

# Modified Cognitive Behavior Therapy for Severe, Treatment Resistant Obsessive-Compulsive Disorder in an Adolescent With Autism Spectrum Disorder: The Importance of Parental Involvement

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The prevalence of obsessive-compulsive disorder (OCD) is higher among young people with autism spectrum disorders (ASD). Case studies and randomized controlled trials show that modified cognitive behavioral therapy (CBT) can be effective for young people with OCD and co-morbid ASD. This case study describes modified CBT for an adolescent with severe, treatment-resistant OCD and co-morbid ASD, and highlights the importance of family accommodation and parental mental health in pediatric OCD. Modifications to the standard evidence-based CBT for OCD protocol included extended psychoeducation, visual session material, mini exposure, and response presentation hierarchies and parallel parent sessions to address familial accommodation and parental mental health. Progress was measured at seven time points throughout treatment using clinician administered, youth self-report, and parent self-report measures. Outcome data indicated significant improvements in OCD symptoms, general functioning, and maternal mental health as well as significant reductions in family accommodation. Gains were maintained over a 12-month follow-up period. This case study illustrates that modified CBT can be effective in youth with OCD and ASD and discusses the importance of familial accommodation and parental mental health.

**Keywords:** obsessive-compulsive disorder; autism spectrum disorder; cognitive behavior therapy; family accommodation; parental mental health

Obsessive-compulsive disorder (OCD) is a common condition affecting approximately 1%–3% of children and adolescents and is marked by substantial distress and functional impairment including poor educational, social, and/or family functioning (Heyman et al., 2001; Valleni-Basile et al., 1996). The prevalence of OCD is remarkably higher among young

people with autism spectrum disorders (ASD); a meta-analysis of data from 31 studies estimated the prevalence of OCD among youth with ASD to be over 17% (Van Steensel et al., 2011).

Cognitive behavioral therapy (CBT) is the evidence-based psychological treatment for OCD (Geller & March, 2012; National Institute for Health and Clinical Excellence [NICE], 2005). Evidence suggests young people with OCD with comorbid ASD have poorer treatment outcomes compared to those with OCD without ASD (Griffiths et al., 2017; Jassi et al., in prep; Murray et al., 2015). Therefore, efforts have been made to enhance outcomes by modifying CBT for OCD in the context of ASD.

To date, there have been a number of case studies (Elliott & Fitzsimons, 2014; Farrell et al., 2016; Jassi & Krebs, 2020; Krebs et al., 2016; Lehmkuhl et al., 2008; Nadeau et al., 2013; Neil et al., 2014; Reaven & Hepburn, 2003; Vause et al., 2014), two case series (Jassi et al., submitted; Murray et al., 2015), and randomized controlled trials (Russell et al., 2013; Storch et al., 2013; Storch et al., 2015; Vause et al., 2015; Wolters et al., 2016; Wood et al., 2009; Wood et al., 2015) that indicate modified CBT for OCD can be an effective treatment for people with ASD leading to significant decrease in symptoms by end of treatment and maintenance of gains in follow-up. In a review examining CBT for OCD in ASD, several modifications to CBT have been highlighted (Kose et al., 2018). These include greater use of visual aids, providing support with emotion recognition, incorporating special interests, use of idiosyncratic rating scales, and link with schools to increase school-based support and generalization of concepts and increased parental involvement (co-therapists and/or separate parent sessions) (Kose et al., 2018).

Parental involvement can be helpful to address family accommodation of OCD but also to train parents as co-therapists, so they can support their child between sessions and after CBT has ended. For young people with ASD, this can be beneficial to support generalization of their learning outside of sessions. Family accommodation has been found to be a predictor of CBT for OCD outcomes (e.g., Garcia et al., 2010; Merlo et al., 2009). Recent studies have found family accommodation is higher for those with OCD and ASD compared to those with OCD without ASD (Griffiths et al., 2017; Jassi et al., in prep). Therefore, this highlights the need to consider and address this in treatment. In addition, studies have highlighted that parenting a child with OCD can have a negative impact on parental mental health (Derisley et al., 2005), and studies have found the same for parents of children with ASD (Weiss et al., 2012). Therefore, having a child with both is likely to have a significant impact on the mental wellbeing of parents. This is important to consider when working with parents; it may be possible they may need their own support in addition to their child receiving treatment or it may be their mental health will improve as their child recovers from OCD. Previous case studies of CBT for OCD in young people with ASD have not considered the issue of parental mental health.

This case study highlights several of modifications to CBT for OCD for an adolescent with severe treatment OCD and ASD, including how to involve parents in sessions and conduct parallel sessions to support them to become co-therapists and address family accommodation, whilst considering the impact on their mental health.

## CASE DESCRIPTION

### Assessment

Ben (a pseudonym) and his parents attended a multidisciplinary assessment at a specialist OCD clinic for children and young people. Ben was 16 years and 11-month-old at the time of assessment and had a 4-year history of OCD. He also had established diagnoses of high functioning ASD and mild dyspraxia. He was assessed using the Children's Yale-Brown Obsessive-Compulsive Scale (CY-BOCS; Scahill et al., 1997). He scored 15 on both the obsessions and compulsions subscales, giving a total score of 30, which indicates severe symptoms. Ben's main obsessions were a fear of

mental contamination following an incident at school and fear that he would regress to an earlier stage of his life. In response to these obsessions, Ben engaged in lengthy washing and cleaning rituals, repeating actions, counting, tapping, and mental rituals. He also had high levels of avoidance; he was for instance unable to talk about school when not at school for fear that non-school "safe areas" would become contaminated and "unsafe."

