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RESEARCH ARTICLE



Designing sensory and cognitive stimulation activities with and for people living with moderate to late-stage dementia

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ABSTRACT

This study addresses a participatory design project involving a researcher in the field of design and dementia, undergraduate design students, people living with moderate to late-stage dementia from a Day Centre run by Alzheimer Portugal and care workers. The project was held during four months as part of the research REMIND, and is grounded on the concept of personhood, emphasizing the importance of considering biographical features, values, interests, and culture of people with and for whom design projects are being developed. Considering the profile of the Centre's users, the stage, and manifestations of dementia in each one, it was necessary to combine qualitative methods, which were systematically adapted according to each situation. Methods included: sensory ethnography, participatory observation, walking interviews, ethnographic field notes and interviewing. The strategies adopted in the participatory design process were designed according to the users' aspirations and interests, prioritizing playfulness, enjoyment, and wellbeing in the moment. Sensory and cognitive stimulation games were designed with these people living with dementia and made available at the Centre for their use. The results of this project provide a basis for reflection on the ongoing research and inform future practices in this area.

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Participatory design; dementia and design; sensory ethnography; cognitive stimulation games; personhood in design; wellbeing in the moment

Introduction

This study is based on two premises considered essential in design practices with and for people living with dementia. The first concerns the concept of personhood, defined by Kitwood (2019, 7) as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship, respect and trust', and which underpins the person-centred care. Although

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many of the intellectual characteristics of the person seem to fade, the fundamental elements of their identity remain and are what define their own individuality. Therefore, paraphrasing E. Matthews in *Dementia and the Identity of the Person* (Matthews 2006), Rodgers (2018, 190) states that ‘a person’s sense of self and self-respect can be fostered through ‘reinforcing any remaining elements of conscious self-identity’; less conscious elements in a person’s identity can be preserved through physical surroundings to retain ‘physical links with their past, which help to support a sense of personhood’.

Accordingly, researchers in design have adopted strategies aimed at preserving and acknowledging the personhood of the person living with dementia, adapting interventions and strategies (Dening et al. 2020; Rodgers 2018; Treadaway et al. 2016). It is worth highlighting the perception of Dening et al. (2020, 13), who consider that ‘the concepts of personhood and person-centred care have limitations since, if the focus is limited to the person, it can overlook or ignore the social and relational aspects of life with dementia’. In line with this, these authors value the person’s social environment, context, and relationships in the research process.

The second premise concerns the importance of involving people living with dementia in research and design processes (Dening et al. 2020; Hendrix et al. 2018; Keady et al. 2019; Tseklevs and Keady 2021), as this will provide a more in-depth understanding of the person, namely significant aspects of their life history, values, interests, and culture, and thus meet their preferences and personhood.

Dening et al. (2020) highlight two essential arguments that justify the inclusion of the person in research and design projects: their right to participate in something that is developed for them (an ethical issue), their knowledge of dementia from their own life experience will bring a qualitative contribution to the project, relevance and validation. Swarbrick and Open Doors (2019, 15) emphasize that ‘good practice’ dictates that all people, regardless of cognitive abilities, should be given the opportunity to be involved in research as participants and as co-researchers’.

Nevertheless, questions are often raised about the ability of people living with dementia to be meaningfully involved in research and design processes, with their involvement becoming more difficult the more advanced dementia is. For Hendrix et al. (2018), the benefits that the person can obtain from a participatory design process are not limited to the results but to the very act of participating throughout the process. Swarbrick and Open Doors (2019) add that the most important thing is that the approach adopted ensures a positive and meaningful experience for the person.

Still, people living with dementia are often not included in studies aimed at themselves, particularly in qualitative methods (Dewing 2008; Hendriks et al. 2014). On the other hand, a large proportion of participatory design

and dementia projects involve people with mild to moderate dementia, while those involving persons with advanced dementia are rare (Hendrix et al. 2014).

