

The third international conference exploring
the multi-dimensions of well-being



WELL-BEING 2016

CO-CREATING PATHWAYS TO WELL-BEING

BIRMINGHAM, 5-6 SEPTEMBER 2016

BOOK OF PROCEEDINGS

EDITED BY RICHARD COLES, SANDRA COSTA & SHARON WATSON



PEER REVIEWED BOOK OF PROCEEDINGS

Well-Being 2016: The third international conference exploring the multi-dimensions of well-being

CO-CREATING PATHWAYS TO WELL-BEING

BIRMINGHAM CITY UNIVERSITY, BIRMINGHAM, UK

5-6 September 2016

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Published by

Birmingham City University

ISBN 978-1-904839-87-3

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FOREWORD

WELL-BEING 2016: CO-CREATING PATHWAYS TO WELL-BEING

In 2011 we initiated a series of international conferences that explored the multi-dimensions of well-being. Several things prompted our decision- being situated in a design faculty we were enthusiastic about exploring the unique contribution that the arts and humanities disciplines offer, while comprehensive research of local community interaction and engagement with green spaces had resulted in, what we then termed, 'social criteria for green spaces' later to morph into well-being parameters. This and other work made us realise that there was a need to bring different disciplines together, academics and practitioners, to discuss and debate the concept of well-being through different lenses with the aim of understanding the concept of wellbeing, defined and demonstrated by the reality of everyday engagement and in doing so to develop better theoretical understanding of the systems that might be operating.

The idea was well received and continues to be equally relevant and urgent now as it was in 2011 with *Well-being 2016* being the third conference in the series.

The twin themes of co-creation and understanding the pathways that exist in pursuing or underpinning the achievement of well-being form the focus of *Well-being 2016*. Here we seek to answer a range of questions about negotiating and navigating the experiences that underpin the achievement of well-being. How positive encounters are or might be embedded in our everyday contacts with the environment where we live, learn, play or work; how individuals are supported in ways that enables them to take control of their personal well-being; what constitutes a pathway; how are the impacts expressed or captured, the techniques involved, the use of electronic media, verbalisation and narratives or through artistic endeavour, design, making and the crafts, the unique role of the practitioner and the growing relevance of the medical humanities approach?

Delegate response has been excellent, the diversity of papers is impressive and the quality of the material offered is, I believe, of the highest standard yet, while practitioners have responded in offering a series of workshops in which you can explore at first hand the potential of an approach. In addition we have five keynote speakers drawn from across the globe who present different perspectives and set the scene for the papers presented in a series of breakout sessions.

Accordingly, I invite you to 'chill out' over the two days, to expose yourself to situations and material that challenges your own position and in doing so to raise the bar regarding our understanding of the well-being paradigm.

I look forward to engaging with as many as you as possible, in debate, though the social event planned and hopefully through follow on initiatives.

Welcome to Well-being 2016



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DESIGNING FOR DEMENTIA: INTERIOR DESIGN AS A TOOL TO ENHANCE WELL-BEING AMONG PATIENTS AND CAREGIVERS

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Abstract

As the most common form of Dementia, Alzheimer's disease (AD) causes behavioural, cognitive and physical impairments. The cognitive impairments, typical of this condition, lead to errors in one's memory of places and a reduced ability to spontaneously adapt to new spaces. As sufferers begin to realise these changes, they may feel a sense of shame and inadequacy caused by emotional borderline situations resulting from difficulties in performing normal daily routines. The purpose of this study is to analyse how design can promote well-being through the creation of physical environments for people with dementia due to AD that are psychologically supportive in order to manage the major stress accompanying illness. In collaboration with caregivers and professionals, involved in different workshops and interview sessions, we delineate a set of design guidelines, with essential quality of dignity and perceived well-being, for supportive environments tailored for people with dementia. We designed a set of future care scenarios around the concepts of meaningful activities, memory and stimulation. An environment designed 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. Findings suggest that there is sufficient evidence to argue that environmental intervention can be able to enhance the perceived well-being of the patients. Therefore, inside the framework of Non-Pharmacological Therapies, design of the physical environment can be recognized as an important aid in the care of people with dementia.

