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THE UNIVERSITY OF VERMONT

ANTHROPOLOGY

UNDERGRADUATE HONORS THESIS



MISUNDERSTOOD:
PHENOMENOLOGICAL RESEARCH OF
THE ILLNESS EXPERIENCES OF
INDIVIDUALS WITH “PURE O” OCD

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May 18th, 2021

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Abstract

Even with OCD being estimated at a worldwide prevalence rate of 2%, the various manifestations of the disorder aren't well known in modern society and the mental health fields. The purpose of this study is to examine how individuals with primarily obsessional ("Pure O") Obsessive-Compulsive Disorder, a rarer form of OCD, access information about the disorder. Also, it investigates whether the ways OCD is portrayed in the media might hinder diagnosis for these individuals. The study's 10 survey questions, related to individuals' experiences of realizing their condition and accessing effective treatment, helped to generate qualitative data for analysis. It discusses the importance of recognizing how relatively-new internet chat groups, that offer the ability to freely discuss with like-minded individuals, have affected individuals' experience of their illness. This thesis argues for the importance of trained mental health professionals who can identify "Pure O" and treat it with Exposure and Response Prevention (ERP) therapy and/or assisted medication. It also highlights the humanness of these individuals and calls for more accurate portrayals of "Pure O" in the media.

Key Words: Obsessive-Compulsive Disorder, Online Support Groups, Media Representations

Chapter 1: Introduction

Looking to my left, I notice that there is a girl sitting not too far from me. *“She’s really pretty. Do you want to kiss her? Look at her lips, they are so glossy. You wouldn’t be noticing that if you weren’t gay.”* I quickly avert my eyes and stare at the ground. Her lips flash before my eyes for a minute. *“Am I aroused? Am I aroused? Am I aroused?”* There is a deafening rush that drowns out any sound around me as panic courses through my body, and I feel like I’m going to vomit. Everything that’s happening around me falls away, and all I’m left with is myself, my thoughts, my sensations, and my emotions. *“It’s just a thought. It doesn’t mean anything. It’s just a thought. It’s just a thought. I’m not gay.”* Disclaimer, this is personal example of the homosexual obsession that can occur in “Pure O” OCD. Individuals with this theme aren’t homophobic, rather, they fear that their own sexuality is changing to something other than it is. Individuals who fall on the LGBTQAI+ spectrum can also have this theme.

This project is a blending of autoethnographical bits like the one above, and qualitative data collected from survey participants who have primarily obsessional (“Pure O”) Obsessive-Compulsive Disorder. It helps to bring light to a somewhat unknown disorder, as well as breakdown some of the stigma about mental illness in general. The biosocial community (a community that bands together over a shared diagnosis) of “Pure O”, will benefit greatly from this research simply from having more research on it. With my subjects stories as a guide, I was left with the responsibility to bring in anthropological theories to analyze and interpret the data, mainly through the medical anthropological lens. Survey responses and my own reflections were used to convey the complex lived experiences of those with “Pure O”, including where information was accessed about the disorder, what treatment was like, etc. At first glance, it may

seem like my writing style is a strange mixture of personal reflection and qualitative data, and that's because it is. I will note however that in every anthropologist's case, their ethnography is influenced by their life histories, conscious and unconscious ignorance, and unique connections. The only way this is different is that the process is out in the open.

Themes of biosociality (Friedner 2010, Halverson 2020) are explored here, as well as virtual peer relationships. This paper doesn't claim to explain definitively why there is a lack of understanding around "Pure O", rather it seeks to provide evidence that it is so. While more psychological studies are needed in psychology, it is important that there are also more studies in anthropology on "Pure O", as unlike in psychology, anthropology conveys the "individual in the illness" rather than the "illness in the individual". For example, looking at each participant's lived experience of their existence with mental illness instead of merely studying just how the illness presents in individuals. For a mental illness that has such few representations in the media, describing phenomenological experience is an important step in reducing the silence around the disorder. Not only would this study make the condition more visible to the mental health profession, but it also may help individuals with the disorder feel more comfortable speaking about their illness experiences.

I imagined connections would emerge through survey responses, and then my own experience could fit within that. Since this research was completed through online surveys due to COVID-19 as well as to reach a more global population, "deep hanging out" or participant observation wasn't possible. However, surveys were beneficial to this project because people with "Pure O" OCD often feel isolated, or like nobody understands them, and have a hard time talking about their experience to individuals without knowledge of the disorder. This is partly due to the popular understanding of OCD that originates through media portrayals: i.e. a person

who is “obsessed” with being neat or tidy and/or gets freaked out by germs. This definition doesn’t include the forms of obsessions (intrusive thoughts/urges/sensations) and compulsions (avoidance behaviors/reassurance-seeking/mental rituals) typical of “Pure O”, so it’s easy for individuals to feel misunderstood. Individuals with this disorder rarely tell others about their struggles (which will be shown in the results of this study), and instead mostly share openly within online support groups. Focusing on this support group vs. real life phenomenon was important to me, as the popular understanding of OCD may prevent some individuals from receiving proper treatment. Given this, the best way to research was to meet individuals where they were most comfortable, in support groups. I hoped that the survey responses I gathered would be rich with individual’s phenomenological illness experiences. Luckily, that was the case, as the direct quotes I will present will show.

This study also questions whether the ways in which obsessive - compulsive disorder (OCD) is portrayed in the media and described in educational literature might hinder diagnosis for individuals with “Pure O”. This thesis also explores how individuals with “Pure O” first realize that they have the condition and whether patients’ access to therapists who can recognize “Pure O” affected how long it took for a diagnosis. It examines how relatively-new internet chat groups, which offer the ability to freely discuss with like-minded individuals, have affected their experience of their illness. Utilizing a research design informed by phenomenology and purposeful sampling, surveys and interviews gather qualitative data about factors impacting access to treatment for Pure O. This thesis research directly contributes to reducing mental health misinformation and stigma. OCD is different than other mental disorders in that stigma usually reduces the disorder to a quirky caricature or a personality quirk, instead of being seen as crazy

or dangerous¹. Nevertheless, it is damaging. I am hopeful that my findings will provide a starting place for filling the gaping hole that exists around “Pure O” OCD research in the anthropological field.

Knowledge is power, but the lack of it can seriously impact those who need it most. The literature around this illness is lacking in general. If I’m not mistaken, this will be the first scholarly work on the subject in anthropology. I am hopeful that this research can help misinformed individuals (mental health professionals, friends, family members) understand a bit more about “Pure O” OCD. That in turn can help individuals with “Pure O” with being seen and understood, which is especially imperative in the therapist-client relationship. Taking a phenomenological approach to this research was necessary because it gives that insider perspective to an illness so often silenced. I will do my best to distribute this study to participants, as well as make it accessible to those who need it. This research should be continued, expanded upon, and taken in new directions as there is so much to be studied here!

¹ As say with Schizophrenia or Borderline Personality Disorder

Chapter 2: Literature Review

OCD Disease Symptomology

Obsessive-Compulsive Disorder is a biomedically recognized psychological condition, characterized by the presence of both obsessions and compulsions. Obsessions are “thoughts, images, or impulses” that repeat in the mind of an individual. (Seibell & Hollander 2014) For example, obsessively fearing that one will act violently towards a loved one or fearing that they will cheat on their partner. Common obsessions are thoughts of contamination, unwanted sexual or aggressive thoughts, thoughts of losing control, scrupulosity, and thoughts around perfectionism. Compulsions, or rituals, are defined by “repetitive behaviors or thoughts” that occur in response to their obsessions (Fiske & Haslam 1997). Commonly recognized compulsions are washing, cleaning, checking, and repeating, as well as reassurance-seeking behaviors. Obsessions are “ego-dystonic,” meaning they are distressing, repugnant, or inconsistent with the rest of who an individual is. Individuals with “Pure O” OCD have varying levels of insight, which allow some to inherently know their obsessions are ego-dystonic.

The cycle of OCD is created when an association is made between an obsessive thought, and the fear it brings. In order to relieve that fear, the individual “has” to perform a behavior that decreases the anxiety; in their mind it is the only thing that will help (“What is OCD”). Every time their OCD is triggered, they perform that relieving compulsion. As this happens overtime, neurons in the brain are trained to form a deeper connection between the feared stimulus and the response, subsequently increasing the illness. Because of this deepening neuronal pathway, over time OCD symptoms worsen exponentially, like “spikes”; an episode, or “spike” is defined as a period of time where a person with OCD has a heightened amount of obsessive thinking and

subsequently performs more compulsions to cope (“What is OCD”). There has been minimal research into the lived experiences of OCD (Fennel & Liberato 2006).

The cause of OCD is unknown. There could be a possible autosomal dominant genetic inheritance, but OCD could also be polygenetic. (Nestadt 2000). According to a study at Johns Hopkins, family members and monozygotic twins were found to have at greater risk of procuring OCD than strangers. Another cause may be a mutation created when fighting off strep throat bacteria. Children who are infected by Group A streptococcus have been linked to a genetic mutation associated with an autoimmune response known as Pediatric Autoimmune Neuropsychiatric Disorder associated with Streptococcal Infections (PANDAS) (Fiske & Haslam 1997). A third theory pertains to every human’s natural tendency to perform culturally meaningful and ritualistic behavior (Fiske & Haslam 1997). OCD could be a malfunctioning of the prearranged neural pathway of ritualistic inclinations. For OCD, a single defining cause has yet to be identified. In other words, OCD can be seen as symptomatic for what makes us human.

“Pure O” OCD

Primarily obsessional OCD is a lesser-known manifestation of OCD that’s popularly referred to as “Pure O,” a misnomer from when it was believed that this form was purely obsessional (Williams et al. 2011, 2013). In reality, alongside obsessions (taboo and intrusive thoughts/images/urges), compulsions usually take cognitive forms or forms not readily visible as abnormal to others (e.g., mental rituals, avoidance behaviors, somatic checking behaviors, and reassurance seeking). Because popular & medical descriptions of OCD often focus on obsessions about cleanliness/ orderliness and compulsions such as handwashing or counting (National Institute of Mental Health 2020), forms of OCD such as “Pure O” may not be readily diagnosed,

which is unfortunate because the debilitating symptoms of “Pure O” can be significantly improved through exposure-based therapies (Williams et al. 2013).

Scholarly literature on “Pure O” OCD is limited in both psychology and anthropology. Works by Williams and colleagues (2011, 2013) provide a foundation. Additionally, Rachman (2007) characterized the content and nature of intrusive thoughts, by examining the formation, duration, and impact of peoples’ first-hand experience. She found that, though the content of the images might be unique to an individual (e.g., fear of insanity or mental contamination), intrusive images that are repugnant or unwanted cause similar psychological distress and disability across the board. Clark et al. (2014) found that obsessions of harm/aggression, sexual deviance, and blasphemy were globally less reported than more traditional forms of OCD - which may have been attributed to the lack of representation of “Pure O” within diagnostic assessment tools. This speaks to the paucity of “Pure O” reports, which may reflect the rarity of the disorder or may indicate better reporting methods are needed for this form of OCD to truly estimate the prevalence of the disorder.

Universality of OCD

Though once considered a rare disorder, current research suggests that an estimated 2% of the worldwide population will experience OCD at some point during their life (Fennell & Boyd 2014). Although individual presentations of OCD are varied, the annual prevalence rates, age of onset, symptom profiles, and rate of co-occurring disorders seem to be similar globally (Lemelson 2003). Williams and Jahn (2017) noted that OCD remains globally understudied in ethnic and racial minorities. Until three years ago, there had not been a single study looking into OCD in African-American youth. Brakoulias et al. (2019) highlights global inequality in access to effective OCD treatments, such as, Exposure and Response Prevention (ERP) psychotherapy.

ERP effectively reduces the severity and frequency of both obsessions and compulsions in individuals with OCD and results in improvements in mood, work, and social adjustment (see also Marks 1997; Hezel and Simpson 2019). Because OCD does not vary geographically, the need for multinational synchronicity regarding OCD guidelines and practices and companion pharmacological treatments is significant (see also Casale 2019).

Anthropologists have focused on cross-cultural analyses of OCD presentation, while drawing from the psychological and neuropsychiatric models created to explain OCD etiology, phenomenology, treatment, and symptomatology (Lemelson 2003). According to national and cross-cultural surveys, the most common obsessions in the US are fears of being sexually deviant or acting out aggressively, while in Turkey obsessions about dirt and contamination are primary, and in Saudi Arabia, religious themes are most common. OCD obsessions seem to act as a lens, magnifying culturally-varied taboos (Lemeson 2003). Like the paucity of studies on OCD in diverse populations, there has been very little anthropological research on how sociocultural factors affect proper diagnosis and treatment for people with “Pure O” OCD.

Biomedical Treatments for OCD

Clinical practice guidelines published by the American Psychiatric Association (2011), and the National Institute for Clinical Excellence (2011) advise using exposure-based cognitive-behavioral therapy to treat anxiety related disorders. OCD used to be considered an anxiety related disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM-4), but it was moved to the Obsessive-Compulsive and Related Disorders category with the new DSM publication (DSM-5). Regardless, exposure-based cognitive behavioral therapy, otherwise known as Exposure and Response Prevention (ERP), is still the typical treatment (Khodarahimi 2009). ERP exposes an individual to their OCD triggers systematically, within a controlled

environment, with the help of a therapist. Compulsions are prevented, allowing the patient to experience sitting with the high levels of anxiety around their obsessions in a safe place. ERP has been deemed an evidence-based, and effective form of treatment for OCD (Khodarahimi 2009).

