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Environment as non pharmacological intervention in the care of Alzheimer's disease

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Abstract: The physical environment can reduce dysfunctional symptoms and behaviours, if the information needed to understand the environment is embedded in the environment itself. Moreover, the environment is regarded as a therapeutic aid, able to enhance well-being among people with dementia. The actual medical model of dementia care is focused on impairments and lost capabilities; considering these features as the focus of care makes hard to aim at enhancing people's with dementia well-being. Hence, focusing on the experience of living with dementia, enables designers to create care environments that accomplish dementia needs. Methods. Through interview sessions with caregivers and professionals, we delineated a set of design guidelines, for supportive environments tailored for people withdementia. Objectives. The purpose of this study is to analyse how design can promote well-being through the creation of physical environments for people with dementia that are psychologically supportive in order to manage the major stress accompanying illness.

Keywords: Alzheimer's Disease, Design, Non-Pharmacological Therapies, Interiors

1. Introduction

Alzheimer's Disease (AD) is one of the most common forms of dementia. It is developed when nerve cells (neurons) in the brain die or malfunction. Dementia is the umbrella term used to describe the symptoms that occur due to AD. It is characterized by memory, thinking and behavioral symptoms that affect person's ability to function in daily life (Alzheimer's Association, 2015). In most instances, the progression of dementia is slow and consistently changes over time.

Alzheimer's disease (AD) affects mostly the frontal lobes, the ones responsible for encoding new information and behaviours, recall knowledge, judge, and plan daily life. Specifically, in the early onset of the disease, the function of the hippocampal complex, is damaged. This part of the brain represents the site of short-term memory as well as what Hobson (1998) calls the "map room of the

brain", responsible for the spatial location of ourselves, for the recognition of spatial relations, and for decoding environmental features. Consequently, people with dementia tend to wander in search of something they can neither clearly visualize nor easily find, and their behaviour is often characterized with agitation and aggression.

Dementia generally occurs after the age of 65 and the prevalence of the condition rises more than 20% after the age of 80. With an increasing number of people being affected by Dementia due to Alzheimer's, almost everyone encounters someone who has dementia or whose life has been affected by it (WHO, 2012). The latest estimate of World Alzheimer Report (2015) is that; today over than 35 million of people are suffering from AD and this number will increase to double in 2030 and even triple in 2050 to 115 million. The main effect of this syndrome is a slow, constant and unrelenting cognitive impairment, which severely compromises people's perception of the world and their environment. Currently, there is no cure for dementia due to AD.

This condition, in its most advanced stages, can primarily be addressed in two ways: through a pharmacological intervention that mainly provides assistance to the person, or through Non-Pharmacological Therapies (NPTs) that aim to reduce behavioural disturbances, a source of discomfort for the individual through personalized paths that leverage residual capacities. Apart from medication, NPTs concentrate on cognitive and behavioral impairments. Emotional, mental and physical activities are the key elements of NPTs. Although some are used with the goal of maintaining cognitive function or helping the brain compensate for impairments (Olazarán et al., 2010). Other NPTs are intended to improve quality of life or reduce behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation, and aggression. Therefore, Pharmacological or Non-pharmacological treatments can only improve the condition of the patients or slow down the progression of the disease (Olazarán et al., 2010).

2. Therapeutic Environment

In 1979, Canter and Canter published the "Designing for Therapeutic Environments: A review of Research" by including various contributions from researchers who shed light on the therapeutic values of settings like the hospital and housing on different users (such as the children and the elderly). In early research samples presented in this book, the benefits of a therapeutic environment were justified by maintained or enhanced satisfaction and social interaction (Canter and Canter, 1979). Another group of studies focused on the therapeutic benefits of natural environments. The main argument is that exposure to certain environmental conditions, such as natural and aesthetic amenities, can alleviate stress and promote physical and emotional well-being (Kaplan and Kaplan 1989; Hartig, Mang, and Evans 1991).

