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Characterizing intrusive destructive behaviors and the core population of patients in which they present

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Thesis

**CHARACTERIZING INTRUSIVE DESTRUCTIVE BEHAVIORS AND THE
CORE POPULATION OF PATIENTS IN WHICH THEY PRESENT.**

by

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ABSTRACT

Background: Intrusive destructive behaviors (IDBs) comprise a behavioral symptom construct initially observed in individuals with Tourette syndrome (TS) and commonly co-occurring conditions such as attention-deficit/hyperactivity disorder (ADHD) with executive dysfunction and obsessive-compulsive disorder (OCD). IDBs are behaviors characterized by feeling compelled to and then acting on intrusive unwanted urges despite (and because of) exquisite awareness of the negative implications.

Objective: This study aims to illuminate the phenomenology of IDBs using a clinical population comprised of youth with tic and OCD spectrum conditions. The study also aims to begin to characterize the prevalence of IDBs in this population, and to explore the correlations between IDBs and commonly co-occurring conditions (such as TS, OCD, ADHD, etc.) often linked to similar disrupted CSTC neurocircuitry.

Methods: Twenty-five participants from the MGH Pediatric Psychiatry OCD and Tic Disorders program voluntarily completed the survey-based study. Statistical analyses were conducted based on the survey results.

Results: From our study sample, 63.2% of participants reported experiencing IDBs. The most commonly occurring co-morbid disorders for participants that selected “yes” to experiencing IDBs were obsessive-compulsive-related disorders (OCRD), including

OCD- and body-focused repetitive behavior disorders (94.7%), tic and related disorders (73.7%), and ADHD (57.9%).

Conclusions: The high rates of reported IDBs in this clinical sample highlight the need for further research into the phenomenology of IDBs so that we can better learn how to identify and treat this impairing behavioral symptom. Future studies should involve sampling a larger tic/OCD population, a neurotypical population, and a population of individuals with non-tic/OCD psychopathology (e.g. bipolar disorder, autism spectrum disorder).

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LIST OF ABBREVIATIONS

ADHD	Attention-Deficit/Hyperactivity Disorder
CBIT	Comprehensive Behavioral Intervention for Tics
CBT-ERP	Comprehensive Behavioral Therapy – Exposure Response Prevention
CSTC	Cortico-striatal-thalmo-cortical
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5 th edition
EF	Executive Function
ERP	Exposure Response Prevention
FBA	Functional Behavioral Assessment
FBI	Functional Behavioral Investigation
GAD	Generalized Anxiety Disorder
IDB(s)	Intrusive Destructive Behavior(s)
MDD	Major Depressive Disorder
MGH	Massachusetts General Hospital
NSSI	Non-Suicidal Self-Injury
OCD	Obsessive-Compulsive Disorder
RAQ	Rage Attack Questionnaire
SSRI	Selective Serotonin Reuptake Inhibitors
TOCD	Tourettic Obsessive-Compulsive Disorder
TS	Tourette Syndrome
Y-BOCS	Yale-Brown Obsessive-Compulsive Scale

INTRODUCTION

Intrusive Destructive Behaviors

Intrusive destructive behaviors (IDBs) are a behavioral symptom construct that was initially described in individuals with Tourette syndrome (TS) and commonly co-occurring comorbidities, including attention-deficit/hyperactivity disorder (ADHD) with executive dysfunction and obsessive-compulsive disorder (OCD). IDBs are behaviors where one feels compelled to and cannot resist acting on undesirable urges despite these actions having potentially serious consequences (Greenberg et al., 2021). These behaviors are frequently experienced by the individual as simultaneously deliberate, upsetting, and satisfying because even though the individual engaging in them knows that the behavior will result in a negative consequence, the tension felt prior to, and the relief/satisfaction felt following the action feels too intense to resist. Some examples of IDBs include having to stare into the sun on a bright day, having to push on a bruise, having to bite tinfoil, and having to step the wrong way in a dance recital.

IDBs are setting-specific, and the urges are often exquisitely undesirable to a particular environment (Greenberg *et al.*, 2021). For example, a child constructing a Lego tower may experience an urge to break it down just as he is nearly finished building it. The child does not want to destroy the structure as he cares about it and has invested time into the project. However, after experiencing that intrusive thought-urge, the unfulfilled urge continues to grow and cause increased distress until it is acted upon and ‘satisfied.’ Individuals with IDBs report that acting on the urge provides momentary relief, but that it is quickly followed by feelings of remorse, embarrassment, and shame.

TS, OCD and ADHD (and other commonly occurring comorbidities) all share an associated dysregulated cortico-striatal-thalamo-cortical (CSTC) circuitry. The CSTC pathway is a particular brain circuit that controls movement execution, habit formation and reward seeking (Rădulescu et al., 2017). When the circuit is disrupted, an individual may struggle with impulsivity, compulsivity, and disinhibition (Jahanshahi et al., 2015). Impulsivity refers to inability to stop oneself from behavior motivated by reward despite known negative consequences, and compulsivity relates to the inability to suppress behavior aimed at relieving an uncomfortable mental state. Disinhibition is defined by the inability to withhold an inappropriate behavior that is not goal-directed (Flessner et al., 2012). Given that IDBs have elements of impulsivity, compulsivity, and disinhibition as well, they are also hypothesized to be associated with dysregulated CSTC circuitry (Greenberg et al, 2021).

Given their confusing nature to the outside observer, IDBs are often mislabeled and mistaken for intentional ‘bad behavior.’ Individuals with IDBs often describe feeling intense guilt or shame over their actions that is then further exacerbated when they are punished for these behaviors. Furthermore, IDBs can be physically painful to the sufferer and potentially lead to longer-term sequelae (e.g. harming eyes from staring into sun). Given the quality-of-life challenges imposed by IDBs on those who suffer from them, it is our aim to better understand their epidemiology/phenomenology (who experiences them, how the experiences are characterized, what are the commonly associated comorbidities, etc.). Once we better understand the phenomenology, we can better determine how to best treat this complex condition.

Comorbidities

As is the case of many developmental neuropsychiatric conditions, it is not uncommon for individuals to present with multiple conditions simultaneously. Our understanding of IDBs has evolved from working with children and adolescents with tic disorders, associated OCD, ADHD with executive dysfunction, and other impulsive-compulsive spectrum disorders. These disorders are intricately linked due to similar genetic and phenomenological factors, and shared dysregulated neurocircuitry and neurotransmitters within the CSTC pathway (Jahanshahi et al., 2015).

Neurocircuitry Impulsive-Compulsive Spectrum Disorders

Neuroimaging studies have demonstrated that several common obsessive-compulsive spectrum disorders (e.g. OCD, trichotillomania, etc.), ADHD, and TS can be defined by similar patterns of dysregulated neurotransmitters and neurocircuitry within the CSTC pathway (Jahanshahi et al., 2015; Zhu et al., 2016). Under typical circumstances, oscillations, and synchronized activity in different regions of the CSTC pathway are essential for carrying out habitual actions. Conversely, heightened activity in particular regions or across the entire circuitry is believed to contribute to the development of OCD and TS (Rădulescu et al., 2017).

Tourette Syndrome

Tourette syndrome (TS) is defined by the presence of more than one motor tic and at least one vocal tic for at least a year, not necessarily concurrently, and appearing before 18 years of age (Swain & Leckman, 2005). Tics are categorized as either simple (motor or vocal) or complex (motor or vocal) (Müller, 2007). Tics are believed to be somewhere in between voluntary (intentional and deliberate) and involuntary (completely outside of one's control), and as such are commonly referred to as being 'non-voluntary'. Individuals with tics often experience premonitory urges, uncomfortable sensory experiences that precede tics. The premonitory urge induces internal distress that can only be relieved by the execution of the tic (Hallett, 2015). The sensation of resisting the urge to tic is comparable to purposefully denying oneself the relief of scratching an itch or holding back a sneeze (Greenberg et al., 2021). Intentionally resisting a tic typically causes significant discomfort for the individual. The action of the tic provides temporary relief, although it is short-lived, as the urge quickly reappears. Thus, a negative reinforcement-based pattern, perpetuating the persistence of tics is established (Hallett, 2015).

Table 1. Examples of simple motor and vocal tics (Müller, 2007).

Simple Motor Tics	Simple Vocal Tics
Blinking	Throat clearing
Turning the head	Sniffing
Shrugging	Coughing
Shaking of extremities	Mumbling
Foot-stamping	Flicking
	Whistling
	Grunting
	Snoring
	Barking

Table 2. Examples of complex motor and vocal tics (Müller, 2007).

Complex Motor Tics	Complex Vocal Tics
Touching	Imitation of sounds
Lying down flat	Repetition of senseless items
Deep knee bends	Coprolalia
Pushups	Echolalia
Steps backwards	Palilalia
Certain order of steps during walking	Echokinesia
Turning around	

Studies on tic treatments suggest that both behavioral and pharmacological treatment approaches may be equally effective (McGuire et al., 2014). The gold standard behavioral treatment for tics in the US is comprehensive behavioral intervention for tics (CBIT), though exposure response prevention (ERP) is also frequently used and has consistently demonstrated success. CBIT has two primary components, habit reversal therapy (HRT), whereby the individual develops tic-specific awareness and competing

responses, and function-based assessment and interventions, whereby one evaluates and modifies the contextual environmental factors that support or maintain tic expression. An advantage of behavioral therapy is the lack of potential medication-based side effects (Frey & Malaty, 2022). Pharmacological treatments for TS include α -adrenergic agonists including clonidine and guanfacine, as well as dopamine receptor antagonists. Notably, dopamine receptor antagonists have shown significant efficacy in suppressing both vocal and motor tics in 80% of patients (Woods et al., 2016).

