants added things that were not there. The exercise triggered the telling of stories and memories related to a specific thing they liked to do. When their preferred activities were chosen, the selection was arranged according to the daily moments. The answers to the other questions were written around them until the participants were happy with their 'day'. Partly because this ended being a lengthy exercise, the participants did not want to reflect so much on how a bad day could be. Therefore, instead of thinking about a whole day, they only spoke about things they disliked, or about what made them feel sad or anxious [Figure 6.15].

importance of cues

focus on positive exercises

6.1.6 Discussion

Openness and its influence on participation

Although the approach started with the personalisation of content in '*incomplete artefacts*', the *design brief* (when artefacts were not appropriate) and the *process* were also personalised in order to make participation happen with this specific group of people. In this way, the project was open in several ways to accommodate the experiences, emotions, needs, preferences and

personalisation of artefacts, brief and process

voices of the participants. This process was essentially codetermined by the relationship between participants and researcher, similarly to what McCarthy and Wright (2015) describe as *relationship-based projects*. We will analyse and illustrate the openness of this project and its several aspects, and how it influenced participation.

Open artefacts

personalising with new content: committed participation

In the artefacts left open for personalisation, the general concept and a blank structure is given to participants to coproduce its content, taking the original versions as an example. This strategy seems to have promoted a more committed participation, maybe because what is asked is straight forward and deals with personal preferences and content, thus allowing participants to have control over a considerable part of the final outcome.

different ways in which the board game was personalised

Although only four families personalised the board game, this approach also allowed to understand the different ways in which artefacts were personalised, yielding important insights to further support personalisation and appropriation. While two families seemed to be happy with the general game (eventually adapting activities as they played) and made only minor changes to the list of activities, adding only a few personal details; one family was keen on making their own game according to their preferences, redefining the game organisation and activities; and another family kept the core of the original activities but changed a considerable amount, in order to include other activities their relative would engage more with and exclude others that would not arise any interest or would not be applicable. This was the case of a person with early onset of dementia, thus activities that considered a context with older people (e.g. talking about grandchildren) did not make sense. The person used to be a hairdresser and still enjoyed doing related activities (e.g. combing, painting nails, etc.) which were also included in the game. Besides this, important moments such as the wedding, and family anniversaries were added as a way of triggering conversations about those events and important people.

importance of providing guidance on personalisation

Independent of the amount of activities that each family changed, it was important to provide a general list of activities as suggestions and guidance, and also to make sure that overall, the type of activities was adequate for people with dementia.

Open design brief

In the two cases where the design brief was personalised, thus developing certain elements from scratch, it was expected that the participants would take more initiative to suggest directions to define a new design brief. Instead, they mainly responded to the proposals of the designer. Perhaps this is related to the initial moment in which feedback was asked about the developed artefacts. Maybe other strategies could have been devised to enable them to participate more actively. However, it might also be that people participated in the way

they were comfortable with, which in these cases, consisted of sharing their experiences in caring or living with dementia.

participating through sharing experiences

> Patients ... find their agency precisely in their voice as patient. ... They speak with authority as patients, with the particular experiences that are different from those of the other stakeholders around the table. It is in their difference that they can find themselves leading and giving direction (McCarthy & Wright, 2015, p. 85)

This is true in this project, where proposals for both cases emerged from the experiences shared by these families, who responded in detail to the exercises about their weekly routines and how their perfect day would be like, thereby strongly influencing design ideation.

One of the families was an old couple that attended the day centre and received domiciliary care from one of the institutions collaborating in this study. The lady had advanced dementia and almost no verbal communication and her husband was her main carer. When speaking about their routines, the carer pointed out that during the weekend, when they were at home, he felt less supported. He enjoyed watching TV or reading, but this was sometimes difficult due to the agitation of his wife who frequently made noise and walked about the house. He agreed that this moment could be an opportunity to make something to stimulate and entertain his wife so that he could have a more restful afternoon. Following that, while doing the 'good day' exercise about his wife, he mentioned how she used to love knitting and lace-making. Also associated with the observation of how the lady would grab the researcher's hand and press each finger one by one, a new brief was proposed: to create an artefact for tactile stimulation using textiles to support her entertainment during weekend afternoons.

non-verbal participation

In order to make it a possibility for the lady to participate in this process, several fabrics were given to her to touch. The ones she seemed to reveal a preference for (non-verbally—spending more time, feeling, twisting, exploring and revealing physical signs of wellbeing) were later used in the prototype. In this case, not only the experience shared by her husband was significant to redefining the brief, but also her non-verbal communication gave hints to her preferences.

different roles of participants within a family

Open process

Since this project concentrates on people with dementia and their families, there was a need for an individualised, empathic and flexible approach, so that people's needs, preferences and availabilities could be accommodated. In this way, after explaining to participants the objectives of the project and what was being asked of them, they were left at ease to lead and manage the process. One could ask in this case, to what extent can the process be altered by participants without compromising the research? Since the project goals were made clear from the beginning, they became the structural element of this open process. Therefore, these adjustments were made within the ambit of the project aims, in order to

the clear presentation of project goals from the beginning became structural to the open process

focus on conviviality

accomplish them. In addition, regardless of how the process unrolled, it was always verified whether participation was valuable for participants in any way.

For one of the families it was very difficult to include their relative with dementia (due to lack of mobility and trouble leaving home) and other family members (unavailability). Consequently, the personalisation of the board game was undertaken mainly by one participant. The will and initiative of the main participant, who voluntarily took part in the project to personalise the game to play with her mother, was recognised and valued, even if not corresponding to the original plan of including the person diagnosed in the process. Since the main participant was likely to benefit from this process, and her mother, even if not included in the process, could possibly benefit from its outcome, participation was supported and the original plan was adjusted in order to make it happen.

In another case, the possible time for a family member to meet for playing the game coincided with dinner time at the day centre. Although in the institution they would provide her the meal later on, the person with dementia preferred to have the meal together with others. Since she was not present, the meeting had to be improvised. The game was explained in detail, instead of being played, and the list of activities was reviewed and personalised. Although the family member had some doubts about her relative's engagement in the game, she was willing to try it. However, she did not have the availability/willingness for doing the collective activity to illustrate the game. Since the person with dementia enjoyed drawing and painting, the game stops were illustrated by her in the day centre, supported by the researcher and a therapist. With this family, the process had to be improvised, firstly to conduct the initial meeting, and secondly to make it possible to achieve the goals of the project.

reflection on personalisation process and the need to provide personalisation options
> more on chapter 7

These examples show how the participatory process was adapted and personalised, resulting in very different approaches to what was initially configured. In the first case, the fact that the person with dementia could not be included in the process was compensated by the possible benefits that the outcome could bring, and by meeting the will of the main participant to try to do something for her mother. On the second one, the person with dementia and her relative participated separately in different parts of the project. Although the family member was unsure about the benefits of the final outcome, she recognised the value of involving her relative with dementia in the process, consisting of stimulating activities which she could take pleasure from. [Figures 6.16–17]

Another aspect to take into consideration relates with people's readiness/hindrance to participating in the collective activity to illustrate the game. The exercise was planned and proposed to the families, based on the researcher's observation of institutional activities in two institutions, where people with dementia benefited from and enjoyed being involved in

6.16



6.17



Figure 6.16–17 Illustrating the board game.

In this case, the family member was not available to participate in making their personalised board game. However, since the person with dementia was fond of the arts and crafts activities at the day centre, the researcher and an art therapist supported her to illustrate the 60 game stops of the board. During six months, this person was engaged in short sessions of drawing and making collage.

Her language was very much affected, as well as her ability to recognise and name objects, which made it very challenging, since she would not associate the word to the representation. In order to cope with this difficulty, for each session, we brought objects or images so she could draw from, different elements to make a collage, or we sought to guide her in the drawing, by drawing next to her for instance.



6.18



Figure 6.18
Family receiving their personalised board game.

6.19



Figure 6.19 Family who organised a collective activity to illustrate their personalised board game.

6.20



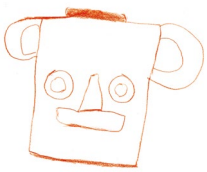


Figure 6.20
Modelling the playing pieces with their relative with dementia.

making things together. However, despite the fact that people perceived the significance of such activity, the amount of work and type of exercise seemed too demanding. Consequently, only one family gathered several family members together to make this activity. [Figures 6.19–20] As mentioned earlier, the process was adapted to the other families' preferences, to accomplish the personalisation of the game. However, it could have been easier if some ready-made stops had been provided for families to combine with stops illustrated by them.

Personalisation, participation and 'definitions of use through use'

In this research, personalisation is seen both as a means to promote meaningful and adequate leisure moments for people with dementia and their social circle, and an opportunity to invite people to collaborate on the project. The four perspectives of designing for personalisation identified by Fan and Poole (2006)—*architectural*, *instrumental*, *relational* and *commercial*—were important to understand and reflect on personalisation in this project. Our approach is positioned between the *architectural* and *relational* perspectives, due to a focus on the individual through incorporating people's concerns, as much as on people's social relationships, thus having an "affect-oriented" purpose. To this discussion, we bring and elaborate on the participation of people both in the process of personalising (explicit and individual) and in the process of designing for personalisation, drawing on Redström's (2008) ideas on 'defining use through use', through *'use' before use* and *'design' after design* approaches, and on the concept of *infrastructuring* presented by Ehn (2008).

reflection on how *'use' before use* and *'design' after design* approaches became intertwined in this project

In this project, the 'definition of use' through involving participants becomes complex and intricate, since it intertwines '*use' before use* with *'design' after design* approaches. Strongly influenced by the observation and direct contact with people with dementia, artefacts were designed and left undetermined, open for personalising and 'defining use' *after design*. The design process was extended *after design*, and people were invited to participate in the project to define the use of unfinished designs, generating a new design. The aim was to understand, accompany and observe the *definitions of use after design*, in order to learn how to design for further enhancing this process. Even if it might seem contradictory, participatory design was used to support a '*design' after design* approach, giving insights on possibilities and patterns of use, and contributing to give meaning to a possible *infrastructure*. Although the board game can be played without personalising, and its use observed, families are encouraged to adapt and appropriate it. The card game [cards-about-what-matters] and the family book, on the other hand, cannot be used without the contribution from the families. Anyway, in all of these artefacts, there is a kind of *infrastructure*, which is being experimented with families, thus *used before use*. Both

artefacts as *infrastructures* for personalisation

in the card game [cards-about-what-matters] and board game, people mainly adapted the content which influenced use definitions, affecting the engagement and reactions with certain themes and activities, and thus the final design—'*design' after design*. In addition, the participants also contributed with suggestions for improving the *infrastructure*, expanding its possibilities of use, providing insights on how its use could be supported, and gave practical feedback to support accessibility and avoid confusions—therefore affecting *use-design* and *thing-design*, through '*use' before use*.

'use' before use approach to support the design of artefacts as *infrastructures*

Another approach was used with the two families with whom a new brief was defined taking into account their specific needs and preferences, thus personalising the design brief. Since the proposed artefacts did not make sense to them, they were invited to define and specify a new use, within something engaging, stimulating and entertaining for the person with dementia and their family. Both created exercises [the weekly routine and good day exercises] aimed to support the definition of use: when they would like to use it, and what/how they would like to use it. After the *use-design* was sketched, then the designer/researcher tried to give shape to *thing-design*. Through presenting physical mock-ups, the use was gradually redefined by participants, namely in the case of the person with advanced dementia, who contributed with her non-verbal reaction to the physical samples. In this case, she was not able to contribute to the initial definition of use, so this was negotiated with her carer. But when there was something physical and tangible that she could react to, she was able to participate. This time, the designs were created based on the direct accounts and experiences shared by participants, using a *'use' before use* approach.

balance and intertwining different forms of participation among people within a family

Configuring participation with people with dementia and their families

Leaving the process open, as well as the artefacts and the design brief was crucial to engage people with dementia and the families in the design project, and make participation happen. Firstly, it allowed an individualised approach, important in dealing with different people with various abilities and experiences of dementia. Secondly, it was a way to work towards meaningful outcomes that embedded the participants' idiosyncrasies, and it facilitated participation by giving an *infrastructure* for the participants to build up, as well as becoming a means to share control of the project, which enabled and possibly motivated people to participate.

Conclusions on personalised approach > elaborated further on 6.3.8

Sharing control between researchers and participants is, according to Vines et al. (2013), one of the aspects that is often overlooked when configuring participation in design projects, alongside different forms of participation, and who initiates and benefits from participation. These aspects are used to analyse and reflect on how the values emphasised for configuring participation in this project [related to person-centred dementia care] were put in practice.

Openness and flexibility

Reflection on our 'translation of person-centred care values to participatory design practice

The open and flexible attitude towards participants and how they are able and willing to participant in the project is a characteristic that was observed and learnt in the institutional activity sessions, as well as influenced by person-centred dementia care literature. In the activity sessions, this attitude is crucial to support and value different kinds of participation, making space for people with dementia to express themselves and exercise control, and being available to listen and demonstrating interest in their communication, despite it being relevant or related to the current activity.

openness of several aspects of project

This attitude is reflected in the configuration of participation and openness of the several aspects of the project—artefact, design brief, process—, which as suggested above, is a means to share control between researcher and participants, both regarding their participation and the final outcomes. Although the first meeting (feedback moment) was quite structured and planned, the rest of the process was left open, to negotiate with families on how to better configure it to suit their needs and preferences. When the artefacts were personalised, participants had a direct control over the content, but also over the appearance of the final outcome, depending on how they decided to make it. In the cases where the design brief was personalised, participants had control over the project by sharing their experience and giving feedback on the iterations of design proposals, deeply influencing its progress.

Everyone is welcome

One of the key values of the participatory work in this research was to welcome everyone, independent of their ability or progression of dementia. This project accommodates different experiences of dementia, therefore constantly adapting activities to different forms of participation. In order to do this, the observation period was crucial to learn how to value all different kinds of participation (from very active to passive, big or small contributions) and to learn how to respond and support them. Having a previous contact with some of the participants with dementia was also of great relevance to understand what would be adequate for each person during the participatory work with families, and adapt accordingly.

importance of initial observation study

importance of making together

importance of simplicity and cues

To address and support the different kinds of participation, it was important to have chosen activities that involve making or doing something, rather relying on abstract ideas and conversation, which may have an adverse impact and may confront people with dementia with their difficulties. This ensured that people were occupied, and thus possibly enjoying the meeting. Being involved in an activity allowed non-verbal reactions to be observed, and with some people, also triggered conversations. At the end of the activity, people were asked about how they experienced what they had just done. The use of cues was found very

effective to support communication and choice, as well as the simplicity of activities, materials and language.

Creating value for participants

Obviously the research benefits immensely from all these exchanges and encounters. However, a big effort was put on trying to make the participation worthy for participants so that people see value in their contributions and somehow benefit from it, either from the process or future outcome. Some examples are the promotion of family reunions to make something together, hopefully generating meaningful moments for both, the company and attention given to participants (namely older participants), the fact that some family members felt that they were contributing in some way to try to develop something that could be beneficial and engaging to their loved one.

effort on conviviality, and creation of value for participants

6.1.7 Conclusions

In the participatory work developed with these families and their relatives with dementia, it was crucial to leave the project open in various aspects so that families could participate and respond as they wished and felt comfortable with, and the process could be adapted to the persons with dementia. In order to support different forms of participation, and turn participatory moments pleasurable for all participants, we had privileged activities that involved making or doing something together. These were assisted by materials carefully designed in a simple way to convey a friendly and warm attitude, both in the appearance and language, that aimed to facilitate participation, namely through the use of cues.

The several ways in which the project was open—*artefacts*, *design brief* and *process*—makes us believe that people with dementia, irrespective of the stage of progression, can contribute to definitions of '*use' before use* and '*design' after design*, when supported by their social circle and researchers. Depending on their ability to understand and verbally communicate, a '*use' before use* approach might need to be started with their carers, to point out directions to shape a physical mock-up to experiment with the person with dementia and observe how they react to it. In a '*design' after design* approach, the process happens inversely. Even if it requires adaptations and personal elements which will eventually need more input from family members, having already a design that can be used facilitates the engagement of people with dementia in the process and enables their participation from the beginning.

Although this open approach based on personalisation emerged from the specificity of working with people with dementia and their families, it explores and discusses relationships between *'use' before use* and *'design' after design* approaches. On one hand, the unfinished artefacts which are open

for personalisation work as *infrastructures* that participants can use and appropriate. In the participatory moments, the researcher was able to observe and learn from this process, in order to improve these *infrastructures*. On the other hand, the fact that the participatory process was also appropriated and personalised by each participant family suggests that the process can also be seen as an *infrastructure*, even if immaterial, capable to be configured, supporting different forms of participation, and sharing control between participants and researcher.

6.2 Tactile explorations in a codesign project involving people with dementia[6]

6.2.1 Introduction

dementia

Dementia is a syndrome that progressively affects cognitive functions such as communication, reasoning and memory, compromising the ability to perform daily tasks, and having an adverse impact on relationships. This work is part of a practice-based doctoral research that explores how design can enable people with dementia and their close social circle to develop personalised strategies for communication, with a special focus on leisure and entertainment. Personalisation, used here as "designing or changing (something) for a particular person" (Merriam-Webster, n.d.), is seen as a way of addressing the underlying diversity of the experiences of dementia and to provide opportunities for meaningful communication.

meaning of personalisation

In this research, people with dementia are invited to take part in the project, so their voices and their experiences are acknowledged throughout the process and in the results. In order to bridge the pronounced differences between the experience of people with dementia and the one of the designer, this research uses an approach based on empathy (Lindsay et al., 2012; Wallace et al., 2013). This approach is also deeply influenced by the *person-centred care* values, consisting of acknowledging everyone's uniqueness as individuals independently of their age and ability, the effort to understand their perspective of the world, respecting and maintaining their *personhood* (Kitwood, 1997)—a relational sense of self that is conferred by others—which is achieved by promoting vivid social environments and relationships, through meaningful communication (Brooker, 2007). These attitudes are crucial to ensure that the main psychological needs of people with dementia—comfort, attachment, inclusion, occupation and identity, and an overall need for love—are met (Brooker, 2007; Kitwood, 1997). Ethical concerns are present throughout the whole process so that participants' needs are respected, and potentially paternalistic attitudes avoided (Cowdell, 2006).

empathy and person-centred care values

personhood

psychological needs of people with dementia

ethical concerns

The preliminary phase of this research consisted of an observation-based study in two care institutions dealing with people with dementia, where the researcher assisted several activity sessions. The direct contact with several individuals with dementia, and the observation of how they

observation study

6 This section was previously published as: Branco, R. M., Quental, J., & Ribeiro, O. (2016) Tactile explorations in a codesign project involving people with dementia. In Desmet, P.M.A., Fokkinga S.F., Ludden, G.D.S., Cila, N., & Van Zuthem, H. (Eds.). *Celebration & Contemplation: Proceedings of the 10th International Conference on Design and Emotion*, September 27-30, 2016, pp. 642-650. Amsterdam: The Design & Emotion Society.



Figure 6.21 Activity sessions observed during the preliminary study. [more on chapter 4]

engaged, participated and enjoyed these activity sessions, were essential to have a deeper understanding and develop empathy towards different experiences of living with this condition, leading to an enhanced sensibility and ethical awareness on how to work with this group of people. [Figure 6.21]

The observation and learning resultant from this first interaction were crucial to define the next steps of research, consisting of bringing together people with dementia and their social circle to codesign personalised strategies for communication. Three previously designed ludic artefacts were used as a starting point to invite people to participate in this project. [Figures 6.1–6.4, pp. 146–147] These artefacts were designed to be left open for personalisation so that content could be selected and adapted for and by the person with dementia and their family members. Participants were asked to personalise one of these artefacts if they found it interesting and adequate. Alternatively, participants were invited to engage in the definition of a design brief according to their needs and preferences, and consequent design process. The following work, still in progress, illustrates one of these latter cases, involving a lady with advanced dementia and her husband, her main carer.

configuration of participatory work with families

6.2.2 Defining a design brief

presentation of Amelia and Gabriel

Amelia and Gabriel[7] attend the day centre and have domiciliary care services provided by one of the institutions where the observation was conducted. Amelia is in an advanced stage of dementia and has nearly no verbal communication. Nevertheless, she intensively communicates non-verbally through facial expressions, gestures and body posture. The couple frequently participates in the activity sessions at the institution. Although not being actively engaged in the exercises proposed, Amelia often shows non-verbal signs of enjoyment, namely when sessions involve music and singing along, and when groups of little children were brought to participate in the activities.

first meeting: proposed artefacts were not adequate

After a year of being acquainted with the couple, they were invited to participate in this research project. The project was introduced and the three artefacts shown to Gabriel, who did not find any of the artefacts adequate for Amelia, due to her cognitive impairment. Therefore, we advanced with the definition of a design brief that could suit the needs and preferences of the couple. In this first meeting, opportunities were already identified: something to be used during the weekend, when the couple is at home and is less supported; something to entertain and stimulate Amelia, since she can be

7 The real names of participants have been replaced to preserve anonymity.

agitated while Gabriel prefers to watch TV or read. Gabriel was asked about using music to engage Amelia since it was clear from previous observations that she reacts very positively to it. Gabriel agreed and mentioned that they sometimes listen to music, but he does not like singing and would prefer something quieter.

Two exercises for a personalised design brief

exercises to define personalised brief

Two exercises were created to support the personalisation of the design brief. These were drawn on the *person-centred thinking tools* (Bailey & Sanderson, 2013), used by dementia services to gather information in order to deliver individualised care. The first one is about the weekly routine of the person with dementia and their close family, in order to identify plausible opportunities of use. [Figure 6.22] The other exercise asks about how a perfect day and a bad day would be like for both the person diagnosed and the main family carer. The goal was to understand what is important for both: things they like and dislike doing, their interests and preferences, so that these were taken into consideration in design ideation. [Figure 6.23]

The insights of the previous meeting were confirmed and the "perfect day" exercise regarding Amelia pointed to the possibility of exploring tactile stimulation with textiles since she used to love knitting and lace making. Gabriel added that she always took care of laundry and clothes and, even today, if she sees clothes she likes to touch them. The idea of tactile stimulation was also associated with the researcher's observation of how

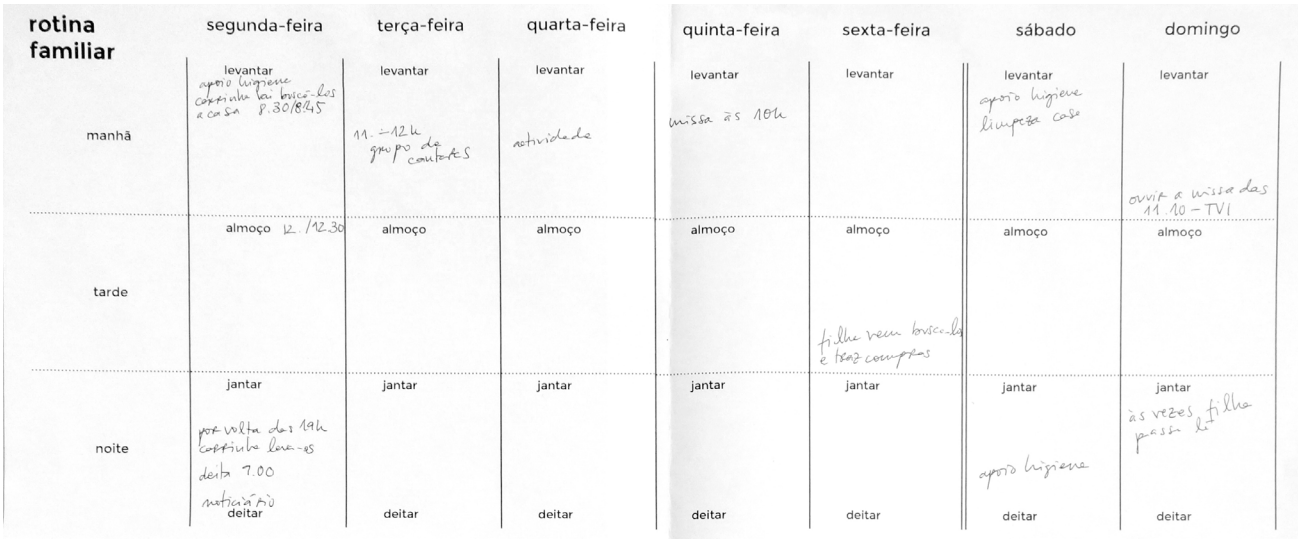


Figure 6.22 Amelia and Gabriel weekly routine exercise. This material served to note down details of the couple's weekly routine to find out possible opportunities for use. The couple attends the day centre every day, except for the weekend when they stay at home.

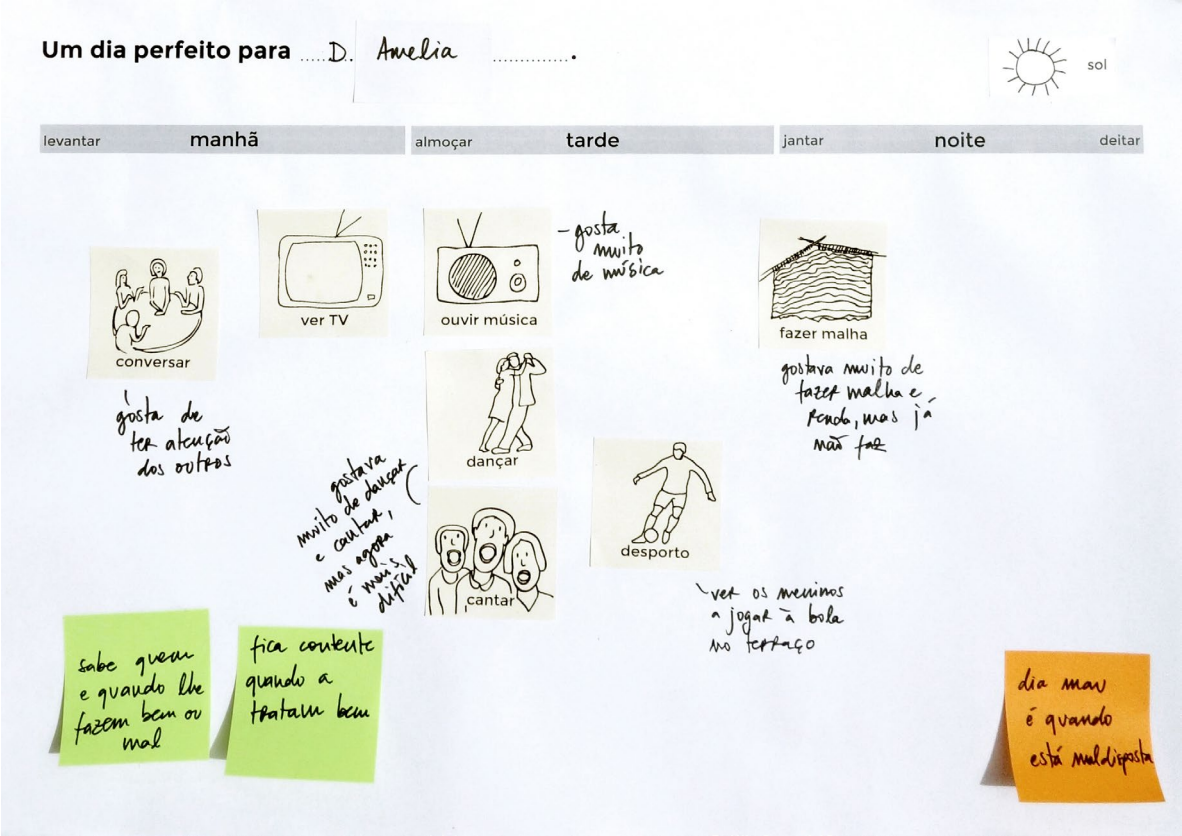


Figure 6.23 Amelia's perfect day exercise.