Ben was significantly impaired by OCD symptoms and was unable to partake in daily activities or maintain social relationships. His parents explained that anxiety from OCD was leading to him to cry and shout for several hours. Due to high levels of anxiety, Ben was unable to disclose the content of his obsessions until treatment was underway and explained that OCD had been triggered by watching a film about supernatural entities and this led him to feel uncomfortable. Since watching this film, Ben associated an intense "feeling" with the idea of something horrific happening and was protecting himself and family members from becoming contaminated by this feeling. He had limited insight into the irrationality of the obsessions and was convinced that he needed to carry out compulsions to prevent something horrific from happening.

Ben's parents reported high levels of family accommodation (see Table 1). They did not use certain parts of the house or have contact with Ben's school as he feared this may contaminate them. They had to shower if Ben felt they had become contaminated and offered excessive reassurance by saying things were not contaminated and that they were "safe." Ben's mother reported high levels of depression, anxiety, and stress (see Table 1) and both parents reported they were struggling to cope due to the impact of OCD on the family.

Ben had previously received two courses of CBT with Exposure and Response Prevention (ERP). Whilst he experienced improvements in symptoms immediately following these interventions, he did not experience complete remission, and symptoms resurfaced after treatment had been completed or if there was a new trigger. Previous attempts of CBT had not incorporated ASD adaptations, in-vivo ERP in all areas where OCD was triggered, and work on family accommodation. Therefore, Ben was offered a course of CBT for OCD with a focus on these areas. It was also recommended that his selective serotonin reuptake inhibitor (SSRI) medication (fluoxetine) be increased to the maximum tolerated dosage of 60 mg prior to treatment.

## Case Formulation

There was a family history of anxiety and depression and Ben had been described as having an anxious temperament from an early age. Ben having ASD is also likely to have predisposed him to developing OCD. The OCD was precipitated by watching a film at school, which caused feelings of confusion and anxiety, and led to obsessions around possible imminent harm to his or his family in the form of regression and contamination. Ben engaged in lengthy compulsions to ensure this would not occur. Ben's poor understanding of his emotions meant that he felt the distressing emotions were an indicator of imminent harm and felt unable to tolerate this distress. The anxiety around these obsessions was exacerbated by his poor insight and cognitive rigidity about what would happen if he were to talk about the obsessions. His parents were unaware of the details of his obsession and given the high levels of distress that Ben was displaying, felt they could only help by accommodating Ben's compulsions and avoidance behaviors. Ben's compulsions and family accommodation however were serving to reinforce the obsessions and anxiety.

## Treatment

The treatment was delivered following the CBT for OCD with ERP protocol, which has been validated in randomized controlled trials (Mataix-Cols et al., 2014; Turner et al., 2014). The protocol was adapted for young people with ASD (Jassi, 2020a). The first author, a Clinical Psychologist (GJ) and a Consultant Clinical Psychologist (CV) delivered a total of 20 CBT sessions over 24

weeks, with an additional six parent only parallel sessions. Twenty CBT sessions were offered as research shows that extending treatment from 14 to 20 sessions improves outcomes for young people with ASD and OCD (Jassi, Fernandez de la Cruz, Russell & Krebs, submitted). Sessions were 1 hour long, delivered weekly and involved a combination of sessions in the clinic and at home. Ben and both parents attended these sessions and where not possible for both parents to attend, the other parent joined over telephone. On occasion when parallel parent sessions were taking place, Ben had sessions on his own with a check-in altogether at the end.

**Session 1 Psychoeducation on OCD and ASD.** In the first session, Ben was given a CBT workbook (Jassi, 2020b). The workbook included session-by-session plans with the material visually presented to suit young people with ASD. An overview of the treatment was shared with the family to increase the predictability of treatment. Therapists explained the first six sessions would be focussed on psychoeducation, sessions seven to 18 would involve in-vivo ERP and sessions 19 to 20 would include work on relapse prevention. Each session had an agenda laid out, to support predictability and adherence to the session plan and so Ben and his family were able to see what would be covered in the session. The therapists explained to Ben and his parents that it was important to attend sessions weekly (20 sessions within a 25-week timeframe) and complete homework between sessions because these factors influence the effectiveness of the treatment.

The first session included a section called "All about you" where Ben and his family had an opportunity to discuss his interests and qualities. Talking about positive aspects of Ben's life, unrelated to the OCD helped relieve the family's anxiety about starting treatment and gave therapists a sense of Ben's interests and life outside OCD. Following this, psychoeducation on OCD was started with a section on the definition and examples of obsessions and compulsions. Ben was encouraged to talk about obsessions and compulsions relevant to him whilst acknowledging that OCD made it difficult for him to talk about some obsessions. The role of avoidance and reassurance seeking was also discussed explaining to the family that these work in a very similar way to compulsions.

