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## Opening up shrinking life-worlds

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Lives change dramatically as dementia progresses. Using observations of people suffering from obsessions and compulsions, I will analyse this change along three dimensions.

Obsessive-Compulsive Disorder (OCD) is characterised by intrusive anxiety-provoking thoughts (obsessions) and rituals aimed at reducing anxiety, which then paradoxically come to exacerbate it (compulsions). I have been studying clinicians working with people who suffer from a severe, treatment-resistant form of OCD. Unresponsive to medication and psychotherapy, these patients are so severely ill that only Deep Brain Stimulation (DBS) might still be effective. Let me briefly describe the two essential phases of the treatment. First a neurosurgeon implants electrodes in the patient's brain. Then, several weeks post-surgery, a psychiatrist switches on the electrical stimulation and fine-tunes the settings of the DBS device (voltage, frequency, active contact points, etc.). I am interested in this latter phase of the treatment, and especially in the delicate and complex decision-making process which it involves. There is no straightforward way of evaluating whether a certain combination of stimulation settings is effective. My assumption is that the sensitivity of clinicians to how a patient and his or her environment relate plays a decisive role.

In the following observation of a clinician visiting a patient at home, we see this sensitivity put into practice:

“It is to test the strength of her obsessive-compulsive symptoms”, the clinician explained to me beforehand. Seeing how she behaves in her own living environment, he hopes to get a better picture of how her compulsive routines work. The minute the door is opened, the diagnostic process begins. As I move along reservedly, aware of the patient's fear of contamination and need for order and symmetry, the clinician moves about seemingly unconcerned. He asks her to show him how she leaves the house. We follow her as she takes the power plugs of all the electrical devices out of their sockets and locks doors and windows, repeatedly going back to check. The patient admits that on many days this routine is too much to bear and she stays in, sometimes not even leaving her

bed. The clinician explains: “The DBS will likely decrease your anxiety. But if you stay on your couch, nothing will happen”.

This home visit is not only of diagnostic value. It also enables the clinician to identify which elements in her compulsive routines should be tackled first. Going over her leaving-the-house routine, he asks her how it feels to leave one power plug in place in its socket. To the patient, not checking the lock of the front door seems more doable. The clinician compels the patient to put this plan into practice immediately. So we go over the routine once again. As we stand in front of the house with the un-checked front door closed, the clinician checks the anxiety of the patient, which is raised to ‘a nine’ on a scale from one to ten. The clinician instructs the patient: “If it is difficult to walk away from the door, give yourself the command to count the windows in the house on the other side of the street. Otherwise, your door will pull you back”.

These observations are paralleled by the findings of a phenomenological study on OCD patients with DBS (de Haan *et al.* 2015). Through in-depth interviews, it is described how OCD patients restrict themselves to a narrow range of (compulsive) behaviours, spending hours on the same washing or checking routine. These patients often avoid going outdoors or meeting with other people. Just as in the above example, the life-world of these patients has shrunk considerably. When DBS works, patients explained, their life-worlds opened up. How can we operationalise this opening up of a shrunken life-world?

Like the interviews with OCD patients, my observations above can be analysed using the term *affordances*. It is a technical term for “possibilities for action offered by the environment” (Gibson 1979). Affordances, as I understand them, do not only depend on the structure of the environment, but are also relative to the abilities and concerns of the individual. In most situations, people are attracted by many affordances simultaneously; that is to say, we are embedded in a *field* of affordances (Rietveld 2008). For heuristic purposes, this field can be seen as having a *width*, which reflects the amount of affordances that a person is simultaneously attracted by, a *height*, which is the intensity of each individual affordance, and a *depth*, the temporal succession of affordances (de Haan *et al.* 2013).

The life world of the OCD patient described above can be characterised by using these three dimensions. As the patient is still very ill, only a limited range of action possibilities are relevant to her. All activities outdoors are very unattractive. This limited width of her field of affordances is related to the height of some affordances: some affordances, such as the affordance

of checking power plugs and locks or that of lying in bed, are so intensely attractive that all other affordances sink into the background. As these affordances become so attractive that they cannot be postponed, the patient gets stuck in the here and now. In other words, the depth of the field decreases.

Characterising OCD in terms of a field of affordances makes it possible to draw parallels with dementia. What would we learn if we would be like the OCD clinician and carefully mapped out the various dimensions of the life-world of people with dementia? Albeit for different reasons, the life-world of the person with dementia shrinks as well. Like people with OCD who are stuck in the here and now due to compulsivity, people with dementia might lose their grasp on the temporal dimension of their field of affordances. And as most daily activities consist of many successive actions, routines break up and people become disoriented. Furthermore, with the loss of abilities such as those for reading signs, particular affordances lose their attraction. Like the OCD patient, the width of the dementia patient's field of affordances shrinks. And as there are fewer and fewer affordances that are still relevant, people's life-worlds might become very narrow and bleak, reflecting a state of apathy.

Thinking with dementia along these three dimensions teaches us that how people in general experience their surroundings depends not only on the material structure of their environment, but also on their abilities, and on the practices in which these abilities are embedded. Perhaps this story affords thinking about how the lifeworlds of those living with dementia may be opened up.

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*This post is a contribution to 'Daily life' in the Somatosphere series [Thinking with dementia](#).*

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