When designers and citizens come together in collaborative processes, decisions should be taken by all parties involved in a balanced way. However, when it comes to people living with dementia, this rarely happens explicitly, especially in cases of advanced dementia, as communication skills are severely compromised. Therefore, Dewing (2008) points out the importance of the researcher analysing each case and establishing creative strategies that allow the person with dementia to be included in the research process. It should be noted that 'research has shown that people living with dementia use body movements as a compensatory strategy to communicate what they mean in various types of activities, especially when some of their communicative abilities are diminished' (Majlesi, Nilsson, and Ekström 2019, 59). Hence, the methodology and analysis of results should include, in addition to verbal communication, interactions with and between people living with dementia, the detailed study of non-verbal forms of communication (such as body movements, gestures, expressions, and reactions) and behavioural patterns.

The strategy of several designers has been based on proximity, on the connection they establish with the person (Dewing 2008; Hendrix et al. 2018). Researchers such as Treadaway et al. (2018), Wallace et al. (2013), Rodgers (2018), van Rijn, van Hoof, and Stappers (2010), Dening et al. (2020) or Hendriks et al. (2018) have highlighted the importance of building a close and trusting relationship between the researcher/designer and the person with dementia for positive results in the collaborative processes and subsequent artefact design. At the basis of their projects is the premise of working with the person and not for the person, so establishing a close relationship by socializing with the person in their familiar environment (e.g. day centre, care home...) is essential.

Lindsay et al. (2012) highlight a number of factors that contribute to establishing an empathetic relationship in participatory design, including, promoting a quality relationship between the designer and participants so that the former can understand and be in line with the needs and aspirations of the latter; openness and availability of the designer towards the participant; considering and favouring the emotional and affective quality of joint experiences. Moreover, the authors state that the use of participatory methods favours an empathetic relationship due to their democratizing nature since the design is based on the assumption that designer and participant contribute similarly, and due to the proximity it provides between them, which results in a more meaningful sharing of experiences.

Rodgers (2018) also notes the importance of the designer not playing a prominent role but rather a supportive role to stimulate collaboration between participants, as well as the importance of involving care workers and family members of the person living with dementia to ensure that the

way of communicating with them, the language used, is appropriate and empathetic.

From this closer relationship and often with mediating artefacts, it is possible to implement participatory design strategies and recognize implicit decisions of participants living with dementia that can inform research, as well as design concepts and processes. Hendrix et al. (2018) note the importance of the person-centred approach (and its techniques) used in training care workers to provide tools, skills, and strategies to build closer and meaningful relationships with persons with dementia. The authors highlight how this approach should underpin and inform participatory design practices, help acknowledge implicit decisions and make those decisions clearer.

Treadaway et al. (2018) consider three factors in projects aimed at people living with dementia, namely: personalization through a design centred on the person life story to reinforce their perception of self-identity and dignity; sensory stimulation aimed at keeping the person *in the moment*; and connectivity, i.e. stimulating connection with others. The authors define such an approach as Compassionate Design.

Lindsay et al. (2012) argue that participatory techniques and the concept of participatory design require reformulation and adaptation when practised with people living with dementia. Participatory design must be adapted to people's capacities and context. The authors note that when they are involved in participatory design processes, their voice is heard, and their contribution to the design is required and valued; the result can be more oriented towards social interaction, stimulating reminiscences, tailoring to people's preferences and interests, in short, centred on the person and their personhood.

This study addresses a participatory design project carried out with and for 13 people living with moderate to late-stage dementia—all with Alzheimer's Disease—who attend a Day Centre from the Alzheimer Portugal association. The project was developed in an academic context, as part of a course centred on the role of social design through the development of projects in real-life contexts. It involved a researcher in design and dementia who coordinated the design project; 11 design students from the third-year Communication Design BA of Lusófona University (Porto, Portugal); care workers and health professionals of the Day Centre who played an essential role as project advisors and consultants. It aimed to design sensory and cognitive stimulation artefacts based on the life histories, interests, culture, and values of this group of people living with dementia. This project was carried out over a period of 4 months as part of the research REMIND – *Design for People with Dementia: cultural, contextual, and biographical components in the production of artefacts for cognitive stimulation activities*, in which the project coordinator is involved.

Methods

Initially, the group of design students was introduced to the REMIND project, its mission and objectives, the methodologies that have been applied and the results obtained to date, including those from two academic projects previously held (Lima 2023, 2024; Lima and Penedos-Santiago 2023). There was a contextualization of dementia, its forms of manifestation and progression, the main symptoms and the designer's potential contributions in this area, particularly regarding sensory and cognitive stimulation.

