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Habitat-Approach for Extra-Ordinary People: the case of Alzheimer's Disease

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Abstract

Behaviours typical of people with dementia (PWD) are often considered inappropriate by "normally endowed" society. Accordingly, people with dementia are often isolated, or hidden, because of stigma or the possibility of negative reactions from neighbours and relatives to behavioural and psychological symptoms. Hence, facing stigma is often a primary concern of PWD and their caregivers, because it represents a significant obstacle to well-being. Analysing deeply this aspect, enormous similarities emerged compared to some issues of contemporary society. The feeling is that the condition of people with dementia is not merely attributable to a state of deficiency or disability. Even in the artists is frequent the presence of certain kind of diversities. But indeed, these diversities are responsible for an extra-ordinary condition, in which, due to their increased level of sensitivity, they are able to perceive reality in a deeper way. For example, the condition of incommunicability has been portrayed in the arid sequences by Michelangelo Antonioni, or the logic of repeating sounds and were analysed in the works of La Monte Young and Steve Reich. From this perspective, the loss of some capabilities, identifies special people with emotional and perceptual characteristics different from the ones experienced by "normal endowed society", completely extra-ordinary and able to live the everyday experience in a completely intimate point of view. In this sense, through research it is necessary to transfer a new approach, referring to individuals considered special, exceptional and extra-ordinary. Working in the framework of a different and extra-ordinary sensitivity, design research, should develop solutions able to convey to this "extra-ordinary patients" a perpetual state of relief, tranquillity and relaxation. An example can be found within the specific setting of Non-Pharmacological Therapies (NPTs), where the environment can act as a prosthesis: enhancing the well-being of the patients, supplying their lost capabilities, reducing dysfunctional symptoms and behaviours. An environment designed for an extra-ordinary sensitivity, created through a system of elements, considered as activators of well-being, able to provide the patients the possibility to regain autonomy, dignity and self-confidence.

Methods.

The approach proposed is supported by empirical data collected as part of a qualitative ethnographic study (rapid ethnography method), which aims to understand symptoms and behaviours as they are perceived by peo-

ple with dementia themselves and their caregivers.

Objective.

Aim of this paper is to propose a new approach, considering the person with Alzheimer's disease (AD), not as a person with a disability, but as a person with an extra-ordinary sensitivity. Therefore, this approach can provide the necessary support to specific anthropological needs of individuals with perceptual and emotional characteristics totally special, exceptional, that make them Extra-Ordinary People. Consequently, as designers, in collaboration with doctors and therapists, it is necessary to reflect on the qualities of an environment that responds adequately to the needs of a space specifically designed for Alzheimer's patients requires and, at the same time, the ability to transfer these qualities in an experimental space that also satisfies the needs of contemporary man.

1. Introduction: background

Aim of this paper is to propose a new approach, considering the person with AD, not as a person with a disability, but as an individual with an extra-ordinary sensitivity. Therefore, this approach can provide the necessary support to specific anthropological needs of individuals with perceptual and emotional characteristics totally special, exceptional, that make them Extra-Ordinary People.

AD is one of the most common forms of dementia. It is characterized by memory, thinking and behavioural symptoms that affect person's ability to function in daily life [1]. In most instances, the progression of dementia is slow and consistently changes over time.

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 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 behavioural 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 [12]. Other NPTs are intended to improve quality of life or reduce behavioural 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 [12].

During the later stage of dementia most people become increasingly fragile and dependent on caregivers due to the progression of the disease. Forgetfulness and repetitive questions increase in this phase of the disease. People with dementia may also encounter huge difficulties in recognising people or confuse them with others. Some people at this stage easily become aggressive or start shouting, due to a sense of frustration or because they are unable to express emotions through words, or because they have difficulties in understanding reality. Other symptoms may include becoming lost even in familiar places, making confusion between day and night, waking up in the middle of the night and sleeping during the day, behaving in unusual ways, such as going outside in nightclothes, becoming very agitated or aggressive, behaving inappropriately in social contexts, experiencing difficulty with perception and, in some cases, having delusions or, less often, hallucinations associated with aggressive mood. Loss of memory may become very impairing, with the person unable to recognise familiar objects, places, relatives, although there may be sudden flashes of recognition. The person may become insecure, sometimes seeming to be searching for someone or something not exactly understandable. Unusual or improper behaviours are typical of this stage: the person look backwards and forwards continuously while walking, use repetitive movements or keep repeating the same sound or word. Occasionally, some people with dementia in the severe sub-stage, experience hallucinations, in which they see, hear, or feel things or people that are not really there.

