CLUSTER ACCSESSIBILITÀ AMBIENTALE

a cura di / edited by
Adolfo F. L. Baratta, Christina Conti, Valeria Tatano

ABITARE INCLUSIVO

Il progetto per una vita autonoma e indipendente

INCLUSIVE LIVING

Design for an autonomous and independent living

SITdA
Società Italiana della Tecnologia dell'Architettura

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Inclusive Design For Alzheimer's Disease: Low-Cost Treatments, Design And ICT

Design inclusivo e alzheimer: terapie low-cost fra design e ICT

Inability to acquire new memories, difficulty to remember recent events and to recognize objects, places and people, visual-spatial disorientation, these are some of the disorders with which who is affected by neurological diseases must learn to live with. In a continuously evolving society, where the decreasing birth rate and the drops in mortality are consistent, the job of Architecture is precisely to interpret the requirements and needs of people who have lost the canonical relationship with the world and give them the possibility to recover it or maintain it through communication channels that use their remaining ability to understand. The indoors and outdoors acquire a "prosthesis function", containing and expressing the knowledge necessary to its right enjoyment, reducing the frustration sense through the safety and well-being feeling that the patient must perceive by living in it.
This essay is a contribution to the dissemination of knowledge and useful information to those who work in the field of organization and design of health services, reporting "non-pharmacological", low-cost and sustainable therapeutic solutions promoted by international and national technological research in the field of Design technology and ICT and which have proven to be able to significantly help both patients and caregivers.

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Introduction

Alberto Sposito wrote (2014, p. 19) "Arthur Schopenhauer, German philosopher and creator of aphorisms, one of the greatest minds of the 19th century, reported that the great Plato considered old age a happy time because the desire to live is appeased. I can say it is true: at this age, one has attitudes, states or moments of wisdom, moments of reflection and your ardour is dampened. But every man experiences the third age in a different way. I know renowned people who, at the venerable age of a hundred, travel alone around the world, write, participate, invent, create, without showing disruption, independent people; I know other people, unfortunately, the majority, suffering from different diseases, more or less serious, that lead to the loss of independence. Among these people, there are some elderly suffering from dementia, the so-called Alzheimer's disease [...]".

Inability to acquire new memories, difficulty to remember recent events and to recognize objects, places and people, visual-spatial disorientation, these are some of the disorders with which who is affected by senile dementia and Alzheimer's disease must learn to live with. Following drops in mortality, there is a progressive increase in the number of dependent people and elderly people suffering from Alzheimer's disease in the world. The wide and increasing spread of Alzheimer's disease, the limited and non-conclusive effectiveness of available therapies and the enormous resources necessary for its management (social, emotional, organizational and economic), which fall largely on the families and which often involve the relocation of the elderly to the facilities for "dependent people", making it one of the most serious social impact diseases in the world. The 2018 World Alzheimer Report, *The state of the art of dementia research*, is an overview of the current situation in dementia research, investigating the actual actions taken, the hopes, the obstacles (ADI, 2018). In a nutshell, the Report highlights an alarming situation: around the world, there will be one new case of dementia every 3 seconds, 50 million people worldwide are living with dementia. In 2018, dementia became a million-dollar disease that will tend to double in 2030. Dementia is the seventh cause of death worldwide, and there is still no cure. Many countries have no diagnostic tools, no access to clinical trials and, indeed, few, or none, specialized doctors and researchers. As already stated in the 2016 Report, in the world, most people with dementia have yet to receive a diagnosis, in addition to full and continuous healthcare.

In Italy, 1,241,000 cases of dementia are estimated, of which about half of the people are affected by Alzheimer's disease (OMAR, 2018; Epicentro, 2018). That is why, currently, in our Country, the design responses to the different problems concerning elderly people affected by dementia or Alzheimer's are increasingly urgent and complex. Moreover, it should be noted that the effects of the economic crisis of the last decade have also affected the healthcare sector, causing undifferentiated cuts and "[...] causing severe social unrest due to the worsening of the inclusion processes, the marginalization of certain needs, the reduction of the overall quality of spaces, facilities and services performance" (Losasso, 2015, p. 6). In a continuously evolving society, where the decreasing birth rate and the drops in mortality are consistent, the job of Architecture is precisely to interpret the requirements and needs of people who have lost the canonical relationship with the world and give them the possibility to recover it or maintain it through communication channels that use their remaining ability to understand. Space acquires a "prosthesis function", containing and expressing the knowledge necessary to its right enjoyment, reducing the frustration sense through the safety and well-being feeling that the patient must perceive by living in it.