Keywords: dementia, dementia-friendly environments, non-pharmacological therapies, interior design,

Introduction

As the most common form of Dementia, Alzheimer's Disease (AD) causes behavioural, cognitive and physical impairments. It is characterized by memory, thinking and behavioural symptoms that affect person's ability to function in daily life (Alzheimer's Association, 2013). In most instances, the progression of dementia is slow, with a potential duration of twenty years, and consistently changes over time. The cognitive impairments, typical of this condition, lead to errors in one's memory of places and a reduced ability to spontaneously adapt to new spaces. As sufferers begin to realise these changes, they may feel a sense of shame and inadequacy caused by emotional borderline situations resulting from difficulties in performing normal daily routines.

Research shows there is no current treatment that can stop AD from progressing. However, pharmacological, and more non-pharmacological interventions, can temporarily slow the worsening of the symptoms and improve the quality of life for people with AD and their caregivers. Specifically, Non-Pharmacological Therapies (NPTs) are treatments that do not

involve the use of drugs, aiming to stimulate, activate and maintain the physical and cognitive functions that are not completely deteriorated, acting on the residual potential (Olazaràn et al., 2010).

Inside the framework of Non-Pharmacological Therapies, research has shown that the environment can be considered as an important support in caring for people with dementia (Zeisel & Raia, 2000) due to its peculiarity of being able to reduce dysfunctional symptoms and behaviours, and act as a prosthesis, enhancing the well-being of the patients, supplying their lost capabilities (Zeisel, 2006).

Aim of this paper is to analyse, through a set of typologies for future care scenarios, how the environment can be able to provide the patients the possibility to regain autonomy, dignity and self-confidence, and be psychologically supportive by managing the major stress accompanying the illness.

Dementia-friendly environment

Everyone has a relationship with his/her environment. Each day we move about in space and time, relating to people, objects and places of meaning. Much of how we think about ourselves is reflected in our environment. Environments of our daily lives give us resources for presenting ourselves to the world around us.

It is the same for people with dementia. Even if their perception of time and space has changed, they live in a world where relationships, objects and situations matter. People with dementia may not be able to speak about the meaning environments have, but a sense of meaning and importance remains in their lives.

In the past twenty years, the importance of the physical and social environment in supporting the person with dementia has gained a much higher profile in dementia care.

The design guides for dementia and Alzheimer's disease typically begin with information on dementia, the physical, behavioural, and cognitive effects of the illness, and the needs of people with dementia. This is generally followed by an examination of the types of residential care available and a presentation of specific design details ranging from the orientation and size of the building to types of door levers. The majority of the guides concentrate on the design of the physical environment although a few stress that environmental design, the management of dementia care homes, and their care policies should be addressed holistically.

But new design literature, published in the last decade or so, seeks to promote therapeutic and supportive environments that enhance residents' wellbeing, strengths and abilities and meet residents' physical, emotional and psychological needs.

Chalfont & Rodiek (2005) argue that it is time to move beyond designing for the purpose of control, affect or to diminish behavioural difficulties and instead move toward understanding 'how environments actively encourage pleasurable and satisfying behaviour, for everyone who lives or works within or near them'; an ecological approach to design that encourages curiosity and engagement in every day activities. Recent resource development focused on the significance of understanding the 'experience' of the person with dementia in everyday life for creating appropriate environments (Davis, Byers, Nay, Koch, & Andrews, 2009).

As Champion argued in the *New England Journal of Medicine*, therapeutic physical environments can positively affect the lives of residents with dementia (Champion, 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)

Neuroscience indicates that in the process of dementia, and specifically Alzheimer’s disease, subjects’ ability to understand and plan their life with their own cognitive ability diminishes.

In the end only the emotional brain remains. In addition, persons with dementia lose their individuality. Their behaviour becomes generic, and increasingly guided and determined by the environment (J.J. Van Der Plaats, 2012).

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

Recent studies have shown that the so called “dementia-friendly environments” can significantly promote health and well-being (Fleming, Crookes & Sum, 2008; Fleming & Purandare ,2010).

To achieve the appropriate fit of the physical and social environment to the person in order to have lasting effects on resident outcomes, many elements need to be taken into consideration (Teresi, Holmes & Ory, 2000).

For people with dementia, their physical and social environments become more and more relevant with changes in cognitive capability. Dementia changes very much how people interpret what they see, hear, taste, feel and smell (US National Institute of Health, 2012).

Anyone trying to create a dementia-friendly environment must first ask how people living with dementia experience their world.

Therefore, the living environment is a critical factor in the ability of a person at whatever level of function to live with comfort and to perform at maximum capability. The living environment in characterized not only by a physical component, but also by a social and a cultural component.

