Introduction

Obsessive-Compulsive Disorder: The Hidden Epidemic

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This supplement arises from a breakfast symposium series titled "OCD: New Perspectives and Practical Management" that took place at the American Psychiatric Association annual meeting in May 1996. It presents an overview of obsessive-compulsive disorder (OCD) and examples of related spectrum disorders and reviews some recent research being done in pharmacologic and behavior therapy, the two most successful types of therapy for OCD. In the papers that follow, Sasson and colleagues present a world view of OCD; Christopher J. McDougle discusses pharmacologic treatment of refractory OCD; Flament and Bisserbe review some recent studies comparing SRI therapies; and Baer and Greist discuss the use of behavioral therapy in OCD patients, including an innovative patient-initiated, telephone voice-activated behavior therapy program.

Today, OCD is classified as an anxiety disorder and is defined as the presence of recurrent obsessions (persistent thoughts, impulses, or images) or compulsions (repetitive behavior or thought patterns induced in an attempt to prevent anxiety) that are excessively time consuming—taking more than an hour a day—or cause marked distress or significant impairment. The person with these symptoms has recognized that these patterns are excessive.[1]

While the definition of OCD has not changed very much since the disorder was first recognized, our understanding has changed radically over the last 10 to 15 years. We have overcome the myth that OCD is a rare, untreatable, and psychologically driven disorder. In its most serious forms, it is a chronic and frequently disabling illness. We now understand that OCD can have a major impact on quality of life and substantial direct and indirect costs. We know that it is much more common than we once thought—2% to 3% of the world's population has OCD.[2] It is the fourth most common psychiatric illness in the United States after phobias, depression, and substance abuse.[2] We know that OCD is biologically driven and that it is highly treatable.

Serotonin dysfunction and certain neurocircuits are thought to be involved in OCD behavior. In studies using oral *m*-CPP, a partial serotonin agonist, about half of obsessive-compulsive patients were found to have a significant increase in their obsessive thoughts or urges to perform rituals during serotonin stimulation.[3]

Certain neurocircuits involving increased activity in the orbital-frontal cortex, the head of the caudate, the globus pallidus, and the thalamus may also drive repetitive behaviors. The more individuals give in to their ritualistic behavior, the more deeply ingrained these neurocircuits become.

Unfortunately, this knowledge has not yet translated into efficient, effective treatment of OCD. There is currently a 10-year lag between the onset of symptoms and the seeking of professional help, a gap attributable in part to the humiliation people feel about their symptoms. There is an additional 6-year lag before the correct diagnosis is made, and another 1½ years before patients finally get appropriate treatment. Thus, there is an average total of 17 years between the onset of symptoms, at age 14.5, and the start of appropriate treatment, at age 31.5.[4]

Every therapy imaginable has been tried for people with OCD. Only two, however, show any significant impact: pharmacologic therapy with potent serotonin reuptake inhibitors (SRIs) and behavior therapy that involves exposure and ritual prevention techniques. These treatments may work by decreasing caudate and, perhaps, orbitofrontal activity. Refractory obsessive-compulsive patients may benefit from neurosurgery, which disconnects the outflow pathways from the orbitofrontal cortex.

QUALITY OF LIFE

To assess the effects of OCD on the lives of people with the disorder and to explore what therapies they perceive as most effective, a 410-item survey was recently conducted that questioned members of the Obsessive Compulsive Foundation (OCF), a patient-oriented organization that dis-

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seminates information and lends support to people with OCD. Detailed assessments were made of demographics, course of illness, cost of treatment, treatment response, and effect of illness on education, career, and relationships, differentiating between current and lifetime factors.[4,5] A total of 2600 questionnaires were sent out, and a surprisingly high percentage—27%—were completed and returned. This provided detailed epidemiologic information about 701 OCD sufferers, the largest number of subjects who have been questioned about such data.

