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Chapter 23

Spatial Clues for Orientation: Architectural Design Meets People with Dementia

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23.1 Introduction

The physical environment holds great potential to improve the well-being of people with dementia when designed appropriately (Sternberg 2009, pp.166-168; Calkins et al. 2001; Van Audenhove et al. 2003; Van Audenhove et al. 2009). However, when designing environments for them, architects are faced with a lack of adequate design knowledge. At the same time, it is hypothesized that the perspectives of people with dementia have the potential to expand architects' design expertise (Zeisel 2001). Starting from this hypothesis, our research aims to gain a better understanding of the spatial experiences of people with dementia in order to expand architects' design knowledge. This paper outlines how this overall objective has become more articulated into more specific research questions through preliminary research, namely:

- by reviewing literature in the fields of anthropology, psychology, phenomenology, human geography, architectural theory, supplemented with a study of (auto)biographies of people with dementia;
- by visiting 22 residential and care environments for people with dementia in Flanders and one in the Netherlands¹;
- by talking to people with dementia, their family and professional care givers and other professionals;
- by conducting open interviews with five architects, experienced in designing residential and care environments for people with dementia, about the design strategies they used in former design projects²;

¹ Henceforth, these will be referred to as (Visits).

- by conducting voluntary work, both in a day care centre and in a residential care centre for people with dementia, one day a week during two months, to become familiar with the daily life of people with dementia.³

Secondly this paper explains which research methods are chosen to address the proposed research questions and why.

23.2 Context

Dementia is a syndrome associated with progressive memory impairment and loss of other cognitive functions (American Psychiatric Association 2000). This causes a very particular way of experiencing and negotiating space (Godderis 1992, chap.4). Family, friends and professional care givers are often faced with a lack of insights into the way people with dementia perceive the environment. It can be difficult, for example, to find out why someone unexpectedly – and seemingly without provocation – gets anxious, suspicious, or aggressive (Voluntary work), how a person can get lost in a familiar environment (Friel McGowin 1993; Visits), or why people with dementia sometimes just sit and stare for a long period of time seemingly detached from what happens around them (Boden 1998, p.71; Visits; Voluntary work).

At the same time, we expect that there is much to learn from people with dementia. As the main thread through the research conducted in our team, we consider people with different abilities and/or conditions – in this case people with dementia – as experts in perception and use of the (built) environment. They can bring forward the very different ways in which people in a diverse and aging society experience and negotiate their living environment and, thus, they can expand and refine architects' knowledge on how to design that environment.

In case of designing a living environment for people with dementia, the client often differs from the future user, *i.e.* people with dementia. If concerned with this future user, the client tries to communicate the user's needs and desires to the architect(s). Although clients often have several years of experience in caring for people with dementia and the (built) environments they live in, interviews with architects reveal that clients can articulate only few insights in the spatial needs of people with dementia. For example, clients tend to emphasize the importance of "normality" and "homeliness", characteristics which architects find too vague to work with (Interviews). On the other hand, here lies an important role for architects, since we expect that their spatial knowledge can render new insights in the daily experiences of people with dementia. In practice, however, architects often do not have or take the time to explore this in depth (Interviews).

Following from the above, we set out to explore the spatial experiences of people with dementia from an architectural point of view. Moreover, we assume that from this exploration we may also learn about the spatial experiences of people in general. Indeed, people with dementia are persons in the first place, who

² Henceforth, these will be referred to as (Interviews)

³ Henceforth, these will be referred to as (Voluntary work).

undergo a relative slow dementing process. Their often unrestrained and spontaneous behaviour (Zeisel 2001) may reveal how other people secretly or unconsciously experience a certain situation.

23.3 Research Focus

23.3.1 Orientation

Each person with dementia experiences a particular situation in a unique way. There are several types of dementia and different, but not clearly discriminated stages in the dementing process, which may succeed each other at different rates. The disease can strike people at different ages and of all kinds of backgrounds (Godderis 1992, chap.4). Since we are faced with such a great diversity of people who often live together in a group housing facility, we do not intend to focus on a delimited target group, *e.g.* women with early-onset Alzheimer's. Instead we focus on one important aspect which all people with dementia have in common, *i.e.* disorientation in time, space and identity, due to memory loss (Godderis 1992, chap.4).

