Comprehensive Treatment Of Comorbid Autism and OCD: How To Do It

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Autism
It’s not a processing error –
It’s a different operating system.
- Unknown author

What this presentation will cover:
1. How to manage expectations – two models
2. What we can change vs. what we may change to a lesser degree
3. How to communicate with your ASD/OCD patient
4. How to create a working therapeutic relationship
5. Potential pitfalls in treating an ASD/OCD patient
6. How to evaluate symptoms
7. How to create a hierarchy for your ASD/OCD patient
8. Making treatment modifications for ASD/OCD patients
9. How to create and assign homework

What this presentation will cover – Pt. 2:
10. How to structure sessions and pace treatment
11. It takes a village: Assembling other resources
12. Case Example #1 – “Ethan and the Slender Man”
12. Case Example #2 – “Daniel’s Contract with the Devil”

Expectations
Expectations are key to treating OCD (or anything else) in those with ASDs.

We need to keep high expectations for each individual, while adjusting them for each one's abilities.

"Nobody rises to low expectations."
- Les Brown

"Low expectations lead to poor outcomes."
- Pam Wright (of Wright's Law)

How To Manage Expectations:

The "Low Expectation Model" vs
The "High Expectation Model"

The Low Expectation Model

1. There is a long tradition in this country of having low expectations for the disabled, in general.
2. It is rooted in old autism misdiagnoses such as idiocy, imbecility, deafness, or hearing-impairment.
3. People still tend to confuse the communication problems, perseveration, and social difficulties seen in ASDs with the unfortunate term "mental retardation." This is aided and abetted by faulty testing that is verbally loaded and only gives minimal estimates of intelligence.
4. It is also assumed that those with ASDs are incapable of understanding, empathy, or being aware of much of what goes on around them.

The Low Expectation Model (cont.)

4. It is not widely recognized that there are many individuals with ASDs who actually possess high intelligence and special abilities.
5. It is assumed that because of their desire for sameness, those with ASDs are incapable of learning, doing new things, or changing in most ways.
6. It is assumed that those with ASDs are devoid of emotions simply because they are less able to express them.
7. Even those with experience in treating those on the Spectrum can fall prey to having low expectations.

The High Expectation Model

1. Not starting out with any assumptions and approaching each person with an ASD as a unique individual with unique abilities.
2. Finding out what those unique abilities are, via observation of their natural inclinations, and giving them opportunities for discovery.
3. Giving them the opportunity to develop those abilities without setting preconditions, imposing limitations on them, or making assumptions about how far they can go.
The High Expectation Model (cont.)

4. Always expecting that they will do their best, rather than something inadequate.
5. Not getting distracted by their self-stimulatory or perseverative behaviors, and instead, seeing the person behind them.
6. Not mistaking a lapse or a setback for overall failure or inadequacy

Expectations that will also need some adjusting are what you will be able to help them change, versus what you may be less successful with.

What we can change in our ASD/OCD patients depends upon a combination of:

- What they find unacceptable and wish to change
- What they view as integral parts of themselves and do not wish to change
- What we can make them aware of and convince them it would be in their best interest to change because it would make their lives better in some way

Parents, in particular, need to be able to strike a balance between having expectations that are overblown, versus having little or no expectations at all.

What Can Effectively Change vs. What Can Change, But To A Lesser Degree

<table>
<thead>
<tr>
<th>Can Effectively Change</th>
<th>Can Change To Lesser Degree</th>
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<tbody>
<tr>
<td>The performing of compulsions</td>
<td>Core features of autism:</td>
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<tr>
<td>High levels of anxiety</td>
<td>• Intense interests</td>
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<tr>
<td>Habitual avoidance</td>
<td>• Expressive language limitations</td>
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<tr>
<td>Feelings of low efficacy</td>
<td>• Social relatedness</td>
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<tr>
<td>Social behavior</td>
<td>• Ability to read social cues</td>
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<td>Depressed mood</td>
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It is important to know that there are other things you may have the opportunity to help your ASD patients with beyond OCD.

- Their self-care
- Increasing and improving the quality of their socialization, and making peer connections
- Developing interests that may enhance their lives in place of perseverative ones
- Vocational training
- Acquisition of life skills and self-care skills
- Pursuing independent or semi-independent living
Is treating someone with an ASD for OCD radically different from treating anyone else?

