

Cumulus Conference Proceedings Wuxi 2018

Hosted by:

Cumulus Association / Jiangnan University

Diffused
Transition
Design Opportunities



School of Design
Jiangnan University
江南大学设计学院

Cumulus Conference Proceedings Wuxi 2018

Diffused Transition & Design Opportunities

31st October-3rd November, Wuxi, China

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978-952-60-0092-3

Printed in Wuxi, China. October 2018

Printed by Wuxi Huguang Elegant Print Co.,Ltd

ISBN 978-952-60-0092-3 (print)

ISBN 978-952-60-0091-6 (pdf)

ISBN 978-952-60-0093-0 (ePub)

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From “Cure” To “Take Care”: A Design Interdisciplinary Approach in the Care of Dementia

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Abstract

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 patients' well-being. Accordingly, the non-pharmacological care approach naturally suggests the transition from the concept of "Cure", meant as sedating behavioral disturbances, to the wider context of "Taking Care", focused on the validation of some peculiarities of the disease (i.e. wandering, repetitive gestures, etc.), in order to design devices that offer the possibility to vent this urgencies. From the perspective of design discipline this approach completely shifts the focus towards considering not only ergonomic aspects, but also anthropological, emotional and relational ones.

Thus, in the framework of dementia care, it becomes necessary to understand how the environment could actively encourage pleasurable behaviours that enable patients to release stress. This means to consider spatial design for dementia not only linked to architecture, but moreover to the design of “activators of well-being” independent from the building, focused on enhancing the patients' well-being.

Based on these theoretical premises, this exploratory paper describes methods and approach adopted in GRACE_Lab, an interdisciplinary Lab. established in a day-care centre in Milan, for the development of environmental solutions for dementia care.

The outcomes of this study are the result of a synergic collaboration between carers at all levels; from family caregivers to medical professionals, and designers/researchers.

Keywords

Spatial Design, Dementia, Non-Pharmacological Therapies, Therapeutic Environments.

1. Introduction

Alzheimer's Disease (AD) is a neurodegenerative disease and, specifically, and represents the most common form of dementia that causes memory and cognitive impairments, and behavioural symptoms, severe enough to interfere with daily life, and lessen the ability to live independently. It's a long process with a potential duration of 20 years or even longer, after being diagnosed. Non-Pharmacological Therapies (NPTs), combined with drug medications, can significantly improve people with dementia's condition, enhancing their well-being and quality of life.

Inside this perspective, the environment can be considered as one important Non-Pharmacological treatment modality, as it can reduce behavioural disturbances, and act

as a sort of “prosthesis” in the compensation of losses and cognitive deficits. The environment is composed not only by physical features, but, moreover, by social and cultural ones. The physical environment it is strictly connected to features, such as ambiance, safety and security of the patients, but also accessibility and comfort. Social environment is intended as the deep meaningful social relationships that surround people with dementia, including family members, caregivers, other residents, relatives, friends, etc. Hence, the cultural aspect of the environment refers to the system of beliefs, ideals, customs and values recognized as own by each patient. Aim of this exploratory paper is to describe methods and approach adopted in GRACE_Lab, an interdisciplinary Lab. established in a day-care centre in Milan, for the development of environmental solutions for dementia care.

2. Aging in place & Day-care services

On average, about 6% of older people in the more developed countries live in residential care communities or nursing homes. A much higher percentage of older people live their last months or years in hospitals or nursing homes due to a severe (Kinsella, 2005).

Aging in place and community care have become a priority in policy making in many countries. These care approaches imply that older people should be able to live independently or in small institutions as long as possible and that, long-term care in an institutional context should be available when necessary, but should be perceived as a last resort. Care in the community and aging in place may remain, in the future, a key element in national aging policies due to the fact that more old people live longer and healthier. However, aging in place is possible only if social and medical support is granted for older people. Such services need to be available in the community, and also residential settings needs to be designed according to older people concerns, taking into account impaired mobility and impaired functioning due to aging process.

2.1 Favourable surroundings

In the last two decades, physical and social environment gained importance, and recognition, in supporting the person with dementia (Verbeek et al., 2009).

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 centered 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 recent years, new models of long-term dementia care have been developed. Their common aim is to recreate an “enriched environment” (Nolan, 2006) essential to enhance well-being and quality of care for people with dementia. This change, was made possible by an increasing understanding and acknowledgement of the “experience” of dementia (Verbeek et al., 2009).

