

View from a Body: Situating the Lived Experience of Painful Obsessions and Compulsions

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

Abstract

Painful obsessions and compulsions have been traditionally consigned to the realm of mental illness. However, an investigation into the lived experience of these tendencies demonstrates that they constitute embodied forms of suffering. Using anthropological and phenomenological insights, I demonstrate how painful obsessions and compulsions exceed categorization as a mental disorder. As someone who lives with obsessive-compulsive tendencies, I use my autoethnographic authority, partnered with ethnographic data, to emphasize the ways in which painful obsessions and compulsions are embodied within the lifeworlds of sufferers. Thus, I argue for a re-conceptualization of obsessive-compulsive disorder (OCD), and I insist upon a radical transformation of best-practice treatments to more adequately and compassionately account for these embodied forms of suffering. Importantly, this approach provides a means to alter the role of the sufferer from being a mere *object* of research, to an active and engaged *agent* of research.

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Chapter 1

The Significance of Painful Obsessions and Compulsions and the Value of Public Anthropology

Obsessive-compulsive disorder (OCD) and the suffering caused by painful obsessions and compulsions carry a high public cost. Ranked as a leading cause of disability world-wide (WHO 2008), OCD is recognized as the fourth most common psychiatric disorder (de bruijn, Beun, de Graaf, ten Have, and Denys 2010). Painful obsessions and compulsions exist within all cultural groups (Sookman 2016), and are known to severely diminish quality of life for both the individuals affected by these tendencies as well as their families (Subramaniam, Soh, Vaingankar, Picco and Chong 2013). In addition, there are high economic and health-care related costs associated with the disorder (Stanford School of Medicine 2016).

Despite advances in the treatment and care for individuals diagnosed with OCD, obsessive-compulsive tendencies remain poorly understood and there is a troubling lack of clinicians with adequate expertise in assessing and treating OCD; this results in “substantial treatment delay, progression to serious illness, and high rates of treatment resistance due to intervention inadequacies” (Sookman 2016). Moreover, research has demonstrated that approximately 50% of individuals will not respond adequately to current best-practice treatments (Sookman 2016). Consequently, painful obsessions and compulsions clearly represent an area of research that warrants urgent and ongoing attention.

Although painful experiences like obsessive-compulsive tendencies have been traditionally relegated to the domain of psychopathology, anthropological approaches to psychiatric medicine demonstrate that they are particularly well-suited to identify the “underlying cultural, social, historic, and economic issues that produce and maintain distress and suffering” (Whitley 2014, 504). In relation to experiences that are typically classified as “mental illness,” important

anthropological work has demonstrated the value of paying critical attention to the life-worlds of sufferers, as well as attempts to understand the basic structure and significance of their lived experience (Corin 2010). In so doing, anthropology contributes alternate ways of understanding the various dimensions of suffering that are intrinsic to painful experiences like obsessive-compulsive tendencies.

In accordance with this, my research findings consistently demonstrate how the suffering caused by painful obsessions and compulsions exceeds OCD's classification as a psychiatric disorder. By employing an anthropological approach that utilizes phenomenological insights, I illustrate in chapter two how obsessive-compulsive tendencies are in fact experienced as embodied, and that the suffering they cause is neither exclusively mental nor physical; rather it is a synthesized experience bound up within the lifeworld of the sufferer. These findings offer critical implications for how painful obsessions and compulsions can be reconceptualised. With this evidence, I hope to motivate a radical transformation within best-practice treatments for OCD, and I urge clinicians to conceive of alternate care modalities that will privilege an attendance to embodied aspects of suffering.

In so far that I have demonstrated the value of applying an anthropological approach to the study of painful obsessions and compulsions, I would also like to suggest that research into the experience of these tendencies illustrates the importance of bringing anthropological knowledge to the public. As someone who has struggled with painful obsessions and compulsions for most of my life, I understand on a deeply personal level how sufferers of obsessive-compulsive tendencies hold a much greater stake than anyone else in the outcomes of research that concern their lived realities. And yet, despite the vast amount of research focusing on the psychopathology of OCD, my research indicates that a large portion of individuals suffering from this debilitating

condition receive little in the way of direct benefits. As Clark (2015) suggests, “more advances have been made in the psychopathology of OCD than its treatments” (129). Similarly, Rachman (2006) reports that for a period of twenty years, “improvement rates are not improving” (quoted from Sookman 2016, 35). In fact, it could be argued that the main beneficiaries of research on OCD have largely been the researchers and clinicians themselves; for salaries are paid and research studies are funded regardless of whether or not a patient recovers. Complicating this issue further, my research demonstrates how these inadequacies of care are exacerbated because of the conceptual models on which OCD treatments are typically framed.

This is of course a deeply troubling reality, one which is not easily brought to light and unlikely to be publicly addressed, especially from the standpoint of predominant psychiatric thought. As a result, there is little accountability to sufferers on behalf of psychiatric medicine and research. In contrast, it is precisely *because* of the insights that anthropology produces that I have been able to attend to aspects of suffering that ordinarily go unrecognized. Moreover, anthropological methods (e.g. autoethnography) have allowed me to transcend and disrupt the traditional boundaries of representation within academic research. For instance, by situating painful obsessions and compulsions within lived experience, the role of the sufferer is transformed from being a passive object of study to an active and engaged agent of research. Thus, an underlying goal of this project has been to demonstrate how anthropology can be enlisted by sufferers not only as a field of knowledge, but as a force for action; whereby the lived expertise of individuals with obsessive-compulsive tendencies can be utilized in partnership with non-sufferer expertise for the purpose of broadening the current clinical understanding of painful obsessions and compulsions.