The most explicit and earliest link between the environment and the possibility to enhance the patients' well-being through its characteristics (salutogenic approach), first appeared in the healthcare environments. The design of hospitals is based on a medical model where each sick body part is associated with a set of spaces in which the illness will be treated. Antonovsky (1996) noted that: *"...every society has developed a social institution, based on its understanding of illness, to deal with the problem. In modern western industrialized societies, what is called the biomedical model provides this paradigm. It is embodied in the complex of medical care institutions we have created*". Yet, as stated in the literature, environment has a lot of potential to contribute to well-being of its occupants. Given this backdrop, the crux of the matter for a designer is to try to pinpoint the ways and means to understand which appropriate design is needed to create the be-fitting environmental conditions in order to restore wellness when it has been damaged.

Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO, 1946). Among the literature, there's a long debate among the effects of the built environment on patients; especially on the healing process and well-being, and about the importance of healthcare service and support necessary in this recovery phase. This discussions extend back to 400 BC with Hippocrates, until Florence Nightingale, in the 19th century. The construction of healthcare facilities has been strongly influenced by these known effects, in order to achieve the maximum level of comfort and well being of patients, aiming at a shorter healing process (Codinhoto, 2009).

2.1 Environment as non-pharmacological intervention for Alzheimer's Disease

The well-being and behaviour of people with dementia is strongly determined by the design of the environment they live in (Marquardt & Schmieg, 2009). For example, the ecological gerontology explains this relationship through established concepts as the person-environment-fit. Moreover, the Environmental Docility Hypothesis, however, indicates that people who are subjected to restrictions on their health or cognitive ability cannot always adapt the environment to their specific needs. Therefore, they are more dependent on their external environment (Marquardt & Schmieg, 2009). This implies that people with dementia have a lesser capacity to regulate the environmental factors, so their environment should be designed in such a way that it meets with their specific needs.

As previously said, Alzheimer's disease affects mostly the frontal lobes, the ones responsible for encoding new information and behaviours, recall knowledge, judge, and plan daily life. Specifically, since the early stages, Alzheimer's disease deeply damages the function of the hippocampal complex in the inner or medial parts of the temporal lobes. The hippocampal complex is the site of short-term memory as well as what Hobson (1998) calls the "map room of the brain". This part of the brain is responsible for the spatial location of ourselves, and also to remember spatial relations. As a direct consequence, people with Alzheimer's disease get lost more often than other people due to this damage. Moreover, they wander in search of something they can neither clearly visualize nor easily find, and their behaviour is often characterized with agitation and aggression. People's with dementia impaired cognitive spatial skills, also affect their mental spatial representation capability. These personal mental representations of the environment are called cognitive maps, and are responsible for personal orientation and allow the successful locating of places. The environmental information, necessary to form a mental cognitive map, are based mainly on the perceptual range of vision. The Precuneus, an area of the brain, is responsible for the mental visual representations of objects, places, and paths. This area results damaged in people with dementia.

The physical environment, if properly designed, can reduce such dysfunctional symptoms and behaviours if the information needed to understand the environment is embedded in the environment itself. As Zeisel (2003) reports, Donald Norman has coined a term for environments and objects designed this way: "naturally mapped" (Norman, 1988; Zeisel, 2001). These environments are characterized with clear pathways, place markers, and destinations. After decades of research, design of long-term care facilities is regarded as a therapeutic aid, able to enhance well-being among people with dementia, and not only as a decorative matter. As Campion argued in the *New England Journal of Medicine*, therapeutic physical environments can positively affect the lives of residents with dementia (Campion, 1996): ''Faced with a patient with progressive Alzheimer's disease, physicians may feel they can do nothing to help. This is wrong…Care in a supportive environment can protect function for years'' (p. 791). Inside this perspective, the environment can reduce dysfunctional symptoms and behaviours, and it can be considered as one important non-

pharmacological treatment modality (Zeisel & Raia, 2000). (Where as non-pharmacological treatment modality, or Non-Pharmacological Therapies we intend “treatments that do no involve the use of drugs, aiming to stimulate, activate and maintain the physical and cognitive functions that are not completely deteriorated, acting on the residual potential”, Olazaràn et al., 2010). Therefore, the peculiarities of an environment take on relevant importance, qualifying as one of the tools that allow the correct activation of non-pharmacological therapies, in order to ensure effective results. Therefore, the physical environment assumes a “prosthetic” value, as it is able to compensate for some cognitive deficits (Zeisel, 2000). Moreover, it is widely recognized its therapeutic value in the enhancement of well-being among people with dementia (Day, Carreon and Stump, 2000) and in the reduction of behavioural symptoms (Zeisel, 2000; Cody, Beck and Svarstad, 2002).

