

A PRELIMINARY INVESTIGATION OF THE RELATIONSHIP BETWEEN THE
ACCOMMODATION BEHAVIORS OF FAMILY MEMBERS OF INDIVIDUALS WITH
OCD AND TREATMENT OUTCOME

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ABSTRACT

Obsessive-compulsive disorder (OCD) is an anxiety disorder in which distress and impairment extend beyond the patient to their immediate family members. Many family members become involved in their loved one's compulsions by engaging in accommodation behaviors, which ultimately make it easier to perform compulsions or avoid obsession-invoking triggers. Accommodation behaviors can indirectly result in negative consequences for the family member, such as reduced quality-of-life, and the OCD individual in the form of more severe OCD symptoms and decreased motivation to seek treatment. The current study utilized a single, case-study methodology to examine whether providing a brief, ten-session behavioral treatment to an immediate family member living with a non-treatment seeking OCD adult would result in reduced accommodation, improved quality of life, and an increased motivation for the OCD adult to seek help. Individual treatment was provided to the mother of an adult son, living at home and diagnosed with OCD, over a three month period at an outpatient anxiety clinic setting. The therapy focused on providing the mother with psychoeducation regarding the nature of OCD and the negative impact of accommodation behaviors, developing alternative coping behaviors in response to rituals, communication training, and the promotion of self-care behaviors. Results indicated that the treatment was effective in reducing accommodation and improving quality of life within the household, but that more treatment was likely necessary in order to consolidate therapeutic gains. The treatment did not appear to impact OCD treatment-seeking motivation for the OCD-diagnosed son. Factors contributing to the results of the treatment are discussed, and suggestions are presented for future research directions. Family members living with

OCD-diagnosed adults not currently seeking treatment can likely derive benefit from brief interventions designed to reduce accommodation behaviors, improve family communication, and promote self-care.

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Introduction

A. Problem Background

Obsessive compulsive disorder (OCD) is an anxiety disorder characterized by the presence of repetitive, unwanted and distressing thoughts and/or ritualistic behaviors and thought processes designed to reduce distress (American Psychiatric Association [APA], 2000). OCD is a fairly common disorder, with a current prevalence rate between 1-4% in both child and adult populations (Weissman et al., 1994; Zohar, 1999). An individual with OCD is likely to experience significant functional impairment and a reduced quality of life. Children and adults with OCD often experience disruption and strain on their family and peer relationships along with significant difficulty functioning in academic and work environments (Cooper, 1996; Koren, Thienemann, & Davenport, 1996; Piacentini, Bergman, Keller, & McCracken, 2003). Examples of such disruptions can include conflict between family members and friends, difficulty maintaining concentration on task assignments, and in more severe cases extreme difficulty functioning in environments that trigger anxiety and an associated urge to perform rituals. OCD also appears to be a chronic condition, with a typical onset in childhood (Rasmussen & Eisen, 1992) with symptoms continuing into adulthood unremittant, without therapeutic intervention (Livingston-Van Noppen et al., 1990).

The disturbances engendered by OCD symptoms appear to extend beyond the identified patient to their immediate family as well. There have been a variety of studies examining the impact of living in a household with an OCD family member (e.g. Albert et al., 2007; Geffken et al., 2010; Steketee, 1997). The results of these studies show family units attempting to cope with OCD are likely to experience relationship strains

characterized by negative feelings such as frustration, hostility and hopelessness, financial distress, and time sacrifices (Geffken et al., 2006; Magliano, Tosini, Guarneri, Marasco, & Catapano, 1996). In an extensive survey of family members of adults with OCD, Cooper (1996) found 75% of respondents indicated their quality of life had been disrupted as a result of OCD. Some of the most common examples of these disruptions were reporting the loss of valued personal relationships and previously enjoyed leisure activities. Given these impacts, it is not surprising that family members may themselves begin to experience their own psychological distress, particularly when feeling hopeless about the possibility of the family's situation ever improving (Geffken et al., 2006).

Family members frequently become influential in the expression of OCD symptomatology, indicating one possible reason OCD has such a powerful negative impact on the family unit. Researchers have developed the term "family accommodation" (Calvocoressi et al., 1995, 1999) to define the process whereby family members of a patient either subtly or overtly assist or participate in their family member's rituals (Cooper, 1996; Steketee & Van Noppen, 2003). Examples of active accommodation behaviors can include providing reassuring statements to a family member with OCD or directly participating in their rituals, such as cleaning supposedly contaminated objects upon request. Additionally, many family members may passively or inadvertently accommodate OCD by changing family customs or routines, taking over responsibilities, and in the case of children minimizing disciplinary actions in response to normal behavioral transgressions (Storch et al., 2010). All of these actions reinforce the performance of rituals by reducing the associated emotional and practical consequences for the patient choosing to ritualize.

Family accommodation of OCD appears to be exceedingly common among family members of both child and adult OCD patients, with studies routinely showing accommodation rates of more than 60% among first-degree relatives (Renshaw, Steketee, & Chambless, 2005; Shafran & Ralph, 1995; Storch et al., 2007). There are a variety of reasons why someone chooses to accommodate their loved one's rituals. Accommodation behaviors have been shown to be related to increased levels of family dysfunction and stress, emotional over-involvement with the identified patient (Van Noppen & Steketee, 2009) and a lack of educational information regarding the nature of the disorder itself. In some cases, family members may elect to accommodate rituals simply as a means of minimizing household disruption. Additionally, according to a study on accommodation by Calvocoressi and colleagues (1995), approximately 40% of OCD-family respondents reported a feeling of responsibility towards their family member's OCD. These numbers are consistent with those found in other surveys of OCD families (Shafran & Ralph, 1995), and suggest that feelings of guilt towards a family member's OCD may drive family members to devote their energies towards removing obsession-triggered anxiety.

These numbers are especially disturbing when the psychological ramifications of ritual accommodation are considered for both parties. According to behavioral theoretical models of OCD, engaging in ritualistic behavior in response to obsessions provides negative reinforcement through the reduction of anxiety and an increased sense of safety from the obsessional trigger (Franklin & Foa, 2008). Therefore, family members accommodating their loved one's rituals are in actuality harming them by strengthening their anxiety-response and increasing their reliance on their rituals. This negative effect is borne out in the literature, as family accommodation has been associated with more

severe OCD symptomatology (Steketee & Van Noppen, 2003; Storch et al., 2010) and poorer outcomes after behavioral OCD treatment (Amir, Freshman, and Foa, 2000; Chambless & Steketee, 1999; Storch et al., 2008;). Thus, families attempting to help their loved one cope with distress engendered by their OCD symptoms are inadvertently making it more difficult to fight back against the disorder.

The negative psychological consequences of accommodating OCD extend beyond the identified patient to impact non-OCD family members as well. Family accommodation is significantly associated with elevated levels of distress among family members and poorer overall family functioning (Albert et al., 2010; Steketee & Van Noppen, 2003). It has also been shown to be highly correlated with increased severity of OCD symptoms (Storch et al., 2010). Thus, it is likely that family members who accommodate find themselves devoting increasing amounts of time and energy to accommodating OCD as their loved one's symptom severity increases. One recent study administered quality-of-life health questionnaires to first-degree relatives of OCD patients and found caregivers of OCD patients and in particular accommodating caregivers were at an elevated risk to experience personal mental distress (Albert, Salvi, Saracco, Bogetto, & Maina, 2007).

Several current evidenced-based psychological treatments for OCD in both children and adults incorporate family members into treatment in response to these findings (For review, see Renshaw, Steketee, & Chambless, 2005). The majority of these treatments provide the family with psycho-education on the nature of OCD and the negative impact that rituals, and more specifically, accommodation of rituals have on symptom expression. Family members are frequently taught non-accommodating coping

strategies that can be utilized in multiple environments outside the therapy office. Some examples include responding to OCD-related questions in a non-reassuring manner, removing ritual-facilitating items from the home and providing encouragement and support to their loved one when they attempt to resist their rituals. OCD therapists may also need to spend several sessions working with the family unit to alter unhealthy communication styles, as family responses characterized by hostility and/or over-involved emotionality towards the OCD patient can negatively impact behavioral treatment outcome (Chambless & Steketee, 1999; Steketee, 1993). OCD therapists typically advocate an approach whereby family members adopt a communication style towards their loved ones of “non-hostile criticism”. This style is characterized by direct, concise verbalized criticism and dissatisfaction towards the OCD-family member for their decision to ritualize (e.g. “I know it’s not an easy thing to do, but I wish you would try harder to fight back against your OCD”) rather than an outright rejection of the whole person (e.g. “I can’t stand being around you when you’re like this!”). Several authors suggest that relying on non-hostile criticism implicitly communicates the belief that their loved one has the ability to cope with and overcome their OCD (Chambless & Steketee, 1999; Steketee & Van Noppen, 2003). Such communications may increase patient’s feelings of self-efficacy towards fighting their OCD and result in increased motivation to seek therapeutic help.

Many OCD therapists now routinely recommend family involvement in OCD treatments for both children and adults. Family-oriented treatments reduce OCD-related distress and quality-of-life in both patients and their family members and have the potential to improve relationship quality between family members (Renshaw, Steketee, &

Chambless, 2005). However, most of these family-oriented interventions have been studied and implemented with a population of treatment-seeking adult OCD individuals and their families, or with children where the adult caregiver typically makes the decision to enter the child into treatment. For adult individuals with OCD the level of motivation for treatment becomes more important, as therapists can typically only legally provide therapy to individuals over the age of eighteen who voluntarily elect to pursue treatment. Thus, some family members may desire that their loved one receive help for their OCD, with the family member being in a position to ultimately decline or accept a treatment option.

The implication of this potential conflict takes on added significance when considering the number of adults with OCD living in the same household with immediate family members (i.e. parents, spouses, siblings). There are estimates based on OCD family research that up to 25% of adults with OCD currently live with their parents (Steketee & Pruyt, 1998). Although some studies find OCD adults are less likely to be married than individuals in the general population, others have found marriage rates for OCD adults to be similar to those in the general population (Koran, 2000). Taken all together, these numbers indicate that adults with OCD tend to have a family constellation characterized by close proximity to immediate family members, a finding which is not surprising when considering the significant distress engendered by OCD and the tendency for family members to take on added responsibilities in coping with a relative's mental illness (Fadden, Kuipers, & Bebbington, 1987).