The segment of OCF members represented by survey responders mirrored what had been seen in smaller clinical samples. Respondents had many checking and contamination concerns, fear of harm to self or others, symmetry issues, religious and moral issues, hoarding symptoms, and sexual and counting rituals. Their symptoms caused marked distress and interference. Almost 90% of subjects had lifetime symptom distress; 88% had significant interference with social and occupational functioning. Between 60% and 70% reported "much" or "very much" interference in their ability to study, work, socialize, and make friends and in family relationships. As with smaller clinical samples, these individuals had a variety of comorbid conditions, suggesting that OCD does not occur in a vacuum. Two thirds of subjects suffered from depression and one fourth from panic disorder. One fourth may also have suffered from hypochondriasis, body dysmorphic disorder, or OCD-related or spectrum disorders. There were also high rates of social phobia and attention-deficit disorder.[5]

There was marked impairment in satisfaction with life. Ninety-two percent of individuals had lowered self-esteem. Thirteen percent had made a suicide attempt.[5]

TREATMENT

Reading about OCD led 28% to seek help. Sixteen percent mentioned having seen something on TV or heard something on the radio as the reason for getting help; 5% cited reading an advice column as the source of their information.[5]

In terms of lifetime treatment, 86% had received psychotherapy; 38%, counseling or guidance; 29%, relaxation techniques; 28%, family therapy; 13%, psychoanalysis; and 11%, hypnosis. A smaller percentage had tried nutritional techniques, biofeedback, homeopathy, yoga, consciousness-raising, and acupuncture.[5]

Of subjects currently receiving therapy, 81% were receiving SRIs and 22% were taking other medicines such as tricyclic antidepressants, benzodiazepines, or neuroleptics. Twenty-two percent were in behavior therapy, 25% were in other psychotherapies, 17% in support groups, and 5% in family therapy. Thirteen percent were not in treatment.[5]

Of those taking SRIs, 70% said that they were "much" or "very much" improved. Forty-six percent said that they obtained significant help from behavior therapy, 43% from reading about OCD, 42% from self-help groups, and 30% from psychotherapy. Other medications, psychoanalysis, and hypnosis were reported as much less effective.[5]

Two thirds of individuals reported a significant improvement in their quality of life with any treatment; over half had improvement in family relationships and in the ability to study and work. Somewhat fewer had improved socializing and friendships, and only about one third had an improvement in their overall career aspirations.[5]

ECONOMIC ISSUES

Major hospital costs are associated with OCD. Twenty-five percent of subjects had been hospitalized, with average total hospital costs of $12,500. Of these, more than 50% had had one hospitalization, and over 10% had had five or more. Total lifetime hospital cost was about $5 billion for all patients.[5]

On average, a person with OCD loses 3 full years of wages over a lifetime, at an average salary of $24,000. This can be estimated at a total of $47 billion in lifetime costs due to lost wages, a significant drain on the nation's economy.[5]

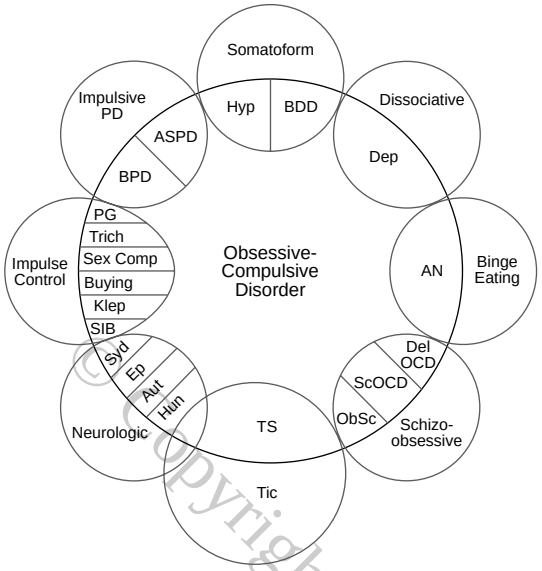
Perhaps most important, the survey found that 28% of individuals are still receiving inappropriate treatment (no SRIs or behavior therapy), spending about $4000 per year on nonproductive outpatient provider costs and $1500 per year for medication. This can be calculated at about $2 billion in yearly costs for inappropriate outpatient treatment.[5]