The Day Centre was presented to the students by its Director. A field visit was made to its facilities guided by a care worker who also showed and explained various cognitive, playful, and recreational activities carried out with the people who attend the Centre. This visit took place before the people arrived in order not to disturb their daily routines and wellbeing with the presence of an unfamiliar group of students. In previous academic projects, it was proposed that students have contact with the Centre's users to get a better understanding of their background and interests and, subsequently, a more effective design response (Lima 2023, 2024; Lima and Penedos-Santiago 2023). This contact has never been possible, partly due to Covid-19 restrictions but also because it was feared that it would disrupt the wellbeing of those attending the Centre.

Recognizing the importance of participatory design practices with people living with dementia to provide answers that are more in line with their personhood, their interests and values, and their culture, in this project, the consistent point of contact method was used (Lindsay et al. 2012) to enable participant observation in the Centre's premises, i.e. the same person, the researcher-coordinator of the project, always made contact and interaction with the Centre's users. This prevented any possible disruption to their wellbeing and daily routines.

All the people involved in the project were duly informed about the procedures to be implemented in the research and their anonymity was guaranteed. The contextualization of the project, methodologies and procedures were also submitted to the Ethics Committee at the University of Porto with protocols approved.

For four months, the period of the project, the coordinator attended the Centre—the first two months, one day every two weeks, and then one day a week, for around 3 hours each day—intending to understand the daily dynamics experienced there; establish a close and trusting relationship with users and care workers, crucial for a more effective response to the needs, aspirations and profile of the group; become familiar with the users, their life history, interests, preferences and aspirations; establish participatory design processes with users and care workers; evaluate the effectiveness of projects at different stages.

To achieve these goals, the project coordinator joined the Centre, assisting and participating in its various activities and tasks, an essential factor for greater proximity and knowledge of the group (Antelius, Kiwi, and Strandroos 2019). These included walks to the beach (the Centre is in a coastal area of the country, and walks to the beach were frequent), cognitive and sensory stimulation games, Reality Orientation therapy (in groups), ludic activities, creative activities, meals, watching films, news and recreational television programmes, among others.

Attendance at the Centre occurred at different times of the day and on different days of the week, allowing for a broader perspective of daily routines, activities, and experiences. During the period of attendance, various ethnographic methods were combined and adapted to the context, including participatory observation, walking interviews, writing of field notes and informal interviewing with care workers (Antelius, Kiwi, and Strandroos 2019; Kullberg and Odzakovic 2019). Direct contact with people with dementia in their environment, the sharing of experiences and involvement in daily activities enabled the practice of sensory ethnography, which was crucial to this project since this method 'draws out the everyday realities of people's experience and practice and provides insights about how to make these experiences and practices more pleasurable and effective' (Pink 2015, 21). Therefore, it was envisaged that knowledge would not be limited to participatory observation centred on vision but rather experience through all the senses, through experimentation and multisensoriality to obtain a deeper and more intense knowledge of reality.

For greater proximity, although the project coordinator was initially introduced to the group as a teacher, she always introduced herself by her first name (to care workers and to the Centre's users). During most of the time at the Centre, conversations and interactions were not related to the projects but to routine subjects aimed at exploring and identifying people's interests.

These long periods of coexistence allowed for greater bonding between the project coordinator and the Centre's users, contributing to mutual knowledge and the sharing of each person's stories and experiences. As mentioned by Hendriks et al. (2018, 65), this helped the researcher to perceive the person 'not as an older person stricken with dementia, but as a human being who enjoys their lunch, likes to sing, etc.' fostering the building of a relationship. On the other hand, spending time in the facility also contributed to getting closer to the care workers, observing how they react to everyday events with the person living with dementia, how they stimulate them to eat, how they respond when they are distressed, how they interact, forms of verbal and non-verbal communication.

