title What's On: Cumulus Spring Conference, Aveiro 2014, 8-10 May, Portugal, On-line Proceedings

editors Teresa Franqueira and João Sampaio

publisher University of Aveiro

handwriting Pedro Carvalho de Almeida

for further information on Cumulus Association and Cumulus Working Papers Cumulus secretariat Aalto University School of Arts, Design and Architecture PO Box 31000, FI-00076 Aalto Finland E: cumulus@taik.fi W: http://www.cumulusassociation.org

ISBN 978-989-98185-1-4

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SPRING CUMULUS CONFERENCE UNIVERSITY OF AVEIRO 8 · 10 MAY 2014

A DESIGN EXPERIENCE FOR THE ENHANCEMENT OF THE QUALITY OF LIFE FOR PEOPLE WITH ALZHEIMER'S DISEASE

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ABSTRACT

As the most common form of Dementia, Alzheimer's disease (AD) causes behavioral, cognitive and Physical impairments, which severely affect people's ability to fulfill their daily activities. Currently, there is no cure for AD, both pharmacological and non-pharmacological treatments can just slow down the process. Design of the physical environment is increasingly recognized as an important aid in caring and treatments for people with Alzheimer's. This paper aims to discuss the role of design, through therapeutic habitat design experience, to enhance the AD patients' quality of life. Therefore, two prototypes of the therapeutic habitats are developed; first organized train habitat by therapist and the second one is designed "therapeutic train" by designer. These two prototypes are tested separately to evaluate effect of design for the effectiveness of the train therapy. The results showed that the patients, who were treated in "Therapeutic Train", responded more effectively to the therapy than the patients who were treated in a non-designed environment.

KEYWORDS

Design. Dementia. Alzheimer. Quality of life. Therapeutic train.

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INTRODUCTION

BACKGROUND

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, 2013). In particular, AD is one of the most common forms of dementia. Dementia generally occurs after the age of 65 and the prevalence of the condition rises more than 20% after the age of 80. In most instances, the progression of dementia is slow and consistently changes over time (Timlin & Rysenbry, 2010).

With an increasing number of people being affected by Dementia due to AD, almost everyone encounters someone who has dementia or whose life has been affected by it (WHO, 2012). 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. Besides, more than 40% of those cases will be in late-stage Dementia due to AD (Prince et al., 2013).

Currently, there is no cure for dementia due to AD. Pharmacological or Non-Pharmacological treatments (NPTs) can only improve the quality of the patients' lives or slow down the progression of the disease (Olazarán et al., 2010).

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. Other NPTs are intended to improve quality of life or reduce behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation, and aggression. Finally, physical rehabilitation therapies that focus on motor activities help individuals with dementia to rehabilitate damaged functions or maintain their current motor abilities so as to maintain the greatest possible autonomy (Gräßel et al., 2003; Olazarán et al., 2010; Tapus et al., 2009).

DESIGN AND ALZHEIMER'S DISEASE

Historically, the main goal of interior design is to provide environments with a certain degree of quality and specific connotations, often filtered by a cultural interpretation.

In the particular relation between interior design and features of AD, the elements of such environmental systems, both tangibles (colors, finishes, etc..) as well as intangible (lighting, sound, video, air conditioning, etc..), are identified through their therapeutic efficacy, especially in terms of their prosthetic dimension, concerning NPTs.

Inside this perspective, the environment can be considered as one important Non-Pharmacological treatment modality, as it can reduce dysfunctional symptoms and behaviours, (Zeisel & Raia, 2000). Furthermore, Campion argued that 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)

Therefore, the peculiarities of an environment take on relevant importance, qualifying as one of the tools that allow the correct activation of NPTs, in order to ensure effective results.

Hereby, design of the physical environment is increasingly recognized as an important aid in caring and treatments. The aim of our research is to discuss the role of design in NPTs for AD through a case study of train therapy. In order to reach to the goal, the evaluation of the Therapeutic habitat prototypes were conducted and discussed by the authors.

The structure of this paper is as follows: Methodology, Design approach used for the design of therapeutic habitat, Case study as train therapy, Therapeutic train design concept, Prototypes conducted both by therapist only and by designers, Cognitive evaluations of the patients for both prototypes, Results, and Final conclusions are drawn, respectively. what's on: cultural diversity, social engagement and shifting education ~ 2014 Spring Cumulus Conference 8 -10 May · University of Aveiro

METHODOLOGY

Our methodology included related background research of design problem; a hypothesis, of how to better support research questions, is proposed based upon an analysis of design problem. This hypothesis is formulated into a project within the field of interest. A solution is then developed, evaluated and the overall results and appropriate documentation generated.

