



Increasing Awareness of Lesser-Known Symptoms of Obsessive-Compulsive Disorder (OCD)

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As we approach **OCD Awareness Week 2023 (October 8th-14, 2023)**, it's a great time to shed light on Obsessive-Compulsive Disorder (OCD), which is a frequently misunderstood disorder that is often described using inaccurate stereotypes and myths, which in turn, only increase barriers to proper care. OCD is a debilitating illness that affects approximately 2-3% of the population, and it is associated with significant disability. It is characterized by intrusive, unwanted, and distressing thoughts, impulses, and/or images, which are typically accompanied by repetitive behaviors and/or mental acts aimed at reducing distress. Whereas lay perceptions of OCD often regard it as a disorder marked by a preoccupation with

germs, handwashing, or excessive organization, there are numerous other presentations of OCD that are not as well-known. This unfortunately results in frequent misdiagnosis and delayed access to evidence-based treatment. The International OCD Foundation estimates that it takes approximately 10-17 years for someone with OCD to receive proper treatment. The goal of this discussion is to increase general awareness of lesser-known OCD symptoms, in effort to facilitate accurate diagnosis and treatment, and therefore improve the quality of life of those affected by OCD.

Taboo Obsessions

A significant portion of individuals with OCD experience intrusive thoughts of an aggressive, sexual, religious, or immoral nature,

and this occurs in adults (Bloch, Landeros-Weisenberger, Rosario, Pittenger, & Leckman, 2008), as well as in children (Stewart, Rosario, Brown, Carter, Leckman, Sukhodolsky, Katsovitch, et al., 2007). Such thoughts are often referred to as "*taboo*" symptoms of OCD, given that the content of such thoughts is often considered to be embarrassing and/or inappropriate.

Obsessions Involving Aggressive Content

Individuals with OCD may experience intrusive thoughts of causing harm to themselves and/or others. Examples of such thoughts might include worries about driving off a bridge, throwing oneself in front of a bus, stabbing someone on impulse, kicking one's

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dog, engaging in a hit and run, or suffocating oneself or someone else. They'll report distress in conjunction with the thoughts, and they'll communicate that they *don't actually want to act on the thoughts*, yet they'll continue to be preoccupied with them. As a result, they may experience doubts about who they are morally, such as whether they are a good person, or a violent, cruel individual who could snap at any moment. Since they don't really want their fears to come true, they'll engage in avoidance and/or safety behaviors to manage their anxiety and *prevent* harm. For example, they may avoid handling sharp objects around family members, due to concerns that they could suddenly stab their family member. They may avoid being alone, or they may be hesitant to manage their own medication, due to concerns that they could do something to harm themselves on impulse. Many of these symptoms are misdiagnosed as actual suicidal or homicidal ideation, and this can lead to consequences of further shame, hospitalization, or an arrest – all of which only reinforce the misperception that the person is a danger to themselves or others, and simultaneously, it will delay them from getting appropriate help.

Obsessions involving Sexual Content

Individuals with OCD may experience intrusive sexual thoughts that they find immoral or inappropriate. Children may experience intrusive thoughts and images related to puberty, private parts, or people being naked. Intrusive sexual thoughts may also involve family members, teachers, religious figures, coworkers, animals, or objects. Content of such thoughts may include themes of inappropriate sexual behavior, incest, molestation, thoughts of experiencing or perpetrating sexual assault, and pedophilia. However, individuals with OCD-related sexual obsessions are incredibly disturbed by their thoughts, and they have *no intent* to act on them. They experience incredible shame and guilt in conjunction with such thoughts, as they often believe that they are a horrible, immoral, and/or disgusting person, as they'll erroneously believe that the thoughts must reflect their true self. As a result, they'll engage in avoidance and compulsions to manage their anxiety and prevent their feared outcomes. Some individuals experience obsessive thoughts about gender identity or sexual orientation, and this

may make it difficult for them to participate actively in relationships and intimacy. An individual with an intrusive thought of pedophilia may avoid being around their niece or nephew, because they don't want to risk a situation in which they could do something inappropriate. Some clinicians incorrectly assume that a patient with such symptoms must have a history of sexual abuse or trauma, and those assumptions may result in improper treatment.

Obsessions involving Religious and/or Immoral Content

OCD symptoms may also center around religious themes, cultural or religious practices, or themes of morality, such as a preoccupation with right and wrong. Patients may exhibit excessive fears of disobeying a religious figure, going to hell, rituals of excessive prayer or adherence to religious observance (beyond what is in line with cultural or religious practice), dietary laws, and cleanliness and purity. There may also be heightened concerns about "being a good person," which may manifest as fears of inadvertently offending or upsetting someone, not taking care of our planet (e.g., not recycling, concerns about wasting water or electricity),



We see perinatal and postpartum OCD, where individuals may experience intrusive thoughts of harm to their unborn baby (e.g., "*What if I fall down the steps?*" "*What if I eat something during pregnancy that harms them?*"), or they may experience excessive preoccupation with fetal movements.

and a general urge to always do the right thing. These symptoms are also often undetected, as they may be in line with desirable behavior (e.g., a child who always seems to make good choices), or assumptions that they are just part of a person's religious practice. In some situations, it is helpful to consult with a religious leader (e.g., rabbi, priest, imam), since the goal of treatment is to reduce the OCD symptoms, while simultaneously respecting one's cultural and religious values.

