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“‘It’s not me, it’s the OCD’:
an Autoethnographic Reflection on OCD, the Self and
the Blurred Lines Inbetween”

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"It's not me, it's the OCD":

an Autoethnographic Reflection on OCD, the Self
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Content Warning: mental illness; OCD; violence; physical harm;
sadism; paedophilia; suicide

Abstract

Fundamentally, 'Pure O' Obsessive Compulsive Disorder (OCD) forces sufferers to question, and fear, who they 'really are'. Further, when treatment requires a level of differentiation between 'normal thoughts' and 'OCD thoughts', this effect can be exacerbated. Even if treatment is successful in reducing symptoms, it is possible to end up feeling lost, when the gaps left by OCD are not automatically filled with a secure sense of self. OCD is not necessarily experienced as an entirely 'external' illness, and can be conceptualised by sufferers to be part of their personality. Therefore, OCD treatment should incorporate the person, and not just their symptoms, into therapy.

Keywords: mental illness, OCD, recovery, medical, treatment, the self

You're standing behind the kitchen door. You left the party for a few minutes to go to the bathroom and you're now on your way back to join your friends. You can hear everyone talking, laughing, shouting. But you can't go through the door. While you were in the bathroom, walking up to the sink to wash your hands, you had caught sight of the bath taps. Momentarily, you took in the smooth, shining curve of the chrome, the way the handle jutted out in a dulled point towards the foot of the bath. And then the thought had flashed into your mind; what if you went into the party, took your friend, Emily, stood her in the bath and smashed her head against the tap? A surge of anxiety washed over you (but, hang on, was it excitement?). A cold wave of fear trickled down from your head to your stomach. Suddenly you were convinced; you wanted to violently hurt Emily. Worse, you would probably enjoy it. Even worse, it felt like you had the urge to do it. You washed your hands and walked out of the bathroom, towards the kitchen, trying to ignore the thought but feeling like you were plunging into a heavy darkness. And now you're here, outside the door.

It doesn't matter that the thought is making your stomach churn – it must be some deep-down desire. In fact, oh god, you suddenly remember a summer day when you were about eight or nine. You had pushed your brother down, he cried, and you found it kind of funny. That probably means that there is something irretrievably and pathologically wrong with you. 'Oh god, okay', you think, 'if I imagine smashing Emily's head against the tap, I can work out whether I'd enjoy

it'. So, reluctantly, you force yourself to picture it. You imagine grabbing Emily's hair, how it would feel in your hands (wavy and coarse though not frizzy). Then you imagine pulling her head down... hang on... would her neck move like that if I pulled her head that way? Maybe not. Okay, go back to the beginning. So, you imagine grabbing her hair and what it would feel like, then imagine jerking her head down to the tap. While doing so, you make a small movement with your hand, a ghost of the motion you would have made in real life. Yes! It seemed correct this time. But hang on, was that momentary happiness because you had succeeded in picturing the movement correctly? Or was it because you enjoyed the thought of hurting her? Go back to the beginning. Check. Grab her hair, move her head down, make the hand movement, and this time you imagine the smash. The tap pounds into the side of Emily's head, blood gushes out, dripping down her face. A wriggling sensation begins in your stomach and washes down your legs. What was that? Was it random? Was it anxiety? What if it was enjoyment? Back to the beginning. Hair, move her head, hand movement, smash it. You can't work out that feeling. Why can't you work out how you feel?

Oh god, you've been out of the party for a good ten minutes now. 'Okay', you think,

'I can quickly imagine it again to make sure and then go back to the party'. Hair, move her head, hand movement, smash it. It still isn't right. You don't want to think about this anymore. But now you can't change position until you've completed the thought properly. Hair, move her head, smash it. Hair, move her head, smash it. Hair, move her head, smash it. Your foot hurts. You really want to move it but you can't. That would mean you'd have to start this all over again. Hair, head movement, smash it. Hair, head movement, smash it. It feels like you're itching inside, like your body wants to make huge movements but your brain won't let it, like you're trapped and want to crawl out of your own skin. A cold sweat starts. Hair, head movement, smash it. Hair, head movement, smash it. That's it! Something clicked, the anxiety fades a little, leaving only a slight stomach ache. Finally, you can walk through that kitchen door. But, the thought lingers; do you really deserve to go back to the party?

For me, like many others, my OCD diagnosis was a total relief. For years, I had been terrified of my own thoughts, believing I was a terrible person who was capable of hurting myself or others. But, one day, as I was standing on the London Underground, scrolling through Facebook, a Guardian article popped up on my feed. Titled *Pure OCD: A Rude Awakening*, it said, "You mentally undress your friends [...] You wonder if you're a paedophile – or just losing your mind. A sufferer describes the nightmare [...] of living with OCD" (Bretécher, 2013). A small wave of adrenaline rushed through me;

this sounded familiar. A few minutes later, back overground in Euston station, I opened the article. And, right there, on the pages of the Guardian website, was the story of a life strikingly similar to my own. The thoughts I'd had, the cold sweats, the fear that I could never be 'normal', the repetitive, obsessive behaviour. London Euston station may not have been the most glamorous location for a life-changing moment but there it was; I immediately texted my family and best friend... "I think I have OCD!". As I sat on my next train, I stared out of the window with an overwhelming sense of relief. And, throughout the trundling journey from London to Manchester, a small, hopeful voice whispered again and again in my mind: "it's not me, it's the OCD".