At the end of each work session, once outside the Centre, the project coordinator wrote ethnographic field notes in a journal, documenting the day's activities, behaviours and routines observed, conversations and

interactions with and between the users, the care workers and them and the users, fun moments, doubts and, occasionally, how the coordinator felt and dealt with specific events. This method was adopted because it was less invasive (Antelius, Kiwi, and Strandroos 2019). Writing notes in front of the person can break the involvement and create distance by demarcating the different roles of the observed person versus the researcher. It was necessary, however, to write the notes as closely as possible to the events observed, trying to understand their meaning and describe them in as much detail as possible.

The information collected was synthesized and anonymised (Tseklevs and Keady 2021) and then passed on to the design students. In every session with the students, the aspects observed, the activities witnessed, and the dynamics of the Centre were discussed. Based on this information, a mind map was built on a wall measuring around 6×2.60 metres with keywords and concepts divided into the following themes: *Dementia/Symptoms*, gathering scientific information provided in the context of the REMIND research, concepts investigated by the students themselves and learnt in contacts with health professionals; *Life experiences*, reported by health professionals, by the students who have relatives living with dementia, and stories reported in the literature; *Design contributions*, also from the REMIND research and research carried out by the students; and *Portuguese Culture* focusing on the 1960s to 1980s, the most striking period for the group of users of the Centre. A fifth column was added—*Biographical Aspects*—and filled in by the project coordinator (consistent point of contact) following each visit to the Centre, bringing together users' biographical characteristics and identified interests in a wide variety of areas, such as recreational activities, games, music, films, among others. This mind map was fed throughout the process of developing the projects as more data and information were collected, with the *Biographical Aspects* area naturally being the most frequently updated (Figure 1).

In addition, an intensive collection of sensory and cognitive stimulation artefacts and games for people living with dementia currently on the market was carried out to analyse possible approaches to evaluate the positive and negative aspects, functional issues and the materials used in their construction.

Considering that only the project coordinator had contact with people living with dementia and seeking to enrich the students' knowledge of the symptoms and ways of manifestation of dementia, as well as its impact on people's daily routines, professional training was given in *Dementia, Therapies and Art*, promoted by Servilusa and led by Ana Costa, a psychologist specializing in dementia and author of the hOpeningDementia¹ project (Costa 2019). Through various activities and experiences, this training allowed students to experience the difficulties that people living with dementia face in apparently simple everyday tasks.

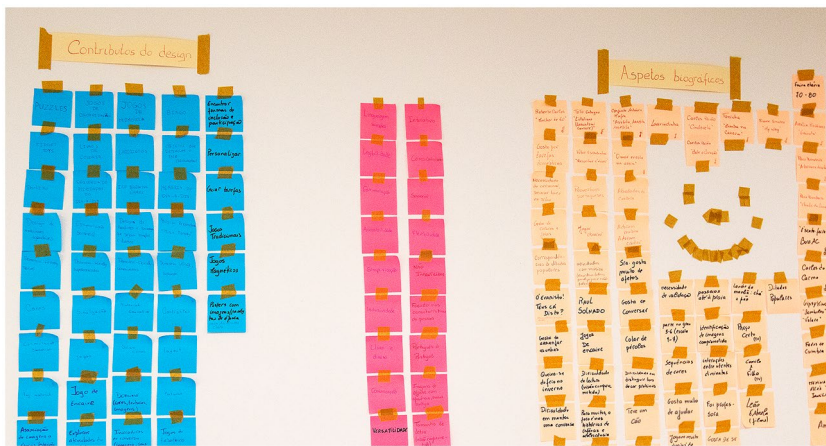


Figure 1. Detail of the mind map produced for the project. Source: Lima, 2023.

These experiences and the information gathered in the previous processes, particularly those related to the users, defined the ways of approaching the project, both in terms of its format and the topics to be included. Based on the life stories, the interests of each person and the common interests, stages and ways in which dementia manifests in each person in the group, a set of cognitive and sensory stimulation games were conceptualized to be played individually or as part of group activities.

Project development

As the first design concepts were defined and ideas sketched out, these were shared and discussed with the Centre’s professionals to assess their feasibility, purpose and relevance to the target audience, functional aspects, and potential material options. In this first phase, different approaches were studied regarding design, materials, forms of use, functionality, and aesthetics. These possible solutions were systematically brought to the Centre, evaluated by the care workers, and experimented with the users for whom they were intended.

