PANDAS-Related Obsessive-Compulsive Disorder: A Single Case of "Failure" Reconsidered

Jason G. Richards
Pacific University

Recommended Citation

This Dissertation is brought to you for free and open access by the College of Health Professions at CommonKnowledge. It has been accepted for inclusion in School of Graduate Psychology by an authorized administrator of CommonKnowledge. For more information, please contact CommonKnowledge@pacificu.edu.
PANDAS-Related Obsessive-Compulsive Disorder: A Single Case of "Failure" Reconsidered

Abstract
A failure analysis of a chronic, severe, and refractory case of Obsessive-Compulsive Disorder with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Beta etiology will be utilized in an effort to understand, explain, and offer potential answers and solutions in a case that did not realize clinically significant improvement. The patient demonstrated an inadequate quantitative response to efficacious interventions while improvements in qualitative markers of treatment success were made, yet were inconsistent with the quantitative information. Subtype differences will be highlighted and new benchmarks for "success" in failure cases will be recommended. Suggestions for using failure analysis in complex cases will be made to improve the understanding and treatment of recalcitrant conditions.

Degree Type
Dissertation

Degree Name
Doctor of Psychology (PsyD)

Keywords
Failure analysis, obsessive-compulsive disorder, PANDAS, failure

Subject Categories
Psychiatry and Psychology

This dissertation is available at CommonKnowledge: https://commons.pacificu.edu/spp/125
Copyright and terms of use

If you have downloaded this document directly from the web or from CommonKnowledge, see the “Rights” section on the previous page for the terms of use.

If you have received this document through an interlibrary loan/document delivery service, the following terms of use apply:

Copyright in this work is held by the author(s). You may download or print any portion of this document for personal use only, or for any use that is allowed by fair use (Title 17, §107 U.S.C.). Except for personal or fair use, you or your borrowing library may not reproduce, remix, republish, post, transmit, or distribute this document, or any portion thereof, without the permission of the copyright owner. [Note: If this document is licensed under a Creative Commons license (see “Rights” on the previous page) which allows broader usage rights, your use is governed by the terms of that license.]

Inquiries regarding further use of these materials should be addressed to: CommonKnowledge Rights, Pacific University Library, 2043 College Way, Forest Grove, OR 97116, (503) 352-7209. Email inquiries may be directed to: copyright@pacificu.edu
PANDAS-related Obsessive-Compulsive Disorder: A single case of "failure" reconsidered

A DISSERTATION

SUBMITTED TO THE FACULTY

OF

SCHOOL OF PROFESSIONAL PSYCHOLOGY

PACIFIC UNIVERSITY, FOREST GROVE, OREGON

BY

JASON GUY RICHARDS

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PSYCHOLOGY

July 23, 2009
Abstract

A failure analysis of a chronic, severe, and refractory case of Obsessive-Compulsive Disorder with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Beta etiology will be utilized in an effort to understand, explain, and offer potential answers and solutions in a case that did not realize clinically significant improvement. The patient demonstrated an inadequate quantitative response to efficacious interventions while improvements in qualitative markers of treatment success were made, yet were inconsistent with the quantitative information. Subtype differences will be highlighted and new benchmarks for "success" in failure cases will be recommended. Suggestions for using failure analysis in complex cases will be made to improve the understanding and treatment of recalcitrant conditions.

