Experience-Based Design and advanced dementia: The influence of Montessori-Based Dementia Programming method in a nursing home.

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1. Introduction

Since the late 20th century, we have observed a rapid increase of the life expectancy. The ageing of the population, although widely regarded positively, comes with age-related issues. One of the most significant one being dementia (Wimo and Prince, 2010). Dementia is a term used to describe a group of symptoms, caused by various diseases (the most well-known is Alzheimer), which lead to a progressive deterioration of a person's cognitive activity. Symptoms intervene on a cognitive and psychiatric level: they can include a deterioration of the memory, the thinking and reasoning capacity, create difficulties in language, communication, feelings of isolation, loneliness, loss of empathy, delirium and so on.

The progression of these symptoms interfere severely with daily life and progressively cause the dependance of the person for everyday tasks (Mayer and Zach, 2013; Hendriks et al., 2013). Help could be provided whether by professionals or relatives, but statistics show that residential long-term care is developed and will be developed significantly with the risen the number of people with dementia (Treadaway and Kenning, 2016). Taking care of a person with dementia is a hard and never-ending process and with the societal and demographic evolution, such as change in familystructures or retirement age, the informal care provided by relatives is limited (Broese van Groenou and De Boer, 2016). At the same time, to face the increasing demand of care for elderlies in residential care and the cutback in professional, new strategies, designs and approaches are needed (Treadaway and Kenning, 2016). However, working with a person with dementia, mostly in advanced stage, is highly challenging for designers who have limited knowledge about these diseases, and their symptoms and the residential care environment (Lindsay et al., 2012). Therefore, involving the expertise of the users of these services (patient and care givers) into the design process is important to provide accurate design solutions (Treadaway and Kenning, 2016). In this paper, I will present a participatory approach I developed within a nursing Home in Belgium, underpinned by theoretical approaches in design research and influenced by the Montessori-Based Dementia Programming method developed by Cameron Camp. The aim of this paper is not to discuss the design project developed but to highlight some methodological principles issued by the meeting of these two approaches for persons with advanced dementia.

2. Participatory approach and patient empowerment

Over the development of dementia, the assistance of caregivers (formal or informal) become more and more indispensable. In the elderlies' point of view, the situation increases the feeling of loss of control and frustration (Kolasinska et al., 2021), while on the caregiver's side, tasks and patient caring become more complex and overwhelming (Royer, 2020). The professional-patient relationship and the pyramidal organization of

the system has been pointed out as a part of the problem (Royer, 2020). That is why, public health policies since decades have aimed to reform these organizational systems to empower more patients, supporting their autonomy on their disease management and reduce the pressure on caregivers (Delanoë-Vieux et al., 2019; Freire et al., 2010). Within which, participatory design is seen as a key resource to change the hierarchical model of organization and deinstitutionalized relationship (Delanoë-Vieux et al., 2019; Sangiorgi, 2011). However, to transform these existing deep-rooted models of interaction within patient and caregiver it is necessary for the designer to ensure the involvement of both sides, institution and end-user, throughout the entire process of change (Sangiorgi, 2011). By building trust and on-going dialogue between providers and users, thanks to adapted tools, the design will work on the change of attitude and culture (Sangiorgi, 2011). In case of dementia, the participatory approaches are highly challenging due to the complex communication with elderlies. Even though some participatory design methods have been adapted for dementia, the traditional tools were not fully appropriate (Mayer and Zach, 2013; Lindsay et al., 2012). Indeed, regarding studies, the traditional methods originally designed for work-related do not work well with person with dementia (Lindsay et al., 2012). Furthermore, these persons in most cases also suffer from visual and hearing impairment, adding complexity in the use of traditional tools (Hendriks et al., 2013). Finally, the persons who took part in these design projects were at an early or middle stage of dementia, which means that they were still able to take initiatives and respond throughout the design process. The case developed in the patter part of the paper will consider persons with advanced dementia. However, these studies developed interesting principles and guidelines to consider while working with old users with dementia (Lindsay et al., 2012; Mayer and Zach, 2013; Kolasinska et al., 2021; Stalker et al., 1999) and question the designer's skills and attitude within these environments.

3. Experience-based design and role of the caregiver

The symptoms of dementia could influence the person's action. In consequence, an evidence-based approach wouldn't be fully appropriate and results would be biased with the designer's point of view (Lindsay et al., 2012; Stalker et al., 1999). On the other hand, theoretical research shows that the use of elderlies' proxies to collect data is also subject to interpretations (Hendriks et al., 2013; Stalker et al., 1999). In both cases, using only these strategies would lead to a misunderstanding of the person with dementia needs, problems and desires. In order to have a deep transformative effect on the relationship between persons with dementia and caregivers, it is important to reinstate an ongoing dialogue between them and have a deep understanding of the experience lived by the elderlies within the service (Bate and Robert, 2006). The experienced-based design approach (EBD) in the case of dementia could be interesting. Based on "what a person thinks, feels and says about the experience of a service, process or product he or she has encountered" (Bate and Robert, 2006). The EBD uses the knowledges of user experience in the service transformation in order to better design the experience of the user. This knowledge is acquired thanks to a direct and deep contact with the person involved (Bate and Robert, 2006). However, "the core problem in studying experience is that […] it can never be accessed or observed directly, but only indirectly through the words and language people use to describe it" (Bate and Robert, 2006). In the case of dementia, language could be approximate, therefore, understanding the symptoms of dementia are essential for the designer to access the perspective of the person (Mayer and Zach, 2013). To do so, caregivers should be involved into the design research to support the development of adapted tools. "Having a range of expertise on hand in one physical location reduced time spent revising inappropriate designs" (Treadaway and Kenning, 2016). However, caregivers face complex and numerous tasks