Individuals with TS commonly experience co-occurring disorders, and the genetic factors associated with TS bear similarities to those observed in OCD, ADHD, and other impulsive-compulsive spectrum disorders (Greenberg et al., 2021). According to one study, 85.7% of TS patients reported experiencing at least one additional co-occurring condition, while 57.7% reported having two or more additional comorbidities (Hirschtritt et al., 2015). The most commonly occurring comorbidities in TS include OCD and ADHD. Additionally, 30% of individuals with TS meet criteria for other mental health conditions, including mood disorders, rage attacks, anxiety, and other disruptive behaviors (Hirschtritt et al., 2015). However, TS most commonly co-occurs with OCD and ADHD (Hallett, 2015). **Figure 1** illustrates findings on the prevalence of the most commonly observed co-morbid disorders for individuals that only have TS, or TS with OCD, or TS with ADHD, or TS with both OCD and ADHD (Hirschtritt et al., 2015).

Interestingly, some individuals may present with Tourette's OCD (TOCD), a distinct phenomenology, where they display symptoms at the intersection between tics and compulsions (Ludlow et al., 2023). Patients with TOCD exhibit tic-like behaviors

alongside compulsions and a general disposition of anxiety (Katz et al., 2022). Although not officially recognized as an independent diagnostic category by the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), growing clinical evidence suggests that TOCD represents an intermediate neuropsychiatric disorder with its own distinct features, setting it apart from both Tourette syndrome (TS) and obsessive-compulsive disorder (OCD) individually (Katz et al., 2022). Similarly, IDBs can be thought of as an intermediate neuropsychiatric disorder as they are not independently categorized by the DSM-5 but display symptomology distinct from TS, OCD, ADHD, and other disorders defined by disrupted CSTC circuitry. **Figure 1** illustrates a study's findings on the prevalence of the most commonly observed co-morbid disorders for individuals that only have TS, or TS with OCD, or TS with ADHD, or TS with both OCD and ADHD (Hirschtritt et al., 2015).

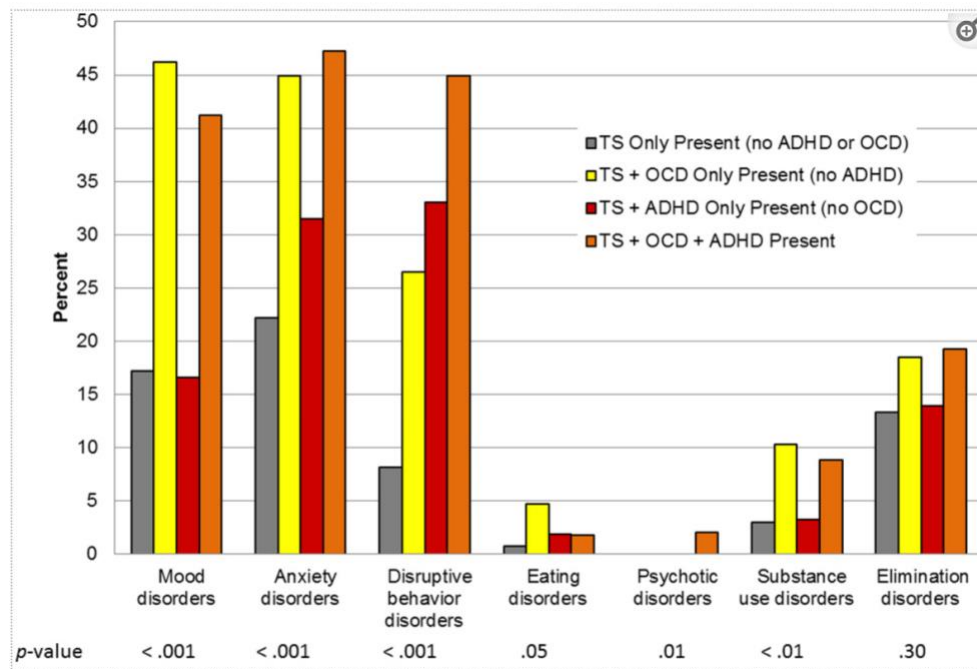


Figure 1. Prevalence of Comorbid Disorders for TS, OCD, and ADHD: the percentage of patients diagnosed with TS with an additional neuropsychiatric disorder/comorbidity (OCD or ADHD or both) compared to patients that display a singular neurological condition without the presence of TS (Hirschtritt et al., 2015).

Obsessive Compulsive Disorder

DSM-5 presently recognizes OCD as a condition characterized by obsessions and/or compulsions (American Psychiatric Association & American Psychiatric Association, 2013; Nazeer et al., 2020). Obsessions are persistent, intrusive, and repetitive ideas, thoughts, images, or impulses. Compulsions are behaviors performed to relieve the distress caused by these obsessions (Stein et al., 2019), or according to rigidly applied rules. It is important to note that the compulsion does not need to align directly with the obsession and/or if it is aligned, is often taken to an extreme (Brock & Hany, 2024). For example, an individual that has a contamination obsession may fixate over their hands being “dirty” and then engage in compulsive handwashing until their skin is raw (Jalal et al., 2020). In an example where the compulsion is not recognizably related to the obsession, an individual may need to tap a table in multiples of five to prevent their loved one from dying.

OCD symptoms are commonly categorized into four subgroups: symmetry, forbidden thoughts, cleaning/contamination, and hoarding. Symmetry obsessions are portrayed as requiring elements in the environment to be exact or “just right;” in regard to symmetry or alignment. Associated compulsions include ordering and arranging, evening up or aligning , writing/re-writing, and touching or tapping (Lochner et al., 2015).

Forbidden thoughts are often aggressive in nature and are commonly -related to religious, sexual, or somatic themes (Greenberg et al., 2021). The associated compulsions often involve individuals repeatedly seeking reassurance that they will not act on their disturbing thoughts. Individuals with forbidden thoughts also frequently engage in avoidance to ensure they are not triggered by their environment (Berman, 2019). Patients with cleaning and contamination OCD experience significant distress related to germs and/or other ‘contaminants’ in their environment. They engage in excessive cleansing habits, which can last for several hours and may result in skin irritation (Jalal et al., 2020). Individuals with hoarding OCD excessively retain seemingly non-valuable possessions. When severe, this behavior can impair daily functioning and lead to unsanitary or hazardous home environments (Wheaton et al., 2008).

Table 3. Examples of Obsessions and Compulsions: definition and examples of common obsessions and compulsions associated with OCD (Krebs & Heyman, 2015).

	Obsessions	Compulsions
Definition	Recurrent, unwanted and persistent thoughts, images or urges that cause marked distress	Repetitive behaviours or mental acts that are often driven by rigid rules and performed in an attempt to reduce anxiety
Common themes	Contamination Aggressive/harm Sexual Religious Making things ‘just right’	Washing and cleaning Checking Reassurance seeking Repeating Ordering and arranging

The gold standard behavioral treatment model for OCD is cognitive behavioral therapy-exposure response prevention (CBT-ERP). ERP involves “exposing” the patient to the distressing thought, image, impulse, or urge and then training them to not engage in the compulsions through “response prevention” (Hezel & Simpson, 2019).

Pharmacologically, the gold standard treatment involves selective serotonin reuptake inhibitors (SSRIs) (Krebs & Heyman, 2015). SSRI’s have proven to be effective in 40-60% of OCD patients (van Roessel et al., 2023). Numerous studies have shown that there is a correlation between OCD symptoms expression and serotonin deficiency. SSRIs block serotonin reuptake and increase the percentage of readily available serotonin (van Roessel et al., 2023). Multiple landmark studies have shown that the combination of medication and therapy is most effective in alleviating OCD symptoms.

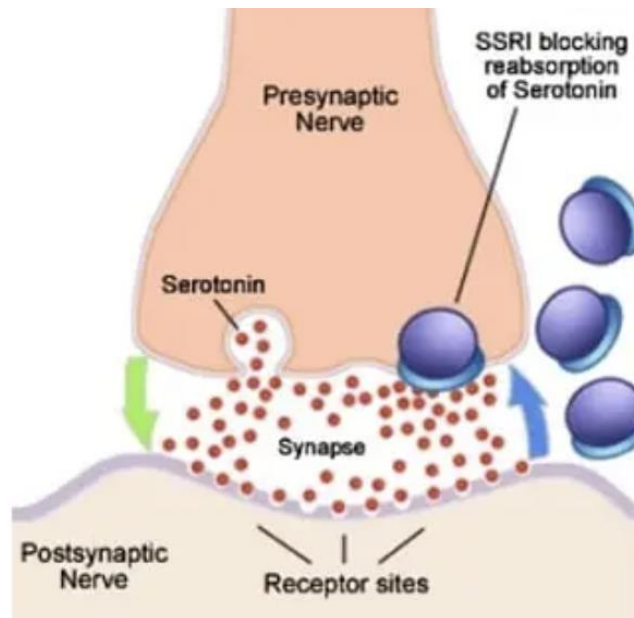


Figure 2. SSRI Diagram: how SSRIs function to block the presynaptic neuron from re-uptaking the previously released serotonin neurotransmitters (Munda, 2023).

Patients presenting with OCD also commonly experience co-occurring conditions. A systematic review study found a 69% comorbidity rate amongst OCD patients (Sharma et al., 2021). The most common co-morbid disorders identified were other OCD-related disorders, mood disorders (e.g. major depressive disorder (MDD)), anxiety disorders (e.g. generalized anxiety disorder (GAD)), and neurodevelopmental disorders (Sharma et al., 2021).