This exercise consists of planning a 'perfect day'. A set of questions helps to guide the exercise:

1. How is the weather like?
2. What do I do?
3. With whom?
4. Where am I?
5. What do I see?
6. What do I eat?
7. How do I feel?

Cues are provided to assist the response to questions 1 and 2, as well as blank cards for what people wish to add. The activities for the day are placed according to the daily moments, and the answers to the other questions are noted down around them, on the main page or on coloured post-its. The bad day exercise used the same materials but ended up being replaced only by an orange post-it. Since the perfect day exercise was already lengthy, and, in general, participants did not feel like thinking about a bad day and only referred some things they dislike.

In Amelia's case, the activities were placed randomly according to what Gabriel said she liked. Amelia likes having the attention from other people. She used to enjoy watching TV, she always loved to sing and dance, but Gabriel says it is more difficult now. However, she still enjoys music very much. When they are at home, she enjoys being at the window watching the children playing football in the backyard. She used to love knitting and lace-making but does not do it anymore. Amelia gets very happy when others treat her well, and despite her impairments, she is able to distinguish who cares for her or not.

Gabriel enjoys going to the day centre every day and spending the day with his friends. He enjoys watching the mass on TV, on Sunday. Sometimes, in the day centre, he is asked to bake cakes, which he loves due to his first job as a confectioner. He really enjoys to go on the tours that the day centre organises. In the evening, he enjoys watching the news on TV or reading the newspaper, and sometimes listening to the radio on his stereo. The fact that her wife is ill makes him very sad.

Amelia would take her hand and "explore it" tactually, pressing each finger one by one, and sometimes the whole hand.

Although Amelia was present, it was not possible for her to respond to the exercises, therefore Gabriel answered for both. These exercises were crucial to deepen the available knowledge about the couple and to give directions on how to start, but it was clear that if Amelia was to be engaged in the design process, it should not imply any verbal activities, but instead giving her things to try out and observe how she non-verbally reacted.

Development of an artefact for tactile stimulation using textiles

collaboration with fashion designer

Since the work with textiles is out of the field of expertise of the researcher, a fashion designer was invited to collaborate. To the proposal of designing an artefact for tactile stimulation that was aesthetically pleasing, adequate, and dignifying for a lady in her 70s, the fashion designer suggested that it could also have a useful purpose, serving as a piece of clothing.

giving Amelia fabric samples

Bearing in mind the difficulty of involving Amelia in activities that required verbal communication, we have started by giving her different fabric samples and observe how she reacted to them [Figure 6.24]. Amelia was entertained for nearly an hour in this activity. She was visibly happy, smiling and laughing at



Figure 6.24 Amelia sensing, moving and twisting different fabrics, and example of the notes of Amelia's reactions. Amelia's reactions were noted for each sample: how she touched them, moved them, fold them, with one hand, two hands, how she placed them on her legs, how she combined them, how long she kept them, if she didn't seem to care too much, if she grabbed it from the researcher's hand, etc.





Figure 6.25 Sample of the combination of different fabrics composed by same-size circles. This combination allows the different fabrics to be touched on both sides, even in a bigger piece, through the holes between the circles, enabling more exploration. The flat circles, permitting to clearly see each fabric, can also work as a visual stimulus namely if a bigger variety of fabrics is combined.

Figure 6.26 Sample of the other combination of different fabrics, using rings within a chain structure. This combination is visually more confusing, but has more movement if swung, possibly provoking a more synesthetic experience. The several rings allow fingers and hands to pass through them, as well as turning and twisting, prompting exploration.







Figure 6.27 Prototype using circles combination, intended to be worn as a shawl or as a blanket. If used as a shawl, most of the different fabrics were not reachable to Amelia's hands. Therefore, in order to provide a more active stimulation, it was better to use the prototype as a blanket.

times. Amelia seemed to have a preference for soft and warm fabrics, namely the ones with lighter colours. She would often join together two or more fabrics, and would spend some time feeling them and twisting them.

combination of fabric samples in two different ways

Drawing on this experience, the fashion designer suggested two ways of combining different fabrics that allow each material to be touched individually on both sides, using circles and using rings. These options were given to Amelia to try, who tactually explored both during some time, and seemed happy while doing it [Figures 6.25–26].

use of the shawl prototype

We have observed that, when seated, Amelia usually places her hands on her legs, and did the same with the fabrics. Therefore, a blanket or a shawl that reached her lap, which served both to make her warm and for stimulation, were thought to be the best option. A prototype was produced, using the circles combination, and was brought to Amelia. She looked tired on that day but engaged with touching the different fabrics of the prototype for a while. Having it on her lap made the various textures more accessible to her hands than having it on her back, as a shawl, where she would only reach the ends of the prototype [Figure 6.27].



Figure 6.28 New prototype using circles combination in a poncho. The circles were only included on the front of the piece, where Amelia's hands could reach them. We have included a bigger variety of fabrics, selecting those that have distinct textures on both sides, and colours, keeping them within a calm/ muted spectrum so that a relaxing stimulation can be provided.

Figure 6.29 Prototype using rings combination. With the purpose of promoting a more active stimulation, vivid colours were chosen for this piece.

[more about the use and the evaluation of these is provided in chapter 7]



6.2.3 Preliminary results—inclusive tactile emotions

In order to better, and externally, evaluate the work developed, the psychologist of the institution was consulted. In her opinion, focusing on a tactile stimulus for Amelia was appropriate and pertinent. The clinician valorised the prototype developed for promoting tactile stimulation that enables exploration and discovery, and for the possibility of being worn, offering involvement, comfort, warmness, which can induce positive emotions and the sensation of protection. In her words she highlighted such gains:

feedback from psychologist

shawl

> *"It seems to me that, in this way, you are able to offer the sensation of protection and warmth which is searched by people with dementia ... it seems able to become a facilitator of a more positive emotional environment. If we get warmer through our emotions, we are then more available to what surrounds us".*
> [the institution's psychologist, personal communication, March 16, 2016]

The ring combination was also appreciated for being more playful. It was suggested that both combinations can serve different stimulation moments, with distinct forms of use. The circle combination can promote a relaxing stimulation while the ring combination can provide more active one. Textures could be, in general, more varied, and soft and muted colours are adequate, namely in the case of the calmer circle combination. In the ring combination, more vivid colours could be used, but being aware of over-stimulation. The psychologist found the results adequate and not infantilised, aesthetically pleasing and attractive, stimulating and playful, suggesting that they could be tried with other people with advanced dementia. In addition, she valued the inclusion of Amelia in this process, referring that in the institution they have noticed that Amelia was more involved with the several things they use for stimulation, that she seems more confident, and that through that she started relating more with other people:

crocheted rings piece

about including Amelia in design process

> *"... now we notice much more involvement [of Amelia] with the diverse elements [for stimulation]. I think that we should attribute, or at least equate, that this is a result of your work with her. From this exploration, she starts feeling more confident, and she then starts looking for more, isn't it? ... and with this, she started to involve herself more with others".*
> [the institution's psychologist, personal communication, March 16, 2016]

These insights were embedded in further developments of two artefacts[8]. The comfort and warmness characteristics were enhanced in a new prototype, which evolved to a poncho with the circle combination of different textile textures at the front [Figure 6.28]. The ring combination was crocheted, since it allows other kinds of textures and could possibly trigger some reminiscence, and used more vivid colours for a more active stimulation [Figure 6.29].

further development of prototypes

Amelia wore the poncho for about an hour. She was well during this

poncho

[8 In the rest of this thesis, we refer these two artefacts as "the tactful things".]

time, always entertained touching the circles, passing from one circle to the other and feeling them on both sides, sometimes also putting her hands in between them. From time to time, she stopped with her hands and looked carefully at the circles.

crocheted rings piece

It was only possible to observe Amelia interaction with the crocheted ring combination for a short time, but she did explore the different textures in the ring. The fact that she offered resistance when the caregiver tried to take it from her hands is also a hint that she was probably enjoying it. Moreover, this piece, probably for the vivid colours but also for the strangeness and non-identifiable shape, aroused interest from other people in the room, who also wanted to play with it. Another lady was visibly enthusiastic about this piece and kept it and explored it for a while.

6.2.4 Discussion

involvement of people with dementia in the design process

Involving people with dementia in a participatory design process is challenging, not only due to their different experience of the world but also due to the methods used, which rely on the use of verbal and visual prompts, compromising their participation. Therefore, in order to include people with cognitive impairment, participation needs to be perceived more broadly, and processes need to be highly individualised and adjusted (Hendriks et al., 2015; Wallace et al., 2013). In this case, it was crucial to adopt a flexible and open attitude that accommodated the participants' needs and preferences, firstly to ensure a personalised brief and results, and secondly, so that the person with dementia and her carer could participate how they felt at ease. Also, knowing the couple beforehand, during the preliminary phase of this study facilitated their involvement and being comfortable with the researcher (McCarthy & Wright, 2015).

different roles of the two family members in their participation in the project

Since verbal communication was required, the initial approach and the two exercises were developed only with Gabriel, who shared his expertise in knowing, living and caring for Amelia. These valuable insights allowed us to grasp what is important to both, pointing directions to understand where to start and formulate a design brief. After this, it was possible to invite Amelia to participate in the process through developing activities that did not require any verbal communication. By these means, the design proposal emerged from experiences shared by Gabriel and from the non-verbal reactions of Amelia to the samples, both having a crucial influence on the design ideation and prototype development.

analysing and interpreting non-verbal data

As pointed out by Hendriks et al. (2015), one of the main challenges of involving people with cognitive impairments in the design process is how to analyse non-verbal data. It is difficult to evaluate whether the use of such tactile stimulus is beneficial for Amelia. She has demonstrated to engage with

tactually exploring the different fabrics, and she has shown signs of enjoyment, through smiles and laughing, and at the end of the first session, by suddenly standing up and hugging the researcher. Gabriel perceived it differently. He apologised for her wife, for not demonstrating more interest in samples and prototypes that were brought to her, thus preferring not to keep the prototype. Nonetheless, he always showed a willingness to participate and esteemed the company and attention given to the couple throughout the process. The comments and observation of the psychologist were crucial to understand the adequacy of the brief proposed, the importance of involving Amelia in the process, and the possibility that the results are not only relevant for her, but also for other people in similar stages of dementia.

6.3 Personalised participation

an approach to involve people with dementia and their families in a participatory design project[9]

6.3.1 Introduction

dementia

Dementia is a cluster of symptoms that gradually weakens cognitive functions, influencing the ability to perform daily tasks and living independently. This paper describes and discusses the configuration of participation and the first results of an on-going participatory design research project involving people with dementia and their families, as well as healthcare practitioners from the institutions that support these dyads. This study is part of a research project that explores how design can enable people with dementia and their social circle to codesign personalised strategies of communication, with a special focus on leisure and entertainment, as a means to build and maintain social relationships. It is a practice-based project that follows a research *through* design approach (Jonas, 2007) using design practice as a method of inquiry, and it draws from the exemplary design research proposed by Brandt et al. (2011).

methodological approach

This research is influenced by person-centred dementia care values, which become the primary drivers for the design process and outcomes. The personalisation of several aspects of the codesign project is deemed crucial to make participation happen. We discuss the importance of such personalised approach and its potential contribution to a broader participatory design context.

6.3.2 Why personalisation?

person-centred dementia care and personhood

Person-centred dementia care "encompasses all those ways of working that consider men and women with all their individual strengths and vulnerabilities, and sees their dementia as part of that picture rather than defining their identity" (Brooker, 2007, p. 47). The valorisation of the person despite their age or ability, the respect for their uniqueness through an individual approach, the effort to understand the world from their perspective, and the promotion of relationships and vivid social environments are the central efforts of person-centred dementia care. These are explained and associated with the concept of *personhood*, defined by Kitwood (1997) as a relational sense of self that is conveyed by others.

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reasons for personalisation

In this project, personalisation is seen as a way of attending to the uniqueness and personhood of people with dementia and providing opportunities for meaningful communication, so that social relationships are maintained. Artefacts can be personalised with content that is relevant to the individuals with dementia and their social circle, with the hope of making it more engaging. In this context, personalising can constitute an opportunity for the person with dementia to exercise control and choice, through selecting content and codesigning an artefact, and simultaneously allow family members to reflect upon and understand their relative while being involved in a collective activity. Therefore, two distinct strategies were devised to embrace personalisation in the design of leisure artefacts: people with dementia and their families were invited to collaborate (1) in personalising the content of open artefacts or (2) in defining a personalised brief for the development of new artefacts.

personalisation strategies

focus on family relationships

The focus on family relationships is pertinent due to the immense impact dementia has on family functioning, both in the communication system and in dealing with caregiving burden (S. H. Zarit & Zarit, 2008). Moreover, all families are also unique, with their own characteristics, strengths, issues and needs, which become a part of one's sense of self. Family members and close friends are usually the ones who know the person better, and with whom they have shared their lives. Therefore, their involvement is crucial to read and provide cues about certain behaviours, as well as to keep the person's narrative and provide valuable content that might be helpful in engaging with their loved one (Zeisel, 2009). This project aims to enable families to use the knowledge they already have, in order to include their relative with dementia in collective, entertaining and stimulating moments.

6.3.3 Designing for uniqueness

personalisation as a way to negotiate design and use

As explained earlier, personalisation is used as a strategy to design in consideration of the uniqueness of participants. The idea of personalisation, whether through defining a new brief or personalising open artefacts, challenges the typical relationship between design/designers and use/users, where "first designers design, then users use" (Redström, 2012, p. 83). It asks users to participate in the definition of use and design at different moments of the design process. Also, it requires the designer to mediate and support this participation throughout the process, where the two personalisation strategies represent different forms of negotiating use and design. Redström (2008) presents two ways of involving users in the "definition of use through use".

definitions of use through use

'*Use' before use* refers to when use is tried, tested and opened up for definition during the design process, ahead of real use. Another possibility, '*design' after design*, is to leave artefacts open, unfinished and undetermined, so that they

allow different options for use to be developed through use, giving origin to a new design through appropriation (Redström, 2008).

appropriation and infrastructuring

The design of open artefacts demands a balance between how much can be designed and how much can be left open to enable response and personalisation from the participants. Ehn (2008) reflects on how design can support appropriation and relates the mediation between acts of design and acts of use inherent to appropriation and design for appropriation to the notion of *infrastructuring*. The same is described by Star and Bowker (2006) as a relational 'socio-material public thing', which is a flexible and open structure that supports many uses without the need to be reinvented all the time. In this way, "a process of design thus is not to impose closure but to allow for everyday life to carry on" which demands "*flexibility*, *foresight* and *imagination* within processes and practices of designing" (Ingold cited in Gunn & Donovan, 2012, p. 1).

importance of doing participatory design with people with dementia

Participatory design becomes vital to this project, not only to explore how design briefs and artefacts can be personalised, but primarily because it also constitutes an opportunity to include people with dementia as actors in the personalisation process. Dementia symptoms progressively hinder independence and autonomy and interfere with people's ability to participate in several aspects of their own life. Using participatory design and its democratising values in a context of dementia becomes an attempt to compensate for this tendency, looking for ways to involve people with dementia as much as possible, in a respectful and ethical manner. Additionally, significant people in their circle of care are also included in the process. Firstly, due to the aim of the project relating to the connectedness between people with dementia and their family; and secondly, because it is important to involve relatives to stimulate conversation and provide support in the activities (Hendriks et al., 2013). The clinicians are also relevant in this process to assess the feasibility of the proposed activities and occasionally assisting them. Therefore, through this process, the designer, persons with dementia, their family members and the clinicians are brought together as team members.

inclusion of people in circle of care in participatory design and different roles they can have

6.3.4 Open artefacts for people with dementia

previous work (book and cards-about-what-matters)

observational study and board game developement

To contextualise the current work, it is important to mention some influential preliminary studies. The potential of designing artefacts that can be personalised was identified in previous research, where two tools for communication were designed based on the researcher's first-hand experience with two grandparents diagnosed with Alzheimer's disease (Branco, 2014). These were a personalised book, and a set of personalised cards [cards-about-what-matters]. [Figures 6.1–6.3, p. 146]

Subsequently, the preliminary phase of this research project consisted of observation and participation in the activity sessions with people with

dementia in two different care facilities. This study culminated in the development of a board game that incorporates characteristics, activities and tasks of the observed institutional sessions. The aim was to take home some of the activities undertaken in the institutions, providing an opportunity for the families to involve their relative with dementia in a collective moment, based on storytelling (about personal preferences and life events), affection (smiling, hugging, shaking hands) and simple challenges (e.g. singing, completing proverbs, drawing for others to guess) (Branco, Quental, & Ribeiro, 2015a). The game uses a spiral structure similar to the classic *goose game*, where each stop corresponds to an activity. These are organised according to the calendar year, where annual events act as triggers to share stories. People with dementia and care staff participated in defining and making this board game, which was offered to the clients' families of one of the institutions. Although only one general board game was developed at this point, the possibility for it to be personalised was envisaged. [Figure 6.4, p.147]

The referred observational study also provided valuable practical and sensible learning that was included in the set-up and development of participatory activities. These considerations related to the structure of institutional activity sessions, the exercises, the materials used to facilitate participation in such activities, and a flexible, positive and warm attitude (Branco, Quental, & Ribeiro, 2015b). Additionally, the preliminary study contributed to an enhanced understanding of, and sensibility, to the different experiences of people with dementia, and a growth in the awareness of ethical values consistent with those advocated by person-centred dementia care practices (Branco, Quental, & Ribeiro, 2015a). Another significant insight was that, despite everyone's different rhythm and active or passive participation, people with dementia enjoyed being included in institutional activities mainly because they felt occupied and were engaged in making things together.

6.3.5 Configuration of participation

Person-centred values

empathy, ethics and person-centred dementia care values

Being aware of the challenges of including people with dementia in a participatory design process (Hendriks et al., 2014), this research uses an empathic attitude (Lindsay et al., 2012), and conducts work individually with each participant (Hendriks et al., 2015; Wallace et al., 2013). Ethical principles are taken into consideration to ensure that the personhood of people with dementia is maintained in research (Cowdell, 2006) protecting them from anxiety and stressful situations, respecting their needs and being aware of potential paternalistic attitudes, with a view to embed the values of person-centred dementia care. These values, centred on the person and his/her relationships (Brooker, 2007), became the main drivers for

configuring participation (Iversen et al., 2012). Firstly, people with dementia are valued as individuals regardless of age and ability. Therefore, this research welcomes everyone to participate, independent of the person's capacities and progression of dementia. It includes people with different experiences of dementia and adjusts the process accordingly, analysing and reflecting on the adapted participatory processes. Secondly, person-centred care advocates an individualised approach that appreciates the uniqueness of each person while trying to understand his or her perspective of the world. Likewise, an open attitude and flexible strategy are used to deliver a personalised approach by accommodating people's perspectives, needs, and preferences and supporting different forms of participation, within the aims of the project. Lastly, person-centred care promotes rich social environments so that personhood is supported and maintained. Accordingly, there is an effort to create benefit for participants to make sure that participation is indeed enjoyed, and that it is of worth to all involved in the process.

Participatory moments

Initial plan for participatory process

In order to explore the two personalisation strategies mentioned before, as well as to facilitate family involvement and gradually build up participation, the initial work plan was divided into three main moments: (1) a feedback moment to try the game, or comment and choose the artefacts to personalise; (2) the personalisation of the selected artefacts and (3) the codesign of a new personalised communication strategy. The personalisation of the previously designed open artefacts (the card game [cards-about-what-matters], the family book and the board game) was the starting point to invite families to participate in this project, so that these ideas could be experimented with more people, and to understand whether these artefacts could be made accessible to others if they allowed personalisation to a certain degree. Later on, participants were invited to take part in a codesign process for devising communication strategies together, based on their specific needs and preferences.

This process, consisting of several moments where persons with dementia and their families were brought together to make something collaboratively, is also an outcome of the project since it sought to provide warm and pleasurable moments of togetherness and eventually added emotional and affective value to the artefacts. Each meeting was planned and adapted according to the structure of the observed activity sessions (Branco et al., 2015b).

Participatory tools

Traditional participatory design tools are too demanding for people with dementia, since they are known to have problems with abstract thinking, memory, understanding visual and imaginary items, following conversations and discussions, keeping focused, and making decisions and since some

people even have difficulties communicating verbally (Hendriks et al., 2014). The decision to use already designed tangible artefacts (good quality prototypes) that participants could engage with, comment and react to, was also a strategy to deal with these difficulties, in order to avoid the discussion on concepts and abstract ideas. Questions were focused on people's experiences and views and were always formulated so that participants with dementia would not feel they were being tested. To facilitate the sharing of experiences, some exercises used words and images as cues to help to recognise possible answers or to serve as prompts for answers, thereby detouring situations that could confront or frustrate the person with dementia for not remembering or not being able to find right words. Since most meetings involved families, the relatives were encouraged to support the participation of the person with dementia, which was also done by the researcher. Exercises observed in the institutional activities, such as drawing or making collages, were also favoured. Legibility and accessibility were taken into account in all the materials, ensuring that language was kept simple and clear to understand, as well as expressed in a friendly manner. In the same way, graphic details, such as type size and font, graphic layout, contrast and choice of colours, were taken into consideration to facilitate reading and to convey an affable look.

adjustments to participatory activities and tools to include people with dementia

6.3.6 Participatory work with families

> this section is similar and more detailed in 6.1.5

Invitation and project introduction

recruiting

The families were initially approached by the clinicians of the two institutions, based on their possible interest and availability in taking part in the project, and on how they could benefit from it. Later on, some families voluntarily showed interest in participating, after a presentation of the project at a local *Memory Cafe*. Even though we only approached the families that revealed some interest in participating and authorised being contacted, people were not readily available to take part in the project. Fourteen families were invited to participate, from which six did not follow up.

project presentation

The project was introduced through a small booklet offered to every participating family as a complement to the consent form. The booklet was specially produced for the families to keep and consult at any time and included detailed information about the project, the research team, previous related work, the collaboration with the two institutions and the work plan for the feedback and personalisation moments. It was carefully written and designed in a simple and friendly way so that it could also be accessible for (at least some) people with dementia [Figure 6.5, p.150]. The project was always presented without the reference to the words *Alzheimer's disease* or *dementia*. The decision to do so was based on the ethical intention to not

confront people with their difficulties and diagnosis and to focus on shared abilities rather than on problems. Therefore, the explanation of the project concentrated on the main aim to contribute to the communication and relationships between different generations within a family, through the development of personalised leisure artefacts. This decision seemed to have left participants at ease and centred the attention on the collective activity rather than on difficulties inherent to the condition.

First participatory moment: feedback

Since some of the participant families had already received the board game, they were invited to play it with the researcher. The intention was to understand how participants played and interpreted the game, how they reacted to the several activities proposed and how they interacted with each other. Participants were then enquired about how they felt while playing the game and were asked to characterise the experience by using a redesigned semantic differential, which consisted of several cards with adjectives (positive and negative). [Figure 6.7, p. 150] Participants were required to choose the ones they would associate most with the game and to place them on a scale of intensity, ranging from 'a little bit', 'rather' or 'very'. All participants with dementia, including a person in moderate to advanced stage of progression, were able to understand the exercise, contribute with at least one adjective and choose its intensity. Afterwards, they were asked about their overall opinion about the game and its activities and elements, and how they could personalise the game: what they would change and what personal interests, themes, stories or important events could be included to make it 'their' game and were consequently required to write everything down on specific cards. [Figure 6.8, p.151] These exercises seemed more demanding for the persons with dementia, although all of them contributed with their thoughts with the help of the family member(s).

semantic differential

other activities in feedback moment

With the families who did not receive the board game, the three designed open artefacts—the book, the card game [cards-about-what-matters] and the board game—were shown and explained to the participants. Thereafter, they were asked to write down their views on each artefact, and whether they would use them and why. Participants were invited to select one or more artefacts, and to think how they could be personalised for their family. [Figure 6.9, p.151] This approach provided the participants with an opportunity to choose the more appropriate and preferred artefact(s). However, this set-up seemed inadequate for people with dementia and was not used if the person with dementia was present. On the one hand, even though the artefacts were physically shown, there was still the need for imagining its use, which might have made it difficult for the person with dementia to comment on them. On the other hand, since they were also asked to justify why they would use the artefacts or not, this ended up, at times, highlighting

showing and commenting on an artefact, without using, was found inadequate for person with dementia—better to play/make something during participatory design activities

and confronting the person with dementia with some of his/her difficulties. Nevertheless, this set-up did not raise any issues in the three cases where the meeting happened without the person with dementia (either it was not possible to have the person present, or it was on upon request of the family members). Instead, it generated significant insights about the three artefacts.

Second participatory moment: personalisation of artefacts

In the personalisation moment, families were asked to contribute with content to adapt and personalise the chosen artefacts. In the case of the board game, it was suggested that the game structure could be seen as a blank space for families to personalise according to their preferences. Following that, the families were challenged to make it together (as in the case of the group activities observed in the institutions), for example, by illustrating the game stops as a collective activity. As a result of this second moment, five artefacts (four board games and one set of cards [cards-about-what-matters]) were personalised by four families. [Figure 6.10–6.13, pp.152–153]

Although we have envisaged some aspects of the process to be adapted to suit the participants, eventually every family defined their participation in the design process. As soon as we became aware of the complexity of people's availabilities and preferences (mainly due to the logistics of caring for someone with dementia, along with unavailability and emotional reasons), an effort was made to set the process as open as possible to let participants take control of it, while maintaining the main aims of the project and its planned activities.

Third participatory moment: codesigning new strategies

In the feedback moment, two families did not find any of the three artefacts relevant in their cases. Consequently, these two families were invited to codesign a leisure communication strategy, in accordance with their particular needs and preferences. In this way, the codesign moment became an alternative for the personalisation moment, rather than coming after it, as initially planned. Considering the general lack of availability of most of the family members, this unforeseen adjustment was found to be more appropriate than the original configuration, which would have been too lengthy and exigent for the families.