The answer is:

No, not really. You just have to be aware of certain things and tinker with treatment a bit.

There may also not be a lot of difference in treating younger versus older ASD/OCD patients.

There isn’t a real body of research on this, but it should be viewed as more a matter of using different scaling of your approach (based upon cognitive and maturity levels).

How To Communicate With Your ASD/OCD Patient

Some Tips for Communicating With Your ASD/OCD Patient – Pt. 1

- They tend to be concrete thinkers, so resist using sarcasm, subtlety, or abstract concepts
- They can be rigid thinkers who believe that they will always feel the way they are currently feeling, or that if something has changed, it has changed forever.
- They do have a sense of humor (it just may be a bit different from yours), so don’t be afraid to use it
- They are often structure-oriented and do better if you lay out a plan for them and keep treatment organized and linear. Using charts and checklists can also help.
- Don’t assume the things you teach them will automatically be generalized to new situations

Some Tips for Communicating With Your ASD/OCD Patient – Pt. 2

- They may try to be agreeable by telling you what they think you want to hear
- Some review of previous sessions or concepts may be necessary at each session
- They may not always be able to explain what they are experiencing emotionally (e.g. “I don’t know”)
- Don’t always expect ordinary social reciprocations – don’t interpret it as rudeness or hostility
- Be careful about using figures of speech – you may well be taken literally – some may also find them confusing or view them as ‘lies’

Some Tips for Communicating With Your ASD/OCD Patient – Pt. 3

- Some of those with ASDs are more visually (than verbally) oriented, so be sure to include more visual aids to illustrate points you are making or to help them express what they are feeling
- Allow extra time when waiting for a response, as some ASD patients may have slower processing speeds than others
Some Tips for Communicating With Your ASD/OCD Patient – Pt. 3

**ASD/OCD patient**
- What did you do each day this week? Let’s start with last Thursday.

**Neurotypical patient**
- How are you doing this week?

- Can you point out on this fear thermometer where your anxiety is?

- Let’s go down our list and see how you did with each assignment on it. We’ll go by the numbers.

- How did the homework go this week?

Some Tips for Communicating With Your ASD/OCD Patient – Pt. 4

**ASD/OCD patient**
- We are working to get you so bored with your thought that you won’t care about it

**Neurotypical patient**
- The goal is to get you to increase your tolerance of your thoughts

- Let’s start by going over what you learned last week

- Looks like you could have worked a little harder on your homework last week

How To Create A Working Therapeutic Relationship

**Pt. 1**

- You need to find out what your patient’s goals for recovery are in order to build motivation - don’t automatically assume your patient isn’t capable of a high degree of motivation

- Be careful to not judge these goals even if they seem quirky or different to you

- Understand that some are more rigid thinkers than others and may be less open to change, but don’t assume they are incapable of change

- Be very open and accepting of them and again, don’t be judgmental. Learn to appreciate who they are as people

**Pt. 2**

- Don’t try to force eye contact

- It’s okay to ask if they understood what you said

- Be aware of the need to correct possible sensory problems or distractions in your office

- Explain all the steps of the therapy process in advance so there are no surprises – can give a list

- Make it clear that this is about working together as a team and depending upon each other (which may not be an easy concept for some people)

- Always believe in their ability to improve
How To Create A Working Therapeutic Relationship – Pt. 3

- Keep things positive - be sure to verbally reinforce good performance (or even good attempts). When discussing problems in performance stress how something could have been done 'even better' rather than criticizing
- You may want to incorporate a patient's preferred interests into sessions as a way of reinforcing good performance and engagement
- Give them choices as to therapeutic assignments
- Be careful to not apply pressure
- Monitor stress levels - give breaks if necessary, or shorten sessions somewhat if you see your patient approaching their limits

Potential Pitfalls In Treating An ASD/OCD Patient – Pt. 1

- Patient's difficulty in expressing and describing what they are experiencing (symptoms, anxiety levels, etc.)
- Lack of interest/motivation to change on the patient's part (due to rigidity, poor self-awareness)
- Lack of insight causing unwillingness to give up their only source of relief from anxiety and accept experiencing discomfort in order to reach desired behavioral goals
- Problems with executive functioning (organization and distractibility) affecting ability to take part in sessions or to accomplish therapy homework
- Only wanting to talk about topics of intense interest to the exclusion of anything else