Hence, the confrontation with this eccentric perception, abnormal, extra-ordinary, represents a major challenge for design.

2. Stigma

The term stigma, by definition, refers to a discrediting or disgraceful mark that sets individuals apart from others and renders them unwanted, tainted, degraded, or inferior in the eyes of other people [2].

In ancient Greece, the word stigmata referred to recognizable sings on the body, such as burns, into the skins criminals, to distinguish them among the other citizens. Over time, the word stigma has been associated to a discredited state, which causes individual's isolation from society.

Individual's characteristics are unique and personal, and determine social roles and abilities. Approaching society, individuals expect to be judged and compared with others on the base of personal attributes and skills, and to carry out determined social roles without any prejudice.

In reality, appearances and reputation play a key role on the judgement of others, and are strictly connected with stigma. In particular, stigma occurs when a specific set of characteristics or gestures represent a reason, for society, to label and discredit some individuals.

Today, stigmatisation is a complex social process. It refers to oversimplified conceptions, opinions, or images, defined stereotypes, about a person or group, negative attitudes or prejudices that reflect such stereotypes, and overt negative discriminatory behaviour towards people with a stigmatised condition. Many definitions of stigma consist of two components: difference and devaluation. Stigma associated with mental illness has its roots in the prejudice that those individuals show undesirable behaviours responsible for a decreased perception of the person. As well as mental illnesses, the diagnosis of dementia, is strongly associated with stigma, caused by cultural beliefs and "uncommon" behaviours due to the impairments typical of the disease. Stigma is a significant obstacle to well-being for people with dementia, especially regarding their behaviours often considered inappropriate by "normally endowed" society. Stigma can also cause a delay in the search for a diagnosis of dementia, due to the negative effects it has on the social perception of people with dementia. Dementia due to Alzheimer's disease is a degenerative illness which can lead to forgetfulness; emotional out-bursts; sudden shouting and unexpected agitation and aggression; an unusual behaviours in public spaces [11]. The main cause of stigma towards dementia due to Alzheimer's disease, are the unusual behaviours and manifestations that occur to individuals with dementia, due to their impairments [7]. These behaviours, challenge the social norms recognized by society as "appropriate conduct" [9].

Stigma, is defined in the Oxford English Dictionary as a "mark of disgrace associated with a particular circumstance, quality, or person". Erving

Goffman, a very well known sociologist that inquired stigma and its associations, describes the lack of social acceptance, defined "spoiled identity", that affects a stigmatised person. This leads to a distorted view of the person, that is seen by other individuals as "less than human" [1]. Goffman defined stigma as a characteristic, behaviour, or prejudice that results discrediting to society. Persons possessing such attribute are seen different from others, in a way that is undesired and shameful. Consequently, the stigmatised individual is devalued and his/her identity risks to be damaged.

Accordingly, people with dementia are often isolated, or hidden, by their relatives and family caregivers, because of stigma, in order to prevent emotional out-bursts in public. In recent years, the stigma associated with mental illness, become a social problem affecting a significant portion of society.

In all stages, the stigma associated with dementia arises and focuses on the various impairments that characterize the person, rather than on the remaining abilities and strengths that still enables people with dementia to interact and enjoy social contact. This leads to a deprivation of social contacts between people with dementia and their family members and friends.

Hence, stigma prevents people from looking for a diagnose, and looking for available support services to maintain a high level of well-being. Stigma around Alzheimer's disease exists in part because of the lack of public awareness and acknowledgement of the condition.

Stigma may add to the burden of Alzheimer's disease as it can prevent individuals and their families from taking benefits from available treatments, or living life to the fullest extent possible.

Stigma affects not only the person with the mental disorder but also relatives and carers that support the person, including professionals. The consequence of stigma towards dementia consists of a negative influence upon psychological well-being of people with dementia, added to a consequent negative impact on carers well-being. Reducing stigma should encourage people with dementia and their carers to be more confident about the illness, and to seek help when needed, looking for the many services offered for dementia care.