Therefore, an adequate response to the aforementioned "emergency" condition requires the organization of new and innovative approaches to guarantee the right to health through low-cost and economically sustainable development models for which the Technological Culture

– long present in the process governance, in the systemic logic, in the conscious response in terms of requirements and performances and in design experimentation – can provide an important and effective contribution to the Italian National Health Service and to private companies of the field. Regarding the specific category of Alzheimer's patients, this essay wants to be a contribution to the dissemination of knowledge and useful information to those who work in the field of organization and design of health services, reporting "non-pharmacological", low-cost and sustainable therapeutic solutions promoted by international and national technological research in the field of Design technology and ICT and which have proven to be able to significantly help both patients and caregivers.

Design and Alzheimer's patients

Knowing the needs of an Alzheimer's patient and the evolution trends of the disease is an unavoidable need to define the design of suitable spaces and areas. Among the most interesting and the most used "non-pharmacological" therapies we highlight the ones attributable to the *Gentle Care* method – followed by who studies the spatial and physical problems linked to the disease – consisting in the creation of suitable spaces for Alzheimer's patients. The method, created and developed in the 1980s by Moira Jones (1996), head of the MJ Resources (Winnipeg, Canada), aims at the organization of a space suitable for the "rehabilitation programme" evaluated case by case, also with the contribution of external architecture supports or with furnishing solutions.

Speaking of architecture, the most recurrent types are those of Daycare Centres, in Assisted Health Facilities, or only Assisted Living Facilities, in Residential Facilities (Iacomoni, 2009) and there are no specific laws regulating the organization and building of a specific building typology for this disease – the Decree by the Prime Minister of Italy dated 28/12/1989 deals generically with the "realization of residential healthcare facilities for dependent elderly people". A true reference for the Public Administrations and for the designers is the study *Alzheimer's Project* promoted by the Tuscany Region and coordinated by the professor Romano Del Nord (2002 a, 2002 b). The study has defined the guidelines for the design of these specific structures, avoiding assimilating the project of spaces for dementia to the design of generic spaces for the elderly, giving the research group a "strong cross-disciplinary nature" and giving fundamental importance to the components of environmental psychology, ergonomics, proxemics and sensory perception. According to Romano Del Nord (2002 a, p. 19), "The environment in which man lives has the main role in defining his identity, allowing him to acquire self-awareness through a journey of constant exchange, of experiences and stimuli coming from space that is the setting of our lives. In other words, man recognizes himself through the relationship he establishes with the physical and emotional environment in which he moves".

As a result, the environment where senile dementia and Alzheimer's patients live must be reshaped according to their needs since, not only people should take care of and protect patients, but also building spaces. The purpose of Architecture is to interpret the unique and unusual needs of people who have lost the canonical relationship with the world and give them the possibility to recover it through communication channels (first of all, technological) different but coherent with their remaining ability to understand. Since the "spatial perception" of an Alzheimer's patient gradually changes until the shapes and colours of the living environment "crumble", triggering unexpected and unpredictable reactions and behaviours, in every stage of the disease the environment can compensate/slow down (if prosthetic) or accentuate (if aseptic) cognitive deficits and behaviour problems. Therefore, organizing a prosthetic environment designed according to the requirements coming from observation and interpretation of the behaviour of the patient, interaction between caregivers and individually designed auxiliary therapy programmes (ergotherapy or occupational therapy, reality orientation therapy (ROT), life review therapy, memory training, art-therapy, music therapy, etc.), are the main guidelines for improving the quality of life of these vulnerable patients.

Fig.01 An itinerant Alzheimer Caffe, organized fortnightly and in different areas of Milan by the social cooperative Piccolo Principe Onlus. *www.villagecare.it*

A first therapeutic "non-pharmacological" factor can be the "diffuse lighting", able to favour the control of the major causes of disturbance of the patients. The positive results obtained with colour therapy have been known for years and it is established that colour has an important therapeutic function in the treatment of the patient's cognitive deficit (Nowak Etcher, 2012). There are many benefits that people with dementia get from exposure to natural light, including the recovery of their biological rhythms (such as the Circadian rhythm linked to the light-dark or wake-sleep cycles), beat insomnia and seasonal depressions: the light causes a relief of the so-called Sundowning (sundown syndrome), the patients get confused and restless at sunset. Direct natural lighting (windows, glass windows, skylights, verandas), preferably overlooking natural elements and with movable sunshades (to avoid over-stimulation), can improve the patient's quality of life. As an alternative, artificial lighting should have a higher intensity to compensate for the decrease of patients' visual acuity and to eliminate shaded areas that are perceived as disturbing elements, without creating dazzling areas.