Usually ERP is used in conjunction with a Selective Serotonin-Reuptake Inhibitor (SSRI), which blocks the reuptake of Serotonin back into the synapses of a neuron, allowing for more of the neurotransmitter to pass through to the next neuron (Goodman 1999, 28). Serotonin is a natural mood stabilizer, so imbalances can cause increased mental dysfunction. Historically, OCD was thought to have a poor prognosis, with many individuals resisting medicinal treatment. However, over the last 30 years, treatments have significantly advanced. SSRI's are now the first line of pharmacotherapy for obsessive-compulsive disorder (Goodman 1999, 28). A few different kinds of SSRIs are available for OCD treatment, so individuals who don't benefit from one type are advised try another (Goodman 1999, 31). Unfortunately, some SSRIs have negative side-effects, causing decreased libido, increase or decrease of appetite, nausea, and/or headaches, which can sometimes be reduced by switching to a different SSRI. For the more homeopathic inclined individuals, some researchers are looking for natural alternatives that have fewer negative side effects than SSRIs, like Valerian Root (Pakseresht et al. 2011).

Issues With Treatment for OCD

Dissemination of ERP

In the psychological community there are barriers to the dissemination of exposure-based cognitive-behavioral therapy (otherwise known as ERP), resulting in rare implementation across the board (Deacon & Farrell 2013). A German study found that though almost every therapist treating OCD billed their client's insurance for Exposure and Response therapy treatment, 80% of clients never saw it put to practice (Bohm et al. 2008). Whiteside (et al. 2016) studied how

Exposure and Response Prevention therapy was endorsed among the psychological community for anxiety related disorders in children. Only 5% of 331 child therapists agreed with using ERP. However a PhD in psychology was seen as a positive correlate to ERP endorsement among therapists. Deacon & Farrell (2013) found that there is a high degree of negative beliefs about ERP in the psychological community, (e.g. that it is unsafe, intolerable, or unethical) which impacts therapists' utilization of this treatment modality in their sessions. However, ERP still remains the best treatment modality for OCD. More therapists willing to overcome their own negative beliefs, to practice ERP for individuals with OCD, are needed.

Cultural Competency

Arthur Kleinman (1991) states that therapists sometimes cannot relate to an individual's understanding of their mental illness, due to the therapist's own limiting cultural frameworks. Improving cultural-competency is a way for health care networks or providers to more effectively interact with people of different cultures, or socio-economic backgrounds. Healthcare organizations need to have ongoing cultural-competency trainings to look at their own institutional biases and overcome cultural barriers to efficacious treatment (Shea 10/8/19). I could not find any articles about the relationship of cultural competency and the practical application of Exposure and Response prevention therapy for individuals with OCD. As this disorder's blueprint is identical globally, with cultural norms only affecting obsessional content, the need for culturally competent providers for OCD treatment seems to be obvious. More research is needed in this area of study, from both psychology and anthropology.

Rates of Recovery

Exposure and Response Prevention Therapy (ERP) and Cognitive Behavioral Therapy (CBT) are the two main psychotherapeutic modalities for treating OCD, and there have been quite a few studies looking into the efficacy of the treatments. One such study (Fisher & Wells

2005) applied the standard Jacobson methodology, a psychological method for defining clinically significant change, to recent clinical trials of both ERP and Cognitive Therapy (CT) outcomes to research efficacy. It was found that though ERP appeared to be the most efficient form of OCD treatment available, with a recovery rate above 60%, only 25% of patients were asymptomatic by the end of treatment. The percentages of individuals who recovered through CT were lower, only 53%, with 21% being fully asymptomatic by the end of treatment. A correlation was found between the numbers of hours partaken in ERP treatment, and treatment rates; recovery and asymptomatic rates increased the longer a patient was in treatment. The reverse relationship was found true with Cognitive Therapy. Similarly, Kyrios (et al. 2015) completed a study looking at the predictors of response to CT and ERP for OCD and found that individuals who had higher symptom severity initially were more likely to have poorer outcomes post-treatment. Interestingly, an initially high level of perfectionism in patients was found to impact success during ERP exposures by reducing their ability to endure triggering material. Other longitudinal studies have found a 32% to 70% post-treatment symptomatic remission rate in individuals with OCD (Burchi et al. 2018).

Historically there has been a high treatment dropout rate of patients with comorbid OCD and MDD (Rector et al. 2009). Rector (et al. 2009) completed a study examining the current relationship of treatment efficacy of CBT with patients with co-morbid OCD and Major Depressive Disorder (MDD). It was found that both regular CBT for OCD and integrated CBT, that included an exclusive focus on treating MDD first, were statistically significant in reducing co-morbid symptoms. However, the high treatment dropout rate of individuals with comorbid OCD and MDD still persists, signifying that additional treatment strategies are needed.

Media Representations of OCD

Stereotypes about mental disorders in the media can negatively influence patient's livelihoods (Stuart 2006). Negative portrayals were found to diminish peoples' ability to seek help, generate high self-esteem, and follow medicinal regimens. On the other hand, positive portrayals can be useful in challenging public perceptions of mental illness. Fennell and Boyd (2014) found, that though more representations of OCD exist in the media today, their portrayals aren't uniform, and the phrase "obsessive-compulsive" when applied to a character didn't necessarily reflect the current definition found in the DSM-5. Essentially, though there are more characters deemed to be "obsessive-compulsive," many of them did not all of them fit the DSM-5 criteria for OCD, instead representing the popular misunderstanding of OCD; For example, being neat and tidy. More generally, Stout (2004) posits that there have been only a small number of studies on how people with mental illness perceive the portrayals of their own mental illnesses in the media and that more research is needed on this relationship to investigate stigma. In today's media world, there are some pretty classic characters with "OCD". Monica from *Friends*, Monk from *Monk*, both are characters who are written to have stereotypical OCD: obsessive cleanliness and orderliness, without an indication of intrusive thoughts. This stereotypical presentation can be used for comedic relief, for example, Schmidt from *New Girl*. This study considers what participants with "Pure O" OCD thought about these depictions.

Warman et al. (2015) explored the nature of stigma caused by misinformation around mental illness by focusing on individuals with violent intrusive thoughts. They noted that giving people who identify with OCD a brief education about the nature of intrusive thoughts causes their perceptions of their illness to positively change. This is important when exploring how the lack of information about Pure O can affect distressed and uninformed individuals.

Underinformed individuals are more likely to feed into the doubt around whether or not they would act on the thought, if they weren't aware that they had OCD (Warman et al.). Instead of having a logical explanation to help understand their experience of their obsessions, the possibility that their thoughts might mean something about themselves was all the more real.

Illness and Virtual Support Groups

In conjunction with the rise of ehealth services, virtual community spaces where peers gather to share experiences, ask questions, offer self-help advice, and offer support are gaining in popularity. These spaces are facilitated through electronic social media and have grown out of the bulletin board and private network systems for peer-to-peer communication that existed pre-internet (Esyenbach et al. 2004). These spaces can be beneficial for individuals that live in rural communities, without access to an in-person support group, those who are uncomfortable by in-person gatherings, or those who can't afford them. For example, the Left Ventricular Assist Device (LVAD) Facebook group is full of members who provide emotional and social support, advice, and check-ins to each other at least once per week (Boling et al. 2015). An excessive focus on fears or negativity, and/or misleading information from peers were some negative aspects observed within this group. Online support groups can be found for almost any biomedically recognized illness, and for those not recognized in biomedicine too.

Few studies exist on virtual support groups for mental illness diagnoses; however, this doesn't detract from the reality that these spaces exist in multitudes. One study found a positive correlation between the use of a virtual support group for individuals who have lost a partner and a reduction in the user's experience of depression (Knowles et al. 2017). This is promising, as depression is one of the main symptoms in quite a few mental illnesses. More research is needed about the nature of these spaces, and if they are beneficial or harmful for these already

marginalized communities. My study seeks to contribute to this goal through the study of individual's with "Pure O" and their relationship to "Pure O" OCD virtual support groups.

Mental Illness and Stigma

Studies on mental illness must inevitably consider stigma related to it. Erving Goffman (1990) posits that society creates the means for categorizing individuals based on agreed upon favorable attributes. For those who are socially judged to have deviated negatively from the agreed upon norm, they are reduced from a whole healthy person to a flawed and discounted one. Similarly Liegghio (2016, 1) writes, "the 'stigma of mental illness' refers to the devaluing of a person based on negative beliefs, attitudes, and perceptions about 'mental illness' that mark a person as different from an accepted social norm." The stigma around metal illness is often compounded by other social inequities. Low socioeconomic status (Foster & O'Mealey 2021) and racial and ethnic minoritization (Misra et al. 2021) have been shown correlate with an increased experience of mental health stigma. The impact of stigma can also change depending on power dynamics and social relationships with others. In terms of parent-child relationships, children are vulnerable to potential assimilation of their parent's beliefs around mental illness. Parental beliefs around stigma and mental illness can also be fueled by misrepresentation of mental illness in the media (Dillinger 2020).

As there has been minimal research into the lived experience of OCD, stigma's relationship with the disorder is not fully understood. According to Fennell & Liberato (2006), OCD is nicknamed the "hidden epidemic," hidden from the academic world as seen by the lack of scholarly publications, despite it being "the world's fourth most common mental disorder." Quite a bit of public misinformation exists around this mental illness (Spencer & Carel 2021),

which surely impacts the public expression of stigma. It has been shown that because of OCD's heterogeneous nature, stigma varies depending on the symptomatic expression of the illness within an individual. Durna (et al. 2019) writes that individuals with sexual and violent obsessions, are equally stigmatized as individuals with schizophrenia². Whereas existential obsessions or pregnancy obsessions weren't as heavily stigmatized. Since OCD obsessions are shaped by cultural contexts, stigma experienced by Orthodox Jews with scrupulosity (obsessions around fearing they might say or do something blasphemous) within their larger Orthodox Jewish community has been shown to be different than stigma surrounding individuals with OCD whose obsessions don't take the form of religious content (Pirutinsky et al. 2009).

Theoretical Frameworks

Phenomenological Psychology

An alternative to mainstream psychology, phenomenological psychology has evolved over the last 80 years, spearheaded by early 1900's psychologist and mathematician Edmund Husserl's post-graduate work (Klein & Westcott 1994). Husserl created three requirements for early phenomenological psychology which have nurtured modern understandings of the field; that it must apply to all sentient creatures; that all conclusions must be true; that it has method. A brief example of this in practice: a psychologist first accepts that an intentional act divulged by their client took place in space and time, supported by the accepted laws of science. Then, to step outside of this natural acceptance of the situation, the psychologist would engage in the "epoch", for a deeper subjective description of the psychological act; essentially, the psychologist would refrain from assuming they knew the truth of the situation regardless of relevant psychological

² Not that individuals with Schizophrenia should be stigmatized. Unfortunately in the US, individuals with that illness face a high level of stigma from others, because of the severity of symptom presentation.

theories, while hearing the subjective cognitive experience of their client. Finally, the psychologist would engage in “eidetic reduction”, a process by which they would gain insight into the essence or truth of the psychological act from intuitive analysis (Klein & Westcott 1994). This process has been described as adopting a “first-person” point of view, imagining oneself in the shoes of another to see the world the way they do (Churchill 2018). Researcher reflexivity is crucial to maintain while engaging in phenomenological psychology. While the researcher is directly and intuitively “looking at” the experiences of another, keeping a critically reflexive position on the intrusion of their own experiences into their analysis is essential for ethical engagement.

More recently, psychologist Amedeo Giorgi has based his understandings of phenomenological psychology within humanistic psychology, the so called “third force” movement in psychology (Englander 2020). Giorgi’s theory of phenomenological psychology grounds the idea of psychology as a human science by working from a phenomenological theory of science within the larger qualitative research movement, amassing anthropology, sociology, and psychology as well (Englander 2020). This turn to qualitative research in the social sciences has come partly from the desire to work against the reductionist quantification and standardization of quantitative psychological research (Giorgi 1970). In psychology, phenomenological methods now include the phenomenological psychological interviewing method, which challenge the more structured approaches in mainstream psychology (Zahavi and Martiny 2019). A key component of the phenomenological psychological interviewing method is the absence of guiding questions by the researcher. Participants are expected to provide detailed descriptions of their experiences in their own way, only prompted to elaborate when their content is lacking clarity or depth (Beck 2013). The researcher takes an active role in the interpersonal

activity of their qualitative interview while focusing on how the phenomenon is contextualized by their research subject. The research questions for this study were in part informed by phenomenological psychology, and critical phenomenology in medical anthropology.

Biosociality

A new phenomenon arising out of biomedical understandings of health and healing, biosociality, is a “biologically-based” form of social behavior stemming from shared diseases or conditions (Halverson 2020). According to Pitts-Taylor (2018) the “body history” (a Western understanding of an individual’s subjective experience contributing to their sense of self) of an individual builds upon itself over time, moment by moment. Body histories are different at every point in time, due to development, growth, aging, and material effects of existing within different environments. Body histories include individuals’ built relationship to culture, over time. In a famous 1990’s essay, Paul Rabinow imagined that new scientific understandings of genetics and predispositions to illness and disease would give rise to new individual or group identities, that would shape new social practices (Sommer 2010). His prediction was correct. The accessibility of new scientific and medical knowledge made public [paired with individual body histories], has contributed to individuals self-identifying with diagnoses, and then seeking out others with the same.

Too often the individuals within these biosocial groups find themselves marginalized by a larger biopower that is a part of Western democracy. Foucault explored the relationship between biopower, the way in which a capitalist state exerts power over its people, and the methods used to do such, which can be “subjected, transformed, and improved” (Lane 1992). Rabinow, working through ideas of Foucault, found that biosocial spaces are created in spite of the power of the oppressive systems within which they exist (Friedner 2020). As an example of this,

Friedner (2010) writes that the deaf community, all too often medicalized and made to feel inferior by hearing people or state governance, have found solace in the capital *D* Deaf communities. Other communities include Autism Speaks, the Little People of America, Saving Downs, and the neurodiversity movement. According to Halverson (2020), these groups provide support and sociality, but also can come together to advocate for furthering political and social goals related to their identities. The community around the “Pure O” OCD diagnosis will be looked at through the lens of biosociality.

