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Content

Insights into living with dementia: Five implications for architectural design

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Abstract

Due to memory loss, most people with dementia are increasingly disorientated in space, time, and identity, which causes profound feelings of insecurity, anxiety and homelessness. The built environment is expected to hold potential for offering support in coping with the challenges resulting from disorientation. However, scientific research offers little adequate architectural design knowledge.

This paper advances three reasons for this lack of adequate architectural design knowledge: prevailing research takes an objectivist approach to value-bound matters, lacks insights into living with dementia, and hardly addresses architects' core business of form and spatial organization. Next, this article presents and discusses a novel research approach that aims to overcome these limitations, illustrated by a study on how architecture could support people with dementia in orientating in space, time, and identity. This study explored three cases from a critical realist and constructionist perspective and by means of ethnographic techniques combined with an architectural analysis.

Insights into living with dementia are summarized and five implications for architectural design are highlighted: create strategic places, articulate proper boundaries and connections, include everyday places and objects, create contemporary architectural qualities, and take into account social dynamics.

The approach taken allowed to give voice to people with dementia and provide insights into their experiences in a format that helps architects to develop affinity with their perspective. Linking insights into living with dementia with architects' core business, i.e. organization of form and space, is expected to enhance dialogues between architects and their clients, and broaden their view on possible roles of architecture in the daily lives of people with dementia.

Keywords: architecture, dementia, experience, ethnography, orientation

Introduction

When living with dementia, people have to deal with the challenges of progressive memory impairment and loss of other cognitive functions (American Psychiatric Association, 2000; Godderis, Van de Ven, & Wils, 1992; Jonker & Slaets, 2009). People with dementia are increasingly confronted with an unsettling not-knowing of, or confusion about the events and actions that led up to the present situation and about what could follow, being out of touch with people and things in the environment. Such experience of disorientation affects a person at an existential level, yet for people with dementia it is very concrete. It causes profound feelings of insecurity, anxiety, loneliness, and homelessness (Bender & Cheston, 1997; Frank, 2005; Holst, Edberg, & Hallberg, 1999; Zingmark, 2000). In current visions on housing and care for people with dementia, attention goes to supporting them by enhancing their autonomy, individuality, community integration and participation, and by offering them normal, familiar, secure, and homelike living environment (Declercq, 2000; Mens & Wagenaar, 2009).

Gerontologists, social scientists and designers recognize that the physical environment holds potential in contributing to such support (Calkins, Sanford, & Proffitt, 2001; Diaz Moore, 1999; Fleming, Crookes, & Sum, 2008; Van Audenhove et al., 2003). A fair amount of research has been conducted on architectural design for people with dementia (Day, Carreon, & Stump, 2000; Fleming et al., 2008; Mitchell et al., 2003; Price, Hermans, & Grimley, 2000). Yet, scientific evidence is only rarely adopted in architectural practice (Mens & Wagenaar, 2009, pp. 147–148). This may indicate a limited adequateness of available evidence as design knowledge. We discern three possible reasons:

1. Objectivist view on value-bound matters. Common discourses on housing and care for people with dementia address features like personalization, privacy, hominess, scope for ordinary activities and small-scaleness. To scientifically underpin the importance of such features prevailing research starts from a “traditional” worldview, which differs from the rich array of worldviews that may shape environmental design (Diaz Moore & Geboy, 2010). Most studies on design for people with dementia aim to correlate design features with dementia related disturbing behavior and other outcomes (Marquardt, Bueter, & Motzek, 2014) in an objective way, while the importance of the features mentioned above cannot be completely objectified. Indeed, they reflect human values, and more specifically, they reflect an emancipation process of people who want to be valued as individuals and social beings, continue their own life as much as possible, and take part in society (Declercq, 2000; Mens & Wagenaar, 2009; van der Kooij, 1987). Despite this protracted call for humanizing design for people with dementia, prevailing research leaves little room for people with dementia to have their voice heard and taking into account human values. Consequently, it does not provide an explanation for the phenomena studied. This challenge of theory development (like in related Evidence-Based Design research (Diaz Moore, 2011)), may hinder adoption of research findings by architects, who prefer to know why and how architectural features may affect people rather than following design standards (Gray, Gould, & Bickenbach, 2003).