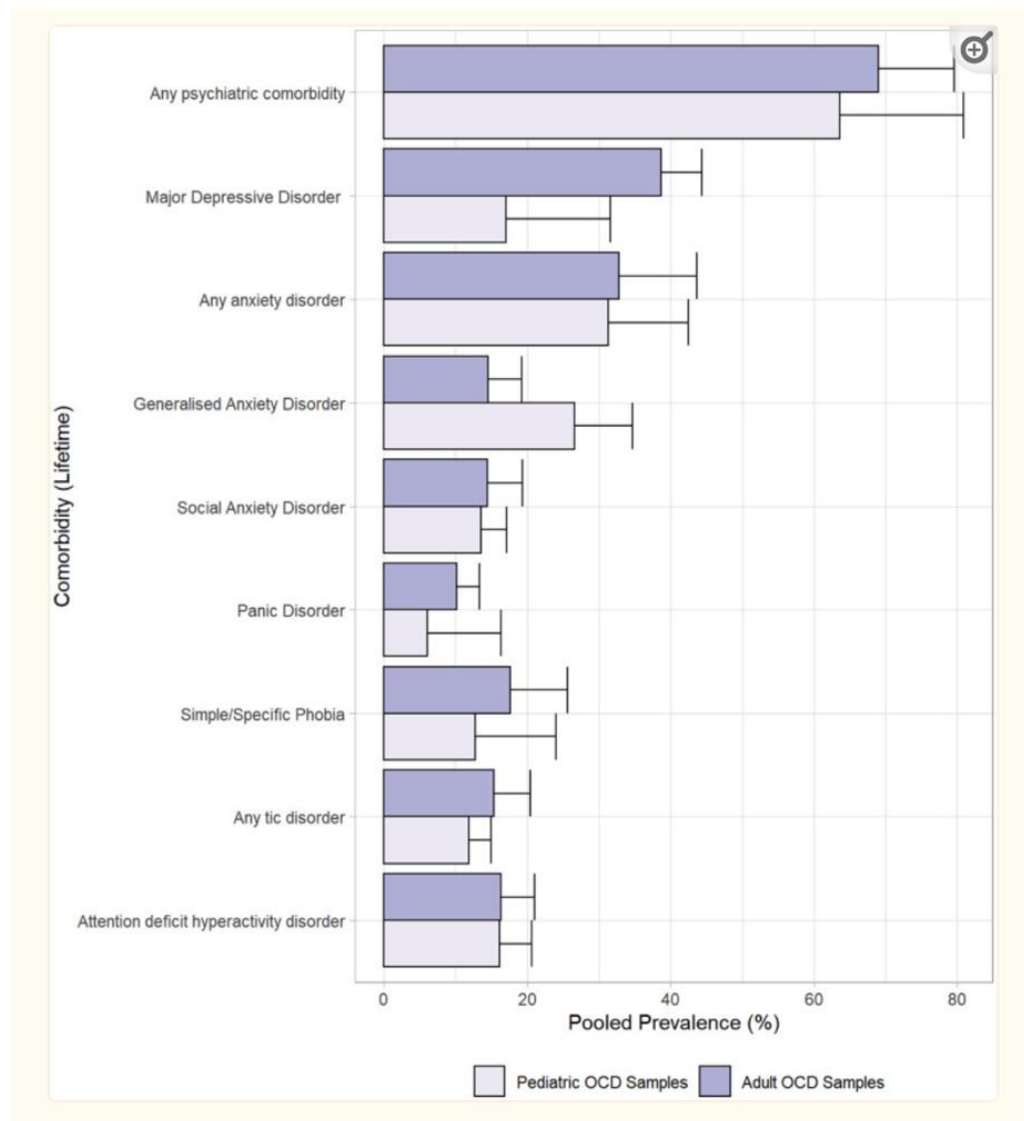


Figure 3. Prevalence of Comorbid Disorders of OCD: rates of the most common comorbidities of OCD in pediatric and adult samples (Sharma et al., 2021)

Attention-Deficit/Hyperactive Disorder

ADHD is a neurodevelopment disorder characterized by developmentally inappropriate levels of inattention, hyperactivity, and/or impulsivity (Austerman,

2015; Brem et al., 2014; Rajaprakash & Leppert, 2022). Per DSM-5, the diagnostic criterion for ADHD requires onset before the age of 12, symptoms must be present in at least two environments (e.g., social, academic, home, etc.), and the individual must display significant symptoms of inattention, hyperactivity and/or impulsivity. Inattention occurs when the individual struggles with focus, distractibility, and staying on topic. Hyperactivity presents as the individual having an inappropriate amount of energy in proportion to their environment. Impulsivity is characterized by the individual acting before thinking when in a reward seeking state. ADHD symptoms are often associated with additional co-occurring learning disabilities and executive dysfunction (Rajaprakash & Leppert, 2022). Executive functions encompass a set of cognitive abilities essential for directing goal-oriented actions, and are crucial for adapting to dynamic environments (Rabinovici et al., 2015). Common executive dysfunction difficulties include challenges with impulsivity, flexible thinking, emotion regulation, working memory, planning and prioritizing, and organization amongst others (Rabinovici et al., 2015).

Table 4: Inattention vs. Hyperactivity/Impulsivity: the difference between how inattention and hyperactivity/impulsivity present in children and adolescents with ADHD (*Attention-Deficit/Hyperactivity Disorder in Children and Teens: What You Need to Know - National Institute of Mental Health (NIMH), 2021* (<https://nimh-catalog-demo.iqsolutions.com/sites/default/files/publications/attention-deficit-hyperactivity-disorder-in-adults-what-you-need-to-know.pdf>))

Inattention	Hyperactivity/Impulsivity
Not paying close attention to details or making seemingly careless mistakes in schoolwork or during other activities.	Fidgeting and squirming while seated.

Difficulty sustaining attention in play and tasks, including conversations, tests, or lengthy assignments.	Getting up and moving around when expected to stay seated, such as in a classroom.
Trouble listening closely when spoken to directly.	Running, dashing around, or climbing at inappropriate times or, in teens, often feeling restless.
Finding it hard to follow through on instructions or to finish schoolwork or chores or starting tasks but losing focus and getting easily sidetracked.	Being unable to play or engage in hobbies quietly.
Difficulty organizing tasks and activities, such as doing tasks in sequence, keeping materials and belongings in order, managing time, and meeting deadlines.	Being constantly in motion or on the go and/or acting as if driven by a motor.
Avoiding tasks that require sustained mental effort, such as homework.	Talking excessively.
Losing things necessary for tasks or activities, such as school supplies, books, eyeglasses, and cell phones.	Answering questions before they are fully asked or finishing other people's sentences.
Being easily distracted by unrelated thoughts or stimuli.	Having difficulty waiting one's turn, such as when standing in line.
Being forgetful during daily activities, such as chores, errands, and keeping appointments.	Interrupting or intruding on others, for example, in conversations, games, or activities.

Current research indicates that pharmacological intervention stands as the primary treatment for ADHD, particularly through the use of stimulants (Corbisiero et al., 2018). Stimulants demonstrate a high efficacy rate, with approximately 70% of patients exhibiting positive responses to treatment (Austerman, 2015). Stimulants include methylphenidate, dexamethylphenidate, mixed amphetamine salts, dextroamphetamine, and lisdexamfetamine (Austerman, 2015; Nazarova et al., 2022). In cases where stimulants prove ineffective, nonstimulants such as guanfacine, clonidine, and atomoxetine offer viable alternatives (Nazarova et al., 2022). The inclusion of behavioral

therapy alongside medicinal interventions may vary in effectiveness depending on the individual's age and circumstances (Corbisiero et al., 2018).

Patients rarely experience ADHD as a standalone condition. It is estimated that great than 60% of youth with -ADHD experience one or more comorbid disorders (Gillberg et al., 2004). The most commonly observed co-occurring disorders are other disruptive behavior disorders (e.g. oppositional defiant disorder, conduct disorder), depressive disorders, tic disorders, and anxiety disorders (Seo et al., 2022).

Differentiating IDBs From Other Impulsive-Compulsive Spectrum Disorders

IDBs are a unique symptom construct, though they share features with tics as seen in tic disorders, compulsions as seen in OCD, and impulsivity/disinhibition as seen in ADHD (Greenberg et al., 2021). That said, there are differentiating factors.

Tics

Like tics, IDBs are preceded by an intense urge or sensation that results in a specific movement, vocalization, or behavior. The action of the physical movement, vocalization, or behavior serves to relieve internal distress and/or tension. In tics and IDBs, the resulting action may also result in the infliction of physical pain. However, a major distinguishing factor is that individuals with IDBs experience a conscious anxiety and tension about acting out the “worst possible” behavior in relation to their environment. Unlike tics, IDBs are highly circumstantial and setting-driven, and the

greater the potential negativity associated with the action, the more difficult it typically is for the individual to suppress themselves. Tics may increase in particularly stressful situations or environments, but they are not unique to the environment (Greenberg et al., 2021).

OCD

Intrusive urges occur in both IDBs and OCD cases; however, the specific reasoning behind the urge helps clinicians distinguish between the two conditions. An intrusive urge in OCD is fear-based, and importantly, not acted upon. In fact, an individual with OCD typically engages in specific compulsions (or avoidance) to ensure that the theoretical bad outcome of the obsession does not occur (Greenberg et al., 2021). In IDBs, however, the individual experiences and then acts on the undesirable intrusive urge. Additionally, the cause of the compulsion/behavior differs between OCD and IDBs. For example, an individual with OCD may wreck their Lego structure to prevent a loved one from dying. In contrast, an individual with IDBs will wreck their Lego structure when it is near completion, despite not wanting to, because in that particular situation it is what they least want to do. Thus, clinicians need to investigate the specific nature of the urge and the individuals' feelings towards the outcome to decipher between IDBs or OCD (Greenberg et al., 2021).

ADHD

IDBs and ADHD have overlapping characteristics as well. Executive dysfunction is commonly seen in ADHD and is also likely a key contributor to experiencing IDBs. 33-50% of individuals with ADHD struggle with executive function (EF)

(Biederman et al., 2004; Nigg et al., 2005). Difficulties with EF manifest as having difficulty with -daily activities that encompass planning, organizing, and problem-solving (Gentil-Gutiérrez et al., 2022). One of the core EFs is inhibition, an individual's ability to resist temptation and combat impulsivity (Diamond, 2013). In both IDBs and ADHD, the individual struggles with inhibition of their urges. In ADHD, the individual has difficulty inhibiting acts that are reward-based (i.e. impulsivity). In IDBs, however, the individual has difficulty inhibiting acts that relieve the uncomfortable mental turmoil that the urge inflicts.