The people living with dementia with whom the project was developed are at different stages (moderate to late-stage); some of them have difficulty in their abstraction ability, significantly compromised memory, and very limited ability to communicate. In this sense, it was necessary to reflect on and adopt participatory design processes according to their capabilities and profile, and to comprehend alternative forms of communication and interaction to explicit verbal communication. Approaches to participatory design were alternated, with some being done individually and others in pairs. Indeed, given the different stages of dementia, group work is not feasible or productive; it is more fruitful to direct attention and conversation to individual users.

For artefacts with textile components, the users were shown various fabric samples to assess their preferences, possible combinations, and the selection of those to be included in the projects. For artefacts with music, the selection was based on songs frequently heard at the Centre and sung by the users. Their reactions when the music was played were a weighting factor in the selection process. In one case where images of Portuguese personalities and monuments were used, these were selected together with the users based on those that proved to be most meaningful. In the case of images to be printed, before moving on to physical prototypes, they were compiled in digital format and presented in group activities, to assess the degree of familiarity and ease of recognizing each image.

For the participatory involvement of users, contextualization and even staging of certain aspects was essential (Hendriks et al. 2018). For example, before a participatory moment, the project coordinator would approach them and explain that she was doing a project with students for the Centre but that they were having difficulties selecting materials. This approach usually elicited empathy from the users, who immediately offered to help (particularly one of them, who had also been a teacher). A conversation was generated around the topic, and, at a certain point, they were shown samples of possible materials and asked to help with the selection, emphasizing the importance of their collaboration. Throughout the process, the contextualization and purpose of their participation were reinforced several times. The way in which the participatory moment was outlined sought to give a sense of purpose and relevance to the user's collaboration and a balance of roles (of the project coordinator and the user). However, it is recognized that this balance is conditioned and affected by the latter's compromised abilities.

Several studies have emphasized the importance of dementia design research focusing on the benefits 'in the moment' (Denning et al. 2020; Rodgers 2018; Treadaway et al. 2016, 2018), in some instances favouring this approach over lived experiences that focus on reminiscences (Tseklevs and Keady 2021). Throughout the methodological process, the focus was on wellbeing in the moment, with the participation of each user constituting a moment of enjoyment, experimentation, exploration, and sensory stimulation and, at times, a moment of playfulness. So, rather than aiming for a final product, the process was intended to be meaningful for the users, to bring them a positive experience and to contribute to their wellbeing.

As the projects were developed, prototypes were built and presented at the Centre, shown to care workers, and tested with the users for whom they were intended. The effectiveness of each project was assessed by observing how they interacted with the artefacts and, where possible, asking for their opinion. As Hendriks et al. (2018) point out, in participatory design processes with people living with moderate to late-stage dementia, the evaluation of their decisions can take place explicitly and verbally or by observing how

they interact and use artefacts. When verbal communication is compromised, as was the case with specific users of the Centre, observing their reactions and forms of non-verbal communication is essential for evaluating the effectiveness of the projects developed. In other words, since it was not possible to make explicit decisions, the participation and involvement of the person living with dementia was made possible by building a relationship with them, which allowed the project coordinator to become familiar with the participant and understand how and in what way they gave input to the work, positive and negative reactions. To this end, the importance of project coordinator spending a long period of time with this group of people to build up a relationship with each of them and better learn about their interests, ways of reacting and other forms of non-verbal communication.

Exploring sensory and cognitive stimulation through games

The design projects developed focused on two fundamental elements in therapies for people living with dementia: cognitive stimulation and sensory stimulation (Costa 2019, Kitwood 2019). Several of these projects explored these elements through playful activities exploiting reminiscences of the Centre's users since these can bring ludic pleasure and fun (Treadaway et al. 2016).

According to van Rijn, van Hoof, and Stappers (2010, 74), playful activities can contribute to meeting the needs of people living with dementia, such as the expression of thoughts and feelings, a sense of belonging, commitment and involvement, and their self-esteem, providing comfort and reducing 'boredom, agitation, and isolation'. Consistently, Vernooij-Dassen (2007) notes that meaningful activities for people living with dementia—activities with a positive impact—are those that provide them with pleasure and promote their involvement, giving them a sense of connection and belonging, autonomy and self-identity.