It is helpful to externalize OCD; a tool derived from Narrative Therapy (Freeman et al., 1997). Giving the disorder a name and identity removes the blame from the child and allows a family to unite in fighting against the externalized condition. Moreover, it can help the child recognize OCD as something separate from their own identity. With Ben, OCD was externalized by using language such as "tell us about OCD" and "what you do for OCD" and encouraging Ben to name OCD. This was done in the first session to help relieve blame and to model use of this language to Ben and parents.

Causes of OCD were discussed, firstly by asking the family what they felt was the cause of OCD. This gave Ben's parents the opportunity to express that they felt that their anxiety and responses may have led to Ben developing OCD. This assumption was corrected by sharing that we know the onset of OCD is no-one's fault and current research indicates that there are a range of vulnerability factors. The therapists shared that in fact we do not know the cause of OCD, but we know CBT works in treating OCD and we would therefore be focussing on this. This discussion relieved blame and allowed the therapists to come alongside parents and Ben in fighting OCD.

Psychoeducation on ASD followed where the family were encouraged to speak about ASD traits that may be relevant to Ben, using examples in the workbook that is, sensory sensitivities, social difficulties, and experiencing sudden intense emotions. The differences and overlap between ASD and OCD were then discussed. For instance, that OCD often causes distress and compulsions have a purpose of reducing anxiety, whereas in ASD, some repetitive behaviors can be enjoyable and may not have a set purpose. This section supported the family in identifying what was OCD and therapists were able to use this information to help the family differentiate between OCD and ASD in later sessions to ensure the focus of targets in treatment were OCD specific. For homework, Ben was asked to complete the unfinished session worksheets, watch a video on OCD and write three things he learnt in the session to consolidate his learning.

**Sessions 2–4 Psychoeducation on Anxiety.** These sessions were dedicated to helping Ben identify symptoms of anxiety and understand the function of anxiety. Ben was encouraged to think about situations that triggered anxiety outside of OCD, to help him understand anxiety can be experienced in a range of situations and there was nothing different about the anxiety he experienced in the context of OCD.

In Session 2, using a visual diagram of the body with different anxiety symptoms, Ben identified physical changes he noticed in his body when anxious, with the support of his parents. He explained that when anxious he would freeze in the moment. Parents were also encouraged to share their physical symptoms of anxiety and the therapists similarly gave some examples to normalize the experience of anxiety. Some time was also spent thinking about physical symptoms when Ben was happy or sad to help him differentiate between physical symptoms of these differing emotions, which is something he struggled with in light of his ASD diagnosis.

The function of anxiety that is, the fight and flight response was discussed and the family's assumptions about anxiety were corrected by explaining that anxiety serves to protect us from danger using the fight and flight response and is therefore a helpful emotion. It was explained that in OCD the fight or flight response was oversensitive and “going off when there was no real threat.” Therefore, the aim of the treatment was to re-train this fight and flight response, so it does not interfere with Ben's daily functioning. For homework, Ben was asked to continue noticing physical symptoms of anxiety to generalize his learning outside of the session.

In Session 3, the focus was on developing an anxiety rating scale. The rationale for this was shared by explaining that anxiety does not turn “on or off, and that we actually experience different levels of anxiety”; it was therefore important for Ben to learn to rate his anxiety levels so that he could communicate his distress. Several visual representations of anxiety rating scales were shared with Ben and he decided to use a clock anxiety rating scale ranging from 0 to 12 because of his special interest in clocks. Ben listed situations that corresponded to different levels of anxiety on this scale, with 0 being a situation where Ben has felt most relaxed and 12 being a hypothetical life-threatening situation, reflecting the most anxious Ben could ever feel. Ben found it relatively easy thinking of situations that corresponded to numbers between 0 and 11, but found it challenging to think about a 12, as this was a hypothetical situation. Ben also tried to use an OCD example in this rating scale and was encouraged to think about a non-OCD example with therapists explaining that this anxiety rating scale would eventually be used as a ruler to measure OCD against. After discussion over two sessions and using Ben's interest in films as a reference point, Ben identified that his hypothetical most feared situation (12 out of 12) would be being lost in outer space with limited oxygen.

In Session 4, the principle of anxiety habituation was discussed with the family, using non-OCD examples. Examples of performing in a play and anxiety reducing with repeated exposure to performing the same play on several occasions was shared by the therapist (CV). Parents were also asked to share examples of anxiety reducing over time and Ben thought about additional examples where he had habituated to anxiety for homework.

**Sessions 5–6 OCD Cycle, Anxiety Habituation, Developing a Hierarchy, and First ERP Task.** The focus of Sessions 5 and 6 were to help Ben and his parents learn about the cycle of OCD and apply their learning of anxiety from previous sessions. An example of an OCD cycle was shared with Ben and his parents in the workbook. It was explained that obsessions can be triggered by environmental situations or cognitive experiences (e.g., a thought). The obsession leads to an increase in anxiety and compulsion(s) are performed to reduce this anxiety. However, doing compulsions only leads to temporary relief in anxiety, which then perpetuates the cycle because whenever there is a trigger leading to obsession, the individual performs the compulsion to reduce the anxiety. Therapists asked Ben and his parents how this cycle could be broken, and they acknowledged it was only possible to break the cycle by not doing the compulsion because this was the only aspect over which Ben had control. Given Ben's cognitive rigidity and poor

