

## The Treatment of Obsessive Compulsive Disorder in a Patient with Down Syndrome

Robert Hudak\*

University of Pittsburgh School of Medicine, USA

### Abstract

Many mental health professionals do not properly recognize the co-occurrence of psychiatric disorders and intellectual disorders. Most mental health professionals do not receive training in the diagnosis and treatment of dual diagnosed individuals. Little is known about the clinical presentation and treatment of OCD in individuals who have Down Syndrome. We describe a case of OCD in an individual with Down Syndrome in which the diagnosis of OCD was overlooked for four years after first contact with mental health professionals. The treatment of the patient is reviewed, including medication management as well as the challenges in using evidence based psychotherapy.

**Keywords:** Obsessive compulsive disorder; down syndrome; OCD; tic disorder

### Introduction

Despite the fact that individuals with intellectual disabilities are at an increased risk for psychiatric problems, a fact that has been well documented in scientific literature for decades, many mental health professionals do not properly recognize the co-occurrence of psychiatric disorders and intellectual disorders [1]. Most mental health professionals do not receive training in the diagnosis and treatment of dual diagnosed individuals, and most clinical treatment studies list intellectual disabilities as exclusion criteria. Obsessive Compulsive Disorder (OCD) likewise tends to be under recognized and missed during mental health examinations [2] and even when it is diagnosed properly, mental health clinicians often do not initiate appropriate, evidence based treatment [3]. Therefore, it is not surprising that little is known about the clinical presentation and treatment of OCD in individuals who have Down Syndrome. We describe a case of OCD in an individual with Down Syndrome in which the diagnosis of OCD was overlooked for four years after first contact with mental health professionals. The treatment of the patient is reviewed, including medication management as well as the challenges in using evidence based psychotherapy.

### Case Presentation

Mr. B. is a 21 year old white male with a past medical history significant for a diagnosis of Trisomy 21 which was diagnosed at birth. He presented to our clinic accompanied by his parents with complaints of behavioral concerns effecting him at home as well as at his supported work program. He had become irritable at both work and home, would refuse to go to work, and was using vulgarity while at his place of employment. He would repeat certain vulgarities over and over, and the words did not always seem to be precipitated by a specific person or event, and were often not targeted at any individual. He described this as an intentional ritual done to relieve distress and it did not appear tic-like. He was also noted to have unusual behaviors- specifically he would continuously ask his mother if she was "OK". She could not simply answer "yes", but she had to use a very specific phrase when responding to him: any other phrasing would prompt him to become anxious and ask the question again. This would occur multiple times in an hour. He was unable to go to bed unless the kitchen and living room was arranged in a specific way resulting in a diminished sleep schedule. He would experience crying spells when his living space was rearranged. He would turn the lights off and on in certain rooms in his

house repeatedly; however, this would not occur in places unfamiliar to him. Mother states that he could spend up to an hour at a time with these routines and that he would appear anxious during these periods. Upon exam, patient appeared embarrassed when asked about these symptoms and would minimize them, saying that they were no big deal and did not wish to talk about them. In addition to the decreased sleep secondary to his late bed time, the patient had a 25 pound weight loss despite having a good appetite. Numerous motor tics in his head and extremities were observed. He denied having a depressed mood, denied suicidal ideation, and no neurovegetative signs were elicited. His past medical history was significant for hypothyroidism and a congenital hearing deficit. A CT scan of his brain was within normal limits.

His developmental history is significant for having walked at 18 months and speaking his first words at 21 months. He was tested in elementary school and found to have an IQ of 63. While he was in the 7<sup>th</sup> grade, teachers had told the family that he would not start his lessons unless his desk was arranged in a certain way. He had been treated by psychiatrists at his local mental health center since age 17, and had been diagnosed with 'anxiety'. He was initially placed on fluoxetine at 20 mg without improvement and remained on this regimen for four years. At that time was switched to bupriopron, titrated to 300 mg, and had remained there for three months with no change.

Upon presentation to our clinic, bupriopron was discontinued and escitalopram was initiated and titrated as rapidly as he could tolerate it to 40 mg daily for a diagnosis of OCD and tic disorder. Risperidone 0.5 mg nightly was added as an augmentation strategy. The patient experienced a partial improvement of symptoms after six months, but still had significant issues with flicking light switches off and on. He remained at this level of improvement for three years, but after receiving services for job training, the parents wished to see if he could obtain greater improvement on a different regimen. His SSRI was switched to fluvoxamine 450 mg daily, and the risperidone augmentation was

\*Corresponding author: Robert Hudak, University of Pittsburgh School of Medicine, USA, Tel: 412-586-9571, Email: [hudakr@upmc.edu](mailto:hudakr@upmc.edu)

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changed to aripiprazole 10 mg. He had further gains in his rituals; his parents noted that his light switch rituals were lessened significantly to a few minutes at a time. His only side effect to these medications was an increase in sleep to 10 hours a day, and the patient and his parents were pleased with his improvement.