Non-suicidal self-injury (NSSI)

IDBs are distinct from self-injurious behaviors such as non-suicidal self-injury (NSSI) (Greenberg et al., 2021). NSSI is characterized by intentional, self-inflicted harm to body tissue, but without the intention of suicide. Examples include cutting, burning, biting, and scratching the skin (Zetterqvist, 2015). Self-harm may result from IDBs but hurting oneself is not the ultimate intention as it is with NSSI. IDBs manifest as obsessional urges in regard to a specific action whereas NSSI arise from negative thoughts or feelings that result in inter/intrapersonal disturbances, often in the context of mood dysregulation. It is undetermined whether IDBs have any shared pathophysiology with mood disorders however, the current diagnostic model projects that they are more so associated with impulsive-compulsive spectrum disorders as seen in CSTC-related conditions vs. mood conditions. Additionally, IDBs are believed to be ego-dystonic whereas NSSI can be defined as ego-syntonic (Greenberg et al., 2021). Ego-dystonic refers to thoughts, feelings, or behaviors that are in conflict or inconsistent with one's

self-perception, values, or ideal self-image. Ego-syntonic behaviors are more consistent with one's "self". As such, they are not perceived as inappropriate regardless of others' perception of them being dysfunctional or socially unacceptable (Sandia & Baptista, 2020).

Table 5: IDBs, TS, OCD, ADHD, and NSSI: the prevalence, onset, clinical presentation, and prognosis of IDBs, TS, OCD, ADHD, and NSSI (Greenberg et al., 2021).

	IDBs	TS	OCD	ADHD	NSSI
Prevalence	Unknown	0.77% ²⁹ (TS) 1.3%–3.7% ¹⁸ (chronic tics)	1%–3% ²⁴	6.7%–7.5% ³⁰	15%–20% ³¹
Onset	Late childhood or early adolescence	Childhood, mean onset between 5 and 7 years of age ²⁶	Bimodal, early onset at ~11 years of age; adulthood onset (late onset) in ~late teens or early 20s ^{32,33}	Childhood, mean onset at approximately 6 years of age ³⁴	Mean onset at 12–14 years of age
Clinical presentation	Intrusive thoughts and urges to perform situationally specific negative actions leading to particular "bad" or "self-sabotaging" outcomes	Recurrent, sudden, stereotyped vocalizations or movements that wax and wane over time, typically preceded by premonitory urge; partial suppressibility	Presence of obsessions, compulsions, or both; time consuming and leading to significant impairment or distress	Persistent inattention, hyperactivity, or impulsivity that impairs functioning and development	Self-inflicted, intentional destruction of body tissue without suicidal intention and not for socially sanctioned purposes ³⁵
Prognosis	Area for future research; likely with some improvement over time, as consistent with tics, OCD, and ADHD clinical courses	Decreased tic frequency in more than three-quarters of patients with significant childhood symptoms ³⁶	Childhood-onset OCD with better prognosis compared to adult onset (~50% with subclinical/no symptoms 7–12 years later) ²⁴	Over half retain diagnosis into adulthood; many with ongoing executive dysfunction symptoms ³⁷	Rate in adults is lower compared to adolescents ³⁸

Abbreviations: ADHD = attention-deficit/hyperactivity disorder, NSSI = nonsuicidal self-injury, OCD = obsessive-compulsive disorder, TS = Tourette syndrome.

Current IDBs Treatments

There are currently no treatments specifically designed for IDBs. In the future, greater understanding of the nature of IDBs will enable clinicians to more appropriately treat patients that present with these behaviors. For now, current models aim to treat IDBs in a similar fashion to other conditions with presumed similar dysregulated neurocircuitry and associated neurotransmitters. Given that the primary pharmacological treatment option for OCD is SSRIs, for ADHD is stimulants, and for tics are alpha-agonists and/or dopamine modulators/antagonists, it is not uncommon to treat IDBs pharmacologically

with any combination of stimulants, alpha-agonists, SSRIs, and/or dopamine antagonists. It is critical to utilize behavioral therapy interventions when treating this set of conditions (Greenberg et al., 2021).

Functional behavioral assessment (FBA) and intervention (FBI) is a primary component of CBIT. An FBA is completed to help understand the internal and external (i.e., environmental) antecedents that precede (and consequences that follow) an unwanted behavior (Fründt et al., 2017; Gresham et al., 2001). Utilizing this CBIT strategy, the provider can assess and target the IDB through modifying the patient's environment. Targeting the situational trigger for the IDB can remove or reduce the potential for the negative consequence, which interestingly has been reported to diminish the compulsive urge. If a patient expresses that they experience a compulsive urge to toss their electronic device out the window of a moving car, an FBI solution would be to keep with car windows closed and locked. This direct environmental modification alleviates the internal distress and reduces the drive to act on the urge. Similarly, some individuals with IDBs have benefitted from adding external stopgaps to their environment which serve to interrupt the flow of thought to action. Given that IDBs often occur suddenly and impulsively, implementing a stopgap gives the individual an extra second to inhibit their behavior before action. For example, for someone with an IDB to touch a hot stove, the clinician can encourage them to wear gloves when they are in an environment with hot surfaces. Therefore, in order for the individual to touch a scorching hot object, they would have to first remove the gloves. The time it takes them to remove their gloves may

provide an opportunity to alter the course of the otherwise disinhibited behavior (Greenberg et al., 2021).

Another strategy that has been suggested, for combatting IDBs, involves replacing the behavior with one that is similar, but will result in a less severe outcome. For example, for an individual that experiences a compulsive urge to chew on tinfoil, the clinician can suggest replacing the tinfoil with something less destructive, such as gum. This strategy works in some cases but anecdotally has not been reported to be effective as those who experience IDBs report that replacement often does not satisfy the urge enough (Greenberg et al., 2021).

SPECIFIC AIMS

Individuals with untreated IDBs typically seek assistance following a series of perplexing and often unsettling behaviors that persist over a considerable duration (Greenberg et al., 2021). Given that IDBs are a newly recognized behavioral construct, clinicians currently lack the requisite knowledge and training to identify and treat them. Considering the distressing nature of IDBs and the potential risks to the patients' well-being, it is important to prioritize further research and enhanced education on this subject. Expanded research efforts should serve to deepen our understanding of IDBs, facilitate their recognition as a distinct and identifiable symptom, and determine the most effective treatments. This study aims to illuminate the phenomenology of IDBs using a clinical population comprised of youth with tic and OCD spectrum conditions. The study also aims to begin to characterize the prevalence of IDBs within this population, and to explore the correlations between IDBs and commonly co-occurring conditions typically associated with disrupted CSTC circuitry, including TS, OCD, ADHD/executive dysfunction. Looking forward, we anticipate that this investigation will contribute to a better understanding of IDBs and eventually help lead to improved treatment interventions for impacted individuals.

METHODS

Study Design

This study utilized a cross-sectional design to begin to assess the prevalence of IDBs in a tic disorder/OCD spectrum clinical population, and determine what, if any, correlations exist between IDBs and common co-occurring conditions (e.g., TS, OCD, ADHD, etc.) that are often associated with disrupted CSTC circuitry. Cross-sectional studies are observational investigations that examine data from a population at a specific moment, providing a snapshot of various variables without following participants over time (Wang & Cheng, 2020). IDBs were originally described in a population of youth with co-occurring tic disorders and ADHD and other commonly co-occurring conditions such as OCD, and as such, our intention was to continue to expand IDBs research by using a similar sample (Greenberg et al., 2021). This program made for an ideal population as the current patients have a combination of tic spectrum and OCD spectrum disorders and ADHD. A survey assessing various characteristics of IDBs was developed and then administered to patients within the MGH Pediatric Psychiatry OCD and Tic Disorders program. Patient selection was non-randomized and participation in the study was entirely voluntary.

The survey consisted of four components, (1) a brief overview of IDBs and how they present, (2) questions around the participant's experiences with IDBs, (3) questions about co-occurring neuropsychiatric and other mental health conditions, and (4) questions regarding non-identifiable participant demographics. The research methods encompassed both quantitative and qualitative approaches. Qualitative questions were descriptive

and/or employed open-ended responses. The survey was designed to take approximately 15-20 minutes to complete.

Instrumentation

Many of the survey questions; for this study were modeled after both the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) and the Rage Attack Questionnaire (RAQ) developed by Budman et al., 2003. The Y-BOCS was designed as a foundational tool to first characterize and then measure the severity of OCD symptoms. The clinician-rated scale comprises ten items, with each item scored on a scale from 0 (no symptoms) to 4 (extreme symptoms), resulting in a total range of 0 to 40. It assesses time spent on symptoms, distress caused by symptoms, attempts to push back against symptoms, success in pushing back against symptoms, and degree of impairment secondary to the symptoms. It includes separate subtotals for the severity of obsessions and compulsions (Goodman et al., 1989).

The Rage Attack Questionnaire was originally developed to assess rage attack phenomenology and determine if specific groups of symptoms could help identify distinct clinical subgroups amongst children with Tourette syndrome experiencing rage attacks (Budman et al., 2003). This survey served as a useful model for the IDBs survey as it was designed to explore the phenomenology of a newly described specific condition, rage attacks.

Questions 1 to 5 are about your obsessive thoughts

Obsessions are unwanted ideas, images or impulses that intrude on thinking against your wishes and efforts to resist them. They usually involve themes of harm, risk and danger. Common obsessions are excessive fears of contamination; recurring doubts about danger, extreme concern with order, symmetry, or exactness; fear of losing important things.

Please answer each question by circling the appropriate number.

1. TIME OCCUPIED BY OBSESSIVE THOUGHTS SCORE _____

How much of your time is occupied by obsessive thoughts?

- | | | |
|---|---|--|
| 0 | = | None |
| 1 | = | Less than 1 hr/day or occasional occurrence |
| 2 | = | 1 to 3 hrs/day or frequent |
| 3 | = | Greater than 3 and up to 8 hrs/day or very frequent occurrence |
| 4 | = | Greater than 8 hrs/day or nearly constant occurrence |

2. INTERFERENCE DUE TO OBSESSIVE THOUGHTS SCORE _____

How much do your obsessive thoughts interfere with your work, school, social, or other important role functioning? Is there anything that you don't do because of them?