Drawing on the *person-centred thinking tools* used by dementia services to gather information for delivering individualised care (Bailey & Sanderson, 2013), two exercises were created to support the definition of the design brief: (1) about the weekly routine of the persons with dementia and their close family, so that plausible opportunities of use could be identified [Figures 6.14, p.154 & 6.22, p.167]; and (2) about how a good day and a bad day would be like for both the person diagnosed and the main family carer, in order to understand what is important for both (things they like and dislike doing, interests and preferences) and for taking into consideration in eventual design ideation. [Figures 6.15, p.155 & 6.23, p.168]

good day and weekly routine exercises

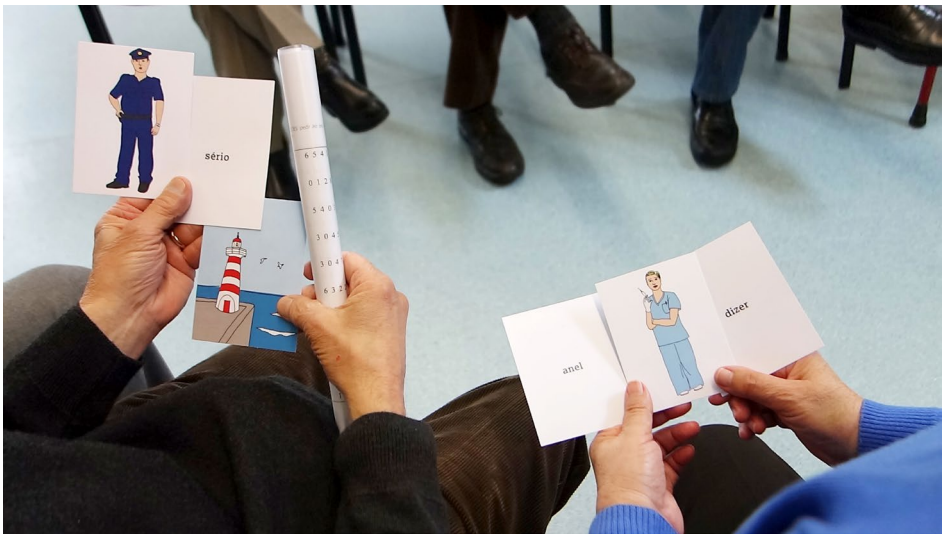


Figure 6.30
Storytelling card game [story-making card game]: The game is composed of cards of five different categories: characters and places, represented by images, and written verbs, adjectives and things. The aim is to combine words and images to trigger stories and create new ones.

results and consequent development of artefacts

Participants comprehensively shared their experiences and responded to these exercises in great detail, producing insights that deeply influenced the design ideation, which were embedded in the proposals developed. As a result, this process gave origin to two proposals. In the case of a female participant with advanced dementia, artefacts for sensorial stimulation were designed for entertaining her during weekend afternoons, when her main carer did not have enough support. [Figures 6.28–29, p.172] The experiences shared by the other family suggested to designing an artefact that avoided testing memory and focused on a single specific theme, due to the lack of common interests among the family members. The artefact was required to be based on creativity, interpretation and humour and would not take too much time to use. This set of characteristics led to the development of a card game [story-making card game] consisting of words and images that could be combined freely, or randomly to create and tell stories.[10] [Figure 6.30]

> this section is similar and has less examples than in 6.1.6

6.3.7 Personalisation of use, design and participation

In this research, personalisation is an invitation to collaborate in the project and a means to develop meaningful and adequate leisure artefacts that mediate moments of togetherness for people with dementia and their social circle. The project was left open in different ways: participants were invited to personalise the artefacts or the design brief; and since we used a flexible approach to accommodate people's availabilities and preferences to allow their participation, participants also personalised the process. For instance, the process of personalising the board game was very different in the case of each

[10 A more detailed and systematised description about the design decisions, use and evaluation of the story-making card game is provided in chapter 7]

of the four families. Therefore, participants were not only active in defining use and design but also in configuring their participation in the project.

Drawing upon Redström's (2008) "definitions of use through use" and on Ehn's (2008) ideas on *infrastructuring*, we analysed the participation of the families in the personalisation of the different aspects of the project, as well as the individual roles of the persons with dementia and their family members, also by reflecting on their contributions to an understanding of how to design for personalisation in the context of dementia.

reflection on how use before use and design after design approaches intertwined

With the two families with whom a new brief was defined, a *'use' before use* approach was used, where the participants were invited to define a possible use, supported by the proposed exercises. The design proposals emerged from the direct accounts and experiences shared by the participants. Afterwards, through presenting physical mock-ups, use was gradually redefined by the participants with dementia, through observing their interaction with the prototypes provided. In the case of the person with advanced dementia, she was not able to contribute to the initial definition of use, so this was negotiated with her carer, but whenever there was something physical and tangible that she could react to, she contributed non-verbally.

The families who personalised the artefacts contributed differently to the definitions of use, and this becomes more complex and intricate since it intertwines *'use' before use* with *'design' after design* approaches. Influenced by observing and interacting with people with dementia, the artefacts were designed and left undetermined and open for personalising *after design*. Here, the aim was also to understand, accompany and observe the definitions of use and design after design, in order to learn how to further enhance this process of personalising. Therefore, *'use' before use* was utilised to support *'design' after design*, giving insights on possibilities and patterns of use and contributing to attaining a possible meaning for *infrastructure*.

The several ways in which the project was open in terms of artefacts, design brief and process, make us believe that people with dementia, irrespective of the stage of progression, can contribute to definitions of *'use' before use* and *'design' after design* when supported by their social circle and researchers. Depending on their ability to understand and verbally communicate, a *'use' before use* approach might need to start with their carers, to point out directions for shaping a physical mock-up that can be experimented with the persons with dementia. In doing so, the learning from observing their reactions contributes to the iterative process. In a *'design' after design* approach, the process happens inversely. Even if it requires adaptations and personal elements which will eventually need more input from family members, having already a design that can be used facilitates the engagement of people with dementia in the process and enables their participation from the beginning. In this way, use and design, and also participation, were in constant negotiation with the participants, making their involvement possible and engaging people with dementia and

their families on their own terms. This individualised involvement, important for dealing with different people with various abilities and experiences of dementia, was a way to work towards meaningful outcomes that embedded the participants' idiosyncrasies. It supported different forms of participation at different moments in the process, through responding to the participants' preferences and needs, with an effort to turn participatory moments pleasurable for all. Therefore, activities that involved making or doing something together were favoured. These were assisted by materials carefully designed in a simple way to convey a friendly and warm attitude, both in appearance and in language, that aimed to facilitate participation, specifically by using cues.

6.3.8 Personalised participation: attending to the uniqueness of participants

"theory inspired design"

This personalised approach to participatory design entails an effort to respect, dignify and celebrate people, motivated and influenced by the context of dementia. Inspired by dementia care literature, we sought to work with and translate the core person-centred values and practices to the participatory processes and design outcomes, similar to what Hassenzahl (2010) proposes as "theory-inspired design". In parallel, it was invaluable to allow some time to get closer and be immersed in institutional contexts before involving people in activities. The encounters with several individuals with dementia and the observation of the work of healthcare professionals became a crucial point of learning that contributed to an enhanced sensibility and understanding; in addition, it contributed to a continuous ethical awareness that was essential for applying the personalised approach in practice, with individuals with such a demanding condition.

importance of observation

empathy and aesthetics

In this approach, people with dementia are not merely an object of study; instead, they are invited to be at the centre of the project together with their families, bringing their voices and their stories. Empathy becomes crucial to respect and relate to every person in order to avoid possibly stigmatising situations and results. Aesthetics also plays a major role in this approach, as a means to dignify people through artefacts that are appreciated and appropriate, and to give emphasis to the perception through the senses, which gets gradually heightened in people with dementia (Hughes, 2014).

views on participation

In a contemporary landscape where participation seems to be promoted and facilitated (Hyysalo, Jensen, & Oudshoorn, 2016), this approach aims to make participation possible for people who are increasingly prevented from being involved in several aspects of their life as a consequence of a dementia diagnosis. With a profound concern for the maintenance and respect of their personhood, we believe that actions such as bringing people with dementia to participate in a project, not making assumptions about their

preferences, and adapting the process to facilitate their participation, are ways of valuing them and their contributions. However, we are also careful not to 'force' participation, by being open and flexible about how people would like to, and can, participate. Different forms of participation are considered and valued, including non-verbal participation. In this case, participation is also cocreated, demanding the researcher/designer to respond and support these different forms of participation.

conviviality

The focus of this kind of participant involvement is the promotion of conviviality, which is described by Illich (1973) as "freedom realised in personal interdependence and, as such, an intrinsic ethical value" (p. 24).[11] In this way, the participatory process becomes a sequence of conviviality moments, where people are invited to play and share, in a bid to celebrate their personhood and what is meaningful to them, and as opportunities to communicate and connect with each other.

negotiation, flexibility and sensibility to deal with unpredictability

Dealing with vulnerable people has impelled us to think carefully about how to make participation happen in a respectful, ethical and empathic way, how materials can be redesigned and, considering the uniqueness of each family, how the process can be pleasurable and convivial, and open enough for participants to personalise their participation. While this approach to personalisation emerged from the specificity of working with people with dementia and their families, we contend that this approach might also be pertinent for other projects and targets (for which the aim is a deep engagement with people's values and history especially people in demanding situations or special needs), since it challenges the traditional roles of designers and users, as well as researchers and participants, to leave open the configuration of participation within the design process. It challenges the designer/researcher to offer different possibilities to design, use and participate, and manage the inherent unpredictability of each design situation. Working in this way requires a broad view of participation, along with flexibility and sensibility to deal with and interpret different kinds of contributions and unexpected results from participants and responding accordingly as researchers and designers. In our case, such openness was achieved by setting the project goals clearly from the beginning as structural elements of the process, as a (material and immaterial) *infrastructure* capable of being continuously configured. In this way, participants participate not only with their views and contributions, but also take part in the configuration of their own participation.

[11 Illich (1973) presented this concept of conviviality and convivial tools to criticise and contrast the dominant industrial productivity. Although this more sociological and philosophical account goes beyond the scope of this research and thesis, and thus we do not refer much to Illich's work, we subscribe to his ideas that give priority to a free and creative relationship among people and with what surrounds them, thus this personalised participation approach: "People need not only to obtain things, they need above all the freedom to make things among which they can live, or give shape to them according to their own tastes, and to put them to use in caring for and about others." (p. 24).]

7 Open artefacts
experiences of use and personalisation

So far, we have focused on describing and reflecting on the participatory and codesign processes involving people with dementia, their families, and healthcare professionals. In this chapter, we will focus on the outputs of such processes. Although the artefacts resulting from the work developed were already presented as they were emerging, here we bring them together in a conjoint manner. In order to make this analysis, family members and healthcare professionals were interviewed in a final evaluation moment about the artefacts they codesigned and used, and about their experience of participation. All created and personalised artefacts—the cards-about-what-matters, the board game, the story-making card game, and the tactful things—are examined: how they were used, how participants responded to them throughout the process, and how they were evaluated retrospectively. Firstly, we describe how evaluation was configured and undertaken during the project, and more specifically in the final evaluation moment. Furthermore, each artefact is presented separately, following a similar structure. In addition, the participants' experiences of personalisation and participation are also outlined. We finalise with a general analysis of the artefacts, similarly to the annotated portfolios suggested by Gaver and Bowers (2012), and the main conclusions that emerged from the evaluation.

This evaluation provided relevant insights concerning how to design more carefully for people with dementia, and how to involve them in this process, as well as a specific set of learnings for the further development of this project, and the possibility of making these artefacts and processes available to a wider range of people, which might be pertinent to design practitioners and researchers working with people with dementia. Moreover, this evaluation might also provide important considerations for healthcare professionals, namely regarding the development and choice of materials to mediate interaction with people with dementia. Additionally, the several aspects of the communication and possibilities of use of these materials that were highlighted by participants are crucial for possible future developments of this research project.

7.1 Configuration of evaluation

Evaluation was conducted in several moments throughout the whole doctoral process: (1) the feedback gathered from families at the beginning of the participatory work, (2) the constant reactions to the product during the iterative process, and (3) a final summative evaluation from participants and healthcare experts involved in the project.

7.1.1 Use and feedback with families

Initially, as described in chapter 6, participants were invited to use and provide feedback on already designed open artefacts (the personalised book, the cards-about-what-matters, and the board game), reflecting on their experience of use, the adequacy and pertinence of those artefacts for their family, and making suggestions on how they could be improved and personalised to their own circumstances.

7.1.2 Assessment during iterative design process

different roles of participants in evaluation during the design process

There was also a constant assessment during the iterative design process, both in the cases where artefacts were being personalised and in those designed from scratch. This assessment involved everyone participating in the project in different ways, varying in each artefact and with each family. In general (1) the person with dementia reacted to participatory activities, mock-ups, prototypes, and when possible, gave verbal feedback on the experience of use. The (2) family members had different contributions, which depended on how they decided to participate. Whenever families took a more active role in the personalisation of artefacts, they gave feedback on the proposed activities for personalisation and adapted them to suit their preferences and availabilities; they made suggestions for improving and personalising the artefacts, but also asked for recommendations and contributions of the researcher (for instance, to make different proposals of game dynamics, or to make illustrations); and they participated in making their own prototype. Other families had a less active participation. Essentially, they gave feedback to the researcher's proposals regarding artefacts and participatory activities with their relative with dementia, and on their experience of using prototypes. The (3) healthcare professionals made important critiques to the artefacts as they were being developed, calling attention to aspects of the mock-ups and prototypes that should be enhanced, suggesting changes, observing use and giving feedback, indicating other potential ways of use and trying them in the institutions. They also contributed to the refinement of participatory activities involving people with dementia, and many times, also assisted them. The (4) research team

contributed to the improvement of the whole process involving people with dementia and their families, to make it more adequate and viable, constantly feeding back on the researcher's activities. Finally, (5) the main researcher (PhD candidate) inevitably had a major part in this process, observing and taking notes on the use and reactions of people with dementia to the proposed activities, mock-ups and prototypes, asking for the evaluation of all actors in this process, and weaving them in the design process and designed artefacts.

7.1.3 Evaluation of final artefacts

When the final artefacts were given to the families, two evaluation moments were planned. The first one consisted of the participants' assessment of the first use of the artefacts. Families were asked to take some pictures and register their thoughts about their experience of using the artefacts. This was a way to allow participants to evaluate the artefacts in their own terms, in their context, and without the presence of the researcher. The idea was also to use these results as a support for the final evaluation moment:

> Presenting users' information back to them not only gives additional insight for evaluation, it also can stimulate new reflection and interpretation among users and gives them a license to participate in the evaluation of a system as well as its interpretation (Sengers & Gaver, 2006, p. 105)

However, no results returned from this proposal. Family members have referred not being natural for them to do it, and in result, they forgot the task when using the artefacts. The second and final evaluation was more comprehensive and took place about six months to one year after the artefacts were delivered. To reflect on and define this final evaluation the "questions for PD evaluation"[1] put forward by Bossen, Dindler and Iversen (2016) were considered.

What is the purpose of the evaluation?

The final evaluation had a summative purpose and intended to understand the participants' perceptions of the value of this research and possible future developments. The aim was also to test and gain new knowledge about our proposal to translate the psychology concepts of personhood and Positive Person Work into design [chapter 5], and overall contributions and conclusions of this study.

Since one of the aims of this research was to facilitate the participation of people living with dementia and their social circle, the participatory design process was also considered an outcome of this project. Even though the participatory process was addressed in the evaluation, (and since this is

1 Although Bossen et al. (2016) propose seven questions, here we opted to focus on the first five. We addressed the other two (*Who is the intended audience of the evaluation?* and *What is the intended use?*) together in this chapter's introduction, to provide a more natural flow of the text.

a practice-based, research through design project) we opted to emphasise the evaluation of the outputs, the artefacts.

The summative evaluation was also a way to find answers for the research question:

> How does the personalisation of artefacts contribute to meaningful communication between people with dementia and their social circle?

This question concerns both the process of personalising and the personalised outputs, and their potential to create opportunities for meaningful communication with people with dementia. Therefore, with this evaluation moment we sought to understand: (1) how these artefacts were **used**; (2) the **value** of these artefacts for participants, and for healthcare professionals; (3) the **experience of participating** in this project; (4) how the process and personalised artefacts contribute to the creation of opportunities for **communication and meaningful moments**; (5) the relevance of **personalisation**.

evaluation scope

Another purpose of the evaluation regards the values related to person-centred care and the maintenance of **personhood** that were taken into consideration in the design of the artefacts and in the configuration of the participatory design process. We were interested in understanding how these values were perceived and associated to the artefacts, which is connected to the research question:

> How can artefacts be designed so that the personhood of people with dementia is maintained and respected?

Who conducts the evaluation?

The evaluation moment was organised by the research team and carried out by the main researcher, in order to learn about the families' and healthcare professionals' views and judgement of several aspects of the project. However, we did not directly evaluate the participants' use of artefacts in their own context; instead, this moment was created to understand the participants' experience with the artefacts (qualitative approach), and to facilitate their own evaluation.

Who participates in the evaluation?

decision to not include participants with dementia in the final evaluation

Ideally, in this evaluation, we wanted to involve everyone that took part in the project. Nevertheless, asking the persons with dementia to participate in this evaluation moment raised several concerns related to the memory problems of all participants with dementia, the lack of verbal communication in some cases, and the risk of confronting the person with their own difficulties (for instance if they did not remember using the artefacts or participating in the project), namely if in the presence of family members (that could, for instance, refer to the person's difficulties in using the artefact). One possible option would have been to invite participants to use the artefacts in the presence of the researcher so that the reactions and observed used counted as evaluation of the artefacts. However, since the aim was to have an evaluation from participants on how

artefacts were used in a family context, this setting would not be natural. In addition, the researcher had already tried all the artefacts: some in a family context, in the first meeting; and others in institutional context supported by healthcare professionals. Therefore, we found more appropriate not to include the participants with dementia in this final evaluation moment, opting to meet family members and healthcare professionals only. In this way, family members could also be at ease to share their experiences of using the artefacts more openly, referring to their difficulties, and to issues related to their relative's disease, without the risk of confronting them.

healthcare professionals involved in evaluation

As far as healthcare experts are concerned, we contacted three professionals who were more intensely involved from the early beginning and throughout the whole process, asking them specifically about each artefact, but also about the project in general, and about their participation. In addition, we also included other healthcare professionals that participated sporadically in the project, by assisting the development or facilitating the use of some artefacts in the institutions.

Who defines the evaluation criteria?

personalised evaluation

The evaluation criteria were not a priori defined. Instead, they were co-determined with participants in each interview, corresponding to each specific situation. Although the research team decided a set of evaluation guidelines that pointed directions for criteria to be delineated, the degree of success was defined by each interviewee, and differed according to each person with dementia involved, the progression of their diagnosis, the setting where the artefacts were used and the perception and sensitivity of family members and healthcare professionals.

This variability of evaluation criteria is consistent with the open-ended generative design approach, that responds to participants' needs, preferences and idiosyncrasies in a personalised way [chapter 2 & 6]. Therefore, since process and outputs were personalised, the criteria to evaluate them had also to be particularised to each situation.

> Explicitly recognizing the legitimacy of multiple interpretations has fundamental implications both for the *process* of design, and its *accountability* (evaluation). Design shifts from deciding on and communicating an interpretation to supporting and intervening in the processes of designer, system, user, and community meaning-making. Evaluation shifts from determining whether an authoritative interpretation was successfully communicated to identifying, coordinating, stimulating, and analyzing processes of interpretation in practice. (Sengers & Gaver, 2006, p. 106)

What evaluation methods are applied?

Semi-structured interviews were conducted individually with at least one member of the six participating families, and with eight healthcare

professionals. This type of interview was chosen to ensure some focus on the defined scope of the evaluation, but also to give some space for participants to bring new interpretations, ideas and themes.

structure of interviews

All interviews, planned not to exceed much more than an hour, followed a similar structure related to the evaluation purposes, but slightly adapted to each interviewee, depending on how they took part in the project and which artefact they used. There were three main interview scripts: for the family members, focusing on their family's specific experience of use and participation in the project; for the healthcare professionals, addressing every individual artefact and a more general overview of the project; and another for those healthcare professionals who participated occasionally to try some of the products, thus making a deeper analysis and focusing on the peculiarities of the artefacts used. In general, all interviewees were asked to describe the moment(s) of use, how they felt about it and what reactions were observed in the person(s) with dementia when using the artefact(s). They were questioned about the artefacts' qualities and potential, whether the materials mediated communication and interaction and if personalisation was important to ensure this.

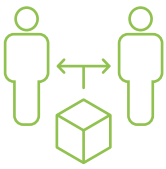




Figure 7.1
The Positive Person Work evaluation exercise

Interviewees were solicited to respond to a card exercise regarding the Positive Person Work interactions [chapter 5]. Each card contained one interaction and our design redefinition of them. Interviewees were invited to select the interaction-cards they associated with the artefact and to explain their choice. In addition, all healthcare professionals were asked to reflect in which ways the artefacts mediate these interactions. Three options were given (related to reflections made in chapter 5): (1) the artefact as direct *catalyst* of the interaction with the person with dementia; (2) the artefact as *support* for the carers to deliver the interaction; (3) the artefact as *symbol* of the values inherent to the interactions. Since this second part of the exercise was more complex and involved a deeper analysis, thus also requiring more time, it was only undertaken with the healthcare professionals. Although the sample was not large enough to draw specific conclusions, these exercises served as a basis for discussing and reflecting on the association between Positive Person Work and the design of artefacts for and with people with dementia. [Figure 7.1]







emergent themes for analysis and discussion

The family members and the three main healthcare professionals were also questioned about their experience of participating in the project, referring to positive aspects and points for improvement. In addition, we took the opportunity for asking all interviewees about a possible future implementation of the project.

The interviews provided data for thematic analysis according to the evaluation questions; new emergent themes were also considered, namely: the

different factors that hindered the use of artefacts, the differences between use in family context and institution, the absence vs. presence of a healthcare professional, and the management of personalisation. The data referring to each specific artefact was analysed together with the previous assessments and feedback collected throughout the project. The other themes are discussed and synthesised in a general manner, to form the basis for making conclusions and defining future directions for the research project.

7.2 Experiences of use

The artefacts developed and used in this project—the board game, the story-making game, the tactile things and the cards-about-what-matters—are now presented separately, in more detail. Drawing on the *annotated portfolios*, proposed by Gaver and Bower (2012) as a methodology to communicate design research, the artefacts are annotated with the multidimensional concerns and decisions to design each of them, including the participants' views and experiences of use, as well as the connection with person-centred dementia care theories.

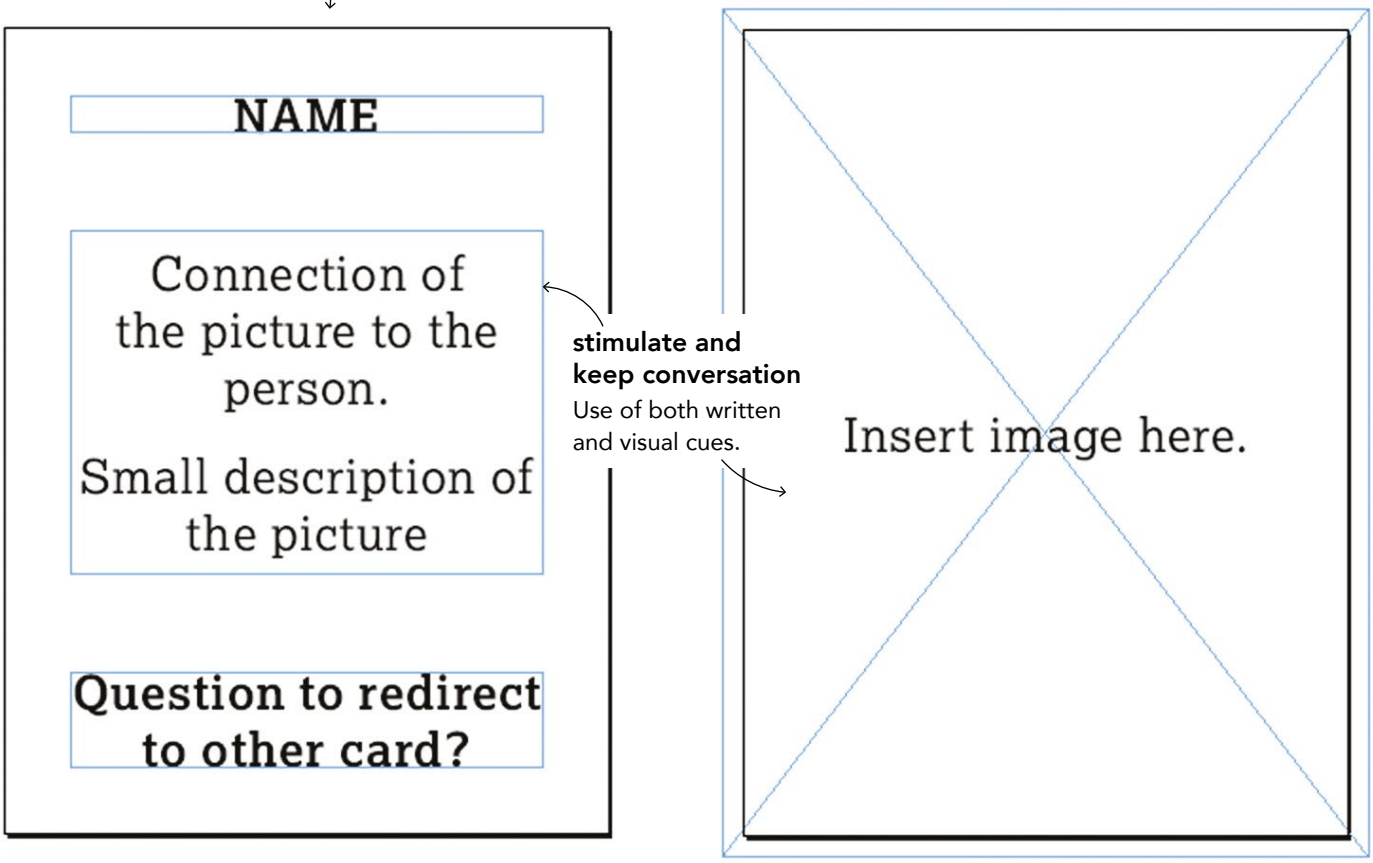
All the observed and shared experiences of use, from the beginning of the project to the summative evaluation, were taken into account to describe how people used and responded to the artefacts, as well as their critiques. In addition, the answers to the evaluation exercise on the Positive Person work interactions are analysed, towards a summary of qualities, critiques, and suggestions for each artefact.

