Mary's Little Worlds: Changing Person-Space Relationships When Living With Dementia

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Abstract

With the case study presented in this article, we explore how people with dementia experience and use their environment to expand our understanding of how architectural environments can improve their well-being. We focus on how relationships between people and spaces change for people with dementia. Using a qualitative analysis of three in-depth interviews with a woman who is living with dementia, we obtained an insider's perspective and a rich account of the changes in her life, including her lived experiences and interventions in her home environment. We contend that looking at people with dementia in relation to and interaction with their environment, combined with an explorative research approach, might reveal multiple and innovative possibilities in designing for people with dementia. To that end, and to build on existing architectural expertise, we suggest focusing on architectural ordering principles across different cases.

An anthropology whose objects are no longer conceived as automatically and naturally anchored in space will need to pay particular attention to the way spaces and places are made, imagined, contested, and enforced (Gupta & Ferguson, 2007, p. 344).

With this case study, which is part of a larger research project, we aim to gain a more articulate understanding of how people with dementia experience and use space to expand architects' ability to design environments that improve a person's well-being. We focus on one important challenge that all people with dementia face, namely the disorientation in time, space and identity caused by memory loss (Godderis, 1992). We interpret time, space and identity as interrelated dimensions, as do many other authors, including Hall (1969), Bollnow (2011), Norberg-Schulz (1971), Bloomer and Moore (1977), Tuan (1977), Piaget (1969), Lynch (2000) and Ingold (2000). We have elaborated on this idea elsewhere (Van Steenwinkel, Van Audenhove & Heylighen, 2012).

Because of these interrelations, the term orientation is not merely used as a concept within geographical navigation. By including identity as a dimension of orientation, we also address questions such as: (a) can I be myself here; (b) does this place detach me from who I am, or from my past and my hoped-for future; (c) can I find a place of my own; and, (d) do I feel at home in this place (Van Steenwinkel et al., 2012). Through an exploration of how time, space, and identity are interrelated, we provide a more articulate understanding of how people in general experience and use their environment. We assume that the condition of living with dementia highlights the existence of these relationships because they are being contested by the disease.

In this case study, we focus on one component of time-space-identity: the interconnection between space and identity. We examine one person's interactions within a specific architectural and social context, to understand how these interactions contribute to experience of self and

environment. Based on the perspective of a woman with early-onset dementia—identified as Mary in this article—we explore how the sense of self is altered because dementia changes one's relationship with space. As a consequence of this changing person-space relationship, Mary became less, differently, and not "automatically," anchored in space.

In the first section of the article we explain our research method. Subsequently, we describe some important changes that took place in Mary's life as a result of her dementia and how she dealt with them, contested them, and how she reinforced, made, and imagined places. We conclude with a discussion of our findings about the experience and use of space, which we then link to the architectural interventions that made it easier for Mary to mediate her environment. Based on these findings, we subsequently suggest focusing on architectural ordering principles to study the potential for architecture to support people with dementia across different cases. Finally, we also address methodological issues and suggest possible directions for future research.

Method

Because our aim is not to prove or predict, but to articulate an in-depth understanding of person-space relationships, the research consists of a case narrative with a constructivist approach. We adopt an open and exploratory approach because we believe that this can reveal multiple and innovative possibilities to design for people with dementia. This multiplicity of possibilities is important, because we think that there is not one perfect or correct design for people with (and without) dementia, "but rather a multiplicity of appropriate responses which, when thoughtfully combined, will make the most appropriate model for that specific time, in that specific place" (Feddersen & Lüdtke, 2009, p. 30). The first author conducted the data collection and analysis and will henceforth be referred to as "the researcher."

Data Collection

On November 21, 2011, Mary appeared on a talk show on television. Via the television station, we contacted Mary by e-mail to ask whether she would like to participate in a series of interviews.[1] The researcher visited her three times[2] to conduct semistructured interviews with open questions, which lasted about 1 to 1.5 hours and were audio-recorded. Mary's husband was not involved in the interviews. Mary showed the researcher around the house and explained how she and her husband had furnished it and why. Pictures and a plan of the house were used as mnemonic devices.

Mary had also written about her experiences and feelings in poems and short stories. During the second and third interviews, the researcher used some of these writings to initiate conversations with Mary about her experiences and feelings. During these conversations, they discussed how her life had changed since she had developed dementia, how dementia influenced her daily activities, how she attempted to make herself feel comfortable, and so forth.

Data Analysis

After each interview, the researcher transcribed the audio-recording,[3] and read this transcript before the subsequent interview, making notes in the margin. These notes contained both verbatim extracts from the transcript which made the long interviews more workable, and the researcher's thoughts on it. This was the first step in trying to understand Mary's lived world. From this exploration, new questions arose for the next interview. The researcher also wrote down what she should pay attention to during the next visit, for instance "take a closer look at and take pictures of the furniture."

