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Getting Closer, Empathising and Understanding: Setting the Stage for a Codesign Project with People with Dementia

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Abstract. This paper discusses the initial work of a doctoral research project that explores how communication design can enable people with dementia and their social circle to codesign strategies to communicate. The ethnographic exercise in two care institutions and a consequent design intervention are described, and its process deconstructed: approaching institutions and participants, developing empathy and understanding towards configuring participation, and defining next stages of research. This study draws from approaches related to Design Anthropology and Participatory Design, which are intertwined and mutually influential, reinforcing their importance in developing a design project *for* and *with* people.

Keywords: communication design; dementia care; design anthropology; participatory design.

1 Introduction

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 [1]. 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 participant’s experience, recognising challenges, and being aware of possible risks of stigmatisation or stress.

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 [2].

Respecting and preserving *personhood* is one of the core values in person-centred dementia care [3]. Kitwood [4] 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 [5]. 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 relationships adversely. Consequently, non-verbal communication becomes extremely important to create meaning and establish rapport with others [6].

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. The project takes a *research through design* approach as defined by Jonas [7, p.202] "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", resulting in artefacts that incorporate *designerly ways* of addressing possibilities and problems, as well as in methods, conceptual frameworks and theories [8]. 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.

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."[1] [9, p.123]

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[1] 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*

Observation was the 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, 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.

This design-led observation [10] followed guidelines of ethnographic *participant observation* [11, 12] and systematised data collection through the production of extensive daily field notes [13], while keeping the intuitive and strategic *poetic observation* of design [14].

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.

2.1 Context: Two Elderly Care 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.

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explicitados, que não aparecem à superfície e que exigem um esforço maior, mais detalhado e aprofundado de observação e empatia."

2.2 Institutional Activities

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 [15], had a common structure. This structure consists of (i) the invitation to participate; (ii) an introductory moment to greet and introduce everyone (if people do not know each other), inform about the date, and speak about recent events; (iii) the activity; (iv) a closing moment where participants are asked for feedback about the session and their participation is acknowledged; and finally, (v) 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.

3.3 Meet Mrs Evans and Mrs Martin[2]

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).

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[2] The real names of participants have been replaced to preserve anonimity.

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). 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 wellbeing 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).

3 From Institutional Activities to Codesign

3.1 Materialising findings of observation: the board game

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 [16]. 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 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 [6] 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, 17/12/2014). 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 [17]. In a study that explored the potential of storytelling as a model for conversation with people with dementia, Fels and Astell [17] 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 (*Fig.1*), acting as prompts for storytelling and conversations.

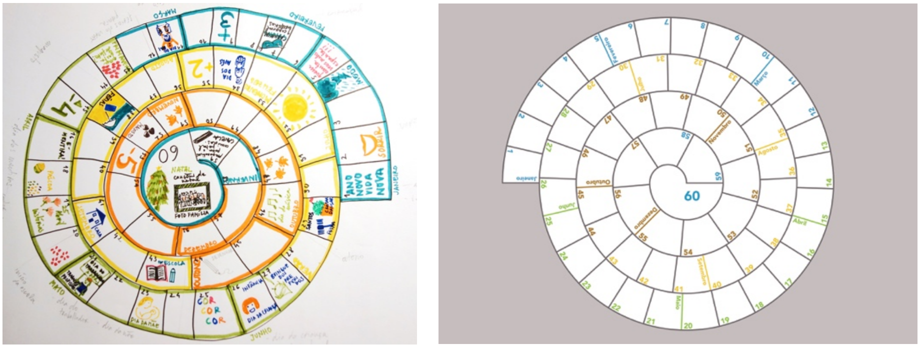

Fig. 1 Early sketch of game idea and final board game frame.

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.

3.2 Codesigning the game

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 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. Later, colour and some missing details were digitally added and the drawings were combined in the board game frame. Two more art sessions were organised by the therapist for modelling the playing pieces (*Fig.2*). 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.

Fig. 2 Drawing, modelling the playing pieces and final outcome of the board game in the day centre.

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. Cut-outs of each individual stop were prepared earlier so that participants could draw directly on them. 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. 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) (*Fig. 3*).

Fig. 3 Drawing, painting the playing pieces and final outcome of board game in the nursing home.

The two main changes in adapting the board game to the nursing home were: (i) the discussion of the annual events which was an activity by itself; and (ii) 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 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 [10, 14]. 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" [18, p.2].

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 [19, 20]. Similarly to Lindsay *et al* [20] and Wallace *et al* [21], 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*" [22]. 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 [3], and perceives equality, as McCarthy and Wright [22, p.53] put it, "(…) as the starting point and difference as the means, rather than inequality being the starting point and homogeneity being the endpoint".

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 [23].

Getting closer. 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.

Although the experience of dementia and designing for people with this condition was already well-known to the researcher through personal experience with relatives [24], 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 [25].

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 exercise more complex and non-linear, where the roles of relative and designer overlap, hence differing from the framework for empathy adapted to the design practice by Kouprie and Sleeswijk [26], 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 the 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. Similarly, the *detachment* phase happened by means of designing, distancing in order to ideate, and developing tools for communication with the people with dementia [24].

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.

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" [22, 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 became less frequent, all running in parallel with *discovery*.

Understanding. 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" [27, 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 [22, p.9] 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." 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, 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 [22, p.41] based on the ideas of Rancière. This s*ensible* dimension seems to be even more relevant when dealing with people with dementia, due to the importance and heightened use of non-verbal communication [5] and, since their cognitive capacities may be weakened they may depend even more on emotion [15]. 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 [28]. Following that, a more strategic aim of this study was to look for ways, similar to Hendriks' [29], to 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.

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 [14] 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* [22], 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 [30] 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. 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 [31, p.36] defends the importance and effectiveness of understanding through participation: “understanding as we intervene”. Likewise, McCarthy and Wright [22, p.58] describe “understanding the other by making participation sensible”. 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.

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 [22], 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 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” [32, 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.

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" [22, 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 sensible*, Participatory Design events become the means through which the work of understanding and developing sensitivity continues.

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