Lastly, because my aim is to engage my audiences in a meaningful and sustained re-thinking of the embodied suffering caused by obsessive-compulsive tendencies, I intend to distribute my research among various venues. Most importantly, I will share my research with the individuals who directly participated as research subjects. Secondly, I will offer to distribute my findings among members of the OCD support groups I connected with both locally and online. This will ensure that my work reaches a wide variety of people who are affected by painful obsessions and compulsions. My hope is that they will offer their own perspectives and feedback. The academic venue I have chosen for the possible publication of my second chapter is *Ethnography*. As an interdisciplinary, international and peer-reviewed journal, *Ethnography* would be a well-suited venue of choice because of its focus on context, the particulars of experience and the structural forces by which they are affected.

Chapter Two

Situating the Lived Experience of Painful Obsessions and Compulsions

2.1 Introduction

Painful obsessions and compulsions have been traditionally consigned to the realm of mental illness. However, attention to the lived experience of these tendencies shows that they constitute an embodied form of suffering. My research consistently demonstrates how painful obsessions and compulsions therefore exceed classification as a mental disorder. Dominant treatment modalities are thus always already inadequate for dealing with these embodied forms of suffering.

Coming from the embodied and situated perspective of someone who experiences painful obsessions and compulsions, my goal has been to purposefully alter the role of the individual who experiences obsessive-compulsive tendencies from being a mere *object* of research, to an active and engaged *agent* of research. Using anthropological and phenomenological methodologies, I highlight alternate ways of understanding the painful experiences caused by obsessive-compulsive tendencies which may hold important implications for how obsessive-compulsive disorder (OCD) is clinically categorized and treated.

2.2 Methods and methodology

Because my research deals with experience, and more specifically with what Dilthey described as that which has been “lived through” (quoted in Bruner 1986, 3), I used qualitative research methods, which privilege experience as “the foundational source of reliable praxis” (Purcell 2000, 31).

The various tactical procedures I used to collect my data involved traditional approaches to anthropological research and fieldwork including literature review, participant observation, as well as unstructured and semi-structured in-depth ethnographic interviews. I also employed the less conventional approaches of autoethnography and phenomenology.

Research sites included in-person support groups, two online international support groups for people with OCD, and the 23rd Annual OCD Conference (a five-day international conference for individuals with OCD, their families, medical professionals and researchers). I monitored both online support groups daily for a period of fifteen months and I was able to observe the day-to-day struggles of a wide variety of individuals. My attendance at the in-person support groups involved many of the same components as my observations of the online groups did, and each group provided me with deeply textured context for the many ways obsessive-compulsive tendencies occur for people across different nationalities, socio-economic backgrounds and ages. At the conference, I also attended talks by researchers regarding the latest research interests in OCD and I engaged in numerous casual conversations with individuals who identified as having the disorder in addition to casual conversations with family members of people with OCD, researchers, and medical professionals.

I conducted six in-depth and semi-structured interviews with individuals diagnosed with obsessive-compulsive disorder. These semi-structured interviews were conversational in nature;

we each had the opportunity to ask questions of one another, tell about each other's experiences, and share our knowledge of *lived through* painful obsessions and compulsions. Thus, I regard the insights they produced as collaborative – generated together with my research participants.

Finally, I used autoethnography as another central method. Autoethnography “seeks to describe and systematically analyze personal experience in order to understand cultural experience” (Ellis, Adams & Bochner, 2011, 1). This method uses emotional recall which involves imagining one's self back in a particular experiential instance both emotionally and physically; this allows for remembering additional details, a process of “moving in and moving out” of past and current experiences for the purpose of engaging in cultural analysis (Ellis 2004, 118). Autoethnography also involves “retrospectively and selectively” not only writing about, but analyzing “epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular cultural identity” (Ellis, Adams & Bochner, 2011, 4).

Lastly, my project is also phenomenological in nature. Phenomenology is the study of the “essence of consciousness” for the purpose of giving a direct description of an experience “as it is, and without any consideration of its psychological genesis or of the causal explanations that the scientist, historian or sociologist might offer of that experience” (Merleau-Ponty 2012, lxx). In this work, I provide accounts of the lived experiences of obsessive-compulsive tendencies *as they are*, without diluting them by portraying them through the more canonical lens by which they have been clinically recognized.

2.3 Sensation and the work of perception

Obsessive-compulsive disorder is not a timeless entity. Obsessive-compulsive tendencies have long been represented as symptomatic of a disordered way of life; however, the names and conceptualizations of this form of disorder have been adapted and re-characterized in different historical and cultural contexts. Dating back as far as the fifteenth and seventeenth centuries respectively, the presence of obsessive-compulsive tendencies were once considered evidence of demonic possession (Jenike 1983), or thought of as an “abnormally intense” form of religious scruples (Miguel, Rauch & Jenike, 1997, 863).

Berrios (1989) discusses the conceptual history during nineteenth century France of what would eventually come to be known as obsessive-compulsive disorder; he chronicles a shift from partial insanity to a disease of the emotions, to a failure of the will to insanity with insight, demonstrating well the ability of painful obsessions and compulsions to resist classification and conventional objective description. These shifting categorizations of obsessive-compulsive tendencies remain. The erasure of OCD from the category of anxiety disorders within the 1994 edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) saw the creation of a new category for the disorder in the most recent edition, DSM-V, known as obsessive-compulsive and related disorders (APA 2013).