3. Methods

The empirical data were collected as part of a larger qualitative ethnographic study, which aims to understand symptoms and behaviours as they are perceived by people with dementia themselves and their caregivers.

One of the author conducted an ethnographic fieldwork, specifically a variant of conventional ethnography - Rapid Ethnography - in collaboration with a dutch architecture and research firm named D/DOCK, where she followed a design project for the development of a SCU's for dementia. D/DOCK is a well known dutch studio that mainly works on the development of healing environments and healthcare.

Aim of this study was to define people with dementia's symptoms, and moreover, specific needs. Rapid Ethnography seemed to be a more appropriate technique for creative design practice. Yet, conducting Rapid Ethnography require not insignificant resources in terms of time and personnel commitments. Therefore, designers and architects need to be able to define exactly their goals prior to initiating a Rapid Ethnography.

Architects typically need to look at and investigate sources, and references, other than their own experience to instruct their design for people with dementia, due to the fact that people with dementia's experiences are totally different from their ones; and this, usually, represents a point of difficulty, because traditional research outcomes are difficult to apply into the design discipline, due to the lack of spatial aspects in the content. Mainly, this represented the reason why the author decided to inquiry directly dementia living experiences, through Rapid Ethnography.

The data presented in this paragraph originate from qualitative interviews and document analysis. Two semi-structured, post-occupancy in-depth interviews were conducted with the nursing staff and the caregivers of people with dementia living in the SCU. The residents of this SCU are mainly in the last stage of the disease, named dementia due to AD.

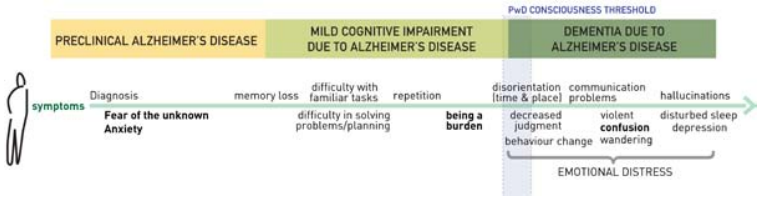

Fig.1. symptoms and behaviours in Alzheimer's disease.

We confronted this ethnographic study with previous observations of patients in other SCUs in Italy, conducted in the last three years, aiming at depicting common or uncommon behaviours occurring among people with dementia. In particular, we found out that, in many cases, in the last stage, people with dementia repeat behaviours and gestures connected to old memories. Most of the times these memories and repetitive gestures where connected to their past memories (i.e. many of them where masons, and during the day they where mimicking typical mason's gestures).

4. An extra-ordinary sensitivity

Analyzing deeply the condition of PWD, enormous similarities emerge compared to some issues of contemporary society. The so-called Alzheimer's disease (AD) is extremely typical in relation to contemporary human condition, it is a disease that has probably always existed, even before it was classified as a type of mental illness. It is characterized by a number of features such as amnesia, delusions, aphasia, exhaustion, but also the compulsiveness, the energy that must be released, the proximity of the other in contrast with the distance from the community, which can be considered at the same time typical of the modern man, because they correspond to a form of "behavioural exception". It is a progressive and irreversible disease, which has no certain origin or beginning, but it skirts along the "normal" and then at some point it flows in a cross mix between "normal" and disease ", in an intense exchange, almost mystical.

There appear the sick, as contemporary mystics, with and extra-ordinary vision of the reality. Through their delusions, we can glimpse a world that we can not fully understand but also that we recognize, again, as a form of creative behaviour. This is obviously a cultural interpretation that does not want to approach Alzheimer's disease from a medical point of view, but it is an attempt to see the sick as a vanguard, and through this investigation to verify the contemporaneity. Therefore, it is possible, for example, to retrace some peculiarities of the disease in the characters' gestures typical of Samuel Beckett Theatre, Eugène Ionesco or Harold Pinter. Furthermore, verbal convulsions and phonetic distortions, in addition to the hysterical movements of the body, can be retraced in Carmelo Bene's interpretations.