2. Lack of insights into living with dementia. Prevailing studies may not strongly impact architectural design because “they may fail to uncover how and why people use spaces the way they do (Chalfont, 2005, p. 342, italics

original). They do not provide insights into living with dementia. Architects are left with very little information about experiences and daily lives of people with dementia within the environments studied. However, to draw from the potential of architecture in supporting people in their daily lives, such information is indispensable (Crilly, Maier, & Clarkson, 2008).

3. Architects' core business hardly addressed. The third reason why research outcomes are rarely adopted in architectural design practice is that they provide insufficient specification of the physical environment studied (van Hoof, Aarts, Rense, & Schoutens, 2009, p. 147) Moreover, only few studies address form and spatial organization (Marquardt et al., 2014, Table 2), and instead deal with details, so to say, like color, signage, and style of furniture. Such features play a role in architecture and how it is experienced, but they are secondary to architects' core business of organizing space and form (Ching, 1996; Unwin, 2009). The latter concerns features like enclosure, the way spaces are relating to each other and organized into a coherent whole.

In light of these reasons, we took a novel approach, aiming to give voice to people with dementia, offer architects insights into the experiences and daily lives of people with dementia, and bring the findings closer to the field of architectural design. Our study explores how architecture could support people with dementia in orientating in space, time, and identity.

Below, we describe the overall approach and methods used. Next, we summarize the insights into living with dementia and highlight five implications for architectural design. Method specifications and detailed descriptions of the results can be found in (Iris Van Steenwinkel, 2015). Finally, we discuss the potentials and limitations of the approach taken, and make suggestions for further research.

Approach and methods

On the ontological and epistemological level we respectively took a critical realist and constructionist approach. From this approach, individuals are not affected by the environment in a deterministic way (Davies, 2008, p. 19). Rather, they have particular degrees of freedom in interacting with it and can transform it and develop diverse understandings of it. This approach follows "a growing tradition" - yet hardly adopted in research on architectural design for people with dementia - "of studying interaction in dementia as meaning-based and situated in a context rather than merely as behavior caused by cognitive impairment" (Örulv, 2010, p. 26).

Theoretically, we considered phenomenology a fit perspective for this study, because in phenomenological discourses important themes of the current discourses on housing and care for people with dementia resonate.[1] Phenomenology (especially since Heidegger) questions a mere focus on functionality or rationality, denounces the sterility, uniformity, universality, loneliness, rootlessness, and alienation in modern societies, and it advocates space for intimacy, security, home, familiarity, identity, and relatedness. From this perspective, we considered being oriented as having a sense of oneself situated within a spatial, temporal and social framework (Örulv, 2010); orientating means establishing a mode of relation with the environment (Zingmark, 2000).

[1] However, we do not go along with the extol of place and identity that is often found in interpretations of Heidegger's phenomenology and his critique on modernism (Hill, 2008, p. 115), and that reflects a romanticized, nostalgic view on the architecture of home environments.

Methodologically, we conducted ethnographic case studies. The aim of coming to a rich understanding of people's everyday lives and gaining insights into their experiences is characteristic of ethnographic research, which is generally attributed to anthropology (Davies, 2008; Geertz, 1993). A case study design fosters detail, richness, and in-depth understanding (Flyvbjerg, 2011, p. 301). The first author conducted data collection and analysis, and is henceforth referred to as "the researcher".

Participants and settings

Three cases were analyzed: two in private housing about Frances (77 years old) and Mary (47), and one in Woodside Residential Care Facility, where we focused on three of its residents, Irene (88), Miriam (74), and Gertrude (87). (All names are pseudonyms.)

Data collection

Two ethnographic techniques were used: semi-structured interviews and participant observation, depending on de competences of each of the participants. Where possible (i.e., in the case of Mary and Irene) the persons with dementia themselves were interviewed. Data collected include interview audio recordings and their verbatim transcriptions, observation field notes, and pictures.