Autoethnography

This research includes some autoethnography, that compliments the research gleaned from participant survey responses. Autoethnography is a style of autobiographical writing that investigates an individual’s background and understandings of life experiences in relation to broader social and cultural systems (Custer 2014). Or in other words, it is ethnography that brings out the personal. Custer (2004) positively views autoethnography because it changes one’s understanding of time; it requires vulnerability; it fosters empathy; it embodies creativity and innovation; it eliminates boundaries; it invites and honors subjectivity; it provides therapeutic benefits. According to Lamott (as cited by Nash 2004), “My students ask, ‘so why does our writing matter?’ Because of the spirit I say. Because of the heart. Writing and reading decrease our sense of isolation. They deepen and widen and expand our sense of life, they feed our soul. When writers make us shake our heads with the exactness of their prose and their truths, and even make us laugh about ourselves or life, our buoyancy is restored. We are given a shot at dancing with, or at least clapping along with the absurdity of life.” His beautiful argument for personal writing compliments the seven lenses through which Custer argues for the legitimacy for autoethnography.

Autoethnography can be a controversial topic within the anthropological field, and some worry that the method involves too much “navel-gazing,” without enough analysis of objective truth. However, Luttrell (2000) posits that researchers using “good-enough methods” work to understand their own privilege and placement as a researcher. This isn’t a permissance of unexceptional work, but rather a nod to the researcher’s own “reflexive positioning,” the concept that individuals take active and conscious actions to question or understand their identities within their work while research gathering. The “good enough methods” can, and should, be included during autoethnographical research. Sherick Hughes (2008), professor at UNC at Chapel Hill, agrees that researchers should do autoethnography because it provides access to writing in first-person as well as opportunities to “embrace the conflict of writing against oneself.” Along with biosocial and autoethnographical literature, this thesis project was also informed by works from digital ethnography.

Chapter 3: Methodology

This project was informed by phenomenology, a method focused on understanding and interpreting social and psychological phenomena from the research participant's perspective (Groenewald 2004). The research-undertaking, or selection of a topic (Groenewald 2004) for this project came from pondering my own experience with the resource inequality, misinformation, and sociocultural and educational factors impacting access to treatment for "Pure O". Coming from an autoethnographical lens was important here, because it allowed me to acknowledge my presupposed beliefs, understanding that I could never truly be removed from them, and design a study where I could actively reflect on my positioning throughout my research. This was important as I have this form of OCD and am in recovery.

My Background With OCD, Support Groups, and Academia

My interest in this project culminated from my own experience with "Pure O" OCD, spurred particularly by navigating the mental health channels that existed in my small town. I experienced my first OCD obsession in the fall of 2007 but didn't receive Exposure and Response Prevention (ERP) therapy until the fall of 2019. During this span of time, I grew interested in why there seemed to be misinformation of OCD in different social spaces (between friends, in therapy, online, etc.). There seemed to be a disconnect between the way some individuals in American society understood OCD. I was curious as to how individuals (therapists, teachers, my own family & friends) were getting their information on OCD and how media representations of OCD may have affected their perceptions. I noticed there was a significant lack of scholarly research providing insight into the lived experiences of individuals with "Pure O" and wondered if that silence contributed in any way to misunderstandings. I was

also curious about how the popular understanding of OCD, being orderly and having external physical compulsions, affected the lives of people with “Pure O” and their treatment.

As a researcher studying an illness that I have intimate knowledge of, I chose to engage in this research both knowing that I would have beneficial insights to the topic and that it would be an interesting challenge to remain objective. I understand the struggle of not having a name for one’s experience, and the hunger for more information on “Pure O” once diagnosed. I also am all too familiar with the idiosyncrasies intrinsically linked with “Pure O” thought patterns, behavior changes, and the like. I was hoping that because of the shame and distress that comes from being misunderstood by those holding stereotypes about OCD, having “Pure O” might create a safer space for people to share their stories because they wouldn’t be as afraid of being misunderstood by me.

Some of the support group spaces that I explored before engaging with this project were private (Intrusive Thoughts FB groups), but most were public (OCDAction, Reddit). They all were full of people who were begging to know if what they were dealing with was OCD. A common theme of users’ posts revolved around those patient-healer interactions that included stereotypes of OCD, and how this left the patient feeling harmed rather than helped. As these support groups are international in nature, this harm appeared to be something that was happening globally. Through these support group channels, I saw a desperate need for well-informed mental health professionals trained in recognizing and aiding all manifestations of obsessive-compulsive disorder.

In the fall of 2019, I decided to write my final research paper for Dr. Shea’s class “Culture, Health, and Healing” on a cross-cultural, deep dive of obsessive-compulsive disorder, biomedical therapies, and alternative medicinal remedies. In that class, I also completed my IRB

Human Subject's Research certificate. Part of the requirements for that class included an interview with someone knowledgeable about our topic. I chose to interview the resident Vermont OCD specialist, Dr. Robert Keith. He shared that primarily obsessional OCD has the same global blueprint (obsessions taking the form of intrusive thoughts/feelings/urges and compulsions primarily manifesting as mental rituals) regardless of region, with the only change being the obsessional themes and the compulsions tailor to the effected individual. That cemented my desire to conduct this anthropological study in international support groups. I could posit my anthropological research questions to a global audience.

Research Gathering, Research Storage, and Coding

I submitted my proposal for review by the College Honors Committee at the beginning of the fall 2020 semester. After I received word that it was approved, I submitted my IRB application for human subjects research on Halloween night of 2020. After a few rounds of requested edits, I was cleared to begin research in mid-December of 2020.

My study used purposeful sampling, to study individuals (with "Pure O") based on their experience with a phenomenon (Palinkas et al. 2013). The field site associated with the study was the internet, with my research subjects gathered through online support groups. Studying people through the internet has become increasingly common, resulting in a new term "digital ethnography," (Underberg & Zorn 2014). This field site was inherently helpful during Covid-19, as all of my research was automatically socially-distanced.

Because of biosociality, virtual group spaces were the best places to recruit participants to explore my research around "Pure O" OCD individuals' treatment journeys. Support groups for mental health are most often separated by mental health diagnoses and have a few loose rules

which vary depending on the diagnosis (no harming others for example, and in the case of “Pure O”, no reassurance). There is a community nature to these spaces which can make for a comfortable and safe place for those who have been affected by similar mental health struggles. It was my hope that the individuals who frequented these virtual spaces would be as keen to share their stories with me as they did in those forums. It seemed helpful to approach these virtual spaces not as an outsider, but as a fellow individual with OCD looking to do research on a shared diagnosis. It was important to me to make it clear to potential subjects that I also suffered from Pure O but was in recovery.

I posted my survey and webform to Reddit (the “Pure O” subreddit feed) and the OCD-UK chatforum. I also attempted to carry out research in OCD Action and the OCD Mental Health Forum, but neither of those forums allowed it. After much deliberation, I decided to try and conduct research through PsychForums, another online mental health forum. Ultimately, it ended up not working out, so I made peace with my significantly smaller than expected survey pool.

The survey had 10 questions, all relating to the phenomenological experience of living with “Pure O”. The webform was a short information gathering questionnaire, that asked for an individual’s email and phone number for a future interview. Both forms were created through Qualtrics XM, a survey making software associated with the University of Vermont. As participants had to be 18 years of age or older; the beginning of the survey and webform included a mandatory question probing whether or not this was true, before participants could continue. I also included my information sheet at the beginning of both forms.

While I was not successful in getting my survey posted on OCDAction and the OCD Mental Health Forum, my Reddit and OCD-UK posts remained up for about 3 months, from

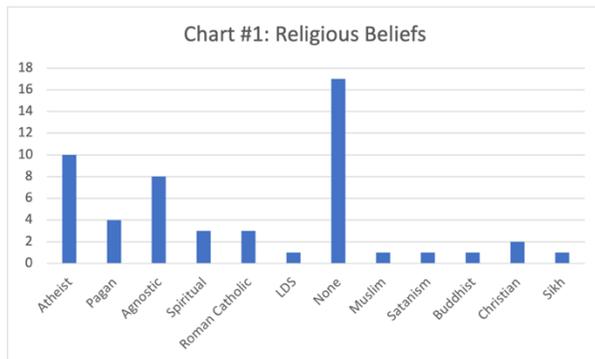
around Christmas 2020 to March 10th, 2021. When I reposted the links in Reddit to see if I could get more responses. After discussing with Dr. Blom and Dr. Shea, we decided that it would be wise for me to include more of my experience with “Pure O” in my thesis through the recognized method of autoethnography. Because of that, I also filled out the survey. I closed my survey and webform on March 19th, 2021, when the survey had gotten 164 responses, and the webform had gotten 3 responses. Unfortunately, none of the three webform participants ended up being interviewed. One of the withdrawal procedures of this project stated that research participants will be withdrawn if 50% or less of the survey is completed, as was the case with my potential interviewees. After I removed the survey answers that weren’t filled out past the informational section (race, gender, location, and age), I ended up with 55 valid survey responses.

In accordance with IRB protocols, I created a locked folder on the desktop of my password protected computer to keep the research files secure. The Qualtrics XM survey was automatically de-identified, but to keep the answers straight, I gave each of the participants an identifier to keep their survey answers together: different zoo animal names. I removed unnecessary categories from the downloaded survey to simplify the document. NVivo 12 was used for coding and analysis. Charts and graphs were generated in Excel. As the Code of Ethics of the American Anthropological Association (1998) states, all researchers should keep their research indefinitely unless the research participants request otherwise. To be in concordance with this, at the beginning of the survey, I included a section about participant preference about their data storage, in case any participant wanted their data deleted post-project. Along the same lines, at any time during this project a participant could contact me and ask to have their data removed from this project. This was made clear at the beginning of both the survey and webform.

Personally, I had gone through a Major Depressive Episode in December, and then contracted appendicitis in January. This resulted in an appendectomy on January 26th, 2021. One week later, my college classes for my senior final semester started. Because of the intensive therapy and self-care, alongside my classes and internship, I definitely struggled a bit not being as focused or driven. I prioritized healing from the depressive episode and my appendectomy. Although I know that sans depression and appendicitis, I would have had more time to devote to this project, I'm really happy that I was able to set aside time to engage in this research. Overall though, despite setbacks, I am confident that the 55 survey responses I received contained a bounty of material to help inform my findings and conclusions.

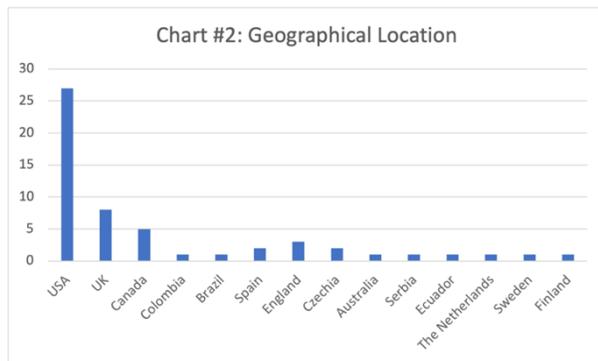
The Study Sample

For the valid survey responses by the end of the research gathering phase of this thesis. The participant's religious beliefs spanned from none (31%) to Sikh (2%), with the majority of participants having no affiliated religious beliefs (31%). In order, atheist (18%), agnostic (15%), and pagan (7%) were the next most common religious identities. Some participants also practiced satanism (2%), LDS (2%), and Christianity (4%). As Reddit and OCD-UK attract a global crowd, participants were from quite a few different countries. The majority came from the



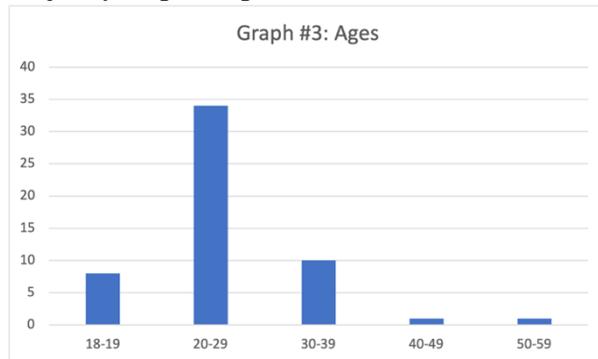
USA (49%), followed by individuals from the

UK³ (15%) and Canada (9%). There were also participants who completed the survey from



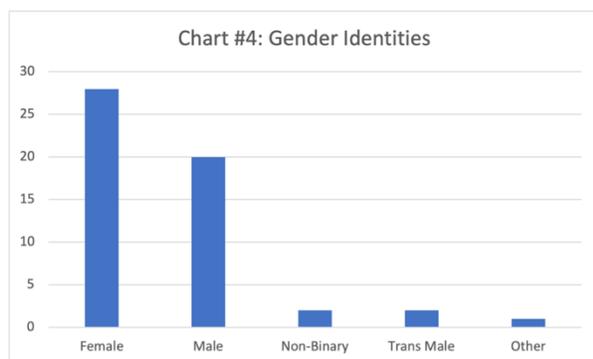
Brazil (2%), Serbia (2%), and Czechia (4%). In terms of ages of the participants, most individuals fell between 20-29 (62%), with 30-39 (18%) being the second largest age bracket. Interestingly, there was one individual who was

between the ages of 40-49 and one individual aged 50-59. Lastly, for gender identities, the majority of participants identified as a female (50%), with those who identified as male (37%)



being the second most prevalent. However, there were also participants who identified as non-binary (4%), transgendered male (4%), and other (2%). I wished that I had included a separate section in the survey for sexual

identity, instead of just including a place for gender. I am aware those two are not necessarily



congruent for some folks and it is important to acknowledge that. All of the participants truly shared some of their rawest moments in their survey answers, and I am honored to be trusted enough to hold those stories. I feel like it is my duty to create this to give a voice to those who

so often feel, “like they are shouting into the void”, as one participant said. Every single one of the survey responses contains a powerful truth, and to reflect that I have chosen to include many

³ Also to note, now that England has gone through Brexit, participants from England were not included in the data from the UK.

quotes from each of the answers. To do this, and to keep with IRB protocol, all survey responses have been de-identified.