Sookman (2016) describes this change as representing “major progress in diagnosis, reflecting convergent research that indicates OCD is distinctive in terms of psychopathology and treatment requirements” (2). Despite these changes to the historical trajectory of the disorder through time, it is important to consider how obsessive-compulsive tendencies have been and continue to be conceptualized predominantly as an affliction located solely within the mental realm of human experience. This characterization of obsessions and compulsions as a mental disorder likely

reflects a residual Cartesian dualism, shaping a tendency in modern Western medicine to “categorize and treat human afflictions as if they were either wholly organic or wholly psychological in origin: ‘it’ is *in* the body, or ‘it’ is *in* the mind” (Scheper-Hughes & Lock 1987, 9).

In fact, the very notion of “mental disorder” exemplifies this view; and I argue that it is largely complicit in the conceptual limitation of recognizing the numerous possible ways suffering may occur within our bodies. My research findings consistently emphasize how *lived through* painful obsessions and compulsions are embodied. Therefore, I insist that the predominant view which portrays our suffering as limited to and bound up within our mental faculties is inadequate. And yet, by claiming this embodied way of experiencing obsessive-compulsive tendencies, I am both acutely aware of and immensely frustrated by the consequences of the Cartesian legacy to modern medicine. As Scheper-Hughes and Lock (1987) have suggested:

We lack a precise vocabulary with which to deal with mind-body-society interactions and so are left suspended in hyphens, testifying to the disconnectedness of our thoughts. We are forced to resort to such fragmented concepts as the bio-social, the psycho-somatic, the somato-social as altogether feeble ways of expressing the myriad ways in which the mind speaks through the body, and the ways in which society is inscribed on the expectant canvas of human flesh. (10)

Thus, I argue that it is not simply that sufferers’ experiences have been misrepresented. Rather, it is that sufferers have been deprived of conceptual tools that are capable of authentically expressing the exact ways in which they suffer. Thus, sensorial features of distress remain absent from the clinical picture of obsessive-compulsive disorder. Yet, if we move beyond the confines of this residual dualism, we can begin to take seriously the notion of embodied suffering as it is revealed in lived experience.

I argue for a phenomenological approach as a viable means for delivering our mindful-whole-bodied selves out of the Cartesian divide. Toombs (1992) summarizes the goals of phenomenology in the following way:

(1) The effort to elucidate the manner in which meaning is constituted; (2) the commitment to a radical reflection upon lived experience which requires (as a methodological device) the setting aside of theoretical commitments and taken-for-granted common-sense presuppositions in order to focus upon the conscious processes of experiencing and the objects of experience; and (3) the attempt to uncover the invariant features of phenomena and thereby to provide a rigorous description of such phenomena. (xiii)

Capable of rendering explicit the entanglement of awareness, sensation, thought and emotion structuring the embodied experiences of painful obsessions and compulsions, phenomenology provides us with a view that encapsulates the power of bodily synthesis: the perceptual process by which we experience our sensory abilities as ultimately always intertwined (Merleau-Ponty 2012; Leder 1992). Using this notion of bodily synthesis, I demonstrate how the suffering caused by obsessive-compulsive tendencies is experienced intuitively as simultaneously psychological and physiological. In other words, it is neither exclusively mental nor physical; instead, it is a *synthesized* occurrence only made possible by and within a thinking, feeling and acting embodied self.

2.4 Getting a *feel* for embodied painful obsessions and compulsions

An anthropological approach towards embodiment suggests that our bodies are not merely objects to be studied as they relate to varied cultural realms; rather, they are the subjects of cultural experience (Csordas 1990). Through this lens, the body is understood as the site of all experience (Csordas 2011). To be embodied therefore, is to inhabit the world in a particular way, wherein our bodies are at once the source of “personhood, self, and subjectivity” (Mascia-Lees 2011, 2). The body is thus never separate from its lived experiences; in essence, embodiment holds that the body is *lived*, and it is “not just one thing *in* the world,” rather it is the “way in which the world comes to be” (Leder 1992, 25). Being that painful obsessions and compulsions constitute a form of experience, the suffering they cause is necessarily always embodied. I will now offer several examples from my ethnographic data to highlight the diverse ways that suffering is embodied within the life-worlds of individuals with painful obsessions and compulsions.

Peter

Peter is a husband and a father in his early forties. Easy to speak with and yet, a self-described introvert, he enjoys creating music and expressing himself through the arts. His love and devotion to his family became immediately obvious during the time I spent speaking with him. It also became clear that he had endured painful obsessions and compulsions for a long time. They began as a teenager, with the incessant urge to make sure that all the doors and windows were locked. During that time period, the Gulf War had just begun and Peter was fearful that if he didn't make sure the doors and windows were sealed shut, a chemical attack might occur during the night and poison gas would seep into the house and harm his family while they slept. At the same time, public discussion regarding HIV and AIDS was becoming more prevalent, with

media campaigns warning of the virus. Peter had always had a habit of biting the skin around his fingernails, and he became convinced that the raw skin on the sides of his fingers had been somehow exposed to the virus and that he had contracted HIV. He constantly worried that he would infect those around him and was fearful of bleeding on or near others. Even multiple blood tests showing he was HIV-negative did not ease his agony as he believed that his results must be getting mixed up with those of a healthy person. He felt constant shame and guilt throughout these years because he had been unable to verbalize these experiences with anyone, and it had felt almost like “he had been living a lie”. In fact, he told me that if he could only use two words to describe the experience of it all, the first word would be “shame” and the second would be “guilt”.