In this context, a set of games was developed, seeking to increase the therapeutic and playful potential. According to Ning et al. (2020), 'games therapy has a better effect on the cognitive abilities of patients than other therapies'. The authors note that games involving tangible objects and pieces can also exercise sensory stimulation and contribute to manual agility. However, games that require several players can be challenging to operationalize or organize due to the difficulty of bringing together a consistent group, a space, and carers to support the activity.

Anderiesen et al. (2015, 156) also note the therapeutic value of games for older people, as they can contribute to 'slow down the deterioration of, or might even improve, memory, hand-eye coordination, reaction times, and self-esteem', as well as stimulating more significant physical and social activity. Nevertheless, they point out the scarcity of games suited to the

characteristics and interests of people living with dementia and their remaining abilities, particularly their perceptual and interaction needs. They emphasize that ‘appropriate leisure products for persons with AD [Alzheimer Disease] are scarce, but may enhance their quality of life and may support caregivers in providing good-quality care’ (157). The authors note that games elicit various types of experiences such as relaxation, exploration, expression, fantasy, fellowship, humour, and challenge competition (among many others) and have an added potential for exploring reminiscences. Accordingly, they emphasize the importance of including reminiscence activities (even in the case of games for people with advanced dementia), focusing on biographical aspects. Considering that sensory stimulation activities tend to reduce agitation and contribute to relaxation, Anderiesen et al. (2015) also recommend including sensory and relaxation elements in games, particularly those designed for people with advanced dementia. Finally, they argue that although the games and activities developed should be suited to the cognitive abilities of the person they are targeted at, they should be challenging for them and stimulating to promote greater involvement and entertainment.

One of the games created in this project was a Tangram with a strong sensory component. Made of wood, it consists of 7 pieces, each with a fabric surface of a different and contrasting colour and texture given by the combination of distinct materials (Figure 2). These materials were selected together with the Centre’s users. The game includes two sets of drawings, one with full-scale geometric shapes for overlaying the pieces and another on a reduced scale for reproducing the drawings by copying. The aim is to provide two difficulty levels for a more inclusive activity. This game stimulates the user’s cognitive and sensory skills, hand-eye coordination, and manual agility.



Figure 2. Sensory tangram. Design by Ana Santos, Gustavo Silva and Joana Oliveira 2023.

A memory game based on the seasons was designed. It consists of a card-board board divided into four parts (seasons), each with four rectangles to place a card (corresponding to the season). For each season, four images (cards) referring to that time of year were selected. The selection was based on the users' familiarity with what was represented and how easy it was to associate it with the season. Seasonal fruits common in the region where they live, and photographs of familiar landscapes taken in each season were represented (Figure 3).

Another card game was designed based on local monuments and Portuguese personalities familiar to the users. The selection of images was inspired by users' preferences and interests, as observed and communicated by them. Each card, in A6 format, has at the top the question 'Who's that?' or 'Where is this?' followed by a picture and a clue (e.g. the personality's occupation or the location of the monument). The answer is on the back of each card. For a lower level of difficulty, small-format cards with the answer have also been designed to allow the player to match the solution. This game, which can be played individually or in small groups, aims to stimulate reminiscences and the sharing of stories through cultural elements recognized by the users.

To stimulate dexterity and coordination, a wooden labyrinth with a transparent plastic lid was designed, customizable with popular sayings or typical local dishes. A card with the first part of a phrase (saying or dish) is placed at the starting point. The labyrinth has two possible endings (the final part of the phrase). For example, it's common in the region to make Caldo Verde² [Green



Figure 3. Memory game based on the seasons. Design by Bárbara Silva and Sarah Chaves, 2023.

Broth] with chouriço [chorizo]. So, in the starting square, a card is placed with the phrase 'Caldo Verde com...' [Green Broth with...], in one of the possible ending squares '...chouriço' [chorizo] and in the other '...cenoura' [carrot] so that the user thinks of the right combination and directs the maze ball to that ending. Various sets of combinations were created to renew the activity and adapt it to the interests and characteristics of different users (Figure 4).