Although the focus in our study was on people with dementia, their family or professional care givers did not stay totally out of the picture. In the case study about Frances, her husband and main care giver Bob offered a rich account of the design of their house and about their life since Frances had dementia (although the focus stayed on Frances). Mary's husband, on the other hand, is present in her accounts on living with dementia, but he chose not to participate in the interviews. In Woodside, two directors were interviewed about how the architectural design had been established from their vision on care and dwelling and their user-expertise in the lives of the residents. A third director provided a questionnaire about design features that had been filled out by professional care givers during the design process. During participant observation in Woodside, the researcher took notice of care givers' actions, such as their interaction with residents and the way they furnished the dwelling unit.

Data analyses

In each case study, a textual analysis of the interviews and field notes was complemented with an architectural analysis of the setting.

As is typical for ethnographic research (Davies, 2008; Geertz, 1993) writing took a major part in the study. The researcher created several types of writings, i.e., from field notes, interview transcripts, labels, annotations, and memos to more developed writings and the final written ethnographic account. In line with a constructionist approach, we considered labelling data chunks as a means 'for thinking about if not actually organizing the data' (Davies, 2008, p. 234) that allows a reconfiguration of ideas. Creating labels was a way of searching through, examining, and getting to know the data. NVivo9 (QSR International, 2010) was used to search through data and organize them by means of coding.

Additionally, the architecture of each setting was analyzed. As a guide for this analysis we used ten themes and subthemes defined by Simon Unwin (2009). These 10 themes are: Basic elements of architecture, Modifying elements of architecture, Elements doing more than one thing, Using things that are there, Primitive place types, Architecture as making frames, Temples and cottages, Geometries of Being, Ideal geometry, Themes in spatial

organization. E.g.: the theme ‘primitive place types’ addresses those types of places that are concerned with important facets of life; ‘using things that are there’ deals with creating places by embedding buildings within existing conditions and among available environmental elements, such as the shade of a tree, the topography of the site, existing buildings, streets and squares. Because a complete explanation of these themes is beyond the scope of this article we refer to Unwin (2009). We also consulted a book by Francis Ching (Ching, 1996), which provides a catalogue, so to say, of principles of form and spatial organization.

For each case study, the architectural analysis was assembled with the textual analysis of interviews and field notes, which resulted in three ethnographic accounts (I. Van Steenwinkel, Van Audenhove, & Heylighen, 2014; Iris Van Steenwinkel, 2015; Iris Van Steenwinkel, Van Audenhove, & Heylighen, accepted). By complementing a textual analysis of the interviews and field notes with an architectural analysis of each setting, we investigated which dwelling actions – including everyday activities, social interactions, (re)furnishing, and (considerations about) moving to another living environment – were possible within the architectural context, and were performed from expertise-by-experience of living with dementia. In this way insights were gained into the experiences of people with dementia in a format that allows architects to develop affinity with their perspective.

Ethics

Each case study was approved by the Social and Societal Ethics Committee of the University of Leuven. Participants with dementia (when possible), their caregivers, and facility directors were informed about the study orally and in written form, with the opportunity of asking questions. Afterwards, they were also debriefed about the study results.

Results

Due to dementia, people have to part with several facets of their daily lives and rely on other people to take over where needed. The dementia process entails attempting to maintain, changing or discarding one’s daily life activities, changing social roles and relations with other people – which is likely to entail loss of privacy and control –, changing perspectives on life, priorities and appreciations. In addition, moving to a residential care facility entails the loss of home and related material things, living together with unknown people, and restructuring one’s daily life according to the care organization.

The case studies also showed people who wish to remain involved in daily activities in a manageable and comfortable way. They made things easier for themselves (on a physical and cognitive level), undertook alternative activities, and maintained their own routines. In times of distress, they sought comfort either in seclusion or in the proximity of others, or in secure places.

Thus, having dementia highly impacts on peoples’ daily life. Their behavior may often seem peculiar. However, our insights into their experiences suggest that their values, desires and expectations, their interaction with people and the built environment are also often not that different from people without dementia, and comprehensible given the circumstances. Consequently, the changes they would like to make to their own living environment may be similar to what other people would like to do in similar settings. Architectural features that enhance the quality of a dwelling to people in general, also count for people with dementia, and might even be more important to them. Both specifications to people with dementia and commonalities are present in the five implications for architectural design, derived from the case studies:

Create strategic places

For people who become increasingly frail, cognitively and physically, the availability of strategic places is of growing importance. Strategic places allow people to be related to the immediate surroundings in a proper way by occupying a place and by being occupied with an activity in a comfortable, more or less active way. We give two examples.