After completing the three interviews, the researcher repeated the entire process of transcript-reading and note-making and listed topics that were then used as codes in NVivo 9 (QSR International, 2010). These codes were either exact words or (parts of) sentences from the transcripts, or were very close to the actual text, except for the code "furnishings (interior and

exterior)." This code was added to incorporate architectural interventions in Mary's home into the analysis. Codes refer to feelings, values or beliefs, objects, places, and architectural aspects.

The codes were meant to help the researchers gain insight into Mary's experiences and the potential role architectural elements play in these. All the fragments of text connected to different codes (i.e., nodes) were printed. A single piece of text could be linked to different codes. This increased the amount of text to be analyzed, but it also allowed the same text to be analyzed with different foci. In an additional round of analysis, new codes were highlighted (and so on). Thus the researcher examined the three transcripts as a whole, looking for connections to develop an understanding of Mary's lived world. The codes were not used to structure this article. The subheadings further on in this article – Contesting and Reinforcing, Making and Imagining – reflect our focus on the way person-space relationships are 'constructed' within daily practices and are challenged by dementia.

Finally, the researcher e-mailed the resulting article to Mary and her husband, explicitly asking them to report on anything that they found of concern, oversimplified, or incorrect. The researcher also proposed to come to their house to explain and discuss the article in person. Mary and her husband responded that they had read the whole text and had no comments. They gave their consent to publish it without further meetings or interviews.

Methodological Issues

In our analysis, we considered Mary an expert by experience. The use of interviews with open questions was deemed the best method for consulting with her expertise. Mary can also be considered as the author of her own life story. In a more or less conscious way, she developed a scenario and tried to link fragments into a whole (Bleyen & Van Molle, 2012). This was not the first time that she expressed her experiences. She had already written some poems and short stories. Mary was also very engaged in bringing notice to the needs of people with dementia,

especially people with early-onset dementia. She had presented her views and experiences on television, had been interviewed in magazines, had spoken at symposia, and so forth. What motivated Mary to participate in this study was the opportunity to reach a broader audience.

This illustrates that the resulting narrative is intersubjective and shaped by the context in which it was made (Bleyen & Van Molle, 2012). However, "the intersubjective relationships that color the narrative are not always manifest: often it is not clear who is talking" (Bleyen & Van Molle, 2012, p. 54, authors' translation). We can speak of a shared authority (Michael Frisch cited in Bleyen & Van Molle, 2012), or an assemblage of the interviewer's voice with the voice of the narrator and others. Although the text of this article stays close to the transcripts, Mary's voice does not directly reach the reader. During data analysis, the authority shifts to the researcher, because the researcher makes the narratives more compact and adds more abstract passages by summarizing, using quotes that cover larger parts, and providing explanatory concepts to clarify the insights they convey (Bleyen & Van Molle, 2012). Because of this shared authority, this article only contains references to a specific interview if quotes or "special" words from the transcript are maintained (although translated to English).

How Mary's Relationship with her Environment Changed

Mist

"Because you have the disease, several things are taken away from you and you will never get them back" (interview 2). When Mary was diagnosed with dementia, a new life began for her. This new life lacked some things she had before, such as a job, colleagues, jogging, driving a car, and acting independently. Sometimes she felt fine; she felt able to deal with life, to have clear insights. Sometimes she even got the impression that she was recovering from the disease, even though she knew that is impossible. At other times, Mary noticed that aspects of her life were disappearing piece by piece. Then she was confronted with reality and "the curtains . . . closed

again" (interview 2). At such moments memories and actions (the way to do things) became vague; they "disappear in the mist, they are gone" (interview 2).

Mary gave examples of the manifestation of this "mist" (interview 2). In one instance, there was a pen on the table in front of her and she wanted to write. However, she was not aware that she could use the pen in front of her to do that. Her husband said, "It is right there, take it!" However, it was not until he put the pen in her hand that she knew what to do. Another time she put her left shoe on her right foot and vice versa. She did not notice the mistake herself. Only when she complained about sore feet did her husband notice what was wrong. After that day, Mary paid extra attention to putting on her shoes correctly, because she no longer did it "automatically" (interview 2). "Her automatic pilot has long disappeared" (poem Mary).

Mary used mist as a metaphor for having no insight. When she had a bad day, she could offer no insight in conversations and had no insight into actions, in response to television programs, and so forth. She described it as being surrounded by a thick mist; although you barely see anything in front of you, you know there is something only a short distance away, but you do not know what it is. You do not understand and have no insight.