The analysis of each artefact follows a similar structure:

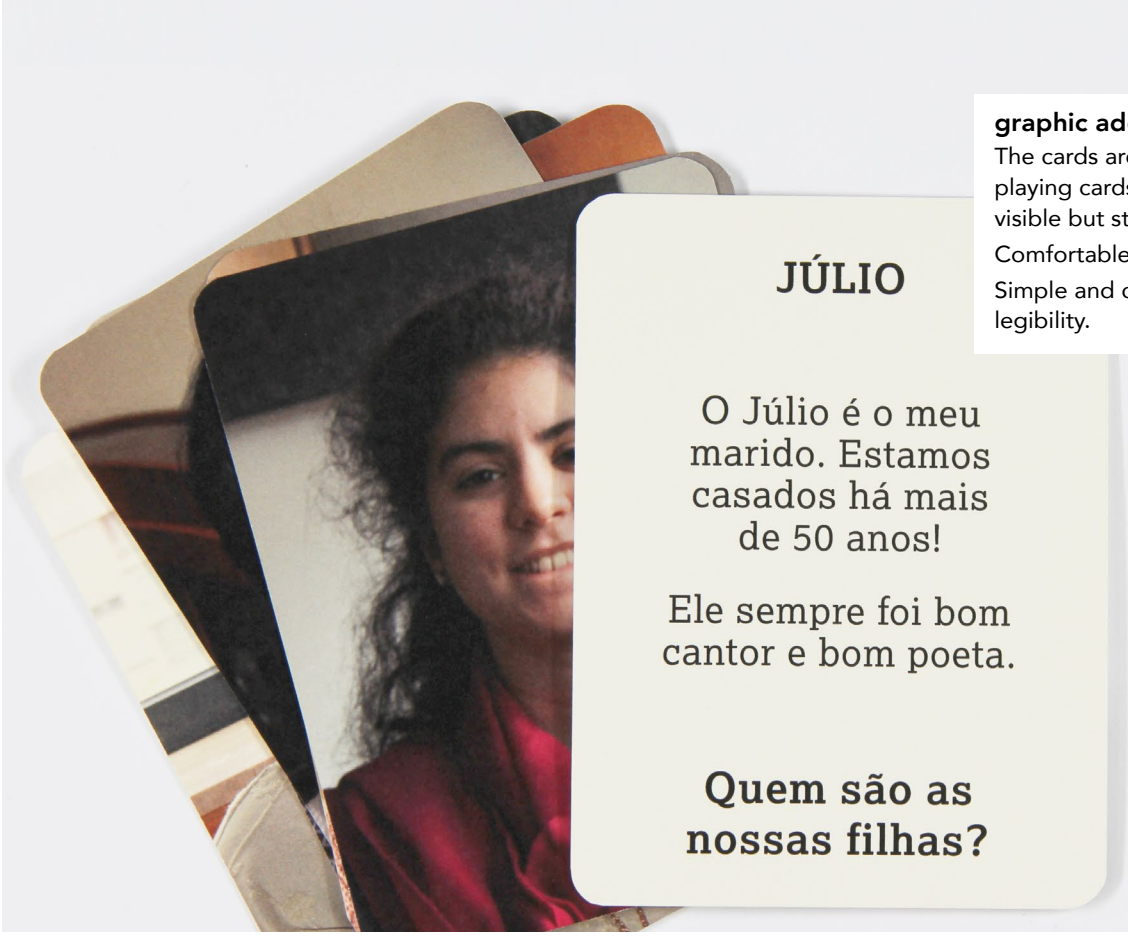
1. **Presentation**: the presentation of the artefact, including main aims and characteristics, and some reference to its development process when relevant[2].
2. **Use**: the description of how participants used the artefact, how they responded to the activity and experienced it, as well as their associations between the artefact and the Positive Person Work interactions, based on the Positive Person Work evaluation exercise.
3. **Value**: a summary of the qualities, critiques, and suggestions about the artefact pointed by participants.

2 In order to facilitate the narrative, we opted to give fictitious names to participants.

meaningful content
Blank templates to be filled with content that is interesting and engaging to the person.



stimulate and keep conversation
Use of both written and visual cues.



graphic adequacy
The cards are bigger than normal playing cards so that content is visible but still comfortable to hold.
Comfortable type size and typeface.
Simple and clear layout to support legibility.

7.2.1 THE CARDS-ABOUT-WHAT-MATTERS

PRESENTATION

Main aims

The main aim of the cards-about-what-matters is to support conversation, through the reference to themes that are important, engaging and personal, where cards act as visual and written tools to trigger and keep the talk going. These cards were designed in previous research (Branco, 2014) to assist the researcher, her family and formal caregivers to speak with her grandmother with dementia, about what mattered to her. The cards-about-what-matters were designed to allow personalisation.

Description

The cards-about-what-matters are blank templates to be filled with what is interesting and engaging to the person, be it about important people, life events, objects, places—any type of content that matters. The template is composed by both visual and written cues: on one side, the card has space for a picture, and on the other side, it is suggested to include the name, a brief description and a question that can redirect to another card.

Figure 7.2 the cards-about-what-matters

USE

Although the cards-about-what-matters were also used in former research (Branco, 2014), here we focused on experience of use of a family who created their personalised set of cards, for their relative with dementia David. Additionally, we have also included the feedback from three healthcare professionals, although they did not use them.

Description of use

To personalise the cards, the family members opted to create cues about their extended family (the 3-generation core family, siblings, cousins, etc). Each card corresponded to a person and, as suggested by the template, they showed the picture on one side and had the person's name, brief description and a question on the other side. The cards were used solely in their familial context. They reported that they have been resorting to them often, particularly the main carer, with whom David spends most time.

Show and tell

The family members described that they generally just show David the pictures in the cards. They either turn the card to read the description, or describe it themselves, and usually ask him about the picture.

Figure 7.3 The cards-about-what-matters in use (Branco, 2014).



Game dynamics

Since David was always very keen on games, the family members suggested the creation of a game dynamics for the cards-about-what-matters, so they could be used both for playing and for conversation. The game dynamics developed during the personalisation process made use of the questions on the cards that redirect to other cards: (1) each player would take three cards; (2) the first player would put one of his cards on the table, and (3) the next player would place the card with the answer to the first card; (4) at the end of each turn, all players would take a card until the deck finished, and (5) the first to finish all the cards would win.
However, the family never played it this way. They referred that David always showed more interest in only looking through the cards.

Individual entertainment

The cards-about-what-matters were also considered a source of individual entertainment for David, just by looking at the pictures on his own.

Responses to use

The family members reported that David responded well to the cards-about-what-matters:

> *"He really enjoys seeing the cards. ... You can notice it by the way he handles the cards, by the look in his eyes, that he is looking at them with satisfaction".* (relative A, 05.03.2017)

Many times, he recognised the people in the cards but did not elaborate more about them. However, family members also mentioned that, as the disease progresses, they noticed that it became harder for him to recall and communicate:

> *"there are days when the reaction is positive and others when... it is not negative, but it is more neutral".* (relative B, 05.03.2017)

The family members showed some concern that the cards could confront David with his difficulties since they felt he was more indifferent on the last time they used it.

cards

Participants valorised the simplicity of the cards layout, the adequacy of type size, and the inclusion of the concise description. Both written and visual cues were found to be helpful:

> *"The cues always help. It is good to conjugate the verbal and the non-verbal. One person might have the visual memory more affected, but maintains another kind of memories, and like this, we can combine both."* (psychologist A, 15.03.2017)

making

One of the healthcare professionals particularised the importance of allowing families to add content that is meaningful to them. She considered that gathering the content and making the cards can be seen as a celebration of the person's life. Therefore, this process might become even more valuable for the family, despite the response of the person with dementia. In fact, the family members referred that for them it was interesting and important to make the cards.

personal content

For this reason, the cards-about-what-matters were found adequate for a family setting. Another healthcare professional also mentioned that it is important for families to feel recognised, and the cards might help maintaining that. The use of very personal content involves affection, emotion, and reminiscence, thus more appropriate for an individual work.

Positive Person Work evaluation exercise

The exercise was undertaken with two family members that personalised the cards-about-what-matters, and three healthcare professionals. **Holding** was selected by all participants, whereas **recognition**, **play**, **validation**, **negotiation**, **relaxation**, **timalation**, **facilitation** were chosen three times, and **celebration** and **collaboration** were picked twice.

All participants associated **holding** to the cards-about-what-matters due to the use of very personal themes:

> *"working with materials that are very close to people, I believe it will bring them this feeling of security. It is something they master, that they know. ... It will work on the emotional expression".* (psychologist A, 15.03.2017)

For the same reason, it can also help the person with dementia to relax (**relaxation**). **Recognition** was chosen for the cards' potential to respect and celebrate the person, her/his uniqueness and her/his life, thus contributing to create empathy and sensitivity towards her/him (**validation**). However, the family members had some reservations to include **recognition**. They were concerned that, at times, the activity could become stigmatising for David, since they were showing him and asking him about those people that he might not be able to identify, and thus confronting him with his own difficulties. The same was discussed regarding **relaxation**: if the activity is conducted in a demanding way, it will not relax. **Timalation** was chosen essentially for the visual cues on the cards. In addition, one healthcare professional also referred that other senses can be approached using these cards as a starting point

> *"besides the images, the cards will transport us to certain places, we can remember the smell and taste of a meal, the smell of a house, the sand... to me, the cards inspire this stimulation of the senses".* (psychologist A, 15.03.2017)

The use of both visual and written cues was found to facilitate conversation (**facilitation**). **Collaboration** was selected for the fact that the cards encourage conversation and a shared activity, but it general, it was not considered very appropriate for group activity.

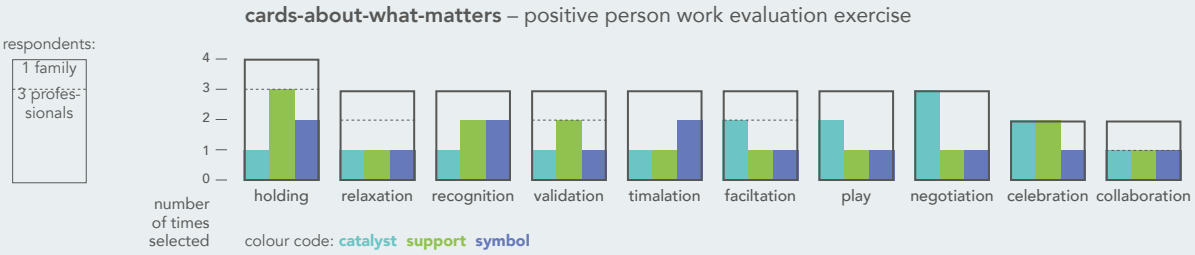


Figure 7.4 Results of the Positive Person Work evaluation exercise for the cards-about-what-matters

The roles of *catalyst*, *support* and *symbol* were attributed to the cards in a balanced way, regarding all interactions. There were only two exceptions. The artefact was considered to have a more *supportive* role in the mediation of **holding**, due to the influence of others in the occurrence of this interaction, and **negotiation** was found to be mainly *catalysed*, for the direct possibility of choice and space for personal expression.

VALUE

The cards-about-what-matters were valued for being simple and concise, providing both visual and written cues that facilitate conversation. The use of personal content was considered important as a way to respect and celebrate the person, to work reminiscence and emotion, since this is something that usually people master until later in life. In this way, it can create a feeling of comfort and security. However, it might also confront the person and make her/him feel frustrated if she does not know the answer:

> *"It can be stigmatising when I show I don't know the answer. This depends on the critical judgement of who is conducting the activity".* (psychologist C, 14.03.2017)

The personalisation work of gathering the content and making the cards can also be significant for the families.

Possibilities and suggestions

Since the cards-about-what-matters were found useful to do life history work, it could benefit from including content from different aspects of the person's life, as well as featuring the person in various moments of her/his life (as a child, young adult, etc).

Since the risk of confronting and frustrating the person depends greatly on who is facilitating the activity, it was suggested that the cards could bring some suggestions on how to do it:

> *"Maybe it should be written somewhere, with the cards «look at the person, see how she is reacting. If it is not the right moment, stop and try another day, another time. If it is the right moment, then it will bring all this* [referring to the positive person work interactions]*»".* (psychologist C, 14.03.2017)

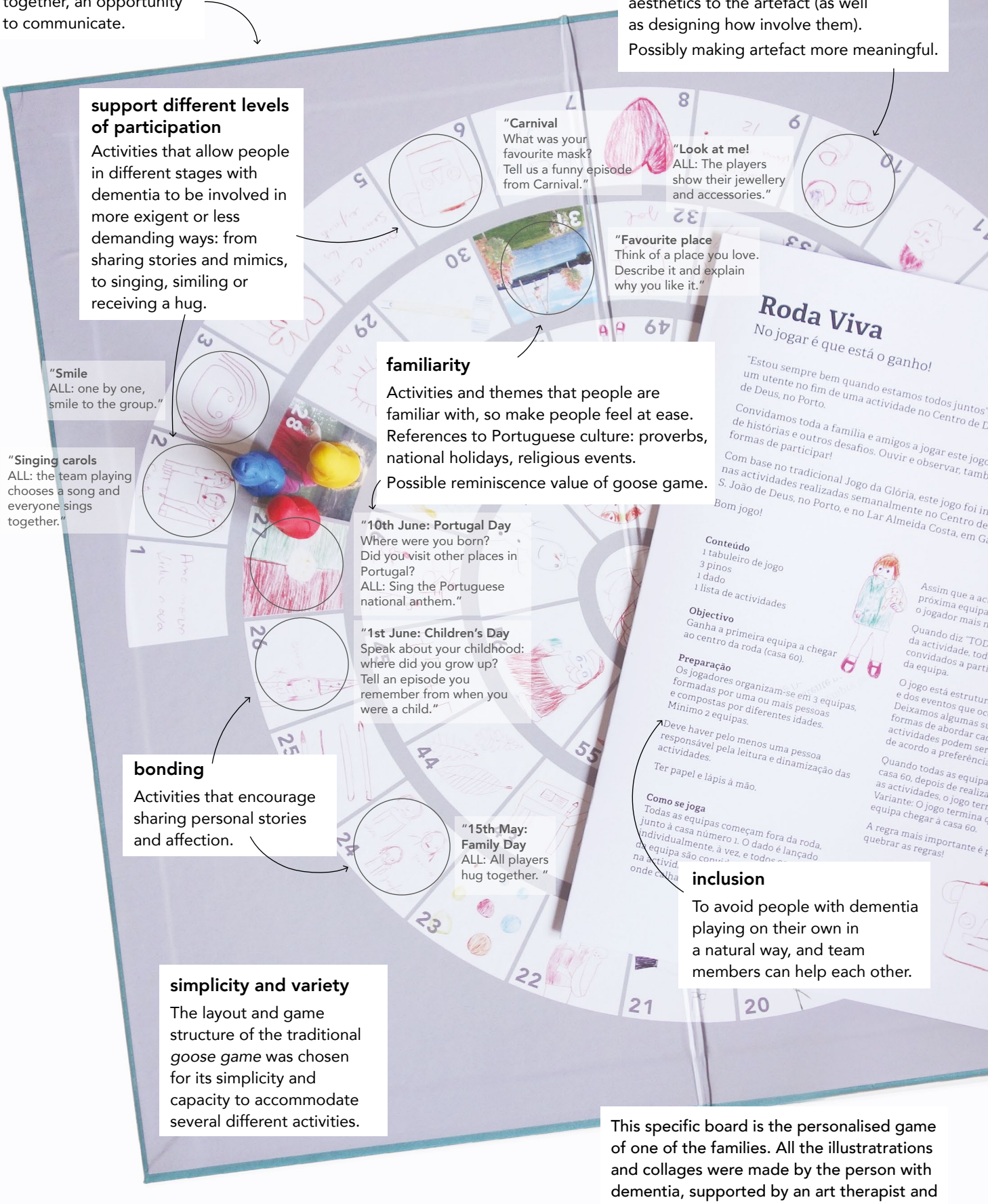
A possible way to develop the activity in a less demanding way would be to place several cards on a table and show them to the person without asking anything, and waiting if she would pick any of them.

Although the potential for use at home was emphasised, professionals also considered the cards could be used in institutions for reminiscence work. A digital platform for creating these cards and sharing of this kind of personal content could be a beneficial contact point between families and institutions.

collective ludic activity
A game to be played together, an opportunity to communicate.

embedding people's idiosyncrasies
Involvement of people in a codesign process and personalisation so that participants bring their culture and aesthetics to the artefact (as well as designing how involve them).
Possibly making artefact more meaningful.

support different levels of participation
Activities that allow people in different stages with dementia to be involved in more exigent or less demanding ways: from sharing stories and mimics, to singing, similing or receiving a hug.



familiarity
Activities and themes that people are familiar with, so make people feel at ease. References to Portuguese culture: proverbs, national holidays, religious events.
Possible reminiscence value of goose game.

bonding
Activities that encourage sharing personal stories and affection.

inclusion
To avoid people with dementia playing on their own in a natural way, and team members can help each other.

simplicity and variety
The layout and game structure of the traditional *goose game* was chosen for its simplicity and capacity to accommodate several different activities.

This specific board is the personalised game of one of the families. All the illustratrations and collages were made by the person with dementia, supported by an art therapist and the researcher.

7.2.2 THE BOARD GAME

PRESENTATION

Main aims

The main aim of the board game was to provide an opportunity for families to engage with their relative in a collective activity, by bringing home some of the exercises delivered in the institutions, in an easy format for families to conduct them. This was the response to a request of one of the institutions to develop a Christmas present to offer to their clients' families.

Description

The board game draws on the observation of activity sessions for people with dementia in two care institutions. This was a way to bring home activities that people with dementia are familiar with, in a format that is easy to use, to promote a social and ludic moment.

Board layout and structure

The layout and game structure of the traditional "goose game" was chosen for its simplicity, its capacity to accommodate several different activities and for the reminiscence value that it could have for some participants.

Teams

It was suggested that players formed teams so that it becomes natural that person with dementia is not playing on their own, and that members of a team can help each other. It was also a way of managing bigger groups. Most activities are to be responded only by the team in their turn, although some invite everyone to participate.

Figure 7.4
the board game

Game stops and activities

The sixty stops contain a wide variety of activities adapted from the observed institutional sessions. These include singing, reminiscing, gestures of affection (like smiling, greeting or hugging) and small challenges (such as drawing or mimicking for others to guess, completing sayings, telling words starting with a specific letter, simple calculations to advance or return stops, matching similar images). The reminiscence component was given priority, due to the importance of sharing personal stories for retaining life history and identity, as well as for bonding with others (Bruce & Schweitzer, 2008). The stops were organised according to the calendar year, including several culturally relevant annual events (national holidays, religious celebrations, commemorative days and seasons) that act as prompts for telling personal stories. Since the board game was initially designed to be given to several families, thus involving people in different stages of dementia, there was an effort to include activities that were stimulating for participants in earlier stages, and others that could be also engaging for those whose participation could be more limited. Activities that encourage gestures of affection were added to the game due to the importance of nonverbal communication and touch. Singing was also incorporated several times throughout the game, since most participants showed signs of great enjoyment in activities that involved music, regardless of cognitive ability.

Inclusion of people in the design process

The board game was also designed to involve others in finalising and making the game. Staff and clients of the institutions participated in choosing and adding ideas to the proposed activities, illustrating the game stops and making the playing pieces. This involvement aimed to pay tribute to the contributions of people with dementia and to bring emotional value to the aesthetics of the product through the inclusion of their drawings.

Personalisation

Since the board game was conceptualised to be open to the contributions from others to finalise it, it was later used as a template for different families to personalise it [chapter 6].

USE

The following descriptions are based on the observation and feedback from playing the game with three families, and with a large group in one of the institutions. In addition, it includes the healthcare professionals' comments on the experience of playing in the institution and the feedback from three families who played their personalised version at home (a fourth family personalised the game but did not play it).

Description of use

Although the board game is simple to use (roll the dice, advance the playing piece according to the number that came out, and do the activity correspondent to that stop), people approached it in slightly different ways presented below. This was noticed through the observation of several instances of playing the game with people with dementia, in three different contexts, with family members, in the institutions among peers, and in a home setting with a formal caregiver.

Game centred on the person with dementia vs. equal participation

It was observed that in some cases, the attention during the game was centred on the person with dementia. Activities and prompts for sharing stories were directed to the person with dementia in the first place, irrespective of whose turn it was. Only after, the other players responded if the person did not do it, or added detail to the story, but not always shared their own stories. This happened more often when playing with family members, who naturally focus their attention on their relative with dementia.

In other cases, turn-taking was respected and the participation in the game was more equal. Especially in the institutions, the attention was evenly directed to all players.

Turn-taking was also not respected in the cases where the facilitator identified a sensitive theme or a difficult task for the person playing, thus asking someone else to do it. Another way of dealing with similar situations was to alter the theme or activity.

Focus on reminiscence

The reminiscence component of the game was also reinforced by most participants through how they played it. Although it was suggested that, in each turn, only the

players of the team responded to the activities, some facilitators opted to ask all players from all teams to share their stories. This was a way to encourage participation by hearing others' stories and to learn from and about everyone. Moreover, some people made an effort to encourage and support the person with dementia to tell and elaborate on their own stories, by prompting, giving cues, or completing something that was said. This was especially rich with family members, who shared or heard the stories and were able to guide the person and provide details.

Playing with two dice

When playing the board game in an institution with a big group, it was decided to use two dices, to speed the game. This brought an extra challenge to the game, as numbers needed to be summed.

Responses to use

In general, the responses to the board game were very positive among those who played it, regarding both the general and personalised versions. Except from one case where a person with dementia lost interest after starting to play with one family member, participants said to have enjoyed playing the board game and that it generated a pleasurable moment, due to the communication and interaction facilitated by the activities proposed:

> *"I felt that when my dad plays the board game, it brings him back to reality. When that happens, he is able to connect with all of us, and that is fantastic".* (relative A, family A, 05.03.2017)

In this way, playing the game encourages and supports interaction among the players, even when communication is non-verbal:

> *"in my case, it is not verbal, but to see her happy, to see her smiling. To see her interested in seeing it and wanting to keep it for her".* (relative, family B 24.03.2017)

Figure 7.5 Family receiving their final board game.



Distraction

Many participants, including some with dementia, mentioned playing the game as entertaining:

> *"It was pleasant. It was an entertaining occasion".* (person with dementia, family G 05.11.2015)

One family also referred that they felt that playing the game was an important distraction to divert the obsessive thoughts of their relative:

> *"It was a moment where he was truly present, as if he didn't have any disease".* (relative A, family A 05.03.2017)

Inclusion and family unity

Family members also said that the board game was a way to include their relative in an activity.

> *"Many times we have difficulties in finding activities we could do with them and they feel comfortable doing. ... Your game manages to validate what she still has".* (relative, family B, 24.03.2017)

Moreover, many families highlighted the adequacy of the game to bring together different generations:

> *"everyone played even K, the youngest, and everyone collaborated. There were three generations and everyone enjoyed it!"* (relative B, family A 30.12.2015)

In this way, the game contributed to creating "*quality family moments*" (relative, family H 21.08.2015):

> *"The game also promotes unity. It was positive, promoted interaction within the family, the recollections of the family, and a happy moment. And sometimes it is difficult to have happy moments."* (relative, family B 24.03.2017)

Reminiscence

The reminiscence aspect was found crucial to stimulate communication and interaction among players, and generate enthusiasm. One of the professionals mentioned that when they played the game in the institution people became increasingly more enthusiastic to participate and share their memories as the game proceeded:

> *"we could see their happiness. They were engaged sharing what was theirs".* (social educator, 04.04.2017)

Most families also emphasised this as a significant aspect of the game to engage and connect with each other. Even when the participation of the person with dementia was more difficult due to language difficulties, it was also important for the rest of the family to remember their stories.

Variety of activities

Participants also valued the variety of different activities included in the game, making it surprising and fun:

> *"I loved it! It is very varied, we can sing, remember. We had fun!"* (relative B, family A 30.12.2016)

Apart from reminiscing, participants' preferred activities included the gestures of affection and singing, and some families also mentioned they enjoyed completing the

sayings, drawing, the small calculations and mimic. Some participants with dementia were also eager to roll the dice, and moving the playing pieces.

> *Mrs H rolled the dice with a great dedication: she would either blow on the dice or shake it before rolling it. She said it was to bring good luck".* (Fieldnotes, 21.08.2015)

In one case, the person showed such enthusiasm for these tasks, that end up doing it for all the teams. On the professionals' perspective, the variety of activities was also important for cognitive stimulation and to allow different people to participate. The simplicity of the activities and questions also permit to adapt to the specific competences of the people playing.

Tiredness

Although most people said to have enjoyed playing, it was also reported and observed that after 30 minutes to one hour participants started to get tired, many times not reaching the end of the game. The duration of playing was significantly influenced by the emphasis put on reminiscing (if everyone playing was telling their stories, how much detail they put into them and how much they were encouraged to do it), as well as by the number of players. Therefore, whereas some participants commented that the game had too many stops, which could also be demotivating, others remarked that the game finished quickly.



Figure 7.6 Playing the board game at one of the institutions [video—click on image to activate]

Game elements

The game elements (the board, the dice, the playing pieces, the activity list) were not only important to mediate the game, but also to create a playing environment, where the playing tasks were also engaging for many participants with dementia. In the first family meetings, some practical details were criticised by participants (such as the size of the board and some confusing elements on the board and activity list), which were redesigned for the following versions. The spiral structure of the traditional goose game was highlighted by many participants, since it was familiar to them. The inclusion of drawings and playing pieces made by the people attending the day centre was also valorised by all participants.

Making the game

The healthcare professionals and a few families that participated more actively on the personalisation of their board game placed special emphasis on the construction of the game. Regarding the games built at both institutions, during the activity sessions, professionals referred to this process as very engaging and stimulating for the participants, while allowing the inclusion of meaningful and adequate elements for them. The involvement in the construction of the game was mentioned as fundamental for people to recognise the game as theirs, which might have influenced their engagement in playing the game:

> *"In general, they adhered well to the game, and I think it is also due to recognising that they participated in that creation process".* (psychologist A, 16.03.2017)

The process was simultaneously a way to value people for having participated in making something that was offered later to their families.

Positive Person Work evaluation exercise

The Positive Person Work evaluation exercise regarding the board game was undertaken with three family members and four professionals. **Recognition** was associated with the game by all participants. **Play** and **collaboration** were also selected by most participants (six), followed by **celebration**, **relaxation** and **holding** (five). Four participants picked **facilitation** and **timalation**, and only two picked **validation** and **negotiation**.

1. Recognition

Participants associated **recognition** with the board game for the respect and valorisation of people, through the life history work that it promoted, for the personalised construction of the game, and for the references to their identity and stories, namely in the games personalised by the families:

> *"If the game was created from those people, it will value those people and who they are".* (psychologist A, 16.03.2017)

According to the participants, the game is not stigmatising. Instead, they might recognise themselves in it:

> *"it makes her identify herself with the game, to see herself as a person. It stimulates the memories of who they truly are".* (relative, family B, 24.03.2017)

2. Play

Play was also associated with the board game for its potential to create a fun environment and enjoyable moments:

> *"it generates moments of great fun, moments of family unity"* (relative, family B, 24.03.2017)

In addition, the professionals also called attention for the possibility for personal expression that the game allows, through some of the tasks and namely the sharing of stories:

> *"although it is a group activity, there is space for individual expression".* (psychologist A, 16.03.2017)

3. Collaboration

All the participants agreed that, since it is a board game, **collaboration** is encouraged in a very natural way, supporting group cohesiveness. Moreover, the game was also considered to be inclusive due to the interactions fostered by the activities, among all people playing, regardless of cognitive condition:

> *"It is excellent for the interaction with others, particularly with our dad".* (relative A, family A, 05.03.2017)

4. Celebration

Participants chose **celebration** for the ludic function of the game, which encouraged moments of conviviality and joy, and supported relaxation:

> *"It is a moment of interaction with the family. It is a moment of conviviality, joy and communication, and in that sense, I chose Celebration first, since I believe the board game accomplishes that".* (relative A, family A, 05.03.2017)

5. Relaxation

Participants reported that the pleasurable and enjoyable moments provided by the game, contributed to a relaxed and easy-going environment. Although it was pointed that the opposite might also happen if the person does not know how to respond to a certain task or theme, the fact that it is a ludic activity, takes away some pressure.

> *"Celebration and relaxation are, in some way, interconnected. The person won't feel she is being evaluated because it is a game context. This context is more natural than the one of cognitive stimulation where the person might feel frustrated because she cannot answer. Since it is a game, it is ludic, thus erases part of this evaluation. This allows the game to be pleasurable and that the person participates in an easy-going way".* (psychologist A, 16.03.2017)

6. Holding

Holding was given more emphasis by the family members:

> *"In her case, I sensed that she was feeling safe, that she was enjoying and feeling comfortable on what she was doing."* (relative, family B, 24.03.2017)

Moreover, although the game furthers bonding among players, professionals also referred that the game is more likely to provide this interaction when played in a family setting than in an institution or with strangers. Participants stated that the game provides **holding** due to the encouragement of togetherness and interaction with those who are close to the person, but also on account of the familiarity of themes addressed in the game.