Gradually, these early obsessive-compulsive tendencies shifted more towards the background and the worst manifestation began to take hold in his early twenties, from which he still suffers today. It has been labeled POCD or pedophilia OCD. He recalls working in a record store and becoming intensely uncomfortable whenever children were around: “I started to wonder am I standing too close to them or are their parents going to think I just looked at them the wrong way?” Being on public transportation became increasingly difficult for him, particularly if there were schoolchildren around. He would worry that if his leg brushed up against someone else’s that he might be inappropriately touching them: “I would just try to make myself smaller and smaller and smaller. And I didn’t know where to look as well because if I looked at one of the children, I would feel really guilty and worried. Thinking should I have done that? Did I stare at them? Did they think I was staring at them like a pedophile?”

Eventually, his painful obsessions and compulsions intruded into his life in an even more horrific of way. Peter explains:

And so now, the worst thing – I thought that it couldn't possibly happen but now, it focuses— since we've had children, I get really worried all the time that I have... done something wrong— done something bad to them. Like say for instance when I change their diaper, I often think 'Oh, ugh, maybe I didn't need to wipe that extra time, why did I do that?' Or even when I hold them, I think 'Oh, my hand might be in the wrong place I should take it away.' And if I don't take it away I think, 'Wow that's pretty much the same as abuse, like I've-I've-I've actually abused my own child.' And so *that*, thinking *that*, is really hard to live with. Because that's the worst, to *me*. You know, to *me*, being a pedophile, or molesting, or harming, or abusing a child, *that* is like *the* worst thing anyone can do. And you can be forgiven for most things, but not that. It seems so unbelievable, and nonsensical, but it's real because you know, in a *real* way it destroys... it destroys a big part of my life. Like intellectually I can understand it doesn't make sense. But emotionally, you know, I feel *s-so bad*. Because I think to myself, 'Well, what do I think about people who abuse children, or beat women?' I think that it's terrible and I don't think I could ever be – you know I would never want to be in their company. Even if they felt really sorry and even if they wanted forgiveness. And I'm thinking well, if it was anyone else, I would want nothing to do with this person.

Lydia

Lydia is a wife and proud mother in her early forties. She comes across as soft-spoken but confident, sensitive, but strong with conviction. She loves to sing and to learn. Her experiences with painful obsessions and compulsions began as a child, most prominently taking the forms of religious, contamination/health and sexual obsessive-compulsive tendencies. She remembers obsessing about verses in the bible and negotiating with God in an attempt to rid herself of tormenting thoughts. She also recalls the times she went to the emergency room or when she had called nurse help lines out of fear that she was having a heart attack. More recently, when Lydia cleans her home with bleach, she becomes convinced that she has not properly washed the bleach from her hands and that it will somehow seep through her baby's bottle while he is feeding and fatally harm him.

By far, the worst painful obsessions and compulsions Lydia endures are sexual. She explains:

So, with the sexual obsessions, uh... it's really scary to talk about this. Like when I was in my twenties... it was awful and I didn't know what was going on with me. I thought I was a psychopath and a predator and I thought I was this *horrible* person and I would

have what I call these freeze spells where I would just freeze from fear. I had guilt for years and years. Like, I hated myself because of these obsessions and when I walked around hating myself and feeling guilty, I thought, ‘Nobody wants to be friends with me. Nobody wants to have anything to do with me’. So, I would avoid people really, just because I thought I was such an awful person. I waited so late to have children, because I was avoiding them for so long. I mean if I saw a child in the grocery store, down an aisle, I would avoid that aisle until the child was gone and then I could come back around. I noticed with my son, like I would hold him at his chest to avoid touching anything lower than that, you know? And I realized that that was a compulsion that I wasn’t even aware that I was doing. But yeah, I would have this fear of touching him inappropriately so I would hold my hand at his chest.

Spikey

Spikey* is a thirty-year-old woman. She is full of zest, never afraid to say exactly what she’s thinking. Exuberant, charming and maybe even something of a “rabble-rouser,” as she likes to say. When I first met her, she greeted me like she might an old friend, quickly endearing me to her. Spikey’s experiences with obsessive-compulsive tendencies began as a teenager around the age of fourteen. They first intruded upon her life when she was in the middle of swallowing.

She described to me an instance in which she was on an airplane headed to Florida with her family for vacation. All of a sudden she became increasingly focused on the bodily process of swallowing. She explained how she became so focused on it, that it no longer felt like an automatic process, something that your body just unconsciously does. Spikey said, “I was jolted because I started noticing that I was swallowing something. And so what happened in that moment is... you know I got that- that jolt and... I was like, “Uhh oh my god I can’t swallow, because I’m focused on swallowing, this is really effortful, this is really annoying, I can’t deal with this”. She related the experience to what a dental procedure might feel like where you are unable to swallow because a dentist is working

*Spikey is a play on words, referring to the term “spiking”; which is used to describe an intense and unexpected bout of obsessive-compulsive symptoms.

inside your mouth – a sort of intensely uncomfortable instance in which you become acutely aware of one of the body’s automatic processes and it becomes laborious and relentless.