Potential Pitfalls In Treating An ASD/OCD Patient – Pt. 2

- Interference by other well-meaning helpers and caregivers
- Family accommodation of compulsions or homework refusal (fear of meltdowns, making them anxious, etc.) can undermine treatment
- Family and impatience and/or anger about symptoms or progress
- Work in one particular area may not generalize to others
- Having to maneuver between parents in divided families (** the divorce rate in families with an ASD child is no greater than in the general population despite rumors to the contrary)

How To Evaluate Symptoms – Pt. 1

I tend to not rely too heavily upon the testing reports of others or to use standardized measures, myself, because:

- These measures rely heavily on verbal abilities and processing, both of which may yield biased results when testing autistic patients.
- I rely more upon direct clinical interviews with the patient, parents, physicians, school personnel, etc. Reports and observations of others must be carefully considered, as most people cannot differentiate between perseverative behaviors and compulsions.

How To Evaluate Symptoms – Pt. 2

- It can also be extremely helpful to interview family members to determine levels of accommodation of symptoms and autistic behaviors as these may also be potential therapy targets. Also evaluate anger and frustration levels in family members.
- A comprehensive behavioral analysis may be necessary to differentiate between a perseveration and an OCD symptom
- Precise questioning may be needed when interviewing patients regarding symptoms to get correct information. You may have to specifically ask the patient what the correct words to use are (they may not like your choice of words) in labeling or describing them

How To Evaluate Symptoms – Pt. 3

- Be sensitive to and respect a patient's limits when engaging in detailed questioning about fearful stimuli - give breaks, and also try to recognize when they may have reached their limit for a particular session
How To Create A Hierarchy For Your ASD/OCD Patient

How To Create A Hierarchy

• Try to first establish what feeling anxious means to the patient - not all are able to label feelings or gauge them accurately
• Explain the purpose of a hierarchy - consider using a "fear thermometer" or a staircase as a more concrete visual aid
• I favor a 0-100 SUDS rating scale – it allows for more gradations between anxiety-provoking situations. Be aware that some may really take to this structure, while others may get too caught up in and hindered by the numbers, themselves. It should not be used in such cases. Better to make a list of things the patient wishes to work on and give them input in deciding the order in which they will be worked on.

How To Create A Hierarchy – Pt. 2

• Use very precise language in posing hypothetical situations (you may have to explain that these are just pretend)
• Accept their ratings unconditionally – but allow them to make changes if they wish
• Don’t just dictate – allow them to have input
• Be careful in discriminating between compulsions and perseverative elements that are common in autism

How To Create And Assign Homework – Pt. 1

• If the patient is especially fearful and resistant, you may have to divide assignments up into the smallest possible increments – at first, so small it may even seem ludicrous, just to get things started
• If there are numerous symptom themes, try to allow the patient to choose the order in which they wish to work on them, however, you may have to give priority to items that affect health and/or safety or that may have more serious social or educational implications
• Give all homework in writing and consider using daily/weekly checklists or charts for them to fill out (on their own, or with help)

How To Create And Assign Homework – Pt. 2

• Keep assignment descriptions concise, clear, concrete, and precise to the point of being legalistic
• Pace homework so that it does not create pressure – keep the completion of assignments more open-ended
• It is okay to incorporate some humor in your assignments. Don’t be afraid to think outside the box.
• Be flexible and pragmatic – if your usual isn’t working, don’t be afraid to try something radically different
• Take time to explain the homework to family and helpers, so they will be able to recognize when it is being carried out. If they will be assisting, be very specific in how they are to do it

How To Create And Assign Homework – Pt. 3

• Try to make the patient gradually more responsible for keeping track of assignments and for carrying them out to whatever degree they are capable of. Don’t allow others to automatically take things over. Caution against nagging, threats, or punishment if homework is not being performed. You must be one to handle non-adherence issues
• Family members may also be assigned homework to deal with their habits of accommodating patient’s symptoms and autistic behaviors, all of which can interfere with treatment
• The goal in treatment is to try to hit symptoms from multiple directions in order to increasingly create an environment of total therapeutic immersion, where escape and avoidance become impossible
Treatment Modifications For ASD/OCD Patients – Pt. 1