An important, little known, experimentation in building typologies is offered by the first *Alzheimer's Café*, created in 1997 in Holland upon the initiative of the psycho-geriatrician Bère Miesen. He has the merit of having started a specific reflection on the nature of the services and the social networks existing in the territory and of having identified a means to achieve support and assistance objectives that the institutions are not able to offer. *Alzheimer's Cafés* a reality that in the last decade has had a great development also in our Country (Fig. 01), also thanks to research called *Alzheimer Caffè: la ricchezza di un'esperienza*, funded by the UniCredit Foundation (Trabucchi, 2012) which has monitored for three months the activities carried out in 11 Cafés (in Lazio, Trentino and Tuscany) finding significant benefits in most of the 62 patients and in almost all the caregivers, offering them support in daily care activities, through information, training and psychological support.

A more recent research was carried out by a group of psychologists who drafted an operating manual (a vademecum) available to operators, service and volunteer centres, Health Institutions and Design Institutions, for the implementation and management of an Alzheimer's

Café, specifying the activities for caregivers and patients, the work and training methods of the team, and providing guidelines and tools of immediate use (Gallo *et al.*, 2017). These Cafes are informal and welcoming places, very different from the hospital and clinic environments, since they offer a furnishing resembling that of a bar or even a house. Nevertheless, the organization of the space must satisfy environmental and psychological requirements, and must include three main types of environment, each with a specific purpose: a public area, for socialization and transition, always respecting the usability requirements and security measures essential for this specific category of vulnerable users; semi-private areas, for activities and therapies not only for patients but also for family members, to be reinforced with help and psychological support; wandering paths that allow the patient to channel their need to walk.

Another typology allowing to give "non-pharmacological" treatments is the so-called *Healing Garden* a fundamental place for the Alzheimer's patient to activate their senses and remaining memory (Valla, 2006). The typology of the *Healing Garden* must be placed within the more general subject of Design for Healthcare and originated from a first reference study carried out in the mid-1980s by Roger S. Ulrich (1984) on surgery patients. The study has proven that patients overlooking a garden had a shorter hospital stay than those overlooking a brick wall, therefore they recovered faster with less need for painkillers and had less impact on the running costs of the facility (Coile, 2002). According to Adrian Burton (2014, p. 448) it is possible to assimilate a garden to drugs taken for a specific disease: "[...] if [gardens] can be shown to shorten hospital stays, reduce the need for pain medication or other drugs, hasten (and therefore reduce the cost of) the rehabilitation process, or reduce staff stress and burnout (as initial research suggests), financing bodies might look on them favourably".

The benefits of adequate planning of therapeutic gardens for Alzheimer's patients found in the scientific literature (Uwajeh *et al.*, 2019) suggest, "[...] their extension also in public open spaces. These, enhanced to become real healing and reconnection places, can become valuable social care aids out of the boundaries of traditional medicine, but within the area of public health" (Valente and Cooper Marcus, 2015, p. 190). Studies show that the use of Healing Gardens reduces behavioural problems such as fear and anxiety, improves walking, promotes positive reminiscences, stabilizes sleep/wake cycles and reduces stress (Detweiler *et al.*, 2008), suggesting this treatment option as a complementary therapy for dementia patients living in facilities for elderly people (Hernandez, 2007). At the same time, caregivers often find comfort in them by identifying them as peaceful places that provide a sense of privacy and allow them to reenergize (Memari *et al.*, 2017).