It is also well-known that despite the presence of effective psychological and pharmacological OCD treatments (Franklin & Foa, 2008), a significant percentage of

OCD adults do not receive any form of treatment. In a review of treatment utilization among Australian individuals with anxiety disorders, researchers found only 11% of individuals had received an appropriate evidenced-based treatment for their condition (Issakidis & Andrews, 2002). This number is consistent with other findings showing 40% of individuals with OCD do not receive needed care when taking into account treatment non-responders, drop outs, and those who outright refuse treatment (Jenike, 2004). In the Australian sample (Issakidis & Andrews, 2002), non-treatment seekers provided a variety of reasons why they chose to not seek out help from mental health professionals, with a majority (58%) asserting a desire to manage their condition on their own. Another potential reason OCD patients in particular may not seek help is that the current gold-standard psychological treatment for OCD, exposure and response prevention (EX/RP), requires patients to devote considerable time and effort and willingly experience high levels of emotional distress for extended periods of time (Maltby & Tolin, 2003). OCD patients may also have experienced limited success during past treatment episodes and now feel hopeless over the possibility of receiving any future potential benefit from therapy. Due to the large number of treatment-refusing OCD patients, researchers have recently begun efforts to incorporate motivational enhancement techniques prior to the onset of exposure techniques as a way to enhance treatment compliance and reduce dropout rates (Maltby & Tolin, 2005; Riccardi, Timpano, & Schmidt, 2010; Simpson & Zuckoff, 2011). However, the results of these efforts so far have been mixed.

In addition to an OCD patient's personal negative beliefs regarding treatment, the results of family accommodation research suggest that the behaviors and attitudes family members take towards OCD may influence treatment motivation. Accommodating

behaviors may decrease an individual's sense of self-efficacy to tackle their OCD symptoms (Steketee & Van Noppen, 2003). Additionally, accommodation reduces the personal cost to the patient of living with OCD by continually removing anxiety and adjusting the family's activities to correspond to OCD. Thus, accommodation behaviors make it easier for a person already low in motivation to continue living their lives in a manner adjusted to their OCD at a reduced cost.

Statement of Specific Hypotheses

Based on the current understanding of the negative impact of family accommodation and the high numbers of adult OCD patients who do not seek appropriate treatment for their condition, the following study proposes to investigate a brief, family-member oriented psychological intervention to be delivered individually to a primary family member living with an adult OCD sufferer currently unmotivated to seek treatment. The intervention will use evidenced-based techniques grounded in existing family-oriented OCD treatments to target specific accommodation behaviors, attitudes, and communication styles in the non-OCD family member that are deemed to be either ineffectual or detrimental. The current study aims to determine whether a non-identified-patient targeted intervention can provide a benefit to families negatively impacted by a family member's OCD and unwillingness to seek treatment.

It is hypothesized that a treatment designed to reduce family accommodation and improve family OCD-related communication will reduce symptoms of depression, anxiety, and general stress in the non-OCD family members and improve their general quality of life. Additionally, it is hypothesized that a family-oriented psychological

intervention will reduce the OCD family member's symptom severity and augment their level of motivation to seek future treatment outside of the study.

Methods

Participants

This study will recruit a single adult, non-treatment motivated, OCD individual and one primary adult relative who are currently residing in the same household. The OCD-family dyad will be recruited either through contact initiated through the general information line of the Rutgers University Anxiety Disorders Clinic or through participation in one of two local OCD support groups for family members of individuals with OCD associated with the Rutgers Anxiety Disorders Clinic. Recruitment will be initially conducted through the non-OCD primary family member who must be inquiring into treatment options, soliciting treatment services for their adult treatment-resistant OCD family member or seeking therapy for themselves to cope with family member's OCD. All treatment will be conducted at the Rutgers University Anxiety Disorders Clinic by the primary investigator who will receive clinical supervision throughout the study by a licensed clinical psychologist with expertise in treating OCD.

Based on definitions from previous research on OCD treatment involving family members (Chambless & Steketee, 1999), both family members must have lived together for at least three months prior to initial contact and intend to continue doing so over the duration of the study. Additionally, a hierarchy of importance will be utilized in the selection of primary family member for inclusion in the treatment, whereby (a) spouses/domestic partners will be chosen over other relatives; (b) if the OCD patient is single, a parent will be chosen over other relatives; (c) when two parents are present, the parent contacting the treatment clinic or attending the support group (see *Procedures section*) will be selected; (d) if no parents or spouses/partners are present, the individual contacting the treatment clinic or attending the support group will be selected.

Inclusion criteria for the adult patient with OCD will consist of being between 18 and 50 years of age, having a primary diagnosis of OCD of at least mild severity with symptoms present at least one year, not receiving current psychiatric or psychological treatment for their OCD and a low motivation to pursue such treatments at the onset of the study. Exclusion criteria for the OCD patient will include current or past diagnosis of psychosis, current suicidality, and a current diagnosis of alcohol or drug dependence.

Inclusion criteria for the primary family member will consist of being between 18 and 65 years of age, no current or past diagnosis of OCD and no current psychological treatment for distress related to their relationship with their OCD relative and a desire to see their loved one receive mental health services for their OCD. Exclusion criteria for the family member will be the same as exclusion criteria for the OCD patient along with not meeting current criteria for OCD.

Procedures

Study Design

The proposed study will utilize a single systematic case-study treatment design (Fishman, 2005) utilizing both qualitative and quantitative assessment methods. The systematic case study design was deemed appropriate for the current study for several reasons. Firstly, there has been little research conducted thus far in the area of OCD and families for the non-treatment seeking adult OCD population. As such, there is a lack of current evidence to suggest whether existing family-oriented OCD interventions will be effective for this unique sub-group. Therefore, regardless of the outcome of the proposed treatment intervention, the use of a single case study design can provide a plethora of

detail about this subset of the OCD population and their family members which can then be communicated to the field and inform future research efforts and refinement of treatment techniques (Dattilio, Edwards, & Fishman, 2010).

Secondly, the systematic case study design conforms nicely with previously established best practice norms for bridging research and clinical practice (Peterson, 1991). Specifically, systematic case studies utilize both qualitative and quantitative data, develop an individualized case conceptualization within an existing theoretical framework that informs the creation of a treatment plan, and emphasize continued assessment throughout treatment using empirical measures. Finally, there is an existing precedent for using a single case study treatment design with a somewhat similar population of OCD patients with low treatment motivation (Riccardi, Timpano, & Schmidt, 2010).

Assessment

Initially, the primary family member will be screened via telephone by the principle investigator to determine preliminary eligibility for themselves and their adult OCD relative. Upon passing this screen and agreeing to participate, the principle investigator will speak with the OCD relative over the phone and explain the nature and procedure of the study. Upon agreeing to participate, an independent diagnostic interview (ADIS-IV-CIS) will be scheduled in the family's home for both the primary family member determined to enter treatment and the OCD relative. The purpose of the interview will be to determine final diagnostic eligibility, obtain both participants' written informed consent, and collect baseline self-report measures. The primary family member

and OCD relative will be separately interviewed by the principle investigator to ensure confidentiality. Additionally, family members will be asked to fill out self-report forms privately and return them to the principle investigator in a sealed envelope, ensuring that neither family member has access to the other's responses.

Treatment

Treatment with the primary family member will be conducted individually with the principle investigator at the Rutgers University Anxiety Disorders Clinic free of cost. Treatment will occur in weekly, 50-minute sessions over the course of ten weeks. During the treatment phase, the primary investigator will have no direct contact with the OCD relative unless specifically requested by that individual. If such contact should occur, no information regarding the non-OCD family member's treatment will be discussed. The family member receiving treatment will continue to have contact with their OCD relative as normal and will frequently be encouraged to speak to them regarding OCD-related family issues as part of their treatment assignments.

The principle investigator, a master's level clinician, will serve as therapist and will additionally receive weekly hour-long supervision from a licensed clinician with expertise in the treatment of OCD. All treatment sessions will be audio taped. Specific treatment interventions will be drawn from existing manualized OCD-family interventions (e.g. March & Mulle, 1998) as well as existing cognitive behavioral treatment theory, case formulation and practice techniques (Persons, 2008) which include elements such as communication training, behavioral analysis, cognitive restructuring and exposure techniques. The use of specific CBT modules or intervention strategies will

be determined through a preliminary case conceptualization derived from the results of the pre-intervention interview and baseline measures. Additionally, a small battery of self-report forms will be administered every two weeks at the onset of treatment sessions.

Post treatment Assessment

At the completion of the treatment phase, both the primary family member and the OCD relative will again receive the same comprehensive in-home diagnostic interview and battery of self-report measures that were administered prior to the beginning of treatment. The data collection procedure will be identical to the pre-treatment assessment for both family members.

At the termination of the post-treatment assessment, the family will be notified that the OCD family member is eligible to receive free treatment at the Rutgers Anxiety Disorders Clinic at any point in the future through their participation in the study. If either the primary family member or the OCD family member requests additional treatment services at the completion of treatment, a referral will be provided by the principle investigator.

Confidentiality

Both family members will be provided with their own unique written informed consents approved by the institutional review board of Rutgers University (see appendix A). The principle investigator will individually review the consent form with each family member, highlight the potential risks and benefits of study participation, address confidentiality concerns and remind them that their decision to participate is voluntarily

and that they may terminate their study participation at any point without penalty. All written and audio subject data will be kept within a locked file cabinet at the Rutgers University Anxiety Clinic for the duration of the study and will be destroyed upon completion of the investigation.

Measures

Yale-Brown Obsessive-Compulsive Scale (Y-BOCS; Goodman, Price, Rasmussen, Mazure, Fleischmann et al., 1989, see Appendix C). The Y-BOCS is a 10-item measure of obsession and compulsion severity over the past month. OCD patients or their family members are asked to provide a symptom rating on a scale of 0 to 4, with a total score derived out of 40 comprised of two subscale scores for obsessions and compulsions. Higher scores equal greater OCD symptom severity. The Y-BOCS has shown good reliability and validity (Woody, Steketee, & Chambless, 1995) and is considered the gold-standard of OCD symptom assessment (see appendix B for copy of measure).

Depression Anxiety Stress Scale – 21 (DASS-21; Lovibond & Lovibond, 1995, see Appendix C). The DASS-21 is a self-report measure which asks participants to rate their experiences of depression, anxiety and stress over the past week using a 0-3 scale. The DASS-21 yields three 7-item subscales between 0-21 and a total score range between 0-63. For both subscales and total, higher scores reflect a greater degree of negative state emotion. The DASS-21 has shown adequate reliability and is a well-validated self-report measure of depression, anxiety and stress (Brown, Chorpita, Korotitsch, & Barlow, 1997, see appendix B for copy of measure).