- | | | |
|---|---|---|
| 0 | = | None |
| 1 | = | Slight interference with social or other activities, but overall performance not impaired |
| 2 | = | Definite interference with social or occupational performance, but still manageable |
| 3 | = | Causes substantial impairment in social or occupational performance |
| 4 | = | Incapacitating |

3. DISTRESS ASSOCIATED WITH OBSESSIVE THOUGHTS SCORE _____

How much distress do your obsessive thoughts cause you?

- | | | |
|---|---|--------------------------------------|
| 0 | = | None |
| 1 | = | Not too disturbing |
| 2 | = | Disturbing, but still manageable |
| 3 | = | Very disturbing |
| 4 | = | Near constant and disabling distress |

Figure 4. Y-BOCS: condensed example of the Y-BOCS (Goodman et al., 1989).

To determine the efficacy of the survey, measures of validity were taken into consideration. Validity pertains to the nature of what an instrument is measuring and the extent to which it accomplishes this task effectively. The validity of this IDB survey is difficult to assess as there are no current validated measures for diagnosing or assessing IDB severity. Despite that limitation, both face validity and content validity were established prior to administering the questionnaire. Face validity involves a casual evaluation of a questionnaire by individuals without expertise, focusing on clarity, comprehensibility, and suitability for the target group. Content validity entails a formal assessment by subject matter experts to appraise content appropriateness and identify potential misunderstandings or omissions (Bagby et al., 2006). To establish face validity, non-participating volunteers took a preliminary version of the study and provided feedback on their overall understanding of what the questions were asking, grammatical clarity, appropriate wording for a fifth-grade reading level, and general flow. Given that the survey was designed by the clinician who initially wrote about IDBs, and that clinician modeled this IDB scale after validated scales for phenomenologically similar syndromes, there is content validity. assessed for content relevance, correctness of definitions, and leading questions. Reliability addresses the accuracy of the data acquired and the survey's capability to minimize random error. As this study is in its initial phases and has only been actively running of a few weeks at the time of this thesis, a true measure of reliability has yet to be determined.

This is a survey study on Intrusive Destructive Behaviors (IDBs), a symptom which has recently been described by individuals who have tic and OCD related symptoms. An IDB starts with an overwhelming feeling or urge to do something (or act in a specific way) despite not actually wanting to do so, and ends with acting on that urge because it couldn't be resisted.

The person experiencing an IDB does not want to act on the feeling or urge because they know it will result in a "bad" outcome (e.g. they will get in trouble, break something they care about, cause themselves physical pain), but they also feel like the urge is too strong to push back against, and that if they don't act on it, the urge will 'never go away.' Therefore, giving into the urge both relieves the discomfort of trying to resist it, and at the same time, causes a negative outcome.

For example, imagine you have spent numerous hours building a Lego structure. You are excited to finish it as you have put so much time into this project and it is looking exactly how you wanted it to look. However, just before you add the final piece, you have a thought/feel an intense urge to break it. You don't actually want to break what you built because you're very proud of it, and you don't want to see all your hard work go to waste; but the urge grows increasingly strong and difficult to resist. On the one hand, you feel like you have to act on it, but on the other hand, you understand that doing so will result in exactly what you don't want. This competing mindset causes even more distress, and before you know it, you impulsively knock the structure over. Though the urge to break it is now satisfied and you may have even felt some temporary relief, you are also now really upset because you broke something you really valued, and you were not able to stop yourself from doing something you didn't want to do.

IDBs can look different for everyone and can appear in many different settings. Other examples of IDBs are provided below. Keep in mind that this is a limited set of examples, and are only here to help you to understand whether you may have experienced or currently experience IDBs.

Examples could include:

Having (and acting on) an urge to break your brand-new phone or gaming equipment.

Having (and acting on) an urge to stare at the sun on a bright, sunny day.

Having (and acting on) an urge to touch a hot stove.

Having (and acting on) an urge to throw an item of importance out a car window.

Having (and acting on) an urge to shut off a video game and/or have your character die just before beating a level.

Having (and acting on) an urge to push on a bruise or an injury.

- 1 Keeping the above examples in mind, can you think of a time when you felt like you needed to do something that you didn't want to do (because it would have a bad outcome), but you couldn't stop yourself from doing it? Yes
 No
-
- 2 Can you please provide (up to three) example(s) of times where you experienced this? Please describe the situation including the urge that you felt and the way you acted on the urge. (For example, "I was building my new Lego structure, and just before I was about to finish, I had an urge to break it, and even though I didn't want to, I kicked it down and then had to start over.").
-
-
-
- 3 How often do these sorts of experiences (IDBs) happen for you? Never.
 Rarely. (e.g. less than once a month).
 Occasionally. (e.g. less than once a week).
 Sometimes. (e.g. a few times a week).
 Often. (e.g. at least daily).
-
- 4 At what age do you remember these feelings/behaviors starting?
- 3
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- 5 When you first feel an urge, and before you act on it, do you ever experience physical symptoms or feel physically uncomfortable (i.e. shaky, fidgety, restless, stomachache, etc.)? Yes.
 No.
-
- 6 How uncomfortable or anxious do these urges make you feel? Particularly if you are not able to act on them? The urge does not make you uncomfortable.
 A little uncomfortable but for the most part you can ignore the urge and focus on other thoughts.
 Moderately uncomfortable, you can focus on thoughts aside from the urge and may even forget about it for a short while (up to a couple of hours).
 Very uncomfortable, but you can distract yourself from the urge for a few minutes at a time.
 Extremely uncomfortable, you cannot focus on anything aside from the urge.
-
- 7 How much do these urges/actions get in the way of your day-to-day life (e.g., social life, school, family life) No interference, these urges/actions do not interfere at all with your day-to-day life.
 Slight interference, these urges/actions are a little bothersome, but don't really get in the way or impair your school experience, home life experience, or time with friends.
 Moderate interference, these urges/actions cause some problems and get in the way to a degree at home, with school-work, and/or time with friends, but you are still able to manage in these different environments.
 Severe interference, these urges/actions may get in the way in school, spending time with friends, and/or with your family, but not all three.
 Extreme interference, these urges/actions cause you to miss school, not be able to hang out with friends, and lead to a lot of conflict and problems at home.
-
- 8 Do you feel a sense of relief (e.g. less stressed, less tense, etc.) immediately after acting on the unwanted urge? Yes.
 No.
-
- 9 What emotions, if any, do you feel after acting on the urge? (Check all that apply) Guilt/Shame.
 Embarrassed.
 Satisfied.
 Happy.
 Disgusted.
 Other: _____.
 None.
-
- 10 When you experience an urge, do you try to stop yourself from acting on it? (This question is in regard to how hard you try to push back on the urge; not how successful you are in pushing back) Always try to stop yourself from acting on the urge (or the urges are so minimal that there is no need to actively stop yourself).
 Try to stop yourself from acting on these urges most of the time.
 Make some effort to stop yourself.
 Almost always act on the urge, but do so with some reluctance.
 Completely and willingly give in to the urge without any attempt to stop yourself.

Figure 6. IDBs Survey: condensed sample of the IDBs survey administered to voluntary participants from the MGH Pediatric OCD and Tic Disorders program.

Study Participants

Study participants were recruited from the MGH Pediatric OCD and Tic Disorders Program. As part of the standard intake procedures, each prospective patient completes an intake form for the program. This form includes a section seeking their consent to be contacted for potential participation in future research projects. Individuals who agreed to being contacted on their intake form received an email explaining the nature of IDBs, the purpose of this study, and the survey link.

The inclusion criteria stipulated that participants must be fluent in English and fall within the age range of 7-23. Exclusion criteria included participants who were not fluent in English or were younger than seven years old. Individuals younger than age seven ~~were~~ excluded as the measures on which many of the IDB questions were based were only validated for youth aged seven and above. It is noteworthy that there were no exclusion criteria based on sex, gender identity, race, ethnicity, or previous diagnoses.

It was recommended that participants younger than 13 complete the survey with a parent. For 13–17-years-olds, it was recommended that the parent/guardian read through the survey questions first, and then have the participant fill it out on their own. Participants were made aware that there was no direct incentive for taking the survey and that it was completely voluntary.

Recruitment Procedures/Data Collection

Individuals who had previously given consent to be contacted about research opportunities received both an email and a message about this study through Patient

Gateway. Specifically, the message was distributed to 472 email addresses. It provided a concise overview of IDBs, the study's purpose, associated risks and benefits, and a link for completing the survey. To uphold the privacy policies set by MGH, all emails were sent using the "send secure" feature. The primary recruitment objective was to secure a minimum of 25 participants.

Data Analysis

The plan for statistical analysis was to determine the prevalence of IDBs within the MGH Pediatric Psychiatry OCD and Tic Disorders program. Though participants were given the option to check "no" regarding presence of IDBs, given the self-selection bias of those who completed the study, prevalence could not be accurately calculated and as such was not formally assessed. Qualitative responses were collected and collated, and prevalence of associated comorbidities of those who did report having IDBs was evaluated.

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RESULTS

The survey was initially emailed to 472 program patients that had previously agreed to being contacted about research opportunities. Of the 472, up to 61 accessed and viewed the survey, though some of those may not have been unique patient participants. Of the 61 times the link was accessed, 26 individual subjects completed the survey.

Of the 26 participants that completed the survey, nineteen attested to experiencing IDBs based on the description and examples of IDBs included in the survey. **Table 6** illustrates participant reported IDB examples. Wording has been modified for consistency, clarity, and privacy protection purposes. Some examples were not included as they were not felt to be consistent with IDBs.

