

Compulsive Body Spaces: Confusions and rationalisations

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CHAPTER 2
IN

Background / Premise of the book

What questions can be asked reflects what is seen as the 'right' problems decided by whom and what is considered important to know.

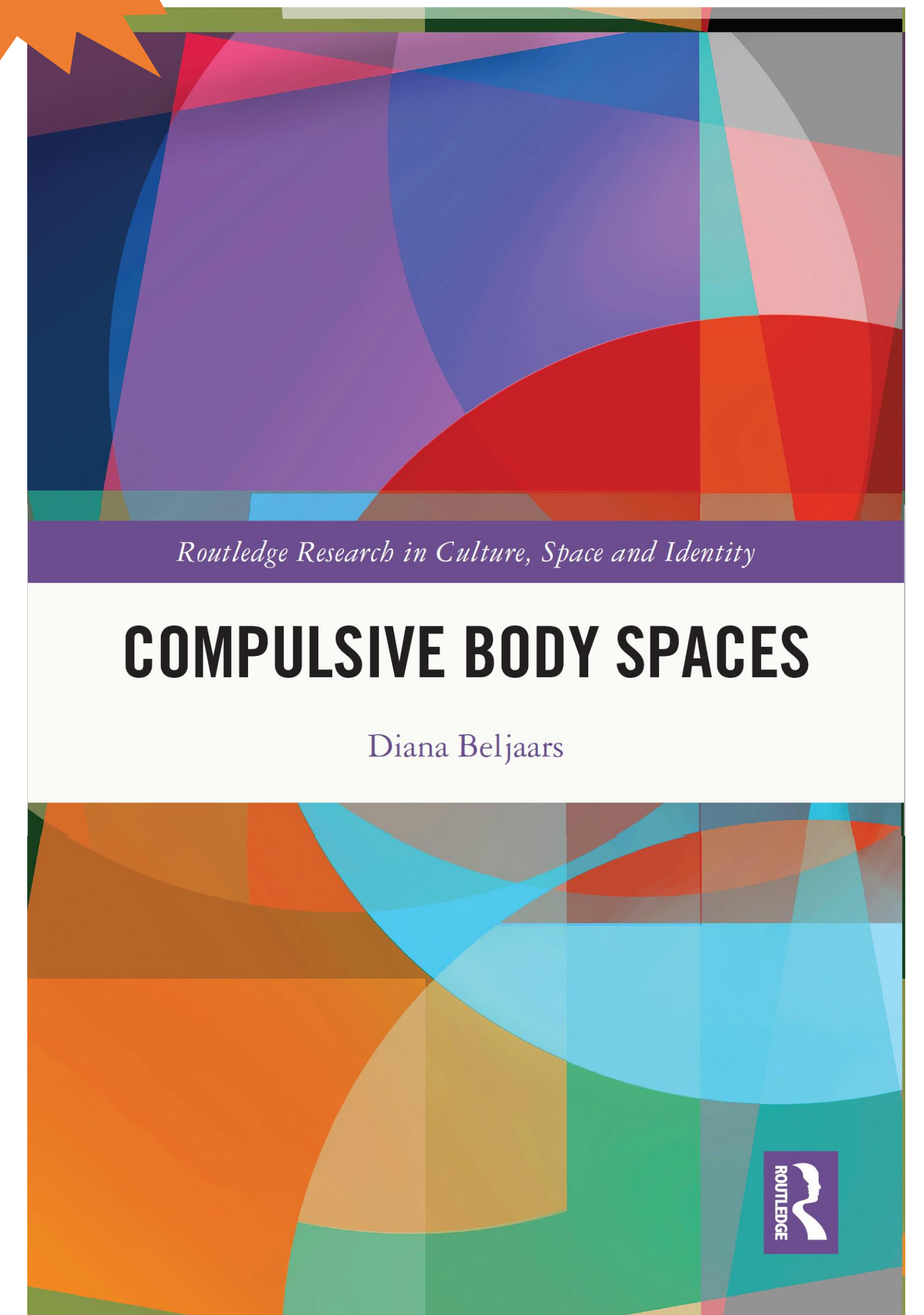
There is an increasing need for:

- Expanded agency of Tourettic people in determining research priorities and analytical styles
- Encouragement of and attendance to new questions
- Space for more nuance in Tourette syndrome (TS) studies

Urge-driven compulsions are an important but still only superficially understood symptom group of the TS symptomatology. Especially compulsions that are bound to certain objects (e.g. tooth brushes) and spaces (e.g. living rooms) tend to be more confusing for Tourettic people than simpler tics. This chapter attends to how biomedical and clinical TS research cannot quite clear these confusions because of onto-epistemological complications.