University of Rhode Island Change Assessment (URICA; McConnaughy, Prochaska, & Velicer, 1983, see Appendix C). The URICA is a 32-item self-report measure assessing readiness to change, with four 8-item subscales representing the constructs of precontemplation, contemplation, action, and maintenance. The URICA has previously shown good reliability and construct validity and has a history of being adapted for use with anxiety disorder populations (Dozois, Westra, Collins, Fung, & Garry, 2004, see appendix B for copy of measure).

Anxiety Disorders Interview Schedule Adult Version, Client Interview Schedule (ADIS-IV; Brown, DiNardo, & Barlow, 1994, see Appendix C). The ADIS-IV is a semi-structured diagnostic interview designed for the assessment of current DSM-IV anxiety, mood, somatoform and substance use disorders in adults. It is designed to provide information sufficient for differential diagnosis among the anxiety disorders along with the creation of a functional analysis. Additionally, the ADIS-IV contains screening questions for psychotic symptoms along with information related to family psychiatric history. The ADIS-IV has previously shown good inter-rater diagnostic reliability (Brown, DiNardo, Lehman, & Campbell, 2001, see appendix B for copy of measure).

Family Accommodation Scale for Obsessive-Compulsive Disorder: Interviewer-Rated (FAS-IR; Calvocoressi, Mazure, Kasl, Skolnick, Fisk et al., 1999). The FAS is a 12-item clinician-administered instrument designed to assess an OCD relative's report of their loved ones symptoms along with a description of their OCD accommodating behaviors. The FAS consists of two sections, one asking relatives to identify current OCD symptoms

based on a Y-BOCS derived checklist, the other consisting of 12 items designed to provide a quantifiable measure of the frequency and severity of accommodation behaviors. The FAS has been shown to have excellent reliability and good validity (Calvocoressi et al., 1999) and has been commonly utilized in family accommodation studies of treatment seeking OCD individuals (see appendix B for copy of measure).

World Health Organization-Quality of Life-BREF (WHOQOL-BREF; Skevington, Lotfy, & O'Connell, 2004, see Appendix C) The WHOQOL-BREF is 26-item self-report assessment measure of quality of life and is comprised of four specific domains: physical, psychological, social, and environment. The WHOQOL-BREF is a truncated version of a larger quality of life inventory and has shown excellent reliability and good validity. Additionally, the measure has shown strong cross-cultural validity and is useful for ascertaining the various meanings different cultures hold in regard to their lives and potential problems they may experience in them (see appendix B for copy of measure).

Treatment of data/Plan of Analyses

The majority of the data will be analyzed according to a pre-treatment/post-treatment model, whereby changes in constructs of interest in both the family member patient and OCD relative (e.g. family accommodation, psychopathology, quality of life) will be determined through a direct comparison of before and after scores along with patient verbal report. Additionally, family member bi-weekly self-report scores will be analyzed descriptively in order to determine rate of change during the treatment phase.

Because this study will only use a single subject, descriptive statistics will be utilized during data analysis. Additionally, a reliable change index score (Jacobson & Truax, 1991) will be calculated for self-report of both subjects in order to determine the presence of clinically significant post-treatment change. It is understood that the study results will be limited by small sample size and lack of randomization and control condition. Therefore, any potential results confirming the initial hypotheses will require replication using a larger sample size and a more scientifically rigorous research design.

Case Description

Client

Brianne* is a 46-year old Caucasian woman living in the northeast. At the time of her entry into the study, she had been married to her husband Jack* for over twenty years and together they had two adult children, Shane*, 21 and Charlie*, 18. Both children still lived at home with Brianne and her husband and she split her time between managing the household and working part-time. Brianne was a high-school graduate and had earned post-high school diploma from a professional career development institute. She reported no history of medical or mental health issues and had never before personally received psychotherapy, taken psychiatric medications or been hospitalized.

Brianne was initially referred to the study through her attendance along with her son Charlie at the OCD Support Group held at the anxiety clinic. Brianne had been referred to the group after speaking over the phone with a current group member, who in her spare time provides outreach services for family members of individuals diagnosed with OCD. Brianne had indicated that she was seeking more information on OCD and treatment options for her son, who at that time did not wish to receive treatment on his own. The current group member recommended the support group due to its open nature for both individuals with OCD and their family members and its emphasis on providing support rather than treatment.

At the group, Brianne spoke openly about her frustrations dealing with her son Charlie's OCD behaviors in the house and her difficulties extricating herself from his rituals and his constant requests for physical comfort and verbal reassurance. Brianne indicated that her son Charlie was no longer interested in receiving treatment for his OCD and had begrudgingly agreed to attend the current support group only after she had made

several requests. Based on her description, the OCD group leader, a fellow graduate student familiar with the current study, briefly described the research project to Brianne and inquired whether she would be interested in receiving more information from the principle investigator. Brianne expressed interest and voluntarily agreed to provide the principle investigator with her contact information in order to speak further about the study over the phone.

Brianne was contacted the following day by the study's principle investigator. The investigator described in detail the nature and procedures of the current study along and provided a brief rationale why she would be receiving treatment rather than her son if they were to enter into the study. She was also informed of the study's procedures to protect confidentiality and made aware of the study's inclusion/exclusion criteria. She verbally indicated that she fully understood the information, including the desire to help family members decrease accommodation and learn new behavioral strategies in response to their loved ones OCD. Furthermore, she stated that she had recently been trying on her own to disengage from her son's rituals and would therefore be highly motivated to receive professional help in this endeavor.

At the request of the principle investigator, Brianne stated that she would go over the study information with her son and inform him that he could contact the investigator if he had any questions or hesitations about entering into the study. The following day, Brianne contacted the primary investigator to inform that both she and her son Charlie were willing to participate. An appointment was scheduled with the principle investigator the following week for the in-home, pre-treatment consent signing and assessment.

Assessment

Prior to the beginning of treatment, an initial assessment was conducted by the principle investigator with both Brianne and Charlie. The purpose of the pre-treatment assessment was threefold: 1) to determine study eligibility; 2) If eligible, to obtain baseline scores of mental health functioning and treatment motivation for Brianne and Charlie; 3) To develop an accurate, comprehensive understanding of the accommodative relationship between Brianne's behaviors and Charlie's OCD, with a particular focus on identifying potential environmental and family systems factors. Along with the approved quantitative measures, the investigator initially utilized an unstructured clinical interview with both Brianne and Charlie in order to ascertain more detailed information on the history of Charlie's OCD and its current impact on Brianne's overall functioning and mental health.

The questions for this interview were derived from the four-factor method of assessment and intervention (Petronko, Harris, & Kormann, 1994). This approach was initially designed for community-based interventions with dually-diagnosed individuals (i.e. individuals with some form of intellectual disabilities and one other disorder). This method is designed to provide the assessor with an accurate functional analysis of behavioral interactions at multiple levels, including individual, caregiver, environment and overall system. This information is then incorporated into the overall case conceptualization and utilized in the planning of treatment, which is often targeted towards primary caregivers when working with a dually-diagnosed population. Through the use of multi-level functional analyses, the four-factor model strives to increase the likelihood of behavioral change not only through accurate behavioral interventions but

also through increasing the likelihood that therapeutic interventions will continued to be implanted by the caregiver once treatment has ended.

The goals of the four-factor model of behavioral assessment were deemed to coincide with the stated aims of the current study, specifically to target a behavioral intervention to the loved one/caregiver of an individual with OCD. Furthermore, the highly individualized nature of four-factor assessment coincides with the pragmatic case study research model, particularly through the ability to generate detailed data on accommodation behaviors and mental health functioning across various contexts and systemic levels.

Clinical History

Prior to the development of his OCD, Charlie as a child had been diagnosed with an auditory processing disorder and mild mental retardation. Despite these diagnoses, Brianne reported that Charlie as a child had functioned normally both at home and at school with the help of an individualized education program (IEP). Although Brianne recalled Charlie displaying some mild avoidance behaviors as a child, she did not recall him displaying any pathological anxiety or distress.

Charlie's OCD behaviors began in 2007 immediately following his being informed that his brother had been involved in a traumatic accident involving a lawn mower while Charlie and his mother were not home. Brianne's oldest son, Shane, had been mowing the front lawn when he accidentally caught his foot in the mower and severed four toes. Brianne and Charlie had been out driving together when she received a phone call describing what had happened and informing her that her son was being taken to the

local emergency room. As they were driving to the hospital, Brianne reported that her cell phone battery died and they became stuck in traffic. She described the time it took to arrive at the hospital as being extremely frightening for both herself and Charlie, due to their inability to receive information about Shane. When they arrived at the hospital, Charlie happened to view his brother's injured foot which Brianne reported caused him to become extremely upset.

Soon after this traumatic incident, Charlie began to experience significant daily anxiety and started avoiding particular areas of the house he associated with his brother's accident, particularly a window in their living room looking out on the front lawn. He would frequently worry about his brother's health throughout the day and became phobic of hospitals. While Brianne viewed these avoidances as stemming from Charlie's reaction to the family trauma, she also began noticing that Charlie was engaging in other odd behaviors which she had never seen before. Charlie gradually became insistent that items in his room, often times clothes, needed to be left in specific areas. If Brianne or other family members attempted to remove or move items, Charlie would become extremely upset and demand they be placed back in their original position.

Also, Brianne observed Charlie engaging in repetitive behaviors such as repeatedly turning light switches on and off and walking up and down a staircase multiple times. As time went by, Charlie began expressing a strong preference for odd numbers and an avoidance of any even numbers. Later, he began incorporating this preference for odd numbers into his repeating rituals, for example turning a light switch on/off only an odd number of times. More recently, Charlie had started engaging in more complex repeating activities, such as feeling the need to return to a location he had recently moved

from in order to leave again. This particular compulsion had been happening with such frequency that the family developed the term “back-stepping” to describe the activity. When family members would ask Charlie why he felt the need to perform these actions, he was unable to verbally articulate any reasons or thoughts that were preceding his behaviors. Instead, he would simply insist to family members that they made him feel better, which they took to mean made him less anxious.

After the trauma, Charlie began experiencing significant anxiety when separated from his mother and became reliant on her for reassurance when he was feeling anxious. He would repeatedly ask his mother to tell him she loved him throughout the day and would become extremely upset if Brianne would leave him alone in the house. He began to request physical contact from Brianne, for example asking her to hug him multiple times a day, sometimes even when they were in the middle of a conversation. If Brianne refused his request, Charlie would try to engage in alternative means of contact, such as holding her hand or putting his foot on top of hers. Charlie would also call Brianne multiple times a day, even when she was at work, usually without any purpose other than just to check in. As Charlie’s dependence on Brianne expanded, he began to socialize less and less with peers in school. He frequently would come home immediately after school in order to wait for Brianne to return from work, participated in very few extra-curricular activities, and had very few close relationships outside of his immediate family. Charlie also refused many developmental milestones common for other students his age, such as learning to drive a car and getting a part-time job. Brianne and her husband believed Charlie was physically and mentally capable of performing these activities, but they

worried he would be unable to handle them emotionally due to his anxiety and compulsions.