RELATED SPECTRUM DISORDERS

We now believe that OCD is closely related to a variety of other spectrum or related disorders (Figure l).[6] Up to 10% of the U.S. population may suffer from an OCD spectrum disorder, compared with 2% to 3% with OCD. Spectrum disorders all involve some degree of compulsive or impulsive behavior and consist of any of three specific core symptoms: preoccupation or obsession with specific bodily sensations or appearance (e.g., body dysmorphic disorder, depersonalization, eating disorders, hypochondriasis); select neurologic disorders (e.g., Tourette's syndrome, Sydenham's chorea, torticollis, autism) often involving basal ganglia dysfunction presenting with repetitive behaviors; and impulsivity or certain types of impulse control disorders (e.g., sexual compulsions, trichotillomania, pathological gambling, kleptomania, and self-injurious behavior). Spectrum disorders share other characteristics with OCD including features such as age at onset, clinical course, family history, and response to SRIs and behavioral therapy.

Such behaviors can be placed on a risk-aversive/impulsive spectrum (Figure 2).[6] At the compulsive end are an exaggerated sense of harm and a heightened sense of risk; at the impulsive end is an underestimation of harm and

Figure 1. Spectrum of Obsessive-Compulsive-Related Disorders*



*Data from reference 6, with permission. Abbreviations: AN = anorexia nervosa; ASPD = antisocial personality disorder; Aut = autism; BDD = body dysmorphic disorder; BPD = borderline personality disorder; Del OCD = delusional obsessive-compulsive disorder; Dep = depersonalization disorder; Ep = epilepsy; Hyp = hypochondriasis; Hun = Huntington's disease; Klep = kleptomania; ObSc = obsessional schizophrenia; PD = personality disorder; PG = pathological gambling; Sex Comp = sexual compulsions; ScOCD = schizotypal obsessive-compulsive disorder; SIB = self-injurious behavior; Syd = Sydenham's chorea; Trich = trichotillomania; TS = Tourette's syndrome.

risk, causing behavior that is dangerous or otherwise troublesome.

Both compulsivity and impulsivity involve difficulty in delaying or inhibiting repetitive behaviors. However, the driving mechanisms for these behaviors differ. Compulsive behaviors are an attempt to reduce anxiety and discomfort, while impulsive actions are an attempt to obtain pleasure, arousal, or gratification.

While both men and women demonstrate impulsive behaviors, they generally do so differently. Men tend to gamble, intermittently explode with anger, set fires, and act out sexually. Women are more likely to steal, pull out their hair, injure themselves, compulsively shop, and binge eat. It is not clear whether such gender differences are hormonal, cultural, or a combination of both.

Pathological Gambling

Pathological gambling is an example of an impulse control disorder. Pathological gamblers feel compelled to gamble and have difficulty resisting gambling impulses. Their behavior disrupts their lives in many ways, increasing during times of stress and creating a vicious cycle: the more their gambling causes problems, the more they gamble to try and get out of those problems.

Perhaps as many as 3% of the U.S. population are pathological gamblers.[1] The affliction has become a major public health problem because of the increased availability of legalized gambling. While self-help and Gamblers Anonymous groups are available, many patients drop out or relapse over time. Behavioral techniques may be effective but differ from behavioral techniques used in the treatment of OCD.

Recent studies with serotonin selective reuptake inhibitors such as fluvoxamine demonstrate that about two thirds of pathological gamblers experience a marked reduction in their actual gambling behavior (Hollander et al. 1996. Unpublished data). One third of individuals, however, relapse after a relatively brief period—3 to 4 weeks. More studies are needed to confirm that a substantial subgroup of pathological gamblers may respond to SRIs.

Body Dysmorphic Disorder

An example of the other end of the spectrum—compulsivity—is body dysmorphic disorder, or the distress of imagined ugliness and/or intolerable physical imperfection. Estimates of lifetime prevalence range from 0.1% to 1.0%, with approximately 0.67% of the population having true body dysmorphic disorder (Hollander et al. 1996. Unpublished data). These individuals are preoccupied with one or more imagined defects in their appearance. They may be obsessed with aspects of their face, body size, or sexual organs. They repeat certain behaviors in response to this preoccupation, such as checking themselves in the mirror over and over again, avoiding social situations, having frequent and repetitive surgeries, and camouflaging themselves to conceal their "defects."