- May require contingency management to increase motivation for treatment – everyone has their price
- Treatment rationale must be explained with care:
  - why and how treatment, change and self-improvement can improve their life
  - why the need to feel some discomfort and anxiety in the present is necessary to achieve long-term improvements
- Establishing SUDS levels (if used) when creating a hierarchy may require extra assistance (e.g. – a visual aid, such as a 'fear thermometer')

Treatment Modifications For ASD/OCD Patients – Pt. 2

- Executive functioning may be a problem so it is recommended to use homework charts, checklists and reminders (signs, cellphone apps, etc.) to keep patients focused and organized
- Also due to executive functioning limitations, sessions may need to be shorter to accommodate difficulties with sitting and attending
- Creating a daily homework schedule can also be a help for those with organizational/executive functioning problems
- Having other family members or aides involved as therapy aides

Treatment Modifications For ASD/OCD Patients – Pt. 3

- Divide homework assignments into smaller increments so that they will seem less overwhelming or intimidating
- To help with motivation, allow patients to have some control over their therapy in terms of choices of what assignments they will carry out and the order in which they will do them
- Assign homework at a pace the patient can manage – not too many assignments at one time or pressure-creating deadlines for accomplishment

How To Structure Sessions and Pace Treatment

- Begin with an overview of things in general during the previous week life at home, school, activities, jobs, etc. Ask about anything new or different
- Make a detailed review of homework checklists from the previous session
- Troubleshoot specific areas of difficulty or nonadherence. Be careful to not display negative reactions to any problems – keep things positive. Stress process over product. If parents or caregivers are present, do not allow them to inject negativity into these sessions
How To Structure Sessions And Pace Tx – Pt. 2

- Verbally reinforce patient for good performance (or even good attempts). Discuss the awarding of reinforcers if contingency management is used. Pick new reinforcers to be earned.
- Allow patients to choose which new assignments to do and in what order (as much as possible) when making up next list of assignments.
- Take care to not give too many assignments at one time – don’t push too fast in an attempt to get speedy results.
- Review each new assignment on the list with the patient (and any parent or caregiver present), and answer any specific questions relative to prospective homework assignments.
- Finish with social conversation (as much as possible) to help decompress and end session on a positive note.

It Takes A Village: Assembling Other Resources

Putting Together A Treatment Team

- Parents
- Siblings
- Physician
- Teacher(s)
- Classroom aides
- Activity coaches and instructors
- Job coaches
- Employers

Accessing Community Resources

- “Best Buddies” and other mentoring programs
- Local ASD socialization and social skills groups
- ASD summer camp programs
- Special sports programs and Special Olympics
- ASD-accommodating jobs and internships
- Driver Ed classes geared toward those with ASDs

Case Example #1

Ethan and “The Slender Man”

Case Example - #1

- Ethan – 16 years old, a sophomore in a public high school, a good student who enjoyed school, never a behavior problem. Parents divorced when he was very young. Diagnosed early in life with Asperger’s Disorder.
- Presenting Problem:
  After several visits to the ‘Creepy Pasta’ website, patient became fearful that the imaginary character ‘Slender Man’ might be stalking him. This resulted in attacks of severe anxiety, fear of walking the halls in school between classes, and school refusal. Patient would frequently retreat to the nurse’s office where
he felt safe. Patient also experienced morbid violent thoughts of somehow losing control and stabbing fellow students.

When anxious, Ethan was only able to express this by saying, “I want to die.” When he verbalized his fears to school personnel, they took him literally, overreacted, judged him a potential danger to himself and others, and pressured his mother to hospitalize him in a local private hospital. He was treated with antipsychotic medication and placed in a unit with thought-disordered patients for 2 weeks. He was extremely traumatized by this and feared returning to a school he no longer trusted. He was placed on home tutoring.