Charlie's avoidance and repeating behaviors around the house grew to such severity that Brianne sought in-home behavioral therapy in 2009 when he was sixteen. Although Charlie initially resisted entering into therapy, he reluctantly agreed when his mother informed him the therapist would come to their home and he wouldn't have to venture outside the home for appointments. The therapist worked with Charlie on gradual exposure exercises of avoided areas of the house, such as the front window and certain areas of his room. Charlie reluctantly participated in his exposures and began to experience moderate reductions in his anxiety and avoidance. At that time, Charlie received diagnoses of post-traumatic stress disorder stemming from his brother's accident in addition to obsessive-compulsive disorder. The therapist explained the nature of OCD to Brianne and briefly highlighted ways in which the family was participating in Charlie's rituals and making it easier for him to avoid consequences of his behavioral choices. At the conclusion of the treatment, Charlie experienced significantly less anxiety related to his brother's trauma, although his phobia of hospitals remained. Although his repeating compulsions also decreased, he quickly became lax about practicing his exposure exercises once therapy terminated and his therapist was no longer present to motivate him. In the two years since that treatment's termination, Brianne reported Charlie's symptoms had returned to their pre-treatment baseline levels.

Current Quality of Life

Individual: At the time of the pre-treatment assessment, Brianne reported that Charlie spent most of his daytime hours working as a teacher's aide at a local elementary school. He relied on Brianne to take him to work every morning, and because he often had difficulty leaving the house without ritualizing, Brianne would often be late for her work appointments. After school, Charlie would typically return home and await Brianne's return from work. Immediately upon her arrival, he would proceed to shadow her movements around the house and make repeated attempts to have physical contact. This type of shadowing behavior would continue throughout the night, and if Brianne ever needed to leave the house he would insist on accompanying her. If Brianne tried to create some separation for herself from Charlie, for example closing the bedroom door in order to speak privately with her husband, Charlie would behave in ways designed to bring his mother's attention back onto him, such as repeatedly knocking on the bedroom door or walking loudly back and forth in the hallway and up the stairs. Although Charlie and his brother shared a videogame system located in his brother's room, Charlie had recently been banned from use by Brianne because the family suspected Charlie of taking important papers from his brother's desk and ripping them apart, in an apparent effort to self-soothe.

Because many of Charlie's rituals and routines were being accommodated by his mother and other family members (see *caregiver* section), he experienced very minimal real-life consequences for his behaviors. The teacher for whom Charlie worked had contacted Brianne in the past to complain about Charlie's morning tardiness, but rarely did Charlie directly experience any reprimands from his parents or the school. When

Charlie would complain that he was unable to pick-up an item from his room because it was located in an area which caused him anxiety, one of his parents would often help him by picking up the item and bringing it to him. Additionally, family members would frequently re-arrange normal family routines, such as the laundry schedule, because Charlie had not done his wash on his specified day or had accrued a large number of towels to be washed due to his repetitive rituals involving drying himself. Finally, Brianne and her husband reported that they would frequently assist Charlie in his “back-stepping” rituals, often by physically driving him to a previous location. Brianne insisted both she and her husband didn’t want to help him “back-step” but felt it would reduce his anxiety in the long-run and prevent him from having difficulty functioning over the next few days due to an acute anxiety spike.

One primary consequence of Charlie’s shadowing behavior was that Charlie had very little incentive to interact socially with peers. At the initial assessment, Charlie would occasionally mention his desire to obtain a part-time job after his school aid position ended in the summer and pursue getting a girlfriend. However, Brianne stated that Charlie had not taken any steps towards achieving these goals despite her frequent encouragement, and she worried that his difficulty being apart from her would prevent him from pursuing these developmental milestones. Brianne felt extremely frustrated with Charlie around the house, particularly during times when he refused to give her space to herself. Frequently, Brianne would raise her voice to Charlie or tell him how he was “driving her crazy”. At some point after these incidents, Charlie would return to his mother and ask her if she still loved him, to which his mother would always answer that she did.

Caregiver (mother): As the primary caregiver for Charlie and the rest of the family, Brianne had become the primary facilitator of Charlie's OCD rituals. Since the lawnmower accident in 2007, she devoted her time and energy to her son and became more and more anxious whenever she was not around him. Brianne explained that she found it difficult not to think of Charlie if she was away from him, in part because she worried what rituals he might be performing around the house. She was aware Charlie had become increasingly isolated from his peers, and she worried Charlie would eventually become totally socially dependent on his family and unable to work or function without his family's care and accommodation.

As a result of her accommodation and anxiety, Brianne's quality of life began to suffer. She rarely had time to herself around the house, and stated that it was impossible for her to feel relaxed at home due to Charlie's constant presence and need for attention. She reported that her work life had been affected by Charlie's OCD, as she was unable to find time in the evenings to create lesson plans and at one time had to pass on a promotion to work more hours because it would mean Charlie would be by himself at home. Also, Brianne would frequently be late for work in the mornings due to waiting for Charlie to finish his rituals before driving him to school.

Increasingly, she had been spending less and less time with her husband and older son as Charlie had taken over her time and attention. She and her husband rarely had time to themselves around the house, something Brianne mentioned she craved after a long day at work. They had not been out for a romantic evening together in the last year because they were concerned Charlie would become anxious and could not handle his parents being away from the house. Brianne had also sacrificed spending time with her

older son, Shane, and stated that she felt disconnected from him and worried that he resented the energy and attention she gave to Charlie and his OCD.

In response to Charlie's OCD and attention-seeking behaviors, Brianne frequently experienced significant feelings of frustration, anger and resentment. She felt as if she "never got any peace" or time to herself and would often get angry and threaten to remove his privileges as punishment when he was attempting to get her attention. Brianne confided that these feelings had become so powerful that at one time she had fantasized about "kidnapping" one of Charlie's stuffed animals and holding it hostage until he decreased a certain ritual. She never went through with this action and felt ashamed afterwards.

At the time of the initial assessment, Brianne reported that her quality of life was extremely poor due to her inability to disengage from Charlie's OCD and anxiety. She had recently begun seeking out educational information on OCD treatment and was frequently encouraging Charlie to re-enter therapy for his OCD. Although she hadn't previously considered entering into treatment herself, Brianne was able to recognize her own role in accommodating Charlie's OCD and she was extremely motivated to learn new ways of reacting to Charlie's rituals and improving her own quality of life.

Environments (home & school): The primary environments for the expression of Charlie's OCD behaviors and Brianne's subsequent accommodation were their single-family home and Charlie's school. The majority of Charlie's rituals occurred in his house, and there were several areas of the home Charlie avoided, including parts of his bedroom and the backyard. At school, Charlie rarely engaged in OCD rituals, however

school officials had become tolerant of his ritual-related morning tardiness and had never implemented a system of consequences.

Family System: In response to Charlie's OCD and separation anxiety, the family had adopted various roles that served to avoid confrontation with Charlie regarding his behaviors and implicitly reinforce the expression of his rituals. Both Charlie's father and brother would frequently disengage and avoid Charlie around the house, particularly at night when he was shadowing Brianne. Charlie's father often had to be up early for work and would frequently go to sleep very early in the evening, despite Brianne asking him to stay up later and help her set boundaries for Charlie. Brianne's oldest son, Shane, mirrored his father's withdrawal and spent a majority of his time outside of the house either in school or at work. Brianne suspected that Shane had grown upset by the amount of attention Charlie received from his mother and felt frustrated and angry with his brother, particularly when Charlie failed to maintain appropriate boundaries or follow rules inside the home, as with the videogame system. Shane's typical reaction to such events was not to speak with him directly but rather to go through his mother as an intermediary, resulting in Brianne feeling more stressed and caught in the middle of family conflict engendered by Charlie's OCD.

Treatment

Initial Conceptualization

From information gathered during the pre-treatment interview, it was concluded that Brianne's accommodation behaviors of Charlie's OCD had both been present for a long period of time and were causing significant distress for Brianne, Charlie and their family. The pre-interview assessment information was analyzed and framed by the four-factor theoretical model. On the individual level, Charlie's ability to continuously rely on his mother for attention and assistance was preventing him from socializing with peers and achieving important developmental milestones, such as getting a job. Furthermore, Charlie's lack of motivation to enter into OCD treatment appeared in many ways to be associated with the assistance he received from Brianne and the lack of consequences and boundaries in his environments.

From the caregiver perspective, Brianne was displaying many of the classic examples of family OCD accommodation, including providing reassurance, altering family routines, taking over responsibilities and in some cases directly participating in Charlie's ritual performance. Similar to other family members, Brianne frequently experienced feelings of anger in reaction to Charlie, and on occasion these feelings had led her to react with hostility, for example by yelling at him. Additionally, Brianne's anxiety and difficulty being away from Charlie indicated an emotional over-involvement with his OCD, whereby Brianne felt incapable of separating her own anxiety from Charlie's OCD. Finally, Brianne described a clear difficulty in practicing self-care and allowing herself opportunities to separate from Charlie and have experiences outside of the sphere of OCD. Brianne believed there was no possibility for her to devote time for

herself and her needs, and because of this, her relationships with her husband, son, family and friends were suffering.

From an environmental perspective, it appeared that in both of Charlie's primary day environments, namely at home and school, there were few consequences and boundaries put in place that might act as behavioral deterrents for his OCD and avoidance. For instance, his school did not feel able to reprimand Charlie for his morning tardiness, therefore there were no impediments for him to perform his rituals in the morning and rely on Brianne to take him late to school. At home, family members had become accustomed to assisting Charlie when his decisions to avoid certain stimuli made it difficult for him to function. Finally, it appeared that the larger family system had over time evolved in way to not only facilitate Charlie's OCD but also to acknowledge and accept Brianne's role as the key accommodator and safety object for Charlie. The father and older son's decisions to withdrawal from Charlie's OCD reinforced Charlie's reliance on his mother and made Brianne feel even more trapped and alone.