The logic of repetition and estrangement were analyzed by the works of La Monte Young, Steve Reich, Philip Glass. The sense of disorder and chaos,

typical of an uncontrollable condition, can be traced in the compositions by John Cage, in the alienated sounds of György Ligeti, or evaporated in electronic compositions by Karlheinz Stockhausen, Luigi Nono and Luciano Berio. The need to forge emotional bonds with tragicomic prosthesis was exceptionally expressed in the Charlie Chaplin film (the inadequacy of its existence can only pass through the use of exaggerated shoes or unsafe and clumsy movements). The state of bewilderment, of laceration and contortion is easily retraceable in the paintings of Francis Bacon. The condition of nothingness, as well as the inability to communicate, was impeccably drawn in the arid sequences by Michelangelo Antonioni. The delicate slowness of different times is the measure of the dialogues of Aki Kaurismaki. The tragicomic gestures were replicated in the extraordinary interpretations of Buster Keaton. The anguish and vertigo have been explored in the hallucinatory visions of Jean-Paul Sartre and Albert Camus, etc.

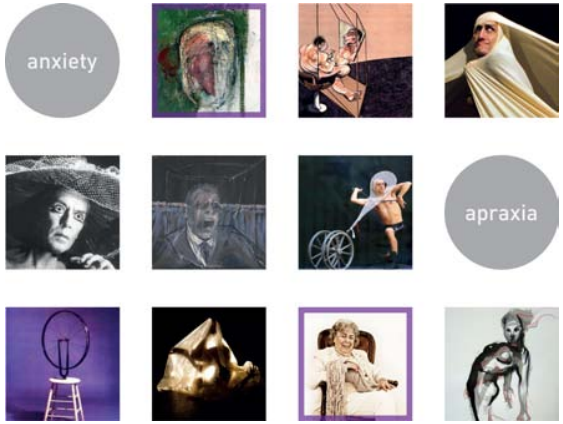

Fig.2. Composition of frames from the works of different contemporary artists.

The list could go on much longer. They are great artists, great personalities, who have been able to deeply understand and represent a single, unique, issue related to the existence of human beings. Exploring its depths, then, they returned to society a reading, definitely eccentric, but that can trigger a new perception of the world. This is often done turning this issue into a fixation, an obsession ... exactly like the Alzheimer's Syndrome leads to make.

5. Therapeutic Environments

Health facilities design traditionally has emphasized the functional delivery of healthcare, as expressed in such concerns as providing efficient spaces to accommodate beds or doors wide enough [13]. This emphasis has often produced facilities that are functionally and ergonomically effective but not from a psychological point of view. Essentially these facilities result stressful or otherwise unsuited to the psychological needs of patients and caregivers. There is an increasing evidence that poor design works against the well-being of patients and in certain instances can have negative effects on physiological indicators of wellness [13].

In the specific case of dementia this stressful condition is even accentuated by the symptoms of the disease. Such negative consequences can be anxiety, delirium, increased intake of pain drugs, etc. In this context, design should do more than produce health facilities that are satisfactory in terms of functional efficiency and marketing costs [14]. Another important goal of designers should be to promote wellness by creating physical environments that are "psychologically supportive". Supportive surroundings facilitate patients to manage the major stress accompanying illness [15].

The environment is important because it is closely linked to quality of life, defined by Lawton (1991) as "the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of the individual".

The focus on people with dementia's needs is extensively investigated in the literature on dementia care. This approach suggests that the development of a therapeutic milieu for people with dementia may lead to positive outcomes. It also requires a change in dementia care philosophy, from managing impairments and behavioural disturbances, to empathically understand and meet people with dementia's needs. Moreover, in the literature, the provision of a safe environment is regarded as one of the basic requirements of residential care, but it is also necessary to provide an active social environment, that offers opportunities of engagement and enhancement of self-esteem. Meeting all these psychological, social and physical needs can lead to the design of an environment of "care", in which people with dementia are not only passively receiving care, but are actively part of it.

Accordingly, interior design has historically moved through the creation of scenographic equipment, often filtered by a cultural interpretation, in order to provide environments with a certain degree of quality and specific connotations [4]. In the specific case of AD, it is necessary to introduce a new approach. Design guidelines for therapeutic environments for people with dementia, usually they take into consideration parameters such as building organization, overall security, provision of outdoor areas, orientation within the building, etc. These are parameters associated to an architectural point of view, strictly connected to the building characteristics. On the contrary, 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 consists of environmental factors, as well as objects and human interactions.