Perinatal and Postpartum OCD

Many people are familiar with postpartum depression and postpartum psychosis, but fewer people are aware of manifestations of OCD in pregnancy and postpartum. Postpartum Support International indicates that *"Postpartum Obsessive-Compulsive Disorder (OCD) is the most misunderstood and misdiagnosed of the perinatal disorders"* (www.postpartum.net). We see perinatal

and postpartum OCD, where individuals may experience intrusive thoughts of harm to their unborn baby (e.g., *"What if I fall down the steps?"*, *"What if I eat something during pregnancy that harms them?"*), or they may experience excessive preoccupation with fetal movements. New parents may also experience intrusive thoughts of harming their infant (e.g., *"What if I drop him over the railing?"*, *"What if I touch the baby inappropriately during a diaper change or bath?"*, and *"What if I drown them in a bath or suffocate them with a pillow?"*). In contrast to what you might see in postpartum psychosis, these parents have *no intent or desire* to act on their thoughts, yet they continue to experience them repetitively. Consequently, new parents often experience feelings of guilt and shame, especially when others seem to only have adoration for the new baby. They may even avoid their infant or engage in safety behaviors in effort to keep them safe. If they share

these thoughts with family, friends, or medical professionals, it is likely that well-meaning supporters may contact authorities or encourage hospitalization of the patient; both of which are unnecessary actions that reinforce the patient's belief that they are a danger to their infant.

Important Factors to Consider in Diagnosis

The previous discussion highlights a few common OCD symptoms that are rarely discussed in the general literature, with the goal to increase awareness. Many of these symptoms can get even more complicated; for example, one might have intrusions that fall in more than one symptom domain (e.g., an intrusive thought that is both violent and sexual), or one might exhibit actual suicidal ideation in addition to OCD-based intrusive thoughts of self-harm. Although there is no definitive way to distinguish between an OCD-related thought and an actual at-

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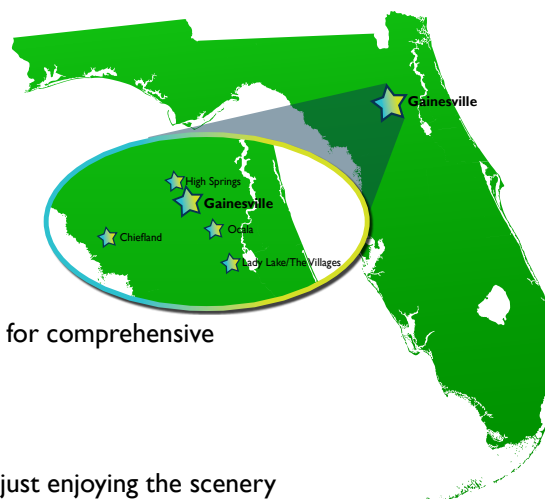
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risk individual, there are a few key factors to look for in the assessment process when considering whether a diagnosis of OCD may be present.

1. OCD thoughts are typically experienced as ego-dystonic

Individuals with OCD are typically aware of their symptoms, and they recognize them as unwanted. They tend to be ego-dystonic (i.e., thoughts that are unacceptable to oneself and inconsistent with who they are as a moral person), rather than ego-syntonic (i.e., thoughts that are acceptable to oneself and in line with one's values and morals).

2. Presence of distress or anxiety

Individuals with OCD tend to experience a variety of negative emotions, such as anxiety, shame, guilt, and disgust, in relation to their thoughts. They report such thoughts to be intrusive, bothersome, and often repugnant, and thus they strive to rid their mind of the thoughts. Contrastingly, someone with true ideations of harm or sexual paraphilias would be more likely to experience the thoughts as wanted, exciting, pleasurable, and not too distressing. A caveat to note is that some individuals with OCD experience doubt about *whether or not* they like the thoughts, though such doubts can often be fairly easily recognized as OCD-related doubts, especially since OCD is often considered "the doubting disorder" (e.g., "*What if I really do like these thoughts?*", "*Did I just get aroused when I had an inappropriate thought?*", "*What if this reflects the real me?*"). Such symptoms almost always

evoke feelings of distress and/or other negative emotions.