Mary was not able to do many things and needed to rest often. She spent much time in her armchair in the living room. There, she could take a nap with the chair reclined, look outside, read a magazine or watch television. In order to do so, she had objects ready-to-hand, like tissues, candy, a reading lamp, a magazine, and the TV remote control. Additionally, she had many blankets and pillows. Mary loved to wrap herself in blankets and support her body with pillows. Often one of her little dogs sat on her lap. The rest of the house had to be quiet. In this way she created a comfortable and secure environment to become at ease and recover when she had a bad day.

In Irene’s private room, the sitting area offered a strategic place, where she spent most of the day (Figure 1). She could TV, take a nap, or read a magazine. From this armchair, when the door was open, she could call a care giver passing by to help her. On a side table she had the TV remote control, a phone, tissues, a magazine, and a bottle and glass of water. Two chairs were available for when her sons visited.

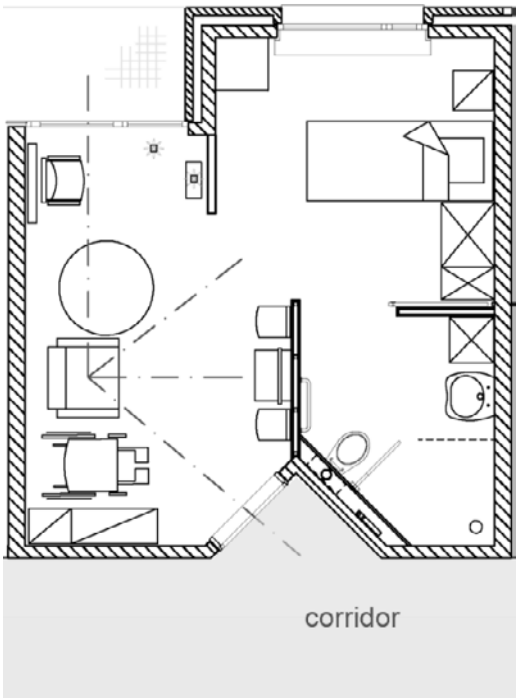

Figure 1: The armchair in Irene's private room offered her a strategic place.

A less fortunate position for Irene was, for example, in a circle with other residents in the living room. She was faced with co-residents, but she did not like them and she could hardly communicate with them. from this position, she could not watch TV or look outside. Her immobility – she sat in a wheelchair, which she could not move herself – prevented her to go elsewhere. Irene withdrew: she closed her eyes and waited until a care giver would bring her to the table for having dinner.

Articulate proper spatial relations

While strategic places concern spatial relations on the smaller scale, articulating spatial relations is also important on the larger scale, especially in the case of larger and more complex programs of residential care facilities, like Woodside. When many people and activities come together, it is important to define proper boundaries and connections, including boundaries between inside and outside a dwelling unit, transitions between private, communal and public places, and connections with the neighborhood.

Woodside's architectural design consists of a U-shaped configuration to which side wings are attached (Figure 2, a). Its main organizational feature was a U-shaped corridor that figured as a thread throughout the whole building.