Before long, this experience morphed and latched onto other automatic processes such as breathing, sleeping and speaking, with the added constant fear that at any moment she could be jolted from everyday life into an unwanted and agonizing procedure of monitoring her bodily processes. Spikey explains:

‘Oh shit, I’m breathing.’ And then I’m focusing on it, right? So it’s happening, and I want it to happen naturally. But then it doesn’t happen naturally because I’m thinking about the automatic process of it. (On speaking) I know that I’ll still be able to, right? But, *but* it’s gonna be hard, because I’m gonna be try- you know I’m gonna be thinking about the words coming out um... so because I’m thinking about the words coming out, I have to kind of... fumble for what I want to say. I’m so preoccupied– So like, I was trying to talk to my six-year-old niece yesterday. It became really effortful. And I was like, gasping for air trying to speak and what I wanted to say I didn’t say, because I was so preoccupied with not wanting to think about the process of speaking, and then I started actively thinking about it.

As these examples demonstrate, painful obsessions and compulsions are highly heterogeneous in how they present for each individual (Sookman, Abramowitz, Calamari, Wilhelm & McKay 2005). These examples also demonstrate the myriad ways in which suffering can be embodied. Guided now by these excerpts from my ethnographic data, we can identify sensorial qualities of embodied painful obsessions and compulsions and the ways they transcend the limits of being symptomatic of a mental disorder.

For instance, Spikey describes how a sudden awareness comes over her regarding an automatic bodily process such as blinking, breathing, or speaking for example. Next, her attention selectively focuses in on the bodily sensations of what blinking, breathing or speaking *feel* like. For Spikey, in these moments of acute sensory awareness of her body’s processes, they begin to feel laborious because in the moments before this awareness occurred, her bodily

processes functioned subconsciously; however, after her awareness shifts and she begins to focus on a particular sensation occurring in her body, she feels like she is now in control of that sensation even though, paradoxically, she does not wish to be.

In contrast to Spikey's radically embodied experiences, Peter and Lydia experience sensorial distress differently. To illustrate this form, Lydia explains:

I don't talk about it much. But you actually feel sensations in your body that you make you think that you're attracted to somebody... that you don't feel you should be attracted to. And I didn't know about that for years and years, and that's one of the scariest things about sexual obsessions. And you definitely feel that in your body and it's terrifying because it's like, 'I actually am a sexual predator because I have this sensation'.

Further, when I asked her what was most distressing about this experience she said:

Oh, I don't know what was worse... I think the sensation was really. Probably if you could categorize it, that would be at the top. Because that was evidence to me that I was a predator, you know? And then that just led to guilt and self-hatred and... but the thought would come first, then the sensation, then the guilt and the shame and they were *all* really interconnected and they were *all* really distressing. I think the sensation was probably the top, but the other two were close behind it. Yeah, it was all really awful.

Like my research subjects, I also experience a great deal of anguish in relation to the sensorial qualities of my obsessive-compulsive tendencies. For instance, I fully comprehend that touching light switches in my home will not cause me physical harm. I will not get sick or die because I touched that light switch. However, I also know, *because I feel it happening*, that an excruciating physical sensation will result from contact with that object. Yet, this physical agony that I am describing is not pain as we understand a cut or burn to be. Instead, what happens is that the site of contamination on the body instantly becomes heavy; the skin crawls; the flesh tingles within as if the bodily matter is itself trying to push away from the contamination – to endure this sensation is chaotic and inexplicably distressing. Thus, it is not so much the thought of having touched the light switch that torments me as it is the actual physiological chaos felt from touching it, and that is the reason I avoid it. And no matter how much I rationalize that nothing

bad will happen from touching the light switch or the doorknob or the chair or any other thing I know to be contaminated, the physical sensation will *still occur*. Further, this sensation is so distressing that I will tolerate other physical pain in order to alleviate it (e.g. I will hold my hands under scalding hot water until the sensation is gone).

Additionally, along with these forms of sensorial distress, sufferers also experience distress as it pertains to our emotional reactions towards our obsessive-compulsive tendencies such as guilt, shame, anger and sadness. These emotive states are embodied as well, in the sense that they are etched into our bodily experience and the ways we express ourselves and interact in our environments, occurring before, after and in-between painful obsessions and compulsions. Peter emphasizes the feelings of helplessness that sufferers feel on daily basis and the loneliness of not being able to explain to others what obsessive-compulsive tendencies feel like:

One of the most difficult things about it is not being able talk about it. And people not being able to see it. They just think I'm miserable, they just think I'm grumpy, they just think I'm rude or lazy or that I can't cope with any stress. You're completely powerless. There's nothing you can do.

In our understanding of embodiment, recall that the body is experienced as the site of one's personhood, their self, and their subjectivity. However, by virtue of being an embodied self, one that is "bound up with, and directed toward, an experienced world" (Leder 1992, 25), embodiment also constitutes the "precondition of intersubjectivity" (Mascia-Lees 2011, 2). That is, a lived body is contingent on its relationship to other embodied selves, other things, and an environment (Leder 1992, 25). By these measures, we are confronted by an additional dimension of the embodied suffering caused by obsessive-compulsive tendencies as it relates to our conceptions of personhood, self, and subjectivity and our relationships with others.