While in the office, the principles of exposure with response prevention therapy (ERP) were explained to the patient and his parents. The patient had good insight into the ego-dystonic nature of his obsessions, and was able to understand the concepts of the treatment, including the increased anxiety during exposures and the goal of habituation. A single trial of ERP was initiated during an office visit, and patient was able to do the tasks assigned. Family reported a resultant decrease in flicking of light switches at home after this trial. However, he was not able to come into our clinic on a weekly basis for therapy as their travel time was greater than 2 hours. In addition, there are no therapists trained in ERP in his geographical region. As a result, behavior therapy has unfortunately not commenced on a regular basis, and treatment at this time is exclusively pharmacologic.

## Discussion

As noted above, psychiatric disorders are often overlooked in patients with intellectual disabilities including Down Syndrome. In addition, while OCD is one of the most common psychiatric illnesses, affecting approximately 2.5% of the population [4], it is often overlooked or misdiagnosed in a clinical setting. It would therefore be expected that OCD would be frequently overlooked in patients with Down Syndrome. One difficulty is that people with intellectual disabilities are often noted to have significant traits of perfectionism: their need for routine and dislike of change will cause them to be very regimented. The compulsions that someone with OCD suffers from may be mistaken for this perfectionism. This was the case with Mr. B.- his rituals of lining things up in school and work was assumed by his psychiatrists as stemming from his need for consistency.

Upon closer examination of the history of his behavior as explained by his family members indicated that he was anxious while performing these rituals, and he was able to verbalize that he did not wish to be performing these tasks which is consistent with compulsive rituals. A proper diagnosis was vital to address these issues. The initial medications used for the patient's crying spells and anxiety were unsuccessful due to the fact that the fluoxetine was not titrated to a high enough dose generally accepted to be effective in the treatment of OCD and bupropion is not an SSRI and is therefore generally ineffective in OCD treatment.

There is very little published work on the comorbidity of OCD in Down Syndrome. Charlot et al. [5] reported on a case series of 11 patients with Down Syndrome who had obsessional slowness without other OCD symptoms noted. Raitasuo et al. [6] reported on a patient with comorbid Down Syndrome, OCD, and Anorexia Nervosa. However, no controlled studies of treatment of OCD in Down Syndrome have been performed. As it has been suggested that people with Down Syndrome may experience alterations in serotonin levels [1] and any subsequent effect that this would have on their response to SSRI treatment is

not known. Mr. B. responded to high dose SSRI therapy in line with recommended guidelines for OCD treatment [7] and in the absence of additional evidence it is recommended to use standard anti-obsessional medication treatment- SSRI's as first line treatment and clomipramine being reserved as second line therapy due to concerns of side effects. Constipation is an especially problematic side effect of clomipramine in patients with Down Syndrome which may markedly limit its use in this population.

In addition to SSRI pharmacotherapy, ERP is the gold standard for OCD psychotherapy and treatment with an efficacy equivalent or superior to medications [8]. ERP was initiated with Mr. B. as it was deemed this this technique would have a reasonable chance of success due to his ability to verbalize the intrusive nature of his symptoms, his desire to stop them, and his ability to give informed consent to a trial. While little has been written about doing ERP in this population, Mr. B was able to do some work in the office. Therapy was not able to be continued because of access problems due to his great distance from our center, but it is felt that the initial trial was a successful proof of concept and it is recommended to attempt ERP in patients with a similar IQ or higher who also meet those criteria. It should be noted that ERP can be difficult to obtain for anyone diagnosed with OCD due to the paucity of clinicians properly trained in these techniques, and finding a trained therapist who also has experience with intellectual disabilities is even more difficult.

OCD and Down Syndrome can occur together and can often be misdiagnosed. Standard anti-obsessional pharmacotherapy should be offered, and patients should be screened for their appropriateness for ERP. More work in this area is needed, and further research elucidating proper protocols in treating OCD in patients with Down Syndrome and other Intellectual Disabilities should be performed.

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