Methodology

1. **In-depth literature review** of the research priorities, methodology and invocation of causality and correlation of a broad range of papers on the problematisation, conceptualisation, and theorisation of TS symptomatology and the situatedness of tics in neurological, neuropsychiatric, and psychological TS research; and
2. **In-depth qualitative interviews** with 15 Tourettic people focussing on their sense-making narratives of being medicalised and receiving clinical treatment and therapy.



The medicalisation of compulsions through diagnosis incites four transformations of experiential knowledge that steer away from asking certain questions, recognising certain instances as (un)problematic, and shaping certain expectations for one's life and living situation.

Transformation 1: Pathologisation

Neuropsychiatric scientific rationalisations of compulsive realities involve clinical diagnosis and start at the point that compulsions are so problematic that professional help is required to cope with them. For many people, this rendition becomes an important – if not the most important – framework of understanding when they are diagnosed with TS. As 'Joe' puts it *"I had it my entire life of course, but officially I know it for only four years"*. In lieu of failing to find sufficient answers to their compulsive experiences and the desperation that accompanies it, this new formal rendition offers a persuasive new understanding that could dissolve many confusions, or at least bring (partial) answers.

The diagnosis changes individuals having to take responsibility for their compulsive bodily movements to the admission that there was a problem in their body, thereby shifting the location of the problem away from themselves, and onto their diagnosed body, and/or Tourette's (Schroeder 2005, Sandle 2012, Bervoets forthcoming, Bervoets and Beljaars, in review). *This transforms compulsivity as confusing acts ('why do I perform this act?') to a problem of the individual ('something is wrong with me') and to a biological problem of their brain ('my brain is faulty').* Nonetheless, the focus of the diagnosis on the individual does help to lift confusions rooted in questions about the self and one's desires.

Transformation 2: Biologisation and neuroscientific logic

Another transformation entails the biologisation of the compulsive interactions as arising from a malfunctioning brain and the distorted processes that make up the nervous system. Compulsivity becomes a 'neurocognitive endophenotypes', *"whereby changes in behavioural or cognitive processes are associated with discrete deficits in defined neural systems"* Robbins et al. (2012: 81). Put simply, what bodies do is a direct expression of the functionality of the brain, so neuroscientific logic holds that if people do things that are considered abnormal, there must be something wrong with their brain. This logic reflects a conceptualisation of the problem fundamentally as a deficit.

The biologisation of compulsion and compulsive processes that precede the acts are then positioned as whole explanation of the phenomenon or as partial explanation that fit the gaps that are left by the incomplete sense-making exercises. The focus on inhibition suggests that acts can be *good* or *bad*, and that therefore the problem just is a lack of neurotransmitter-mechanics to impair the *bad*. *This creates a reality that takes away the need to ask questions about this act, because it effectively shifts the focus to how any compulsion happens in the first place because it is a manifestation of a problem.*

Transformation 3: Erasure of performative difference

The pathologisation and biologisation of compulsivity that analytically situate the brain and further nervous system as the sole causal focal point, lead to compulsive bodily movements being understood as *effects* of a *brain problem*. *Their rendition as 'symptom' is considered more important than the intricacies of the compulsions themselves.* A notable exception to this is phenotype studies that offer understandings in the descriptive mode but not an analytical one.