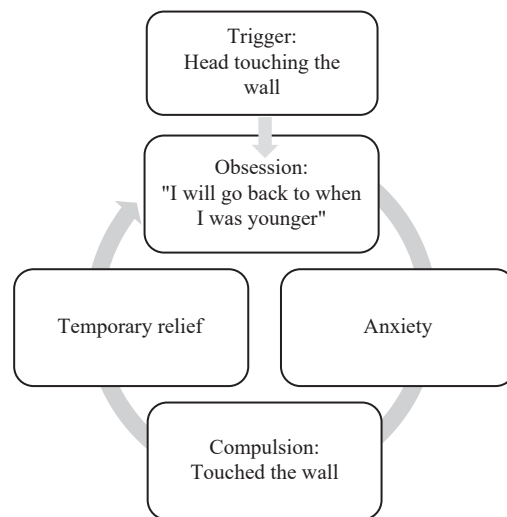
insight, the therapists also explained that we cannot stop experiencing intrusive thoughts images or impulses, because intrusions are a common human experience and similarly anxiety cannot be suppressed or avoided, despite our best efforts.

Avoidance behaviors had increased over the past year for Ben and the therapists spent some time explaining the role of avoidance in the OCD cycle. Avoidance was conceptualized as functioning to reduce contact with triggers but inadvertently reinforcing obsessions and increasing anxiety. Therapists explained to Ben that although “avoidance works in the short term, in the long term, anxiety grows and avoidance gives OCD more control.” Parents were asked to give concrete examples from Ben’s life to help his understanding of this.

Once Ben had a good understanding, he was asked to complete the cycle using his own examples (see Figure 1) and it was discussed how anxiety habituation could be applied to challenging OCD. Ben looked through graphs depicting habituation and was asked what he thought would happen if he resisted a compulsion; these questions aimed to increase cognitive flexibility. Ben reluctantly noted that anxiety might come down over time and with repeated exposure.

Ben was supported in starting his ERP hierarchy by listing all the behaviors he was doing for OCD. This included compulsions Ben did for OCD, things Ben avoided because of OCD and, things that family members did for OCD. Ben was asked “how anxious would you feel if you or others did not do the [compulsion].” Ben rated his anxiety using his clock anxiety rating scale.

Avoidance was discussed as a compulsion that could be targeted for an initial ERP task as this was possible to work on within the session and was lower on his hierarchy. Ben reported he avoided the clinic room used during Session 1 as this was where his obsessions were discussed (so now “unsafe”). A structured ERP worksheet was completed, which outlined the steps to planning an ERP task. Step 1 involved identifying what OCD wanted Ben to do, which was avoidance of entering room and touching items in the room because OCD felt this might contaminate “safe areas.” He also identified that OCD wanted him to wash excessively if he touched something in the room. Step 2 was deciding what the task would be, in this case the task was entering the room, touching several items, and resisting washing himself after the session and not increasing his showering compulsion later that evening because he completed this task. Step 3 involved Ben rating how anxious he would feel if he did not do the compulsions discussed and he predicted he would feel 8 out of 12 anxious. Step 4 involved discussing any tools that may help him complete



**FIGURE 1.** An example of Ben’s OCD cycle. *Note.* OCD = obsessive-compulsive disorder.

the task and Ben identified helpful thoughts “by the end of next week, I’ll wonder why I was even worried about this.” Step 5 involved doing the task, therapist (GJ) modeled touching of items in the room to Ben and prompted him to touch objects using both hands. Ben was also prompted to rate his anxiety just after he completed the task, and then 5 minutes, 15 minutes, 30 minutes, and 1 hour from the time he completed the task. His anxiety rating was 8–9 out of 12 during the task but decreased to 6 out of 12 after 15 minutes. After discussion with Ben, it was clear that 4 out of 12 (anxiety halving after task) indicated that his anxiety had habituated. These ERP worksheets were used throughout treatment to ensure a consistent and predictable approach.

For homework, the family were asked to repeat this task daily over the coming week and therapists highlighted the importance of daily ERP tasks to ensure recovery. Ben felt he could go into an avoided room of the house and not do washing compulsions afterwards, which triggered similar levels of anxiety. The details of the task (e.g., time spent in avoided room) were agreed collaboratively with Ben by asking him what task he felt he could do daily over the week without doing additional compulsions. The parents’ role in supporting this task was agreed; they had to ensure that Ben would complete the task and help him rate his anxiety.

**Session 7–13 Therapist Led ERP in Clinic and at Home.** In-vivo ERP tasks were conducted within sessions and involved Ben continuing to touch items in the room that OCD said were contaminated and entering parts of the clinic or house that were previously avoided. Ben repeated tasks daily and anxiety ratings were reviewed at the start of each session and it was noted that anxiety was decreasing over time and with repeated exposure during each task. Ben was asked what he learnt from completing these tasks, to reinforce his learning that it was resisting compulsions that decreased his anxiety and loosen his cognitive rigidity around this. Once an ERP task was completed, the therapists explained to the family that they would be repeating this task daily. This meant that as sessions progressed, Ben was completing more ERP tasks daily and found earlier tasks no longer evoked high levels of anxiety.