3. Presence of compulsions, avoidance, and/or safety behaviors

Given that individuals with OCD *do not actually want to act on their thoughts*, they often engage in avoidance, compulsions, and/or safety behaviors in response to taboo OCD thoughts in effort to prevent their feared outcome from occurring. Someone with an actual interest in acting on taboo thoughts would likely seek out such content to pursue satisfaction or feelings of desire, whereas someone with OCD will do whatever is in their power to *prevent* the feared outcomes from occurring. The person with OCD thoughts is terrified of committing harm, so they engage in safety-seeking behaviors and take precautions, all to avoid acting on them.

- **Compulsions** could be overt (e.g., knocking on wood in response to a taboo thought to prevent it from happening; excessively checking on an infant to ensure they are breathing), or mental compulsions (e.g., mental reviewing of intrusive thoughts to try to figure out whether one feels excitement or disgust in response to a thought; attempts to suppress, neutralize, or counteract negative thoughts with more positive thoughts). Compulsions also frequently involve others (e.g., confessing thoughts to others to seek reassurance that one is not a bad person).

- **Avoidance** may include staying away from situations, content, or people that trigger OCD thoughts (e.g., particular TV shows, certain family

members, religious services), or not wanting to be alone, due to concerns that one may impulsively act on such thoughts.

- **Safety behaviors** may include subtle behavior changes such as staying away from ledges, turning one's body away, or keeping one's hands in their pockets when sharp objects are nearby.

4. Consideration of history/past behavior

Since individuals with OCD are quite unlikely to act on their thoughts, they typically have no prior history of acting on such thoughts. In fact, OCD symptoms often pick on people in relation to things of high importance to them, so we might see a loving teacher who experiences intrusive thoughts of harming her elementary school students. Individuals with no history of violence may experience an onset of violent, graphic images. A new mother, whose lifelong dream it has been to be a parent, may suddenly experience unwanted thoughts of harming her infant. Individuals with OCD-related taboo thoughts tend to live their lives with a particular set of values, such as things or people they care about most, and OCD tries to hijack those values and make the person doubt their sense of self.

Treatment

Cognitive-behavioral therapy (CBT) with Exposure and Response Prevention (ERP) is widely-regarded as the gold-standard treatment modality for OCD, given its strong empirical support in both children and adults with OCD (McGuire, Piacentini, Lewin, Brennan, Murphy, & Storch, 2015; Olatunji, Davis, Powers, & Smits, 2013; Skapinakis, Caldwell, Hollingworth, Bryden,

Fineberg, Salkovskis, et al, 2016).

Despite the presence of efficacious treatment for OCD, a variety of individuals with OCD are treated with inappropriate and non-evidence-based treatments, which often results in harm and other negative consequences (McKay, Abramowitz, & Storch, 2021). Such consequences may include increased hopelessness and discouragement due to symptom worsening, ongoing distress and impairment, and both emotional and financial costs associated with ineffective treatment. Further, some well-intentioned providers may attempt to provide CBT with ERP, but due to limited training and experience, they end up providing ineffective and or harmful treatment. This can be very discouraging for someone seeking help, and it may lead to treatment drop-out and feelings of hopelessness about their ability to get better. Since effective treatment for OCD is available, it is important for individuals with OCD to see an experienced provider with a specialization in OCD. The International OCD Foundation (www.iocdf.org) is an incredible organization and resource that will help connect people to proper treatment.

Summary

Though a comprehensive discussion of assessment, diagnosis, and treatment of taboo symptoms in OCD is outside the scope of this article [see Jacob & Storch (2015) for a more detailed review], the aforementioned article highlights some under-recognized presentations of OCD in order to increase awareness. Given the "taboo" nature of these thoughts, they are misdiagnosed and misidentified at a high frequency, even by mental health professionals (Glazier et al., 2013). The toll of improper diagnose and treatment is vast, as consequences may involve 911 or the police being called, hospitalization, a rupture to the therapeutic alliance, or legal ramifications. Many well-intentioned therapists break confidentiality due to good intentions, but

such misdiagnosis can be very detrimental to the person seeking help. Thorough assessment is key, and a referral to, or consultation with, a specialized provider is often necessary to prevent a path of ineffective, and potentially harmful treatment. The National Institute for Health & Clinical Excellence (NICE) Guidelines specify: *"If healthcare professionals are uncertain about the risks associated with intrusive sexual, aggressive or death-related thoughts reported by a person with OCD, they should consult mental health professionals with specific expertise in the assessment and management of OCD. These themes are common in people with OCD at*

any age, and are often misinterpreted as indicating risk." Hopefully this article will spread awareness and increase access to proper diagnosis and treatment for those with OCD.

If you'd like to get involved in spreading awareness about OCD, we encourage you to check out OCD Awareness Week programming at the calendar link below. The International OCD Foundation and its affiliates are hosting events all around the globe, and we encourage you to join us in raising awareness about OCD!

<https://iocdf.org/programs/ocdweek/>

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