This metaphor is so strong that it is almost real. Mary and her husband actually bought a bigger television screen because Mary could not see well.

> We bought a bigger one. I did not see the smaller one anymore. That is, uh, things that I, I need a big television. . . . I cannot follow movies and things like that anymore, but I still watch little, little programs and things like that . . . . I cannot understand the English anymore and the subtitles are gone too quickly. (interview 1)

Mary's vision was deteriorating, and, at the same time, it also became more difficult to cognitively comprehend images and conversations. Mary offered the example of television programs, stating that she could only watch "simple" programs (interview 1).

Dust

Because of her loss of insight, Mary needed extra help with daily activities. Several days a week a household assistant came to her house. However, in the beginning Mary did not feel comfortable with the presence of "strangers" (interview 2) in her house. Because she felt like an independent woman, she got the impression that the assistants were meddling in her affairs and that everyone was whispering about her in conversations in which she could not participate. Mary became rather suspicious and withdrawn, not willing "to fall into the hands of other people" and not always able to get more involved (interview 2).

"A little world with big things, in all of that I am only dust. Invisible for many, precious for others" (poem Mary). Many things seemed to pass her by; Mary could watch from the sidelines but was unable to participate, which left her feeling lonely. Because many things in her environment started to become fleeting, she began to feel more and more like dust herself. Increased difficulties in taking part in daily activities changed her relationship with space. In the beginning, Mary found it difficult to cope with these changes. This is reflected in her writing,

> I used to write a chapter as if it was about someone else. . . . Now I don't do that anymore. All of my latest poems are written in the first person. In the beginning I couldn't do that. (interview 2)

This shift to the first person might express her recognition of a new identity.

When Important Becomes Unimportant and Vice Versa

Mary lost touch with certain things, but the life she used to have—with her job, family, household chores, friends and so forth–also had a certain fleeting quality. Her previous life had content, but the content was totally different from her life with dementia. Although some things disappeared "in the mist" after Mary developed dementia, other "things that didn't exist before" became apparent to her (poem Mary).

Mary started to pay more attention to what she called "little things" (interview 2), such as a hug from her husband, a bird's nest or a beautiful flower: "How beautiful is this flower! Look at it! Such a fine structure, how it is put together!" (interview 2). "Now the garden is important, a piece of oneself" (poem Mary). Mary spent ample time in the garden, observing nature's cycles and details. For example, she watched how the plants and flowers grew and bloomed, and anticipated a particular bird's nests and eggs in the spring. In the garden, she was able to calm down. She seemed to have a strong connection to her garden. She expressed this as "becoming one" with the garden (interview 2).

This shift in what is important and what is not also affected other aspects of her life. For instance, an article in the newspaper about a young person who was killed in an accident moved her much more than it would have in the past. Thus, although some things were not part of her life anymore, other things had become more important to her.

How Mary Deals with Changing Relationships

Contesting and Reinforcing

Clearly, Mary was aware of important changes in her life. She also knew that she might not reach the age of sixty. She had a clear view of how she wanted to spend the rest of her life. She and her husband have arranged their life in accordance with that plan, even if that implied contesting "normal" values and life goals. For example, in Belgium, it is common to save money over a long period of time to make (major) changes to one's house or to buy a bigger house. In spite of what

their friends thought about this, Mary and her husband were not saving a large amount of money for later and they did not make extra efforts to advance in their careers. Their focus had shifted to the very near future. "It's now that we should live. . . . I shouldn't lay out the garden patio in ten years, you know. If I [ever] want to enjoy it, I should do it now" (interview 3).

"I really want a good quality of life and I don't want to spend my time on this and that; I really want to do the things I like to do" (interview 1). This was a shifting of priorities, not a matter of laziness. Mary was very motivated to do many things: "My mind is set to do a thousand things. . . . but I don't have the strength"(interview 3). Both physically and cognitively, she did not have the strength to accomplish certain tasks. Often she also needed more time to complete them. Even simple tasks, like getting up in the morning, using the bathroom, getting dressed, and having breakfast, required more time. Over and over again, her husband had to tell her what to do.

Even when she was able to finish a task, she could still get frustrated, angry or stressed, because it was too demanding. For example, she might have to redo things many times because of "stupid mistakes" (interview 3). Moreover, when she had too much on her mind or when there was too much bustle in the house, "a switch" turned in her head and she was unable to switch it back (interview 2). She would become nervous and tense, and might even get angry or start to cry. Sometimes she even ran out of the house. When she confronted the little gate—which separated the front yard from the street and was easy to open—she sometimes realized that it was best not to go any further. In the worst case, her cognitive abilities would diminish drastically until she became "like a plant" (interview 3). Whenever that happened, she needed several days or weeks to recover.