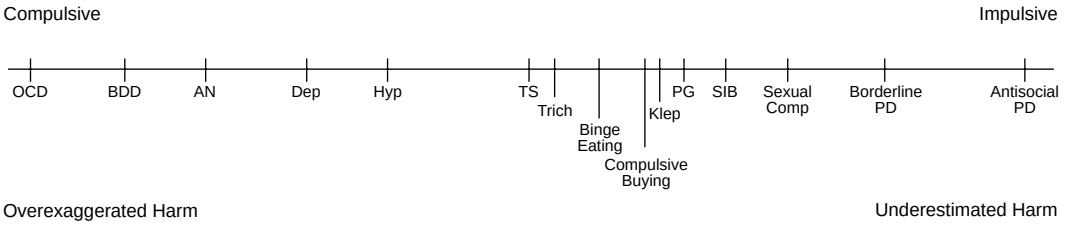
Rarely, an individual is instead obsessed with the appearance of somebody close to him or her, often a spouse or a child. We might describe this as body dysmorphic disorder by proxy.

To determine whether SRIs are helpful for body dysmorphic disorder, our group is currently conducting a controlled crossover trial comparing the SRI clomipramine to desipramine, a norepinephrine reuptake inhibitor. The SRI appears to be very effective in reducing the preoccupation with body obsession. The norepinephrine reuptake inhibitor appears ineffective.

Autism

Autism is an example of the neurologic cluster within the OCD spectrum. It is characterized by a compulsive core, along with difficulties with social interaction, speech, and communication. Serotonin abnormalities may be linked to the compulsive, repetitive behaviors; stereotyped, habitual behavior; aversion to change; and narrow restricted interests seen in autistic individuals.[7] Peptides such as oxytocin may be linked to deficits in social attachment or difficulties with empathy.

Figure 2. Dimensional Aspects of Obsessive-Compulsive Spectrum Disorders*



*Data from reference 6, with permission. Abbreviations: AN = anorexia nervosa; BDD = body dysmorphic disorder; Dep = depersonalization disorder; Hyp = hypochondriasis; Klep = kleptomania; OCD = obsessive-compulsive disorder; PD = personality disorder; PG = pathological gambling; Sex Comp = sexual compulsions; SIB = self-injurious behavior; Trich = trichotillomania; TS = Tourette's syndrome.

Several studies have shown that SRIs such as sertraline, clomipramine, fluvoxamine, and fluoxetine are effective in treating not only compulsive core symptoms in autism but also social difficulties and other problems such as self-injurious or aggressive behavior.[7]

CONCLUSION

In the current era of managed care, it has become increasingly important to document the costs, both in dollars and in quality of life, of specific disorders to ensure access to appropriate treatment. U.S. census data suggest that $8.4 billion per year is spent for the management of OCD, compared with $43 billion for heart disease, $100 billion for cancer, and $66 billion for AIDS.[8] Yet there are almost as many OCD sufferers in the United States as there are heart disease patients and cancer patients, and there are many more people with OCD than there are people with AIDS. While OCD is not a life-threatening disease, it is a chronic, disabling illness that causes suffering equal to that of any physical pain. In a primary care environment, heart disease, cancer, and AIDS are recognized, but there is little recognition of OCD. This is especially ironic since treatments for the first three conditions are variable in terms of success, while we have very successful treatments for OCD. Logically, if we can increase OCD recognition, we can increase successful treatment and reduce lifetime incidence and overall costs.

It has been suggested that a diagnosis of OCD will increase demand for treatment, increasing managed care costs. On the contrary, more rapid diagnosis and appropriate treatment of OCD and spectrum disorders reduce the costs of management. With early, appropriate treatment, the number of providers, visits, and total outpatient fees can be significantly reduced and suffering significantly alleviated. With this goal in mind, we need to support continued research into the nature, causes, and treatment of OCD and its related disorders.

Drug names: clomipramine (Anafranil), desipramine (Norpramin and others), fluoxetine (Prozac), fluvoxamine (Luvox), sertraline (Zoloft).

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