Table 6: Participant reported examples of IDBs.-

Non-identifiable Participant Number	IDB Examples		
3	Participant stares at sun.	Participant insists on locking windows, so he is not tempted to throw anything out of car window.	Participant feels an urge to touch a hot stove.
14	Participant blinks at the sun even though it causes spots in their vision.	Participant repeatedly makes a specific hand motion, because they feel like they must, despite knowing that it will trigger their OCD.	Participant blinks or stares at certain objects despite knowing it will trigger their OCD.
17	Participant must go back and touch the toilet after they wash their hands.	Participant does not want to share their food with others but	N/A.

		always feels the need to offer it to everyone before they eat.	
21	Participant feels the need to throw cereal bowls and cups into the air when they are empty or full.	N/A	N/A.
25	Participant will sometimes tear up a picture or destroy an art project that they have worked hard on.	Participant has been told not to touch the TV screen because it damages the screen, but they continue to do so.	N/A.
26	Participant often feels the urge to power down devices while in the middle of doing/watching something (ex. while watching TV, scrolling on their phone, doing classwork on a computer) When the participant sees the power button or just randomly gets the urge, they usually act immediately without thinking of what they are doing. Participant will try to remove the remote from their hands, but reports that the urge continues to linger.	N/A.	When the participant sits in the front seat of their car for a long period of time, they have the urge to kick the windshield and see it shatter. Participant notes that they did shatter the windshield one time in the past.
27	When participant has a bruise on their body, they feel the urge to push on it despite knowing it will exacerbate their pain.	Participant has the urge to stick their hand in something “gross”, despite knowing that their hand will get “icky”.	N/A.
31	Participant was building something out of clay and had the urge to smooch it into a big ball even though they did not want to. They ended up breaking their piece and had to start again.	N/A	N/A
36	Participant walked past a hot stove and felt an intrusive urge to touch it. Participant put their index finger on the top of the stove until they felt it get	Every morning, before school the participant got into the car with their siblings and blasted the radio to full volume. They did not want	N/A.

	hot. They immediately wanted to place their other index finger on the stove.	to do that because it annoyed their siblings.	
45	N/A.	Participant sprained their wrist and felt the urge to keep poking the area where it was most painful. Even though they didn't want to and knew it would hurt, they kept poking it.	N/A.
47	When the participant has their dolls and playset set up in their room, they often feel like they must put everything away even though they don't want to because they want to continue playing with them.	N/A.	N/A.
51	Participant was texting their father, who was being very nice to them, and suddenly got the urge to swear at him and say awful things. Even though the participant rarely swears and did not want to do this, they couldn't let go of the thought until they sent him an awful message full of cusses and swears.	At school there was an iron being used for the scrapbooking group. The participant did not know if it was hot or not but had a thought that wouldn't go away that it would be really bad if they touched the hot iron. Despite not wanting to hurt themselves, they stood up, made sure no one was looking and then put the iron against their palm.	Participant's friend was doing an art project using wire. The school clinician warned the friend to be careful that no one else use the wire, since they were afraid, they might hurt themselves with it. If someone did hurt themselves, the friend would not be able to complete the project. The participant did not want their friend to get in trouble or to lose this art project privilege but couldn't get the idea out of their head that they wanted to use the wire to scratch themselves. The friend accidentally left a piece of wire behind, and when no one was looking, the participant scratched their leg with the wire.
59	Participant's lips were infected and had an urge to put their lips on a hot cast iron pan.	Participant broke their arm and while it was in the cast, they kept banging it on the kitchen table causing more pain.	Participant received a brand-new computer mouse and had the urge to slam it down causing it to break.

Frequency of IDBs

After the participant confirmed-experiencing IDBs and provided examples, our next objective was to evaluate the frequency of these behaviors. Participants were presented with single-select multiple-choice frequency measures, spanning from never, rarely (less than once a month), occasionally (less than once a week), sometimes (a few times a week), to often (at least daily).

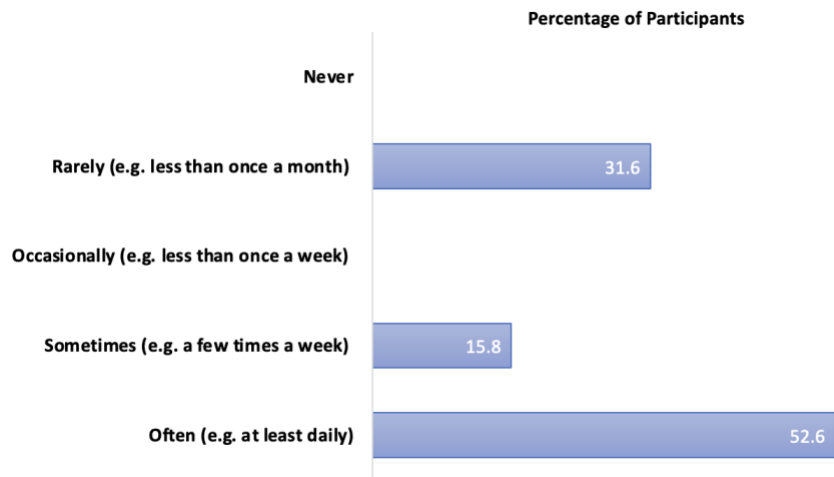


Figure 7. Frequency of IDBs: percentage of participants and the frequency at which they experience IDBs.

52.6% percent of participants reported experiencing IDBs “often”. In contrast, 31.6% indicated that they “rarely” experience IDBs, and 15.8% attested to experiencing them “sometimes”.

Age of Onset for IDBs

The age range that participants were provided to choose from was 3-23 years of age. The mean age of IDB onset was 7.7 years of age with a standard deviation of 3.0.

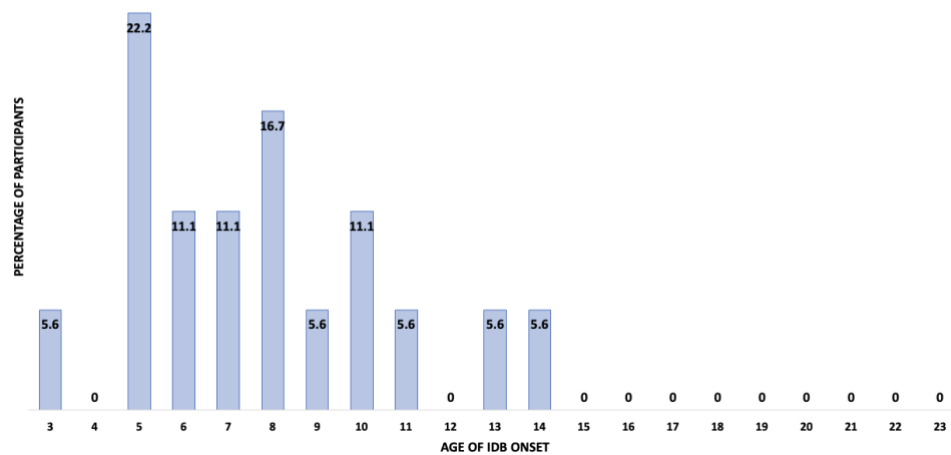


Figure 8. IDBs Age of Onset: reported age (age range 3-23) of IDBs onset.

Physical Symptomology of Urge(s)

Participants were instructed to contemplate the physical sensations they experience when an urge occurs, including shakiness, increased fidgeting, restlessness, stomachaches, etc. This inquiry was formatted as a single-choice question with options for "yes" or "no." The findings revealed that a substantial majority of participants, 63.2%, affirmed experiencing physical symptoms associated with the onset of their urges.

Discomfort Associated with Urge(s)

Participants were asked to articulate the level of discomfort or anxiety they experience when faced with urges, particularly if they are unable to act on them. Participants were presented with single-select multiple-choice measures of discomfort, ranging from the urge does not lead to discomfort, “little uncomfortable” (can still focus on other thoughts), “moderately uncomfortable” (can focus on other thoughts for at least a few hours), “very uncomfortable” (can distract themselves from the urge for a few minutes at a time), to “extremely uncomfortable” (cannot focus on anything aside from the urge).

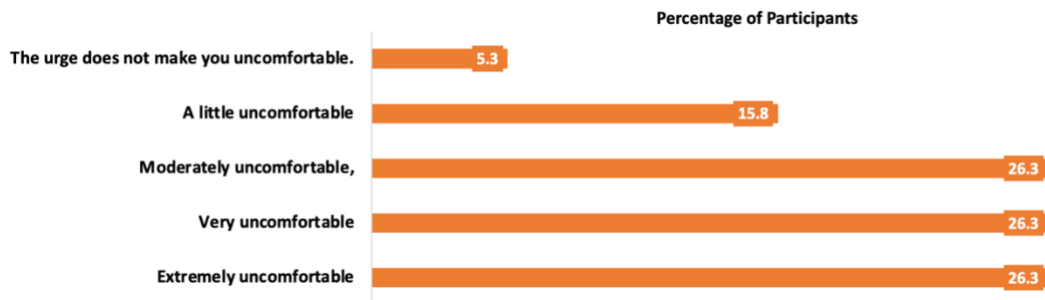


Figure 9. Degree of Discomfort: The degree of discomfort that participants experience in regard to their urge.

There was an even distribution of participants representing almost 80% of the sample divided between moderately, very, and extremely uncomfortable discomfort associated with an urge.

Interference of IDBs

Participants were asked to report the extent of interference their urges impose on their day-to-day lives, particularly concerning their social, school, and

home activities. They were provided with single-select multiple-choice measures of interference, ranging from "No interference", "Slight interference" (the urges are bothersome but do not hinder participants in their school, home, or social lives), "Moderate interference" (the urges cause some problems and somewhat impede school, home, and/or social life), "Severe interference" (the urges do hinder school, home, or social life, but not all three), to "Extreme interference" (the urges lead to missing school, being unable to spend time with friends, and facing significant challenges in their home life).

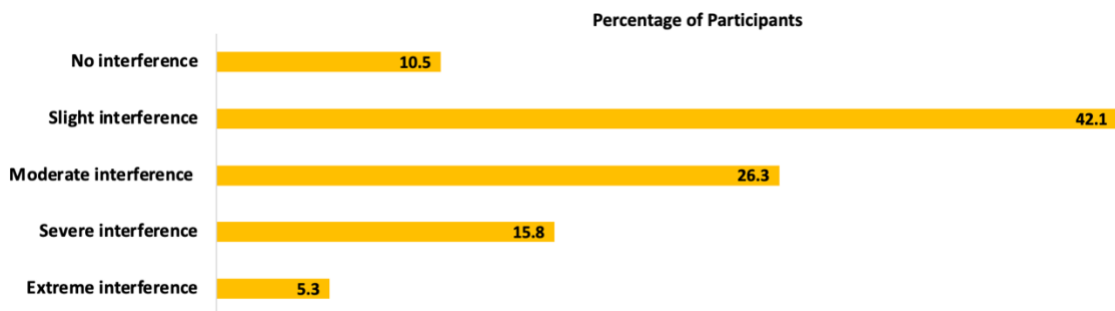


Figure 10. Degree of Interference: the degree of interference that IDBs have on participants' lives.