Having dementia challenged Mary's previously experienced relationship with space. Doing only the things she liked was her way of reinforcing this relationship. She needed to let

"the bustle of the world" pass her by (interview 2) to live to her potential and enjoy the time she had left. At the same time, she reestablished a connection with her environment via other people. Most of the household chores were done by a household assistant and her husband, in exactly the way Mary wanted them to be done.

> If they put the laundry in the wrong place, I worry about that, or if those towels aren't correctly folded and things like that, I worry about that. I don't know why. I know it's silly . . . but I would get them all out and fold them again and put them back. (interview 1)

In the past, her behavior had sometimes led to tension or arguments between Mary and her husband or household assistants, but they generally tried to be understanding and attempted to do things Mary's way. Mary was not able to do the laundry herself (not without any difficulty, frustration or exhaustion), so she let others do it for her exactly the way she would have done it. Mary was letting go of many things but, at the same time, she tried to hold on to some other things. To do this, she needed other people to take over the things that were too demanding for her, to help her to keep the connection with her environment as strong as possible.

Making

Mary's vision of life—partly letting go, partly holding on—was also reflected in the way she and her husband furnished and arranged the interior of their home. They made efforts to establish order, through the creation of "little worlds." They also made changes that allowed the home to feel roomier without major additions or renovations.

Making peaceful, little worlds. First, we discuss how Mary tried to hold on, or maintain agency. Apart from demanding that things were done her way, Mary also claimed certain spaces and belongings in the house. For instance, in the kitchen, Mary had her own cupboard in which her husband and the household assistant always put her things away in the same place: her corn

flakes; her water glass; her wine glass; her jar; and so forth. "It is all mine and no one should touch it" (interview 1). Similarly, she had her own chair at the dining table. In the sitting area, there was a place that she called her own environment, which consisted of her armchair, which was placed next to her husband's, with her blankets, her basket, her coffee table, her books, her drinks and her candy within reach. In the garden, there was a particular place where she often sat during summer. She could not tolerate anyone else—not even her husband—sitting in her chair or eating her candy without asking, even though she was aware that this might be ridiculous. In the bathroom and bedroom, her belongings were also clearly separated from her husband's.

According to Mary, everything was well ordered. Her belongings were kept separate from her husband's belongings, always arranged in the same location and some things sorted by color. If someone would have displaced her belongings, she would not have been able find them. She would have been confused.

This makes sense if we recall that Mary was trying to hold on to her environment via other people. Her husband and household assistants, who knew Mary well, helped her to get around in the house by keeping a limited number of things that Mary often needed in one particular place. That way she did not need to remember how every kitchen cupboard was organized, because if she just opened that one particular cupboard, she would probably have found what she was looking for. Everything else could disappear in the mist. However, if someone took away one of her things, she would not know what to do. Her cupboard was a "little world" she could cope with; beyond it, her insight was uncertain. In a similar way, Mary also held on to a limited number of places in the house, such as her chair at the dining table and her armchair in the sitting area. There was a strong connection between her and those places; they served as "little worlds" within the house.

Because of her dementia, Mary's energy was consumed by activities of daily life. To recover, Mary slept a lot, especially when she was "not feeling well" (interview 1). She often slept in the armchair in the living room or in a small bedroom. In both places, she had plenty of blankets in which she wrapped herself, as well as pillows and teddy bears to support her body. Often, one of the dogs lay on her lap. She found this warm and cozy. She did not previously have this habit and was unable to explain why she liked it so much, but she felt that she really needed it. Even when she left the house, she took a blanket and a teddy with her. In the evening, Mary and her husband also tried to create a cozy environment by drawing the curtains, closing the shutters, lighting many candles and putting their armchairs closer together.

Mary and her husband were intuitively arranging their environment to feel comfortable. They might not have been able to explain it, but their actions make sense in light of the previously mentioned changes in Mary's perception. How can you fall asleep when your surroundings are illegible—as if covered by a thick mist—and therefore stressful or frightening? What if the mist is so close that you are out of touch with your own skin? In that case wrapping yourself tightly with blankets and supporting your body with pillows, teddies and a dog might offer you the extra stimuli you need to stay aware of your own body. This technique is more and more used, with weighted or ball blankets and pillows or a dynamic bed orthesis, to treat people in very late-stage dementia. It helps them relax their muscles, which otherwise would be cramped, longing for some stimuli from the outside world (J. De Clercq, personal communication, October 13, 2011)[4].