The process method to plan these open spaces is the Evidence-Based Design (EBD) – the same used for healthcare facilities – that bases the design on the relation between the physical environment and the effect on well-being and health: regulatory standards, of course, but also participatory practices with the close collaboration of the medical staff (Cooper Marcus and Sachs, 2013) and with patients able to provide valuable information on the specific needs necessary to build and determine a system based on requirements and performances. The garden project must be characterized by the presence of a circular path that satisfies the patient's compulsion towards vagrancy but at the same time tries to distract them by attracting them towards "[...] three main indoor areas designed with specific natural elements to stimulate their sensory and perceptual skills. The area of colour, made with natural essences particularly characterized by different chromatic palettes, changing according to the seasons; the area of taste and touch, where the patient can practice horticulture; the concentration area, equipped with tables and chairs to allow the patient to develop practical and manual activities immersed in a natural setting" (Del Nord, 2002 a, pp. XIII-XIV).

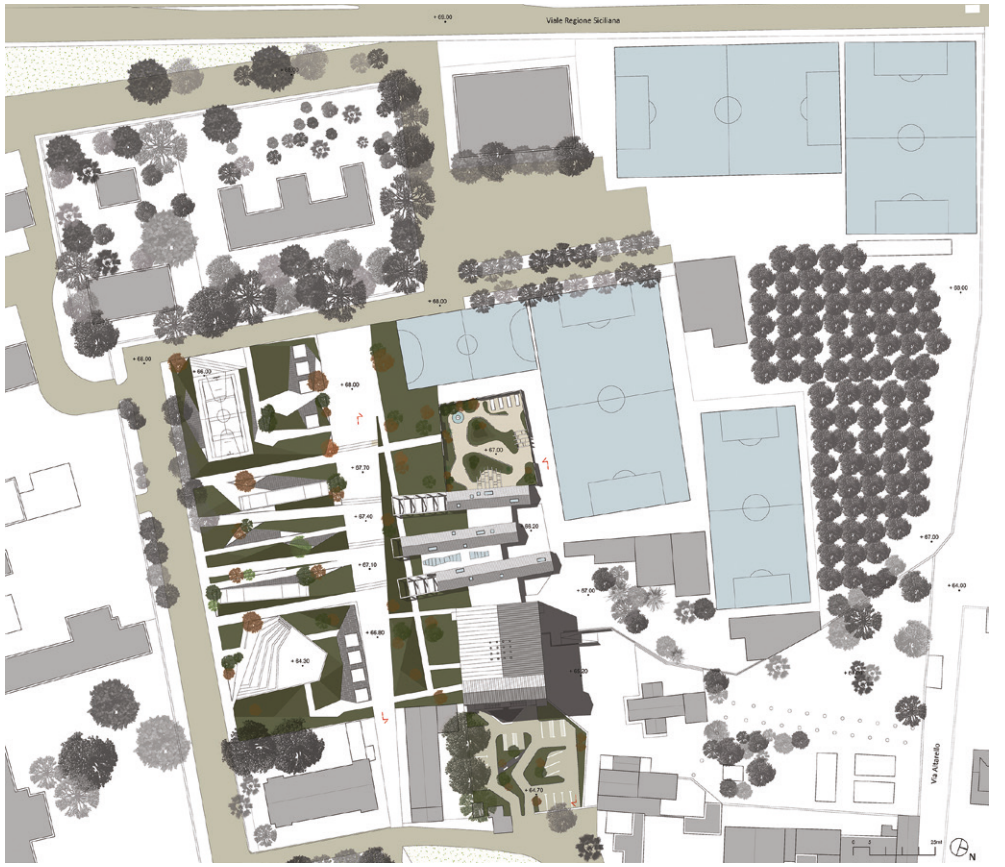

Fig.02 Plan of the Requalification and Re-use Project in RSA of Vignicella in Palermo (Italy) with the realization of the new pavilions and the Healing Garden. *Ferrante, 2013*

Some design experiments carried out by the Research Group in Palermo coordinated by Prof. Giuseppe De Giovanni and Prof. Cesare Sposito have provided interesting results in the recovery of existing but no longer functional healthcare buildings or disused industrial buildings and their transformation and adaptation to the needs/requirements of this particular category of users. One such example is the redevelopment and reuse as a nursing home of a building part of a monumental complex – called *Vignicella* – located within the area of the former Psychiatric Hospital of Palermo (Fig. 02).

Three new areas were added to the existing complex: the Alzheimer's Centre, the rooms where the different therapies are carried out and a small urban park that includes the Alzheimer's Garden, characterized by a sinuous path, shaded resting areas, a homogeneous, clear and luminous pavement, specific and ergonomic furnishings or aids for walking; the vegetation has been chosen with precise characteristics based on the function it must perform, for example: shading, sensory stimulation or boundaries. There are also Orangeries, fundamental to ease the mental and physical recovery and maintenance of the patient's residual sensory skills in the coldest months, thanks to the presence of not harmful and perennial flower beds and plants, or fruit trees and aromatic plants.