Hence, the mental and physical health state of these persons is extremely fragile and their needs demand careful consideration. Researchers, professionals and practitioners should perceive PWD, not as problems to be solved, not as merely sick people, but as people with a different sensitivity and, so, design suitable environments around that information. Dignity and autonomy are important values that have to be preserved, as well as self-confidence. Recently, research culture has shifted from a negative focus on solving behavioural problems to a positive focus on the remaining capabilities of persons with dementia. We have become aware just how much of the self is retained within a cognitively impaired person, and how important it is to their sense of well-being. Although environmental interventions constitute only a fraction of what is needed for people with dementia to remain as independent as possible, there is now sufficient evidence to argue they can be recognized as an important aid in the care of PWD, able to enhance the perceived well-being. As Campion [3] argued in the New England Journal of Medicine, therapeutic physical environments can positively affect the lives of residents with dementia: "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''.

Such environments are constituted by both tangible (colours, finishes, and linguistic elements of signs, etc..) as well as intangible (lighting, sound, video , air conditioning, etc..) elements, identified through their therapeutic efficacy, especially in terms of their prosthetic dimension, concerning Non-Pharmacological Therapies. Furthermore Zeisel affirmed that environment can reduce dysfunctional symptoms and behaviours, and can be considered as one important non-pharmacological treatment modality [16].

6. Habitat of care

Starting from this point we propose the concept of Habitat, a fluid system, based on tangible and intangible aspects. Products and furniture, technical equipment, instruments, objects, services. All interconnected. A large organism made of small pulsing interventions that function as activators, giving the lymph in small doses, enhancing well-being, supporting each others. Starting from this point we can think about interior design as an environmental system design, composed by different levels – from tangible aspects, to more intangible ones – able to go beyond the architectural container, adapting itself to the changes in order to satisfy human needs.

However, the term Habitat is strongly connected with the concept of inhabit, which represents the cornerstone of the discipline of interior design in the contemporary world. "Indeed, the expression Inhabit the Planet refers to a man-made complex system, which goes beyond the limits of the metropolis and the built. But it is also connected with biology, in fact the term habitat indicates that certain set of conditions that guarantee a species, animal or plant, to take root, spread and reproduce, in a given environment". Especially in the context of Care, we want to introduce the term Therapeutic Habitat, to describe a wide context of care, that place the person in the centre, involving physical, cultural, social and anthropological aspects of human life.

7. Discussion

Design discipline, works within a dynamic and flexible dimension, that is well suited to the changes constantly in place. Therefore, this kind of approach can give the necessary answers to the changing anthropological needs and to the quick and sudden changes typical of the contemporary society. Introducing a new approach means shifting the point of view, assuming that, for the well-being of the patients, it is necessary to validate some peculiarities of the disease (such as wandering, vocalisms, repetitions in movements, need to focus on material details, etc.) rather then sedate them.

For example, the need for safety and security varies from person to person, depending on their stage of dementia and their behavioural symptoms. Although independent movement and the ability to wander have been shown to benefit people with dementia, it needs to be managed safely and the environment has a significant role to play in that process, allowing PWD to release their stress not preventing their movements, but providing them a comfortable and safe environment.

Therefore, this approach can provide the necessary support to specific anthropological needs of individuals with perceptual and emotional characteristics totally special, exceptional, that make them Extra-Ordinary People.

8. Conclusions

If it is true that the mentally ill, in the past have served to all the cultural movements such as art, painting and writing as a mean through which denounce an unexpressed human condition that needed to find a location within the social dynamics, in the same way AD can be considered as a starting point for a new sensibility. Working in the framework of a different and extra-ordinary sensitivity, research should identify a scenario, able to convey to the patients a perpetual state of relief, tranquillity and relaxation. As designers, in collaboration with doctors and therapists, it is necessary to reflect on the qualities of an environment that responds adequately to the needs of a space specifically designed for Alzheimer's patients requires and, at the same time, the ability to transfer these qualities in an experimental space that also satisfies the needs of contemporary man. A Habitat, an extremely human environment, with a high degree of comfort and protection, able to act as a filter with the outside world, an environment that meets the needs of information and communication that are the basis of our contemporary society, an intangible place that can be freely customized, but at the same time present with well-defined characteristics.

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