Contrary to popular opinion, not all types of OCD include a desire for cleanliness, neatness, handwashing or counting. I have 'Pure O' or 'Primarily Obsessional' OCD, a subset of the disorder in which sufferers mainly experience compulsions as obsessive thought patterns rather than physical actions (Phillipson, 2016). These thoughts are usually frequent, persistent and relating to societal or personal taboos (Ferrier and Brewin, 2005: 1363). Common themes include aggression, violence, sadism, religious blasphemy, sexual orientation, paedophilia, incest and other perceived 'transgressive' behaviours or personality traits. These thoughts trigger (sometimes extreme) anxiety in the sufferer, who may worry that they enjoy them or are capable of carrying them out. This then leads to 'compulsions', which temporarily reduce anxiety (Anxiety and Depression Association of America, 2016). Often, for those with 'Pure O' OCD, compulsions will involve 'checking'; repeated, looped thoughts, followed by the analysis of one's own emotional responses (OCD Center of Los Angeles, 2016). Alternatively, some try to completely push the thought from their mind, while others may repeat words, phrases, and small movements or actions.

Sometimes called the 'doubting disease', "OCD is the result of 'the brain sending false messages that the person cannot readily recognize as false'" (Fennell and Liberato, 2007: 322). Therefore, even after diagnosis, many still struggle distinguishing between so-called 'real' and 'OCD thoughts' (Fennell and Liberato, 2007: 315). Certainly, even when I identify that I am engaging in OCD behaviors, the thoughts still feel 'real' in that moment. Moreover, this is so bad for some that they become confused between thoughts and action (in a neurotic, rather than psychotic, sense). One patient interviewed by Fennell and Liberato said "I would get guilty for having [thoughts about raping his girlfriend] and then I would have to ask her did I rape her... sometimes it's hard to distinguish between reality and fantasy" (Fennell and Liberato, 2007: 315).

Nevertheless, it is not only OCD itself that blurs these lines; treatment, both in its methods and its consequences, can exacerbate this. Typical OCD treatment is a combination of medication and Cognitive Behavioural Therapy (CBT), which generally aims to alter the way an individual perceives

and responds to certain thoughts and situations (OCD UK, 2017). As random intrusive thoughts are considered psychologically 'normal', CBT does not seek to eliminate them (although they may reduce in frequency).

Accordingly, I was told to conceptualize 'OCD thoughts' as leaves in the wind; to acknowledge and observe them but to understand that they did not reflect reality, not to engage, and let them float by. However, if I were able to effectively distinguish 'OCD thoughts' from 'real' ones, I wouldn't be in therapy. Furthermore, this is a disorientating task; our entire lives are constructed by perceptions; being told that many are erroneous is deeply confusing. Fundamentally, it led me to question, if I should ignore some of my feelings, why shouldn't I ignore all of them? If I can't trust my own mind, what can I trust? If recovery distances a part of my consciousness from the 'real me', what is the 'real me'?

However, it is not only the process, but also the consequences, of OCD treatment that can have dysphoric effects, even if OCD symptoms are successfully reduced. Kennett (2009: 91) writes that mental illness is often interpreted as obscuring a person's 'true' self, with the goal of treatment being its restoration. In this way, mental illness is framed as quasi-parasitic, consuming the personality of the sufferer. Accordingly, Kennett argues, mental illness makes it harder to maintain self-identity, as identity claims presuppose a degree of continuity in future thought patterns, feelings and behaviours (Kennett, 2009: 95). In short, "we need to identify with our future to be what we are even now" (Korsgaard, 1988 in Kennett, 2009: 97), which may not be possible for those whose feelings and behaviors are made unpredictable by mental illness. Interestingly, however, this argument applies more to my experience of recovery than mental illness itself. As my OCD was triggered when I was around eight, I cannot remember not having the disorder, and my 'OCD self' has always been my 'true self' too. Consequently, the decrease of symptoms following treatment, while pleasant in many ways, was disorientating, as it essentially represented the disappearance of a familiar and central aspect of my life.

Furthermore, while my treatment seemed to be conducted with the assumption that OCD is the cause of self-uncertainty and that I could conceive of my 'self' free of OCD, this was not necessarily true to my experience. Doron, Kyrios and Moulding (2007: 434) suggest that those with a fragile sense of self are more likely to be affected by the disorder in the first place. Indeed, I have found that, while symptoms of OCD may be reduced, this does not mean that a secure sense of self suddenly materialises to fill in the gaps. Perhaps like an auto-immune disease, I do not experience OCD as something external attacking my otherwise healthy self. OCD is a part of my very substance and the way in which I know the world. Just as stripping away the immune system of a Lupus patient would

certainly not improve their overall health, stripping away my OCD does not necessarily leave a self-secure, stable person behind.

Richard writes that literature on illness rarely features voices from those who experience it (Richard, 2008: 1717), which marginalizes their situated subjectivity within treatment. In her autoethnography, she added, “I keenly felt the irony, as a [kidney transplant] patient, that my medical treatment was all about me and the intimate details of my anatomy, and yet I seemed entirely absent from the process” (Richards, 2008: 1719). For me, a similar effect occurs in psychological therapy for OCD; thoughts and behaviors are treated as externalized aspects of illness, rather than part of phenomenological self-conception. As Bruce et al comment, personal accounts of mental illness and recovery “underscore the need for a shift of emphasis from a focus solely on the symptoms of mental illnesses to a focus that includes the person in his or her environment” (2008: 490). There is no place where I end and OCD begins; we are each a part of one another.

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