In developing a short-term treatment plan, it was deemed important to address all four factors in order to both increase the efficacy of the initial intervention and the likelihood of Brianne implementing changes consistently over the long term. It had been anticipated that the therapist would need to devote initial sessions to enhancing caregiver motivation for treatment or addressing concerns that treatment was not being directly provided to their loved one. However, for Brianne this was deemed unnecessary due to her extremely high level of motivation at the beginning of treatment and her strong desire to separate herself from her son's OCD. In keeping with a cognitive-behavioral orientation, the treatment plan was designed to utilize a short-term, problem-focused

approach whereby Brianne and her therapist would learn new ways of understanding and reacting to Charlie's OCD. The material learned during therapy would be reinforced through the administration of homework assignments designed to facilitate Brianne's practice and generalize treatment effects into the home environment. Finally, at the end of treatment Brianne's achievements would be summarized, appropriate relapse prevention techniques would be administered, and a referral for additional treatment would be made if necessary. The following is a brief, session-by-session breakdown of the course of Brianne's treatment, including a subjective rating by the clinician of Brianne's past-week total accommodation behaviors in which a score of ten denoted the highest possible level of accommodation behaviors, five moderate accommodating behaviors, and zero no presence of accommodation within the home.

Session 1

The first treatment session focused on re-assessing Brianne's motivation for treatment, elaborating Brianne's short term/long term goals, providing psycho-education information on the function of rituals in OCD, and assigning Brianne an initial behavioral homework assignment. Brianne reported that her motivation for treatment remained high and she had already attempted to set a limit with Charlie by asking him to give her some time to herself before going to bed. However, it had been difficult for her to maintain this boundary with Charlie due to his frequent attempts to gain her attention by engaging in distracting behaviors in her presence. Both Brianne and the therapist examined the consequences of her reactions to Charlie's behaviors, which typically involved her giving Charlie attention by discussing her annoyance with his actions. Brianne was encouraged

to maintain her evening-time boundary and some alternative strategies were suggested designed to limit her engagement with Charlie, such as ignoring him or relocating to her bedroom with the door closed. The therapist rated the past-week accommodation **5 out of 10.**

Session 2

At session two, Brianne reported that she had experienced success maintaining her evening-time boundary. As a result, she had used the time to herself to prepare for work the next day, something she had not been able to do in the past. Brianne believed that Charlie had been more anxious during the week as a result of not being around his mother in the evening. Perhaps due to his anxiety, Charlie had violated a family rule by eating his brother's yogurt in the refrigerator after Charlie had already finished his own allotment. Brianne reported that she had been very upset at Charlie and had yelled at him, but had eventually gone to the store and bought more yogurt for Charlie and the rest of the family. A discussion followed regarding the importance of Charlie experiencing the natural environmental consequences of his rituals and rule-breaking behaviors. It was explained to Brianne that her response to Charlie often prevented him from experiencing these consequences, such as when she bought him more yogurt or when she waited for him to complete his rituals in the morning and drive him to school. Brianne expressed understanding and identified a goal of setting a boundary with Charlie around the morning routine. It was agreed that she would no longer drive him to school in the morning, and it was up to him to walk himself to work. The subjective rating of past-week accommodation was a **4 out of 10.**

Session 3

Brianne arrived to her third session in a very positive mood and reported that she hadn't driven Charlie to school at all during the week in addition to continuing to maintain her evening-time boundary. She had been surprised to find that it made her anxious to be away from Charlie and that her attention was usually occupied wondering if Charlie was ritualizing. Together, Brianne and the therapist examined what specific thoughts she had about Charlie performing his rituals that led to her anxiety. Brianne's thoughts centered around two themes: 1) that Charlie's OCD would never get better if ritualized; 2) that he would damage or disturb the house if he was left alone to perform his rituals. The therapist normalized Brianne's anxiety by explaining that it was very common for family members of individuals with OCD to become "emotionally over-involved" with their loved one's anxiety to the point where they begin to experience anxiety themselves. Oftentimes, these family members will similarly seek to reduce their own anxiety by assisting or reassuring their loved one with their rituals. Brianne stated that she was surprised to learn how much anxiety she had about Charlie's OCD and acknowledged that she would have to learn to cope with her own feelings about Charlie's OCD in order to create distance for herself. For homework, she was asked to track some of her anxiety thoughts related to Charlie's OCD during the week. Her subjective rating of accommodation was **a 4 out of 10**.

Session 4

Brianne arrived at the fourth session reporting a high level of stress, feelings of anger and frustration toward Charlie and discouragement over her progress. Brianne reported that Charlie had been extremely anxious during the week, had been “back-stepping” continuously in the house and constantly seeking verbal and physical reassurance from her. Brianne suspected that Charlie’s anxiety was elevated due to the fact that Brianne would be away the following week for an out-of-state bridal shower. On several occasions over the week, Brianne had accommodated Charlie’s OCD by taking over his responsibilities in the house or helping him avoid feared objects. Although she had continued to resist taking him to school, she admitted she was having thoughts about giving in and driving him again because he was showing up late. The therapist reflected the way in which Brianne’s anxiety and stress had become elevated as a result of Charlie being more anxious over the past week, resulting in increased rituals and accommodation. In the course of this discussion, the therapist explained to Brianne that Charlie’s OCD was not her fault and it was neither her responsibility nor within her control to stop his rituals. Brianne found the discussion on control and responsibility helpful and stated that she would try to remind herself of this while she was away on vacation. Brianne was encouraged to think of her own self-care and need for relaxation while she was away from Charlie. For homework, Brianne was asked to practice thought-acceptance strategies when she became anxious and uncertain about what Charlie was doing, and to avoid giving in to her anxiety by calling him. Brianne was also asked to limit her phone calls to and from Charlie to one per day while she was away. Her subjective rating of accommodation for the past week was **7 out of 10**.

Session 5

After a week hiatus for Brianne's vacation, she arrived at the fifth session in a positive mood and reported that she had successfully handled her time away from Charlie. She had followed her homework assignment and limited her phone contact to one call per day, and perhaps most importantly stated that she felt less anxious and had an easier time attending to her vacation activities rather than worrying about what Charlie might be doing. Additionally, upon returning home Brianne was pleased to learn that Charlie had not ritualized more than usual and had functioned normally. Brianne stated that her time away from Charlie had helped her realize just how much attention she devotes to Charlie and his OCD. She understood that her attention was valuable to Charlie and that it was likely one of his goals in performing his rituals. For homework, Brianne was asked to make a list of the pros and cons both for herself and Charlie, focusing on the consequences of deciding to engage with Charlie when he ritualized versus choosing to disengage and ignore his behavior. Her subjective rating of accommodation for the past week was a **3 out of 10**.

Session 6

In Brianne's sixth session, the focus was expanded to include the roles of other family members, particularly her husband given Brianne's report of feeling she was the only caregiver willing to set boundaries with Charlie. During the past week, Brianne and her husband had taken Charlie to the hospital for a doctor's appointment. This had been very difficult for Charlie, as hospitals still made him extremely anxious and were typically avoided. Brianne felt very proud of herself for encouraging Charlie to attend by

using critical, non-hostile statements (e.g. “You don’t want your OCD to keep you from doing something other people your age can do, right?) without overt reassurance.

However, Brianne became frustrated when, upon arriving home from the hospital, her husband accommodated Charlie’s request that he be driven back to the hospital and home again as part of a “back-stepping” ritual. Brianne objected and refused to participate, remaining at home while her husband drove Charlie. Brianne was given encouragement for both refusing to accommodate her son’s OCD request and refusing to stay in the car while her husband drove Charlie back. This episode provided Brianne the opportunity to explore her feeling isolated against the OCD, particularly during times her husband would go to bed early in the evenings instead of remaining to help Brianne with Charlie. Brianne indicated that she believed it would be helpful for her husband to attend a session and learn about the work she had been doing, and it was decided her husband would attend in three weeks when he had a free day in his schedule. Brianne’s subjective rating of accommodation for the week was a **5 out of 10**, higher than the previous week because she had difficulty maintaining her agreed upon boundary for limited hugging with Charlie throughout the day.

Session 7

At the seventh session, Brianne arrived in a distressed mood and stated the previous week had been difficult as an old ritual of Charlie’s had re-emerged, involving him taking prolonged showers. Brianne described that she had found it difficult to ignore Charlie’s showering, particularly when she was in the house and could hear the water running. Brianne acknowledged that one possible reason this ritual had re-emerged was

that Charlie knew it made her agitated and more likely to engage with him in the evening. Brianne and the therapist reviewed a list of non-engagement strategies she could use in response to the ritual, including telling Charlie before the shower that if he went over a certain time limit she would turn off the hot water, or simply ignoring by going to bed. The second half of the session was spent discussing some of the positives Brianne had identified that Charlie might begin to experience if household accommodation was reduced. Brianne believed that if she took a less active role with Charlie, it would encourage him to become more self-reliant and engage more with his peers, something she feared he would never be able to do because of his OCD. Brianne had been encouraged during the week when Charlie told her he was going to play basketball with a neighborhood friend, something she had never known him to do before. Brianne was asked to keep her desires for Charlie in mind whenever she was confronted with a decision to accommodate his OCD or provide reassurance. Her subjective rating of accommodation for the week was **4 out of 10**.

Session 8

The eighth session was one of the most significant over the course of Brianne's brief treatment. At the outset, Brianne reported that she had been more successful in resisting engagement with Charlie's shower ritual and had decided to use the strategy of going outside to garden whenever she heard the shower go on because it took her away from the noise of the water. Along with this development, Brianne reported that she had begun to realize that the anxiety she felt towards Charlie extended to both her husband and older son, and she concluded that she frequently sacrificed her own needs and care

due to worry about the family's overall functioning and cohesion. The therapist validated this insight and normalized by informing Brianne that mothers often find themselves feeling they need to keep a family together, particularly when the family is attempting to cope with the presence of an illness in the household. Brianne was encouraged to use the remaining sessions of treatment to focus on ways in which she could practice self-care and allow herself to engage in enjoyable personal activities she had previously sacrificed. Brianne stated that for homework she would call up a girlfriend whom she hadn't seen for some time and schedule a date to go out for food and drinks. Brianne felt better at the end of the session and excited about the opportunity to begin taking care of herself. Her subjective rating of accommodation for the past week was **3 out of 10**.