> *"The game ends up facilitating that [holding] due to the themes. Another game maybe wouldn't provide that. There are other games that can be discouraging … When he doesn't control the game, he might feel insecure and inhibited. In the case of the board game, the themes are familiar to him".* (relative C, family A, 05.03.2017)

However, similarly to **relaxation**, it was also noted that **holding** can be undermined if the game becomes too exigent, and the person gets too tired or frustrated by not being able to respond to something.

> *"Sometimes, she might feel insecure or less comfortable when playing, because we might be too demanding".* (relative, family C, 23.02.2017)

7. Facilitation

The game was considered a **facilitator** of communication and sharing stories, since it proposed themes that otherwise could not be talked about, and in that sense, triggered memories. The person who is mediating the game was also found crucial to ensure the game facilitates action.

8. Timalation

Although some participants mentioned that the game does not provide opportunities for a multi-sensorial stimulation since it relies mainly on talking, a few participants picked **timalation** for the variety of activities of the game.

9. Validation

The participants who selected **validation** referred that since it is a game to be played collectively and involving turn-taking, each person needs to allow space for others to speak, listening and relating to their stories, thus **validation** also happens. Nonetheless, it was mentioned that the creation of empathy needs a deeper intervention and that the game might contribute to it, but in a minor way.

10. Negotiation

Negotiation was not considered very present in the game because the choice of activities is mainly made by rolling the dice. However, **negotiation** was also associated with the personal expression to respond to the activities.

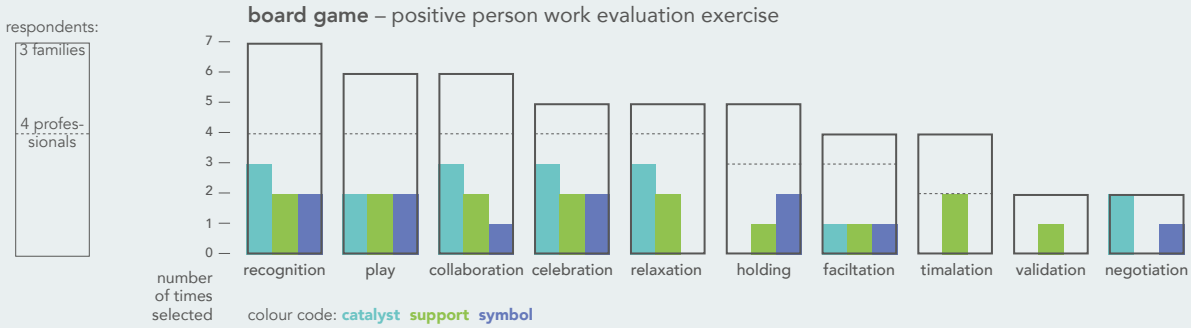


Figure 7.7 Results of the Positive Person Work evaluation exercise for the board game.

The board game was found to be mainly a *catalyst* of most interactions, meaning that the artefact was able to directly prompt people to participate. However, participants did not consider the artefact to have this role in mediating **holding**, **timalation** and **validation**, probably

because these interactions were more conditioned by the involvement of others. For this reason, the *support* role was often chosen regarding all interactions except **negotiation**. The *symbolic* role was less present in the participants' selections, although it was attributed to the mediation of **holding**, most likely due to the presence of personal references and familiar themes, as well as the traditional board structure, which might have contributed to a feeling of security among participants. **Relaxation**, **timalation** and **validation** were not found to be mediated *symbolically*, as these interactions might not be obviously represented in the artefact.

VALUE

The board game was valued by participants for its capacity to stimulate communication and interaction among players, for its focus on reminiscing in parallel with a big variety of other simple activities that encourage personal expression and that can be adapted to meet the abilities of participants. The fact that the game promotes a collective activity that is inclusive for people with dementia, reinforced by the reminiscing aspect, was referred to contribute to family unity by providing fun moments of conviviality and joy. The compilation of these activities in a game format, with a simple and familiar dynamics (since it borrowed the structure of a traditional game), was considered adequate and valuable for both institution and home settings.

Participants mainly associated the board game with the mediation of the following interactions:

— Recognition, since it respected and valorised the person through the inclusion of personal elements and activities that acknowledged people's stories;

— Play, due to the fun moments it generated and the space it offers for personal expression in a group activity;

— Collaboration, because it created an opportunity to include people with dementia in an adequate and collective activity;

— Celebration and Relaxation, which were found to be interconnected, due to the ludic function of the game that promoted a joyful, convivial and easygoing environment, thus inducing relaxation.

— Holding, associated with the encouragement of bonding, namely when playing with those in the close social circle, and due to the familiar themes addressed in the game.

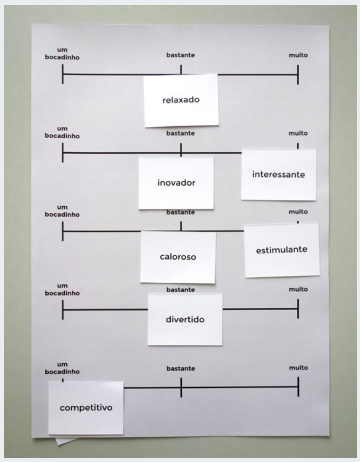


Figure 7.8 Example of a family's response to the semantic differential exercise. [more in chapter 6]

Results from semantic differential exercise

In the first meeting, families were invited to play the board game. Later, they were asked to characterise it, using a redesigned semantic differential [Figure 7.8]. The board game was mainly characterised as interesting, stimulating, fun, warm, relaxed, and fairly innovative. A few participants also classified the game as original, competitive, inclusive, adequate, and ordinary (referring to the traditional goose game structure). [Figure 7.9]

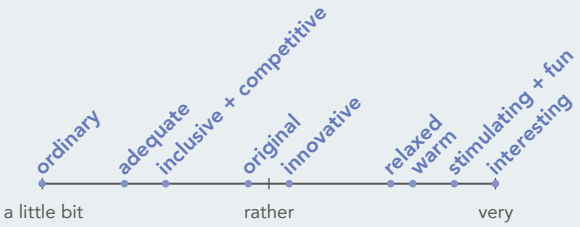


Figure 7.9 Combined results from four families.

Drawbacks

The board game was found demanding to play with big groups, and since the original version implied much storytelling, it became hard to play with people who have bigger difficulties with language. It is crucial to consider that the game can become tiring, that it can be too centred on the person with dementia, who might get frustrated if she is not able to answer. According to professionals, all these aspects depend greatly on who facilitates the game, on their observation and respect for how the person is feeling, stopping the game if necessary, and on their ability to adapt questions and task to each person.

Involvement of people with dementia

The healthcare professionals considerably emphasised the process and the involvement of people with dementia in several aspects of making the game (deciding list of activities, illustrating board game, making the playing pieces). They understood this process as a way of giving voice to people which contributed to a personalised game, made by them and for them, distinguishing it from other ludic or stimulation materials.

Involvement of family members and healthcare professionals

The development and playing of the board game also captivated some participants to do more. One of the

family members said to have greatly enjoyed contributing to the personalisation of their game, namely collecting pictures (that were used directly in the game or to support the drawing sessions with her relative with dementia). This inspired the family member to look for more and create a dedicated photo album for her relative.
In addition, one of the healthcare professionals reflected on the value of the board game to know better the people in the institution. The game contributed to learning different interests of residents, which stimulated the development of new activities according to things learnt while playing.

Possibilities and suggestions

Process

Due to the richness found in the process, healthcare professionals suggested that making the game could constitute an activity in itself, to be repeated in different institutional contexts. However, it was also mentioned the need for clear guidelines to replicate the process.

Audience

Due to its themes and activities, the game was considered to be also relevant and appropriate for an older population without cognitive impairments. However, it would always benefit from being personalised. One family member referred the potential for the game to be used by formal caregivers in domiciliary care.

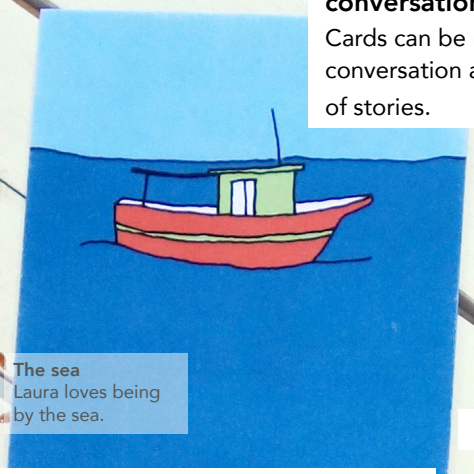
Board

There were several proposals made regarding the board. In order to make it more accessible and viable, it was suggested to develop a general board that would only have some blank stops where content can be added, to still allow some personalisation. Another suggestion made by a healthcare professional for an institutional setting, would be to have a blank board that they could personalise for specific activities and themes to be approached in a specific session. In addition, one family proposed a modular board, with several activity stops that can be changed and combined differently at each time, adapting to the mood and will of the person, and allowing it to accompany the needs as dementia progresses.

conversation and co-creation
Cards can be used to prompt conversation and the co-creation of stories.



PLACES



The sea
Laura loves being by the sea.

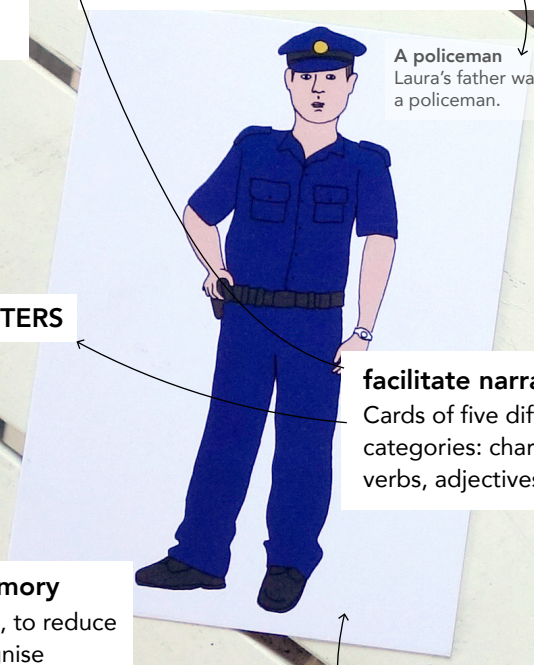
perguntar

VERBS

'hidden' personalisation
Some personalised cards were included in a non-personal way.
The aim was to trigger participation by including things that the person with dementia could possibly identify with.

creativity, interpretation, humor
No right or wrong way to play accepting nonsense, improbable and unexpected associations.





A policeman
Laura's father was a policeman.

distraído

CHARACTERS

facilitate narrative
Cards of five different categories: characters, places, verbs, adjectives and things.

ADJECTIVES

refrain from testing memory
No use of personal content, to reduce pressure of having to recognise specifically who/what it is.

graphic adequacy
Legible font and type size.
Simple drawings, not infantilising.

THINGS

ice breaker
Prompt conversation and collaboration among players.

supporting different forms of participation
Use of words and images to engage people with different abilities in the activity, and provide distinct stimuli.

agulha

7.2.3 THE STORY-MAKING CARD GAME[3]

PRESENTATION

Main aims

The main aim of the story-making card game is to support the co-creation of stories with people with dementia. The focus on co-creation and narrative was a response to the preferences and idiosyncrasies of a specific family, and derived from the intention to design an activity to prompt conversation and collaboration among family members, based on creativity, interpretation and humour, that refrained from testing memory.

Description

The story-making card game is a set of cards that contain multiple narrative suggestions to choose from, talk about and put together, to collectively create a story. It is composed of cards of five different categories: characters, places, verbs, adjectives and things. Characters and places are represented with images and the other categories with written words.

definition of a new brief

This proposal evolved from the collaboration with a family—Laura (a lady with mild dementia who attends the day centre service in one of the institutions) and her daughter Matilde—, who did not find any of the initially proposed artefacts relevant and adequate for them: the board game did not suit family routines and was perceived as difficult to use due to the lack of common interests

3 This section includes fragments of Branco, R. M., Quental, J., & Ribeiro, Ó. (2017). Co-creating stories with people with dementia: experiences of using a cards game in familial and institutional settings. Presented at the *Dementia Lab*, Dortmund, 2017. (Proceedings will be published in the beginning of 2018)

Figure 7.9 The story-making board game

among different generations [Figure 7.4]; the cards-about-what-matters seemed too easy and not very interesting for them, namely if they regarded the close family [Figure 7.2]; and the personalised book [Figure 6.1–2, p. 146] did not correspond to Laura's preferred activities since she did not have reading habits. However, they showed interest in collaborating to pursue a collective family activity.

The 'good day' exercise [chapter 6] was conducted with Laura who revealed her constant need from being with others, and her enjoyment of conviviality, conversation and laughing. The 'weekly routine' exercise [chapter 6] was done only with her daughter. Since the family's routine was rather busy, having only a gap to spend time together between dinner and going to bed, the activity was required to be easy and do not imply too much time and effort. This exercise also prompted a long conversation about Laura's difficulties and behaviours due to dementia in certain situations. The diversity of interests among family members was clear, so it was agreed that the artefact to be designed should encourage them to collaborate on an activity that did not focus on specific themes, and enable a feeling of creating something together. Due to Laura's memory problems and difficulties in following precise rules, the artefact should not have right or wrong answers. Instead, it should trigger creativity and humour.

The insights collected in both exercises and the observation of the very active and creative participation of Laura in the activities promoted by the institution she attended influenced the idea of designing an activity where new stories could be co-created. The story-making card game was the result of joining these considerations in a familiar, tangible, economical and easy to use format. The family agreed with the new activity proposal and was disposed to try it, but did not show availability to participate in its development.

Multiple-choice

While doing the 'good day' exercise with Laura, it was noticed that it was much easier for her to speak about her interests based on the multiple-choice suggestions that she recognised rather than having to recall them. This is explained by Sabat (2014), who distinguishes recall and

recognition as different ways of remembering, and affirms that the ability to recognise is commonly preserved longer in dementia cases. In this way, narrative elements could be suggested for people to select, speak about and put together to create a story.

Pictures and words

The decision to present some of the categories using pictures and others using words is related to the aim of providing different stimuli, which could result in different responses and serve distinct preferences and abilities. Allan (2001) describes her approach of using cards with both pictures (people and objects) and words (emotions) to elicit people with dementia to express their views about the services provided to them. They were encouraged to comment the pictures in their own terms: some participants initiated long talks about the picture or word, others made only brief comments, and others just looked at the cards without a verbal response. Pictures and words were used to support people to speak about their experiences indirectly, or as direct triggers for discussion, but they were also used to spend time together and communicate with staff, which sometimes also helped to relax. Although pictures are more commonly used as cues for conversation and storytelling (e.g. Timeslips, SeeWhatIMean), Allan (2001) observed that "it definitely seemed that having the words easily visible helped to promote the fluency of the conversation" (p. 61).

Since the main aim was to stimulate creativity, the use of general (rather than personal) pictures seemed more appropriate, in order to eliminate the pressure of recognising personal references. This influenced the decision to make simple illustrations, which also responded to the intention of reducing a picture to its essential (removing unnecessary visual inputs that could be too demanding or confusing) while allowing some degree of interpretation. Being aware that illustrations can sometimes be seen as childish, there was an effort to make them as neutral as possible.

"Hidden" personalisation

The aim of the activity was not about reminiscence. However, the materials were partially personalised with few personal preferences and references to the life history

of the person with dementia that were incorporated in the middle of other characters, places, verbs and things, so that the person identified with the content on the cards, facilitating recognition and conversation. For instance, Laura referred her appreciation of being by the sea, thus several cards related to the sea were included. This decision was also influenced by the observation during the 'good day exercise' with Laura. Although not directly asked, the exercise materials triggered her to share some personal stories.
It was also envisaged that, after trying this prototype, a new one could be 'more personalised', involving Laura in creating her cards, with words and images chosen and drawn by herself and/or conjointly with family members.

USE

The prototype delivered to the family was accompanied by a proposal of use: each player gets a card of each category randomly (randomness could give origin to funny, or even non-sense stories, thus putting humour into play); then, in each turn, the player places one of the cards on the table, adding that element to the story that is being created. It was also explained that there was no right or wrong combination of cards and that players could freely add something to the story that was somehow related to their cards. It was suggested that they could add or reduce the number of cards if they found it necessary and that if they would like to make it a bit more competitive and stimulating, the first player to finish the cards could be the winner.

Responses to first use in family context

Family's response

Matilde reported that when they started playing with other three family members, Laura started participating inappropriately, diverting to things that were not in the cards. She did not respect the turn of the other players, making inadequate suggestions. When asked again their experience in a final evaluation interview, Matilde described how Laura responded to it:

> *"I explained the game to my mother three or four times, that she should continue the story. I encouraged her to start, but she refused, so another person started, I believe it was my daughter. But then she wouldn't carry on with the story. She started talking nonsense and turned off".* (Matilde, 15.03.2017)

Despite her initial interest, after a while Laura got tired from being there and left. The other family members continued playing for a little longer and said to have enjoyed it. Matilde explained that for them it was difficult to entertain Laura, since she loses interest in most activities after a short while:

> *"The problem was not the game. The problem is that she cannot keep focused on anything. ... If she is talking with others, she might pay attention, but when there are some kind of rules, or that others need to intervene, it's over. She loses interest".* (Matilde, 15.03.2017)

The family also recognised that maybe trying another day, another time (it was after dinner) or maybe with her peers at the institution the game could work better. However, in general, they did not believe that Laura would engage in the activity as intended.

Comments from the healthcare professional

After the family's unenthusiastic response to the artefact, we sought comments from a healthcare professional to understand the artefact's adequacy, and how it could be improved. The feedback about the materials was very positive. However, the game dynamics was probably too demanding for the person with dementia. In addition, since the family had the expectation that the stories created have some logic, they might have added even more complexity to the activity, which is likely to partially explain why the family found their relative's participation inappropriate. Based on these comments, we proposed both collaborating institutions to use the cards during their activity sessions, involving several healthcare professionals and people with dementia in trying, providing feedback and contributing to the definition of different uses for the story-making card game.

New descriptions and definitions of use

The story-making card game was used in four activity sessions with people with dementia. These were conducted by healthcare professionals: two group sessions of cognitive stimulation in one institution, and two arts-based sessions involving small children in Laura's institution.

After the success of these intergenerational sessions, this nursing home organised an event dedicated to the story-making card game, where residents from

other institutions in the organisation, and children from the nearby kindergarten were invited to participate. In this event, participants were divided into four groups, in separate tables, each accompanied by one psychologist who was facilitating the activity.

The following descriptions of the artefact's use are based on the observation of how healthcare professionals worked with the cards, their reflections on the activity, and how participants responded. Although there were some differences, mainly depending on the group playing and on how the activity was facilitated, these experiences of use can be grouped in three approaches.

Only with picture cards

Images (places and characters) were placed on the table. Participants were asked to select one card and share why they chose it. After everyone spoke about their card, they were asked to draw or write something related to the content of the card.

One card to co-create a story

This was the most commonly used approach. No more than two or three cards from each of the five categories were shown to participants. They were asked to choose one card, and speak about it to the other participants. In smaller groups up to 6 people, participants were supported in co-creating a story with the chosen cards, and then sharing it with the other groups, or registering it. Variations to this approach included:

1. randomly giving the cards to participants, although it was found more interesting to give the option of choice;
2. after selecting their cards, participants were asked to briefly describe it to others and, in some cases, they were encouraged to tell others why they selected it;
3. the process of co-creating the story happened more organically in some groups, with all participants contributing and helping each other to fit their card in the story, mediated by the health professional. In other instances, this occurred more orderly, with individual contributions at a time;
4. in the sessions where smaller groups were created

and stories were shared at the end, a person from each group volunteered to be the spokesperson. Other sessions put more effort on registering, namely when children were present, which was done as the story was being created. Participants were encouraged to illustrate elements of the story with drawings, and some older participants also contributed through writing it. Other times, the health professionals would make written notes, which supported the co-creation process.

Associations

After following the same sequence of choosing from no more than two or three cards per category, participants made possible associations between all the selected cards. This approach emerged during the event, in a smaller group of four participants that stayed after the others left, and intuitively started using it in this way. At the time these associations were only written, but drawings and new stories could be also made using them as a starting point.

Responses to institutional activity sessions using the story-making card game

The following insights were collected in the observation and comments from healthcare professionals and people with dementia at the end of the sessions using the story-making card game (in the event it was also asked to some participants to leave a written feedback), as well as in posterior evaluation interviews with seven healthcare professionals—six psychologists and one art therapist (five of whom used the artefact).

Attention, interest, and fun

All the six professionals who used the game were enthusiastic with the results. They highlighted the interest and attention of participants over a long period of time (around one hour or more), and the pleasurable and easy-going environment generated. In general, older participants referred to have enjoyed building stories with the cards, except one participant who said the activity had no interest for him. Participants described the activity as entertaining, fun, novel and creative [Figure 7.10]. Laura also integrated the

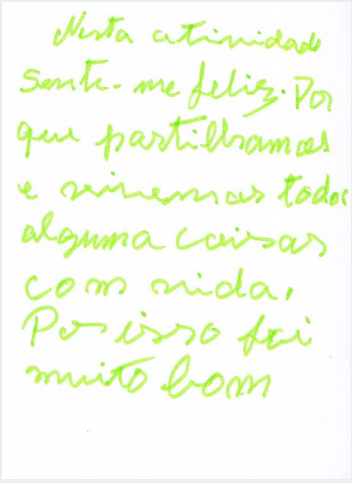


Figure 7.10 Written feedback from a participant about the event: *"In this activity I felt happy because we all shared and lived some things with animation. Thus, it was very good." (13.07.2016)*



Figure 7.11 Laura spontaneously started drawing from one of the game's cards.

two sessions as well as the event organised at the nursing home. In all occasions, she demonstrated interest and participated actively, contributing to the stories and making drawings [Figure 7.11].

Creativity and inclusion

Some participants considerably appreciated conceiving the stories, for being a stimulus to their creativity and imagination. One participant with early dementia also referred that *"creating the story makes the activity more meaningful"* (Fieldnotes, 17.05.2016). Some of the healthcare professionals also reinforced this creative aspect, since they observed that the materials allow freedom for different interpretations and associations, many times unexpected and improbable. In this way, there was an 'absence of error', which is particularly important to promote a pleasurable, relaxed and inclusive environment when working with people with dementia:

> *"As the game progressed, the participants got more at ease and contributed more to the story ... I noticed that they felt secure about what they were doing, I believe they didn't feel frustrated. I think they felt valued for having contributed to the story".* (psychologist B, 29.03.2017)

Another health professional emphasised the collective aspect of the activity, which managed to bring together and include people with different abilities, who could contribute without being judged:

> *"Even if we were all in the same group, around the same table, ... the activity doesn't expose the capacities or difficulties in the task. Through the product, it involves you regardless of what you can do".* (psychologist C, 14.03.2017)

According to another professional, this involvement occurs mainly due to the invitation to choose a card:

> *"even the people with more cognitive difficulties, the cards managed to unlock. ... In this activity of co-creating a story, obviously, there will always be some people that perform better than others, but the fact that we asked them to pick a card allowed everyone to be involved in the activity. Many times, in the activities, people lose attention. In this way, everyone was involved, even if they only picked the card and held it while they waited to see how it would fit in the story. They have a role in the activity. In this case, we don't speak as much of individual cognitive stimulation, even if it has that potential, but about the group well-being".* (psychologist D, 04.04.2017)

Some participants with dementia also highlighted the collaborative aspect of the game, even if it can become more demanding:

> *Mr J found the game entertaining and appreciated the coordination of everyone's cards, the fact that all participants contributed to the same goal. Mr A agreed, found it challenging because they were many people, thus many cards to bring together.* (Fieldnotes 24.05.2016)

Flexibility and facilitation

Several participants mentioned they found the materials interesting, simple and easy to understand, and considered them to facilitate the creation of stories, working as an encouragement of participation:

> *"it isn't intimidating, and there are many things that are easy to recognise. In this way, we give the necessary encouragement to do the activity".* (psychologist B, 29.03.2017)

All health professionals valued the multiple possibilities of choice that the game offers, both for the people participating in the activity, as well as for who is conducting it. The use of words and pictures was found stimulating, and helpful to unblock language and narrative:

> *Mr F commented that the conjugation of both images and words demands a mental exercise that is important* (Fieldnotes 24.05.2016)

This combination also promoted rich intergenerational collaborations in the sessions where children were present. While children naturally contributed with creative ideas for the stories, encouraging and loosening up the participation of everyone, older participants would support the children by reading the word cards and writing parts of the story. [Figure 7.12–13]

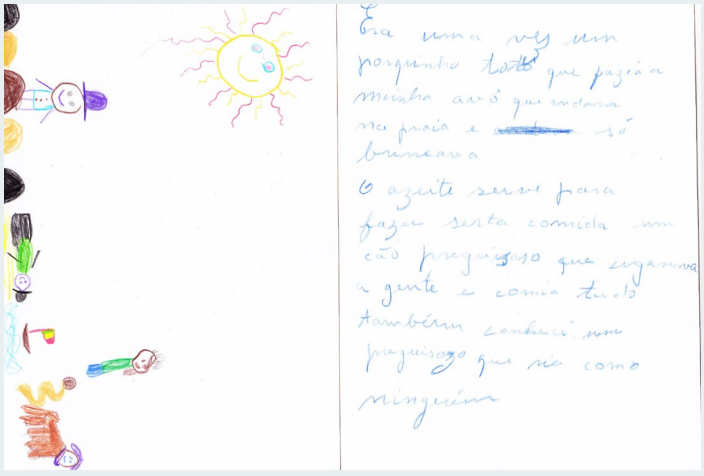


Figure 7.12 Example of a story co-created in collaboration between an older person with dementia who wrote the story, and a child who illustrated it.



Figure 7.13
Intergenerational interaction and collaboration.

Having both words and images also contributed to the inclusion of people with different abilities. Images were more flexible and easier for people whose language is weaker, whereas the words become stimulating for people with fewer difficulties, even those without any cognitive impairment:

> *"It integrates two distinct realities, and this makes the game very complete. It is possible to easily adapt to people with and without cognitive impairment".* (psychologist E, 23.03.2017)

Although they added complexity, the inclusion of adjectives and verbs was appreciated, since they instantly facilitated building a narrative. The pictures were found more appealing and captivating, having generated a positive conversation dynamics, which contributed to the fun and joyful environment.

Logistics

The story-making card game worked better when played in small groups (up to six people), preferably in separate tables to avoid confusion and distraction. The complexity increased with more cards. Showing a small number of cards (having one or two cards of each category) was found to be more appropriate. During the event, which lasted longer than most sessions, the game was played more times. It was observed that after the second round people started getting tired.

Positive Person Work evaluation exercise

The Positive Person Work evaluation exercise regarding the story-making card game was undertaken with Matilde and seven professionals (two of them did the exercise together). Matilde preferred to make her selection based on her expectations and on the potential she believed the game had, rather than on her experience of playing it. Four healthcare professionals choose all cards because they found the material very complete. **Negotiation** and **play** were the most selected interactions (six). **Negotiation** was picked by all professionals. **Facilitation**, **collaboration** and **validation** were also elected by most participants (five). Five participants also chose **relaxation** and **holding**, even if the professionals who did the exercise jointly had reservations about including them. In their opinion, those interactions relied on how the activity was facilitated.