At international level, there are several examples of healthcare buildings with a therapeutic garden. Among the best-known, there are the two gardens of *Oak Bay Kiwanis* and the *Alz-*

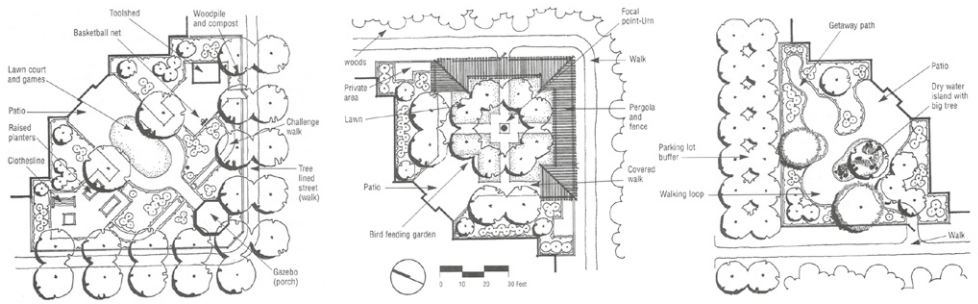

Fig.03 The Healing Gardens of Sedgewood Commons in Falmouth, Maine (USA): Hawthorne, Longfellow e Millay, each one specializes in supporting a certain degree of dementia. *Masala Canaglia, 2015*

heimer's of Providence garden in Canada, the garden-courtyard of the *Alois Alzheimer Centre* in Ohio, that of the *Hearthstone* of New Horizons in Massachusetts and the three *Sedgewood Commons* gardens in Maine. Although they are constantly updated according to the results they get with patients, the *Sedgewood Common* certainly represents good practice for the organization of the building in three separate pavilions, each one specialized for a certain degree of dementia. Each pavilion has its own therapeutic garden (Fig. 03), designed by the landscape architect Robert Hoover, with structures, equipment and paths suitable to the different stages of the disease, thus ensuring a specific treatment for each patient.

ICT and Alzheimer's

In the Industry 4.0 era, ICTs are getting an important role also in the healthcare system, thanks to the dissemination of new digital tools (Baricco, 2018) and their ability to acquire information, to analyse and to re-elaborate the data to create databases and profiles (Ficocelli, 2019). Defined as value-based healthcare, this new era in the healthcare field represents a totally new strategic approach to improve health systems, an efficient and sustainable solution both for environmental and economic costs, provided that the data updating is continuous, their recording is systematic and the results can be consulted remotely by human and artificial intelligence. Investments made in this field by large multinationals, such as Philips and Alliance, confirm the global trend towards the systematic adoption of digital tools to support healthcare, called connected care (Drobac and Gaus, 2014).

In this light, the *IN LIFE* project – funded by the EU in 2015 and ended in 2018 – is very interesting. It has developed customized ICT services with open access to help elderly people with cognitive disabilities to independently perform simple actions such as eating, physical activity, meeting with friends and relatives, going to the doctor and moving around (AAL Programme, 2018). *IN LIFE*, coordinated by Spain, has created pilot locations in the eight involved countries to test and develop customized services – such as a memory training tool, a programme to connect users and tutors through video-links, an application to assess the ability to safely move around in the streets, a bracelet that can detect if someone has fallen and a navigator for people using public transport. The results of the trial showed that ICT-based services can help elderly people with cognitive disabilities to stay healthy and active and to live independently for a longer time, as long as the interfaces are easy to understand, and adequate training is provided.

The international scientific literature provides many technological solutions, such as virtual reality and three-dimensional simulation, used to reduce anxiety and agitation in patients (Davis, 2015; García-Betances, 2015; Manera *et al.*, 2016; Doniger *et al.*, 2018). Using a VR visor that shows peaceful settings of the beach, forests and animals, underwater coral reefs and dolphins has improved the mood of the patients (Ashford and St. Peter's Hospitals, 2018).