Session 9

The ninth session marked the arrival of Brianne's husband in the treatment. The beginning of the session focused on having Brianne and the therapist fill her husband in on what Brianne had been working on during the treatment and what successes and challenges she had encountered. Brianne brought up the recent incident in which her husband had helped Charlie "back-step" to the hospital and used it to highlight ways in which she believed her husband was still accommodating. Her husband indicated that he frequently chose to accommodate in order to prevent Charlie's anxiety from escalating, which would in turn further disrupt the household. The therapist discussed with both parents some of the strategies Brianne had been using for dealing with Charlie's anxiety. Towards the end of the session, Brianne told her husband directly that she felt as if she was alone in dealing with Charlie's OCD around the house because of his tendency to

withdrawal and go to bed. Her husband indicated that he hadn't known Brianne felt so alone in dealing with Charlie's OCD and recognized that it might be helpful if he supported Brianne's right to self-care by telling Charlie to give his mother space and time to herself. The couple left the session motivated to work together to support one another in resisting accommodation and devoting time for themselves away from Charlie. Brianne's subjective rating of accommodation for the past week was **3 out of 10**.

Session 10

In the final session, Brianne and her therapist reviewed the course of Brianne's treatment and highlighted many of the accomplishments she had made over the past three months. Brianne indicated that her relationship with her husband had improved since the last session, and reported that he had been asking Charlie to give his mother space to herself around the house at night. Furthermore, Brianne excitedly described how Charlie had begun to talk about wanting to look for a part-time job after his school semester ended. She stated that Charlie had never previously spoken about personal goals. Brianne indicated that she didn't believe Charlie was any more motivated to seek treatment for his OCD now than at the beginning of treatment, but she felt that this might change over time if she continued to resist engaging and accommodating his OCD. She reported that Charlie had told her he was glad she would no longer be coming in for treatment, believing that this was a sign that Charlie had noticed the change in her behavior and was unhappy that she would no longer help him with his OCD. Finally, Brianne expressed her desire to continue in treatment with a new therapist at the anxiety clinic once her post-treatment study assessment was completed. She felt she had come

very far in her treatment and identified areas for further work, including coping with her own feelings of anxiety in response to Charlie performing his rituals. Her final subjective rating of accommodation over the past week was **2 out of 10**.

Results

At the pre-treatment assessment, an attempt was made to assess Charlie using the study-approved quantitative measures (e.g. Y-BOCS, URICA) and clinical interview (ADIS-IV), however it became clear that due to his developmental issues Charlie was unable to fully comprehend the language of these measures when presented both visually and verbally. It was decided that Charlie's scores on self-report and interviewer-administered study measures were unreliable and thus could not be accurately recorded. Instead, Charlie's OCD diagnosis and pre-treatment levels of OCD symptom severity and treatment motivation were derived from qualitative interviews with Charlie and Brianne.

At the post-treatment interview, Charlie agreed to sit down with the investigator and describe his experience while his mother was in treatment. He reported that he believed his mother had become "stricter" towards him in general while she was in treatment and cited her refusal to engage with him after 10:30pm as an example of this change. Charlie also indicated his belief that Brianne had been acting "stricter" towards his OCD and had noticed her "yelling" more often for him to stop his rituals. Charlie indicated that Brianne had explained to him why she had been acting stricter during treatment and that he agreed his mother probably "needed a break from him" occasionally and that he was ok with her taking time to herself. When asked if he believed his OCD had become worse while his mother was in treatment, Charlie stated he felt it was about the same but that he had become more aware of it as a result of his mom ignoring him more often. When asked how he had been coping with his mom no longer helping him with his OCD, Charlie stated that he had turned to asking his father for help, such as with picking up items in his room from areas he didn't want to approach. Charlie then confirmed that although he believed his mother would continue ignoring his OCD

and acting “strict and angry” towards him he did not desire treatment for his OCD at this time. At the end of the interview, Charlie was asked what advice he would give to someone he knew if they had OCD and needed help. Charlie responded that he would tell them to “ignore it” because being aware of it makes it worse.

At the pre-treatment assessment, Brianne did not meet criteria for any current or past Axis-I disorder on the ADIS-IV clinical interview. Brianne’s total pre-treatment score on the DASS-21 was a 7, falling within the normative range. Her three clinical subscales (depression, anxiety, and stress) were also all within the normal range. Brianne’s quality of life pre-treatment standardized scores were 81st percentile for physical health, 81st percentile for psychological health, 69th percentile for social relationships and 69th for environmental stress on the *WHOQOL-BREF*. Finally, Brianne’s pre-treatment total score on the *Family Accommodation Scale – Interview Rated* scale was 26. Brianne’s highest levels of accommodation fell into four domains, specifically facilitating Charlie’s avoidance behaviors, waiting on Charlie to complete his rituals, assisting him in completing simple tasks around the home and taking on Charlie’s responsibilities around the home.

Throughout the course of treatment, Brianne completed a DASS-21 at every other session. Her total scores never deviated outside of the 0-30 normal range, and she displayed no elevation of the depression, anxiety and stress subscales. At the post-treatment interview, Brianne’s *WHOQOL-BREF* quality of life score was 88th percentile for physical health, 69th for psychological health, 69th for social relationships and 63rd for environmental stress. Her post-treatment *FAS-IR* score was 7, a 40% decrease from her pre-treatment score. Specifically, Brianne displayed significant decreases in most

domains of accommodation, especially “waiting for family member”, “helping with simple tasks” and facilitating avoidance. Although it had been intended to calculate a reliable change index score for Brienne’s pre and post treatment FAS-IR scores and determine clinical significance, this was not possible due to missing information on the FAS-IR’s test-retest reliability and standardized pre and post treatment scores for experimental groups derived from the measure’s creation. Thus, it is only possible at this time to report percentage decrease in Brienne’s total score over the course of her treatment.

Measure	Pre-Tx	Post-Tx
FAS-IR	26	7
DASS	7	5
<i>WHOQOL Physical Health</i>	81%	88%
<i>WHOQOL Psychological Health</i>	81%	69%
<i>WHOQOL Social Relationships</i>	69%	69%
<i>WHOQOL Environmental Stress</i>	69%	63%

Measure	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8	Week 9	Week 10
Subjective Weekly Accommodation	5	4	4	7	3	5	4	3	3	2

Discussion

The primary purpose of this study was to examine whether a brief intervention targeted to an individual living with an adult family member diagnosed with OCD could be effective in reducing accommodation behaviors and improving that individual's overall quality of life. Additionally, the study aimed to examine whether such decreases in family accommodation might in turn lead to an increase in willingness to seek out OCD treatment for the diagnosed family member. Based upon the quantitative and qualitative results at post-treatment, the primary hypothesis that treatment would lead to decreased accommodation and improved quality of life for the patient was supported. Over the ten-week course of treatment, Brianne experienced a substantial decrease in her accommodation behaviors towards her son's OCD and an improvement in communication with her husband and older son. During treatment, Brianne strove to reduce the sacrificing of her own responsibilities to her son's OCD and to increase her focus on her own needs and the needs of her other family members. Although Brianne experienced a benefit from her short time in treatment, she indicated at the conclusion of treatment that additional sessions were necessary to consolidate her treatment gains and continue working towards her goals. Thus, it may be the case that a ten session treatment, while helpful, is not a sufficient treatment dose for accommodating family systems in which the OCD has been present for several years.

While the primary study hypothesis was supported, the secondary hypothesis regarding improved OCD treatment motivation for Charlie at post-treatment was not supported. Over the course of the study, Charlie acknowledged a change in his mother's attitude and behavior towards his OCD and Brianne reported noticing Charlie describe an

increased awareness of his OCD and the impact of his anxiety on his behavior. However, at the conclusion of treatment Charlie reported no change in his level of motivation for OCD treatment and indicated he had attempted to incorporate his father's help with his OCD in response to his mother's refusal. There are several possibilities for the lack of change in Charlie's level of motivation. Perhaps Brianne's post-treatment level of accommodation, while decreased, was still too elevated to allow Charlie to experience sufficient environmental consequences as a result of his rituals to warrant treatment.

It may also be the case that any effect decreased accommodation might have on treatment motivation will take a longer period of time to develop and therefore an assessment immediately post-treatment was too soon to detect impact on motivation. To this point, several of the changes Brianne reported noticing in Charlie over the brief course of treatment, such as socializing with a peer outside of the home and verbalizing his desire for short-term employment, could represent signs of developmental growth in Charlie that may one day become incompatible with his OCD and reliance on rituals. In addition, Charlie's appeared to suggest that he had become more aware of his OCD in response to reduced accommodation might serve as a precursor for a future desire to seek treatment, since it would have become more difficult for him to ignore his illness.

Because the present study utilized a single case-study design, it is possible to examine in depth the course of treatment and determine which factors may have been instrumental in creating positive therapeutic change. For instance, the use of the four-factor model of therapeutic intervention in conjunction with the detailed information gathered during the pre-treatment assessment allowed for the creation of a treatment plan designed to intervene at multiple systemic levels impacting Brianne, Charlie, and OCD.

Although the study provided individual treatment, a four-factor perspective provides evidence that the OCD accommodation involved the entire family system and negatively impacted all involved. Therefore, a significant portion of the intervention focused on raising Brianne's awareness of the systemic impact of accommodation, such as how her engagement with Charlie's OCD prohibited his social and occupational development and resulted in negative feelings and withdrawal in her husband and older son. The four-factor model also enabled Brianne and the therapist to identify potential environmental resources that she could utilize to assist in coping with Charlie's OCD, such as relying on school officials to introduce negative consequences for Charlie, or assertively requesting her husband's assistance in creating and maintaining boundaries within the home.

While it is encouraging to see that a brief, 10-session course of therapy can provide a benefit for accommodating family members, it is also likely that several patient-specific variables factored into the course of treatment and overall results. Specifically, although never officially assessed quantitatively, Brianne's pre-treatment levels of motivation for therapy and awareness of her role in accommodating her son's OCD were quite high. From the moment the principle investigator described the nature of the study, Brianne reported excitement over entering into therapy and a firm willingness to examine and correct her own thinking patterns and behaviors as they related to Charlie's OCD. At no point did the therapist have to utilize motivational enhancement techniques with Brianne and there was never a disagreement over targeting treatment intervention towards Brianne rather than Charlie. In many ways, Brianne's motivation and self-awareness of her accommodation may be unique, as many family members typically accommodate out of a belief they are helping their loved one and may not fully

realize or accept the negative impact of their actions. Therapists may need to devote more time in the beginning of treatment to resolving ambivalence, explaining why the treatment will focus on changing their behaviors rather than their loved one's rituals, and reinforcing the OCD model highlighting the long-term negative impact accommodation has on OCD. Therefore, therapists looking to work directly with OCD family members should routinely assess for motivation and accommodation-awareness at the outset of treatment, and be prepared to plan for more than ten sessions of treatment should these issues need be addressed.