For instance, on the condition of being a person emplaced within a historical and cultural context, lived selves are expected to embody particular social and moral values. However, for the

individual with obsessive-compulsive tendencies, this embodied struggle to be-in-the-world in accordance with the values they deem personally significant is experienced within the sufferer's body as being at odds with the sensorial experiences they endure: Peter and Lydia *feel* in their bodies that they have sexually abused someone, even when they have not. They *feel* guilty and ashamed of a crime they have not actually committed. Regardless of their morality, they *feel* immoral. As Peter told me, "It's a conflict really because I have to live with myself. So I feel like I'm sort of, taking care of ... an abuser. I'm feeding an abuser, you know, I'm ... you know, I'm this, this *abuser* that I think, that I feel is inside of me". Similarly, I *feel* in my body that I am contaminated and that I can contaminate others, even though I know I cannot. Thus, despite the way we rationally appraise ourselves and the world around us, our embodied knowledge of real threats – as they are given in our experiences – stand in perpetual conflict with what can be rationally known.

Additionally, because of our embodied knowledge of these threats, we experience an overwhelming sense of responsibility for them, thus causing us to conduct ourselves in a manner that ensures the well-being of ourselves and/or others. *This* is why Peter makes himself smaller and smaller on the bus. *This* is why Lydia refuses to hold her son below his waist. *This* is why I wash my hands. In these ways, our bodies inadvertently become the tools by which we alone are responsible for protecting others from the most potent social threats of our time: be it demons, chemical warfare, HIV or pedophilia.

Because the hyper-responsibility caused by obsessions and compulsions is shaped by contemporary social anxieties, an interesting parallel is drawn between sufferers and a community of individuals called the Elder Brothers who live along the Sierra Nevada de Santa Marta mountain range in Columbia. As children, the Elder Brothers are taught that their rituals

alone maintain the cosmic balance of the world and every day, these individuals pray for the protection and well-being of all humanity (Davis 2008). In many ways, the Elder Brothers' embodied responsibility for the world can be likened to the experiences of those with painful obsessions and compulsions. Like these individuals, sufferers are also keepers of the world; the main difference between them is simply that one type of embodied experience is a form of socially acceptable ritualized belief, whereas the other is typically accounted for in psychiatric literature as being pathological. This parallel serves to disrupt common public perceptions of the obsessive-compulsive experience, whereby obsessive-compulsive tendencies are often viewed by others as quirky, annoying, rude or crazy.

Importantly, these examples of *lived through* painful obsessions and compulsions show the plethora of ways suffering is embodied, occurring for the sufferer not merely as mental or physical sensations, but rather, as a unified experience of the whole self that is always in relation to multiple others. Consequently, through a phenomenological model of parsing out features of distress, as they are given in experience for the sufferer, we may begin to reconfigure our understanding of the significance of what is typically understood as the obsessive-compulsive event.

First, a dis-ordering of an individual's body occurs through a synthesized bodily experience of distress. Next, the individual then attempts to re-order themselves by engaging their bodies in some type of act such as praying, washing, checking, or counting for example. Additional distress arises however, from the inability of these acts to alleviate the dis-order or to sustain order. Importantly, the resultant anguish of the synthesis between the segments of one's body is "not produced gradually and through accumulation"; as Merleau-Ponty (2012) argued, "I do not assemble the parts of my body one by one. Rather this translation and this assemblage are

completed once and for all in me: they are my body itself” (151). In other words, bodily synthesis is never achieved through “the application of mental rules and categories,” rather it is achieved pre-consciously (Leder 1992, 26). As well, while the various sensory abilities of our bodies do indeed navigate ordinary life through distinct phenomenal realms, the body as *lived* ultimately always “weaves these together into one world” (Leder 1992, 26). Understanding the experience of painful obsessions and compulsions in this way helps to resist a dualistic division of obsessive-compulsive tendencies into separate categories like the mental, the physical or the emotional. Accordingly, this enables an acknowledgement of the whole individual and their complete and subjective reality.

In sum, I have argued for an embodied approach because it seeks to establish a lived understanding of painful obsessions and compulsions rather than a presupposed or codified one. Additionally, it is capable of revealing features of suffering which are misrepresented and/or unacknowledged by the predominant clinical view of OCD, and in effect, this view offers great implications for the treatment and care of individuals suffering from these debilitating experiences.

2.5 Particulars in a crisis of care

Within the psychiatric community it was once believed that diagnosing a patient with obsessive-compulsive disorder was the equivalent of them receiving a life sentence (Lack 2012). Before the 1960s, the disorder was considered an “intractable condition” and prognosis was poor due to the failure of traditional therapies (e.g. “talk therapy”) to provide relief from symptoms (Olatunji, Deacon & Abramowitz 2009, 172). While the root causes of the disorder remain largely unclear today (Sookman 2016, 10-11), specific treatment strategies have been developed.

Currently, the primary interventions for the treatment of obsessive-compulsive disorder include cognitive behaviour therapy (CBT) with exposure and response prevention (ERP), and pharmacotherapy with serotonin reuptake inhibitors (SRIs) (Lack 2012). Importantly, research has indicated that behaviour therapy is more effective than medication overall, and behaviour therapy combined with SRIs is more effective than treatment with medication alone (O’Connor et al. 2006; Foa et al. 2005; Romanelli et al. 2014). In particular, specialized CBT which involves “specific cognitive therapy and behaviour therapy interventions that are combined throughout treatment *and that address subtype specific characteristics*” is regarded as “the first-line treatment of choice for OCD” (Sookman 2016, 12, 33).