The majority of participants, comprising 42.1%, reported that their urges caused slight interference in their daily lives. Almost 50% of participants reported at least moderate interference from their urges.

Sense of Relief Associated with IDBs

Participants were then asked if they experience a sense of relief or feel less stressed/less tense after acting on an urge. The question was formatted as a single-choice question with options for "yes" or "no." The results showed that the majority of participants, comprising 94.4%, affirmed that after acting on their urge, they do feel a sense of relief.

Emotions Associated with IDBs

Participants were prompted to consider the emotions they experience after succumbing to and acting on their urges. The survey presented them with a range of emotion options: guilt/shame, embarrassment, satisfaction, happiness, disgust, none, and an "other" box, allowing participants to specify emotions not listed. The question was structured as a multi-select format, enabling participants to resonate with more than one emotion.

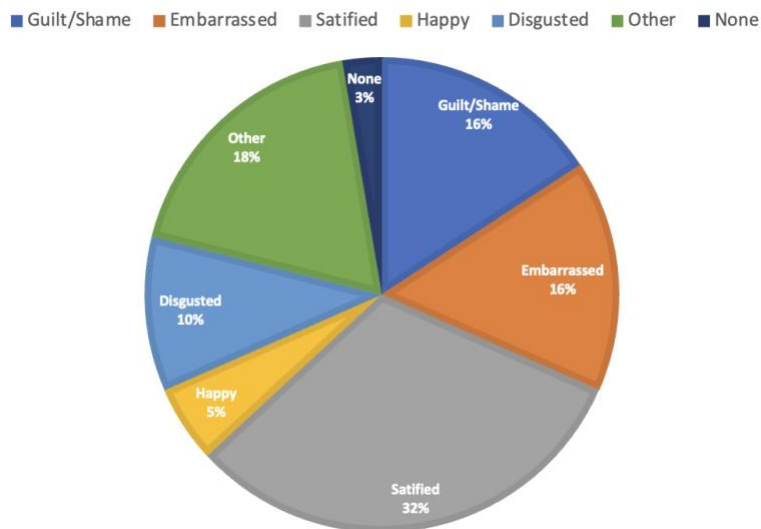


Figure 11. Emotions Associated with IDBs: The percentage of participants and the emotions that they experience after they act on an urge.

32% of participants reported feeling satisfied following acting on their urge. 18% of participants chose “other,” and reported emotions including sadness, annoyance, frustration, anger and pain, and also physical expressions such as crying or sighing. 16% reported feeling guilt/shame or embarrassment, and 10% said they felt disgusted after acting on their urge. Happiness was reported by 5%.

Ability to Resist Urge(s)

The following section of the survey evaluated the participant's attempts to suppress their urges. Participants were presented with a single-select multiple-choice question that covered a range from the least severe to the most severe measures of their attempts to refrain from acting on their urges.

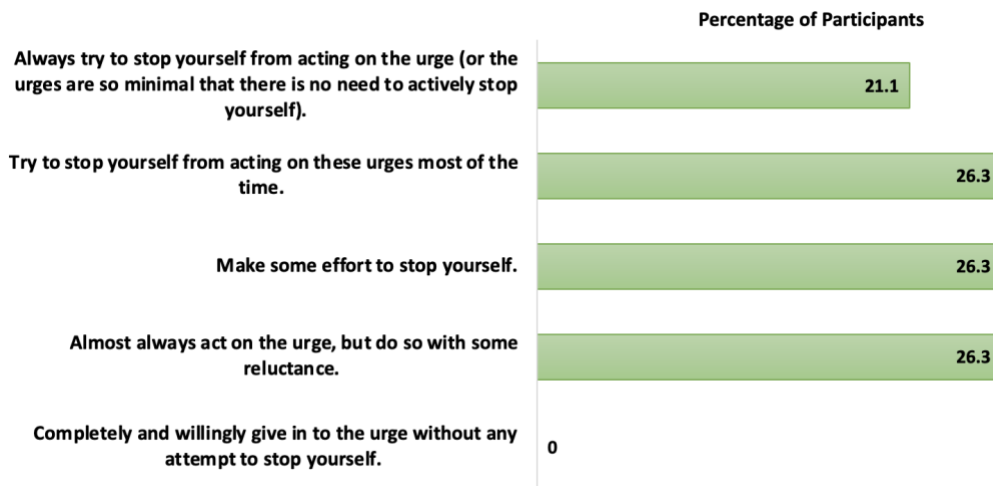


Figure 12. Urge(s) Resistance: percentage of participants and the degree at which they attempt to suppress their urges.

There was an even distribution of participant response between each of the choices of trying to refrain from action. No participants reported always giving in to their urges without any attempt to resist.

Success with Suppressing Urge(s)

We then assessed the overall success of suppressing urges. Of the participants who reported that they do attempt to suppress, were given a single-select multiple-choice question assessing success in blocking an urge.

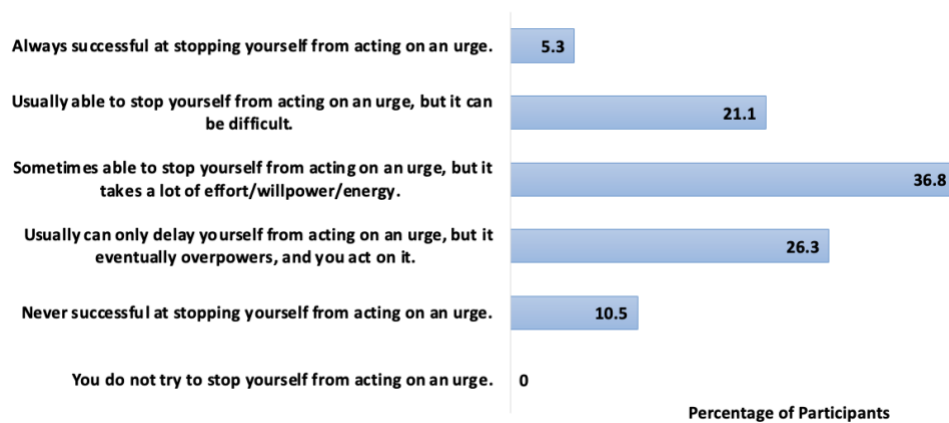


Figure 13. Urge(s) Suppression Success: Percentage of participants and their degree of success in regard to them suppressing an urge.

36.8% of subjects; indicated that they are sometimes able to stop themselves from acting on an urge, although it requires a significant amount of effort, willpower, and energy. 26.3% agreed that they can usually delay themselves from acting on an urge, but eventually, the need to satisfy their urge overpowers them, leading them to act. 21.1% reported that they are usually able to stop themselves from acting on an urge, but it can be challenging for them to do so. 10.5% stated that

they are never successful in suppressing their urges. 5.3% reported either always being successful at not acting on an urge. All participants reported attempted to stop themselves from acting on urges.

Tools Implemented to Prevent Action(s)

Finally, participants were asked to share the tools that they use to suppress an urge if they are able to do so. They were presented with various possibilities, including a “other” free-response choice. The question was designed as multi-select, allowing participants to choose more than one answer at a time.

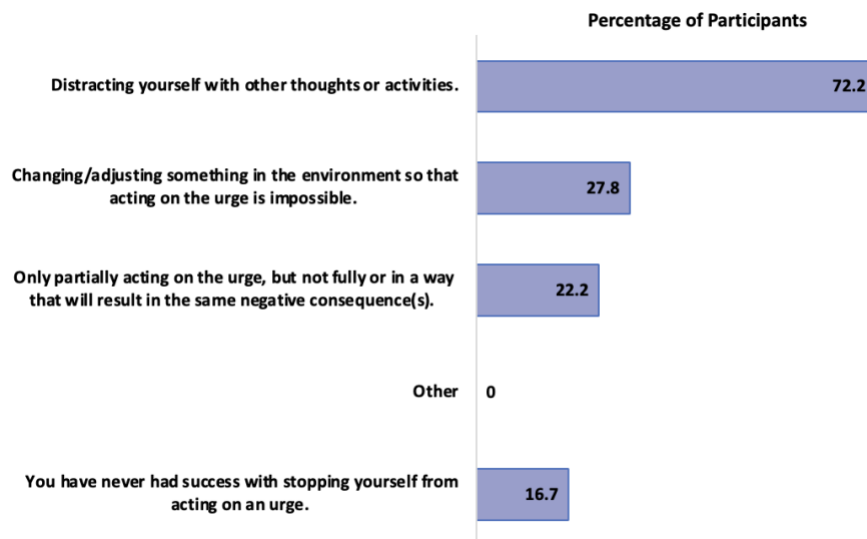


Figure 14. Tools Implemented to Prevent Urge(s): percentage of participants and the tools they employ to suppress and urge.

72.2% of the participants endorsed using distraction to help prevent themselves from acting on an urge. 27.8% of participants indicated that they would attempt to alter their environment to make acting on the urge extremely difficult or

impossible. 22.2% stated they would try to partially act on the urge, and 16.7% indicated that they never have any success with employing tools to prevent themselves from acting on their urges. Notably, no participants provided additional tools that they use to suppress their urges.

Previously Diagnosed Psychiatric Disorder(s)

This section of the survey assessed whether participants had previously been diagnosed with other psychiatric disorders. This aspect was of interest as one of the overall study objectives was to determine which, if any, commonly associated comorbidities exist alongside IDBs. The question was designed to be multi-select, allowing participants to choose multiple diagnoses at a time. The provided diagnoses encompassed common psychiatric disorders often observed in youth with tic and OCD spectrum disorders.