In the experience of people with dementia, their sense of time may become upset or even lost. Now and then they do not know which (time of the) day or year it is, like Christine Boden, a women with early-onset Alzheimer, witnessed:

"I don't seem to have space in my brain for that sense of 'Thursday-ness' (or whatever day it might happen to be), or 'April-ness' or '1981-ness'."

(Boden 1998, p.62)

One of the possible consequences is that their (daily) routines may get mixed up. A person with dementia may, for example, want to go shopping in the middle of the night (Braam 2005, p.14). Something similar may happen concerning orientation in space. A person with dementia may get lost in space and be baffled when, in the morning, "everything seems new" (Braam 2005, p.62). Additionally, people with dementia show a particular way of knowing people, as Christine Bryden described:

"You see, I did not know their name, whether they were married or not, whether they had children, if they had a job. I knew nothing about them, nothing in the 'normal' sense of how you know people and recognise them. The way I know people is in a spiritual and emotional way. There's a knowing of who a person really is right at their core. But I have no idea who they are, in terms of who they are meant to be in your world, of cognition and action, and labels and achievement."

(Bryden 2005, p.110)

The fact that people with dementia sometimes are disoriented in time as well in space and identity may not be a surprise, since - according to several authors - time, space and identity are interrelated dimensions. Edward Hall (1969) touched upon the idea that the differentiation of time and space as two distinct dimensions is only an arbitrary one, since in lived experiences they are actually "*inextricably*

bound up in each other” (Hall 1969, p.92). Christian Norberg-Schulz (Norberg-Schulz 1971, p.10) also explained that “*perception mediates a world which could also very well be described as ‘events in a four-dimensional space-time’.*”

Moreover, Hall (1969) points out that space and thus time, are also related to identity:

“Man’s sense of space is closely related to his sense of self, which is in an intimate transaction with his environment. Man can be viewed as having visual, kinesthetic, tactile, and thermal aspects of his self which may be either inhibited or encouraged to develop by his environment. “

(Hall 1969, p.63)

Because of these interrelations we henceforth use the term ‘orientation in time-space-identity’. Thus, we do not consider orientation merely as a means for way-finding, *i.e.* knowing how to go from one geographical location to another. We use ‘orientation’ in a broad sense of the word. Including identity as one dimension of orientation, we also consider questions like: *Can I be myself here? Does this place detaches me from who I am, my past and my hoped-for future? Can I find a place for my own? Do I feel at home in this place?* In fact, ‘home’ is a special reference point in all dimensions of orientation, *i.e.* time, space and identity. Indeed, one’s home is a particular meaningful place (Madanipour 2003, chap.3; Tuan 1977; Norberg-Schulz 1971, pp.19, 34) and it has an important role in colouring one’s identity (Madanipour 2003, chap.3; Tuan 1977, p.166; Chapman 2006). Yi-Fu Tuan (1977, p.127) elicits the time dimension of home by writing that “*in an ideal sense home lies at the center of one’s life, and center (we have seen) connotes origin and beginning.*”

Exploring how an entity like home carries a sense of time, space and identity may reveal how, for a particular person, it can serve as a point of reference for orientation. The particular experiences of people with dementia may elicit new insights, or vice versa, such an exploration may reveal why people with dementia sometimes can (not) orient themselves. After all, people with dementia not seldom express the desire to go home, even when in fact they are at the location where they currently live (Visits; Voluntary work).

Based on these considerations, we delineate our research question a little further: *How can the physical environment afford or impede a person to orient oneself in time-space-identity?* In other words: *How can physical entities carry a sense of time, space and identity, through which they can be points of reference for orientation?* Hence, we look at how one dimension of orientation, *i.e.* the physical entities of space, contributes or hinders the overall orientation, *i.e.* orientation in time-space-identity.

23.3.2 Movement

If we take our research question a step further, the question arises: How does a person develop a sense of time, space and identity? Literature study revealed that ‘movement’ is a very important, if not an essential key to the development of a

sense of time, space, and identity. We found strong indications that a focus on movements may yield an understanding of the lived experiences of people with dementia.

Tim Ingold (2000, p.203) contends that “*movement is the very essence of perception*” and Tuan (1977) explains the role of movement in orientation in time and space (and therefore also in identity) by writing:

“We can have sense of space because we can move and of time because, as biological beings, we undergo recurrent phases of tension and ease. The movement that gives us a sense of space itself is the resolution of tension. When we stretch our limbs we experience space and time simultaneously – space as the sphere of freedom from physical constraint and time as duration in which tension is followed by ease.”