3. A design approach

When people with dementia move to a nursing home, they are often unable to locate places, feel a sense of belonging, and orient themselves within the unfamiliar new setting. This results in a loss of autonomy, and also affects the quality of care provided. The transfer from ones home to a care facility, or day care regime, depends on the public care services provided and the availability of family care. Van Hoof (2007) defines this succession of living situations “*The housing continuum for persons with dementia*”: it starts with independent life at home, or with the provision of health service, and can be followed by long-term dementia care, if the symptoms of the disease worsen.

Despite efforts to move aged care away from a medical model, based on the hospitalization, to a more balanced social model of care, still the focus and the aim of most of the care providers is centred on decreasing the symptoms of the disease, and only a smaller percentage is focused on providing experiences and meaningful engagement to people with dementia. In the last two decades, physical and social environment gained importance, and recognition, in supporting the person with dementia (Verbeek, 2009). Usually, environments are continually being manipulated and modified to reach the maximum possible comfort, to enhance professional productivity, and personal satisfaction. For people with dementia the physical environment can have a key role in supplying impaired capabilities and avoid causing any unnecessary disability (Marshall, Brown, Stewart, & Hoskins, 1999). In recent years, new models of long-term dementia care have been developed. Their common aim is to recreate “enriched environment” (Nolan et al., 2006) essential to enhance well-being and quality of care for people with dementia. These researches focus on the remaining abilities, rather than seeing dementia as a disability, with a consequent focus on its impairments and behavioural symptoms and manifestations. It is also highlighted the needs for residents to be an active part of the community that surrounds them, with active roles, according to their skills and abilities. Moreover, Chalfont & Rodiek (2005) argue that it is time to move beyond designing only for safety control and decrease of behavioural symptoms, and take into consideration the understanding of “*how environments actively encourage pleasurable and satisfying behaviour, for everyone who lives or works within or near them*”; a design approach that encourages curiosity and action, rather than focusing on decreasing symptoms. Furthermore, recent literature focused on the acknowledgement of the significance of “everyday experience’” of living with dementia in order to design suitable environments (Davis, Byers, Nay, Koch, & Andrews, 2008). Emphasizing the experience of living with dementia, rather than focusing on symptoms and impairments, represents an important change in the vision, that enables the creation of environments that allow the person with dementia to actively participate in everyday life rather than just passively receive care.

4. Methods and Objectives

The qualitative study conducted aimed at exploring the perceptions of caregivers and medical staff regarding environment-behaviour relationships and needs in people with dementia due to AD. In qualitative research methods, focus-group interviews are one of the most used tool. Focus-group inteviews are extensively demonstrated to be useful tools to obtain efficient qualitative data collection, to explore emergent and pragmatic issues, and to check and balance on differing opinions. The authors conducted focus-groups interviews with facility staff members and caregivers to collect information regarding needs and urgencies of people with dementia connected to the physical and social environment. Individual interviews were conducted, each lasting maximum 2 hours. Medical staff members were interviewed at the facility they are employed in; caregivers were interviewed in the same facility. A semi-structured interview guide was used to establish a general direction for the interview while encouraging participants to direct the conversation to areas of concern to them. Participants focused on the description of supportive characteristics of the environment strictly connected to three main human needs: individual needs, community/social needs, structural needs. These needs comprise implications for both the social and physical environments. These two, are proved to significantly impact on people with dementia behaviour and quality of life.

5. Results

All participants agreed that people with dementia should be cared for in an environment that resembles what they had experienced before they became institutionalized. Elements associated both to the social environment, as the organization of daily meaningful activities, or an individualized care plan, as well as to the physical environment, as a home-like ambiance, the presence of domestic elements, and the possibility to personalize the patients' rooms, were regarded by participants as important elements able to facilitate a sense of comfort and familiarity in people with dementia towards the care environment. Consequently, care facilities design should promote a **non-institutional character,** introducing home-like features, in the form of objects, decorations, space sizes, staff not wearing uniforms, in order to foster residents' comfort, encourage attachment towards the environment they are living in, decrease stress coming from a sterile environment, decrease patients' disorientation. **Home-like objects**, such as, domestic furniture, plants and flowers in indestructible vases, paintings, etc… recreate a familiar ambiance, crucial to foster people with dementia's sense of belonging. Hence, the main result of the study was the identification and development of five main guidelines, through the interviews with participants:

// ***Familiar & comfortable environments.*** Environment may be easily recognizable and understood by people with dementia. A familiar and comfortable environment has home-like features, such as halls or hallways, music room, library, laundry room, or bedrooms, in contrast to an institutionalized environment, with corridors, multi-purpose rooms, nursing stations, that results sterile and hostile for people with dementia. A home-like environment increases the sense of familiarity towards everyday life, fosters family involvement and intensifies familiar and social relations. It also allows people with dementia to feel at ease, to enjoy spaces, walking freely around them, without discomfort. Home-like features also include soft furnishings that absorb noise, private bedrooms filled with personal belongings, fully equipped kitchen, or a fireplace to recreate social rituals, large windows with interesting views and natural light; It means the provision of calm and favourable surroundings to people with dementia. Physical environment should provide occasions to perform social rituals proper of the residents past life. It helps them to take control over the environment,

feel comfortable, and help them to gain back a sense of belonging towards the environment they are living in.

// ***Legible & distinctive environments.*** Legible environments help people with dementia's wayfinding and orientation. The layout has an important role in enabling these tasks; if it is organized offering spate rooms for different functions (dining, relaxing, activities with therapists) rather than providing having one multi-purpose space, it helps people with dementia to recognize the different spaces, and provide different small environments, each one different from the other, that stimulate their attention and curiosity. In fact, participants agreed on the fact that long endless corridors, large un-characterized multi-functional rooms, enhanced a sense of disorientation in people with dementia. Small characterized environments, such as living rooms or kitchen areas where easily recognized by people with dementia. Moreover, legible and distinctive environments, through their features, support people with dementia's orientation and understanding of space and time. Legibility is expressed through the clear distinction between private, semi-private, semi-public and public spaces. Visual access throughout all the facility, enhance personal orientation and independence, as many participants agreed on the fact that hidden corners, or hidden turning points can disorient peopel with dementia. Furthermore, it is important to provide interesting and positive stimuli throughout the environment, such as art works, plants, ornaments, photographs, placed at strategic spots, to attract people with dementia's attention and provide clues for orientation. Walls and floors painted or finished with distinct and contrasting colours, helps people with dementia to clearly identify pathways, avoiding darkish colours, as they are seen as barriers by people with dementia, according to the participants opinions. The personalisation of the environment, using residents' personal belongings, also turns the environment into a legible one, as they trigger people with dementia's old memories.

// ***Safe & accessible environments.*** Safe and accessible environments provide overall safety and security while supporting residents' independence. Therefore, they allow people with dementia to independently use, enjoy and move around interiors without fear or risk to fall and hurt themselves, regardless of any physical, sensory or cognitive impairment. Safety always represented a big issue for dementia care facilities. In fact, it is important not to let safety concerns become prevalent impairing person independence. Participants agreed on the fact that people with dementia are encouraged to move freely into the environment, if a certain level of visual access is granted. Moreover, participants reported that locked doors represent a source of stress for people with dementia, as they are unable to open them, causing a sense of frustration. In this direction, camouflaged doors represent a solution to decrease exit seeking, and prevent people with dementia to enter unsafe areas, without representing an unpleasant barrier for them. Curtains and blinds are important interior elements to avoid glare, shadows and frightening reflections. Flat and non-reflective floors and pathways, with different colours and tones from the walls, help people with dementia to move independently inside the facility.

// Respect privacy, dignity and personal possessions. Privacy and dignity for people with dementia, may mean being able to decide to spend time in their own room alone, without any strict surveillance, or being on their own rather than being involved in activities with others. Personal spaces are very important for people with dementia. They are not only private rooms, but the environment should also provide occasions to sit in a more quiet and separate corner, just to relax, not being involved in any activity. Dressing, and moreover bathing, are activities that require a certain level of privacy. Enable people with dementia to dress up independently can raise their self-esteem. Personal belongings help create a familiar environment and can be a source of joy and foster old happy memories for people with dementia. They are strictly connected to the person's character

and personality, and can be a topic of conversation for visitors and family members. The environment should offer opportunities of personalisation, not only in residents' rooms, but also throughout the facility, allowing the presence of paintings, self-made knitting works, plants and flowers or photographs of familiar places.