94.7% of subjects with IDBs reported having diagnoses of obsessive-compulsive-related disorders (OCD). Of those who stated OCD, 84.2% reported having OCD, and 21.1% indicated having body-focused repetitive behavior disorder (trichotillomania or skin-picking disorder). Having an anxiety disorder (generalized, separation, social, mixed) was reported in 84.2% of participants. 73.7% reported having tic and related disorders with 42.1% specifying tics, 52.6% specifying Tourette syndrome, and 10.5% specifying chronic motor or vocal tic disorder. 57.9% reported a diagnosis of ADHD (inattentive, hyperactive/impulse, combined). 26.3% of participants reported having mood disorders, with 15.8% specifying major depressive disorder (MDD) and 5.3%

reporting bipolar disorder/disruptive mood dysregulation disorder. Additionally, 15.8% of participants reported executive dysfunction, and 10.5% reported oppositional defiant disorder. 15.8% reported diagnosis with a learning disorder (e.g., dyslexia, non-verbal learning disorder), and 15.8% reported being diagnosed with autism spectrum disorder (including Asperger's). There were no endorsements of co-occurring conduct disorder, eating disorders (anorexia nervosa, binge eating disorder, or avoidant/restrictive food intake disorder (ARFID)), or other psychiatric disorders.

In contrast, of the seven participants who did not endorse IDBs, 28.6% of participants indicated that they had previously been diagnosed with tic disorders; 42.9% of participants reported having been diagnosed with obsessive-compulsive-related disorders, and only 14.3% of participants reported a previous diagnosis of ADHD (inattentive, hyperactive/impulse, combined).

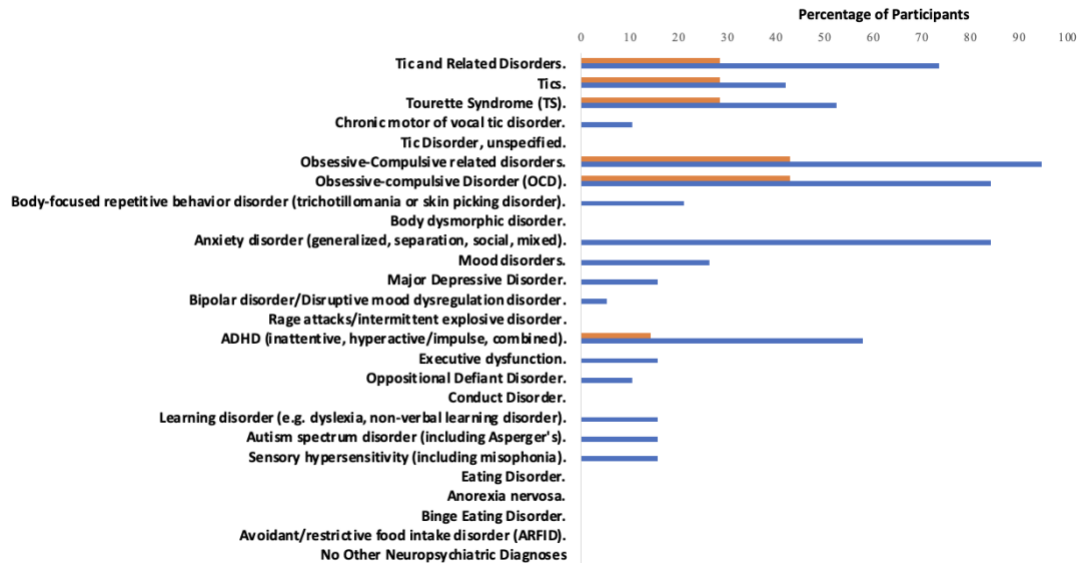


Figure 15. Prevalence of Reported Psychiatric Diagnoses: the prevalence of reported psychiatric diagnoses from the Survey Results. *Blue bars specify

participants that selected “yes” to having IDBs. Orange bars specify participants that selected “no” to having IDBs.

DISCUSSION

This preliminary study has provided enhanced insight into IDBs, particularly among patients in the MGH Pediatric OCD and Tic Disorders program. However, there is more that can be done to further advance this study and, more broadly, to continue understanding the phenomenology of IDBs. Most importantly, there is a need to explore effective treatment approaches for individuals presenting with these behaviors.

Self-Reported IDBs

Some of the most pertinent and unique data obtained from the survey pertained to the participant reported examples of IDBs. Many of the provided examples clearly fit the definition of IDBs. For example, one participant reported that while they were building a structure out of clay, they had an urge to "smoosh" it into a ball despite not actually wanting to. When they eventually gave in to the urge, they were forced to start their project again. This is a great example of an IDB, as the participant clearly did not want to ruin the structure they were making, but felt intensely compelled to do so, and likely experienced significant distress when trying to resist that was only relieved by "mushing" the creation.

Of the examples provided, 31.6% reflected processes that would be more consistent with either typical tics, typical OCD symptoms, typical impulsivity, or typical body-focused repetitive behavior disorders.

Some examples proved difficult to conclude whether or not they represented IDBs. For example, one participant reported that they could not stop themselves from

watching pornography, despite knowing that it was bad for them and that it could get them in trouble. For this experience to qualify as an IDB, the participant would have to express that they do not *want* to watch pornography, but rather feel compelled to do. Alternatively, if they *were* interested in watching pornography, but didn't/couldn't stop themselves from doing so despite awareness of a negative consequence, then this experience would be more consistent with an impulsive condition.

Another example described that would be better characterized as a non-IDB condition involved a participant reporting that they have to touch their dog and water bottle eight times before they can go to bed, or else they believe that something bad will happen. This example is most consistent with OCD. The participant does not note that they do not want to touch their dog and water bottle; rather, they are doing so to relieve themselves of the mental strain that is associated with believing something bad will happen if they don't act in a specific way.

Survey Results

The survey results offer intriguing insights into the individual experiences of IDBs amongst our patient population. Contrary to earlier literature that speculated the emergence of IDBs as being in middle to late childhood or early adolescence (Greenberg et al., 2021) these results suggested a different pattern. As the mean age of IDB onset was 7.7 years of age with a standard deviation of 3.0. The observed variance in the onset age of IDBs warrants investigation as an earlier onset age may presents the potential for more timely and possibly improved treatment interventions.

The survey results demonstrate the negative impact of IDBs on the quality of life for affected participants. A large number of participants reported experiencing intense discomfort fueled by active urges, subsequently leading to a range of negative emotions such as shame, guilt, sadness, and anger upon acting on these urges. Findings also demonstrate that IDBs are not easily suppressed by the majority of participants who experience them, thus further contributing to associated distress.

The survey evaluated participants' ability, degree of success, and employed tools for suppressing urges. Results unveiled a prevailing capacity in some participants for greater self-control/inhibitory strategies. This insight illustrates the importance of increasing focus on which treatment intervention strategies help, and which characteristics of participants who can suppress may be most pertinent to others also obtaining success.

Psychiatric Co-morbid Disorders

An aim of this study was to determine if correlations between IDBs and certain commonly co-occurring conditions (e.g., TS, OCD, ADHD, etc.) that are often associated with disrupted CSTC circuitry exist. The diagnoses of greatest prevalence among subjects who endorsed having IDBs included obsessive-compulsive-related disorders, specifically OCD, and anxiety disorders (generalized, separation, social, mixed). Too few participants reported not having IDBs to accurately assess whether certain conditions were more likely to be associated with *not* having IDBs. As IDBs were originally conceptualized during a treatment study of children and adolescents with tic disorders

and commonly associated OCD, ADHD with executive dysfunction, and/or additional impulsive-compulsive spectrum disorders (Greenberg et al., 2021). It is interesting to note that in this small sample, more participants reported having obsessive-compulsive-related disorders than tic-related disorders. However, it is important to note that that may be related to ascertainment bias.

Limitations

Although there were a number of strengths in this study, including the evaluation of a novel symptom complex, there were several notable limitations. Sampling bias was present as the survey was only administered to a patient population within a tertiary care center. Tertiary care centers typically provide care to individuals with the most severe cases, and as such as typically not thought to be representative of the broader population. The participants within this study are already being treated for one or more psychiatric disorders, thus the prevalence of IDBs amongst this patient population is most likely greater than it would be if assessed within a non-tertiary care population.

The study's generalizability is also affected by two additional factors: self-selection bias and small sample size bias. Given that the subjects in this study were self-selecting, there likely had a heightened interest in the topic thus potentially skewing the representation of the broader population. Furthermore, the limited sample size greatly restricts our ability to extend the findings to a wider population.

Another limitation is that the format of the survey was altered a week following its initial administration after a logic error was detected (where those who reported 'not' having IDBs weren't given an option to report their diagnoses or demographics).

Finally, the specific examples of IDBs provided by the participants need additional thorough review to ascertain whether they genuinely represent IDBs or if they are more closely aligned with other similar disorders (e.g., TS, OCD, ADHD, etc.). Without ongoing review, the results may lead to an overestimation of the number of participants who resonate with IDBs. .

Future Directions

The promising nature of this study, along with the valuable data derived from the survey, facilitates high probability for further expansion on characterizing and understanding IDBs. Potential avenues for future utilization of this survey includes ongoing administration within our existing patient demographic, other clinical populations, and non-clinical populations. Additionally, we plan to have additional formal statistically analyses done once a greater number of surveys have been returned.

Our target for participant recruitment and survey administration was aimed at 25 subjects. This represents a small pilot sample, and based on their preliminary responses, the survey could be amended and improved as seen fit. Twenty-six surveys have been collected as of the time of this report. We plan to maintain accessibility to the survey to allow for a more substantial patient participant pool going forward.

Going forward, it will be important to ascertain the true prevalence of IDBs and of reported comorbidities compared to the prevalence of these conditions in a non-clinical population.

Additionally, it will be important to extend this survey to non-clinical populations and other patient populations, including those diagnosed with autism and/or bipolar disorder. Through examining these diverse groups, we can gain deeper insights into the prevalence and potential associations of IDBs across different demographic cohorts, enrich our understanding of these conditions, and gain insight into how to best begin to treat them.

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CURRICULUM VITAE