Research in the neurosciences indicates that in the process of dementia, people with dementia’s ability to remain independent and planning their daily life, diminishes as the cognitive loss increase. In the end only the emotional brain remains (Rosso et al., 2003). Another important loss regards the individuality: as the disease progresses, people with dementia’s behaviour becomes generic, more and more determined by the environmental stimuli.

As their behaviour becomes more predictable it opens up the possibility to manipulate the environment in such a way that it leads to improved perception by people with dementia. Hence,

analysing every situation, the environment can be either favourable or unfavourable. In unfavourable situations, agitation and wandering are increased, decreasing the overall well-being of the individuals. Research report that through the environment it is possible to evoke deliberate behaviours. This is possible also dealing with people with dementia, designing facilities that clearly show pathways, highlighting the function of each space. Taking into account the abilities of the emotional brain, as well as the layout, decoration, sounds, and lighting, can make for a safer and more comprehensible environment. In other words, a favourable environment for dementia will include both the caring approach, and the design, in terms of space organization, furnishing, and finishing, including indoor and outdoor areas. An enriched environment provides peace and brings unity of purpose in behaviour (Colombo, 2011).

2.2 The “experience of dementia” and the role of the environment

Emphasizing the experience of living with dementia, rather than focusing on symptoms and impairments, represents an important change in the vision. It enables the creation of environments that allow the person with dementia to actively participate in everyday life rather than just passively receive care.

Sense of self, self-esteem and social interactions can be encouraged and strengthened through the design of the physical environment (Gramegna, 2017). In order to have long lasting positive effects on residents, it is necessary to take into consideration many elements in order to achieve the appropriate fit of the physical and social environment (Teresi, Holmes & Ory, 2000). Until a cure for Alzheimer's disease is not found, one of the main aims, at an equal pace with the search for a cure, is to focus on the development of interventions to improve quality of life and patients' well-being. Regarding this issue, the environment plays an important role (Brawley, 2008).

Thus, in the last decades most studies focused on the development of therapeutic and supportive environments, designed according to the residents' remaining abilities, able to fulfill their physical and psychological needs, and able to enhance residents' quality of life.

This body of literature focuses 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.

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).

3. Environmental stimulation

Environmental stimulation and support has to be balanced in the right way, in order to reach positive results in the enhancement of well-being and reduce behavioural symptoms and problems (Alzheimer Disease International, 2015). For example, under-stimulation may cause a sense of boredom and restlessness in people with dementia. On the other hand,

over-stimulation doesn't lead to positive outcomes, as it can caused confusion and agitation in people with dementia (Alzheimer Disease International, 2015).

Here after are reported some typical agitated or aggressive behaviours of people with dementia, connected to a sense of lack of control over reality felt by the patients, and the related strategies and design solutions in terms of environmental adaptation.

Verbally Agitated and Non-Aggressive Behaviour.

These behaviours are a major source of stress for caregivers. They include repeating words or questions, making strange repetitive noises with voice or other body parts, complaining or having a negative attitude towards any activity. These behaviours often reflect a need for reassurance.

Useful strategies to help people with dementia to feel reassured and to have a sense of control on daily life can be:

- suggest to perform a familiar activity well managed by the person with dementia;
- fill in a daily schedule, hang it in a visible place, and point to it starting a conversation with the person with dementia (Alzheimer's Association, 2017).

Physically Agitated and Non-Aggressive Behaviour.

These behaviours include purposeless wandering, inappropriately looking and following people, hyperactivity, repetitive movements and gestures, and restlessness. They are caused by silent boredom, inappropriate sensory stimulation, or a need to feel useful for the social context surrounding the person with dementia.

To decrease these behaviours, Alzheimer's Association (2017) suggests:

- Provide new or more meaningful activities to include different sensory stimulation;
- provide opportunities for a greater involvement in every day activities.

To properly adapt the environment to the changes and impairments typical of dementia condition, and provide a proper sensory stimulation, it is necessary to respect interests and habits of the person, preserve old memories and respect his/her past life (Hunter, 2013).