In Italy, the Department of Architecture of Roma Tre University also carried out research on the ICT field. It tested "machine learning" algorithms for learning neural networks with the support of a BIM software aimed at the creation of Augmented Reality (AR). The goal is to improve the use of living environment for vulnerable users, eliminate barriers that cause social isolation, constantly monitor the health of users, reduce hospitalization, improve healthcare assistance, thus minimizing the social costs of disability and ageing (Formica and Magarò, 2018), through the new technologies of artificial intelligence and virtual reality. The research, still ongoing, has developed two apps: RAdARt, able to recognize the plan of a building when you point it with a smartphone and to mix it with the augmented reality view of its three-dimensional model, suggesting a path without architectural barriers; LISMuzic, able to superimpose on a simple image a multimedia content, for example, useful in museums to create video guides in Sign Language, with no cost since they can be used from a personal mobile device (Magarò and Baratta, 2019).

Another ongoing research with industrial manufacturing purposes, started by the LudoMi team and continued by/at the Design Department of the Politecnico di Milano, is *Merlino*. Through "multisensory environments" (MSEs) *Merlino* aims to increase the development of cognitive faculties and motor skills, promoting learning and the development of communication and relational skills for users with sensory, intellectual and motor disabilities. *Merlino* refers to the *Snoezelen* multisensory therapy, developed in the Netherlands in the late 80s in the Hartenberg Institute (Slevin and McClelland, 1999) – based on providing sensory stimuli in a controlled way, for relaxation and leisure in a specially designed environment, with dimmed lights of different colours, display, fiber-optic lighting, wall projections, tactile objects, bubble tubes, aroma diffusers, sound system and furniture suitable for relaxation. *Merlino* is characterized by: "optimization of production costs (the components can be found on the market [...] at low and accessible price); ease of use and handling (quick and easy installation, [...] while the entire room is controlled via a single interface that is easy to use for non-specialized operators); transportability (the structure can be transported with a medium-sized van, manageable by one or two people [...] and can be easily assembled); scaleability of the project (it must be reproducible in different places and contexts, such as schools, hospitals, public places, civic centres, organizations, etc.); flexibility over time (the room is set up for future implementations [...]); attractiveness (the project has an easy interface for the users, concealing its technical/technological aspects)" (Bisson *et al.*, 2019, p. 177).

Conclusions

One of the aims of the Technological Design Culture is interpreting the requirements and needs of patients, especially, people who have lost the canonical relationship with the world and give them the possibility to recover it or keep it through communication channels that use their remaining ability to understand. In this particular day and age – dealing with often undifferentiated cuts to healthcare and spending reviews, over the last decade – it is necessary for researchers to develop proposals and structure new and innovative approaches capable of guaranteeing the right to healthcare, on the one hand, by allowing the provision of quality services for the assistance and care of the patient, while overcoming the problem of economic sustainability, management costs, maintenance costs and efficient use of resources. "Non-pharmacological" therapy solutions listed for Alzheimer's patients should be understood in this sense.

The two terms *value-based healthcare* and *connected care* represent a new era in the healthcare field, based on a totally new strategic approach to improve healthcare systems, to give an efficient and sustainable solution both for environmental and economic costs. In the field of international scientific research, the space for healthcare is not only evaluated for its primary

function of treating the disease, but its role is extended to the greater objective of improving the well-being of patients and staff: it is indeed established the link between the characteristics of the space, the quality of treatments and the effectiveness of the service provided. Changes in the space we live in do not change the natural history of Alzheimer's disease patients, but they can reduce behavioural disorders, maintaining the residual autonomy in everyday life actions and fostering the improvement of the quality of life. In this sense, the environment and the physical space can become a precious therapeutic source.

In this light, it seems useful underlining some of the researches that have analysed the role of *Healing Gardens* as design projects to better the physical, social and psychological health of the patients, as "non-pharmacological" intervention to daily treat dementia patients, to reduce stress, pain management and improve cognitive skills. At the same time, other studies suggest that ICT (mainly augmented reality and virtual reality) can be used to simulate or recreate many different natural environments and multisensory conditions to improve mood, cognition and overall experience in dementia patients. Some of these researches are still in the testing stage, but they certainly give promising results that can encourage designers and healthcare professionals to take up the challenge of creating therapeutic solutions, without using drugs and low-cost treatments, which can welcome and improve the experience of people living with dementia. Therefore, future studies should examine the positive aspects of non-invasive tools, including ICTs, to maximize treatment options for dementia patients.

The contribution, resulting from a common reflection, is to be attributed in equal parts to both Authors.

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