Keywords: Failure analysis, obsessive-compulsive disorder, PANDAS, failure
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>ii</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>iii-iv</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>v</td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td></td>
</tr>
<tr>
<td>A Single Case of &quot;Failure&quot; Reconsidered</td>
<td>1</td>
</tr>
<tr>
<td>Failure Analysis</td>
<td>2</td>
</tr>
<tr>
<td><strong>METHODS</strong></td>
<td></td>
</tr>
<tr>
<td>Participants, Measures, and Procedures</td>
<td>10</td>
</tr>
<tr>
<td><strong>RESULTS AND DISCUSSION</strong></td>
<td></td>
</tr>
<tr>
<td>Case Introduction</td>
<td>12</td>
</tr>
<tr>
<td>Analysis</td>
<td>16</td>
</tr>
<tr>
<td>Probable Causes</td>
<td>16</td>
</tr>
<tr>
<td>Client Factors</td>
<td>16</td>
</tr>
<tr>
<td>Treatment Recalcitrant PANDAS Subtype OCD</td>
<td>16</td>
</tr>
<tr>
<td>PANDAS Phenomenon, Course, and Effects</td>
<td>22</td>
</tr>
<tr>
<td>&quot;Just So&quot; Tactile Sensory Obsessions</td>
<td>26</td>
</tr>
<tr>
<td>Poor Insight</td>
<td>29</td>
</tr>
<tr>
<td>Social and Family Environment</td>
<td>35</td>
</tr>
<tr>
<td>Family Expressed Emotion and Accommodation</td>
<td>35</td>
</tr>
<tr>
<td>Social Delay</td>
<td>38</td>
</tr>
<tr>
<td>Treatment Design and Implementation</td>
<td>42</td>
</tr>
<tr>
<td>Prompt Recognition and Treatment of PANDAS</td>
<td>42</td>
</tr>
</tbody>
</table>
Pharmacotherapy Influences.................................................................44
Psychosurgery Effects........................................................................48
Measures of Treatment Effectiveness..................................................52
Quantitative Measures: Yale-Brown Obsessive Compulsive Scale.........52
Qualitative Measures: The Global Assessment of Functioning Scale....54
Discussion of Failure Modes and Recommendations..........................59
Client Factors.......................................................................................59
Social and Family Environment............................................................62
Treatment Design and Implementation................................................66
Measures of Treatment Effectiveness..................................................68
Limitations of Current Study...............................................................71
REFERENCES....................................................................................73-89
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lisa's average monthly Y-BOCS scores</td>
<td>15</td>
</tr>
<tr>
<td>2</td>
<td>Client factors logic tree</td>
<td>34</td>
</tr>
<tr>
<td>3</td>
<td>Social and family environment logic tree</td>
<td>41</td>
</tr>
<tr>
<td>4</td>
<td>Treatment design and implementation logic tree</td>
<td>51</td>
</tr>
<tr>
<td>5</td>
<td>Measures of Treatment Effectiveness logic tree</td>
<td>58</td>
</tr>
<tr>
<td>6</td>
<td>Client factors logic tree with solutions</td>
<td>61</td>
</tr>
<tr>
<td>7</td>
<td>Social and family environment logic tree with solutions</td>
<td>65</td>
</tr>
<tr>
<td>8</td>
<td>Treatment design and implementation logic tree with solutions</td>
<td>67</td>
</tr>
<tr>
<td>9</td>
<td>Measures of treatment effectiveness logic tree with solutions</td>
<td>70</td>
</tr>
</tbody>
</table>
Chapter I
Introduction

PANDAS-related Obsessive-Compulsive Disorder:
A single case of "failure" reconsidered.

Obsessive-Compulsive Disorder (OCD) is a common anxiety disorder, with prevalence rates of approximately 1.9 to 3.3% in the general population (Karno, Golding, Sorenson, & Burman, 1988). Left untreated OCD, generally does not improve and is in fact well-known for following an insidiously deteriorating course, causing gross debilitation in the affected individual, typically in multiple areas of functioning (e.g., work, social life). Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Beta (PANDAS), as a subtype of OCD, has an exceptionally treatment resistant reputation. Individuals who suffer with this particular subtype of OCD rarely achieve satisfactory outcomes, often experiencing a "saw-tooth" clinical course (Swedo et al., 1998), with even poorer outcomes associated with those who have an onset before age 20 (Skoog & Skoog, 1999).

"Failure" in psychotherapy is, in the usual sense, most often demonstrated by a lack of sufficient or satisfactory change in progress or outcome measures (e.g., clinically significant change [Jacobson & Truax, 1991]). Of particular interest in the case of OCD is the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS [Goodman, Price, Rasmussen, Mazure, Delgado, Heninger, & Charney, 1989]), which represents a simple yet comprehensive symptom checklist and severity rating system. Cognitive-Behavior Therapy (CBT) interventions for OCD (i.e., exposure and response prevention [ERP]) have been shown to be consistently effective in the amelioration of symptoms in OCD cases (Chambless et al., 1998). However, individuals with the
PANDAS subtype of OCD consistently fail to obtain clinically significant outcomes (J. Rosqvist, personal communication, August 18, 2008).