Furthermore, two multimedia applications were designed. One of the applications is based on the ability to recognize sounds, with four sets being presented: domestic animals, selected considering the users' pets; wild animals from South Africa and Mozambique, since two users have lived in these countries for many years and have shown great interest and familiarity with these animals on several occasions; sounds characteristic of professional activities, based on those practised by the users (such as a sewing machine for a seamstress); and expressions from Portuguese films that have become iconic and widely recognized, such as 'Ó Evaristo! Tens cá disto?'¹³ [Evaristo, do you have any of this?]. The game presents the sounds, divided into four categories, for users to guess. If they cannot guess initially, an image related to the theme is shown as an additional clue. Given the users' lack of digital literacy, the game was designed to be handled by a carer, and the activity can be performed individually or in group. It should be noted that the users regularly take part in group activities with audio-visuals shown on a TV screen.

The second application consists of a multimedia music game also to be operated by the carer. The goal is to guess a particular song using a set of

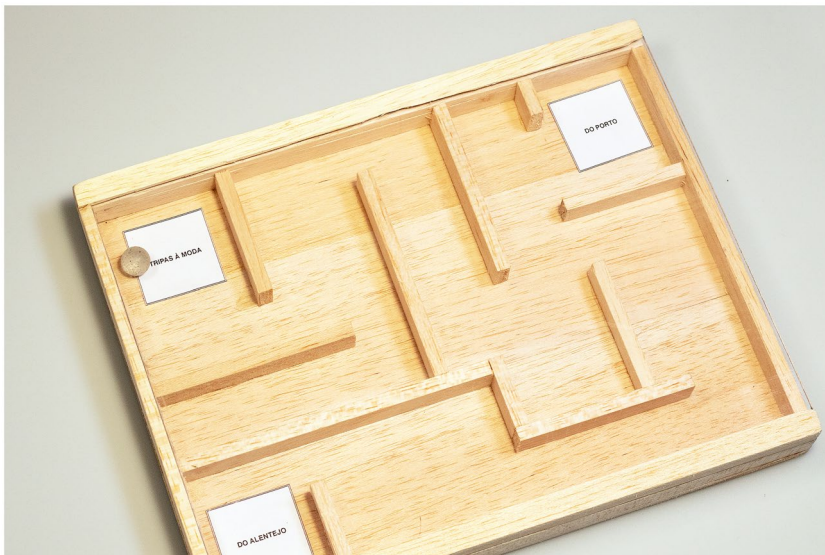


Figure 4. Labyrinth with popular sayings or typical local dishes to match. Design by Joana Teixeira, 2023.



Figure 5. Application screens with retro style. Design by Catarina Sousa, 2023.

clues. The songs selected were based on the users' preferences, particularly the ones they sing frequently. In the first stage, the user is shown a photograph of the singer and tries to guess which song it is; in the second stage, the lyrics of the chorus appear, followed by the instrumental. Finally, the music video clip is shown on a television set, followed by the answer to the question. The elements depicted, such as the television set, are presented in a retro style (1980s) in line with the era of the song, the most striking time for this generation of users (Figure 5). Like the previous application, this game can be played individually or in groups. However, it is recognized the more significant potential of group activities to stimulate the involvement of participants who, in similar activities, tend to sing and dance together.

Discussion

The perception of daily life events experienced by the people living with dementia who participated in this study was a key factor in the ideation of the projects. Ethnographic study entails analysing phenomena in the natural space where they occur to identify and interpret patterns and situations based on the participants' experiences and their own points of view (Pink 2015, 2021). The results of a study of this nature depend very much on the relationships that are established with informants (Antelius, Kiwi, and Strandroos 2019) and the long periods of time spent at the Centre facilitated the building of a closer and more trusting relationship with users and care workers, with the project coordinator also becoming a sort of member of the Centre. The choice not to write ethnographic notes in front of the users contributed to this integration and proximity, reducing the potential sensation of observer and observed. However, the fact that the notes were only written at the end of each work shift occasionally hampered the accurate recall of

the succession of events observed. For each event recalled, it was possible to describe it in detail. Still, the events were only sometimes remembered in their entirety (sometimes they were recalled on the next visit to the Centre when similar ones were observed).