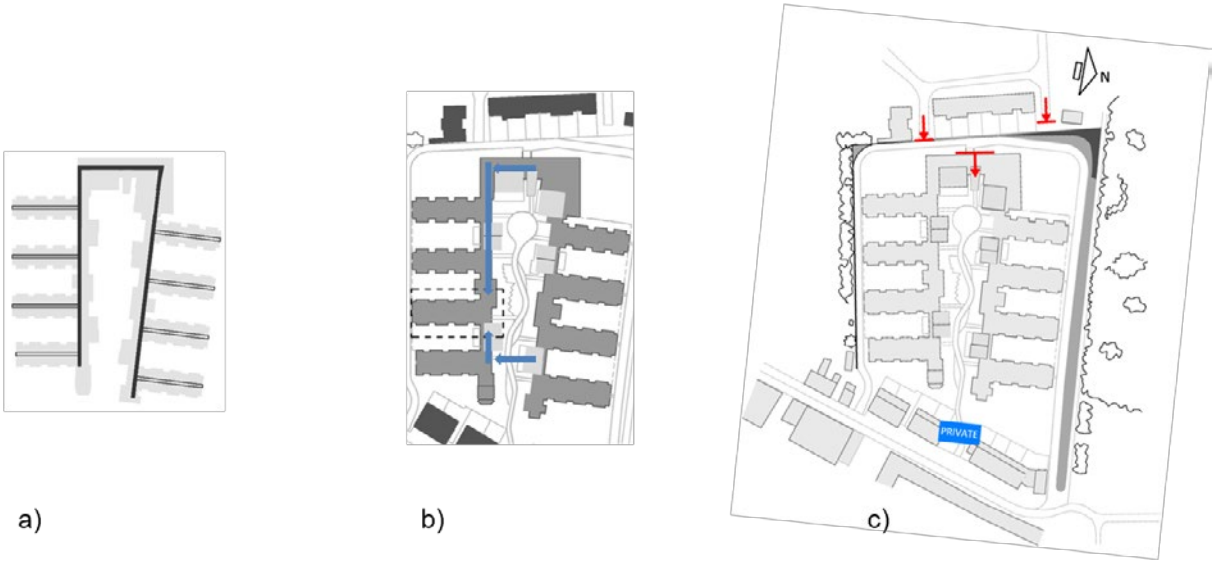

Figure 2:a) Woodside's U-shaped configuration with side wings; b) The corridor offers a rather public passage way through the different dwelling units; c) Woodside's relation to the neighborhood.

This corridor provides a convenient logistic thread, e.g., for care givers on night duty. However, because the corridor ran through all dwelling units, it nullified boundaries between them. In this way, it countered the articulation of each dwelling unit as separate spatial and social unit, and rather formed a rather public, interior passage way along private places (Figure 2, b). On the open side of the U, this configuration allowed to make a connection with the neighborhood. Yet, spatial integration is only limited, because the short segment of the U backs onto a residential area to the west of Woodside, where streets come to a dead end at the border of the site (Figure 2, c).

Because corridors are often used to spatially organize residential care facilities, it is worth considering the several desired and undesired roles they might play in the design at hand.

Include everyday places and objects

People with dementia often want to and can be involved in daily activities provided that due places and objects are available. This was particularly highlighted in the case study of Frances. Despite the difficulties Frances encountered, she continued to participate in daily acitivities in a way that was manageable for her. When her husband asked her to go for a bottle of water in the basement, e.g., she also found the clothesline. Then, she had the old tendency to check whether the clothes were dry, to put them into a basket and bring them upstairs. She also helped her husband preparing meals, and she could put some music on. Her husband had bought a CD-player that functioned according to the old logic, e.g., with a turn button for the volume instead of push button on a remote control. Thus, examples of everyday places and objects are a clothesline, a kitchen, a CD-player, also a piano corner for playing music, a garden with a garden shed, and even an outdoor café in the neighborhood for having a drink, enjoy being outdoors and enjoy social life.

The importance of meaningful occupation has already been addressed by other researchers (Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008; Zingmark, 2000, p. 24). Considering everyday activities in their architectural context highlights the importance of everyday places and objects. This is something to keep in mind when designing residential care facilities, which often have difficulties with transforming their hospital-like character into the everydayness of home environments.

Create contemporary architectural qualities

The fourth implication of the case studies for architectural design is to create architectural qualities that are often found in contemporary housing, i.e., light, roominess, relation with outdoors, and an interior with few embellishments.

This implication was highlighted in the case study about Mary. The living room in Mary's house used to be busier, more oppressive to her. When the environment became too busy for her, she could become angry or run out of the house in order to escape from it. In order to counter such oppressive feelings Mary and her husband painted the walls white to make the interior lighter. They also replaced the dark-colored, and highly decorated, antique cupboards with white and simpler cupboards, reduced the number of embellishments, and kept everything well-ordered. In this way, their house became calmer and roomier. There is more room "to breathe" as said in a colloquial sense. When it is nice weather, Mary increased this effect by opening the windows, which gave her more energy, countered oppressive feelings and helped her to become more at ease.

