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## **“I’m always well when we are together”: Observation of institutional activities with people with dementia and its implications for a co-design research project**

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### **Abstract**

*This paper describes an observation based preliminary study within a PhD research project that explores how communication design can enable people with dementia and their families to create personalised strategies for interaction. This study consisted of an 11-week period of observation and participation in activities with older people with dementia in two care institutions in order to deepen the understanding of living with dementia, gain sensibility towards working with this population, and to learn how they are engaged in activities in institutional environments. Additionally, this observation was aimed at inspiring the design of communication artefacts through identifying aspects considered to be relevant for a subsequent design process. Overall, it consisted of design-led observation and included the development of a pilot project (a board game) with users and staff. Preliminary findings revealed that the combined methods used in this study were fundamental to notice various details regarding communication between people with dementia and others, as well as among themselves, while ensuring that a design perspective was kept. The board game developed during the study placed design in the centre of the observation process, and worked to summarise the observed activities. Experiencing how group sessions are structured, and how people with varying abilities engage in several activities raised important insights into the inclusion of people with dementia in the design process.*

**Keywords:** communication design, dementia, observation, participation

## Introduction

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

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

## Personhood, communication and creativity in dementia

Despite the difficulties that dementia entails, people with dementia are equally unique and sensitive human beings, whose thoughts and emotions should be acknowledged. As opposed to more traditional accounts based on the dehumanisation and stigmatisation of dementia, Kitwood (1997) claims that people with dementia do not lose their personhood, and that maintaining a relational sense of self that is conveyed by others should be a priority of dementia care. This is reinforced by Zeisel (2009, p152), who refers to social relationships as "a treatment that reduces Alzheimer's symptoms". Communication plays a major role in strengthening relationships and therefore reinforcing personhood (Allan and Killick, 2008). In addition, good communication is also important to help understand needs of people with dementia and facilitate caregiving. On the other hand, dementia affects communication in several ways, which has adverse impact on relationships. Difficulties with communication include struggling to find the right word, confusing and ambiguous speech, repetition, difficulty following a conversation and making non-verbal sounds, towards a gradual reduction of language use. Despite these difficulties, people with dementia are often resourceful and inventive in the use of language and demonstrate a heightened sensibility for non-verbal communication, such as facial expression, tone of voice, gesture, touch and eye contact, whose combination brings meaning to the communication and becomes essential in establishing rapport with others (Killick and Allan, 2001).

The arts can be a vehicle of communication for people with dementia. Creative practice enables self-expression, exercises control, enhances self-esteem, promotes self-discovery and constitutes an opportunity for making something together, thus nurturing relationships (Killick and Craig, 2011). Playfulness also contributes to alleviate some difficulties and humour can be a way to cope with, and resolve challenging situations, thus enhancing relationships (Killick, 2013).

## Inclusion of people with dementia in research

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

## Inclusion of people with dementia in the design research process

Designing for and with people with dementia is a significant design challenge and requires an extensive comprehension and empathic understanding of their life experiences (Lindsay *et al*, 2012, Hendriks *et al*, 2013, Wallace *et al*, 2012). The use of participatory methods allows the design process to concentrate on the contributions of people with dementia instead of focusing on their impairments, thus designing for personhood rather than dementia (Wallace *et al*, 2013). In order to build a good relationship, reciprocity and flexibility are essential, as well as a sympathetic and uncritical attitude, to make individuals express themselves comfortably, without a need to justify. It is also necessary to be conscious of not following assumptions, and making inaccurate interpretations of expressed needs (Lindsay *et al*, 2012, Hendriks *et al*, 2013, Hendriks *et al*, 2014, Wallace *et al*, 2012). People with dementia have difficulties with abstract thinking, understanding visual and imaginary items, keeping focused on a task, and making choices, thus rendering participatory design too demanding (Hendriks *et al*, 2014). Traditional participatory techniques need to be adapted to find a common ground, and to create strategies that enable and motivate people to participate despite their difficulties (Lindsay *et al*, 2012, Wallace *et al*, 2013, Hendriks *et al*, 2013).

## Preliminary study: Observation

During the period of study, observation was undertaken in two different care facilities; a nursing home for older people; and a specialised dementia care day centre; and involved taking part in activities with older people with dementia. These activities included arts and craft, music, cognitive and sensory stimulation, and reminiscence. In the nursing home, the artistic activities were energised by the presence of small children.

This design-led observation (Bichard and Gheerawo, 2010) draws upon the systematised data collection method of ethnographic participant-observation, through the production of extensive daily field notes (Angrosino, 2007, Calabrese, 2013), while keeping an intuitive and outcome-oriented glance of the designer, described by Fulton Suri (2011) as poetic observation.

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

Additionally, the board game was adjusted to the intergenerational sessions in the nursing home. In order to increase levels of participation, annual events were discussed and listed together with participants before drawing.



Figure 1: Development and final outcome of board game in day centre.

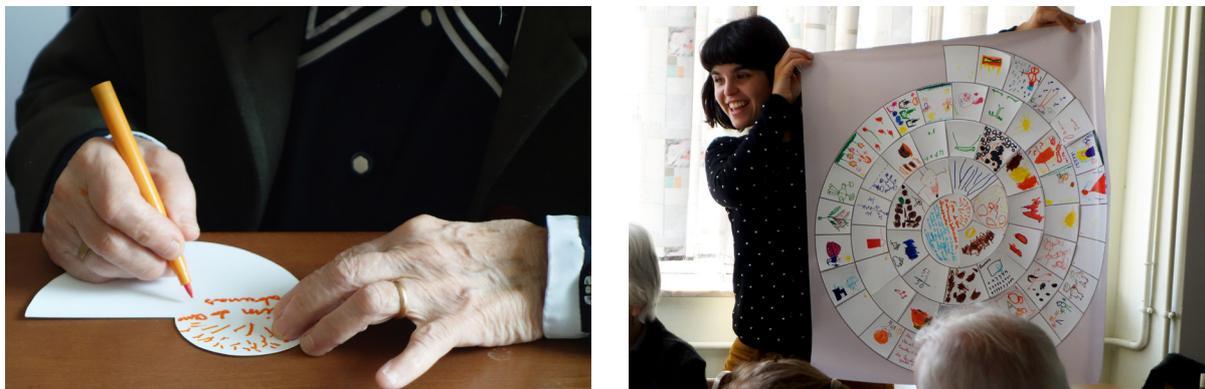


Figure 2: Development and final outcome of board game in nursing home.

## Discussion of preliminary findings

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

### Learning about people with dementia

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

### Considerations for design ideation

The participant-observation of activity sessions facilitated learning how different people with dementia engage in various activities and react to a range of distinct stimuli, which yielded workable

ideas for design. It became apparent that regardless of personal preference, most people valued the activities as moments of meaningful occupation and togetherness, and this could prove relevant in defining the aims for design outcomes. Additionally, the study raised insights on visual perception, mainly regarding colour, image quality and characteristics.

## Considerations for participatory design process

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

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

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

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

## Participatory development of the board game

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

## Conclusion

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

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

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

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

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

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