The research question is: What is the role of design in NPTs for AD?

Our hypothesis is that design increases the realism and effectiveness of NPTs that can improve the patients' quality of life.

Case study on train therapy was selected for testing the hypothesis. Accordingly, two prototypes were conducted; one by the therapist only and the second prototype named "Therapeutic Train" is designed by the principles of primary design. The testing and data collection were held by the authors. The cognitive evaluation of the first prototype is conducted at Pio Albergo Trivulzio in Milan (Italy) and 20 patients have been participated in the Train Therapy sessions. The second prototype experimentation is conducted at Institute Santa Maria Ausiliatrice in Bergamo (Italy) and the data is collected from 37 patients. The results will be discussed in the conclusion part.

DESIGN PRIMARIO (PRIMARY DESIGN) APPROACH

The Design Primario approach adopts the set of intangible qualities of an environment to define a new dimension of the project. This specific design approach has been chosen for this research, in order to explain the significance of the parameters for the use of the physical environment in NPTs for AD.

Design Primario term was created in the mid-70s by Clino Trini Castelli. More than designing an object, Design Primario deals with designing sensory states and sensory experiences related to objects and environments. Design Primario perspective is concerned with the use of very subtle effects, like smell, light, color, amplifying them to a degree that becomes significative at the figurative level.

Commonly architects and designers believe that the quality of an object or an environment is determined by its formal, constructive and structural peculiarities, considering of negligible importance anything concerning with the sensorial use of a space connected to its chromatic, luminous, acoustic, tactile and climatic stimuli. The requirements of the people living or working in a certain environment are connected more to such physical peculiarities. The sum of these qualities is related to structures that we can call "soft" in contraposition to the "hard" structures corresponding to the solid structures of a room. The control and design of those "soft" qualities requires a new kind of cultural approach and new instruments. Soft qualities of an environment characterize the physical and subjective experience of products and environments (Castelli, 2000).

CASE STUDY: THERAPEUTIC HABITAT APPROACH IN TRAIN THERAPY

THERAPEUTIC HABITAT

Environmental systems are composed both by tangible (e.g. colors, finishes and linguistic elements of signs) and intangible elements (e.g. lighting, sound, video) and we describe them as *Therapeutic Habitats*.

Therapeutic Habitat is a highly recognizable and identifiable presence, able to cause a controlled emotional and affective state in the users.

In this environment, the highly recognizable and distinguishable peculiarities are calibrated to stimulate a feeling of familiarity, trust and intimacy.

Therapeutic Train is a *Therapeutic Habitat* with high aesthetic impact and a strictly defined therapeutic purpose.

It is based on the need of creating an environment with a high level of control about environmental qualities. Its intrinsic aim is to support therapies as Non-Pharmacological ones that stimulate and activate cognitive and physical functions not completely deteriorated, intervening on their residual potential (Cilesi, 2011).

Since 2005, Ivo Cilesi (therapist), Lapo Lani (architect) and our research group Lab.I.R.Int – Laboratory of Innovation and Research about Interiors (designers), have designed

environments in order to maximize the effects of NPTs for AD. All these professional profiles deriving from different backgrounds developed a strong teamwork through both applied research and experimental learning activities, mainly in the Design School of Politecnico di Milano

TRAIN THERAPY

Train Therapy is a therapeutic treatment useful to slow the cognitive and functional decline caused by AD. It stimulates the senses of sight, hearing, touch, smell and phonetics with the activation of dialogue, of long-term memory and relaxation. Train therapy is focused on people being affected by Dementia due to AD, that show particular behavioral disorders (i.e. wandering), expressed agitation and aggressiveness. These are behavioral disorders (BD) strictly connected to the perception of being inside a closed space. Due to this difficulty of acceptance of closed spaces, it is necessary to stimulate inside patient's mind a separation from the reality in order to stimulate relaxing.