4. Meaningfull daily life activities

Meaningful activities are coordinated, or spontaneous, actions typical of a normal daily life. It is important to offer a wide variety of daily activities that people with dementia can freely decide to join in order to respect individuals' personal interests and habits, encouraging them in expressing their feelings and concerns (Hunter, 2013). In fact, people with dementia, even if affected by a disease, still have a strong feeling of their past habits and lifestyle, that should be preserved in daily-care environments and, moreover, in long-term care environments (Livingston et al., 2017). Daily activities can range from helping in housekeeping (supported by the staff), commonly deciding the menu for the meals, lay the table, prepare the dishes, suggest and discuss receipts, discussion of newspapers news, knitting, tea time with other residents, watching old films, helping on farming or harvesting, or do the grocery along with staff members. Activities should occur, as much as possible, in a "setting" that looks like the right kind of place for that specific activity, based on residents' history, culture, lifestyles and should provide the right work surface (Hunter, 2013). Multi-purpose rooms enhance disorientation in people with dementia, due to the fact that multiple activities take place in the same space.

Daily activities enhance trust among residents and staff, and also represent an opportunity of conversation and involvement of family members. Daily living activities should be part of a routine, done at the same time and in the same order each day. The aim is to allow people with dementia to continue to live a normal life, filled of activities that were familiar for them and mean

something, and to be seen by others as a productive and vital member of one's community (Laver et al., 2017). Designing daily life around habits and past lifestyles gives people pleasure and foster the use of people with dementia's skills and abilities. It also adds variety and interest, and is stimulating for people with dementia, reducing boredom, anxiety, stress and frustration. Roles and lifestyles, typical of past lives of people with dementia, should be investigated by staff members, in order to provide activities that resembles them. It allows staff members to really get to know the residents they are caring for, and help them to better understand their behaviours. To maintain identity and foster self-esteem, it's important for people with dementia to have engaging social relations with relatives, friends, residents and staff (Brooker & Woolley, 2007). A variety of spaces, from individual and personal, to spaces for small-groups conversation, to larger community spaces, should be provided in a care facility, to allow people with dementia to choose between different living situations, throughout the day. Engagement with friends, family members and staff represent an important opportunity to maintain and foster relationships, create a sense of trust and intimacy, and feel part of a community (Long, 2017).

5. GRACE_Lab experience

Within our research team Lab.I.R.Int. (Laboratory of Innovation and Research about Interiors) we are pursuing a reflection on Interior Design discipline, through the definition of its tool and its skill, its intrinsic competencies and the ones acquired in a multidisciplinary exchange. This process of re-reading the discipline gave birth to a centripetal vision of the Interior Design System: in the main core there is the culture of "living" to be understood in a broad sense. Starting from this perspective, since 2005, we are actively researching on the influence of interiors on the well-being and perception of people with dementia. At the beginning of 2018, our research group, together with Genera Onlus – an organization active in the care of elderly with dementia, founded an experimental living lab. for the development of environmental solutions for dementia care, named GRACE_Lab. GRACE_Lab is located in Figino, a peripheral neighbourhood of Milan, inside the spaces of GRACE, a day care centre for dementia. GRACE hosts and takes care of 30 elderly with dementia, providing them daily care assistance 6 days a week.

GRACE_Lab is an experimental lab. involving designers/researchers, therapists, medical professionals and caregivers. Aim of the ongoing research is to determine the aesthetic / functional identity of the day care center environments and defining environmental devices and integrated services for the community, which can be used by therapists and caregivers to manage the relationships between patients, medical staff, relatives, visitors, etc. GRACE_Lab works following a "virtuous circle process" described in Figure 1.

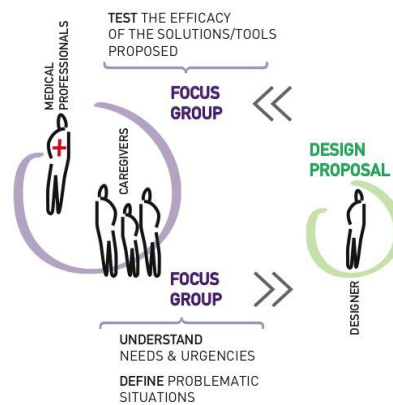


Figure. 1. Design process in GRACE_Lab.

In the day care center therapists work together with designers in order to develop environmental solutions to enhance the efficacy of care methods and improve the well-being of the patients. Designers can observe and interact with the patients, helped by therapists and caregivers; therapists can indicate to the designers daily life needs of the patients. The result is a set of design artefacts, designed and tested through the creation (*conditio sine qua non*) of a strong relationship between designers, therapists, and carers in order to develop more effective environmental solutions and services.