Although these treatments demonstrate great advances in care, there is a dearth of experienced clinicians and resources available to adequately diagnose and treat obsessive-compulsive tendencies (McKay et al. 2015). Many individuals never receive CBT (Goodwin, Koenen, Hellman, Guardino, & Struening 2002). Or, the forms of CBT they do receive are largely inadequate (Shafran et al., 2009). This ultimately leads to patients being erroneously labeled as “treatment-resistant”, resulting in profound and long-lasting consequences for these individuals (Krebs & Heyman, 2010). Moreover, because there is a troubling absence of knowledge

regarding how obsessive-compulsive tendencies take form, many patients are misdiagnosed or receive unnecessary and iatrogenic forms of care. As a result, there exists widespread disillusion and resentment towards mental health practitioners in general, and some patients are fearful to return to treatment or avoid it altogether. I include the following excerpts from my ethnographic interviews to highlight these issues.

Anita describes her experience with medication:

I got arrested on medication. It made me crazy, it made me feel like I couldn't get caught and stuff like that. It gave me this false illusion, it was weird. I mean I don't know, I was not scared of anything. I mean I still wouldn't touch dirt because I still had my OCD really bad, but I mean I wasn't scared of things that normal people would be. Like, I thought if I ran in front of a car, I'd survive.

As well, she explains the resentment she felt regarding her treatment with CBT:

He gave me sheets that I'd have to fill out at certain times of day, like how I would feel at that time of day. He would give little exercises to do, like try not snapping at the door and how long it would take me before I started snapping at the door, like how long I could refrain from doing that and how I would feel at that time. And I did for a bit but I couldn't just be like "Oh, okay I can just wait because of the sheets." It was just like, no! This is an extreme example but it's the only thing I can think of with the same emotional kind of thing. It's like if someone is about to get hit by a car, and you're right there. Like, that feeling of having to save them you know what I mean? You have to do it. You can't just turn your back. I felt like the paper was me turning my back. Because I had that fear, it was kind of like a survival thing, like I had that need to flee. I had to do it, I couldn't stand there and not do it. Because I thought it was my family's life, right? If I didn't do this then it's my fault. They're trying to stop me from doing this to save my family. And I was really resentful towards them, I could see where they were coming from but at the same time I was just like, "You haven't experienced this so don't talk to me about this." And I felt really mad about that. I understand they're trying to help and that's their job. I get that. But I was just like, "No you don't understand". Because then if I stop doing something and something happens to my family, it's my fault and I'm gonna have to live with that guilt forever. And that's what it was. I felt like people would actually die. Like people would come in and murder my family with knives and stuff. And when I imagined it, it was a really gruesome death.

Frieda was misdiagnosed with an eating disorder because her obsessive-compulsive tendencies revolved around fears that her food had been contaminated; even though she was hungry and wanted to eat, she avoided eating because she was convinced her food had been

poisoned with chemicals. As a result, she lost a dangerous amount of weight and had to be admitted into the hospital. She explains the challenges she faced because of her misdiagnosis:

When I was in the hospital I felt like they didn't understand because, they were pushing anorexia on me. Or they would weigh me and they wouldn't let me see what my weight was and I was like, "I don't care, it's not about my weight right now". And then there was another psychologist who came in and he was – I didn't like him at all. He tried to convince me that I had anorexia. And I was like, "I can't tell you enough that I would rather be 100 pounds overweight than have this problem". Like, it's not about weight, it's about fear you know? Yeah, he just kept being like "Oh we can give you this drug, we can give you that drug and I was like, "I don't want drugs I just want you to tell me what's wrong with me so I can fix it".

As a teenager, Jade was treated for her obsessive-compulsive tendencies. However, the care she received ultimately exacerbated her suffering, leaving her deeply traumatized and fearful of seeking more treatment as an adult:

Sometimes I get these images of something really scary. Like, I'll see horrible images of demonic faces or evil things and when I was younger I started to believe they were really there. But as I grew older I realized it was just my intrusive thoughts. Even still, I see these things and I become really nervous, like I'll be standing doing something and I'll get a flash of a face or a figure as though they were standing behind me and I always look to make sure even though I know there is nothing there. And I start to become afraid because sometimes I really feel like they are there. At the time, when I was seeing a psychiatrist and a counsellor, they told my parents that I had made up some kind of fantasy world in my head and that's how they explained me experiencing these things. They knew I had OCD but they only recognized my contamination fears. They never gave me CBT for it though, just medication. And eventually they labelled me as treatment resistant and I was admitted into a psychiatric ward for children against my will. That was one of the worst experiences of my life. To this day, I get flashbacks from being in there. I kept telling them I wanted to leave but they made me stay there for three days and then after that, they couldn't legally keep me there. I hated them for doing that to me. I never went back to them or anyone else. I am so afraid that could happen to me again. I don't tell doctors about my experiences anymore. Nobody gets it. It makes me really sad. Some days I want so badly to go and talk to someone but I can't bring myself to do it. It's too scary and I honestly think they wouldn't help me anyways.