Supporting your body with blankets, pillows, and so forth is a way of holding on to your very close surroundings, that is, your own body and its edge, your skin. Even people who are not experiencing an extreme situation such as dementia can enjoy the comforting effect of a soft blanket, pillow or hug. Additionally, drawing the curtains, closing the shutters, and lighting

candles can have the effect of creating twilight in your living room, as described by Bollnow (2011):

> The reduction of the world to a narrower region through the falling away of the more distant zones is felt here too, but to the extent to which these disappear in the darkness, there also disappears with them the hostile menace of the world, while the narrower surrounding area, now no longer threatened by outside forces is perceived as a sheltering cover, one which practically belongs to us. It is a world falling asleep, which invites man too to fall asleep. (p. 210)

Remarkably, the images of mist and twilight are very similar, although these phenomena could have opposite effects. Both mist and twilight create a small world around a person. The difference lies in the character of the surroundings: an oppressive and terrifying area versus a peaceful, sheltering cover. We think the metaphors of mist and twilight help paint a clear picture of Mary's experiences and feelings.

Making room. Mary and her husband also made more permanent changes to the interior of their house. Their living room used to be "busier," partly because of the dark and richly decorated antique furniture. They wanted to furnish it in a way that would make it feel both calmer and more spacious. To accomplish this, they replaced the antique furniture with white, contemporary furniture. This made it easier for the household assistant to clean and for Mary to walk around and, perhaps in the future, to navigate in a wheelchair. They also painted the walls white. Mary was convinced that this light and roomy space gave her more energy. In the summertime, she often opened the windows to intensify this effect. In a small and cramped house she would not have felt well. They also replaced the sofa with two armchairs. Mary spent a lot of time in her armchair, so it was important to her that it be relaxing and roomy, a chair in which she

could sit at ease, with her legs lifted and her neck supported. For the dining table, they bought new chairs with high backs. These were easier for Mary to sit on because of her diminishing muscle strength.

Some adaptations were also made to the bathroom. They installed a special hairdryer that hangs on the wall, like in a swimming pool locker room. Mary no longer had the strength to hold a regular hair dryer. With this new one, she only needed to press a button and stand underneath it to dry her hair. When feeling oppressed, Mary often took a bath. Her husband would put some music on and Mary could stay in the bath for an hour and a half to relax. Next to the bath there was a mat, a stool and a handrail to make it easier to step in and out. As long as she was able to manage, she preferred to keep the bath, because it was so relaxing. However, in the future, they hoped to install a shower for its ease of use as Mary's mobility became more limited.

The house contained two bedrooms, a small one and a large one. The small bedroom included a desk, two little cupboards, a bed and a night table. At the desk, Mary's husband provided one button to turn on and off the computer, printer and desk lamp. On the night table, there was a light and a radio-cd player, which could both be turned on or off with the same switch (a red button on a multiple socket). There was also a small white cup for Mary's daily medication and a bottle of water. On the lower shelf of the night table, she kept some books and a remote control for the television against the wall at the foot of the bed. Mary used most of those objects on a daily basis. Above the night table, a headset was hanging from a little hook, and compact disks, teddy bears, and a box were placed on shelves against the wall. Next to it were two pillows. "There are only a few things and not more than needed" (interview 1). Everything was very well organized and always kept in the same place. Another purchase they had made since Mary's diagnosis was a higher bed, which made it easier for her to get in and out of bed.

In the large bedroom, they had rearranged the position of the wardrobe and the bed to make the room seem "emptier" (interview 1). A large mirror was also added to make it roomier. Three walls were painted white and one was painted green. There were few adornments or objects in this room as well; they deliberately had "not more than needed" (interview 1). They owned a large, white wardrobe in which everything was well organized; Mary's belongings were kept separately from her husband's and were sorted by color.

This need for order extended to the garage as well. For Mary this was very important: "I need room. I have to be able to breathe" (interview 1). Finally, in the hallway, "everything is equipped for when I need to go to the toilet in the evening; I never have to put on the light. All the lights go on automatically" (interview 1).

Mary's explanation of the changes they made to their home reveal an interweaving of the physical and the cognitive. For example, while lying in the bed, the objects on the night table were "ready-to-hand", a concept which Bollnow (2011) borrowed from Heidegger. Or rather, a new arrangement of objects was created with and for Mary so that she continued to be able to navigate it as ready-to-hand. This made it easier for Mary, both on a physical and on a cognitive level. Physically, she just had to stretch her arm to grab the object she wanted while lying in the bed. They were made easily accessible and therefore ready-to-hand. Other things in the house that made it physically easier for Mary were, for example, the higher bed, the special hair dryer, the chairs with the higher backs, the comfortable armchair, and the extra space that made it easier to walk.

Cognitively, the objects at the side of the bed were made ready-to-hand as well. First, they were familiar to Mary; she used them every day. Second, they were always put in the right place, so there was no excess of randomly placed objects, but only a few things which were always put back where they belonged. Third, they had a certain spatial relationship to Mary when

she was lying in the bed. That is, they had a certain direction and distance in relation to her body. For these three reasons, Mary did not need to search too much.

