Psychotherapy Resources

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OCD: WHY AM I NOT GETTING BETTER?

*By Laurie Krauth, MA, LLP**

Fred Penzel, PhD, successMichigan treated an 89-year-old woman whose OCD began when Calvin Coolidge was president. (She was 6). Like many of his patients, she could have been helped many years earlier, but she went without proper diagnosis and treatment for most of her life.

"There are many reasons why people appear to fail to recover, even after seeing four or five therapists," Dr. Penzel told his audience at the 12th Annual OCF Conference. He identified nine reasons why people fail-but shouldn't.

Dr. Penzel, director of the Western Suffolk Psychological Services, in Huntington, New York, spoke to the conference audience in San Diego July 31. He is on the OCF Scientific Board of Directors and has written widely on OCD. His books include *Obsessive-Compulsive Disorders: A Complete Guide to Getting Well and Staying Well (2000)* and *The Hair-Pulling Problem: A Complete Guide to Trichotillomania (2003).*

These are nine common reasons he gives for OCD sufferers' poor progress in overcoming their symptoms:

1. **Misdiagnosis**
2. **Active Mood Disorder**
3. **Wrong Treatment**
4. **Non-Comprehensive Treatment**
5. **Weak & Ineffective Treatment**
6. **Lack of Acceptance of OCD**
7. **Low Frustration Tolerance**
8. **Sabotage by Others**
9. **Comfort in OCD's Discomfort**

1. THEY WERE MISDIAGNOSED

Some people are diagnosed with OCD when they have another mental illness with similar symptoms. Others are told they have another disorder when they really have OCD. Many therapists lack the training and supervision to properly diagnose OCD, he said. They fail to tease out the details that confirm or rule out the diagnosis. They may fail to distinguish how similar symptoms more accurately fit another disorder.

The proper diagnosis is essential to tailoring the right psychological and medical treatment to each person. To complicate matters, people with OCD may also have other disorders as well. So therapists may need to make more than one diagnosis to develop a treatment plan addressing all of a patient's problems.

Clinicians ultimately must determine if a patient meets the criteria for a disorder as delineated in

the DSM-IV, the American Psychiatric Association's diagnostic manual. The DSM describes OCD as recurrent obsessions ("persistent ideas, thoughts, impulses or images that are experienced as intrusive and inappropriate") and compulsions ("repetitive behaviors--e.g., hand washing, ordering, checking-- or mental acts-e.g., praying, counting, repeating words silently--the goal of which is to prevent or reduce anxiety or distress, not to provide pleasure or gratification."). OCD causes marked distress or significant impairment-or both.

For those who may have been misdiagnosed with OCD, he said, some of the disorders with similar symptoms that might fit them better include:

- *Asperger's Disorder*. Included in the DSM criteria for Asperger's are significant problems with functioning due to a "qualitative impairment in social interaction..., restricted repetitive and stereotyped patterns of behavior, interests and activities..., [but no significant] delays in language...or cognitive development."

Asperger's is similar to Autism but less dramatic in its presentation, said Dr. Penzel. It is a disorder of social relatedness: people with Asperger's may often be the odd-person out, said Dr. Penzel.

Features of Asperger's mistaken for OCD include "a focus on very specific, limited, and intense interests, which people with Asperger's often pursue to the exclusion of everything else, occupying many hours per day." They may lecture repetitively on favorite topics, he said, or "adhere to rigid schedules or ways of doing particular things that cannot be altered in any way." Unlike with OCD, people with Asperger's are motivated by pleasure, not anxiety, to spend excessive time on activities such as video games, math problems, on-line searches, and reading of numerous books on a subject of interest.

- *Obsessive Compulsive Personality Disorder.* OCPD is described in the diagnostic manual as "a pervasive pattern of preoccupation with orderliness, perfectionism, and mental and interpersonal control, at the expense of flexibility, openness, and efficiency..."

One of Dr. Penzel's "unofficial diagnostic criteria" for OCPD is met when patients contact him because "their back is against the wall, like their job is threatened or their wife brings them in for treatment," he said. "They don't want to change. They feel these things they do are an integral part of them and give them pleasure." Often their behavior doesn't cause them distress, even if it's messing up their lives, he added. People with OCD, however, "find their symptoms unpleasant or repulsive." Further, he notices that the difference between preventing someone with OCPD and OCD from behaving in these classic ways is that the first will likely become angry and the second, anxious.