The cognitive limitations of the Centre's users who participated in the project hindered greater involvement. They live with moderate to late-stage dementia, and their cognitive and communicative abilities are highly compromised. As stated by Hendriks et al. (2014), the cognitive limitations of the participants are a challenge in participatory design processes. The lack of a more significant body of research into participatory design methods and processes with people living with dementia that can inform practices in this field forces experimentation with different forms of approach that become time-consuming, requiring process reviews and readjustments of work schedules.

Indeed, when research and projects are based on participatory design processes, the issue of time takes on a different dimension since the participant—the person living with dementia—is not always willing to participate. The methods selected for this purpose, although working in other studies with specific individuals at the same stage of dementia, may not work with different ones, which means that processes must be revised to suit better the profile of the person taking part. In short, dementia manifests itself differently in each person, so participatory methods must always be adapted to the person we are working with.

Even when the person is willing to participate, it is necessary to assess any signs of tiredness or apparent desire to end the interaction, especially when their ability to express themselves and communicate is more compromised. In this study, rather than aiming for a result embodied in a product developed with the user's participation, the aim was to create participatory moments characterized by enjoyment, playfulness, and wellbeing in the moment.

Regarding time, and since the involvement of people living with dementia has always occurred at the Centre, it is worth mentioning that the participatory moments had to be framed in time within the activity programmes defined at the Centre. There are several dynamics and daily activities that must be done at a particular time, and that may be longer than initially expected. As a result, the time available for participatory design processes was often reduced and interrupted, which led the project coordinator to increase the frequency of attendance at the Centre to ensure that the project was carried out within the defined parameters.

Another challenging point concerns the interpretation of results in a participatory design process. It was often found that the response to questions such as 'What do you think of this fabric?' was positive, but this was true for all fabric samples. When sets of fabrics were later placed close to the person, the reaction to each sample—the time they spent touching it, holding it, or

the absence of touch, indifference—proved to be more enlightening, with some moments in which the participant even verbalized their preferences and fabric selections. That is, presenting several samples simultaneously and talking about them brought more significant and more reliable results than asking direct questions about each one individually. It should be emphasized that since the abilities of several group members are highly compromised (particularly verbal communication skills), small expressions made spontaneously when they see a particular sample can be particularly important.

Finally, it should be emphasized that the issue of equality in the participatory process, of similar roles and balanced interventions between designer and participant, becomes utopian when the participants are living with late-stage dementia. The projects undertaken were based on the life stories and particular interests identified in the group of people who attend the Centre, and the participatory approach adopted was aimed at different forms of intervention for each person and adjusted to their cognitive abilities. However, it is recognized that each person's involvement was different and conditioned by their remaining abilities. Even so, over the course of the four months at the Centre, strategies were found to involve each user in the different phases of the project.

The outputs—a set of sensory and cognitive stimulation games—have been prototyped and made available to the Centre's users. The project is set to continue, bringing together new students not only from the bachelor's degree but also from the master's degree in design.

Notes

1. This project addresses dementia through psychology, design, and participatory methodologies.
2. Traditional Portuguese soup.
3. Famous line by Vasco Santana in the Portuguese movie *Pátio das Cantigas* (1942).

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Notes on contributor

Cláudia Lima research is focused on the recovery of community stories and local art and design stories through biographical testimonies and visual analysis. This was done within FCT funded projects, including: ‘Wisdom Transfer: towards the scientific inscription of individual legacies in contexts of retirement from art and design higher education and research’ (POCI-01-0145-FEDER-029038); ‘Echoing the Communal Self: designing the dissemination and replication of self-initiated practices in underprivileged urban communities in a post-pandemic world’ (EXPL/ART-DAQ/0037/2); ‘An Infodemic of Disorientation: communication design as mediator between scientific knowledge and cognitive bias’ (2022.08322.PTDC).

She is currently coordinating the research REMIND: Design for People with Dementia, under which pedagogical practices are being developed in partnership with Alzheimer Portugal association.

She has coordinated national and international events including conferences, symposia, seminars, exhibitions, and workshops; and developed pedagogical projects aimed at the interpretation of works of art from past generations through digital media, in partnership with museums including Tate Modern, UK, via Atkinson Museum; the Soares dos Reis National Museum, Portugal; and the WOW Museum, Portugal.

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