Asking Tourettic people to primarily note frequency and severity and accept them as idiosyncratic more or less lifts the confusion as there seem to be no answers. However, it introduces anxieties around what movements count as tics, as it led 'Lowri' to closely examine all her movements, habits, routines, rituals, and preferences that she could not quite explain, and consequently *feeling ashamed for "not knowing" that a particular movement she used to do "was a tic"*. In effect, the clinical rendition of her movements made her question her knowledge of her body as gathered throughout her life. *This de-individualisation transformation of compulsive interactions thus cannot help explain why this compulsion takes place here, now, and with this pattern.* Therefore, we remain with very little insight into how specific kinds of compulsive acts come about and what differential effects they have on further life.

Transformation 4: Erasure of circumstances

Compulsions and tics are also deemed to be 'waxing and waning', which alludes to both the kind and temporal variations of compulsions in a given period. Situational variations in the clinical sciences have served to acknowledge how social worlds and activities have salience (Cohen and Leckman 1992, Conelea and Woods 2008, Woods et al. 2009, Cavanna and Nani 2013). However, the natural scientific pursuit of universal truths prevents the analysis of these circumstantial relations in all their complexity. *Indeed, circumstances of compulsions are largely encouraged to be understood in quantitative psychological measures (e.g. stress), as physical activity only (Jackson et al., 2020), or through vague description (e.g. "spending time with friends") (Christenson et al. 1993, Silva et al. 1995, Miltenberg et al. 1998), and not by thorough examination of compulsive situations in spatial socio-material terms.* Reflecting their marginal presence in TS research, more complex and highly situated compulsions remain unaddressed in evaluations of clinical interventions.

This transforms TS compulsivity into a sole matter of inhibition and personal control over the body, regardless of the circumstances (see Hollenbeck 2003) and in which the surroundings are narrowly cast as function of such control.

Question: Can we find ways to corroborate or challenge this in the neurosciences? Can such awareness open up new ways of researching the Tourettic brain, psyche and/or sense of self whilst keeping attuned to kinds of complex compulsive tics and their circumstances?

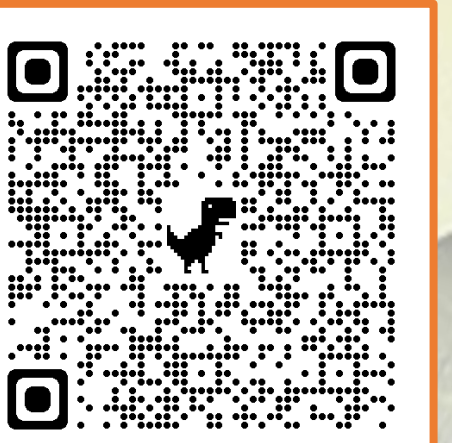
Results / Moving forward

To a certain extent, the four knowledge transformations about compulsive interactions are helpful for Tourettic people through the depersonalisation that diagnostics grants. However, these transformations do not provide complete answers to people's own experiences and conceptions of compulsion in Tourette's. Indeed, because the neuroscientific conceptualisations immediately problematise TS compulsions and seek its materialisation in the biology of the brain, questions about them are reduced to how they are (un)healthy or (ab)normal behaviour. Regarding idiosyncrasy and bodily surroundings in all their complexity as new source for scientific analysis rather than realities to shun presents us with a requirement of a radically new ethics of analysing compulsivity in Tourette's. In turn, this might open up new lines of heterogeneous and transdisciplinary lines of inquiry in which Tourettic people can play a guiding role.

Conclusions / Remainder of the book

The book continues to develop a theory that highlights the intricate patterns with which the bodily surroundings mediate and, in turn, are mediated by compulsive interactions. What follows is a sophisticatedly balanced ecology of just-rightness and situated wellbeing, which is further examined on its potential to create the foundations of a new kind of therapeutic engagement. Considering Tourettic people as having particular sensibilities that to a certain extent are shared by a broader humanity, its insights give rise to a groundbreaking spatial conceptualisation of wellbeing beyond pathology. The book ends with an exploration of politico-ethical questions that this conjures. As such, this book suggests what a new wave of patient emancipation in biomedical and clinical research may look like, to raise renewed considerations of what empathetic, context-sensitive care may look like in the 21st century.

The book



My work