Despite making good progress with initial ERP tasks, Ben struggled to speak openly about the obsessions. The therapists completed a mini ERP hierarchy with Ben focussed on speaking about obsessions. Ben identified that words loosely associated with the fear of contamination were at the bottom of his hierarchy (e.g., name of teacher who had chosen the film watched at school) and saying the name of the film he had watched at school was at the top of this ERP hierarchy. Ben was encouraged to work up this hierarchy, but it was evident these tasks caused significant anxiety because Ben cried and froze as a result. Ben was reminded in these moments that “OCD would try to fight back to telling him that something horrific might happen.” Therapists asked Ben to talk after tasks and label the physical symptoms of anxiety to support his understanding that anxiety is what is expected during tasks. As Ben progressed up this mini hierarchy, he was able to describe that the core fear was feeling “strange,” which he associated with something supernatural and the Devil, and felt this feeling would lead to harm to him and his family. Due to Ben’s limited understanding of emotions, this feeling was consistently labelled as anxiety and normalized using previous psychoeducation material on anxiety, highlighting consistently that “OCD plays tricks on people into thinking something bad would happen.”

**Sessions 14–16 Parent Led ERP in Clinic and at Home.** Session 14–16 were focussed on supporting Ben and parents in planning ERP tasks independently so that they could continue with ERP after treatment was completed. Ben and his parents were asked what specific areas of concern were left to tackle in treatment and the family created different mini-ERP hierarchies to address these areas, with therapists contributing minimally to support this. The family developed mini hierarchies for word contamination/moving around the house, touch contamination/showering, avoidance of local town, and avoidance related to school (called the “Big Four” by the family). Ben and his parents identified specific steps in the mini hierarchies to ensure everyone had a shared understanding of the steps needed to reach the top of each mini ERP hierarchy. The mini hierarchies were helpful given Ben’s ASD diagnosis, because he had a visual representation of main

areas of OCD that he needed to work on, predictability about what tasks would be completed in upcoming sessions and how tasks could be broken down in smaller steps if needed. The hierarchies were also used as a motivational tool by pointing out to Ben that he was habituating and tolerating distress as he progressed up each step.

In each session, parents completed an ERP worksheet and carried out in-vivo ERP tasks related to the one of the "Big Four" areas. Ben and parents were encouraged to focus on all these areas to ensure that compulsions were not increasing in one area whilst Ben worked on another area of OCD. Examples of tasks included parents shouting the name of the film in the house whilst Ben moved freely around the house and Ben gradually reducing shower time and shower gel usage. Therapists observed Ben and his parents plan and complete the tasks and offered their feedback to help parents feel more confident in planning and carrying out ERP tasks.

In Session 14, the therapists emphasized that given Ben's progress with the Big Four, he would need to start taking "bigger steps with ERP to get rid of OCD." This led to ambivalence in both Ben and his parents, who feared pushing Ben "too far" would mean OCD symptoms would worsen to an unmanageable extent. The therapists validated the family's concerns but encouraged them to think about the most challenging ERP task, which they identified as watching the film that triggered Ben's OCD. The therapists reminded the family that Ben had habituated to anxiety despite experiencing high levels of anxiety after previous tasks and although this task was higher up on Ben's hierarchy, we would expect for anxiety to habituate in a similar manner. An analogy of thinking of OCD as a plant was also used; the therapists explained that watching the film would be "pulling OCD out at the roots and making sure that it does not grow again"; not reaching the top of Ben's hierarchy might mean OCD is not "completely pulled out" and OCD might re-surface as it has done in the past. This message was reinforced in all future sessions.

**Sessions 16 and 17 ERP Sessions at Home.** Two sessions were conducted at home (where OCD was most debilitating) facilitated by both therapists to ensure that Ben was generalizing his learning to the home environment and not doing any covert rituals during ERP at home. He completed two in-vivo tasks around home items being contaminated at the higher end of the ERP hierarchy and was not observed doing any covert rituals before or after tasks. The therapists discussed with the family that parents would need to continue to support engagement with ERP because Ben was unlikely to complete challenging tasks independently due to a long history of avoidance and freezing when he got anxious.

**Session 18 ERP to the Obsession.** Ben felt it would be too challenging to watch the film at that stage in treatment, and this task was therefore broken down into smaller steps. Ben planned a task involving looking at the DVD cover with encouragement and some persistence from the therapists and his parents. He experienced severe anxiety after this task and therapists and parents repeated the same statements as in previous sessions to ensure consistency that is, that the "feeling" is anxiety and to notice what happens to anxiety over time. Ben acknowledged that this task might lead to increase in compulsions and planned with parents about monitoring symptoms more closely over the coming week alongside his daily ERP homework.

**Parent Sessions.** Parents were offered six sessions in parallel to Ben's sessions. Parent sessions were carried out in parallel to Ben's sessions as the family travelled a distance to the clinic and because Ben initially benefited from ERP sessions on his own due to fears of parents being contaminated during ERP. The decision to have six parent sessions was based on the therapists' clinical judgment and this was reviewed with Ben's parents at the end of each parent session to collaboratively agree how many sessions were needed to address parental accommodation. These sessions gave parents some space to express how living with OCD impacted on them and to discuss the details of how they were accommodating OCD. Both parents spoke about their own struggles with anxiety and his mother also spoke about her struggles with depression and how difficult it was to see Ben in the "grips of OCD." Therapist (CV) acknowledged the negative impact OCD



was having on parental mental health and how this contributed to them feeling unsure about how to support Ben and inconsistencies in how they responded to OCD.