6. Methods & Objectives

Semi-structured focus groups with researchers/designers, therapists, medical professionals (geriatricians) and caregivers, were conducted in the day care centre in order to identify daily needs of people with dementia. This method was chosen to inquiry a range of views and underlying opinions from trained carers and medical professionals that have experience with the pathological symptoms of AD, and their management in daily care environments. This method implies the identification of major themes, and moreover, the direct validation of concepts (Denscombe, 2002).

Focus groups were used in order to identify criticalities, and reframe spatial design solutions proposed according to the patients' needs.

Focus groups allowed participants to interact, discuss the proposed concepts, and report personal experiences regarding the relation between the environment and the patients' reactions to environmental stimuli. The study conducted aimed at exploring the perceptions of caregivers and medical staff regarding environment-behaviour relationships and needs in people with dementia. Focus-group interviews 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 (Denscombe, 2002). Researchers used a set of cards to introduce different daily scenarios to encourage the participants to develop their own analysis of common and personal experiences. Thus, focus groups allowed the researchers to identify group norms and cultural values common among the target group. Moreover 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 behaviours and quality of life.

7. Results

The first set of interviews was focused on the definition of “stress release behaviours”, according to each patients’ symptoms and past habits. Therapists and medical professionals agreed that most of the patients would benefit from activities like rummaging and performing very simple gestures resembling house duties (i.e. folding tissues or reordering clothes). Moreover, therapists and medical professionals agreed on the importance of social rituals as opportunities of engagement for all residents, enhancement of self-esteem, identity, and sense of belonging.

Starting from the analysis of the abovementioned “stress release behaviours” and common habits, the aim of the design intervention has been to define a system of environmental devices in the form of “sensorial corners” and environmental features, that could offer to the patients opportunities to release stress through reassuring gestures.

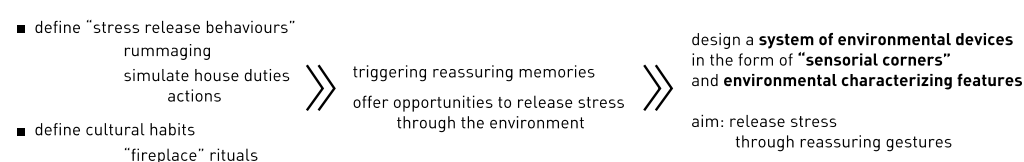


Figure. 2. Results of the first phase of focus groups and interviews.

The second phase of interviews and focus groups was focused on the definition of a set of environmental devices that has to be integrated into GRACE’s interior spaces. Therapists, medical professionals and designers agreed on the need to have environmental features, in the form of kitchen furniture and of a fireplace, as necessary elements to support people with dementia’s experience, in order to make it “real”, as they suggested. Daily life in care centers should resemble, as much as possible, a normal daily life routine life, in order to decrease a sense of hostility towards the environment. The “fireplace rituals” (i.e. relaxing, watching the fire, sipping a tea) are commonly recognized by the majority of the patients as past common rituals that enhance patients’ relaxation and comfort, and help them to mutually accept each other as member of the same community.

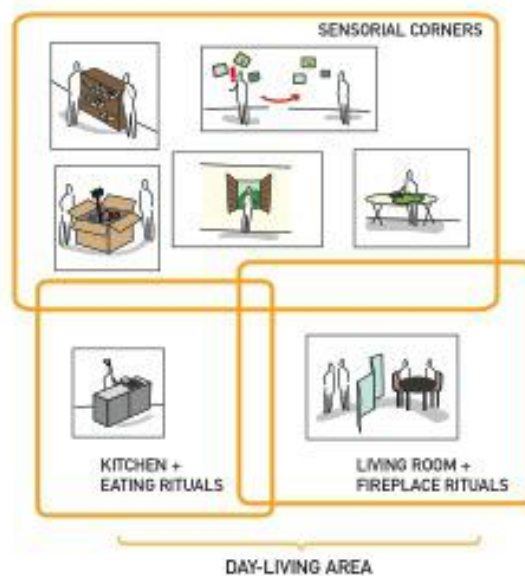


Figure. 3. Opportunities of engagement in the environment of the day-care center.