As mentioned before, making it easy on her was not meant to allow her to be lazy. It was a necessary and clever way to keep her environment manageable. The ready-to-hand-ness was an important characteristic of Mary's little worlds. These arrangements made it easier for Mary, especially on days when she was feeling oppressed. Having her bath, for example, allowed her to relax and escape from the pressure of her life once in a while. It helped her muscles relax, and allowed her, with the help of some music, to let go of her thoughts and worries.

As mentioned above, Mary and her husband made some important changes to their house, for example: replacing the dark-colored, antique furniture with white, contemporary furniture; painting the walls white; reducing the amount of adornment; making the rooms emptier; placing mirrors in the large bedroom; and, keeping everything well-ordered. White walls and furniture make a room lighter. This appears to widen the room because, as opposed to twilight, the contours of objects are now clearly visible, and the distance between objects—the empty, intermediate space—is perceived. Mary and her husband made the house roomier by clearing a busy, oppressive interior of clutter, thereby creating an emptier space.

Whereas "space closes in on the tormented person" (Bollnow, 2011, p. 221), a roomy space helps to counter oppressive feelings. The oppressiveness was both a characteristic of the house and of Mary's emotional state. This quality of oppressiveness is mentioned multiple times in the transcripts of the interviews. For example, Mary describes that,

> When it becomes really oppressive, although all the people who work here know and it's quiet here, it's calm, but when I'm in such a situation that is too oppressive, and my husband also knows, I get nervous, tense, and either I start to get angry, or I start to cry, or I just run away. I can't manage anymore. . . . It's beyond my control. (interview 2)

When the interior was calmer, Mary could be more at ease. In that sense, the changes also hold a complexity of the spatial and human.

Clearing the interior finally becomes equivalent to cleaning, according to Bollnow (2011) and:

> In the same way, 'aufräumen' means returning objects negligently and indiscriminately scattered in the room, a workshop, etc., to their place, and thus, after the constricting disorder, again at last acquiring room to move, or 'to breathe', as we say in a loose colloquial sense. (p. 36)

The interviews with Mary show that she found it very important that everything be well ordered. Not only did order make it easier to walk, or, possibly, in the future to use a wheelchair, it also allowed her some room to "breathe." Ordering things, putting them where they belong within a less cluttered space, creates a coherent organization of separate things. This made it easier for Mary to manage a larger world. In other words, it made it easier for her to think clearly.

Clearing, cleaning and ordering have the effect of creating more distance between a person and the objects in the house. The surroundings do not impinge on one so much anymore. This might be the reason why Mary did not like "a little house, without space to walk around" (interview 2) and why she literally opened up her house in the summer by opening the windows to let in more air and light, and why she claimed to need light and space to be able to breathe. Within a clear, larger world (the roomier house), the intermediate space between person and objects becomes slightly larger, allowing for little worlds to be created where belongings can be ready-to-hand. Making room in the house makes it easier for Mary to mediate space, to either

maintain a distance (letting go), or choose to get in closer contact (holding on) with objects that are more or less ready-to-hand.

Imagining

Mary read the researcher a short story that she wrote. It is "about a stupid teddy bear, but I found it impressive" (interview 3). It is not about dementia, she said, but she considered it to be important nonetheless. "And it is the truth. It is the truth that I wrote, it's not fiction" (interview 3). The story goes as follows: one day, she saw a large teddy bear along a road. It was left behind. Her full attention was drawn to it. She wondered where it mysteriously came from and what could have happened to it: "How would he endure? . . . Would he be cold? Maybe he is lonely" (interview 3). She longed for the teddy bear. She felt sorry for it, as if it were alive. She wanted to save it and take it home, but it was literally out of reach. The road bear, as she called it, kept fascinating her. She started to make teddy bears herself, and "Each teddy had its own name, and its own story, but was actually never as fascinating as [the story of] the road bear . . . ." (interview 3). Mary gave away a few teddy bears, but these *little things* were still important to her and this is visible in the living room and the small bedroom where the teddies are displayed.

Mary thought of this as a non-fiction story, but the road bear existed just as much in her imagination as it existed in the real world. In your imagination you can think beyond the present moment, beyond the place where you are, beyond yourself (i.e., thinking of yourself in a different relationship with the environment). Mary longed for the road bear, though it was out of reach. Because dementia was changing Mary's world, what lay just beyond this world, that is, a mythical world, was also changing.