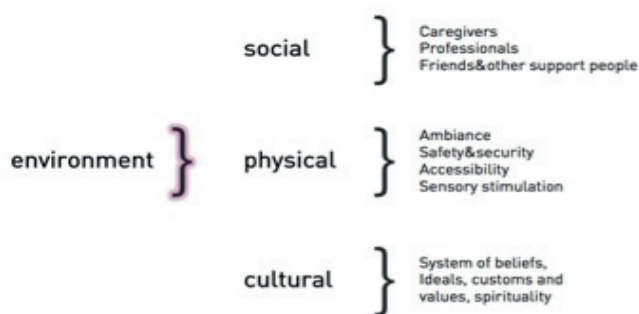


Figure 1 - Living environment around people with dementia.

Considering the physical environment it is important to take into consideration some critical elements: ambiance, safety and security of the patients, accessibility, comfort and appropriate sensory stimulation (Jones, 1998). Social environment is intended as the “relatives and significant others” dimension of the environment, including family members, caregivers, other residents, friends, etc.

The cultural aspect of the environment refers to the system of beliefs, ideals, customs and values recognized as own by each patient (Jones, 1998).

Hence, a dementia-friendly environment can be defined as “a cohesive system of support that recognises the experiences of

the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way” (Davis et al., 2009).

The physical and social environments and the structure of the organisation can work together to support the unique needs and abilities of people with dementia. A dementia-friendly environment helps people with dementia reach their full potential and does not cause needless disability. The result is quality of life for people with dementia, their families and staff.

Methods and results

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 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. We established a solid collaboration with different therapists, professionals and Alzheimer’s associations for people with dementia and their caregivers. This allowed us to conduct, through the years, different focus groups and interviews focusing on the influence of interiors for people with dementia, in order to enhance the perceived well-being, dignity and autonomy of people with dementia.

Following the onset of the disease, in the last stages of Alzheimer’s disease, a combination of factors such as severe behavioural problems and exhaustion of the primary caregiver almost always leads to a transition to a care residence, in order to provide the necessary assistance. The cognitive impairments, typical of this condition, lead to errors in one’s memory of places and a reduced ability to spontaneously adapt to new spaces.

Aim of our study was to define, in collaboration with professionals, therapists and caregivers, a set of main guidelines and a series of typologies, designed as a system of elements, considered as activators of well-being, in order to overcome the loss of the sense of belonging typical of this transition and able to provide the patients the possibility to regain autonomy, dignity and self-confidence.

Through the combination of a literature analysis (various electronic databases were searched for references, including Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed) and series of interviews conducted with therapists, professionals, and caregivers we defined six main guidelines to delineate environmental characteristics with essential quality of dignity and perceived well-being, for supportive environments tailored for people with dementia. Hereby:

Familiar environments that people with dementia recognize and understand. To be dementia-friendly, facilities need to have a home-like environment; the language of ‘home’ is very different from the language of ‘healthcare’. A home-like environment adds continuity and familiarity to everyday life, encourages continued family involvement and strengthens family and friendship ties (Brawley, 2006). It involves: personal control and decision making, individualised care, meaningful relationships, smaller scale living arrangements, greater environmental texture, personalisation of care, discrete medical support (Calkins, 2005).

Legible environments which give clues to help people with dementia understand where they are, with a clear hierarchy of spaces including private, semi-private, semi-public and public spaces. It helps residents to identify different spaces and helps protect their privacy and sense of home.

Provide safety and security while supporting independence. Daily living should be about options for people with dementia to join in and pursue their interests without taking needless risks. They should be able to move about and do things without injuring themselves. Obstacles, barriers, poor lighting, glare and hazards should be removed. (i.e. designing a *loop path* to create a whole environment where to walk, reduces stress and agitation; *open and transparent doors* increase safety, transparency improves the independence and the comfort of the patient, they already know what can be found behind a door or a drawer).

Support continuation of roles and lifestyles. People with dementia have different interests and pastimes. Designing daily life around interests and pastimes gives people pleasure and foster the use of their skills and abilities; It also adds variety and interest, and is stimulating for people with dementia, reducing boredom, anxiety, stress and frustration.

Support abilities through meaningful daily living and activities. Focus on what a person with dementia can do and encourage them to join supports their engagement in daily life. It is important to offer a variety of daily activities that people with dementia can freely decide to join in order to respect a person's decisions about their life and support them to do and say what they want, as far as they can.