(Tuan 1977, p.118)

Movements can be of different kinds and of different scales. For example, the possible bodily movements in a room influence how a person experiences that room. At a bigger scale, the daily commuting between home and office has a part in the ‘image’ a person develops of one’s living environment. Cycles like night and day or the seasons are also movements, which “*are embodied, incorporated in to our very constitution as biological organisms*” (Ingold 2000, p.200). Such movements contribute to orientation. Being out of tune with them may be stressful and/or confusing. For example, when a person with dementia gets up in the middle of the night and thinks he/she needs to buy some food, but finds all stores closed (Braam 2005, p.14), or when, in the late afternoon, a person feels it is time to go home, but is hindered by carers or locked doors (Voluntary work). Movements, sequences of tension and ease, should not only be considered as physical, but also cognitive and emotional, e.g. being ‘moved’ by a(n emotionally charged) conversation with friends or family versus a peaceful time on your own.

Piaget and Inhelder (1971) describe that a comprehension of the physical environment evolves from internalized actions rather than from mental images. We know things not only by using our brain, but also by incorporating the movements of other parts of our body. The following quote from a person with dementia illustrates that his hands ‘know’ his PIN code when standing in front of the keyboard, while his head could not remember it in advance:

“En route, I try to remember the PIN code. [...] When I stand in front of the desk, I know.”

(Braam 2005, p.15)

The development of a sense of time also requires movements, and more precisely the co-ordination of moving entities (like your own body, that of others, or objects) at different velocities (Piaget 1969).

Norberg-Schulz (1971) – drawing on the work of Otto Friedrich Bollnow (1963) – describes the importance of movement to human beings as follows:

“How we get from one place to another is a basic aspect of man’s being in the world. [...] Life itself can be understood as movement from one condition to another. This movement is incessant and continuous, but it has rhythm and form. [...] Furthermore, man is part of a system of natural rhythms, such as night and day, the change of seasons, and his own ‘ages’.

(Norberg-Schulz 1971, p.34)

Therefore, movement seems to be a basic aspect of a person's well-being or ill-being. In the context of care for people with dementia we thus consider it valuable to investigate the 'movements' of people with dementia through time, space and identity and the way their built environment may reveal or hide cycles like night and day or possible other events that mark particular points in time.

Consequently, we reformulate our research question as follows: *How can the physical environment as a motor medium afford or impede a person's orientation in time-space-identity?* Setting out our exploration by considering the experiences of people with dementia raises several sub-questions: *Which activities, pauses, events make up or are left out of the 'timescape'⁴ of a person with dementia, supporting or hindering orientation in time? Which physical features induce movements that constitute 'the image' of the environment⁵ for people with dementia and, therefore, operate as clues for orientation in space? How can the physical environment afford a place for one's own affording orientation in one's own identity? And how can the physical environment afford the feeling of coming or being home, supporting orientation in time-space-identity?*

23.4 Methodological Issues

Addressing the proposed research questions requires considering both the physical environment and people living with dementia and these two in relation to each other. We plan to tackle the research questions in two ways: firstly, through ethnographic research that is a combination of an analysis of the physical environment, interviews and observations, and secondly, through 'research by design'.

23.4.1 Ethnographical Research

Studies on people with dementia typically focus on one particular housing context, *e.g.* either large scale residential settings (nursing homes or Alzheimer's special care units) (Sloane et al. 1998), or small group living facilities (Van Audenhove et al. 2003; Elmståhl et al. 1997), which limits the transferability of the findings to other contexts. By contrast, our research project aims to study the spatial experience of people with dementia across different contexts and housing schemes. Possibly, these differences can even accentuate how people with dementia can (not) orient themselves in time-space-identity. We take into account persons at their homes – like individual houses, apartments, service flats – and

⁴ By analogy with 'landscape'. Ingold (Ingold 2000, chap.11) uses the term 'taskscape', yet we prefer 'timescape' because it refers more explicitly to the dimension of time.

⁵ By analogy with 'the image of the city', described by Kevin Lynch (1960), though we will not limit our study to only visual aspects of space.

persons in group housing facilities – like small group living facilities or traditional large-scale nursing homes. These settings are analyzed in terms of five spatial aspects:

- spatial articulation, which deals with social aspects of space, like being (semi-)private or public;
- enclosure, which deals with how spaces are delineated by physical entities like walls, windows, level changes, furniture, signs, etc.;
- sensory qualities, like colour, sound, smell, warmth, texture, etc.;
- materials, which will be analyzed not only for their sensory qualities but also for the meanings they may evoke;
- form, measurements and proportions of rooms, openings in rooms, outdoor places, objects, etc.