Jade gave me an excerpt from one of her journals to help explain the lasting effects this experience had for her. Tragically, the trauma inflicted by her treatment became part of Jade's embodied experience:

Sometimes when I close my eyes I am suddenly jarred violently back into that room. Back into that horrible smelling room with the stained walls and the graffiti scratched into the mirror. The words spoke of all the pain that had passed through there before me. I am alone

and abandoned and scared. I am that 16-year-old girl again, curled into the corner of the room staring at the nothingness which surrounded me and trying to block out the wails of the other patients. No not the patients, the other people who have hearts and lives and who are trapped in this sanitary hell with the white covered devils who creep quietly into the rooms and force those awful little pills down your throat choking you, choking out any kind of human feeling left in you, except of course for the dull pain. And you realize suddenly, frightfully, that you have somehow crossed over into a mere shadow of the one you used to be. The one who loved to laugh and watch butterflies and feel the sun on her face. But eventually I come back, I leave that room in the shadowy places behind my eyes. In the grey matter where it lives, permanently etched. But I am always left wondering, when any of us go into those places, do we ever really leave? You can take the patient out of the psychiatric ward, but can you take the psychiatric ward out of the person?

My intention in outlining these issues relating to the treatment of individuals diagnosed with obsessive-compulsive disorder has not been to undermine the work of clinicians who are dedicated to improving the quality of life for their patients; nor has it been to trivialize the efficacy that treatment has had for a great number of individuals. As Lydia reminded me, it may have taken her years to find a therapist who finally understood her and her experiences, but once she did she felt like she had finally been released from prison.

Instead, I have sought to draw urgent attention to the larger implication left in wake of these issues: a crisis of care. When I attended the Annual OCD Conference as a site for my research, the overwhelming message for sufferers from researchers and proponents of treatment facilities was that treatment for OCD is not only available, it works. And yet, each of the numerous sufferers I have spoken with have been tragically left wanting. Moreover, research indicates “approximately 50% of patients do not respond optimally to CBT even when combined with pharmacotherapy. This includes patients who refuse to participate or drop out of ERP (20%), do not improve (25%), or have relapse at follow-up” (Sookman 2016, 38). Thus, not only are best-practice treatments poorly accessible, for many individuals they are disturbingly ineffective.

2.6 Being *here* and getting *there*

My research findings point overwhelmingly to a crisis of care regarding the treatment of painful obsessions and compulsions which has deeply impacted many individuals. While it is clear that lack of access to specific treatments with demonstrated efficacy represents a major barrier to successful and sustained recovery for sufferers, I argue that accessibility of these treatments is not the only key factor.

I have discussed how features of suffering in painful obsessions and compulsions far exceed what the current clinical picture of OCD can account for. For these aspects of suffering to have been lost within mainstream psychopathology of the disorder represents a critical negligence within best-practice treatments to identify crucial elements of an individual's painful experiences. I argue that this is in part due to the conceptual model upon which cognitive behaviour therapy is based. Sookman (2016) states, "Among the aims of CBT is to modify the personal meanings of thoughts from threatening to benign. After successful treatment, distressing obsessions should have declined and the associated avoidance and compulsive behaviours become absent (preferably) or insignificant" (32). However, a phenomenological examination of the embodied experience of lived painful obsessions and compulsions problematizes this theoretical model. The suffering intrinsic to these experiences cannot be reduced to the understanding that if only our beliefs change, we will have relief. The obsessive-compulsive experience is one of bodily synthesis. Indeed, the thoughts and images which we perceive as distressing constitute a vital role in our experiences of suffering; but they do not singularly cause our pain. To disregard our embodied sensations of distress is to negate our *lived through* experiences.

In one study examining patient utilization of CBT, fear was cited as a main reason for failing to initiate CBT, as well as a main reason for prematurely dropping out of treatment (Mancebo, Eisen, Sibrava, Dyck & Rasmussen 2011). While fear is certainly a prominent factor, I suggest that the reason many individuals refuse or drop out of CBT is because of how painful it is to endure. Simply put, it hurts in ways that have yet to be fully understood and accounted for.

Accordingly, it is not that we fail in the implementation of best-practice treatments, rather, it is that they have failed us; and I insist that the potential for treatment modalities to adequately alleviate painful obsessions and compulsions will only be realized if embodied suffering is acknowledged. The intervention I seek with this research has been to direct serious attention to the lived experience of painful obsessions and compulsions and to demonstrate above all, how embodied suffering caused by these experiences far exceeds the dominant framework in which they are encased; thus, they require modalities of care which will adequately account for embodied forms of suffering. Therefore, my research findings emphasize an urgent need to radically transform the way obsessive-compulsive tendencies are conceptualized.

In closing, it was my autoethnographic authority that first attuned me to the failure of obsessive-compulsive disorder's categorization as a mental disorder to fully account for the ways painful obsessions and compulsions are embodied. If anthropology teaches us anything, it is that there are many ways of being-in-the-world and these lived accounts of suffering foreground the necessity of taking the notion of *embodied care* seriously. In other words, lived accounts justify a re-imagining of care that focuses not merely upon our "pathological" pieces, but instead addresses our whole-bodied selves. Thus, the inherent value of anthropological knowledge lies not in the application of reductive formulas, but in its ability to draw out possibilities of analyses which attend to the substances of life (Geertz 2005). In the same ways anthropological work

demands legitimacy for cultural truths like those of the Elder Brothers, who intend to keep the world regardless of who believes they do, so too does it necessitate the same ethnographic generosity to experiences like painful obsessions and compulsions. And thus begins the task of drawing out alternate possibilities of *caring*; ones that will reciprocate to sufferers the same dedication to detail that *they* exhibit whenever they engage in their own ways of keeping their worlds in order.

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