Chapter 4: Symptoms of Research Participants

Participant survey responses were grouped by question, for analysis. Because each participant had the option of recording an answer to the length of their satisfaction, the length of response varied, some being one-word answers and others a paragraph in total. Each of the following chapters contain multiple survey questions, grouped together by theme, with corresponding analyzed participant responses as results. This initial chapter discusses the obsessions and compulsions of study participants. Their responses provide a deeper look into how “Pure O” manifests in individuals.

Obsessions

Each of the participants in this study had at least one main obsessional theme during their time experiencing untreated OCD (and even sometimes after). Since the content of the obsessions isn't actually the core of OCD, but rather it's a fear of uncertainty, the themes can change along a person's lifetime. For example, I first experienced the fear that I was transgendered at age 9, which quickly morphed into an 11-year fear of being gay at age 10⁴. Common themes overall were a fear of being a sexuality or gender that wasn't their own, fear of being a pedophile, and fear of causing physical harm to others. Less common, but still distressing were a “constant rumination about past events in my life,” “obsessed about not getting a job with the college degree I was about to start,” and a fear of existential what-ifs.

Emotional Weight of Obsessions

⁴ It felt so awful because I fully supported, as many people do with themes of sexuality and gender, LGBTQAIIP+ individuals. It just didn't feel true to who I was as a person. These themes can also impact people who do identify with the LGTBQAIP+ community, as being afraid they are a gender or sexuality that isn't their own.

Twenty out of the fifty-five (37%) participants noted that their thoughts or obsessional content caused them significant emotional distress. For example, some participants noted that they had, “two months of confusing and terrifying thoughts/images,” and “extremely exaggerated levels of guilt.” Each person’s negative feelings associated with their obsession could manifest differently. One individual stated that, “At 23 I had transgender OCD for four months, I was debilitated, felt the world was ending, isolated myself.” Here, they were so overwhelmed with their obsession and feelings of their world ending, that it caused them to remove themselves from society and isolate. Another stated that, “I had intense spouts of depersonalization and derealization.”

In my case I remember one night where the back and forth “I’m gay, I’m not gay, I’m gay, I’m not gay,” was too much. I took a knife and sat in the shower with it. I remember feeling the weight of the questioning. It felt like I was drowning, and in that moment, I sort of like I had finally realized I was gay. It felt agonizing, the potential realization that I was losing myself. Then the small part of me who knew who I actually was piped up and said, “no, this is just your OCD⁵.” That doubt of the legitimacy of the doubt that I had about my sexuality made me put down the knife. I realized in that moment all I could feel is fear (typical of an OCD episode).

Compulsions

The term “Pure O” is actually a misnomer because there are compulsions associated with their intrusive thoughts, they are just usually hidden or hard to spot. These can be in the forms of avoidance behaviors (of things that trigger their OCD), compulsive reassurance-seeking (that their thoughts aren’t true), and mental rituals (Williams et al 2011, 2016). All of the participants have multiple compulsions that they engage in, to reduce some of the distressing emotions

⁵ This self-reassurance about being truly not your obsession is another form of mental compulsion.

around their obsessions. For example, one participant wrote about lesser-known confessing compulsion that fits in the larger theme of reassurance-seeking behavior. “I had crippling fear for years about my sexuality. I approached my husband and told him I thought I was gay. I was prepared to divorce him.” Confessing compulsions are done when an individual can’t bear the internal questioning any longer, so they confess their OCD thoughts as a way to achieve certainty.

Thirty-five out of the fifty-five (64%) individuals mentioned that they used Google to reassurance-see. One wrote, “part of my compulsion (but I didn’t see it as a compulsion at the time) – but also part of me trying to find what the f*ck was going on – was researching my symptoms online.” This compulsion is tricky because it can help inform individuals OCD but can also feed the need for reassurance. For example, one participant reported, “I looked up articles about obsessively doubting sexuality and came across an article about homosexual OCD. I did days of nonstop research.”

Another common compulsion is avoidance of things that trigger their obsessive thoughts. Some of the participants said, “(I) began to avoid sharp objects and driving,” “I am now avoiding going outside and being around children,” and “I thought I was so bad of a person I shouldn’t be let out of... custody.” This compulsion can significantly interfere with daily life, as some of the most innocuous things can be avoided. In one of the participant’s life, there was a period of time where they avoided any TV or movies with women in them. This was very distressing for them, and hard to achieve.

For me, my main compulsions were obsessive googling, which is a form of reassurance-seeking, and mental rituals. My mental rituals looked like testing thoughts - imagining having sex with a girl and then trying to figure out if I liked it – and searching through past memories to

try to figure out if there were any indicators that I was or wasn't gay. Externally, this probably looked like I was just lost in thought or checked out. I also "came out" as gay to my friends and family over FB, but quickly retracted it when I realized it nothing changed. It didn't make the OCD go away; in fact it made the questioning worse. Later on in my illness I "came out" as heterosexual biromantic, but that also didn't feel right. I realized soon after that was also a compulsion. With every compulsion, the individual uses it to get some relief from the distressing uncertainty around their obsessions.

Chapter 5: Information Gathering

There is limited scholarly material about “Pure O” in both the field of psychology and anthropology, as well as in general. As this disorder isn’t well known, it is important to research how individuals with “Pure O” access their information to discover what methods exist. In the following sections, how individuals initially came to be diagnosed, as well as how their methods of information gathering changed throughout their illness are discussed.

Initial Diagnosis

As “Pure O” OCD is a lesser-known disorder, there are multiple ways that individuals gather their information about the illness. My participants revealed that go through therapists (if their mental health professionals can recognize “Pure O” OCD), find their information through Google, or through their family and friends. Interestingly, about twenty out of the fifty-five individuals (37%) (that answered question 1⁶) stated that they were initially diagnosed by a medical professional initially. One participant said, “It was something that my therapist brought up that I would never have even considered as a diagnosis.” Another wrote, “I went to the psychologist for a theoretical anxiety disorder. When I got tired of that psychologist who did not seem to find the correct treatment, I decided to change. After working with several psychologists and psychiatrists, they diagnosed me with OCD. When I saw a specialist and clarified the symptoms, I was diagnosed with Pure OCD.”

Twenty-one out of fifty-five participants (39%) said that they learned they had “Pure O” through self-research. One participant said, “I researched what these thoughts were and then found out it was OCD.” Another said, “the internet led me to seek (a) diagnosis from OCD.” Yet

⁶ See Appendix 1 for the entire survey question set

another participant found out they had this form of OCD while they were doing a presentation on OCD for their high school psychology class. Sometimes the realization this disorder is what they are experiencing comes from accidentally stumbling on an article about “Pure O”. Other times it was a more deliberate search to find what is going on. More specifically, four out of the twenty-one individuals (19%) who did self-research said they learned what “Pure O” was through reading Reddit feeds.

Breakdowns and the “Aha” Moment

Eighteen out of all the fifty-five recorded responses (33%), including some individuals who self-diagnosed, and some who saw a therapist for an initial diagnosis indicated that a significant emotional breakdown led the individual to seek answers. For me, it was while watching a YouTube video of a girl discussing how she learned she was gay⁷ when she was in her late-teens. I was 17 at the time and had daily intrusive thoughts about my sexuality changing, or not being what I thought it was. Watching the YouTube video and having the intrusive thoughts was so challenging for me because the thoughts began to feel simultaneously real and not real at the same time. I thought, “I’m gay,” and broke down sobbing so hard I couldn’t breathe. I remember sitting in my living room on the black shag rug, crying, thinking my life was over. This led me to obsessive googling to prove my thoughts weren’t true, and I stumbled on an article about homosexual OCD, “Pure O” OCD about fearing your sexuality was gay when you were straight. Similarly other participants had distressing experiences like this that led them to a discovery about themselves and their truth. One individual said, “Obsessive thoughts and doubts about my sexuality drove me to confess I was a lesbian to my husband, had a breakdown, and accidentally found an article on HOCD.” Another said, “I’ve had it since I was 23-24. I only

⁷ I didn’t realize this at the time but watching video content to prove or disprove an obsession is a compulsion.

found out what it was at 28 as I started researching after starting to have suicidal thoughts as a result of the condition.” In all eighteen cases, the breakdown led to a better understanding of themselves and their condition.

Four out of the eighteen individuals (22%) discovered they had OCD when their symptoms became severe enough to require hospitalization. One person said, “After a night of smoking heavy THC cannabis, I woke up in the morning with severe intrusive thoughts. I had thought at first that I was having a psychotic break, so I went to the hospital where they diagnosed me with Pure-O OCD & PTSD.” Another wrote, “After two hospitalizations and multiple psychiatrists, during my second hospitalization I was diagnosed after finally ‘confessing’ my thoughts about harming my family.” Interestingly, the first individual went to the hospital under the notion that they were going crazy and was diagnosed. Whereas it wasn’t until the second individual “confessed” to their thoughts that their mental health practitioners were able to diagnose them correctly (and see that their obsessions were antithetical to who they were as a person). That breakdown seemed to be a turning point for those eighteen individuals.

Seven out of fifty-five individuals (13%) talked about an “aha” moment that happened once they finally had a name for what they were experiencing. For me, it was the moment where this thing that lived inside of me went from being this gigantic, scary unknown to something I could understand. It took the focus off of the obsessions and allowed me to see the bigger picture of what I was struggling with. Similarly, one of the participants said, “I found that I ticked every single box for that specific obsessive focus, and then as I read more, many past strange instances began to click into place.” Here, this individual was able to reflect back on their life and make sense of all the times their OCD impacted them. Another participant said, “I read about OCD on the internet and knew it was me.” That experience of making sense of or validating the

legitimacy of something that feels so foreign can be really powerful. Two of the participants (4%) noted that once they found out they were experiencing “Pure O” OCD, and that their thoughts were merely obsessions and not reality, they cried tears of “sweet relief.”

Anecdotal Diagnostic Journeys

Few participants experienced going straight from getting diagnosed, to undergoing effective treatment. One individual explained how:

I was told by a previous therapist/psychiatrist that I had OCD-like tendencies and obsessive thinking, but she did not see enough external compulsions to diagnose me with OCD. I started looking into Reddit forums for OCD to learn more and I stumbled upon Pure-O. I found this label incredibly helpful, and I had found a group of people with similar struggles. I brought this new term to a new psychiatrist, but he shook his head and told me that is not a thing and that everyone has obsessive thinking to some degree. I have not been officially diagnosed because the disorder has not been acknowledged by any of my therapists or psychiatrists.

Here this individual who was suffering was forced to do their own research, found out about “Pure O”, and then was disregarded by a medical professional. As they noted, at this point, they still haven’t received a proper diagnosis of “Pure O”. In summary, this individual wasn’t properly provided the help that they needed from their care team, and unjustly struggles still because of it.

Another individual’s journey looked a little different, but they also experienced doubt from their mental health practitioners about the validity of their OCD. “I have been experiencing symptoms (intrusive thoughts, obsessions, rituals) since I was about 9 years old, but I only learned they were symptoms of a disorder at 16 when I came across the term ‘intrusive thoughts’, I looked it up and it perfectly described me. In the same year I had a bad episode

revolving around one of my obsessions that lasted about 6 months, after the episode ended, I did some research and found both my intrusive thoughts. My obsessive episodes were symptoms of OCD. I didn't know about the term Pure O until a few days ago when I came across it on Reddit. It made sense to me. Prior to this, doctors didn't take my OCD seriously because I said that I don't have many rituals that affect me in my day-to-day life." It's important to note that both individuals found the label of "Pure O" and had that "aha" moment with it, where they felt like it adequately described what they were going through. In all of the cases though, all 55 participants had a smattering of web searches, therapy, or supplemental books to help inform them of their condition.

Learning About "Pure O" Diagnosis

Because this disorder is still relatively unknown, in both the medical field and otherwise, individuals often turn to different sources for information on their illness. Participants noted there were various methods of information gathering. Of the online variety, blog posts by fellow individuals with "Pure O", articles & videos, and support rooms were the main methods. Other similar methods of information gathering were books and listening to podcasts. Twenty-one out of the fifty-five participants (38%) (that answered question 3) indicated that they had used Reddit to learn about the disorder. One individual stated, "finally I recently joined a subreddit for "Pure O", where I got positive feedback from some people and felt less alone." Another individual said, "I looked up OCD-related subreddits. I'm still awaiting treatment, so these subreddits have been my biggest source of support and info." However, not all support room users were as happy with their experience, as those spaces can be a breeding ground for reassurance seeking behaviors. One individual called them "potential reassurance farms," which resonated with me.

Support rooms are sometimes private, but the public ones are easily accessible for folks compulsively googling (without being a user). The irony of the label of “user” in reference to folks who frequent OCD chatrooms is interesting, as the relief from completing the reassurance-seeking compulsion can be like getting a fix from a drug. After someone would reassure me in just the right way, there would be this instant calm that would wash over me, and the thoughts would quiet temporarily. However, the potential for encouraging reassurance-seeking behaviors in support groups doesn’t negate the fact that they contain a wealth of information about the disorder that is still relatively undocumented; it is an “and” situation, not an “or”. One individual said to that effect, “Though I typically use it for reassurance seeking, which obviously is not good, the OCD and OCD memes pages on Reddit are very good in my opinion.”

Forty-five out of the fifty-five participants (82%) said that they learned about their condition from a mental health professional at one point or another. For example, one response was, “I learned about OCD from my psychiatrist. She also experienced “Pure O” OCD and PTSD which is why she went into psychiatry.” Another individual said they were waiting to get a pay raise so that they could afford therapy for their OCD. Some initially learned of their diagnosis through a mental health professional, whereas others sought out a specialist’s opinion after they had conducted their own research.