A similar comment was made by another professional:

> *"these four (**recognition, facilitation, negotiation, collaboration**) apply well [to the game]. The others might or not apply, they depend more on how the session is conducted. I can imagine this being used in a negative way and going wrong. The object itself is not a guarantee. I believe this material is a guarantee of these four, but the others depend on the facilitation of the activity".* (psychologist D, 04.04.2017)

Celebration, **recognition** and **timalation** were selected by four participants.

1. Negotiation

Negotiation was associated with the multiple possibilities of choice that the game offers, both for the people participating in the activity, as well as for who is conducting it:

> *"You can include it [**negotiation**] in the activity or not, depending on what works better with the people you are working with, but the object potentiates this".* (psychologist F, 23.03.2017)

Some professionals also reflected on the effects of this possibility of choice. On one hand, it can make people feel that they are in control of what is happening, creating proximity to the activity. It might also make people feel more secure

> *"we feel more secure with the card we chose because it is likely to be something we identify with, word or image".* (psychologist B, 29.03.2017)

On the other hand, since for some people with dementia decision-making becomes harder, it might also create some apprehensiveness

> *"sometimes, the fact of asking to choose something can create tension. The person might not be comfortable with so many options. It is necessary to adapt. Thus **negotiation** can promote **relaxation** and **holding** for being used or not".* (psychologist F, 23.03.2017)

2. Play

Play was chosen for the fun and creative environment that the game generated. Some professionals highlighted the ice-breaking qualities of the game, important to promote socialisation and comfort. Another professional emphasised the capacity of the game to stimulate personal expression and creativity.

3. Facilitation

The professionals selected **facilitation** since they considered that both words and pictures unblocked language and narrative, thus supporting participation

> *"[the game] is easy. Unless there is a big cognitive impairment. If you can't do it with words you can do it with images. If you can't do it with images, you can do it with words. ... The game encourages the creation of meaning because there is no error".* (psychologist F, 23.03.2017)

It was also referred that the cosy and fun environment that the game generates also facilitates participation.

4. Collaboration

Collaboration was considered to be provided through the activity of co-creating of the story. Some professionals mentioned again the icebreaking qualities of this activity, which might make people more at ease to participate in other group activities.

5. Validation

Validation was associated with acts of listening and accepting the choices of others, which can play a part in respecting the contributions and the pace of others, and in creating empathy towards them.

> *"Since the moment in which the other person looked at the image and saw something different, others can understand why the person saw it that way. So, it validates. This helps to create empathy and sensitivity towards the person. Even if the interpretation was not the same, having the conscience of the interpretation of the other person, one can have the possibility of identifying with it".* (psychologist F, 23.03.2017)

6. Holding

Participants who chose **holding** essentially connected it with the occurrence of other interactions. It was associated with **collaboration**, **validation**, and **negotiation**, which can reinforce the feeling of being secure and at ease. However, it was also mentioned that, for instance, if the group is too big, or the decision-making is too demanding, this could be lost. **Holding** was linked with **relaxation** too, since being relaxed in an easy-going environment was seen as a necessary condition for feeling supported. As mentioned above, professionals considered that this interaction relies substantially on how the activity is conducted, as well as on the group, on

the room setting, and on facilitator's sensitivity to observe and adapt the activity to the person, her abilities and her specific mood on that moment.

7. Relaxation

Some professionals highlighted the game's capacity to provide a pleasant and **relaxed** environment, where the person can contribute without being judged. They observed that the initial anxiety was diluted as the activity progressed and people were enjoying it. However, **relaxation** was also considered to be conditioned by the same factors mentioned in **holding**, namely the activity and group dynamics, and the sensitivity of the facilitator.

8. Recognition

Recognition was attributed to the game mainly because participants did not find it stigmatising.

> *"It is not stigmatising, and that is important. It is not infantilising and it does not focus themes that can be associated with dementia. It is ludic and neutral".* (psychologist D, 04.04.2017)

It was also mentioned that, indirectly, the game promotes a moment where people are encouraged to respect and valorise the person, due to the individual interpretations of the cards.

> *"The way an image is interpreted is highly personal. There are so many ingredients of the person... they are unconsciously there".* (psychologist F, 23.03.2017)

9. Celebration

Participants agreed that the game can contribute to a convivial and joyful atmosphere, but that is also dependent on how the activity is coordinated. Taking into account that the game can have personalised elements for a specific person, one professional also referred that in this way the game can also **celebrate** the achievements and life of that person.

10. Timalation

Participants refrained from selecting **timalation** because they considered that the game does not offer a multi-sensorial stimulation. However, some professionals emphasised the visual richness of the images, the fact that people can hold and feel the cards, and that the material allows reminiscing about the other senses.

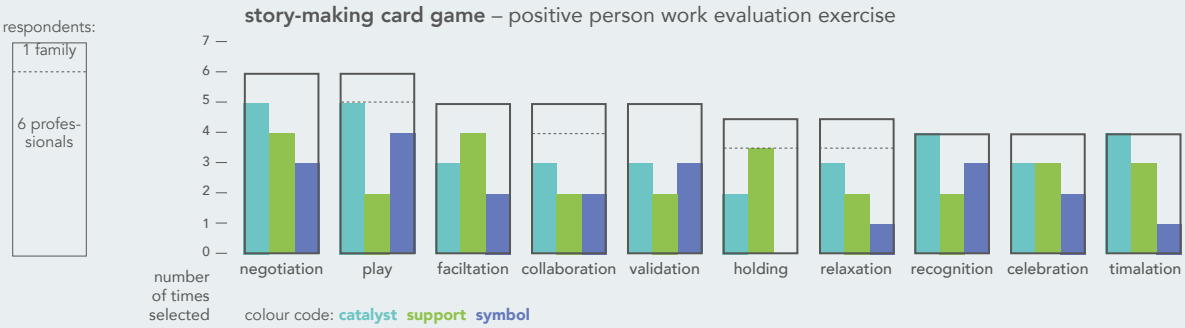


Figure 7.14 Results of the Positive Person Work evaluation exercise for the story-making card game.

The *catalyst* role of the story-making card game was clearly prevalent across all interactions since it directly stimulated people to make use of their abilities and participate in their own way. However, *support* was considered to be the artefact's main role in mediating **facilitation** and **holding**, due to the referred need of others to ensure they happen. For the same reason, this *supportive* role of the story-making card game was also associated with all interactions. The artefact was also found to *symbolically* represent most interactions, except **holding**. The artefact was considered to have a more *symbolic* role in **recognition**, **play** and **validation**, which is likely to be related to the visually playful, inviting, but not stigmatising or infantilising pictures.

VALUE

On the one hand, the story-making card game was appreciated both by older participants and professionals for acting as an incentive to creativity, allowing great freedom in how people contribute to the activity by embracing improbable and nonsense associations, thus lessening the possibility of error. In this way, the game provided an inclusive activity that enabled people with different abilities and ages to take part, generating a pleasurable environment and well-being in the group. Professionals valorised the quality, diversity, ease of use and versatility of the cards, which held interest and attention and encouraged involvement among the participants. The combination of pictures and words contributed to the collaboration between different people and permitted professionals to adapt the activity to different needs. Images were considered visually rich, not infantilising and descriptive, and more adequate for people whose language is weakened. Words, namely adjectives and verbs, facilitated narrative. The story-making card game was recognised as being appropriate and valuable in the institutional contexts, working well in small groups.

On the other hand, Laura's family said they were unable to engage her in playing the game, thus not accomplishing its intended purpose of promoting collective and convivial activity with their relative. New activity instructions were created and delivered to Laura's family based on the playing experiences in the institutions. However, the family did not play it again.

Participants mainly associated the story-making card game with the mediation of the following interactions:

— Negotiation, for the multiple options of choice both for the participants playing and for the person who facilitates the activity;

— Play, since the game stimulated personal expression and creativity and promoted a fun environment;

— Facilitation, because the cards unblock and facilitate narrative and participation;

— Collaboration, through the co-creation of stories and for the ice-breaking qualities of the game;

— Validation, due to listening and accepting the choices of others that the game encouraged;

— Holding and relaxation, for the easy-going and cosy environment that the game can provide, although depending considerably on how the activity is conducted.

Possibilities and suggestions

Possibilities of personalisation

Since the story-making card game was partially personalised for Laura and the possibility to develop it in a more personalised way was also taken into consideration, we asked healthcare professionals about their views on personalisation regarding this artefact. Even if the game had some personal elements of the participating family, these were general and diverse enough to be relevant for everyone. Most professionals did not believe that personalising the story-making card game was beneficial since it allows the activity to be personalised through playing:

> *"When I interpret an image, I am automatically personalising. My life history will have an influence on how I deal with the images or words and the associations I make with them. In that sense, the game is personalised at each moment".* (psychologist F, 23.03.2017)

However, one professional also pointed out the potential of using a personalised version of the artefact to do more individual life history work. The fact that pictures and words are not personal it allows the person to identify her/his own history without the pressure of recognising people or moments, and to speak about it in her/his own terms:

> *"To provide the opportunity of seeing a life history in images and words is more creative and adequate for someone with dementia ... it allows the person to enjoy their life history".* (psychologist C, 14.03.2017)

Playing at home

The disparity between the experience of using the story-making card game at the institutions and at home, as well as the differences between Laura's involvement perceived by her family and observed in the institution, initiated a discussion on how to ensure an appropriate and enjoyable use at home. Despite all the already acknowledged potential and positive outcomes that the game can provide, the cards are not enough to yield these outcomes, even if they have this potential. Professionals reinforced the argument that the success of the artefact highly depends on how the activity is conducted, as well as on the group, on the room setting, and on facilitator's sensitivity to observe and adapt the activity to each person, taking into consideration abilities and mood. In a family context, high expectations, fatigue, emotional

charge, lack of sensitivity, and the attention centred on only one person with dementia can be some of the reasons that can lead to an unsuccessful experience of playing.

> *"What bothers me to play this at home is that there will only be one patient. Everyone will be focused on her/his deficits, on the disease. It might become more heavy than ludic. ... It also depends on how is the family dynamics, if they are worn out, if they don't understand that some of the behaviours are symptoms and think the person is being stubborn or ill-disposed... if the family is not working well, then any strategy to implement at home will also be difficult".* (psychologist D, 04.04.2017)

The recommendations gathered among professionals mainly regarded guidance for using the cards. Different possibilities of play, with various levels of difficulty, should be suggested in order to demonstrate how the activity could be adapted to what is adequate and engaging to the person with dementia and suiting family availability. This also might also allow the family to adapt use throughout the progression of dementia. It was also proposed that the artefact could be presented less as a game and more as an activity. While the idea of a game might be stimulating, families might associate it with having specific rules and becoming less flexible about their relative response to the activity. Instead, the creativity and humour prompted through playing should be emphasised, challenging the family to 'lose their filter' of rationality and logic. It was also mentioned that it would be important to encourage sensitivity, possibly by including some guidance on how to communicate, pay attention to their relative's reactions, adapting and responding accordingly. It was also considered that if families could be engaged in making the cards, at least by including some blank ones to be personalised, the game could generate more interest.

After these interviews, the story-making card game was given to another participating family that was willing to try it. The different ways of playing used in the institutions were provided, and some of these considerations were shared with family members. This family reported that they laid out several cards, words and images, on a table, and asked their relative with dementia to pick a card and make associations. [Figures 7.15–17]

> *"The themes were always very simple, like words related with home, money... In general, he reacted very well to the stimulus and was able to make some interesting relationships between words".* (relative, family A, 26.05.2017)

The picture cards were mainly associated with his life history.

> *"For instance, starting from the card with the church, we spoke my parents' wedding. ... Of course, he did it with lots of help and many memory lapses. The most important thing is that he was always, during about 45 minutes, very collaborative and participative".* (relative, family A, 26.05.2017)

Other possibilities of use in institutions

Most professionals also highlighted the qualities of the game to work different cognitive domains, namely language, thus having the potential to be used therapeutically in cognitive stimulation programs. One of the professionals, an art therapist, also saw many possibilities of using the cards in arts and crafts activities, such as to continue the drawing from one of the cards, to construct a visual narrative or making a collage using the cards as a starting point, among others.

Cards

It was also suggested to balance the number of pictures and words (at the moment the game is composed by many more words than pictures, due to lack of time to produce more images); to make a version only with images; to produce theme specific decks to be used for cognitive stimulation, that can be added to the original deck (as in deck building games).







Figure 7.15–17
Using the story-making card game at home. (photos by the family members).



entertaining and appeasing tactile exploration
Use of different textures and warm and soft fabrics.

adequate and appealling
Visually stimulating and not stigmatising.

movement
Playful structure and smaller size to allow more possibilities of twisting, rotating and moving.
Vivid colours.

possible reminiscence
through crocheted textures.

involvement, warmth, relaxation
Sensorial stimulation. Offering comfort and warmth by being wearable.

accessilibity
The position of the circles in the garment allow person to explore the different textures, while wearing it.

embedding person's gestures
These artefacts were a response to a specific person's need to touch and hold things with her hands, and to the observation of her particular gestures to sense fabrics.
These artefacts are also a reference to her past devotion to knitting and lace-making.

7.2.4 THE TACTFUL THINGS

PRESENTATION

Main aims

The tactful things are designed to provide adequate and appealing sensorial stimuli, mainly based on touch. These artefacts emerged from the aim to entertain and appease Amelia, a lady with advanced dementia and no verbal communication so that her husband and main carer Gabriel could have a more relaxed time next to her.

Description

The tactuful things are two artefacts that make use of textiles to deliver tactile and visual stimulation, which generated from the participation of Amelia and Gabriel in the design process—Gabriel on the definition of the design brief, and Amelia in the configuration of the artefacts shape (the process of involving this family is described in detail in chapter 6). The choice of using textiles is related to Amelia's past hobbies of knitting and lace-making. The design of the tactful things takes into account the observation of how Amelia sensed the fabrics, feeling each of them individually with two fingers on both sides of the material, and the attention to her preference for soft and warm fabrics. Both artefacts were developed in collaboration with a fashion designer[4].

4 Carla Pontes has a degree in Product Design (2008) at ESAD Matosinhos and Politecnico di Milano, and a degree in Fashion Design at Citex-Modatex school, Porto. She presented her first collection in 2012, a few months after finishing her fashion studies, and was selected to integrate Portugal Fashion's incubation platform. Since then, she has been developing her homonym brand, showing her work at Portugal Fashion's national and international circuit. Since 2014, Carla teaches at Modatex fashion school. In 2015 she won the national prize at the European Young Designers Contest and in 2016 became part of the official selection of BID'16 – the 5th Bienal Iberoamericana de Diseño, organized by renowned Fundación Diseño Madrid.

Figure 7.18
The tactful things.





Figure 7.19–20
The shawl.

Poncho

The poncho joins the double function of providing sensorial stimulation and offering comfort and warmth by being wearable. It combines circles of different fabrics, placed at the front of the garment so that the person can easily reach them with her hands, inviting her to explore and discover the different textures. The chosen fabrics have distinct textures on both sides, and a variety of colours within a calm/muted spectrum so that it could also be visually stimulating, but still relaxing. The first iteration of this piece was a shawl. [Figure 7.19–20] It evolved into a poncho to enhance involvement and warmth. Although it was not the final prototype, this iteration could become an option for warmer days, when the poncho is too hot to be worn. [Figure 7.21]

Crocheted rings piece

The artefact consists of several rings combined in a chain structure, and provides a more active sensorial stimulation, through the way it allows moving, turning and twisting, which is reinforced by the choice of vivid colours. The rings were crocheted due to the possibility of having different textures and for the reminiscence value it could have, related to the Amelia's past hobbies. [Figure 7.22]



Figure 7.21
The poncho in use.
[video—click on image to activate]

USE

These descriptions are based on our observation of Amelia's use and interaction with the artefacts, as well as on the observation and comments of three healthcare professionals that occasionally brought her these pieces. Two other healthcare professionals that did not accompany the use of the artefacts were also asked to comment on the artefacts' potential.

Description of use

The use of the poncho was observed for about one hour. Amelia wore the poncho and engaged with touching the different textures, feeling the circles on both sides, and placing her hands between them. Sometimes, she also stopped these movements to look at the circles. It was only possible to observe Amelia using the crocheted rings piece for a shorter time. She placed the piece on her lap and was calmly feeling the different textures of the rings, and putting her hands and fingers between them. Another person was observed interacting with the piece. In this case, the person moved, rotated and twisted the artefact energetically, occasionally held it up with her hands, and praised its colours.

Although the original idea was for the couple to use these artefacts at home, Gabriel preferred not to take them home. Both pieces were left at the institution



Figure 7.22
The crocheted rings piece in use.
[video—click on image to activate]

for the healthcare professionals to give them to Amelia whenever appropriate. However, due to lack of resources to watch over, both pieces were not used many times, and the poncho was too warm to wear in summer.

Responses to use

Healthcare professionals also witnessed Amelia's positive reaction to both artefacts:

> *"She was pleasantly involved with the object [the poncho], which also warmed her".* (psychologist C, 14.03.2017)

This was observed when both pieces were tried but also confirmed with the observation of healthcare professionals over a longer period of time:

> *"It worked really well. She was very focused, paying attention to the textures. ... Every time we dressed her the poncho she was very... the colours, the textures... she was radiant and curious about the textures all the time ... regarding the little one [the crocheted rings piece], which we gave her more often because it was summer, everytime we had to take it away from her (because it was mealtime, or something else), she would refuse. She wanted to keep it".* (psychologist E, 23.03.2017)

Appeasement

The healthcare professionals found the development of artefacts rich in textures and colours appropriate and pertinent for Amelia. They referred that she used to be unreceptive to most stimuli and activities in the institution, thus highlighting the importance of the careful process of looking for what she engaged with. Healthcare experts also mentioned that, while being visually stimulating and pleasant, these objects responded to her need to hold, touch and move with her hands, which all professionals mentioned being common in people with advanced dementia.

> *"Many of them, with an object in their hands ... it seems that things become different".* (psychologist A, 15.03.2017)

Therefore, both pieces were opportunities for distraction and appeasement. Gabriel also recognised that the artefacts might have partly helped his wife to become calmer and less aggressive.

Reference to idiosyncrasies

Professionals also applauded how the preferences and history of Amelia determined and were embedded in the design of the artefacts, as well as the careful observation of her current gestures and responsiveness:

"If we can understand those particularities of each person in order to reach them, it is important, it can work".
(psychologist A 15.03.2017)

Aesthetics

One of the healthcare professionals added that the aesthetic value of the artefacts contributed to counter the stereotype of dementia:

"They are also beautiful elements. For us, caregivers, we recognise that that person deserved that a designer worked on something for her. ... Maybe it is a positive wake up call. Because, if someone did this, just the fact that, with the poncho, the lady became prettier, I believed it worked the stereotype of dementia. It questioned it. Why did someone design this for someone that most people think doesn't care what she is wearing?" (psychologist C, 14.03.2017)

Positive Person Work evaluation exercise

The exercise was conducted with five healthcare professionals. All of them elected **timalation**, **recognition**, **relaxation** and **holding**, and four chose **facilitation** and **validation**. **Play** and **celebration** were also selected twice, and **collaboration** was picked once. No one selected **negotiation**.

1. Timalation

Timalation was an obvious choice for all participants, due to the artefacts' focus on sensorial stimulation

"the colour, the movement, the touch... Also, the possibility to include other stimuli with sound and smell".
(psychologist A, 15.03.2017)

2. Recognition

Recognition was associated with the objects for two main reasons. The first one is related to the inclusion of personal aspects to create an artefact for a specific person, which was referred to be a way to valorise the uniqueness of that person. The second reason is linked to challenging the dementia stereotype mentioned above, thanks to the aesthetic qualities of the artefact. Another professional reinforced this idea since she believed that through seeing the Amelia engaged in an activity, able to do something, others could recognise her value:

"They saw she was able to do something ... and recognised her potential. ... This is very good, and also promoted the inclusion in other activities". (psychologist B, 29.03.2017)

3. Relaxation

Participants believed the artefacts assisted Amelia to **relax** due to the touch and warmth they provide, as well as the choice of soft and pleasant textures that were likely to comfort her:

> *"the fact that it promotes some comfort will help the person's restlessness, and support the person to stay calmer, more relaxed".* (psychologist A, 15.03.2017)

4. Holding

Similarly to **relaxation**, **holding** was associated with the artefacts' capacity to soothe and comfort, thus contributing to a feeling of cosiness and safety—specially the poncho where this aspect was enhanced by the fact that it can be worn, hence more involving.

5. Facilitation

Participants selected **facilitation** because the artefacts enabled Amelia to use her abilities. Moreover, the artefacts **facilitated** exploration, meeting a common need of people in more advanced stages of dementia to hold and move things with their hands.

6. Validation

Some participants mentioned that the artefacts helped others to interact with Amelia, allowing her to connect with others:

> *"Although she doesn't speak, there are other things that communicate at a higher level. It was noticeable that she understood that there was empathy and sensitivity towards her. She felt recognised".* (psychologist E, 23.03.2017)

7. Play

Participants who chose **play**, referred Amelia's enjoyment when using the artefacts:

> *"you can notice in her facial expression that is an pleasant activity".* (psychologist B, 29.03.2017)

8. Celebration

Celebration was associated with the presence of Amelia's personal references and preferences in the artefacts, and to the fact that they do not make cognitive demands:

> *"I also chose* **celebration** *because it is something that does not expect anything from the person on that task. Everything is possible. ... Whatever she does will be positive and has value".* (psychologist A, 15.03.2017)

9. Collaboration

Most participants did not choose **collaboration** since these artefacts essentially provide an individual activity. However, the participant who chose **collaboration** referred that the **recognition** and **validation** these artefacts contributed to, promoted the inclusion of this person in other activities.

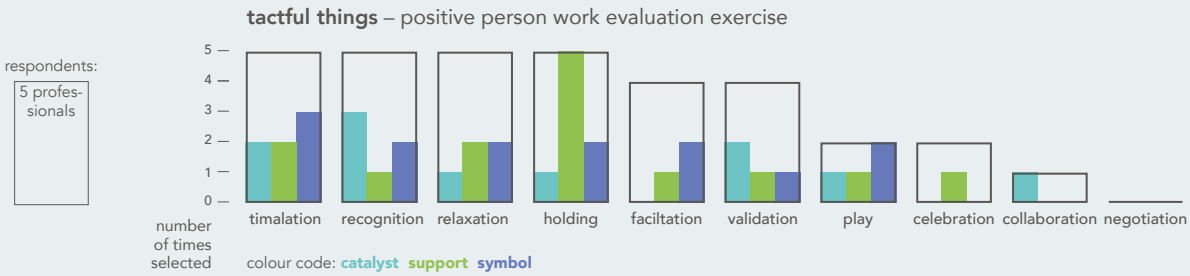


Figure 7.23 Results of the Positive Person Work exercise for the tactful things.

The tactful things were considered to have more *symbolic* and *supportive* roles in the mediation of most interactions. The artefacts were less associated to being *catalysts*, which is probably related to the advanced stage of dementia of the person to whom they were designed for. However, the *catalyst* role was found relevant in promoting **recognition** and **validation**. This might be justified by the potential of the artefact to be a contact point between the person with dementia and others, or by calling the attention of others to **recognise** and **validate** that person. The *support* role was substantially attributed to **holding** since it relies more on the presence of others.

VALUE

The tactful things were valued for providing sensorial stimulation without being cognitively exigent, which is important for people in later stages of dementia. Both artefacts facilitate exploration and appeasement in different ways, using pleasant and comforting materials: one is warmer and more involving since it can be dressed, and another one is more playful and dynamic. The use of these artefacts can help a person to relax and to feel comforted and secure. The involvement of Amelia in the design process, the references to her idiosyncrasies in the artefacts, and their appealing look were considered important to valorise her and to encourage others to recognise her uniqueness and value.

All participants associated these artefacts with the mediation of the following interactions:

- Timalation, for the multi-sensorial stimulation the artefacts provide;
- Recognition, due to the personal references that influenced design ideation and the questioning of dementia stereotypes;
- Relaxation, since the artefact quiets restlessness, thus helping the person to relax;
- Holding, because the artefacts appeasing qualities can provide comfort, cosiness and safety.

Possibilities and suggestions

Although these artefacts were designed with and for a specific person, which was considered crucial, professionals also referred that both artefacts could be engaging for others. In fact, other people in the institution sporadically used them and responded positively to them. One healthcare professional suggested that, namely if it involves knitting or crochet, many people attending the institution can be also involved in making their own piece, or to do it for others. Moreover, it was proposed that different types of stimuli (smell, touch, other activities like tight/untight, button/unbutton) could be included in this kind of artefacts for sensorial stimulation.

7.3 Experiences of underuse and non-use

Participants shared several reasons for not using the artefacts. These were related to the condition of dementia, to how the activities using the artefacts were conducted and, in some cases, to the artefacts themselves, particularly because they lacked guidance on how to use them.

Most family members mentioned that using the board game, the story-making card game and the cards-about-what-matters, became more difficult due to the progression of their relative's condition. A striking example is one person who almost lost her language from the beginning of the personalisation process to the evaluation moment:

difficulties due to the progression of dementia

> *"nowadays she uses around four to five words for everything ... it was not like this when we started this process".* (relative, family B, 24.03.2017)

Other families mostly referred the gradual loss of interest of their relative to take part in activities in general, and the difficulties in responding to them. However, in the previous case of the family whose relative lost her language, they were able to adapt the activity to include her:

> *"we [the family members] played more and, in her case, she would identify the pictures, she was very happy to see them ... she also did more mechanic activities. ... I found it a very positive moment". (relative, family B, 24.03.2017).*

Nevertheless, most families felt that the artefacts did not accompany the progression and that they did not know how to adapt the activity to those changes. Moreover, some families were aware that the activity could confront their relative with their difficulties:

possibility of activities to confront person with dementia with their difficulties

> *"he keeps looking at the picture and... it seems he got constrained because in some way he thinks he should know it, but he doesn't. I mean, I am imagining that he might eventually feel that".* (relative C, family A, 05.03.2017)

This is connected to the second reason concerned with the impact of the activity dynamics on the experience of using the artefacts. This became one of the main differentiating factors between use in the institutions, conducted by a healthcare professional, and at home. Most families were unsure of how to communicate and adapt use, and this was not clearly addressed in the artefacts:

influence of how activity is conducted

> *"Sometimes, I don't know if I am doing it well or not. A more objective perspective, taking into account the person but also the characteristics of the disease. I felt that lack".* (relative C, family A, 05.03.2017)

Some professionals explained difficulties of families to engage their relatives in activities. Family carers might have high expectations and focus on the person's difficulties, they might get nervous and anxious to see their relative fail, they might lose their patience. There might be a high emotional charge. Many times, family carers might also be experiencing burnout and fatigue, and do not have the necessary emotional availability and sensitivity

hindrances to use in family context

to undertake this kind of activities. Additionally, another aspect that distinguishes institution and home environment, is the fact that in a family context there will only be one person with dementia, which might put her/him on spot, emphasising and confronting the person with her/his difficulties, and possibly infantilising her/him. Besides this, the lack of availability, time and, in a few cases, the distance of not living in the same city, made use difficult in family contexts.

hindrances to use in institutional context

Despite the active collaboration of the two institutions, they also recognised that in institutional contexts, the use of such artefacts might be impeded mainly due to the lack of human resources, and sometimes to some resistance to using new materials.

Specifically in the case of the tactful things, other factors were an obstacle to use. These included the type of fabrics, chosen to be warm and cosy, but too hot to use in summer. In addition, the fact that there was only one prototype of each artefact also hindered use, as professionals found them too 'unique' to be used without having someone to watch over.