While Mary's behavior of becoming angry or running out of the house may seem peculiar, the changes to their house are not that peculiar. Actually, many other people may make similar changes to this type of house, i.e., a fermette (a farm-style house, cf. a cottage in England). Mary appreciated the secure character of her fermette, but also its limitations, namely a lack of light, roominess, strong relation to outdoors, and the calmness of an interior with few embellishments. These are architectural qualities that are more often found in contemporary housing. The case study about Mary suggests that people with dementia can benefit from them.

Take into account social dynamics

The fifth implication for architectural design is to take into account the social dynamics among people living together. As mentioned earlier, social relations and the social environment are likely to change due to dementia. This should be kept in mind when designing architecture.

The case study of Frances, e.g., highlights the importance of places for privacy and togetherness. The house met Frances' changing need for privacy. In the beginning, she preferred to be alone from time to time. She used the bedroom that had belonged to her oldest daughter as a place to retreat. Later, she preferred to have her husband nearby. Of course, he also wanted to continue his daily activities. The articulation of the living room into several 'corners' allowed Frances and her husband to be 'together apart', so to say. There was a piano corner, a sitting corner, a corner with a table and one with a desk. Her husband could work at his desk, while Frances watched television in the sitting corner. In this way, her husband could pursue his own activities (or some of his activities, at least) while his proximity offered Frances a feeling of security.

When many people live together, social dynamics are more complex. In addition, people in wheelchairs need more free circulation space. Also, every seating configuration should provide empty spaces where wheelchair users can take place, which causes the configuration to partly fall apart when the wheelchair users are not there. In addition, flexibility may be needed to accommodate different activities, to change the configuration when more residents come to use a wheelchair, or deal with changes in social dynamics among residents. Aspects such as these create higher challenges to the design of residential care facilities.

Discussion

This study took a novel approach to studying architectural design for people with dementia. We consider a constructionist approach more fruitful than an objectivist approach. Indeed, the experiences of people with dementia and most architectural aspects that stood out in our study can be comprehended better by viewing them within a socio-cultural context than by formulating them in terms of objective (causal) relations. Our study focused on how daily life meshes with space rather than correlating architectural design features with, e.g., dementia symptoms. In this way, our study responds to the pursuit of people with dementia to continue their own daily lives as much as possible. Moreover, it responds to the potential of architecture, which, in our view, is more likely to consist of providing a proper framework for daily activities and social interaction, rather than countering the dementia process. Therefore, one suggestion for future research on architectural design for people with dementia is to look beyond dementia, and take into account the persons studied as social beings within their cultural context. Broadening the scope in this way also offers the opportunity to draw from and further develop knowledge from beyond the specific field of architectural design for people with dementia, which still largely lacks theory development (Diaz Moore, 2011).

Conducting ethnographic case studies was useful for giving voice to people with dementia, gaining access to the private domain of their home environments, and learning from experts-by-experience. Because in-depth case studies are time consuming, however, the number of cases that could be studied is limited. Ethnographic techniques have been extensively developed within anthropology, but techniques for analyzing architecture as part of scientific research methods are still in their infancy. Exchange between (visual) anthropology and architecture might result in fruitful research methods, and continue the effort of our study to match research findings with architects' approach to designing the built environment.

While it was possible to derive five implications for architectural design, the resulting ethnographies (Iris Van Steenwinkel, 2015) are rather open-ended and descriptive. This may cause some frustration in those who expect the design solution or a set of design standards. However, it may also trigger interest from practicing architects, who are often reluctant towards design standards (Gray et al., 2003). Additionally, through their open and rich character the case studies may inform readers from different backgrounds (Flyvbjerg, 2011, p. 312), like architects and care givers, and facilitate a dialogue between these parties and with people with dementia. Such a dialogue is also facilitated by introducing architectural themes that allow to link experiences of living with dementia with architects' core business. In this way, the case studies can broaden architects' and care givers' insights into the possible roles of architecture in the daily lives of people with dementia.

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Future design of a children's hospice

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