Changing Resources Over Time

Study participants used several resources for gathering information on OCD such as books, podcasts, and blog posts of individuals with OCD and the source of info changed as time passed. For me, I used all modes of information gathering at different times. I began seeking out articles through Google when I was in high school. Once I had read all of the articles I could find

on “Pure O” OCD, I moved to watching YouTube videos made by others with the disorder⁸. Then when I began college, I began to read books (Bretecher 2016, Bailey 2019) on the subject, written by people who had the disorder but were now in recovery. I found them inspiring, hopeful, and helpful in making me feel like I wasn’t alone. When I could, I had qualified therapists, and a specialist help me along the way as well. Somewhere in-between, I listened to podcasts and used support groups to gather information.

This developing and changing mode of information gathering is reflected in a number of participant responses. One participant said, “luckily, I was in grad school at the time and had access to scholarly databases, so I started researching my specific subtype of OCD. Over time the resources I use have become less intense. I now use things like Reddit or Instagram to connect with people who have OCD or to offer resources on OCD.” Another participant said, “I found articles about doubting sexuality, homosexuality OCD, and then began doing more research. I sought more information through reddit, approached a good friend who has OCD for support, and found an exposure therapist⁹.” As this disorder is one that grows with an individual as they age, it makes sense that the methods of information gathering would change as well.

⁸ Namely Chrissie Hodges’s YouTube channel.

⁹ Someone trained in Exposure and Response Prevention therapy (ERP), which is the biomedical gold standard of OCD treatment. It involves an individual systematically exposing themselves to their feared obsessions with their therapist, to train their brain not to fear them. Doing ERP changed my life.

Chapter 6: Illness Experiences

Obsessive-Compulsive Disorder is nicknamed the “silent illness,” because it isn’t popularly known or understood. Within that, there are very few phenomenological accounts from individuals with “Pure O”. A crucial part of breaking that silence around the disorder has include conversations with individuals who have the illness. Nobody knows what it’s like to live with the condition better than they do. Documenting the illness experiences as told by individuals with “Pure O” not only helps to shine a light on the disorder, but it also helps to reduce mental health stigma overall. The beginning sections analyze the “naming experience” of an individual with “Pure O”; i.e. the time before having a diagnosis, and after obtaining one. Further sections provide results about individuals’ treatment journeys, experiences of OCD “spikes”, and experiences of social doubt around their disorder.

Individuals’ Illness “Naming” Experiences

Pre-naming

Before having the label “Pure O” to describe what they were going through, the pain of not having a diagnosis is clear throughout the participants’ responses. Thirty out of the fifty-five research participants (55%) (that answered question 2) thought that they were somehow deviant, for example, “a dangerous person,” “possessed by the devil.” Many individuals felt alienated from others and lost. One participant stated that they, “always knew there was something wrong. Thought I was a bad person. Totally identified with my thoughts, had suicidal ideation, and was very depressed.” Some individuals felt like this was something they were doing to themselves, and it was their fault for feeling bad. Poor self-esteem was echoed through many of the survey responses, as well as fear of losing control. “Before I had a name, I thought I was crazy, or evil, or bad. I thought there something inherently wrong with me because the OCD thoughts in my

head were so loud. It felt like I was hiding the crazy inside of me and at any minute I could lose control and act on one of my thoughts.” Another individual poignantly wrote, “Before I knew that what I was experiencing were symptoms of a disorder, I mistakenly thought that I had been possessed by a demon (I was raised in a fundamentalist catholic household with very little knowledge of mental health). I assumed I must be the only person struggling with this.”

Confusion was a common response to this experience as well, sometimes with an inherent desire to just finally know what was “wrong” with them. For me, I remember feeling utterly confused about what was going on inside of me before I knew I had “Pure O”. It was like there were three perspectives in my brain: the watcher, the doubter, and the fighter. The doubter was that little voice in my head that made me second-guess myself: “what if I actually want to kill my cat?” Once the doubter had spoken, the fighter would rush to my defense and state my truth: “No, I would never do that.” Then the doubter would respond, as if whatever thought I was having was suddenly put on trial. While my brain did this back and forth¹⁰, the watcher was like the people in the courtroom who just watched it all go down. Not very many thoughts would arise from this perspective, just a knowing that the back-and-forth wasn’t me, rather it was something that was happening to me. Before I knew it was “Pure O”, I just thought that I was going crazy because I’d never heard anyone talk about anything like this happening to them.

Post-naming

For the majority of participants (67%), once they had name for their experience, it positively changed their daily life. For example, one individual said, “I felt relief. I match every symptom. I thought, ‘I’m a good person, I just have OCD.’” Another said, “after I had a name, I knew there would be people well-suited to help me.” That hope seemed to not only be returning

¹⁰ I call this back-and-forth compulsion mental ping-ponging.

to some's sense of self, but also to the prospect of healing from their disorder. Even though individuals still experienced their obsessions, for some the label allowed them to reframe them so that they weren't as affected by them. These individuals didn't identify with the diagnosis. They were okay. They just were sick and knew they could get better. "After learning about "Pure O", the first thing that gave me great comfort was knowing that my thoughts are 'ego-dystonic'. Knowing that I am not more likely to commit violence really started me on recovery." Another individual stated that, "after finding out I felt somewhat relieved because it meant all those awful thoughts weren't my fault. It also made me realize that many of the things I had struggled with throughout the years were not normal, but part of this condition." In their case, it helped them reframe their life and take the blame off of themselves. It also brought many individuals a sense of being part of a larger community, instead of feeling isolated. Others (5%) weren't as affected by it, but it still helped a bit to have deeper insight. For those more in the middle, not super negatively or positively impacted, a common response was, "it didn't change too much other than it just clicked why I am the way I am." Also, "the information about "Pure O" made me slightly less anxious." It seemed like for these individuals, there was a slight positive impact, but the language they used to talk about it wasn't as euphoric.

On the flip side though, for a few individuals (5%), having a diagnosis increased some anxiety around potentially suffering from this disorder forever. Others (9%) still felt horrible but, "at least I can now blame something." One individual still felt fundamentally broken as a person, so having a name for what they were going through didn't really matter.

Treatment Journeys

Twenty out of the forty-nine participants (41%) (that answered question 6), reported that they had experienced helpful therapy. Cognitive-Behavioral Therapy was deemed a useful

therapy modality and “helped create... more healthy habits.” Some individuals had to wait a period of time before being able to see a therapist that could help with “Pure O”. One participant wrote, “It took me three months to get in with a specialist, but she is incredible, and ERP has been very helpful.” Others (6%) had to do some therapist shopping before they came upon one that made a significant difference in their daily life. For example, “One therapist made me feel worse, essentially telling me I wasn’t doing anything to help myself because I wasn’t exercising or eating healthily. My new therapist tries to help and offers more grounding techniques.” However, of all forty-nine responses, only five individuals (10%) had mentioned engaging or being about to engage in ERP therapy. Out of those five, only two (4%) had had successful experiences with it and are now in recovery due to that treatment. Two others (4%) had negative experiences, where the ERP wasn’t conducted properly. The last individual was on a waitlist for ERP at the time of the survey.

Twenty-five out of the forty-nine individuals (51%) said they largely had negative experiences with therapy. Two experiences were so bad, the individuals have stopped treatment all together. Other therapy sessions were not helpful for individuals (27%) because “they were treating the symptom – anxiety and depression – and not the cause: OCD.” One individual stated:

I have struggled with my care team because they too are unfamiliar with this manifestation of OCD. I would appreciate if more therapists were given training in what exposure therapy looks like for people with no visual rituals. I have had some practitioners applaud me for mentally arguing with myself about why I’m not a bad person/would never perform an intrusive thought. This allowed me to continue a harmful compulsion of engaging with obsessive thoughts.”

This desire for more education on the part of mental health professionals was echoed in all twenty-five out of the forty-nine responses where therapy was unhelpful.

Eighteen out of the forty-nine individuals (37%) felt like none of their therapists knew what 'Pure' O was. Within that, some experienced psychiatrists or therapists that told them, "they just have anxiety, and everyone's brains do weird things sometimes," and to "just look at what you think and realize it's not true." For me, most of my therapists didn't understand what "Pure O" OCD was and just tried to treat it as they would GAD. Interestingly, one of the participants also happened to be a therapist (LCSW) and wrote, "we are not trained on the different presentations of OCD in school, or employment unless we seek to find out how ourselves." The lack of mental health professionals that know how to spot, diagnose, and treat "Pure O" OCD has led to some participant's suicidal ideation. One participant stated, "My interactions with doctors and therapists have been terrible. I tried therapy but it doesn't help. Our mental health system here isn't great. I gave up trying to get better a long time ago. I don't want to live my life like this, but I can't do anything to stop it. I'm not suicidal but I do intend on ending my life because most doctors don't even know what "Pure' O is, how can they help me when they haven't even heard of it." It was clear that some individuals with "Pure O" OCD can't seem to find therapy that works to help them into recovery.

Medication & "Pure O"

In twelve of the forty-nine responses (25%), participants noted that having added medication "worked wonders" to ease some of the physical and mental symptoms of "Pure O". Some individuals were mainly medication-based, whereas others added it alongside their therapy. Many were prescribed SSRIs (Zoloft, Prozac, Mirtazapine, etc.), and/or SNRIs (Venlafaxine) to reduce the severity of their intrusive thoughts and physical anxiety. A few individuals found that their dissociative symptoms (depersonalization, and derealization) were

greatly reduced. In my case, Mirtazapine hugely reduced the physical anxiety symptoms, whereas Venlafaxine helped pull me out of my dissociative episodes. Similarly, one participant said, “meds (Zoloft) have worked very well for taking away almost all of the dissociation.” Another individual stated that, “medication was trial and error for a long time, but after starting Clomipramine, my intrusive thoughts are much less frequent. I don’t react to them with the same strong emotional response that I did without medication.” Getting the right medication can be a touch and go situation for a long time, but for many individuals, it was worth the hassle.

Social Doubt About Diagnosis

Twenty-seven out of forty-nine individuals (55%) (who answered question 7), have experienced external doubt or misunderstanding from another person. For example, a mental health professional telling an individual “Pure O” wasn’t real; a friend saying, “I have OCD too” when they didn’t; other individuals with more “traditional” forms of OCD invalidating “Pure O”’s legitimacy on chat forums. One individual stated, “most people [don’t understand]. It takes a lot of explaining. I don’t like to discuss or describe my intrusive thoughts because they are, by very nature, abhorrent to society and myself. Sometimes I’m weak and pretend to just be tidy so people will believe me.” For me, I have said I’m a compulsive cleaner only, because it is easier than explaining I also have thoughts that I fight with, about things that I’m afraid of.

On a different note, sometimes the popular understanding of OCD will come up in conversation when an individual is describing their “Pure O”. For example, one individual said, “mostly people will comment that they ‘have OCD too’ because they love to organize by alphabet or ‘I lock my door 3 times sometimes’ (said by a counselor). Those things are not only NOT OCD, but it really belittles the struggle I deal with every day.” Another participant said, “(it’s) very frustrating. It makes my blood boil or when someone says, ‘oh I’m sooo OCD too, I

know what it's like!' No, you don't." It can be very frustrating when this happens because it is invalidating to the daily experience of someone with "Pure O". "Pure O" OCD is not a quirk. For me, it's helped to see OCD not something you can try on and take off like a hat, but rather a chronic condition like diabetes. Learning to live with it is possible, but just like diabetes, it can be deadly if not treated.

Sometimes when this misunderstanding or doubt comes from a mental health professional, it can be really confusing to individuals. Some research participants (10%) already doubt the legitimacy of their disorder because OCD is a disorder full of doubt, so when they experience doubt from a knowledgeable person, it can be traumatizing. One individual said, "Yes, (I have experienced this, it was) my psychiatrist. They didn't have the homosexual theme of OCD or the relationship theme of OCD as types of OCD in their diagnostic measure. It was confusing and invalidating." Another individual said, "Yes, multiple times. Because of the theme I have, if people aren't familiar with how OCD can manifest, they assume I'm going through a sexuality crisis. I've had friends, social workers, and therapists all tell me they think I should experiment with a girl 'to figure out my sexuality.' They don't understand that rather than it being an issue of my sexuality, it is an issue of not tolerating uncertainty well."

For eight out of forty-nine individuals (16%) the doubt or misunderstanding of the disorder by loved ones seemed to be particularly upsetting. For example, one participant said, "yes, (by my) own partner. I'm quite emotion-free, but that really pissed me off." Another said, "yes, (by) some people from my family and friends. It was pretty hurtful because sometimes they make me feel like I'm faking it." For me, it has been really hard to find people in my real life (not through the internet) who understand what "Pure O" is. I still try to educate individuals on "Pure O" regardless, because hopefully it will plant a seed. Similarly, another participant stated

that, “my family doubts that I have it. They constantly use ‘OCD’ as slang. People who doubt it don’t understand it, so it’s okay. It still hurts that they won’t believe me, or they make fun of me, but I can only try to educate them. They have to actually want to be educated.” In these cases, there is a natural inclination to want to be accepted fully by those you are closest to, so it makes sense that this misunderstanding might be extra hard. It would be helpful if friends and family of people with “Pure O” would seek out education on the disorder¹¹.

Twenty out of the forty-nine participants (41%) haven’t experienced external doubt or misunderstanding. This was due for some to being particularly cautious with who they opened up to, and/or coming with credible sources to help explain the disorder to those who might be unfamiliar. For others, they seemed to just not have experienced it. One participant said emphatically, “thank God, no.” 7 out of the 22 just said definitively, “no.” It seems that those who had a supportive safe collective to share their experience with was really beneficial. For example, one participant said, “So far no, everyone in my immediate circle has been very understanding and supportive.” Another said, “I have not because I only confide in people who I knew would believe me.” There were a few individuals (4%) who worried that one day they might experience doubt or misunderstanding from another but hadn’t up to this point.