Respect privacy, dignity and personal possessions. Privacy and dignity may mean being able to spend time in your room or the garden without someone watching you, or being on your own rather than with others. Personal possessions help create a familiar environment and can be a source of joy for people with dementia.

Further discussion, led us to propose a set of typologies regarding meaningful daily activities and proper sensory and therapeutic stimulations that directly affect interiors (as shown in Fig 2 and Fig. 3). There are typologies connected to a reminiscence approach (i.e. rummage box, being engaged in little house duties, personalization of self-spaces..) that tap into memories from the past and helps people with dementia feel empowered and secure in familiarity.

Other typologies, for example, include the introduction or the artificial reproduction of nature, the use of music as a mean of expression, or the recreation of common artistic activities.

Research has shown that facilitating meaningful activity for people with dementia can lead to improved 'wellbeing', a term which encompasses an individual's achievement of a satisfactory existence.

The provision of opportunities to engage with ordinary activities of daily living is often associated with the principle of home-likeness (Verbeek et al., 2009). There is moderately strong evidence for the beneficial effects of providing people with dementia with an environment that gives them this opportunity (Melin and Gotestam, 1981.; Reimer et al., 2004).

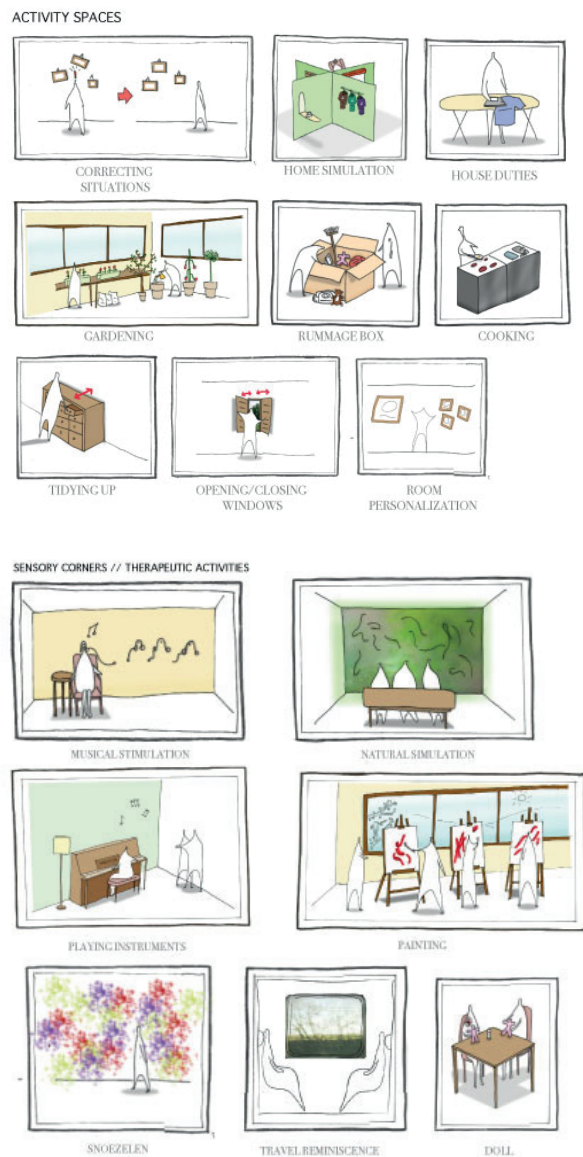


Figure 2 and Figure 3 - Environmental typologies

Discussion and conclusions

Dementia-friendly environments are created around the experience of dementia, a flexible approach to maximise people's freedom and involvement, and minimising regimentation.

It is widely recognised that a building and an environment can have a significant effect on a person with dementia. It can support them or it can hasten their deterioration. The environment can support or hinder social connection and a sense of self: it can give utmost independence or force dependency. So too can management styles, approaches to care, and connections with families and the local community. Design for people with dementia should be in line with people's social and cultural activities, their needs and capabilities, and organisational policies and procedures (Alzheimer's Association USA, 2007).

People with dementia do not experience themselves and their physical and social environments as separate. Each part, personal, physical and social, is in a lived relationship to the other. The physical and social environments of life are interlinked and equally important. They should be designed together to engage people, support independence and give meaning, comfort and safety.

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