Accommodation of OCD was explained as involving any change in their behavior and routine because of OCD and described as working in a similar way to compulsions, in that it reinforced anxiety and the obsessions. Parents were encouraged to notice and list ways in which they were accommodating OCD, for example, avoiding saying certain words and reassurance. Parents identified statements they could use instead of reassurance, for example, "you can do this" to encourage and support Ben when he was feeling anxious. Parents gradually reduced accommodation by initially selecting one item of their list which they thought would be anxiety provoking but manageable for Ben (e.g., not offering lengthy reassurance seeking statements after a specific ERP task) and progressing to more challenging items on their list (e.g., ignoring Ben when he asked for reassurance or refusing to shower). Parents were encouraged to be consistent in how they reduced accommodation so that this was predictable for Ben. Any decision in reducing accommodation was shared and agreed with Ben by having the final 10 minutes of the session altogether.

**School Intervention.** School staff were accommodating Ben's OCD by for instance not having Ben's lessons in classrooms that triggered OCD. The therapist (GJ) worked closely with the school to ensure there was a shared understanding of how to approach OCD and so that school staff reduced accommodation as Ben progressed through treatment. This was to ensure there was consistency across environments in responding to OCD and also to support Ben in generalizing his learning from sessions to other environments. Towards the end of treatment, Ben also informed his teachers about his progress and parents resumed contact with school to ensure that school was not accommodating OCD, as the family identified this as an area where OCD could easily re-surface. The re-opening of line of communication between parents and school marked the family taking ownership over Ben's continued recovery.

**Sessions 19 and 20 Relapse Prevention.** Given Ben's history of deterioration in symptoms following treatment, Sessions 19 and 20 were focussed on ensuring Ben maintained his progress post-treatment. Ben was encouraged to reflect on what he had learnt in treatment by writing down his golden rules for fighting OCD. He identified his golden rules as doing ERP tasks step by step, recognizing that "the feeling is actually anxiety and will go down over time" and telling parents if OCD symptoms grow. These rules were used to illustrate that his learning from ERP tasks could be generalized and applied to any compulsions, old or new. The therapists helped the family think about common symptoms that may re-appear and what steps they would take in these circumstances. Any potential upcoming stressors were also discussed to help the family know when to be vigilant for possible increases in symptoms. The family were labelled as experts in fighting OCD as they had been leading on ERP tasks since Session 14. The therapists reminded them of their successes during treatment and handed over the continued "fight against OCD."

Ben's achievements during treatment were celebrated by presenting him with a certificate of achievement. The therapists praised Ben and his parents for their hard work and emphasized that Ben needed to continue doing ERP tasks and taking steps to reach the top of his ERP hierarchy during the follow-up period.

**Follow Up Sessions.** Ben was offered four follow-up sessions at 1, 3, 6, and 12 months. Follow up sessions were focussed on reaching the top of the ERP hierarchy and continuing to work on residual avoidance. Ben and his parents reported during the follow-ups that avoidance increased somewhat. Ben for instance had been avoiding a café he associated with "the feeling." In follow-ups, it was clear that Ben's mother was more confident in challenging OCD and had been noticing areas where OCD symptoms were increasing. She explained she had encouraged Ben to go the café he was avoiding, and he managed to do this. Ben however continued to find it difficult reporting all compulsions openly and therapists therefore reviewed all hierarchies to identify areas where Ben needed to continue completing ERP tasks with his parents' support.

With encouragement from parents and therapists, by his 12-month follow-up, Ben had watched the film and was not avoiding any aspects of his school and his local town. He was planning for his future and applying to universities and both Ben and his parents appeared happy and hopeful about his future.

## Measures

Several questionnaires were administered at assessment, during treatment, and throughout follow-up.

**Clinical Administered Measures.** The *Children's Yale-Brown Obsessive-Compulsive Scale (CY-BOCS)* is the gold standard clinician rated semi-structured interview for the assessment of OCD symptoms (Scahill et al., 1997). This measure consists of a symptom checklist and 10 items assessing the severity of obsessions and compulsions by measuring time spent, interference, distress, resistance, and control. Scores on the CY-BOCS range from 0 to 40, with higher scores indicating higher impairment. The CY-BOCS has high inter-rater reliability, construct validity, convergent validity, and treatment sensitivity (Scahill et al., 1997; Storch et al., 2004; Wu et al., 2014).

The *Children's Global Assessment Scale (CGAS)* is a clinician administered rating of a young person's psychological and social functioning (Schaffer et al., 1983). CGAS scores range from 1 to 100, with higher scores indicating better functioning. The CGAS has good reliability between rates and across time, good concurrent validity, and adequate discriminative validity (Bird et al., 1987; Schaffer et al., 1983; Steinhausen & Metzke, 2001).

**Parent and Youth Self-Report Measures.** The *Children's Obsessive-Compulsive Inventory (ChOCI-R)* is a self-report measure assessing severity of OCD symptoms and has a parent and child version (Uher et al., 2008). ChOCI-R scores range from 0 to 48, with differing cut-offs for the parent (ChOCI-P; mild 16–27; moderate 28–40; severe 41–48) and child version (ChOCI-C; mild 12–23; moderate 24–37; severe 38–48). The ChOCI-R has good internal consistency, divergent validity, and convergent validity (Uher et al., 2008).