Phenomenology of an OCD “Spike”

Twenty out of the forty-seven individuals (43%) (who answered question 9), stated in some fashion that their biggest OCD episodes or “spikes” were all-consuming. Once an episode had begun, one individual described it as, “using every cell in my body to fight off the intrusive thought.” Another said it was like, “forgetting about the outside world and starting to ruminate

¹¹ The IOCDF.org/families/ web page has great resources for families of those with “Pure O”.

about the thought on a loop.” For me, it feels like my heart drops into my stomach. My body fills with dread and cold anxiety. My focus goes completely inward, and I start fixating on whatever the obsession is. Everything I’m seeing externally and everything I’m thinking or feeling internally might become evidence to prove or disprove the initial intrusive thought (and any subsequent ones that fire in rapid succession). Across the twenty participants’ experiences previously mentioned, there was a shared instant hyper-fixation on the obsession and only the obsession when the episode starts. As one individual put it, “I feel hopeless/powerless, and I am sucked into my own mind.” Another wrote, “I hardly talk, I don’t eat. I can’t sleep. I can’t watch tv because I am afraid of triggers. I have regular panic attacks. Mostly appear very solemn from the outside but inside is pure agony from the second I wake up until I manage to get to sleep.”

There were some vivid metaphors participants used in their responses to describe the emotional internal experience of an episode. A few included, “like being sucked into a whirlpool,” “like I’m constantly falling into a dark pit where the end is never there,” and “physically it’s a dreadful feeling in my stomach, as if I had a black hole that was sucking everything in.” Across all three, there is a feeling of being sucked inside, in a way where they are completely losing control. This definitely speaks to how isolating, distressing, and scary an OCD episode can be. One individual stated that, “I feel heavy. I feel dark. I lose all sense of individuality. I have no contact with any ‘wise mind’ skills. These are my worst days.” For some, it seemed to be a complete temporary severance from any mindfulness they may have cultivated in other parts of their day.

Thirteen out of the forty-seven individuals (28%) explained that when an OCD episode begins, they can’t think of anything else. They can become “trapped in their thoughts,” unable to ground themselves. One individual stated, “When there’s a spike, I can barely think of anything

else. It affects my work and personal life because it's hard for me to be mentally present with my surroundings. It also feels like I can't trust my thoughts and I feel guilty for staying in a relationship while having ROCD thoughts." Negative feelings emerge alongside this inward fixation, namely guilt, panic, and despair. Some individuals have physical symptoms like digestive issues, or headaches that will accompany a "spike." One participant wrote, "It feels awful, it can get so bad that I start having a headache, I usually have a complete breakdown and just cry." Six out of the fifty-five individuals (13%) said that they have to isolate themselves during an episode because they are afraid that they will act on a thought. These thoughts have been described as "loud" and "incessant." One individual said that, "I don't hear the thoughts, but I feel as if I could if that makes sense. They're at the forefront of my mind." It can be extremely mentally painful to experience this.

Suicidal Ideation

Since the episodes are recurrent and "agonizing," some (13%) of the participants disclosed that they had experienced suicidal thoughts or ideation. They described wanting to feel relief and feeling like they didn't deserve to live. Others used fantasizing about suicide as a means to escape from the misery their OCD caused them. One participant said, "I often think of putting a gun to my head and pulling the trigger, just so the thoughts stop. But it's just a fantasy, I'm not suicidal. Really." Another said, "I am suicidal. Just want the pain to stop, to feel relief." To validate this, I have also felt this way when I have been at my lowest. It wasn't that I wanted to die, I just wanted to experience relief from the thoughts.

Chapter 7: Media Representations

The majority of OCD representations in the media portray the popular understanding of OCD, i.e. fastidiousness and cleanliness. “Pure O” OCD portrayals in the media are very rare, which might contribute to misunderstandings about the illness. Little research has been done about the way individuals with “Pure O” relate to stereotyped OCD depictions. The first section of this chapter includes results about survey participants’ thoughts about media depictions of OCD. Additionally, to explore “the individual in the illness,” participants’ own depictions of what a character with OCD should be (if they were based on them) are detailed.

OCD Depictions in Media

Nine out of the fifty-three participants (17%) (that answered question 4), found a depiction of OCD to be helpful, and 5 of the 9 referenced the British TV show *Pure*¹². One individual said, “there’s a series called Pure. I think it showed it very well but also I think that “Pure O” is a lot worse than it was portrayed... but I think that’s mostly because of what we can and can’t put on TV.” This TV show seemed to be the closest representation of “Pure O” OCD out there, unfortunately it isn’t streamable in all countries. Of the remaining four individuals that found a depiction helpful, two referenced a character who wasn’t obviously written to have OCD. One participant said to this effect, “I haven’t seen any accurate representations of OCD or Pure O on tv, but I do have intrusive thoughts and rumination about being a bad person and experience mental contamination. So I often try to go out of my way to be good because I’m scared that I am bad. So lots of characters in movies kinda demonstrate this dilemma (i.e. Ray

¹² A TV show based on Rose Bret cher’s book *Pure*, about her experience with the homosexual theme of “Pure O” OCD.

from *Star Wars*) although they typically don't depict them having OCD." Here they found connection with a character who had some of their traits but wasn't explicitly stated to have OCD. The last two participants referenced *The Aviator* by Martin Scorsese. However, none of these individuals had learned they had "Pure O" OCD through these depictions.

Forty-six out of the fifty-three participants (87%) did not find depictions helpful. Many (60%) found these depictions to be "a joke" and "extremely inaccurate" to what they were experiencing. One individual stated that, "yes I have (seen OCD depicted in the media), and it didn't help me at all. I feel like a lot of times OCD is depicted as a cute quirk that will keep your house organized. Or it is heavily focused on specific compulsions, mainly cleanliness and counting. This has not been my experience at all and therefore I never thought OCD was a possible diagnosis for me." Another individual said, "Sadly, all representations I've seen in movies and TV shows weren't accurate and sometimes felt even mocking. It's usually the typical 'I need things to be organized' and 'I need everything to be perfect, oh I'm so OCD.' It makes me sad that they never portrait the real illness and just give people the wrong idea about it. How are they supposed to learn how serious of an illness it actually is?" Conversely, some other participants just shrugged off the fact that there were no depictions they could relate to and didn't seem that effected by it.

In my case, I never in a million years suspected I had OCD because I thought the symptoms were compulsive handwashing and needing things to be "just so." This trope in the media has given rise to a stereotype of OCD, that can be used by people without OCD to connect with people who do have it, or other's without it. For example, one individual stated, "No the stereotypes is just being clean. When I told my friends about the disorder, they told me 'they like to be clean and organized too.'" In my own life, I have heard people say, "I'm so OCD," to one

and other, when referencing needing to be particular about something. As one participant said, the need to be neat and orderly is more indicative of Obsessive-Compulsive Personality Disorder, not Obsessive-Compulsive disorder. Portraying OCD in this misconstrued, or shallow way has impacted some individuals with “Pure O” by adding to the doubt about if they actually have the disorder. One participant stated that, “most of the depictions focused on physical actions and not in the thought process. This made me doubt I had OCD.” Another individual said, “it’s horrible. My main doubt of, ‘what if this isn’t OCD’ arises because there’s no depiction I can relate to.” None of the participants who found depictions unhelpful learned they had the diagnosis from media representations.

Participant Depictions of their OCD Character

Six out of the forty-eight participants (13%) (who answered question 5), highlighted their bravery and resilience as something they were proud of. One individual said, “probably my favorite quality in myself is that I do not give up, especially when something is important.” Another stated that, “I’m fighting [OCD] and that takes a lot of strength.” One of my favorite quotes was a participant who said they were, “a nervous, but brave man.” Usually what follows the word “but” in a sentence negates what came before it, so this example seemed to elude that his bravery was stronger than his nerves¹³. Though sometimes the act of merely living with “Pure O” doesn’t feel brave, it really is. For example, when an individual chooses to love their husband despite having intrusive thoughts about killing him, or a mother holds and rocks their baby even though they are afraid they might be a pedophile, that exhibits great strength. The alternative is

¹³ Damn straight!

avoiding anything that brings them real joy and connection, and that would negatively impact not only them but their loved ones too.

Twelve out of the forty-eight participants (25%) spoke about having a deep sense of right and wrong, or wanting to be nice and good. One individual said they are, “a nice person who really cares who has a difficult time accepting that they are nice and that they care.” This desire to be good seems to stem from the inner belief that there is something intrinsically wrong with them. However, the very fact that they are so afraid of being horrible means that they aren’t horrible people deep down. Another individual said, “that I’m a very caring person and that’s why my intrusive thoughts are so sticky. They are antithetical to my core values and who I am. I’m also a good mom. Thoughts do not define who we are as a person.” This speaks to the belief that a lot of individual’s with “Pure O” have, that what their thoughts say mean something about who they are as people. If someone with “Pure O” has an intrusive thought that they are a rapist, they are going to partially believe it because it wouldn’t make them so freaked out if it wasn’t true... right? This is an essential part of how they get so caught up in the OCD trap, and why it’s so hard to let their illogical thoughts go.

Impacts & effects of OCD

Twelve out of the forty-eight participants (25%) wanted their portrayals to include the messy bits of the disorder. As one participant put it, “a young woman with thoughts she cannot control white-knuckles through life hopping from one maladaptive coping skills to the next in order to find relief (anorexia, self-injury, substance abuse). She finally discovers the truth about the root cause of her pain, goes through grueling treatment, then turns around and helps others who are going through the same thing.” Another wrote, “It would include how detail-oriented I am and how much a sense of humor I have about myself. It would also show the utter despair:

the unshaven legs, the messy kitchen, the literal days I spent ruminating so hard I forget to pee.”

Yet another stated that:

It would be a big ol’ queer show, first of all. My character would be a cook who goes to night school to become a social worker. She would have trouble concentrating on her studies, because of these weird, awful thoughts that are spinning through her mind. She will be singing a lot, because she always has a song stuck in her head and the only way to get it out is to sing every word right. Whenever she’s alone she needs to listen to a podcast, so she won’t have to listen to her own thoughts. Also, she will be weirdly holding either her feet, her boobs or her ears because she worries someone will come touch them if she doesn’t. She’s slowly starting to share her diagnosis with her partner and friends, but it’s tough because talking about the intrusions can also trigger them. And some are so weird or awful, she’s afraid of their reaction.

Honestly for me, the character would have to have moments where they are utterly immobilized by fear, glued to the couch for a day obsessing about a thought. They would also have moments of a breakdown in skillful behavior, where, for example, they felt like they were going to act on a thought, so they drank so much to prevent it that they ended up in the hospital. However, this would all just help to depict how multi-faceted and human the character with “Pure O” is. While reading these ideas for character portrayals, I was amazed by and grateful for the depth and complexity of each response. Any portrayal would help educate others on what it’s like to have “Pure O”.

Inward-Outward Dialectic

Because there is a big difference between the way “Pure O” OCD presents in an individual externally vs. internally, many participants (44%) wanted this captured in their

portrayals. As one of the participants said, “it’s nicknamed the silent disorder,” because it’s really hard to identify the mental illness from an outsider’s point of view. As one participant put it, “It should portrait how I’m just trying every day to keep going although there’s a war in my mind. That even when I keep getting awful thoughts and visions in my head, I have to act like nothing’s happening on the outside and I can’t ever talk about it with anyone.” Another said, “(I’m) a creative and nice person who likes to paint and hang out with her family, helps her grandmother a lot, and who struggles with thoughts and feelings about killing her husband.” As “Pure O” is an internal experience, so their characters would have to show their thought processes instead of just how it looks to others. Another individual wrote, “Well it would be a two-part person, a very strong and confident man that secretly thinks he is a monster and that gets devoured by his own thoughts. That wobbles on the line between these two powers in his life always trying to stay on the sane side. An emotion-less person driven to feel numb to try and cope but that eventually finds the courage to face his life and cry for all those years that he didn’t allow himself to be sad for the condition he didn’t know he had.”

Chapter 8: Support Rooms & Motivations

In concordance with the rise of other shared diagnoses virtual chat room spaces, online support rooms for “Pure O” have popped up privately and publicly. There has been limited research on how individuals with “Pure O” OCD experience interacting in these spaces. The beginning section of this chapter reports results about how “Pure O” OCD chat room spaces impacted the illness experiences of individuals with the condition. As the results will show, the virtual chatforum spaces significantly helped some participants exist with and learn about their illness. As “Pure O” can be so difficult to live with, other ways that individuals with the condition have found to keep going through the hard times will be shared in this section.

Online Virtual “Pure O” Support Rooms

Twenty-nine out of the forty-nine participants (53%) (who answered question 8) felt less lonely, once they had connected with others who had “Pure O” in online support room spaces. These spaces ranged from Reddit, OCDAction, and the FB Intrusive Thought group, among others. Those individuals stated that they felt like they were a part of a larger community or had a sense of solidarity to others with this mental illness. Within that, some individuals were positively influenced by the community and felt less guilty or weird because of their thoughts. For me, when I first stumbled on OCD chatrooms that were full of individuals with “Pure O”, I felt extremely validated in my experience and no longer alone. Similarly, one participant stated that, “It has clarified a lot for me, I learned a lot about OCD and Pure O. It has been nice to see that some people have the same intrusions as me, makes me feel validated.” Another said, “it has been very helpful to be able to speak with people who know /exactly/ what I’m going through, and even joke about it too. Having a sense of humor has been very helpful with OCD, a disease

which forces you to take yourself and everything extremely seriously all the time.” Along that same vein, some support groups share memes about the disorder that take the serious off of the experience for a minute, which can be really helpful.