7.4 Experiences of personalisation and participation

Participants were also questioned about their views on the relevance of personalisation. Their comments embraced both their experiences of using the personalised artefacts and participating in the process of personalising.

advantages of personalisation

In general, participants considered personalisation one of the most important and distinguishing aspects of the research project, both for the possibility of having personalised products and the opportunity for people with dementia and their families to take part in the process of codesigning. Personalised artefacts were found to be more adequate to the people they were created for, contributing for the person to recognise her/his own references, which becomes even richer if the person was directly involved in the process of personalising.

Personalisation allowed to adapt the artefacts to different experiences of dementia, which happened both in the cases where the artefact was open to being personalised—both through including personalised content or through the collective making of the artefact—, such as the board game, or those cases where a personalised brief was defined and a new product developed from scratch to meet the needs of a specific family, like the tactful things. Personalisation was considered to be a good starting point for the design of new artefacts, even if the artefacts emerging from this process can suit other people, such as the story-making card game. In this specific case, although there were some personal elements, the game was general enough to be appropriate for the groups in both institutions. Considering that the

personalisation as a good starting point for the development of artefacts for people with dementia

story-making card game was played in group activities in institutions, having personal content was not seen as an advantage; however, the game's versatility was emphasised, since it allowed use to be adapted and personalised as it was being played.

Professionals considered the participation of people with dementia and their families in the personalisation process as the most positive and significant aspect of the project. Giving persons with dementia a voice in the design of the artefacts was seen as a way to acknowledge and value them. According to one of the healthcare professionals, this kind of project *"affirms people's identity"* (psychologist C, 14.03.2017). Apart from identifying with their personal references, they might also recognise their participation in the design of the artefact, which might contribute to the engagement with the materials:

significance of the involvement of people with dementia

> *"It is also important that people look at the materials and recognise them because they were involved in the making. It is important that the patient feels involved in the process, feel part of it, and not someone from outside".* (psychologist A, 15.03.2017)

Moreover, the participatory process was deemed enjoyable and stimulating. Some healthcare professionals and family members referred that this involvement heightened the capacities of participants with dementia, supporting them to feel more confident, which, in some cases, contributed to bonding. For instance, during the development of the tactful things, the person involved in this process started showing more interest and becoming more engaged with other things they use for stimulation in the institution. She also became more available to connect with others, which healthcare professionals also attributed to her participation in the design process [chapter 6]. It was also found essential that people were encouraged to enjoy the process, participating at ease without worrying about the final results.

The importance for the families to participate in such process was particularly emphasised by some professionals:

importance families' involvement

> *"The condition is so incomprehensible for most people that it can help, in some way, to understand that person as another person, that was affected by a disease but is still there, that has her/his capacities and limitations. And, maybe, it helps to manage those limitations ... it ends up diluting the incapacities of the patient".* (art therapist, 15.03.2017)

In addition, it might also contribute to deal with grief and loss:

> *"Essentially, I think these kind of products are a celebration of a person's life. ... It will benefit those who stay and gradually feel the loss. They [the family] will always remember that moment where they participated, as something very beautiful and positive".* (psychologist C 14.03.2017)

Family members characterised their participation in this project as positive, stimulating, gratifying and worth it, even in the cases where their relatives did not respond so well to artefact:

> *"at least we didn't fail because we didn't try. We tried, but sometimes things don't go as we expect".* (relative, family C, 23.02.2017)

In general, families enjoyed collecting and thinking about the content for personalisation. One family referred that participating was interesting to make them think about the disease of their relative and to pay more attention. Another family member commented that participating in this project was an incentive for her to do more. The family that opted to illustrate the board game together referred that such moment created a good integrative family dynamics that accounted for the effective participation of the person with dementia. Nevertheless, although they found the personalisation process worthy, family members' major constraints were the lack of time and availability. Additionally, it is important to mention that in some cases the project reinforced the relationship between family members and institution, since the product became a way for some families to continue the work of the institution at home.

professionals' experience of participation

The three professionals that collaborated since the beginning of the project were also asked about their experience of participation. They all found it pleasant and enriching, challenging them to work in a different way, namely in putting an effort on finding ways to facilitate the participation of people with dementia, through the observation of how people expressed themselves. Although they strive for having a big variety of activities, the project brought some novelty. One of them also mentioned it was rewarding because she sensed that people felt valued through this process. Some participants also mentioned the accessibility and availability of the researcher and highlighted her sensitivity and competence to work with people with dementia, namely the attention given to non-verbal communication.

7.5 Conclusions

To conclude, the annotations made for each artefact are brought together in an overall vision of the collection, towards the construction of an annotated portfolio (Gaver & Bowers, 2012). This analysis dwells on the relations between the artefacts and Positive Person Work interactions, on the significance of including people with dementia to participate in the project and on how the artefacts facilitated ludic interaction and communication between people with dementia and their families, and discusses the importance and possible strategies to guide the use of artefacts and manage personalisation.

collective analysis of Positive Person Work interactions regarding artefacts

7.5.1 Artefacts seem to mediate Positive Person Work

Although there were some critiques to the artefacts and difficulties in using them (namely in family settings), the feedback about all artefacts was mainly positive. When asked to associate the Positive Person Work interactions to

the artefacts, none of the participants had difficulties in selecting at least a few. Some participants chose all the interactions they considered the artefact could mediate, even if they pointed some that they could be hindered by how the setting or how the activity was conducted. Other participants selected only those that they believed were more obvious to occur through the use of the artefact. Nonetheless, although there were different opinions and choices of the interactions regarding each artefact, the justification for the selection was most times coincident and complementary.

The exercise conducted with professionals to reflect on the roles the artefacts could have in the mediation of these interactions—*catalyst*, *support* or *symbol*—yielded more complex and diverse results. Considering all artefacts together, **recognition** and **holding** were the interactions elected more often by participants. The artefacts were found to be mainly *catalysts* and *symbols* of **recognition**, which was linked with participants' main association of this interaction with the inclusion of personal content and activities that acknowledge people's stories and characteristics, as a way of respecting and valorising them, and something that people could identify with. Conversely, **holding** was considered to be essentially *supported* and encouraged by artefacts, but not so much mediated *symbolically* or *directly*, since it mainly depended on others and how the activity was conducted. **Holding** was associated with the familiar themes and activities that were also regarded as crucial to make people feel secure in participating, to the promotion of a comfortable and friendly environment, namely if playing among those who are close, to the encouragement of bonding, and to the feeling of safety that can emerge from it. This was also regarded as being closely connected to **relaxation**, which was the third most often chosen interaction, connected to the creation of a comfortable and easy-going environment. The artefacts were viewed both as *catalysts* and *support* for **relaxation**. Although its occurrence was also conditioned by how others facilitated use, the ludic function of the artefacts was believed to directly contribute to making participants at ease, encouraging them to participate without feeling judged, and constituting an entertaining distraction and appeasement.

Play was also markedly linked to the artefacts, mainly considered *catalysts* and *symbols* of this interaction. Once more, the ludic purpose and, in this case also the playful appearance, stimulated a fun and enjoyable environment, where there was space for personal expression and creativity. The *symbolic* aspect was probably related to the enjoyment and pleasure revealed when using the artefacts, but also to the game elements. Particularly in the board game, the playing pieces and dice seemed to have contributed to creating a playful mood among the participants.

There was a balance in the *catalyst*, *symbol* and *support* roles attributed to the artefacts in the mediation of **facilitation**. This interaction corresponded

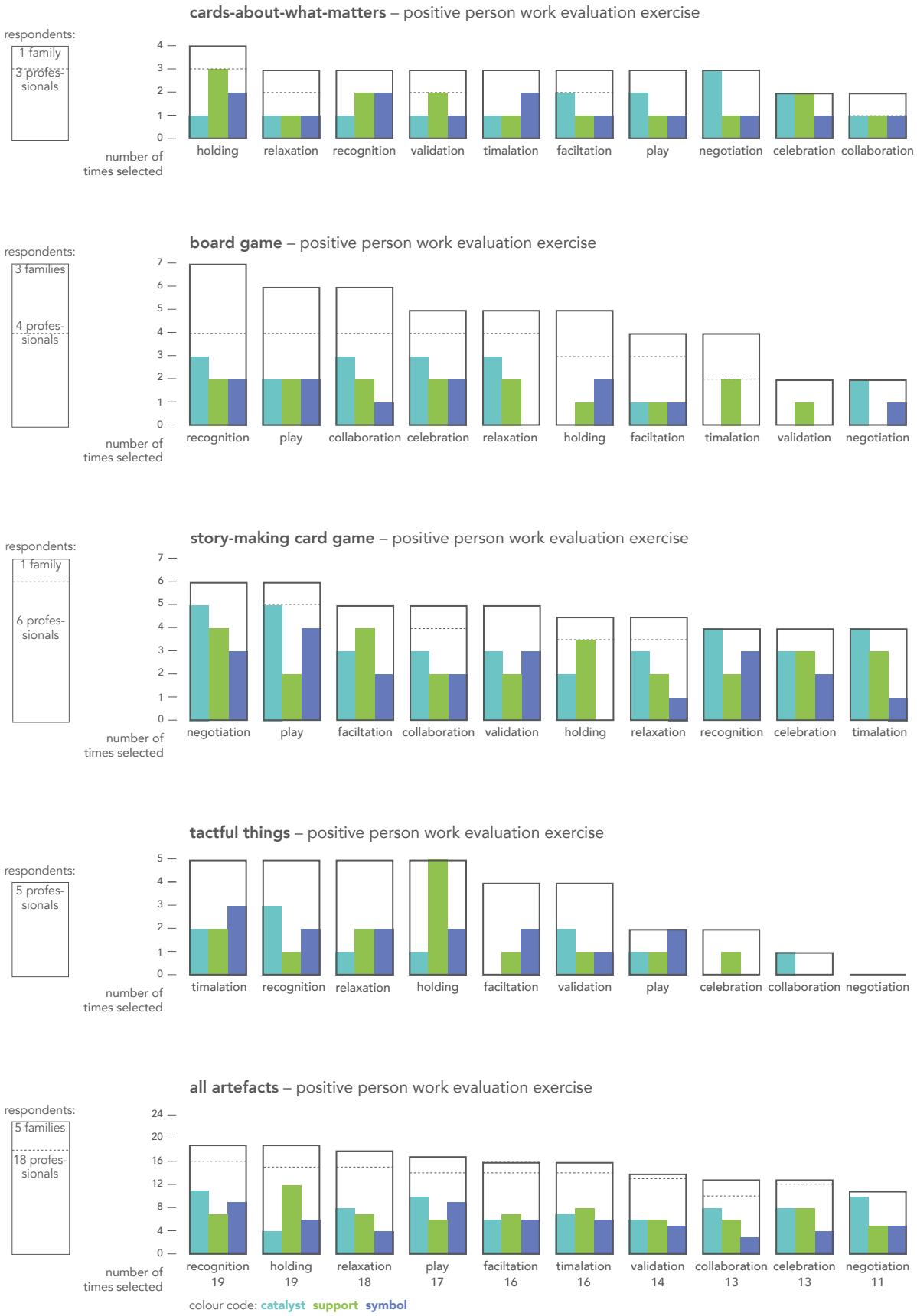


Figure 7.24 Results of Positive Person Work evaluation exercise for each artefact and joint analysis of results.

to the artefacts' capacity to assist the person to use their abilities, and unblock communication through the use of different types of prompts and cues, which needs to be in part stimulated by the person conducting the activity.

Although only the tactful things had more multi-sensorial qualities, **timalation** was also selected regarding the other artefacts, due to their visual appearance. This interaction was also found to be *catalysed*, *supported* and *symbolised* by the artefacts in a balanced way, with *support* having briefly more prevalence. This is likely to be related to the possibility of using the materials as prompts, working and reminiscing about the senses indirectly.

The three roles were also equally assigned to **validation**. Although the presence of others and the activity dynamics are crucial to the development of this interaction, the space created for personal expression, and specifically the turn-taking aspect of the games, encouraged to listen, respect and acknowledge the stories and choices of others. Also linked to **recognition**, the inclusion of personal material might *symbolically* contribute to **validation**.

Many participants elected **collaboration** concerning the board game and the story-making card game, which promote collective activities that bring together bigger groups. Both the cards-about-what-matters and the tactful things suited an individual use, or involved only one carer. **Collaboration** was found to be both *catalysed* and *supported* by the artefacts, for constituting opportunities to invite people to participate in a joint activity, for their ice-breaking qualities that can encourage well-being in the group and the participation in other activities, and in the case of the story-making card game, for supporting co-creation.

Although the artefacts were considered to promote a joyful and convivial atmosphere, namely through their ludic function, **celebration** also relies on the operationalisation of the activity. This is reflected in the even choice of *catalyst* and *support* roles for artefacts concerning the mediation of this interaction. **Celebration** was also associated with the references to people's lives and preferences in the artefacts, as well as to the development of artefacts that do not make cognitive demands, such as the tactful things, thus applauding and celebrating all kinds of responses.

Finally, **negotiation** was the least selected interaction, even if it was the most chosen for the story-making card game. According to the participants, the other artefacts do not offer many options for people to choose from. Many of them also related this interaction with the increasing difficulties people with dementia have in exercising control. However, **negotiation** was also associated with the personal expression stimulated by the artefacts. With a noticeable difference from other roles, artefacts were found to be *catalysts* of choice, namely through the presence of multiple-choice.

7.5.2 The artefact is not enough

differences between use in familial and institutional contexts

The dissonant experiences of use shared by participants revealed different ways of approaching the artefacts, namely in the board game, the story-making card game and the cards-about-what-matters, depending on the activity operationalisation and the capacity of the facilitator to adapt use, observe and respond to people's reactions. The institutional setting, that included healthcare professionals and more people with similar mental health conditions, facilitated a beneficial use of the artefacts. At home, although many families have the need and will to communicate and have meaningful moments with their relative, the setting, the emotional charge, the lack of sensitivity and other reasons mentioned above, make it more difficult to use the artefact in an enjoyable way. Many times, family members recognised they were unsure of how to approach the artefact, and how to deal and respond to certain reactions of their relatives. The suggestions to tackle this issue are:

recommendations to support use at home

1. the provision of different ways of using the artefact, from more demanding to less exigent, so that people are aware of different possibilities of use which can suit their relative with dementia, their circumstance in a specific moment, or to accompany the progression of dementia, so that they do not get attached to a particular way of using.
2. the provision of 'technical support', as one family called it, meaning that each artefact could be accompanied with some simple recommendations on how to engage with a person with dementia in an activity, how to stimulate her/him to participate, how to respond, what attitudes to avoid, among others, in order to ensure a better use of the artefact. In this way, the artefacts could also become vehicles of communication strategies that can be of overall relevance when caring for someone with dementia (Downs & Collins, 2015; Killick & Allan, 2001).

7.5.3 Many times, the process is more important than the final output

involvement of people with dementia and their families is beneficial and worthy

The importance of inviting people with dementia to participate in the design process was often emphasised by participants, as described in the previous section, not only for their crucial input to more adequate and personally significant artefacts, but also for the possibility to take part in something. The participatory design process can be cognitively stimulating, enjoyable and meaningful, and since it gives voice to people with dementia and values

their contributions, it can contribute to reinforce identity and support bonding. The involvement of families in such process might be equally important. It can challenge them to pay more attention to the person, seeing beyond the disease, and encourage them to do other activities, which might also help to deal with feelings of grief and loss. Moreover, as also suggested by Rodgers (2017), participatory design project can be a means to publicly raise awareness and demonstrate how people with dementia can still contribute to society, in a bid to reduce stigma and isolation.

involvement of people with dementia as a way to counter the stereotype and raise awareness

Therefore, regardless of the final output, codesigning with people with dementia and their families is deemed to be relevant and beneficial per se, and thus should be encouraged. This strengthens the idea of developing open artefacts since it becomes a way to invite and enable people with dementia and their families to participate. In addition, it is pertinent not only to carefully design the artefacts, but also to mindfully craft the participation and the codesign activities, which, in turn, can be influential too on the design of the artefacts.

design of open artefacts and subsequent codesign activities, as strategy to provide more opportunities for people with dementia to participate

7.5.4 Personalisation is ideal, but…

Personalisation was appreciated by all participants interviewed as one of the differentiating and significant characteristics of the project and artefacts developed. In general, the process of personalisation was valuable in itself, as explained in the previous point, with the advantage of yielding more appropriate and engaging specific artefacts. When asked whether general and not personalised, products would be preferable, all participants mentioned that it would be a shame to lose personalisation. However, personalisation can also be an obstacle for artefacts to reach people with dementia. To personalise an artefact requires motivation, energy and time, which is often difficult for both families and institutions due to availability constraints. Therefore, most participants preferred a personalisation option that would not take too much effort and time. The possible degree of personalisation also depends on the artefact to be personalised and what it demands. For instance, the family who personalised both the board game and the cards-about-what-matters commented that it was enjoyable and interesting to personalise the cards from scratch (which is required by this artefact), but it would have been too much to do it for the board game, where they only personalised a few stops. Therefore, in order to maintain the possibility of personalisation, it is necessary to provide different options of personalising so that people can opt for what suits best their situation and find a balance between having a personalised artefact and the effort it requires.

personalisation can also be an obstacle

importance of providing different options for personalisation

different ways in which personalisation happened

Following that, these interviews pointed out that personalisation can happen in different ways. In this project we have been using two personalisation strategies related to the inclusion of personal content in the artefact, and to the design of artefacts that starts from the collaboration of a designer with a specific person and family, taking their needs, preferences, characteristics and stories into account. However, personalisation can also be about the participation in making the artefact, as an activity. Thus, even if the content is not personal or personalised, the action of making also personalises the artefact. This option can be more suitable for groups, such as in an institution, where the use of personal content might be difficult and less relevant, due to the number of people. In addition, personalisation can also happen through use, when the activity is adapted to a person, or when the artefact encourages personal expression. Thus, if artefacts are versatile, they can allow use to be personalised too. Despite how personalisation is done and to which degree, it was also found crucial to provide guidance and support to any of these processes. In this way, personalisation can occur at the 'beginning', as part of the design process, embedding personal content and characteristics in the design of the artefact; in the development, by filling it with personal content; in the making, with or without including personal content; and through use, if artefacts are flexible enough to allow it. Although dedicated and personalised artefacts would be ideal, considering these alternatives, which are also valuable possibilities, might ensure that the artefacts can be more easily accessible to people with dementia and their families, with some degree of personalisation.

7.5.5 Communication and meaningful moments

Despite the different experiences with each one of the exposed artefacts, all of them contributed in different ways to the communication between people with dementia and others. They generated cosy and pleasurable moments, where participants showed signs of well-being, such as their engagement in the activity or their smiling and interested facial expressions. Both games and the cards-about-what-matters provided opportunities for conviviality, prompted by the activities, which encourage communication and interaction among who is playing. The ludic aim of these artefacts promoted an easy-going and fun environment, important to remove some pressure and make people feel at ease. Creativity and freedom of interpretation, namely on the story-making card game, contributed to include and encourage collaboration between people with different abilities and ages. The personalisation of artefacts through the inclusion of personal elements

ludic function promoted conviviality, easy-going and fun environment

creativity and freedom contributed to collaboration

was important for people with dementia to recognise their references and identify with the artefact, as well as to feel secure and engage with themes that are familiar and stimulate reminiscence. This was particularly important for some families where sharing and remembering their stories nurtured unity among different generations. All artefacts offered moments of distraction and appeasement, which helped people with dementia to relax by focusing on an activity and, through that, they became more available to connect with others, verbal or non-verbally.

personal elements contributed to meaningful moments

relaxation and appeasement contributed to availability to connect

8 Concluding remarks

In this chapter, we present a more general description and deliberation about the research activities, bringing them together to respond to the research questions that delineated this project. We conclude by presenting some possible directions for further research and implementation of this project.

This thesis started by presenting our research approach. [Chapter 2] This was composed by a strong focus on design as the main form of inquiry (Brandt et al., 2011; Gaver, 2012); the choice of participatory design (McCarthy & Wright, 2015; Sanders & Stappers, 2008; Vines et al., 2013) and design anthropology (Clarke, 2010; Gunn et al., 2013) as main methodological approaches; and the compelling influence of dementia care literature, also used as ethical guidance, namely the ideas on personhood and Positive Person Work put forward by Kitwood (1997), the emphasis on communication and relationships, creativity and playfulness explored by Killick, Allan and Craig (Allan, 2001; Allan & Killick, 2008; Killick, 2012; Killick & Allan, 2001; Killick & Craig, 2011), as well as by Zeisel (2009), the person-centred values and its application to dementia care services explicated by Brooker (2007), and the aesthetic approach to people with dementia proposed by Hughes (2014), among others. These references, interpreted through a design lens, became the theoretical foundation for design practice, used to respond to participants and generate tangible proposals, and a series of participatory encounters where artefacts were codesigned, tried and analysed.

In the following chapter, we introduced figures and facts about dementia, exposed in an entirely visual way, in an effort to understand better and to make this information easier to grasp. [Chapter 3]

Further to this, we described our preliminary observational study [Chapter 4], a design-led observation that combined the strategic and poetic gaze of design, with the structured, systematic and detailed look of ethnography. The importance of this personal contact with people with dementia and healthcare professionals at institutions was emphasised, as a means to gain sensible and practical insights: the sensitivity and ethical awareness;

the structure, the exercises and the flexible and warm environment created in institutional activities. These were found to be invaluable for configuring and doing participatory design events with people with dementia. During this preliminary phase, we also developed the first design experiment, the board game, which was both a way to materialise the findings of the observation in a tangible artefact, and a proposal to take some of the activities undertaken in the institutions to family contexts, in a familiar format. It was also the first opportunity to include people with dementia and healthcare professionals in the project, to make the game together. These initial encounters, during the observation-based study and the participatory events to produce the board game, were important starting points to configure the core work of this research, where people with dementia and their families were involved.

As a complement to the observation, and as a way to embed dementia care literature in the design practice, we sought to identify the Positive Person Work interactions suggested by Kitwood (1997) in our fieldnotes. Based on the theoretical and empirical understanding of these interactions, we developed a speculative exercise that deconstructed them and brainstormsed about how they can be communicated, mediated and elicited through the design of artefacts. [Chapter 5] This exercise resulted in a reflection and a series of considerations and strategies to design for people with dementia, as well as how to involve them in the design process taking into account these ten positive interactions.

Based on both preparatory research activities—the observational study, (including the board game development) and the speculative exercise— we embarked on the main research moment of codesigning with families [Chapter 6]. Here, we explored the ideas of personalisation and openness, as a means to attend to people's uniqueness and design something more adequate and engaging, as well as to support their participation in the codesign process. Two strategies were used inquire into these ideas: families were challenged to try and/or comment on already designed artefacts (the board game developed during observation, as well as the cards-about-what-matters and the family book, which were outputs of previous research), and to personalise them according to their idiosyncrasies. Alternatively, if families did not find any of the artefacts suitable for them, they were invited to participate in the definition of a personalised brief and consequent design process of developing the artefact. As a result, four families personalised the board game (one of which also personalised the cards-about-what-matters), and other two were engaged in developing new artefacts from scratch, which yielded the story-making card game and the tactful things. Throughout this process, and in order to make it happen, our participatory design approach was gradually being defined and readjusted to respond to the participants. The person-centred dementia care values delineated by Brooker (2007), were translated to the configuration of participatory design: (1) welcoming everyone regardless of cognitive ability

and progression of dementia; (2) having an open and flexible attitude to adapt to and support different forms of participation; (3) ensuring that participatory events become moments of conviviality, and that are enjoyed and by participants, without the pressure of achieving results. Besides this, drawing on the learnings from institutional activities obtained in the observational study, as well as on the work of other design researchers who involved people with dementia in design processes and research (Hendriks et al., 2014; Hendriks et al., 2015; Hendriks et al., 2013; Lindsay et al., 2012; Wallace et al., 2013), we carefully prepared the participatory encounters, based on the use of tangible artefacts and on making things together, being mindful about the simplicity and accessibility of tasks and tools, designed to facilitate participation. As the meetings with families progressed, we realised the importance of being open to respond and support their preferred ways to participate. Like this, the research goals, which were presented clearly from the beginning of the collaboration, functioned as an infrastructure for an open codesign process, where participation, design and use were negotiated with the different participants from each family, and in diverse ways, also involving the healthcare professionals. Even though participation was kept open, this process could have been made even simpler, by suggesting distinct possibilities of participation upfront. In addition, more guidance, and a range of options for personalisation, could have also been provided from the beginning.

As the collaboration with families was being concluded with the production of final prototypes, families kept the artefacts to try them. To conclude and discern the value of both the participatory design process and the artefacts, we conducted a summative evaluation. [Chapter 7] Family members and healthcare professionals were interviewed about the artefacts and its use (or non-use), and their participation in the project. In addition, an evaluation exercise was devised to understand if participants perceived and associated the Positive Person Work interactions to the artefacts. This research moment was pivotal to reflect and discuss on pertinent aspects of the project in general, and specifically about participation, personalisation and the artefacts in use: the value of inviting people with dementia to participate in a codesign process, seen as a tribute to their identity; the relevance of personalisation, and how it can be approached in different ways beyond those primarily explored; how the artefacts were used in both familial and institutional contexts, as well as how, and why, they were misused or not used at all; the perceived role of these artefacts on the mediation of Positive Person Work interactions, and subsequently its potential to provide opportunities for communication and meaningful moments; the emphasis on the ability and sensitivity to facilitate a successful use; and further directions on how to support and provide recommendations of an appropriate and positive use.

After this general overview of the main research moments and contributions, we return to our research questions.

8.1 How can artefacts be designed so that the personhood of people with dementia is maintained and respected?

This research question is mainly addressed and explored in chapter 5, but also present throughout the research, in the design of artefacts, in the participatory events and tools to support them, and finally in the evaluation moment.

This question emerged from the conviction that everyone, irrespective of age and ability, deserves carefully designed artefacts (including both pragmatic and hedonic attributes) which, in the context of dementia, can play an important part in supporting and mediating communication. After getting acquainted with person-centred dementia care literature, and the idea that respecting and maintaining personhood should be the main effort of dementia care, we sought to understand how design could endorse this task. The idea that specific interactions can support the psychological needs of people with dementia and contribute to their well-being—Positive Person Work (Kitwood, 1997)—seemed to be an interesting starting point. Drawing upon Hassenzhal's (2010) research on experience design and Desmet and Pohlmeyer's (2013) proposal of Positive Design, we speculated on how to design for the experience of these specific interactions, taking into account different roles that artefacts can have in mediating them. The result is a reflection on how to be mindful about possible positive outcomes that artefacts might have on supporting well-being for people with dementia and their carers, as well as a set of considerations and potential strategies to design for the experience of these interactions.