The *Child OCD Impact Scale (COIS-R)* (Piacentini et al., 2007) is a self-report measure, which assesses for the functional impairment associated with OCD and has a parent and child version. It consists of 33 items assessing impact of OCD in different areas of life and scores range from 0 to 99. The COIS-R has good test-retest reliability, internal consistency, and concurrent validity (Piacentini et al., 2007).

**Parent Self-Report Measures.** The *Family Accommodation Scale-Parent Report (FAS-PR)* (Calvocoressi et al., 1995) is a 13-item self-report measure that assesses parental accommodation of OCD symptoms and level of distress or impairment to family functioning. Total scores on the FAS-PR range from 0 to 52, with scores of 13 and above indicating clinically meaningful family accommodation (Merlo et al., 2009). The FAS-PR also gives scores separately for mother and father ratings. The FAS-PR has excellent internal consistency, good convergent validity, and adequate discriminant validity (Flessner et al., 2010).

The *Depression Anxiety Stress Scales (DASS-21)* (Henry & Crawford, 2005) is a 21-item self-report measure assessing for symptoms of depression, anxiety, and stress. It provides scores separately for depression, anxiety, and stress and was administered to both parents. The DASS has very good reliability (Antony et al., 1998; Clara et al., 2001) and good construct validity (Henry & Crawford, 2005).

## Outcome

Ben and his parents' scores on all outcome measures are presented in Table 1. Ben's CY-BOCS scores decreased from 30 at pre-treatment to 8 at post-treatment (Session 20) and gains were

maintained over a 12-month follow-up, with Ben scoring 10 at the 12-month follow-up. This indicated he was in remission at the end of treatment (CY-BOCS < 12) and maintained this status for the 12 months following CBT. This was echoed in self-report measures of OCD severity (ChOCI-C and ChOCI-P). His CGAS scores, giving a measure of global functioning, increased from 46 at pre-treatment to 80 at 12-month follow-up, indicating a change from "moderate/severe degree of interference" to no more than "slight impairments in functioning." In terms of functional impact of OCD specifically (COIS-R C and COIS-R P) also decreased during treatment, reaching subclinical range at post-treatment, with these gains being maintained through to the 12-month follow-up.

Ben's parents had markedly reduced their accommodation of OCD during treatment. This was reflected in their FAS-PR scores, which showed a significant decrease in family accommodation, a score of 0 at post-treatment and throughout the 12-month follow-up period. There was also an improvement in parental well-being with both parents reporting that they felt more confident in supporting Ben "fight OCD" using the CBT strategies and that family life had significantly improved. DASS scores showed that Ben's mother's mental health improved during treatment, with scores changing from extremely severe levels of depression, anxiety, and stress at pre-treatment to normal levels at 6-month follow-up. Given Ben's consistent engagement with ERP and parental involvement in monitoring and supporting Ben over the 12-month period, his prognosis was considered to be good.

## DISCUSSION

This case study describes CBT treatment for severe OCD modified to account for a comorbid diagnosis of ASD, high levels of family accommodation and significant levels of parental depression, anxiety, and stress. The treatment involved parallel parent sessions alongside CBT sessions where parental mental health was discussed, parents were trained as co-therapists and family accommodation was targeted. The outcomes show significant improvements in Ben's OCD symptoms and general functioning across clinician, youth, and parent-rated measures. There was also a significant improvement in parental accommodation and maternal mental health. Gains made during treatment were maintained 12-months post-treatment and support previous research demonstrating that gains made by youth with OCD and co-morbid ASD during CBT treatment can be maintained in the longer-term (e.g., Farrell et al., 2016; Krebs et al., 2016; Nadeau et al., 2013; Neil et al., 2017; Russell et al., 2013; Vause et al., 2015; Wolters et al., 2016).

Ben had received two previous courses of CBT treatment and struggled to maintain gains and it is therefore important to consider what was different about the current treatment. The success of the current treatment may be due to ASD specific modifications, in-vivo ERP in all areas where OCD was triggered and specific work on family accommodation. Treatment included several ASD specific modifications to support a structured approach, predictability, and generalizing of skills. A workbook containing visual and written information for each session, a clear agenda for sessions and ERP worksheets allowed for a structured approach. The written and visual material was reviewed regularly to support learning and allow for consistency and predictability across sessions. Extended psychoeducation sessions were used to discuss co-morbid presentations (e.g., differences between OCD and ASD) so that therapists could maintain the family's focus on OCD in later treatment and to support the family's understanding of the differences between emotions for example, anxiety, happiness, and sadness. Ben's special interests were also incorporated into treatment by helping him develop an idiosyncratic rating scale. These ASD specific modifications helped Ben to easily access the session content, remember the information discussed and maintain focus on OCD.