Seven out of the twenty-nine individuals (24%) who had a positive experience, noted that through support groups they were able to learn more about themselves. It was posited that these spaces helped participants realize new insights about their symptoms, and the depth their disorder reaches in who they are. One individual stated that, “I realized that a significant amount of my behaviors and things I thought were just quirks of mine were actually OCD (Imaginary audience, rehearsing conversations, reassurance seeking).” Another said, “It’s helped me ground myself and discover so many resources and perspectives. Every day is a great reminder from others that we can be people who are kind to ourselves.” These individuals seemed to benefit greatly from participating in support groups.

Four out of the forty-nine participants (8%) reported that it hadn’t made a difference in their life to use chat rooms. The feedback wasn’t overly negative, rather participants stated things like, “it hasn’t” and “I’ve had some chat room experience but nothing to write in about.” In addition, two other individuals felt that using chat rooms worsened their experience. In both, there was a feeling of increased distress that came once they learned others were experiencing “Pure O” OCD too. The first individual stated, “being in chats and forums just reminds me of how little there are of people with this type of OCD. We’re just screaming into the void. No one is listening, and no one can help. We’re only passing our anxieties on to each other. (It) kind of brings the feeling of hopelessness.” The second participant said, “It has also been a little triggering, whenever I read about someone having ‘worse’ OCD than me, I start ruminating about me faking OCD and tricking everyone in feeling sorry for me.” It’s interesting that the first

individual became overwhelmed when they saw how many other people were struggling, whereas the second individual was sent into an OCD spiral. Just goes to show that two individuals with the same mental illness aren't impacted by things in the same way.

Reassurance Farms

“Reassurance farms” was a phrase shared by one of the participants, and it perfectly describes what support groups can be for those with OCD. As briefly stated before, one of the main compulsions for “Pure O” is reassurance-seeking. Being able to get this reassurance from fellow “OCD-ers” can feel amazing. However, like previously explained, it can become like a drug habit that is hard to kick. One individual said to that effect, “Sometimes it’s (the support groups are) helpful. Sometimes I have to start away. It’s heartbreaking seeing someone go through the pain of an ‘OCD attack’ and they are asking strangers on the internet for reassurance. It is so hard not to give in and give them the reassurance. However, avoiding reassurance seeking is a very big part of treatment, so sometimes I just have to stay away from certain groups.”

Motivation to Keep Living

The Future and Social Supports

Twelve out of the forty-seven participants (26%) (who answered question 10) stated that thinking about the future in some capacity helped them through their darkest moments. Some examples of this are an individual’s future aspirations, their obligations to others, or a creative pursuit. For me, before treatment it was thinking about how music was going to impact my life in the future. Now that I’m in recovery, the fact my OCD has lessened, as well as wanting to know my future children keeps me going. For others (26%), the hope that one day they could get better was enough to live. One individual said, “Mainly the knowledge that it will get better. I’ll always have ups and downs but I’ve come back from my lowest points before so I can do it again.” This also ties into the theme of belief in the self that some individuals included in their responses. 10

out of the 55 individuals stated in some way that the belief that they could get through it, that they were “brave,” was motivating. One participant said, “knowing that every time it’s gotten bad before, it always gets better. It always gets SO good. And that good is always worth every single hardship. Humans are so adaptable. So much can be taken in stride at the end of the day. Even on my darkest day I remember, I get to try again tomorrow.” That kindness to the self when you are low is such a such an important part of healing.

Eighteen out of forty-seven individuals (38%) referenced their support systems being an important motivator to not give up. This looked different for different people. Some didn’t want to pass on the pain to their parents if they committed suicide, whereas others found solace knowing their loved ones cared about them. One individual stated that, “Every night my daughter (5 years old), husband and I tell each other our favorite part of the day. Even if it was only 30 seconds, I can find a little bit of good each day and I hold onto that during the dark times.” Another said, “When my OCD gets bad, the things that really keep me going are seeing my girlfriend and family, I love being around them because they tend to bring me some peace.” These supports didn’t weren’t always human in nature, as many participants noted their comfort and joy coming from their loving pet. In my case, my cat has my emotional life so much better.

Skills & Distractions

In every person’s journey with healing from mental illness, they build up a toolbox of skills that they can use in different situations to help them navigate their life productively. Twelve out of forty-seven individuals (26%) stated that they do engage in some sort of skillful behavior when it comes to living with their OCD. For me, I journal a lot to get thoughts out of my head, so that they aren’t taking up space there. I also meditate, and practice DBT¹⁴ skills

¹⁴ Dialectical-Behavioral Therapy, a therapy created by Marsha Linehan for Borderline Personality Disorder (BPD).

daily that help me. Others mentioned practicing creative arts, yoga, and/or keeping a gratitude journal. One individual stated that, “A macro dose psychedelic trip every few months has definitely helped me with some obsessions (albeit I only do it when in a good headspace).” Another said, “Having something to look forward to (a holiday with friends). When it gets really bad and I can’t do much except stay in bed movies (like *Christopher Robin*, *Paddington*, *It’s A Wonderful Life*, *Chef*) and books (like *Siddhartha*, *Man’s Search for Meaning*, *East of Eden*, *Meditations*) help.” Some apply a moment-to-moment approach when trying to get through an OCD episode. Another individual’s coping technique is taking an ice bath. They explained that if they were able to stay in their for 10 minutes, then their obsessions would significantly reduce. Then, they could face whatever came next in their life.

Chapter 9: Illness Stages

During my research, supplemented by my own experience, five main stages of “Pure O” OCD seemed to occur in a majority of the research participants. Most of the participants seemed to be stuck in stages 3, limbo, and 4, treatment; never quite making it to stage 5, recovery. This seemed to be due to access to mental health professionals that could practice ERP. Each illness stage has been separated and described in the coming section. Granted, there are exceptions to this framing of the condition. These steps just seem to be the most common out of the participant responses. I wanted to detail these steps to help mental health practitioners, loved ones, and even individuals with “Pure O” understand a bit more about the disorder. This research may contribute to a decrease in misunderstanding about the disorder.

Stage 1: Pre-Naming

At the beginning of almost every individual’s journey with “Pure” O OCD, there is a period of time before they have a diagnosis where they experience symptoms. However, during this time, they don’t have a name for their experience. All they know is some part of the individual’s life, that they were certain about before, is now generating unanswerable amounts of doubt. They may try to ignore, suppress, or distract from the obsessions. An individual might also try to hide their obsessions from others, for fear of being seen as crazy or delusional. How long an individual will stay in this stage depends on their age of onset, social supports, and severity of symptoms among other things. Depending on how much insight an individual has into themselves, some may begin Googling for answers at this stage. I was 9-years-old when I had my first “Pure O” OCD obsession and didn’t learn about “Pure O” until I was 17. There were many nights when I was a teenager that I spent holed up in my room, anxiously searching

online for answers. At this stage, individuals are focused on proving that whatever their obsessions are telling them isn't true.

Stage 2: Post-Diagnosis

After a period of time, something will happen (be that a breakdown, hospitalization, or a particularly successful Google search) and an individual will stumble onto the name "Pure O" OCD. This realization that the thing in their life that was causing immense amounts of existential self-doubt and pain is something that can be named, causes some to cry out of relief. This post-diagnosis reality feels almost surreal. Then the OCD monster (as I envision it) comes in and takes away that sense of certainty. The individual may start to doubt the diagnosis, thinking something like, "what if I really don't have "Pure O" OCD and ____ is true?" Instead of only focusing on proving that their obsessions aren't real, as in stage 1, individuals experience the added compulsion of proving that they actually do have "Pure O" OCD. This stage can be comprised of a lot of Googling or reading up on "Pure O" as a way to make sure they really do have the disorder. Some may join chat rooms to get that reassurance from other peers that their experience is similar (and therefore must be "Pure O").

Stage 3: Limbo

Some more time goes by. By now the individual has partaken in a fair amount of information gathering, through a variety of channels; some read books while others look at articles online or obtain information through YouTube. The individual might have come across the term Exposure and Response Prevention Therapy in their reading but can't access any therapists who practice it in their area. Or perhaps a nearby therapist does, but the provider is out of the individual's price range. Maybe the individual is so worried about exposing themselves to

their fears, that they purposefully choose to avoid treatment. Whatever the reason for lack of access to ERP, the individual copes, continuing to peruse resources that they may or may not have already spent time with. They might have even begun therapy, but the sessions don't really help with their OCD. Their life continues to go on, despite not having proper treatment. The individual tries to make the best of it. Perhaps the social supports in their lives are really motivating them to keep going. Or perhaps the fact living is just what one does, motivates the individual. Regardless, somehow at this stage the individual amasses negative and positive coping skills that keep them going.

Stage 4: Treatment

Hurray! Somehow the individual has found a therapist who they can meet with who practices ERP. Perhaps this came out of a partial or full hospitalization. Or maybe the individual moved to an area where their access to specialists increased. The individual may be frightened by the concept of facing their fears, but they feel ready to do so. Maybe they are at a point in their lives where they have to, in order to survive. Stage four is full of bravery and courage because the individual is confronting their very deepest fears. If they are doing ERP with a capable therapist, and they are engaged in the work, the therapy may be successful. If so, they graduate to stage five.

Stage 5: Recovery

Coming out of treatment, the individual may start to experience the world in a different way. Their brains will most likely be much quieter on average. They may or may not have added an SSRI to their treatment plan, which may have helped reduce some of their physical anxiety.

Hopefully by this stage, the individual can see how incredible it is that they were able to survive and overcome their OCD.

Chapter 10: Resources

ERP and Resources

These results show that there is a gap between the need for mental health professionals properly trained in Exposure and Response Prevention Therapy (ERP), and the accessibility of such by those with “Pure O” OCD. As Khodarahimi (2009) states, ERP is still regarded as the primary evidence-based biomedical treatment for OCD. Yet only five individuals mentioned that they had engaged in or were engaged in ERP therapy for their disorder. Out of those five, only two had achieved recovery. Deacon & Farrell (2013) mentioned that there is a reluctance across the board among psychologists to utilize ERP, as some therapists consider it potentially unethical, unsafe, or ill-suited to their practice. As one of the two individuals who have successfully recovered from “Pure O” OCD through ERP, I invite mental health practitioners to open up a conversation around their reluctance to use this therapy modality. After 11 years of an almost daily struggle with obsessions and compulsions, I can say that my mind works in a completely different way now that I’ve finished my ERP treatment.

For those study participants who spoke about being on the verge of suicide, providing access to Exposure and Response Prevention therapy could help to alleviate their pain. Less extremely, ERP can also help individuals who “fake it” through their days, while having a near constant obsessive chatter in the back of their minds. As ERP helps individuals sit with high levels of anxiety, helping them to realize their feared outcome won’t occur if they face their greatest triggers (Khodarahimi 2009), this bravery may ripple out to other areas of individuals’ lives. This ripple effect could potentially positively impact their education level, personal relationships, and even their personal health. Marks (1997) reviewed a decade of behavior therapy research in OCD and found that ERP effectively reduced obsessions and compulsions

(see also Ponniah et al. 2013). I can only speak for me, but by reducing my obsessions and compulsions through ERP, my brain was provided with all this space that I could put to use in other areas of my life (for example, my college education, job opportunities, and friendships).

As ERP trained therapists can be quite hard to access, the following suggestions of resources may be of use to individuals with “Pure O” who need guidance. The International OCD Foundation website contains a list of therapy resources (therapists, in-person support groups, etc.) for individuals with all manifestations of OCD; the resources are divided by geographical location, so they are very easy to search through (“International OCD Foundation” 2021). The foundation puts on a large annual OCD conference every July, each time changing the location to a different city in the US. The conference includes multiple events each day, all tailored to specific topics under the umbrella of OCD. I’ve personally been to this conference, and it was a great way to meet other people who have OCD.

Books by other people with OCD are also great to read, if an individual seeks the camaraderie of another’s story. *Because We Are Bad* by Lily Bailey (2019), and *Pure* by Rose Bretecher (2016) are two great autobiographies of two individuals who lived with pretty serious OCD and are now in recovery. Similarly, *Pure OCD: The Invisible Side of Obsessive-Compulsive Disorder* by Chrissie Hodges (& Ethan Raath 2017) and *Is Fred in the Refrigerator?* by Shala Nicely (2018) are two more autobiographies of individuals with “Pure O” who have conquered their illnesses. If books aren’t a preferred method of information gathering, the podcast *the OCD Stories* by author Stuart Ralph is excellent. Weekly interviews with therapists who treat OCD and individuals who have recovered from OCD are regularly posted on *the OCD Stories* website (“The OCD Stories” 2021). Along the same lines, if an individual seeks a TV

show, *Pure* has regarded by participants to be “the only TV show that portrays “Pure O” OCD” in a realistic manner.

If an individual and their therapist are looking to learn how to do ERP together, the *Treating Your OCD with Exposure and Response (Ritual) Prevention Therapy: Therapist Guide* (Foa et al. 2012) and the companion book *Treating Your OCD with Exposure and Response (Ritual) Prevention Therapy: Workbook* (Yadin et al. 2012) are informative resources. These two books work in tandem with each other, providing the therapist and the individual with an understanding of how the exposure-therapy relationship is built. Other helpful guidebooks for working on OCD are *Overcoming Unwanted Intrusive Thoughts: A CBT-Based Guide to Getting Over Frightening, Obsessive, or Disturbing Thoughts* by Sally Winston (& Seif 2019) and *Managing Obsessive-Compulsive Disorder: A Sufferer’s Question and Answer Guide: With Commentary by Therapist Steven Phillipson, Ph. D.* by Mark Berger (& Phillipson 2004).

As shown in the results, individuals have varying relationships with online virtual support groups for “Pure” O. Meaning, that depending on the individual, these spaces have been shown to positively impact their illness experience. Some even found a sense of biosociality among peers with “Pure O.” I remember meeting in-person, by complete happenstance, two individuals who also had “Pure O.” When we learned that we shared the diagnosis of “Pure O”, an instant connection was made. It seems that a similar sense of camaraderie can occur within support room spaces. However, the drawback to these spaces is that being amongst individuals who understand the disorder, the urge to ask compulsive questions can be overwhelming. However, if an individual desires to join a “Pure O” OCD support room, find one with active moderators. That way if an individual begins to perform compulsions within the space, a moderator will step in and help. The *Intrusive Thoughts* Facebook group is a fairly moderated community.