and could see the participatory approach as a constraint, even though the transformation aims to facilitate their daily work (Royer, 2020). By giving them time, patience and energy supporting their task, the designer will build a relationship based on trust, reaching a consensus which will ensure on one hand the contribution of every stakeholder toward the design process (Delanoë-Vieux et al., 2019; Royer, 2020) and on another hand, reinstate a form of dialogue and meeting between both caregivers and patients. As a facilitator, one of the roles of the designer would be to balance the relationship of strength between patient and caregiver while ensuring to hear everyone's voice, needs and interests (Delanoë-Vieux et al., 2019; Royer, 2020).

4. Montessori-based dementia programming method influence

The project thus presented has been developed during two years within the nursing home Les Jardins de Scailmonts in Belgium. As mentioned above the topic of the project won't be discussed in this paper, however the method I employed with the caregivers and elderlies allowed me to work with persons with advanced dementia, with little language, no initiative to answer their needs and almost no short-term memory. Les Jardins de Scailmonts is a nursing home using the Montessori-Based Dementia programming method to enhance its inhabitants' autonomy. This approach is inspired by Maria Montessori's research and has been developed by the neurobiologist Cameron Camp for person with dementia. This approach aims to empower persons, enhancing their autonomy and ability to act by adapting the objects and environments to their needs and giving them responsibilities. It alone works on strengthening the capacity left of a person and on reinforcing his/her individuality thanks to personalized and adapted activities (Simon Erkes, 2019). This approach, focused on the empowerment of the person with dementia and the change of the posture towards them, uses an ongoing process of tools adaptation. This paper won't discuss the results of the method itself but expose what I learned from the combination of Montessori-Based Dementia Programming method and Experience-Based design method; how it helped to develop participatory activities and what can we learn from it.

5. Methodology

The Corner of the room

The first moments inside the nursing home have been dedicated to the deep observations without intervention of the daily routine, persons' behaviors and interaction between the inhabitants and caregivers. Phone pictures and voice recordings allowed me to discreetly collect data on non-verbal communications and conversations. Thus, I gathered quantitative insights to cross with qualitative ones and more precise ones later. Then, Caregivers gave me information on individuals backgrounds, tastes and passtimes which allowed me to start informal conversations with different persons. As Treadaway and Kenning say "collection of the qualitative data involved unstructured interviews which provided a series of narratives to inform the design process. These included background and environmental information about the people with dementia and their lives, families and preferences". Indeed, the loss of memory and the difficulties in language complexify the conversation. Focusing on people's backgrounds and taste reinforce their individuality and help to build a relationship based on trust.

Adapt the posture, the tools and settle rituals

In Les Jardins de Scailmonts, inhabitants are empowered thanks to a display, using a combination of words and images (principle I followed during the activity to facilitate their understanding), reminding them where the different objects, spaces etc. are. Displays in rooms are adapted to the person's visual capacity in order to retain her

autonomy without stigmatizing her. Before starting participatory activities, I made my participants read stories with decreasing the typography size in order to design all my tools regarding their visual capacity. We also settled editable timelines and installed reminders in their room in order to remind them the project and its evolution at the beginning and during the sessions. Finally, the Montessori approach points-out the importance to work on our verbal and non-verbal communication with persona with dementia in order to respect the rhythm and communication capacity of each of them in order to be respectful and improve the receptivity of the person.

Binary choice questionnaires

At an advanced stage of dementia, it becomes difficult for the person to do choices more complex than binary ones. According to studies open-ended "Yes/No" or "Either/or" questions lead to biased answers from the participants (Stalker et al., 1999). To go more in depth with the persons preferences, we settle a binary questionnaire, evolutive regarding the answers, which asked the participants to place the answers in a box. Thus, there was no hierarchy between the different options and the choice seemed more impartial.

Interactive models, use of objects

As design research and Montessori approach show, non-verbal methods are accurate to communicate with the participants and start to elicit valuable feedback (Stalker et al., 1999; Mayer and Zach, 2013). For this project, I used photography and objects to prompt memory and support conversations. I also used interactive models and prototypes to interact with participants and collect their feedback (verbal and non-verbal).

6. Discussion and conclusion

This project doesn't aim to be a specific guideline to use in order work with advanced dementia. However, the influence of the others disciplines already working in this environment, allow me to develop a participatory method which engaged both caregivers and elderlies with advanced dementia. The Montessori approach has a lot of similarities with the experience-based design. Thanks to the caregivers' expertise on symptoms and their habits to constantly adapt solutions, it has been possible to develop large scale purpose-based tools in order to implement new mechanisms of communication between patient and caregivers. By empowering the elderlies and collecting their experience within the service, it has been possible to better understand their needs and change our attitude and opinions towards them. The design here, allowed to reconnect inhabitants and caregiver's, involving them in a same project but also to facilitate dialogue between the different users thanks to the tool development, improving their mutual understanding and so empowering both sides on decision making for changes. By using the competences of caregivers towards the communication tool, it has been possible to enhance the existing culture of exchanges between caregivers and patient. Even though it has been implemented on a single project, this meeting between these two approaches could be interesting to develop and evaluate at a larger scale.

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