While in this reflection [Chapter 5], Positive Person Work interactions are interpreted from the point of view of design, of who designs; the evaluation [Chapter 7] brings also the perspective of who uses. This shift brought important considerations and conclusions, some of which were posteriorly included in chapter 5. Being aware that some of the considerations presented were subtle, it was insightful to hear the analysis made by who uses, families and healthcare professionals, and to understand what design intentions become apparent and how they are perceived. Although many times they overlap with the design intentions, the observations made by participants were revealing. For instance, it was surprising that **holding** was one of the most favoured interactions when, from a design point of view, it was more difficult to find design strategies to deliberately mediate and promote it through an artefact; or that **relaxation** was associated with the use of all artefacts for the fact that they were a ludic occupation, whereas we mainly associated it with the specific intention to slow down and relax. The perspective of use also reinforced the role of the caregiver in ensuring a beneficial use of the artefact, and in promoting these interactions. Despite the value attributed to the artefacts, and even if families

were involved in the process, the artefacts are not enough to provide the experience of these interactions. Although the designed artefacts aimed to create opportunities for people to communicate (including the tactful things, even if in a more subtle way), they always need to rely on caregivers to be used. The evaluation interviews highlighted this aspect, suggesting that a bigger effort should be put on supporting an adequate, sensitive and flexible operationalisation of the artefact, namely in family settings where, usually, there is only one person with dementia and no healthcare professionals. In this way, this would be a way to reinforce the support role of the artefact, not only through the activity it mediates, and the recommendations on how to conduct it, but also by suggesting tips to families on how to communicate with their relative.

This analysis from participants validated our proposal to associate the Positive Person Work interactions with the design of artefacts. Therefore, without the intention of being prescriptive or to propose one way of designing for people with dementia, we believe that to have them in consideration seems to be a valuable source of inspiration and a direction to contribute to a positive experience of use, capable of promoting well-being, as well as a way to gather a discerning feedback on the outputs of design.

Another aspect addressed in chapter 5, and reinforced by participants in evaluation [Chapter 7], regards the involvement of people with dementia in codesigning artefacts, considered as another way to respect and maintain personhood, through including their voice (or non-verbal communication), their needs and idiosyncrasies, and through the acknowledgement of their value as persons, capable of participating. It was emphasised that such process can be, in many cases, more important than the final artefact, thus making the codesign process valuable in itself. Positive Person Work interactions can also be a useful and important guidance to plan and conduct participatory events, being aware of our own interactions and attitudes, and ensuring a pleasant and enjoyable environment.

8.2 How can participatory design be adapted to involve people with dementia and their social circle in finding and designing personalised strategies for communication and entertainment?

This question is primarily explored through the collaboration with families [Chapter 6], although it is underlying the observational study [Chapter 4] and partly addressed in the design analysis of person-centred dementia care literature [Chapter 5]. The already referred Positive Person Work interactions were used in participatory design events as a set of recommendations for

positive and ethical interpersonal interactions with people with dementia, and as an influence on the design of some tools and strategies to engage people in the process, for instance, the focus on using an artefact or making something together (**play**, **facilitation**, **collaboration**, **relaxation**), the use of multiple-choice (**negotiation**), the simplicity, accessibility of materials, and the use of visual and verbal cues (**facilitation**), the warm and friendly look of materials and language (**holding**), and the decision not to mention dementia and being careful about how questions and exercises are formulated so that they do not confront participants with their difficulties (**validation**, **recognition**). In addition, as mentioned in the summary above, person-centred dementia care values (Brooker, 2007) were transposed to participatory design and used as main drivers to configure participation.

To consolidate this theoretical framework, we accentuate the pertinence of having allowed time to be in direct contact and immersed in the two institutional settings in the preliminary observational study, before we started the participatory encounters. Besides getting closer to people with dementia and healthcare professionals, necessary to proceed with research activities, this study allowed the development of empathy and understanding, crucial to the involvement of people with dementia in research, as well as to gather noteworthy practical recommendations for configuring participatory design events. Another key observation was the enjoyment people had from doing something together, regardless of the type of activity, which called attention to the need to commend the process and participation as outcomes of research. Therefore, we sought to ensure that participatory design events were convivial and enjoyable moments, seen as opportunities to bring people together.

The understanding about the experience of dementia, and how to codesign with it, was continuously developed, first during the observational study and then through the participatory activities. Our approach to participatory design constantly evolved towards the personalisation of the process with each family, which entailed a broad view of what participation can be, and a flexible attitude, supportive of different forms of participation: working with verbal and non-verbal participation; understanding what activities the person with dementia responded better and adjusting the process to engage her/him in that way; including both the relative with dementia and the family member in the activities, or managing their participation in different parts of the process; dealing with and compensating the lack of availability of family members, accepting and acknowledging their preferred ways to participate. In a general analysis of the process with each caregiving dyad, main codesign activities can be grouped into three types: use and feedback; personalisation of an open artefact; or, alternatively, the definition of a personalised design brief and subsequent development of a new artefact. For every family, each of these activities happened differently. [Figure 8.1] The process was left open to negotiation with participants, which was

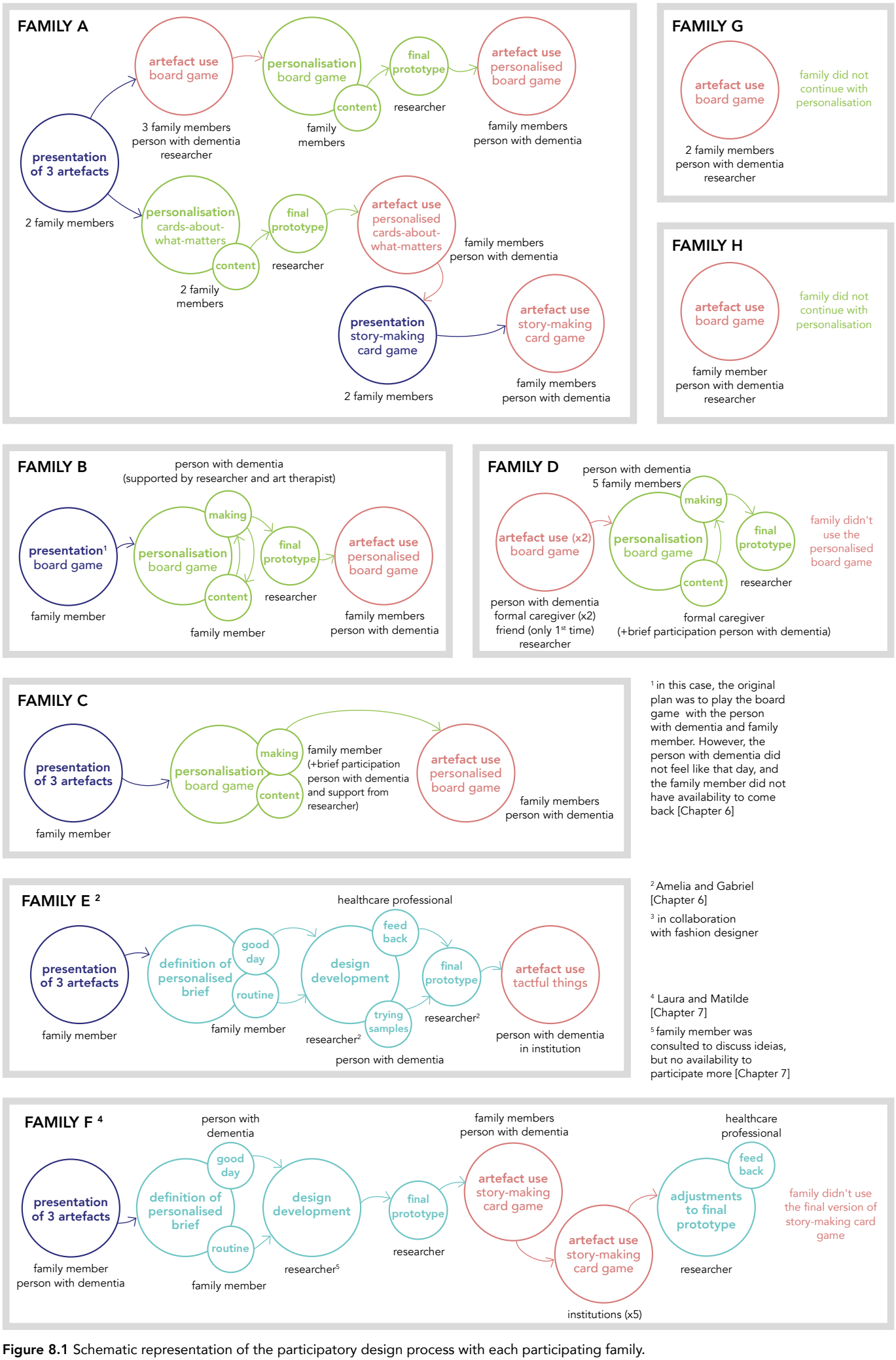


Figure 8.1 Schematic representation of the participatory design process with each participating family.

crucial to make participation happen, through respecting, responding and adapting to their needs, availabilities, preferences, and in this way attending to their uniqueness.

Despite how these activities were undertaken and combined in the process with each family, they were found appropriate in involving people with dementia in the design process. Having a tangible artefact as the starting point, allows use and the observation of participants' reactions and engagement, and permits gathering feedback on the experience right after use. This is a way to avoid abstract thinking and making the activity more natural and enjoyable. To support feedback after use, we also designed some materials, not only for us to be easier to trace and keep participants responses, but also to act as cues. Here, we distinguish the tangible semantic differential, where the suggestion of adjectives to characterise the board game, and the simplicity of the tool, facilitated people with dementia (who still retained some verbal capacity) to contribute. [Figure 8.2] The personalisation of an open artefact also presupposes working from something concrete. Based on the experience of personalising the board game in the two institutions and with families, we found that, in general, the definition of the content was more difficult for people with dementia, thus made mostly by family members. In order to overcome this difficulty, if there is enough time (and language ability), it is also possible to organise an activity around the creation of content so that people with dementia can also contribute, as done initially in the institutions. Nonetheless, people with dementia can be involved in another part of personalisation that consists in making (even if it may also relate and influence the content). Here, the exercises undertaken in institutional settings can be an inspiration: choosing images, words or colours, drawing, painting, writing, making a collage, etc. Thus, not only for configuring participatory activities, but also to design the templates for open artefacts, it was important to consider how to allow and enable people to participate in personalisation.

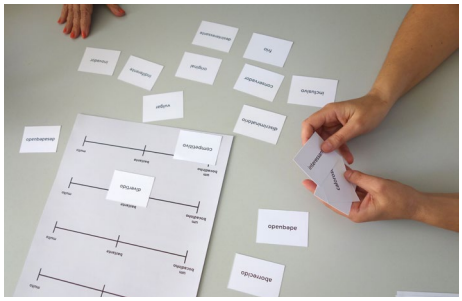


Figure 8.2
Semantic differential
[more in chapter 6]

Finally, in order to support participants to personalise a design brief, for which the broad aim was to provide opportunities for communication and entertainment, two exercises were created to find out about plausible opportunities of use within the family's routine, and about the interests and preferences of the person with dementia and family members. Although in one of the cases (a participant whose verbal communication skills were very impaired) was not possible to undertake the exercise, these were found to be insightful starting points for design ideation. The "good day exercise" [Chapter 6], composed of simple visual and verbal cues and multiple-choice options that were organised on a surface, enabled the participant with dementia to contribute, and trigger conversations and personal stories. Apart from the definition of the brief, and similarly to the other two activities, people

with dementia can be included in the following iterative development of the artefact, for instance by choosing elements, materials and colours, by trying samples and prototypes, and embedding the observation of their reactions and use in the shape and function of the artefact. This point emphasised the importance of paying attention to non-verbal communication, as it can be a valuable source of inspiration and information for design.

One final consideration concerns the significance of conducting activities that are positive and enjoyable. A third exercise was planned for defining the brief, regarding what participants did not like, the "bad day exercise", so that these aspects were avoided. In both cases, people were not keen on elaborating on this, mentioning only one or two things, and abandoning the exercise. This is explained by the fact that as people get older, there is a tendency to remember positive events more frequently than negative ones (Afonso et al., 2016). This experience reinforces our aim to organise participatory design events as pleasurable and convivial moments, that celebrate people and focus on what is important for them.

8.3 How does the personalisation of artefacts contribute to meaningful communication between people with dementia and their family?

Although the experiments developed to explore the previous research questions pointed already to some answers for this one, it was through the summative evaluation that these insights were consolidated [Chapter 7]. In this question, personalisation refers both to the personalised artefacts and to the process of personalising. Personalised artefacts allow the uniqueness of each person to be taken into consideration. They are adjusted to become vehicles of personal references that the person can identify with, valuing and celebrating that person, their life history and what is important to them, as a means to support their identity. These personal references do not need to regard specific life events or people. They can also be related to their hobbies, their present gestures, their "embodied selfhood" (Kontos, 2014), such as in the tactful things. In addition, they can be "hidden", like in the story-making card game, so that that the pressure of having to recognise these references is avoided (as well as the possibility of confronting the person with her/his difficulties). In this way, personalised artefacts can be adjusted to the personal experience of dementia, and facilitate the engagement in activities that are adequate. When used appropriately, the personalised artefacts constituted opportunities to bring people together in a relaxed and enjoyable environment, and acted as triggers and mediators of communication between people with dementia and others, due to their ludic function and familiarity.

The process of personalising, including the personalisation of an open artefact and the development of a personalised brief, was considered equally valuable, or even more, for several reasons. It encouraged and supported people with dementia to participate in activities that were both stimulating and enjoyable. It was a way to give them a chance to participate in a project, giving them voice and acknowledging their contributions, thus affirming their identity. At the same time, personalisation was found to bring emotional value to the artefact, resulting in a more engaged use. In a few cases, it also helped feeling more confident and contributed to bonding with others. The inclusion of family members was also emphasised. Although challenging for some families, mainly due to their lack of availability, the personalising process was satisfactory at several levels. Similarly to the Carer's Assessment of Satisfaction Index (CASI), a tool to evaluate the subjective experience of satisfaction of the carer (Brito, 2000; Mayor, Ribeiro, & Paúl, 2009), and based on the feedback received during the evaluation interviews, family members' main reasons for satisfaction can be (1) intrapersonal, associated with (2) their relative with dementia, and with their (3) interpersonal relationship. Family members (1) referred that participating in this process was enjoyable and stimulating in several ways, allowing them to be creative, inspiring them to look for more personal materials and to do other activities, encouraging them to pay more attention to their relative and how they communicate, and reflecting on their condition. Although not directly mentioned by family members, professionals highlighted that the process of personalising might help family members to gain understanding of the experience of dementia, and to deal with feelings of helplessness, loss and grief. Regarding the persons with dementia (2), family members were satisfied to feel that their relative was valued by being included in the process and that her/his contributions are appreciated by others. They took pleasure from seeing their relative happy and engaged in an activity (during the personalisation process, or the artefact use), and to see them relaxing and more available to interact with others. Finally, family members felt that the personalising process resulted in pleasurable family dynamics (3) of making something together, that the artefacts helped them to support their relative to participate and communicate, and contributed to meaningful family moments. Moreover, in a few cases, the personalisation process strengthened the relationship between family and institution.

The evaluation interviews also highlighted different possibilities and strategies for personalisation that should/can be offered. Since personalisation demands time and effort, thus possibly constituting a hindrance to making these artefacts available to people with dementia, providing different levels of personalisation allows families to personalise according to their availability and effort they want to put on this process. Besides the personalisation strategies used in this project, consisting

in defining a personalised brief and artefact from scratch and personalising an open artefact (content and making), other two were also recognised—personalising through making (without personalising content) and the possibility of a ready-made versatile artefact that allows personalisation on the moment of use.

8.4 How can design enable people with dementia and their social circle to develop personalised strategies to communicate?

Lastly, we return to our initial and main research question, starting with an overview of what we believe to be the primary contributions of design to dementia care, informed by what was mentioned by professionals in the evaluation interviews. Following that, we respond specifically to this question, self-reflecting on our research decisions and experiments.

We argue that design contributions to dementia care are mainly aesthetic, ethical and functional. Throughout the thesis, we draw on several authors that emphasise the importance of aesthetic experiences for people with dementia (e.g Hughes, 2014; Killick & Craig, 2011; Pullin, 2009; Zeisel, 2009) to justify our belief that the ability of design to make beautiful things is crucial when designing for people with dementia, providing them aesthetic experiences, and turning their environment and objects more pleasing and attractive, thus more inviting and stimulating to use. Design can explore and make use of the senses through resorting to different materials, textures, visual elements, the inclusion of sounds and even smell, in order to engage and communicate non-verbally with people with dementia. In addition, we see the effort required to design appealing artefacts as a means to dignify and value people, showing that it is worth paying attention and designing carefully for them. This is already related with the ethical dimension that design might be able to bring to dementia care, challenging prejudice and stereotypes about people with dementia and, thus, the understanding about them. In this way, through designing *for* and *with* people with dementia, or directly *for* and *with* carers, we believe that it is possible to *design for empathy* (Gamman, Ehn, Davis, & Wong, 2015; Devecchi & Guerrini, 2017), aiming to support dealing with the condition. The design sensitivity as a cultural mediator between people and things, the design capacity to observe, interpret and respond to people and their needs, can also be used to reach people with dementia. This sensitivity can be used to find strategies to involve them and mediate their communication with others, through the understanding of their gestures and reactions to what surrounds them, through stimulating and supporting their creativity, and validating their participation, through

embedding their contributions and their uniqueness, including their needs, stories, idiosyncrasies and preferences in the design of artefacts. However, this process of transposing the traditional design sensitivity to the context of dementia care is not straightforward. Artefacts can very easily become stigmatising and confront people with their difficulties if, going back to the previous point, there is no attention to the aesthetic qualities, if the knowledge about what might detract people is limited, or if design fails to recommend appropriate and sensible ways of using the artefacts. Efforts to design for dementia are often well-intentioned and careful, but many times this might not be enough, if the awareness of possible positive and negative experiences that might be mediated through the artefacts is limited, and if healthcare professionals and people with dementia are not involved in the design process.

Both aesthetic and ethical inputs conduce to the functional contribution of design to dementia care. Here, functional refers to design's potential to enable and facilitate the action and participation of people with dementia. Design can create things that are easier to use and more accessible, in parallel with making them more inviting and adequate to the specificity of people's experiences. The hands-on ability to visualise, make, prototype and transform concerns into proposals of use, allows change to happen, supporting the work of healthcare professionals, encouraging activity, triggering opportunities for social interactions, and facilitating the involvement of the different actors in the caregiving process (person with dementia, family and institution).

We would like to reinforce the fruitful collaboration with healthcare professionals, who recognised various qualities of the presence of design in the institutional context. Specifically, psychologists and therapists benefit from a variety of materials for their daily activities with people with dementia, but most times do not have the competencies to produce them, recurring to the available materials, which in the Portuguese case frequently come from abroad and are often culturally inadequate. The institutional settings, as well as the familial contexts, are full of opportunities for design. We believe that people with dementia can gain a lot from this collaboration, which should happen more regularly and continuously. In fact, Hendriks and Wilkinson (2017) argue the importance of a regular presence of designers in nursing homes, moving their practice to the real context they are designing for, which they have been applying in a student module they run in Belgium.

The specific aim to design for supporting communication with people with dementia, including them and their families in this process, and the fact that there is still a limited body of knowledge about these subjects, led to the wide focus of this research. Several aspects could have been explored deeper. In fact, each of the previous research questions could have been studied independently. For instance, the analysis and reflection on Positive Person Work [Chapter 5] could have been taken further, developing design experiments for each interaction, instead of being restricted to a brief speculative exercise;

the participatory approach to codesign with people with dementia and their families could be a research theme in itself, as well as the emphasis on personalisation, which could have been more explored in this and other contexts. Although it might lack depth in several aspects, this specific project, with a strong focus on the design outputs, emerges from interweaving these multiple directions. The generative and qualitative nature of this study, constantly adapting to respond to participants, resulted in a messy and complicated process, that was dependent on others to advance. The decision to work with families, instead of keeping it only in institutions, for instance, added extra complexity, mainly due to their lack of availability, forcing us to reduce part of the initial plan of codesign activities, so that it was possible for them to participate, and feasible within the PhD timeframe. For this reason, the number of participants was also restricted—six families. However, this corresponded to six different processes that involved an intricate management of different activities, preferences and approaches. Another challenge on designing with and for families is the perception of family dynamics, involving them to understand what contributes to the family well-being and interpersonal relationships, instead of concentrating exclusively on the person with dementia. For instance, although the core of the project was always the communication between people with dementia and their family, the tactful things were found to be a more appropriate response to that specific family situation, even if it provides a more individual use.
In this way, we believe that design can enable people with dementia and their family to develop personalised strategies to communicate through:

1. defining personalised briefs and designing responses to them—in collaboration with the care dyad (and facilitating their involvement)—in order to respond to a specific experience of dementia, with particular needs and wishes. This is an inspiring starting point to create new artefacts which many times might also be valuable and address the needs of other persons with dementia;
2. designing open artefacts that can be personalised, filled with engaging content or/and built together with the person with dementia, plus providing adequate support for the personalisation process and use;
3. designing artefacts that create opportunities for making things together, and giving guidance on how to conduct those activities;
4. designing versatile artefacts that can be personalised through use, along with providing a variety of possibilities and recommendations of use;
5. taking advantage of these artefacts to also suggest some communication tips for families to deal with their relative in the context of the activity, which might also be useful in their quotidian.

8.5 Future developments

As mentioned already, there are many aspects of this research that can be taken forward, for instance, continuing to explore the Positive Person Work interactions from a design point of view, and enquiring more about how they are experienced through the use of artefacts, as well as the 'translation' of other theories from dementia care that might help designers to work with and for people with dementia. Methodologically, the personalised approach can also be further investigated, involving more families, and eventually relating to other conditions and issues, or adapting it to other settings, such as the institutions. We already referred the potential of the presence of design, in collaboration with healthcare professionals, to bring value to these contexts. However, these are commonly one-off collaborations, within academic setups, where the sustainability and continuity of these projects are often overlooked, yielding outputs that rarely evolve to become accessible, distributed and used. This concern was also raised during the Dementia Lab event in 2016, where the organisers prepared a workshop dedicated to reflecting about possible business plans for this kind of projects. Partly inspired by this and by our aim to make the outcomes of this research available, we briefly asked about the possibilities of implementation of this project during the evaluation interviews. This discussion was more open with the healthcare professionals, and with the family members, we created a possible scenario with multiple options for them to comment and choose from.

In general, all interviewees saw advantages in implementing this research and making the artefacts available, since there is a need for them. Most participants, including families, saw institutions as the ideal context of use for these artefacts. However, the possibility to make them appropriate to use at home was also considered invaluable for many families that are eager to give continuation to the work done by healthcare professionals. In these cases, the institutions (including nursing homes, day centres, memory clinics, and even health centres and hospitals) could be final clients as well as crucial contact points to inform people with dementia and their families about the project. Apart from this, institutions could also be partners in the design of new artefacts, pointing to needs that could be explored and addressed by design. Although recognised as valuable, personalisation was found more complicated to conduct within institutions. The lack of resources, time and availability of professionals can be a hindrance to undertake a personalisation process, which reinforces the importance of taking into account the alternative approaches to personalisation presented above, also considering the personalisation for groups, instead of individual.

Families were specifically asked to imagine a scenario of being clients of a shop with this kind of artefacts, that simultaneously offered a personalisation service. [Figure 8.3] They were asked to reflect on the several

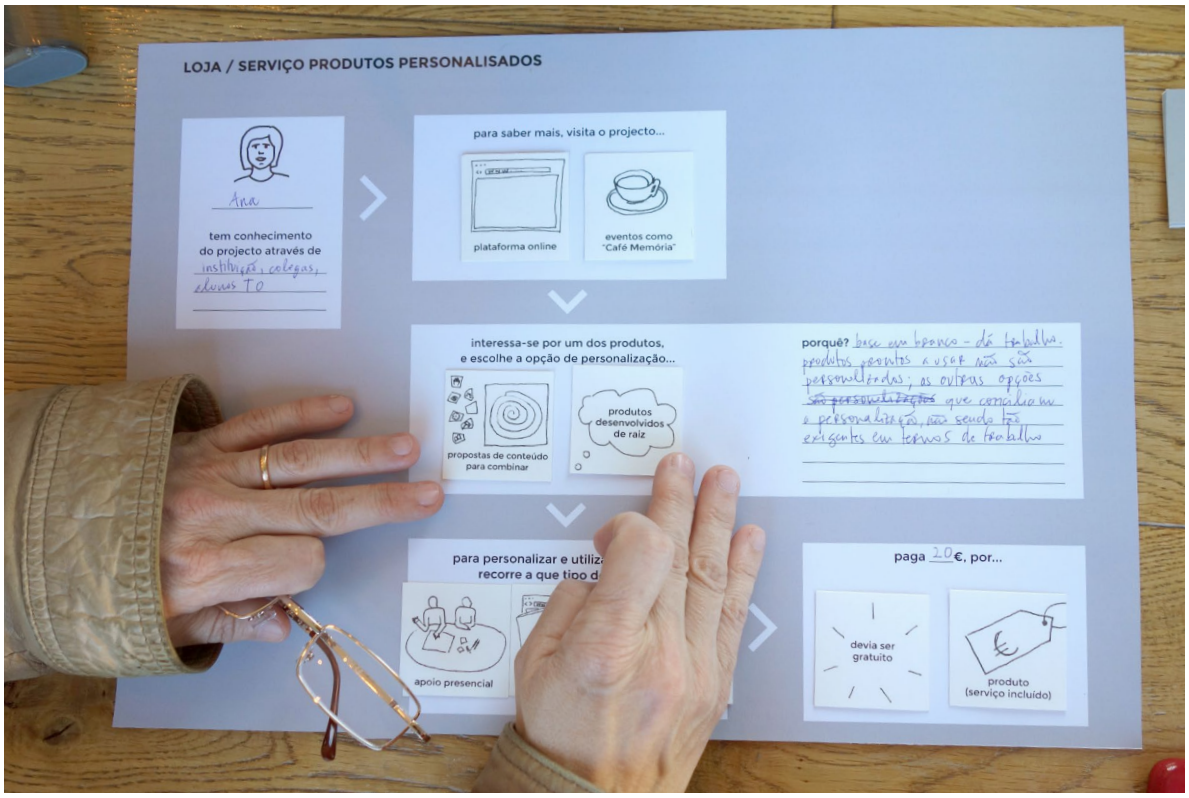


Figure 8.3
Building a scenario of the project implementation with a family member.

steps of getting to know the project, personalising and purchasing a product. In parallel with online information, families said they saw themselves hearing about this project in events like the Memory Cafe, through the institutions and word of mouth. When presented with different personalisation options—ready-made artefacts; having several components to choose from and combine; a blank template; or a personalised brief—no one chose the ready-made object, since they felt the possibility to personalise was a distinguishing and valuable characteristic of the project. All participants chose the option of having different components to combine, as a good compromise between having a personalised artefact and the time and effort that personalisation involves. This could also be a way to make artefacts more all-embracing, and thus more viable. Another suggestion was to make these components moveable so that personalisation could be done in each moment of use, thus making objects more versatile. All family members appreciated the possibility to define a personalised brief and an artefact from scratch, for the freedom and potential to respond to specific needs. Although some families discarded the option of personalising a blank template, mainly due to the effort that this would entail, others included this option for the possibility of having a higher degree of personalisation, namely if using personal content. They all agreed that they would need help in personalising the artefacts and considered that face-to-face support was ideal, although the provision of more general recommendations and online support could also be important.

Finally, families were also asked how much they would be willing to pay for this personalised product and support provided. This question triggered reflections about the value and effort put into the personalisation of artefacts, which would not be affordable for most families. To circumvent this issue, it was suggested to find sponsors and to separate the value of the product and service, so that people could choose it or not.

Despite being very superficial, this inquiry was a starting point to understand the perception of how this project could reach more people, both in familial and institutional settings. In parallel with the other pertinent topics presented for future research, we argue that it is crucial to find strategies to create sustainable ways to make the outcomes of design research for people with dementia accessible so that they can benefit from it.

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