Features of Obsessive-Compulsive Personality Disorder that are frequently mistaken for OCD, he said, are an insistence on perfectionism and exactness; having rigid routines; having to be very controlling of others, and being meticulous and rule-governed; and the hoarding of useless or excessive numbers of things.

- *Attention Deficit/Hyperactivity Disorder.* ADD, according to the DSM, includes inattention, and with ADHD, impulsivity and hyperactivity.

Ironically, some ADHD sufferers compensate with behaviors that can look like OCD, such as extensive list-making; doing things in a certain unvarying order; repeating actions; counting while doing things; and double checking to avoid a reckless omission or error, said Dr. Penzel. A person with OCD, however, may be driven to do those things to reduce anxiety caused by obsessional thoughts that they may have made an (unlikely) error. "ADD is a disorder of attention and concentration, not of doubt and guilt as in OCD."

These are just some of the other mental health issues that resemble features of OCD. The plethora of such possible diagnoses can overwhelm someone eager to nail down the right one for them. Some end up saying, "Doc, I'm suffering from the DSM," said Dr. Penzel. The bottom line is that if you suspect you have OCD, you need to be diagnosed by someone who specializes in treating it.

2. THEY HAVE A MOOD DISORDER THAT ISN'T UNDER CONTROL

OCD sufferers may be pursuing appropriate treatment, but be waylaid by a mood disorder. If they're experiencing a major depressive episode, their mood is depressed or they have lost interest in nearly all activities. It may be a reactive depression caused or exacerbated by living with OCD, or a biological depression that persists even as your OCD improves, said Dr. Penzel.

They may be stymied by crushing fatigue, which makes even the smallest effort seem impossible. They may lack motivation due to extreme negative thinking, believing that they will be unsuccessful in treatment, that they do not deserve to recover, or that nothing can help them, he said.

At the other end of the mood spectrum, if they are having a manic episode, according to the DSM, they're experiencing "an abnormally and persistently elevated, expansive, or irritable mood," which can distort their self-esteem, need for sleep, goal-directed or pleasurable activities. They may throw their medications away and feel like they're invincible and are 'cured' without doing the necessary therapeutic work, noted Dr. Penzel.

In either case, patients need to stabilize their mood disorder with medication and therapy so they have the motivation, energy and persistence to follow through on treatment.

3. THEY'RE GETTING THE WRONG TREATMENT

Cognitive-Behavioral Therapy (CBT) and antidepressant therapy are the treatments of choice for OCD, said Dr. Penzel. He said he has not seen scientific evidence-well-conducted and reported studies that can be replicated by others--supporting other treatments, although individuals may cite success with one or more of them. Some of these alternative treatments that have been used for OCD but not extensively researched include relaxation training, biofeedback, hypnosis, diet changes, homeopathy, psychoanalysis or other non-specific talk therapy, and EMDR (eye movement desensitization reprocessing).

4. THEY'RE NOT GETTING COMPREHENSIVE TREATMENT

Comprehensive treatment involves cognitive-behavioral therapy, medication, and life balancing, said Dr. Penzel.

- *Cognitive-Behavioral Therapy*

Assignments involve a behavioral component-exposure and response prevention-as well as a cognitive component-"recognizing the illogical thinking of your OCD."

- *Medications*

Medications, specifically the SSRIs, such as Prozac and Zoloft, or the older tricyclics, such as Anafranil, can help. He said there is some scientific evidence suggesting some benefit in the B vitamin inositol, and uncontrolled evidence showing promise in the herb St. John's Wort, but he added that store products of the herb are undependable.

- *Life balancing*

"Health comes from a state of balance-work, school, volunteering, and helping at home; exercise; sleep; eating well, and socializing," said Dr. Penzel. People with OCD benefit from reducing the extremes of stress and excessive free time.

5. THEY'RE GETTING WEAK AND INEFFECTIVE

TREATMENT

Despite a proper diagnosis and CBT treatment, people with OCD "get watered down assignments that don't sufficiently challenge sufferers' symptoms."