Main treatment objectives –
• Elimination of compulsions and compulsive avoidance
• Decrease anxiety levels and eliminate panic attacks
• Develop insight into what OCD is and how it manifests itself
• Take responsibility for managing his own symptoms
• Developing coping skills to be able to handle the idea of having OCD, for how it was mishandled, and for not being able to attend school with his peers
• Effect a return to school on a regular basis
• Rebuild trust in school personnel
• Educate school personnel about Ethan’s disorder and its manifestations, and about how to treat him

Techniques Utilized –
• Overarching approach was self-directed E&RP – with once-per-week sessions
• Psychoeducation for patient and his mother to explain treatment and how it could help
• Cognitive Therapy – used adjunctively to cope with idea of having OCD and not being able to attend school with his peers
• Referral for medication via an OCD-specialized psychiatrist
• Mother was utilized as a therapy aide, and sat in for part of many sessions
• School aide was also utilized upon patient’s gradual return to school

Specific Behavioral Assignments
• Write the words ‘Slender Man’ 25x per day
• Draw a picture of Slender Man every day and hang it up
• Listen to a series of 2-minute graduated recordings (6x daily) about Slender Man
• Begin resisting asking mom for reassurance
• Use a picture of Slender Man as phone wallpaper
• Try to agree with thoughts of being stalked by Slender Man and allowing them to ‘be there’
• Resist checking for Slender Man’s presence

Specific Behavioral Assignments
• Try to agree with thoughts of being killed by Slender Man and allowing them to ‘be there’
• Make a small replica of Slender Man to keep in his bedroom
• Make a life sized replica of Slender Man – move it around the house; take a photo with it and use it as phone wallpaper
• Visit the ‘Creepy Pasta’ website and read about Slender Man daily
• Playing video games or watching TV while holding a blunt, and later, a sharp knife

Specific Behavioral Assignments
• Download pictures of Slender Man from the internet and hang them up
• Make a gradual return to school, starting with visiting school when empty, then moving on to only attending his favorite class, and gradually building up as possible to a full day
• Walking between classes, at first accompanied by his aide, then moving on to aide being in the vicinity, then finally walking on his own
**Case Example #1 – Pg. 8**

**Case-specific Challenges:**
- Ethan was wary of treatment following his misguided hospitalization and medication.
- Mom had limited time to assist him at home, due to being a single parent.
- Ethan initially had low insight into how feeling anxious would ultimately be good for him.
- Just when the main symptom appeared to be under control, it morphed into a new (though similar) type of thought.
- Ethan had become extremely school phobic due to both his treatment there, and fear of the feared stimuli being there.

**Case Example #1 – Pg. 9**

**Case Outcome:**
- Made a gradual return to school, finally taking on a full schedule and getting good grades.
- Ceased checking for Slender Man or avoiding places where he might be – walking the halls in school unaccompanied.
- Stopped asking his mother for reassurance.
- Stopped experiencing panic attacks.
- Decreased anger and distrust toward school personnel.
- Accepted his OCD and conducted maintenance following the cessation of therapy.

"In order to get and feel better from my OCD, I needed to work closely with my doctor and have support from my family. The recovery wasn’t the easiest to do, and at times it all made me feel very uncomfortable. Facing my fears was the hardest part. I started to visit my doctor every week. At the end of my session I would be given a homework assignment. It started with simple writing assignments like writing a sentence about 25 times. Next homework assignment was to hang up pictures of the character, all around my house. Everywhere I looked I would see him looking at me. This made me feel very uneasy and was the hardest part to do. I was assigned HW to hold knives and keep them next to me when I watched TV or played video games. I even made a life-size cardboard cutout of the character." 

"Eventually, I became so tired of the writing, the pictures, and the cut out that I became bored of the character. So bored that I started to wonder why I was even scared in the first place. Soon my OCD started to leach onto other scary characters. This did affect my performance in school to the point that I required an aid to get through the days. So I followed the same instruction from my doctor, and soon they all disappeared one by one."

"Now school is becoming easier each passing day, and I have an average in the upper 90’s instead of the 70’s or 80’s. I’m now a part of school actives and community service projects. I’ve been accepted to both A University, and M College, and I’ve become more social than ever before. Overall, the recovery not only helped fix my problem, but it helped improve my life as a whole. I’ve never been happier in life than now and the recovery from my OCD."