Just as it is important to study myths and beliefs when studying a people's culture, it is also important to take notice of a person's imagination and dreams in an attempt to understand the world as he/she experiences it and how this can be reflected in the materiality of objects and

the built environment. For people with dementia, dreams and imagination might be even more important, because they experience difficulties in trying to be involved in the present time and place. Additionally, the fulfillment of their dreams might be hindered by their disease and their limited life expectancy, or, as Mary described it herself , someone suffering from dementia might be a "little person with big wishes, unrealizable, but still ideal to dream of" (poem Mary).

Discussion

Experience and Use of the Environment

The metaphors of mist and dust, which Mary used to describe how she sometimes experienced her environment and herself, offer a glimpse of changing person-space relationships. When things got fleeting, when they disappeared in the mist, she sometimes felt as if she was becoming fleeting like dust herself. Therefore, we suggest that the sense of self and the sense of space are intertwined. "My world"—that is, the world as I experience it—and "me" disappear together. They disappear together as they might have originated together, according to Damasio (2000), who wrote about the making of consciousness, that is, the notion of "me" thinking, acting and feeling things. We consider identity an extension of this basic notion of "me" involved in the world. Identity includes knowledge of facts such as name, job, address, type of car, and so forth. An extended memory is needed to have such knowledge. When a person's memory fades because of dementia, one's relationship with the world and extended consciousness also decline. At the same time, the person's sense of self changes and diminishes.

Similarly, Zingmark wrote that "during the process of the disease, the connection with others, things, activities, place, time, and transcendence becomes disrupted, and the connection with one's self and body is affected" (Zingmark, 2000, p. 32). Following Zingmark, we also contend that "behavior related to dementia - wandering, withdrawal, aggression, and screaming, could be seen as expressions of experiences in the demented person" (Zingmark, 2000, p. 75).

Withdrawing, for example, was one way for Mary to cope with some changes in her life caused by dementia. Mary's behavior toward her husband and household assistants – such as claiming spaces and ways of doing things – and the architectural interventions in their house could be interpreted as attempts to maintain connections or attempts to relate to the environment again. Therefore, they might also be interpreted as a way of home-making, that is, to become "present," "related," and "part of" (Zingmark, 2000).

In that sense, Mary was not automatically "anchored" in space. Extra effort and help is needed to make connections with her environment. Mary intuitively tried to maintain as many connections as possible, supported by her husband who shared her vision of life, and other people such as the household assistants. This illustrates that when the social environment (care) and physical environment (architecture) complement one another, they have the potential to support people with dementia in (re)establishing connections and in developing a sense of self proper to the stage of the disease they are in.

Architectural Interventions

We revealed multiple ways in which Mary, her husband, and her household assistants tried to make it easier for her to mediate space. Making it easier, we explained, is a matter of both low cognitive and low physical effort. The house contained "little worlds" for Mary, spaces that were narrow enough to provide a sheltering environment and that offered personal places where Mary had her belongings ready-to-hand. A good example of such a little world was Mary's comfortable armchair in the living room, with her blankets, pillows, books, candy, and so forth close to her. In the evening, the sheltering character of this little world was strengthened by drawing the curtains, closing the shutters and lighting candles so that the more distant areas disappeared. In broad daylight, the little worlds each had their distinct place within a larger space wide enough in which to move, "breathe," and think clearly. This larger space was created by installing white furniture,

white walls, mirrors, and by removing unnecessary objects and adornment. In all of this, order was paramount, because through order, objects had a particular relation to Mary and separate spatial elements were related to each other within a more coherent whole.

Order is at stake at different scales, from the objects on a night table, to places within a room, and, by extension, rooms in a building, and buildings in a city layout. An interesting way to build on existing expertise in architecture might be to explore the potential of architectural ordering principles to make it easier for people with (and without) dementia to mediate the environment and to orient themselves in time-space-identity. Such principles, as described by Ching (1996), von Meiss (1990), and Unwin (2009) allow for a multiplicity of design solutions. Students in architecture learn about principles of ordering form and space, such as symmetry, rhythm and repetition, as ways of dealing with the "diversity, complexity, and hierarchy in the programming, designing, and making of buildings" (Ching, 1996, p. 320). Order in architecture counters confusion and adds to the legibility of a built environment and to the identification of places. However, to our knowledge, this potential has not yet been explored in the research on designing for people with dementia.

Methodological Issues

We explored several social and architectural interventions meant to aid one specific person in her private home environment. Only through further research can we comment on the transferability of the research findings. Mary's interventions are comments on more than themselves (Geertz, 1993, Chapter 1): individual narratives can reveal cultural patterns (Bleyen & Van Molle, 2012), for instance in how we treat people with dementia. In further research, we could explore why a person chooses to furnish a house in a particular way or design a particular kind of housing facility from a vision of living with dementia and/or caring for people with dementia. Such an exploration could reveal design possibilities for a broader context. Based on this case study, we

cannot determine whether other people with (and without) dementia could benefit from similar architectural interventions as Mary and whether insights from this case study might also help us to understand why other people can(not) orientate in time-space-identity. Researchers could compare accounts of different people to gain more insight into when, why, and for whom particular architectural interventions might be beneficial.