How to Help Someone with OCD

For Mental Health Professionals

As indicated by the results of this study, reassurance-seeking is a common and tricky compulsion that can appear in biosocial spaces, such as virtual “Pure O” support groups. This compulsion perhaps stems from the initial desire to know more about the quietly researched illness one is diagnosed with, or stumbles upon if they self-diagnose. The desire to learn more about “Pure O” can grow as individuals begin to doubt the legitimacy of their “Pure O” diagnosis. This may begin to happen because OCD, “the doubting disease,” can make individuals doubt themselves about anything to do with definitive labels; for example, “being a serial killer”, “being a pedophile,” or “being real” are all things that people are or aren’t at given points in time. Similarly the label of “Pure O” OCD is something that someone can have or not have at a given point in time, and individuals with the disorder will inevitably want to know if what they are experiencing is “Pure O”, or if they are the exception. At this stage, instead of using self-research as a mode of information gathering for information gathering’s sake, it becomes a compulsive tool an individual can use to help determine certainty about the legitimacy of their disorder diagnosis. If not stopped, this compulsion can take up hours of time. It can impact others in virtual and in-person community spaces, when an individual gets lost in the desire to know if they are in fact experiencing OCD.

So, what to do about this. Recommendations are for strong and clear explanations from mental health professionals about “Pure O” symptomology early on in individuals’ illness experiences with the condition. That way individuals’ will understand more about how their illness will present and will have a roadmap built by a credible mental health practitioner. This roadmap will help to reduce anxious checking and reassurance-seeking behaviors around the question of “is this “Pure O” OCD?” because it will help individuals have more insight and

awareness during their illness journey, which helps with recovery. Strong guidance around stopping this particular reassurance-seeking compulsion is needed, because if left to its own devices, anything can become fodder for this behavior. Along similar lines, more mental health practitioner participation in virtual “Pure O” community spaces is needed, to limit the “reassurance farm” phenomenon. As of right now, most of the moderators in these spaces are peers with “Pure O” who may not be properly trained in how to help de-escalation compulsions. This leads to many individuals either feeling powerless to help someone else who is going through a OCD spiral online or being the ones to go through the spiral themselves.

Another suggestion is for mental health practitioners to come together to figure out where the misunderstanding is happening regarding a “Pure O” OCD diagnosis from the DSM-5. The current definition from the DSM-5 (Substance Abuse and Mental Health Services Administration 2016) states mental rituals as a category of compulsions. Though 82% of individuals in this study had learned about “Pure O” from a mental health professional at one point, only 37% were initially diagnosed through a therapist or psychologist. Many had experienced therapists who didn’t know what “Pure O” was, or who unintentionally fed into their compulsions with the kind of therapy offered. It would benefit the “Pure O” community and patient-healer dynamics at large if the mental health practitioner involvement in diagnosis and treatment was explored.

Where are mental health practitioners getting their information about “Pure O”?

Otherwise, validation from mental health practitioners around the struggle of “Pure O” and the difficulty having an invisible illness to their future clients is needed. “Pure O” is a very complicated illness and leaves a lot of individuals with it feeling like no one understands them. This fear of being misunderstood, or discomfort around talking about “Pure O” experiences can show up in therapy settings. Validation is key to building better patient-healer relationships and

can help to reduce the barrier between the client with “Pure O” and their therapist. Lastly, educate, educate, educate. Part of being able to validate is to put oneself in another’s shoes and imagine what they might be going through. As “Pure O” is such an unknown disorder, this validation could be difficult to achieve for a mental health professional who doesn’t understand how the disorder works. Though efforts on the part of the mental health practitioner to validate the client’s experience with the disorder come from a good place, they could unintentionally do more harm than good. For example, I went through an OCD episode while in a therapist’s office and they told me that I needed to experiment with a girl to figure out my sexuality. They were being supportive around my perceived sexuality crisis but were completely missing the fact I wasn’t really questioning my sexuality and was rather experiencing an OCD spike. Education on the part of mental health practitioners can mitigate some of the unintentional harm caused in patient-healer situations such as this.

For Allies

Mothers, sisters, friends, I imagine it can be so difficult to be on the outside, not really sure if what you are doing is helping or hurting a loved one with “Pure O” OCD. There are a few basic steps that may help you in these kinds of situations. Step one, if your loved one starts going through an OCD spike when you are with them, know it will pass. These can look like sudden fixations on a question or questions that they just can’t let go, no matter how hard you reassure them that it will be okay. For example, “do you think that I am a pedophile?” Know that if they ask you about a theme that their OCD has chosen to latch onto, they are looking to you to completely convince them that whatever they are afraid of either isn’t true or won’t happen. It is a losing battle either way, because if you happen to reassure them in just the right way, resulting in them feeling better, it is helping them need more reassurance in the future. However, if you

don't reassure them at all and ignore it, they will be harmed in the moment. I've found what works for me is to be simultaneously validated and reminded to check in with my body. For example, saying something like, "I know that you must feel so terrified that X is going to happen or is happening, and it must be hard to feel so much anxiety in your body right now. You don't feel like anything else matters right now except for the question in your mind. I can't answer your fears because that would feed your compulsion, but how about I lead you through a grounding exercise instead?" can be really helpful. Become familiar with grounding techniques that work for your loved one. "Pure O" spikes are a very all-consuming and internalized experience, so helping your loved one to ground when they can't help themselves can be a real gift. But also know that it's not your job to fix them, and you can't be their only support in their illness recovery.

Step two, learn as much as you can about the disorder and the particular themes your loved one has. That way you might be able to understand more about how the illness is affecting them. Also research how to best be an ally for someone with "Pure O" OCD. If your town or city has an OCD specialist, or a therapist who has been trained in Exposure and Response Prevention therapy, see if they would be willing to talk to you about how best to support your friend/family member with "Pure O". This will help better inform you about your loved one, and also may help them feel more comfortable talking to you about their experience because you are putting in the work to understand them better. Invite your loved one to talk about their experience to you if they feel comfortable, while making it known that you may misunderstand them, but your intention is to understand underneath it all.

Step three, it can be really helpful for individuals to personify their OCD, because the intrusive thoughts are so ego-dystonic that it can feel as if something else is making them

happen. They might give it a name (like monster, or gremlin, or “my OCD”), or draw it out on a piece of paper. Plus, it can be fun to make something that seems so scary into something physically identifiable. Children especially benefit from this practice, but adults and teenagers do too! Helping your loved one to think of their OCD in this way can be helpful. If you have younger kids, you can help them to draw their OCD. For me, it’s helped to think of my thoughts as separate, between “me” and “my OCD,” because the OCD thoughts always manifest in my mind in the same way. This “othering” process helps to reduce the fear around the obsessions and can help bring a little more insight into one’s illness experience.

Step four, help your loved one to find a therapist who specializes in OCD treatment or who has successfully learned how to do ERP. Also broach the topic of psychiatric medication with them, as this can be very beneficial during treatment as well. It isn’t your job to fix your loved one, but you can help them find the right kind of therapy that will help.

Chapter 11: Discussion

A anthropological qualitative study of the illness experiences of individuals with “Pure O” was undertaken to explore how individuals gathered information about their illness, how virtual “Pure O” support groups impacted treatment journeys, and how individuals experienced representations of OCD in the media. Also as a side-goal, this study aimed to gather as much phenomenological data on what it’s like to be someone with “Pure O” OCD, as limited literature exists with the same agenda. A 10-question survey, posted to OCD-UK and Reddit, gleaned 55 usable responses. All 55 participants had at least one theme throughout their illness experience and explored a variety of sources to gain information about it: books, podcasts, online articles, etc. About half of the participants felt less lonely and felt like they were a part of a larger community of like-minded individuals when they participated in “Pure O” online support rooms. However, some individuals noted the “reassurance farm” phenomenon that can occur in these spaces, which is when an individual engages in their reassurance-seeking compulsion to peers because they “know” more of what OCD is than a layman. Many participants felt like the portrayals of characters with OCD in the media weren’t accurate, and no participants realized they had OCD through watching a TV show or movie with a character supposedly with the disorder. Only 2% of the participants had successfully gone through ERP treatment and were now in recovery.

Participants either used a variety of sources to self-diagnose (63%) or were diagnosed by a mental health professional initially (37%). Overtime, modes through which information was gathered about the disorder changed. Some (38%) had used Reddit to learn about the disorder. Other methods were reading books, listening to podcasts, or reading blog posts by peers with “Pure O”. It’s interesting that there is a learning about the disorder continues, even after the

individual has been diagnosed for some time. Speculation is needed here, while being supplemented by my own experience. “Pure O” has obsessions (taboo and intrusive thoughts/images/urges) and compulsions that usually take cognitive forms (like mental rituals, somatic checking behaviors, and reassurance-seeking) (Williams et al. 2011, 2013). As compulsive googling, or otherwise seeking out information are forms of reassurance-seeking, and the majority of the individuals in this study hadn’t gone into recovery from their symptoms, it makes sense that this reassurance-seeking/information gathering behavior would continue.

Twenty-nine out of forty-nine participants (53%) felt a sense of kinship among those that they met through “Pure O” support groups. Seven out of these twenty-nine (24%) who had a positive experience found the community helpful in terms of learning about themselves. Then four out of the forty-nine participants (8%) said it hadn’t made a difference in their lives. Similarly to the study (Knowles et al. 2017) finding a positive correlation between the use of support groups for individuals who have lost a partner and the user’s experience of depression, over half of the reported participants of this thesis project saw a decrease in their experience of loneliness and self-deprecation. Relating that to the idea of biosociality (Halverson 2020, Friedner 2020), some of the individuals with “Pure O” found the “Pure O” support spaces to increase their sense of belonging, because the community had shared lived-understandings of their so-often misunderstood illness. However, unlike the capital *D* Deaf community, or Autism Speaks, the results of this study didn’t show a coming together in the “Pure O” community around advocating for furthering political and social goals related to their identity, yet. Perhaps once more information exists out there about “Pure O”, more individuals can learn about their illness earlier from mental health professionals. Then maybe, more individuals can come together around those agendas. Personally, I would love to see a grassroots campaign about

changing the popular understanding of OCD, led by those with “Pure O”. Or another idea would be to come together to advocate for more therapists trained in ERP.

Forty-six out of the fifty-three participants (87%), who responded to the section on media representations of OCD, did not find the depictions helpful. 60% of the study participants found the depictions to be upsetting and very inaccurate, and often furthered the popular misunderstanding of the disorder. Only nine out of the fifty-three (17%) found a portrayal to be somewhat relatable, and of the nine, five individuals referenced the British TV show *Pure* (which is based on a book written by a woman with “Pure O” OCD, Bretecher 2016). However, no participants learned they had OCD through any of these depictions. These findings were in line with the study by Fennell and Boyd (2014), which found that though there has been an increase in portrayals in the media of characters with OCD, many don’t fit the DSM-5 diagnostic criteria for the disorder. As positive portrayals, or accurate portrayals can help in challenging public misconceptions around mental illness (Stuart 2006), more accurate portrayals are needed that show the reality of life with “Pure O” OCD.

Chapter 12: Conclusion

The general take-aways from this study were that media representations of OCD were not helpful for individuals with “Pure O”. More studies on how the stereotypical presentations may hinder diagnosis for individuals with OCD are needed. Similarly, studies on mental health practitioners’ influence by popular media depictions of mental illness, specifically OCD portrayals, are needed. Support groups for “Pure O” biosocial spaces could be helpful in providing a community for struggling individuals, but they could also be “reassurance farms”. Studies on the effects of how “Pure O” virtual chat forums change with highly engaged moderators vs. spaces without them, looking at the potential for community engagement in compulsions, are needed. Access to therapists who could identify and treat “Pure O” through exposure-based therapies highly effected individuals’ treatment journeys. More therapists who are willing to explore their relationship with Exposure and Response Prevention therapy are needed.

Limits of this study were the age limit, 18+, as well as the scope of the study. This research should be expanded on, particularly around experiences of “Pure O” in children. Exploring how family relationships of children with “Pure O” may impact diagnosis and treatment would be valuable research. In terms of the scope of the study, only a handful of countries were represented in this research. Further research on how “Pure O” presents globally is needed. Gender identities weren’t included in the demographic questions, so a larger look into how “Pure O” presents differently among different gender and more inclusive sexual identities would be interesting.

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Appendix 1

Research Questions:

1. How did you come to realize you had "Pure" O Obsessive-Compulsive Disorder (OCD)? (characterized by intrusive thoughts/urges/sensations and compulsions that take the forms of reassurance seeking/avoidance behaviors/and mental rituals)
2. How did you feel about yourself before you had a name for what you were struggling with? How did that change once you realized you had "Pure" O?
3. How did you learn about Pure O OCD? How did those resources change over time? (ex. did you start watching YouTube videos about intrusive thoughts and then join a support group later on?)
4. Have you seen any depictions of OCD in movies, or TV shows? If so, how do you think the depiction accurately or inaccurately portrayed your manifestation? Did it help you realize you had OCD?
5. In an ideal world, if someone could base a character off of you, OCD included, what would that depiction be like in order to be true to who you are? (Include some things that you love or admire about yourself)
6. What has your journey with treatment been like so far? What have your interactions with therapists been like? What ways have they been helpful, and what ways could they improve?
7. Have you ever experienced someone doubting that you had OCD? If so, what was that like for you?
8. How has meeting other people with your mental illness through online chat rooms/forums changed your experience with "Pure" O?
9. What does it feel like when the thoughts get bad (and you go through a "Pure" OCD episode, or spike)?
10. When your OCD gets bad (or got bad if you are in recovery), what keeps you going in life? Is there anything else you'd like me to know?