- Ethan

**Case Example #2 – Page 1**

**Daniel’s Contract With The Devil**

- Daniel - 18 years old, a freshman in a community college. Extremely bright, excelled at academics, very computer adept, and taught himself to speak fluent Japanese. No history of behavior or emotional problems. Also worked in a family business after school and on weekends. Diagnosed at an early age with High-functioning Autism. Raised in the Catholic faith.
- Presenting Problem - About 3 months prior, began to have intrusive thoughts that he wanted to sell his soul to the devil and would burn in hell for eternity. He also had thoughts of being possessed. This resulted in compulsive praying, magical rituals, asking for reassurance, going to church excessively, very high anxiety, seriously depressed mood, neglect of personal hygiene, withdrawal to his room, and an inability to attend college classes.
Case Example #2 – Page 2

- He stopped going to church due to his fear of it eliciting blasphemous thoughts. He had attended some talk therapy sessions and had some visits with his parish priest, but without result. He was only offered reassurance and debates about the illogic of his thoughts. His psychiatrist recommended hospitalization, but the family did not agree and did not follow through. Levels of functioning were seriously deteriorating. On a side note, he had no friends or social life prior to onset of his OCD.

Case Example #2 – Page 3

**Main treatment objectives** –
- Elimination of compulsive rituals and reassurance-seeking
- Decrease anxiety levels in response to obsessions
- Psychoeducation regarding OCD and how treatment could help him
- Developing a working relationship with his therapist
- Take responsibility for managing symptoms independently
- Make a return to attending his college classes
- Educate family about Daniel’s disorder and its manifestations, and about how to assist him
- Developing the beginnings of a social life, developing new interests, and taking part in school activities with other students

Case Example #2 – Pg. 4

**Techniques Utilized** –
- Psychoeducation for patient and family to explain tx rationale and features
- Main approach was self-directed E&RP together with some in-vivo work
- Enlisted parents as aides to help particularly with reassurance-seeking
- Referral for medication to an OCD-specialized psychiatrist
- Enlisted help of college counseling service in reintroducing patient to classes
- Later in tx, attended a social skills group run by a High-functioning Autism organization and also joined two campus clubs.

Case Example #2 – Pg. 5

**Techniques Utilized** –
- Educating parish priest about ASDs and OCD, as well as this specific subtype, and also getting his approval for the type of homework assignments we would be asking the patient to carry out
- Obtaining approval and help from the college in assisting patient in making a gradual return to classes at a pace he could manage, while obtaining notes and taking tests at home
- Getting patient to try out and then join some campus clubs
- Encouraging the patient to join the social skills group and explaining how it could benefit him

Case Example #2 – Pg. 6

**Specific Behavioral Assignments**
- Gradually learning to agree with intrusive thoughts and allowing them to ‘be there’
- Writing 25x daily, first, different names for the devil, and later, feared sentences about liking the devil, selling his soul, and possession
- Listening to 2-minute long graduated voice recordings containing feared material – first produced by therapist, then by the patient
- Looking at 6 pictures of the devil daily – later on, pictures of hell
- Resisting asking anyone for reassurance

Case Example #2 – Pg. 7

**Specific Behavioral Assignments**
- Working on daily/weekly targets for staying out of his room
- Reading articles about the devil, devil worship, possession, and hell daily
- Watching daily videos about the devil, hell, etc.
- Writing the number ‘666’ on his hand
- Hanging pictures of the devil and hell in his room
- Using a picture of the devil as phone wallpaper
- Hanging up a pre-printed ‘devil contract’ in his room and eventually signing it in a therapy session as his ‘graduation exercise’
Case Example #2 – Pg. 8

Specific Behavioral Assignments

• Setting up and following a schedule for gradually increasing class attendance while keeping up with the work from home
• Gradually increasing level of personal hygiene
• Review homework assignment list daily, and fill in daily homework checklist

Case Example #2 – Pg. 9

Case-specific Challenges:

• Convincing patient of the benefits of feeling anxious in the short-run to achieve relief in the long-run
• Educating and enlisting the help of the parish priest in approving assignments that had the appearance of blasphemous acts
• Convincing the patient that his therapy assignments would not be considered blasphemy
• Getting parents to not accommodate pleas for reassurance
• Assisting patient in organizing himself via checklists and a homework schedule he posted and also kept in phone

Case Example #2 – Pg. 10

Case Outcome –

• Patient's obsessions no longer elicited anxiety
• Compulsive prayers, magic rituals, and reassurance-seeking all ceased
• Personal hygiene levels returned to normal
• Patient no longer behaved reclusively
• College attendance normalized, grades improved markedly
• Patient began attending a social skills group for High-functioning Autism
• He joined two campus clubs and did participate in them

The End