//Visual Orientation. Concerning the layout of the circulation system, the importance of a direct visual access to all places relevant to the residents becomes evident. The absence of a cognitive map can be partially compensated by using other kinds of orientation strategies. Guiding elements, such as a straight wall running though the whole living area, can be supportive features. Moreover, participants indicated that people with dementia need visual cues to remember and understand the environment. Visual cues are of primary importance. People with dementia are likely to have difficulty integrating large space into familiar place. They have no trouble identifying specific visual cues or unique objects, but they understand the spatial relations among them poorly; hence they easily feel disoriented outside the small areas of habitual contact. Hence, "memorable reference points" are needed by people with dementia to support their allocentric orientation. These elements can range from architectural elements, such as an open kitchen, to characterized pieces of furniture, to fixtures and finishing. These reference points should be placed throughout the environment, at the end of corridors, or where there's a change in the direction. Examples of positive behaviours stimulated by environmental cues included social interaction, self-care, and reduced pacing.

6. Discussion

Participants in this qualitative study described a number of characteristics of the physical and social environments that resulted helpful and meaningful in the enhancement of people's with dementia quality of life and functional ability. The staff and caregivers interviewed in this study indicated that people with dementia, as a group, have unique needs in terms of the social and physical environments. However, participants emphasised that each person with dementia has individual significant differences. To achieve optimal levels of comfort and quality of life, is important to tailor the environment in order to meet these individual needs. To support the inability of people with dementia to learn or interpret a new environment (Camberg et al., 1999), interiors should be designed in order to facilitate the retrievement of memories related to past experiences through the use of environmental cues. Thus, a familiar ambiance is important for people with dementia; introducing the sense of familiarity into a new environment it helps people with dementia to develop a sense of belonging towards the environment they are living in. In fact, quality of life is strongly related to the quality of the socio-environmental system in which Alzheimer's patients live. This system consists of environmental factors, as well as objects and human interactions, in which designers have to manage the emotional fragility of people with dementia. This means to consider interior design for dementia not only linked to architectural design or adaptation, but moreover, connected to the design of "activators of well-being" independent from the building, designed for the enhancement of the well-being.

The five main guidelines identified in the study defined the basic principles to follow in the development of specific design environmental solutions for dementia, in terms of familiarity, legibility, safety, privacy and orientation. Specifically, the design approach is summarized in Figure 1.

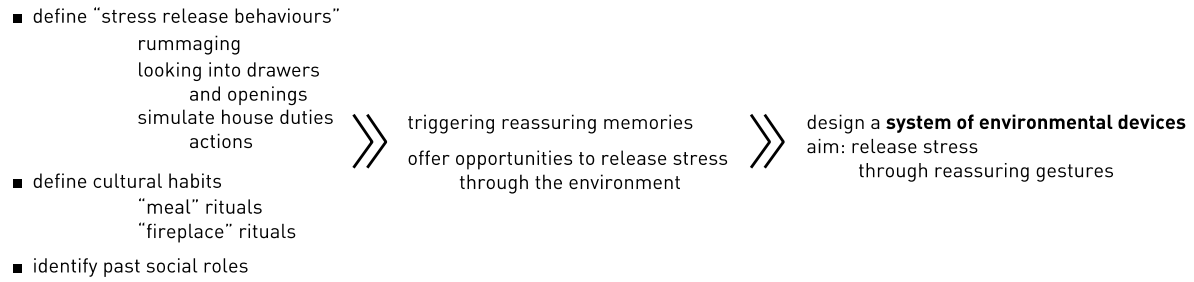

Figure 1. Design strategy for the development of therapeutic environments.

Introducing this new flexible approach means shifting the point of view, assuming that in the specific case of dementia it is necessary to validate and accept some peculiarities of the disease (such as wandering or repetitive gestures etc.) designing devices that offer the possibility to vent this urgencies, rather then sedate them. Therefore, interiors designed for people with dementia should be focused on using elements of prior familiar environments such as smells, music, foods, objects, and pictures, to maximize their functional ability. As designers, it becomes a matter of recreating the best conditions around people with dementia, to enable them to live their life maximising their capabilities, to actively continue to be part of society, enhancing their self-esteem and independence.

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