Lastly, it is important to discuss the manner in which Brianne coped with her own feelings of anxiety and responsibility surrounding Charlie's OCD during the course of her treatment. In accordance with previous research findings of family member's tendency to become over-involved emotionally with their loved ones' OCD (Van Noppen & Steketee, 2009), Brianne would often begin to feel anxious when Charlie ritualized, and her subsequent attempts to accommodate during these occasions resulted in a decrease of her own anxiety. Initially, she was surprised that her own emotional state could have been so closely associated with her son's. However, a monitoring of her anxious thinking revealed that Brianne held the mistaken belief that Charlie would never stop ritualizing without her help. This insight into her accommodation subsequently led Brianne to the understanding that she adopted the care taker role with all her family members as a result of her anxiety over their health and well-being. Once this connection had been made, Brianne committed herself to being less emotionally reactive and hypersensitive towards her family members and OCD. This commitment was viewed as a major treatment accomplishment, as it began to allow Brianne the freedom to pursue goals of practicing

self-care and devoting time to herself which had gone neglected over the years prior to her therapy.

There were several limitations to the current study. First, in utilizing a single case-study design, the study lacked the methodology necessary to create true experimental conditions, such as randomization, presence of a control condition and the use of a large, diverse sample size. Thus, it is possible that the results were influenced by the passage of time, individual factors or that another treatment approach could have produced results equal to or exceeding those in the current study. Second, in the current study a decision was made to include a family in which OCD co-occurred with developmental issues, which was different from the original intention to recruit for OCD with minimal Axis-I comorbidities. The decision was made to include this family due to the clear impact of OCD on the household, the significant level of accommodation behaviors by the mother, and the belief that the uniqueness of the case would fit with the case-study approach. In addition, there is no evidence to suggest that individuals with co-occurring developmental disorders experience attenuated OCD treatment outcomes. To this point, it is noteworthy that Charlie, as expected, did not experience a significant increase in his OCD or display acting out behaviors in response to his mother's reduced accommodation.

The results of the current study suggest that providing a brief, behavioral treatment to a family member can be an effective method of reducing OCD accommodation and improving quality of life within the household. While the treatment did not result in an increase in OCD treatment-seeking motivation, it is possible that a higher dose of treatment (i.e. more sessions) or simply the passage of time would result in greater motivational influence. Future studies should expand on the current case-study by

incorporating larger, more diverse samples and different patient-family member dyads, such as providing treatment to spouses or siblings in addition to mothers. Additionally, the use of randomized, controlled experimental designs will be necessary to scientifically establish the efficacy of a family-member centered treatment approach. Finally, researchers should examine whether accommodating family members would derive equal benefit from treatment in the presence of different OCD subtypes and levels of symptom severity.

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Appendices

A Preliminary Investigation of the Relationship Between Accommodation Behaviors of Family Members of Individuals with OCD and Treatment Outcome

Informed Consent Non-Patient Family Member Version

You are invited to participate in a research study that is being conducted by James Marinchak, Psy.M., who is a doctoral candidate at the Rutgers University Graduate School of Applied and Professional Psychology.

This consent form contains information about the study that the primary investigator will go over with you. You will have the opportunity to ask questions and have them answered. When all of your questions have been answered, you will be asked to sign this consent form if you agree to be in the study. A copy of the form will be given to you to keep for your records.

1. Nature and Purpose of the Study

The purpose of the study is to examine the efficacy of cognitive behavioral therapy (CBT) for individuals living with an adult family member with obsessive compulsive disorder (OCD) who does not currently desire treatment. Previous research has shown that OCD can cause significant stress, disruption and reduced quality of life for family units, and that family members can often become incorporated into the performance of OCD rituals and compulsions. Cognitive behavioral therapy can be an effective form of treatment for individuals attempting to cope with a family member's mental illness. The goal of this study is to determine whether a brief, CBT treatment reduces distress and improves quality of life for non-OCD family members.

2. Explanation of Procedures

If you and your family member decide to participate in this study, you will participate in the following procedures:

Before beginning treatment, you and an adult family member will be interviewed in your home by the primary investigator and asked to fill out questionnaires about current and past psychological treatment and symptoms. You will be interviewed separately and all your answers will remain confidential and will not be shared with your family members. Each interview should take approximately 1 ½ - 2 hours, for a total of 3-4 hours. You and your family member will be asked to participate in a similar assessment approximately one week after your family member's 10th treatment session. The procedures and materials used during this termination interview will

be the exact same as those used during the initial study interview. There will be no audio or video recordings made during your interview.

Page 1, Participant Initials _____

After the interviews are completed and your eligibility is confirmed, your family member will participate in 10, 50-minute therapy sessions at the Rutgers University Anxiety Disorders Clinic where you will receive cognitive behavioral therapy (CBT) for coping with your adult family member's OCD. The primary investigator, a graduate student in clinical psychology who has received specialized training in the treatment of OCD and OCD-related issues, will provide the therapy. The therapist will receive weekly one-hour supervision from a licensed professional psychology with expertise in the treatment of OCD. Your family member's treatment will focus on providing educational information regarding the nature of OCD, improving family communication, reducing psychological distress and teaching strategies to help them cope with the presence of OCD rituals in the household.

During treatment, the primary investigator/therapist will not initiate contact with you and will not discuss the nature of your family member's treatment. However, if you wish to contact the primary investigator/therapist, you may do so at any point. If at any point during your family member's treatment you wish to receive cognitive behavioral therapy for your OCD, you may notify the primary investigator and you will be offered treatment at no-cost at the Rutgers University Anxiety Disorders Clinic.

At the termination of treatment, you will be offered free, weekly individual treatment from a graduate student at the Rutgers Anxiety Disorders Clinic for your OCD. There is no requirement for you to enter into treatment, and your decision to enter into treatment will remain completely voluntary.

If you or your family member have any questions about the study, you may contact James Marinchak, Psy.M at 732-445-5384 or at James Marinchak, GSAPP, Rutgers University, 152 Frelinghuysen Road, Piscataway, NJ 08854.

3. Discomforts and Risks

Participating in this study may expose you or your family member to some discomfort or risks. The first risk of participating is a possible loss of privacy. Since we will be collecting personal information about you and your family member there is some risk of a loss of confidentiality. However, we will minimize this risk by keeping all information you give us completely confidential and available only to the research staff.

It is possible that some of the topics discussed or techniques used during the interview may cause you or your family member some degree of discomfort. However, the expected level of discomfort is not greater than the level of

discomfort that is expected during any psychological treatment. You may also be uncomfortable providing sensitive, personal information on the questionnaires. Most people do not experience any discomfort while completing questionnaires

Page 2, Participant Initials _____

such as these, and many find them to be very interesting. However, if you or your family member find the questions to be upsetting, you may refuse to answer specific questions. The primary investigator will make every effort to ensure that you feel comfortable with the questionnaires, and when appropriate, will provide you with skills to reduce your discomfort.

You or your family member may also experience risks that are currently unforeseeable to the primary investigator. If you or your family member experience severe distress, please speak with James Marinchak at 732-445-5384.

4. Benefits

By participating in this study, your family member will receive a state-of-the-art treatment for distress related to the presence of OCD in the household provided by a specially trained therapist. They will likely experience reduction in their overall distress, improvement in their quality of life and relationships with you and other family members, an increase in their OCD knowledge and the acquisition of alternative ways of coping with the presence of OCD rituals in the household.

By participating in this study, you will also be advancing psychological knowledge regarding the effect of OCD on families. You will help us answer the question of whether or not treatment provided to a family member of a non-treatment motivated adult with OCD is effective in reducing family distress and improving quality of life within the household. With this information, it is likely that you will help improve psychological services for others. If you are interested in the results of the study, you can request to be provided with copies of all resulting publications as they become available.

5. Costs and Compensation

There is no cost to you or your family member for participating in this research. There is no direct compensation, however you will be eligible through your participation to receive cognitive behavior therapy at the Rutgers Anxiety Disorders Clinic free-of-cost.

6. Confidentiality

All of your records from this study will be treated as confidential. Confidential means that the research records will include some information about you and your family member, such as your name, gender, age and address. The principle investigator will keep information containing personal information confidential by limiting individuals' access to the research data and keeping it in a secure location

available only to project research staff. The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to view your information, except as may be required by law. If a report of this study is published, your name and other identifying information will not be linked to the

Page 3, Participant Initials _____

data. Your questionnaires will not be linked to your name and will be kept in a secure location.

The therapist conducting your interview is graduate student, and thus must participate in clinical case supervision with a Licensed Clinical Psychologist with expertise in the treatment of OCD and OCD-related issues. The contents of your interview will be shared during clinical case supervision. Your case will only be discussed with the Licensed Clinical Psychologist who is providing supervision, and all information discussed in supervision will be treated as confidential.

7. Refusal/Withdrawal/Termination

Participation in this study is voluntary. The decision whether to be in this study is entirely up to you and your family member. You and/or your family member may withdraw from the study at any time, and you both may refuse to answer any questions that you are not comfortable with. If, during the course of your treatment, your family member should choose to withdraw, you will still be eligible to receive weekly cognitive behavior therapy at the Rutgers University Anxiety Disorders Clinic free-of-cost. If you choose to withdraw once treatment has begun, you and your family member will be provided with a referral for an appropriate treatment provider if you are willing. There will be no consequences if you choose not to participate, or if you choose to withdraw from the study.

If at any point during you or your family member's participation, your therapist or your therapist's supervisor feels as though you or your family member's condition has significantly worsened, you both will be withdrawn from the study so that you may receive appropriate treatment. Additionally, if your therapist or your therapist's supervisor feels that you or your family member are at risk of hurting yourself or someone else, you both will be withdrawn from the study. If you and your family member are withdrawn, you will both be provided a referral for an appropriate treatment provider.

If you do not participate in the study or choose to withdraw, Rutgers is not responsible for the cost of alternate treatments. Further, Rutgers is not responsible for the cost of any additional treatment for you or your family member sought outside of the Rutgers Anxiety Disorders Clinic following the completion of your participation.

8. Alternatives

There are currently no published reports of efficacious treatments for individuals living with an adult family member with OCD who is not motivated to seek treatment. You and your OCD-family member's alternative is not to participate.