"I'm an industrial strength therapist," said Dr. Penzel. "You have to be to get the job done. You must experience anxiety up to the level you can tolerate and stay with the anxiety [until you habituate to it.]. Every week I want you to know you're done something better than the week before. Warm, fuzzy therapists don't challenge the patients enough."

This doesn't mean "rocking and socking people with their anxiety at a level they can't tolerate," he added, but finding assignments that are demanding enough to produce change. They also need cognitive therapy that "challenges the illogical in their own thinking."

6. THEY DON'T ACCEPT THAT THEIR OCD IS A PROBLEM

To succeed in treatment, said Dr. Penzel, "sufferers need to accept that:

- They have OCD
- It's a chronic problem like asthma or diabetes. 'Some sufferers have a magical belief that God will take it away or they'll outgrow it'
- They will never 'perfect' their OCD
- They cannot keep on compulsively protecting themselves and others and still recover ('If I do all my compulsions just right then I won't have any anxiety')
- There are tasks they will have to accomplish on their own, in order to recover. The only way out is through, not around [the symptoms]."

7. THEY'RE SUCCUMBING TO LOW-FRUSTRATION TOLERANCE

"The *shoulds* that frequently accompany low frustration tolerance are:

- I should not have to work hard at getting the things I want-these things should come easily to me.
- I should never have setbacks, but always make continual progress.
- Getting recovered should happen very quickly.
- Treatment for my symptoms should not make me uncomfortable in any way, and above all, should not make me anxious."

Added Dr. Penzel, "It's like saying you should get surgery without getting cut or getting stitches."

8. THEY'RE BEING SABATOGED BY OTHERS

Family members and friends are profoundly affected by a loved one's OCD. They may be drawn into the sufferers' pain and rituals, make decisions for them, take over responsibilities. When the sufferers begin to get better, loved ones react in different ways-not all helpful.

Certain kinds of "help" do not help, he said:

- *Intentional sabotage*. "In one case, the sufferer's husband undermined her progress because he made all the family decisions and he liked it that way. His temper got worse and he made nasty comments."
- *Impatience*. Family members become invested in seeing rapid progress and get too invested in each step of the therapeutic journey. With someone overcoming a contamination fear, "now you can open the door knob without a paper towel and they'll say, 'But what about all these things you *can't* do yet?'"

Dr. Penzel noted how much family members often suffer in watching and responding to loved ones with OCD. Nevertheless, he encouraged family members to step back and allow sufferers to do what they have to do on their own, even if they have occasional lapses, or even if they lose their momentum and quit altogether. Which led him to his final obstacle:

9. THEY'RE COMFORTABLE IN THEIR DISCOMFORT

"They are living with their symptoms full blast, with multiple compulsions, and everyone else has to accommodate their symptoms. Being a patient has become their full-time job," he said.

Maybe they are suffering from one or more of the other eight obstacles, such as severe depression, inadequate medication, or simply feeling demoralized by several failed treatment efforts. The bottom line is that they are not willing to get help and do the work they need to do to get better. Until they do, no one else can make them better, and Dr. Penzel encourages family members not to take responsibility for their loved ones' recovery. If the OCD sufferers live at home, he said, family members can make staying there conditional on their continued efforts to get better. Otherwise, they can live in community-supported housing until they are ready to return to doing the work to improve.

Despite those who are not ready or able to sustain the work to get better, many sufferers can and do get better, even after multiple tries.

"I don't like the terms "refractory OCD" [unremitting symptoms] or "treatment resistant,"[not responsive to therapy], said Dr. Penzel. Many people given those labels could succeed under the right conditions. "The worst thing is to take hope away from you."

Success depends upon an OCD sufferers' proper diagnosis, treatment plan, and own effort. Dr. Penzel's 89-year-old patient spent most of her life living in fear of being contaminated by others. "She didn't know what it was or that anything could be done about it," said Dr. Penzel.

Then one of her daughters read an article about OCD that described her elderly mother's symptoms. "Actually, it went rather quickly, once she started working on it. She was very diligent about doing her [ERP] homework," said Dr. Penzel. And her life changed.

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