TABLE 1.. SCORES ON MEASURES FROM ASSESSMENT TO FOLLOW-UP

	Pre-treatment		Mid and post-treatment				Treatment follow-up		
	Assessment	Session 7	Session 14	Session 20	3-month	6-month	12-month		
<b>Clinician rated</b>									
CY-BOCS total	30	24	23	8	10	11	10		
CGAS	46	42	50	69	75	74	80		
<b>Child</b>									
ChOCI-C total		29	28	14	13	10	8		
COIS-RC		53	69	38	37	12			
<b>Parent</b>									
ChOCI-P total	33	44	13	7	0	5	0		
COIS	61	78	14	0	0	0	0		
FAS-M	44	47	9	2	0	0	0		
FAS-F	30	42	13	0	0	0	0		
DASS-M									
Depression	34	-	-	6	0	0	-		
Anxiety	33	-	-	1	0	0	-		
Stress	40	-	-	4	3	0	-		
DASS-F									
Depression	9	-	-	2	1	3	-		
Anxiety	3	-	-	5	1	0	-		
Stress	14	-	-	13	7	8	-		

**Note.** CY-BOCS = Children's Yale-Brown Obsessive-Compulsive Scale; CGAS = Children's Global Assessment Scale; ChOCI-C = child-completed Children's Obsessive-Compulsive Inventory; COIS-RC = child-completed Child OCD Impact Scale; ChOCI-P = parent-completed Children's Obsessive-Compulsive Inventory; COIS = parent-completed Child OCD Impact Scale; FAS-M = mother-completed Family Accommodation Scale; FAS-F = father-completed Family Accommodation Scale; DASS-M = mother-completed Depression Anxiety Stress Scales; DASS-F = father-completed Depression Anxiety Stress Scales.

ERP was carried out in all parts of Ben's life where OCD was having an impact to support generalization of learning from tasks and to reinforce the message that Ben could tackle OCD in a similar graded manner in any area of his life. Due to high levels of anxiety, mini ERP hierarchies were used to support Ben and his family in identifying steps needed to achieve the goal and how they could break down challenging tasks into smaller, achievable steps. These hierarchies also helped ensure that Ben continued to work on all areas of OCD.

The treatment delivered involved emphasis on reaching the top of the ERP hierarchy and completing overlearning tasks to ensure recovery. Parents expressed a fear about a possible deterioration in symptoms by completing challenging ERP tasks and it is well acknowledged that clinicians express similar fears when considering or delivering exposure therapy (Becker et al., 2004; Olatunji et al., 2009). This fear may be more pronounced in clinicians when working with youth with ASD due to ASD related anxiety and difficulties. Whilst it is important to acknowledge the additional difficulties and challenges young people with ASD face, they can also be supported in recognizing the steps needed to achieve recovery from OCD. The therapists used clear and consistent messages that reaching the top of the hierarchy was needed to achieve remission, whilst allowing for this to happen over a longer period of time, that is, during the follow up period. They also used the psychoeducation material covered and examples of where Ben had habituated to anxiety as examples that he could reach the top of his hierarchy and would habituate to anxiety. This aspect of treatment was considered important to his recovery and highlights that youth with ASD can be supported in reaching the top of their ERP hierarchies. Where it is not possible to reach the top of the hierarchy, it can be helpful for youth to be aware what a task at the top of their hierarchy would involve so that they can continue to work towards this in their journey to recovering from OCD.

Parents were heavily involved in the present case, with therapists offering parallel parent sessions focussed on parental mental health and parental accommodation of OCD. These sessions allowed for discussions on the impact of OCD on parental mental health and their confidence in parenting. Sessions also focussed on identifying and reducing parental accommodation. The extended psychoeducation sessions allowed for discussions around causes of OCD where therapists emphasized parents were not to blame for OCD, externalizing OCD to support the family in working as team to fight OCD and a space where parents were able to express their emotional distress and where this distress was normalized and validated. Supporting parents in gaining confidence through working as co-therapists in leading in setting up ERP tasks from Session 14 onwards and reducing family accommodation was important to the intervention as parents had a clear framework about how to support Ben and could support him in maintaining gains into the follow-up period.

ASD is a heterogeneous condition (Georgiades et al., 2013) and although several modifications described here (e.g., visual worksheets) may be relevant to other young people with ASD, it is important to consider how modifications can be varied to suit a range of ASD presentations. For instance, the present case study involved parental involvement in session but also allowed Ben to have time alone with the therapist. This was beneficial given Ben's age and his reluctance to initially talk about obsessions in front of parents. However, where ASD traits specifically impact on engagement with session material, it may be beneficial to involve parents in all sessions to support learning and repetition of session material (see Krebs et al., 2016 for an example). Explicit and concrete improvements in daily functioning were used for to support Ben's motivation throughout treatment due to his age and high functioning ASD. Younger children and youth with higher levels of cognitive rigidity may instead benefit from tangible rewards to support engagement with ERP tasks.

This case study demonstrates that CBT for OCD can successfully be modified for youth with ASD and gains can be maintained in the longer term. This case also highlights parental accommodation and parental mental health as vital components requiring intervention when treating OCD

youth with co-morbid ASD. Future research can use larger sample sizes within case series or a randomized controlled trial to determine whether CBT and parental intervention improve outcomes for young people with OCD and co-morbid ASD as opposed to CBT alone. Further research on parental mental health is also warranted as OCD affects the whole family. This research could evaluate the relationship between parental mental health and familial accommodation and help determine targets for parental intervention.

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- AQ1:** AU: Neil et al. (2014) is not listed in the Reference list. Please provide complete reference details or remove from the text citation.
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