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9. Research Questions

If you or your family member have any questions about the study, you may contact the principle investigator/study therapist James Marinchak, Psy.M., by telephone at 732-445-5384 or by email at jamma789@yahoo.com

10. Subject Rights

If you or your family member have any questions about your rights as a research subject, you may contact the Sponsored Programs Administrator at Rutgers University at:

Rutgers University Institutional Review Board for the Protection of Human
Subjects
Office of Research and Sponsored Programs
3 Rutgers Plaza
New Brunswick, NJ 08901-8559
Tel: 732-932-0150 ext. 2104
Email: humansubjects@orsp.rutgers.edu

Page 5, Participant Initials _____

I ACKNOWLEDGE THAT I HAVE READ THE ABOVE EXPLANATION OF THIS STUDY, THAT ALL OF MY QUESTIONS HAVE BEEN SATISFACTORILY ANSWERED, AND I AGREE TO PARTICIPATE IN THIS RESEARCH STUDY.

Printed name of Participant

Signature of Participant

Date

I AGREE TO HAVE MY THERAPY SESSIONS AUDIOTAPED FOR RESEARCH PURPOSES.

Printed name of Participant

Signature of Participant

Date

I CERTIFY THAT I HAVE EXPLAINED FULLY TO THE ABOVE PATIENT THE NATURE AND PURPOSE, PROCEDURES AND THE POSSIBLE RISKS AND POTENTIAL BENEFITS OF THIS RESEARCH STUDY.

Printed name of Researcher

Signature of Researcher

Date

A Preliminary Investigation of the Relationship Between Accommodation Behaviors of Family Members of Individuals with OCD and Treatment Outcome

**Informed Consent
Patient Family Member Version**

You are invited to participate in a research study that is being conducted by James Marinchak, Psy.M., who is a doctoral candidate at the Rutgers University Graduate School of Applied and Professional Psychology.

This consent form contains information about the study that the primary investigator will go over with you. You will have the opportunity to ask questions and have them answered. When all of your questions have been answered, you will be asked to sign this consent form if you agree to be in the study. A copy of the form will be given to you to keep for your records.

1. Nature and Purpose of the Study

The purpose of the study is to examine the efficacy of cognitive behavioral therapy (CBT) for individuals living with an adult family member with obsessive compulsive disorder (OCD) who does not currently desire treatment. Previous research has shown that OCD can cause significant stress, disruption and reduced quality of life for family units, and that family members can often become incorporated into the performance of OCD rituals and compulsions. Cognitive behavioral therapy can be an effective form of treatment for individuals attempting to cope with a family member's mental illness. The goal of this study is to determine whether a brief, CBT treatment reduces distress and improves quality of life for non-OCD family members.

2. Explanation of Procedures

If you and your family member decide to participate in this study, you will participate in the following procedures:

You will participate in 10, 50-minute therapy sessions at the Rutgers University Anxiety Disorders Clinic where you will receive cognitive behavioral therapy (CBT) for coping with your adult family member's OCD. The primary investigator, a graduate student in clinical psychology who has received specialized training in the treatment of OCD and OCD-related issues, will provide the therapy. The therapist will receive weekly one-hour supervision from a licensed professional psychology with expertise in the treatment of OCD. You will complete a few brief questionnaires every other week prior to the beginning of your treatment session. The questionnaires will likely take you around five minutes to complete. Throughout the treatment, the primary investigator/therapist

will not initiate contact with your adult OCD-family member and will not disclose any information regarding the nature or course of your treatment.

Page 1, Participant Initials _____

Your family member will be free to contact the primary investigator/therapist if they wish, however no information regarding the therapy will be provided.

Before beginning treatment, you and your adult family member will be interviewed in your home by the primary investigator and asked to fill out questionnaires about current and past psychological treatment and symptoms. You will be interviewed separately and all your answers will remain confidential and will not be shared with your family members. Each interview should take approximately 1 ½ - 2 hours, for a total of 3-4 hours. You and your family member will be asked to participate in a similar assessment approximately one week after the 10th treatment session. The procedures and materials used during this termination interview will be the exact same as those used during the initial study interview. You will have your therapy sessions audio taped for supervision and research purposes.

At the termination of treatment, you will be offered continued no-cost weekly CBT treatment at the Rutgers Anxiety Disorders Clinic if you desire to continue your therapy. Additionally, if at any point throughout the study your adult family member desires cognitive behavioral treatment for their OCD, they will be offered free, weekly individual treatment from a graduate student at the Rutgers Anxiety Disorders Clinic.

If you or your family member have any questions about the study, you may contact James Marinchak, Psy.M at 732-445-5384 or at James Marinchak, GSAPP, Rutgers University, 152 Frelinghuysen Road, Piscataway, NJ 08854.

3. Discomforts and Risks

Participating in this study may expose you or your family member to some discomfort or risks. The first risk of participating is a possible loss of privacy. Since we will be collecting personal information about you and your family member there is some risk of a loss of confidentiality. However, we will minimize this risk by keeping all information you give us completely confidential and available only to the research staff.

It is possible that some of the topics discussed or techniques used during treatment may cause you or your family member some degree of discomfort. However, the expected level of discomfort is not greater than the level of discomfort that is expected during any psychological treatment. You may also be uncomfortable providing sensitive, personal information on the questionnaires. Most people do not experience any discomfort while completing questionnaires such as these, and many find them to be very interesting. However, if you or your

family member find the questions to be upsetting, you may refuse to answer specific questions. Your therapist will make every effort to ensure that you feel comfortable with the therapeutic process and questionnaires, and when appropriate, will provide you with skills to reduce your discomfort.

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It is also possible that you may receive greater benefit from an alternative form of psychotherapy. The likelihood of this risk is minimal given that previous research has shown that the type of treatment being used in this study is the most effective psychological treatment for families coping with a family member's OCD, and currently there is no alternative treatment proven effective for individuals living with an adult family member diagnosed with OCD and unwilling to seek treatment. If you feel as though the treatment is not helpful, you may withdraw from the study at any time and request an alternative referral.

You or your family member may also experience risks that are currently unforeseeable to the primary investigator. If you or your family member experience severe distress, please speak with James Marinchak at 732-445-5384.

4. Benefits

By participating in this study, you will receive a state-of-the-art treatment for distress related to your adult family member's OCD provided by a specially trained therapist. You will likely experience reduction in your distress, improvement in your quality of life and relationships with your family members, increase your OCD knowledge and learn alternative way of coping with your family member's requests for assistance in performing their OCD rituals. Additionally, your participation in treatment may eventually result in an increased motivation in your adult OCD-family member to seek treatment.

By participating in this study, you will also be advancing psychological knowledge regarding the effect of OCD on families. You will help us answer the question of whether or not treatment provided to a family member of a non-treatment motivated adult with OCD is effective in reducing family distress and improving quality of life within the household. With this information, it is likely that you will help improve psychological services for others. If you are interested in the results of the study, you can request to be provided with copies of all resulting publications as they become available.

5. Costs and Compensation

There is no cost to you or your OCD-family member for participating in this research. There is no direct compensation, however your family member will be eligible through their participation to receive cognitive behavior therapy at the Rutgers Anxiety Disorders Clinic free-of-cost.

6. Confidentiality

All of your records from this study will be treated as confidential. Confidential means that the research records will include some information about you and your family member, such as your name, gender, age and address. The principle investigator will keep information containing personal information confidential by limiting individual's access to the research data and keeping it in a secure location available only to project research staff. The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to view your information, except as may be required by law. If a report of this study is published, your name and other identifying information will not be linked to the data. Your questionnaires and tapes will not be linked to your name and will be kept in a secure location. All audio session tapes will be destroyed upon the completion of the research project.

The therapist who is providing your treatment is graduate student, and thus must participate in clinical case supervision with a Licensed Clinical Psychologist with expertise in the treatment of OCD and OCD-related issues. The contents of your session will be shared during clinical case supervision. Your case will only be discussed with the Licensed Clinical Psychologist who is providing supervision, and all information discussed in supervision will be treated as confidential.

7. Refusal/Withdrawal/Termination

Participation in this study is voluntary. The decision whether to be in this study is entirely up to you and your OCD-family member. You and/or your OCD-family member may withdraw from the study at any time, and you both may refuse to answer any questions that you are not comfortable with. If, during the course of your treatment, your OCD-family member should choose to withdraw but you should wish to remain in treatment, you will continue to receive weekly therapy until the end of treatment at the 10th session. If you choose to withdraw once treatment has begun, you and your OCD-family member will be provided with a referral for an appropriate treatment provider if you are willing. There will be no consequences if you choose not to participate, or if you choose to withdraw from the study.

If at any point during you or your OCD-family member's participation, your therapist or your therapist's supervisor feels as though you or your family member's condition has significantly worsened, you both will be withdrawn from the study so that you may receive appropriate treatment. Additionally, if your therapist or your therapist's supervisor feels that you or your family member are at risk of hurting yourself or someone else, you both will be withdrawn from the study. If you and your family member are withdrawn, you will both be provided a referral for an appropriate treatment provider.

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If you do not participate in the study or choose to withdraw, Rutgers is not responsible for the cost of alternate treatments. Further, Rutgers is not responsible for the cost of any additional treatment for you or your OCD-family member sought outside of the Rutgers Anxiety Disorders Clinic following the completion of your participation.

8. Alternatives

There are currently no published reports of efficacious treatments for individuals living with an adult family member with OCD who is not motivated to seek treatment. You and your OCD-family member's alternative is not to participate.

9. Research Questions

If you or your family member have any questions about the study, you may contact the principle investigator/study therapist James Marinchak, Psy.M., by telephone at 732-445-5384 or by email at jamma789@yahoo.com

10. Subject Rights

If you or your family member have any questions about your rights as a research subject, you may contact the Sponsored Programs Administrator at Rutgers University at:

Rutgers University Institutional Review Board for the Protection of Human Subjects
Office of Research and Sponsored Programs
3 Rutgers Plaza
New Brunswick, NJ 08901-8559
Tel: 732-932-0150 ext. 2104
Email: humansubjects@orsp.rutgers.edu

I ACKNOWLEDGE THAT I HAVE READ THE ABOVE EXPLANATION OF THIS STUDY, THAT ALL OF MY QUESTIONS HAVE BEEN SATISFACTORILY ANSWERED, AND I AGREE TO PARTICIPATE IN THIS RESEARCH STUDY.

Printed name of Participant

Signature of Participant

Date

I AGREE TO HAVE MY THERAPY SESSIONS AUDIOTAPED FOR RESEARCH PURPOSES.

Printed name of Participant

Signature of Participant

Date

I CERTIFY THAT I HAVE EXPLAINED FULLY TO THE ABOVE PATIENT THE NATURE AND PURPOSE, PROCEDURES AND THE POSSIBLE RISKS AND POTENTIAL BENEFITS OF THIS RESEARCH STUDY.

Printed name of Researcher

Signature of Researcher

Date