Train Therapy consists on the staging of a real trip in a train compartment environment (Therapeutic Train). It is important to consider and to analyze the idea of the train trip: this particular event is chosen as the focus of the therapy because is a common experience in the past lifetime of old people. The idea of a trip stimulates memories and activates socialization between patients or patients and therapists, creating a relational space (Cilesi, 2010).

Train Therapy is articulated into three consequential levels. The first is related to the improvement or maintenance of a certain individual well-being. All the activities concerning the therapy have to guarantee a fundamental psychophysical balance in the patients. The second level takes into account the spaces of socialization and the communicative dynamics among people. All those activities able to create connections with the external social reality are related to the third level. It is important to design specific and adequate opportunities for interaction that lead to a kind of osmosis between the microcosm and the social context outside (Cilesi, 2010).

The therapy begins with the gesture of ticket-printing. Patients are encouraged by therapists to obliterate their ticket before entering in the compartment. The doors of the compartment open only after this fundamental gesture. The destination of the trip is often undefined. Therapists leave the patients free to imagine it, guided by their old past memories. As a consequence, the rituality of the actions that characterize the trip assumes fundamental importance. The virtual trip lasts a maximum of 30 minutes. Therapists are seated with patients for the entire virtual trip. The trip ends when the virtual train stops in a station. At this moment, doors open and patients are accompanied out of the train compartment. In this particular condition it is important to consider and validate the fictional reality that the patient is living, keeping in mind that it doesn't correspond to ours. Staging a train trip allows a reinterpretation of historical memories related to travel, in order to reassure from the loss of memory typical of people being affected by Dementia due to AD. These kinds of memories are re-elaborated inside the patient's mind as a moment of escape from normal reality inside a personal fictional world.

Train Therapy sessions are organized according to the onset of disorders, especially in correspondence of an acute phase of them. The goal of this program is to decrease significantly expressed agitation, aggressiveness and BD; also to stimulate attention, relational capability and relaxing.

"THERAPEUTIC TRAIN" DESIGN CONCEPT

Therapeutic Train, specifically its prosthetic and therapeutic concept, is part of those NPTs specific for people being affected by Dementia due to AD. *Therapeutic Train* consists in the design of a safe, embracing and comfortable environment, with a prosthetic aim entrusted to the memory of a train trip. This personal memory is triggered and managed through the use of appropriate technologies that work on specific deficiencies of the individual patients. This environment has to be recognized by people being affected by Dementia due to AD as a real compartment of a train. This indispensable condition prejudice the effectiveness of the Train Therapy. As explained previously in this paper, Train Therapy consists in the staging of a fictional train trip.

Inside the internal monitor that works as a virtual window, a video of a real train trip is shown. The program of the trip is antecedently organized, defined and memorized inside the integrated computer. Previously, sounds and sensory stimulations can be modulated specifically on the patients' needs and BD. The various stimulations aim to evoke awareness and orientation in the patients reducing anxiety, pain and depression. They also promote the activation of memory processes. The study of the internal configuration has been developed through a constant dialogue between designers and therapists. (Cilesi, 2011).

This continuous dialogue enabled designers to understand the unique characteristics of the users; as a consequence they can design a series of solutions able to satisfy some requirements in terms of security, without a prejudicial perception of overall familiarity and environmental well-being. This cognitive comfortable setting enables opportunities for individual cognitive rehabilitation, with a high possibility of monitoring user's reactions.

1ST PROTOTYPE: SENSORY VIRTUAL TRAIN

The initial prototype of Therapeutic Train was developed within a protected area of Alzheimer's ward in Pio Albergo Trivulzio in Milan (Italy), under the name of *Sensory Virtual Train*. The therapist Ivo Cilesi worked on an environment aiming to recreate the experience of a compartment of a train. It consisted of a wooden panel with two sliding doors, as shown in **Fig.2**. Inside, he placed side by side two pairs of common old-style looking armchairs, with a common small table and a domestic lamp. Beside them, he adjusted two LCD monitors in which patients could see movies taken from real moving trains, as shown in **Fig.3**.



figure 2 Wood panel with sliding doors.



figure 3 Internal configuration.