The list is based on spatial aspects described by Ola Nylander (1999), which have been modified in a study on living environments for older people (without dementia) (Author 1, 2010). We do not consider this list of spatial aspects fixed, but allow it to be modified during the research if necessary.

The spatial analysis is complemented with both interviews and observations. Through interviews we try to explore how entities in a person's physical environment carry a sense of time, space and identity. All too often, cognitive impairment is assumed to obliterate the ability of people to evaluate and share their evaluations with others (Cotrell & Schulz 1993). Interviewing people with dementia may be challenging, but it is not impossible. In fact it has been done many times before. Louise Nygård (2006) draws on more than 10 years of ethnographic research to reflect on and make suggestions for how the scientific exploration of the experiences of people with dementia may be undertaken. She suggests that "*a combination of qualitative observations and adapted interviews may make it possible for people with dementia to participate as research informants.*" (Nygård 2006, p.101)

Interviews should be adapted to the participant's capacities, in terms of formulating questions and interview duration (Nygård 2006, pp.103, 108). Therefore, the researcher must be very flexible. Number, length, focus and context of interviews may be different with every participant (Nygård 2006, p.103). In our research, the number of interview participants will be decided based on a pilot study.

Observations will offer extra material on the daily life and experiences of people with dementia by mapping out (*i.e.* making notes and drawings) the 'movements' by persons with dementia and their environment. These 'maps' are made over a period of time and include accounts of what people do and say, when they use a space, where they sit, the way they walk, etc.

23.4.2 Research by Design

In a second part, we will confront the perspective and appreciation of people with dementia related to the physical environment with the perspective of architects, and

in particular with their designerly ways of knowing (Cross 2006). The approach used in this work package shows similarities with research by design in the sense that the activity of designing is used as a way to generate knowledge. However, unlike in typical instances of research by design (Pedgley 2007), the researcher will not perform this design activity herself, but will call in others' design activities. We plan to involve architects in the research process in two ways:

- by challenging architects to freely (*i.e.* without any precondition) reconsider (the design of) space from the perspective of people with dementia, introduced through information from the ethnographic fieldwork;
- by introducing insights from the ethnographic fieldwork as input for a real-world design assignment.

In this way we call in architects' expertise to tackle our research questions. The thoughts of these architects are expected not only to offer a glimpse of future possibilities, were architectural design to meet people with dementia, but also to further our understanding of the spatial experience of people with (and without) dementia. Unlike scientists who set out specifically to study a problem/issue, architects (like other designers) learn about the nature of the problem/issue largely as a result of trying out solutions (Lawson 1998; Cross 2006).

Moreover, the design outcomes of both approaches are presented to people with dementia, their relatives and/or care givers. Indeed, former research projects have shown that the evaluation of (unrealized) designs by possible users can elicit additional insights in their experiences, like in research projects dealing with the experiences of visually impaired people (Vermeersch et al. 2011).

23.5 Conclusions

The general aim of our research is to better understand the spatial experiences of people with dementia, firstly because the physical environment holds great potential to improve their well-being, and secondly because of the assumption that their perspective could expand architects' design expertise.

Based on preliminary research we figured out that – beside space – dimensions of time and identity should be included in the research, since time, space and identity are inextricably bound up with each other. Moreover, people with dementia, because of their memory impairments, find difficulties in orientating in all three dimensions. A literature study elicited useful concepts and theories to explore the experiences of people with dementia. Most importantly, many authors consider movement being essential to perception. That is why we focus on how the physical environment as a motor medium affords or impedes people to orientate themselves in time-space-identity.

Our research covers several (if not all) types of dementia, several types of housing facilities, and people with different backgrounds. In this way, insights can be transferred to different contexts. Nevertheless, we are aware that important factors, *e.g.* socio-cultural background, have a part in how people negotiate space.

For that reason material from the fieldwork should be interpreted deliberately with regard to the transferability of insights to different contexts.

We hope to add new insights on important aspects of how people with frailty and cognitive impairment negotiate space and that our results will help designers to improve the orientation and wellbeing of people with dementia.

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