As regards this case study, the question is not whether or not the research participant is representative. Rather, the question is whether she was able to tell a story that provides rich access routes into her experiences and imagination as well as the actions through which she tried to get a grip on her life and on the world (Bleyen & Van Molle, 2012). Moreover, a "typical or average case is often not the richest in information" (Flyvbjerg, 2011, p. 306). Mary's ability to speak, which other people with dementia might have lost, offers an opportunity to gain access to information and insights that might otherwise be inaccessible. Therefore, we see this case study as the beginning point of a larger research project focused on developing an understanding of how people with dementia experience and use space.

Notes

1. We contacted the television station, provided a short description of our research, and asked them to inform Mary about the research and to ask her to contact us if she was willing to participate. People from the television station passed our message on to Mary by e-mail, mentioning that it was free of obligations. She responded that she was willing to contribute to our research project. Before each interview, she reaffirmed her willingness to participate. This case study has been approved by the ethical committee of the Humanities of the KU Leuven.

2. The interviews were conducted on November 16 and 29, 2011 and March 9, 2012.

3. Entire audio-recordings were transcribed, except for some irrelevant parts, such as a conversation between Mary and a household assistant that was not part of the interview.

The transcripts included expressions such as "uh" and "oh", pauses, distinct actions and gestures accompanying speech, dialect words, distinct tone and volume of voice, and indication of unintelligible words. For this article, quotes from interviews and poems have been translated from Dutch to English. By consequence, dialect words are not visible anymore.

4. Jo De Clercq is a physiotherapist and freelance dementia comfort care consultant.

References

Bleyen, J., & Van Molle, L. (2012). *Wat is mondelinge geschiedenis? [What is oral history?]*
Leuven; Den Haag: Acco.

Bloomer, K. C., & Moore, C. W. (1977). *Body, memory, and architecture* (1st ed.). New Haven:
Yale University Press.

Bollnow, O. F. (2011). *Human space*. London: Hyphen Press.

Ching, F. D. K. (1996). *Architecture: form, space, and order* (2nd ed.). New York: Van Nostrand
Reinhold.

Damasio, A. (2000). *The feeling of what happens: body, emotion and the making of
consciousness*. London: Vintage.

Feddersen, E., & Lüdtke, I. (2009). *Living for the elderly: a design manual*. Berlin: Birkhäuser.

Flyvbjerg, B. (2011). Case study. In D. Norman K. & L. Yvonna S. (Eds.), *The Sage handbook of
qualitative research* (4th ed., pp. 301–316). Thousand Oaks, CA: Sage.

Geertz, C. (1993). *The interpretation of cultures: selected essays*. London: Fontana Press.

Godderis, J. (1992). *Handboek geriatrische psychiatrie [Manual of geriatric psychiatry]*.
Leuven: Garant.

Gupta, A., & Ferguson, J. (2007). Beyond "culture": space, identity, and the politics of
difference. In A. C. G. M. Robben & J. A. Sluka (Eds.), *Ethnographic fieldwork: an
anthropological reader* (pp. 337–346). Oxford: Blackwell Publishing.

Hall, E. (1969). *The hidden dimension*. Garden City N.Y.: Doubleday.

Ingold, T. (2000). *The perception of the environment: essays on livelihood, dwelling & skill*.
London: Routledge.

Lynch, K. (2000). *The image of the city*. London: M.I.T. Press.

Norberg-Schulz, C. (1971). *Existence, space & architecture*. London: Studio Vista.

Piaget, J. (1969). *The child's conception of time*. London: Routledge and Kegan Paul.

QSR International. (2010). NVivo (Version 9.0) [Computer software]. Retrieved from
        www.qsrinternation.com

Tuan, Y.-F. (1977). *Space and place: the perspective of experience*. London: Arnold.

Unwin, S. (2009). *Analysing Architecture*. London: Routledge.

Van Steenwinkel, I., Van Audenhove, C., Heylighen, A. (2012). Spatial Clues for Orientation:
        Architectural Design Meets People with Dementia. In Langdon P., Clarkson P., Robinson
        P., Lazar J., Heylighen A. (Eds.), *Designing Inclusive Systems* (pp. 227-236). London:
        Springer-Verlag.

von Meiss, P. (1990). *Elements of architecture: from form to place*. London: Van Nostrand
        Reinhold

Zingmark, K. (2000). *Experiences related to home in people with Alzheimer's Disease* (Doctoral
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