Professional caregivers and designers agreed on the creation of a “house duties room” following the principles of occupational therapy. The room will contain an environmental system made up of pieces of furniture resembling a kitchen closet, living room libraries and bedroom drawers, which can be activated on at a time by therapists. Those three corners will allow the patients to perform activities resembling house duties, in small groups or with a single elderly, in order to release stress, anxiety and agitation, through performing well known simple gestures.

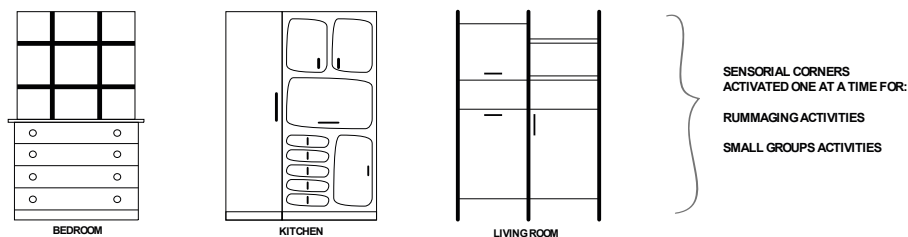


Figure. 3. Sensorial corners in House Duties Room.

Moreover, therapists suggested to offer opportunities of spontaneous engagement throughout the environment, to encourage people with dementia to interact with the environment, triggering their past-memories, in order to enhance their sense of belonging. All the group agreed on setting up “sensorial corners” where the patients can freely engage in simple and stress-relieve activities (i.e. telephone booth with phone book, vitrines with seasonal objects to stimulate conversations, photos of season landscapes to encourage temporal orientation, home-like furniture corners to give vent to the need to re-order objects or rummaging activities). In the end, they agreed on the need to provide environmental cues that support people with dementia to recognize spatial functions, and distinguish private, personal areas, from common ones.

The set of environmental devices aforementioned are at the moment in a first phase of test with the patients. A preliminary test has been done with therapists and medical professionals.

8. Discussion: From “Cure” To “Take Care”

Regarding AD and dementias in general, the great change in the therapeutic actions of the last decades has been considering the person with dementia not as a sick person “to cure” but rather as a person with his/her own vision of the world, that we need to “take care of”, to safeguard frailties, often relying on its residual capacities, to ensure a pleasant and not frustrating life experience.

People with dementia, due to their disease, are characterized by a different view of reality, often expressed with behaviours and reactions considered “abnormal” by society. If those behaviours are accepted just as one of the possible visions of life, we don’t have to “cure” it, in order to solve the problem, but the focal point moves on “taking care” and accept the reality and personal truth of another’s experience. This is an important statement from a designer point of view, because it completely shifts the focus towards considering not only ergonomic aspects, but also anthropological, emotional and relational. Thus, following Andrea Branzi (2009) “Design should inquire a New Dramaturgy which comprises emotional levels and the relationship that design can finally establish with those certain anthropological themes typical of contemporary human existence”.

Concerning dementia care, most of the times this “feeling of being safe” is connected to ergonomic and technical aspects: for example, rounded corners to avoid hurts, proper flooring materials to avoid falls, a minimum amount of square meters per person in each room, hygienic surfaces, and so on.

Moreover, the non-pharmacological approach proposes the transition from the concept of “Cure” to the wider context of “Take Care”. This dimension has completely changed the point of view, introducing new dynamics in the therapist-patient-family relationship. “Taking care” can be associated with the approach widely discussed in the literature of favouring behaviours, which means not trying to correct those recognized as “abnormal” by the majority of society, but trying to indulge them, reassuring people with dementia, enabling them to feel comfortable, fostering their memories and enhance the personal well-being. We can consider this approach close to a person-centred one, focused on the “user” needs and habits. As designers, in order to be able to understand real needs of people with dementia, it becomes crucial to foster a fruitful interdisciplinary cooperation involving caregivers, with first-hand experience of the condition, and therapists, the medical figures able to delineate the therapeutic needs. Thus, a person-centred approach can moderate the effects of “objectification”, which occurs when a person with dementia is treated as if they had no opinions or feelings, and help identity and self-esteem to persist, during the onset of the disease. Taking care of the residents’ needs can have positive effects of cognitive and functional deterioration, decreasing their process. Personhood and identity, are constantly encouraged and enhanced in the social relationship that surround people with dementia. These two characteristics can be diminished if the person is provided with a depersonalized care.

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