2ND PROTOTYPE: THERAPEUTIC TRAIN

The second prototype of Therapeutic Train was developed within a protected area of Alzheimer's ward at the Institute Santa Maria Ausiliatrice in Bergamo (Italy). This more complex version of the Train was developed with the intervention of our research group in collaboration with Lapo Lani (architect), assisted by therapists. They underlined difficulties and suggested to make changes on our proposed solutions, due to their intimate knowledge of the patients. As shown in **Fig. 4**, the train compartment recreated is designed as an "environmental device", with its own autonomy in terms of space, equipment and energy. It is a space carefully calibrated in its aesthetic -that strongly characterizes the objectand dimensional components, through a specific study of the internal and external proportions.



figure 4 Therapeutic Train



figure 5 Internal configuration.

Inside there are two pairs of armchairs, especially designed on the needs of the users, placed side by side in order to turn on communicational dynamics among passengers. Beside them, there is a monitor, integrated in the wall, in order to be considered as a virtual window. Movies taken from real moving trains are reproduced through this element of the system, supported by a complex environmental sound system. Therapists can monitor patients reactions through the digital camcorders placed inside the Train. All these implemented technologies enable therapists to create customized scenarios modulated on the specific cognitive residual functions of each patient treated inside Therapeutic Train.

RESULTS

RESULTS OF 1ST PROTOTYPE

The experimentation conducted at Pio Albergo Trivulzio in Milan (Italy) gave a negative result. 20 patients, assessed using the MMSE to ascertain their residual cognitive capabilities, have been included in the Train Therapy sessions. All of them received an evaluation that underlined their minimal residual cognitive capabilities.

Patients involved did not recognize the environment as a compartment of a train, even if they were in a severe stage of the disease. The environment did not trigger the patients' old memories related to travel. Patients involved associated this environment to a domestic living room.

Consequently, the data collected about the acceptance of the train compartment environment were completely negative.

RESULTS OF 2ND PROTOTYPE

After three months of experimentation conducted at Institute Santa Maria Ausiliatrice in Bergamo (Italy) the data collected are the following: 37 patients assessed using the MMSE to ascertain their residual cognitive capabilities, have been included in the Train therapy sessions. All of them received an evaluation between 6 and not assessable, underlining their minimal residual cognitive capabilities. Designer's intervention in the developing process of the prototype made possible the recognition of the Train as a real train compartment.

31 of the patients involved have positively accepted the Therapeutic Train space (**Graph 1**). As explained previously in this paper, the behavioral disorders affecting them are strictly connected to the perception of being inside a closed and retentive space.

This prototype of Therapeutic Train was able to arouse patient's old memories connected to travels. They perceived the Therapeutic Train environment as a safe place and accepted positively to enter inside it and sit down.

Among them (**Graph 2**) 12 were suffering from wandering, 9 showed expressed agitation, 3 showed anxiety, 7 showed constant apathy, 3 showed expressed irritability and 3 of them were suffering from sleep disorders. As can be seen in **Graph 3** these behavioral disorders have been treated efficaciously, enhancing their quality of life.

In particular: 9 of the 12 patients suffering from wandering positively responded to the therapy, showing pauses in their purposeless movements. 8 of the 9 patients suffering from expressed states of agitation positively responded to the therapy, decreasing their onset of the behavioral disorder. The same positive results were observed for the decreasing of anxiety, apathy and sleep disorders.



ACCEPTANCE 83,78%
REFUSAL 16,22%
100,00%

Graph 1 Therapeutic Train



Graph 2 BD of patients



Graph 3 Percentage of reduction of BD in patients after the treatment

DISCUSSION AND CONCLUSION

DISCUSSION

The Culture, as well as the practice of design has always had as one of its main goals the improvement of the quality of life of people.

NPTs propose a new approach, which consider the human being, the "Person", as the center of the issue. A new approach in which the "person" re-acquires a dignity. Dignity represents an important topic within the main issue of "quality of life", especially during the last stage of AD.

The quality of life is even more strongly related to the quality of the complex socio-environmental system in which Alzheimer's patients live. This complex system consist of environmental components, as well as objects and human interactions.

A complex and multi-layer system, in which we have to manage the emotional fragility, as well as the extremely sensitive nature, of people being affected by dementia due to AD.

A complex and multi-layer system, that requires a complex and multi-layer approach, as well as a developed sensibility to human factor.

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CONCLUSION

The experience of Therapeutic Train supports the idea that Design can play an important role on enhancing the quality of life of people affected Dementia due to AD, due to its capability to work on multiple levels (environments, products, services). A role that belongs to the predisposition of the Designer to interpret, and to understand, needs, in order to develop solutions.

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