The formulation of new hypotheses and novel approaches to this vexing problem rely on carefully observing, documenting, and evaluating reasons for failure. The case of "Lisa" (pseudonym), an individual suffering with chronic, severe, and refractory PANDAS subtype OCD will be examined in an effort to understand, explain, and offer potential answers and solutions to a less than desirable outcome. While the patient demonstrated inadequate response to efficacious interventions (e.g., inpatient, outpatient, medications, psychosurgery), as measured by the gold-standard Y-BOCS, subtype differences will be highlighted and new benchmarks for markers of "success" in otherwise conventional failure cases will be recommended. Suggestions for using failure analysis in complex cases will be made to improve the understanding and treatment of recalcitrant conditions. The investigation will focus on what constitutes failure in PANDAS subtype OCD with a tactile sensory symptom presentation and if current ways of analyzing clinically significant change in these cases are ineffective as illustrated by this "failed" case.

Failure Analysis

Charles Latino, president and founder of Reliability Center, Inc. suggested (Latino, n.d.) that we strive to "reduce" our workloads by looking at situations (here referring to failures) from a different perspective. He contests that doing the same thing over and over again and expecting a different result is akin to "insanity." He further stated that repetitious work and/or failure needs to be reduced or eliminated in order to free up time to be "proactive." His suggestion for elimination of repetitious failure is the prediction of failures, via failure analysis, in order to
prevent the inefficiency of repetition and failure from occurring in the first place. He specifically suggested performing a Root Cause Failure Analysis (RCFA). He described this as a "disciplined vertical problem solving method" that can determine the "root cause" of failure events.

Latino (n.d.) further recommended prioritizing the RCFA based on personnel’s (in our case analogous with therapists or clinicians) beliefs of what may be the most important to them in regards to best completing their work. These field personnel should further record repetitious failures that they encounter as they know best what "prohibits them from doing their best work."

As is common practice at the Psychological Service Center (PSC) Solutions for Anxiety Clinic, where the therapists responsible for the care of Lisa worked and trained, extensive notes have been kept on file. These notes detail every interaction between client and clinician throughout the entirety of Lisa’s treatment.

Next, personnel are asked to analyze the failure event utilizing a "Logic Tree." This method of deductive logic is designed to guide the personnel through the process of eliminating possible causes of repetitious failure and aid them in arriving at the "root cause" of the failure. In this phase of the RCFA it is critical to properly define the failure event in the top block and then to begin placing the likely causes of the failure in the second tier of the tree. At a presentation at the National Petroleum Refineries Association (NPRA) Maintenance Conference (May 1996), Robert Latino suggested that the top of the "Logic Tree" should contain the event that first drew our attention to the failure in the first place. In a personal communication (August 22, 2008) with the supervising clinician in the case of Lisa, Johan Rosqvist, PsyD., reported that there was no one "event" which drew attention to failure in Lisa’s treatment. However, he cited perpetually flat-lined Y-BOCS scores in the severe range as the main indication of treatment failure. He
stated that this was despite hundreds of therapist hours of exposure based therapy, regular
treatment with psychotropic medications, and psychosurgery.

After clearly defining the failure the investigating individual should determine which
potential cause is occurring most frequently and follow this path to the "root." In order to
construct this "Logic Tree" the personnel should ask the question "How can the preceding event
occur?" Subsequent levels of the "Logic Tree" will become more and more specific as the
questioning continues until the investigating individual is left with "two all-inclusive
possibilities" for how the failure could have taken place. These specific "causes" are then
scrutinized to determine if they did indeed take place and can be labeled as the "root causes."
Robert Latino suggested that this scrutinizing not be based on "hearsay or assumptions" but
should instead be scientifically based, specifically, through direct observation and documentation
(Latino, 1996). Continuing the process of questioning while scrutinizing each level of the "Logic
Tree" in this stepwise manner of hypothesis testing we can ensure validated conclusions.

"Root causes" can be of two types "component roots" or "human roots" (Latino, n.d.). He
described component roots as "tangible" or "familiar," and defined human roots as "points of
inappropriate human intervention." In order to continue utilizing the "Logic Tree" when one
uncovers "human roots" one must ask a series of questions such as; "Why did the person decide
to do what they did?" "What was their rationale?" "What about the systems in which they were
operating, allowed them to do what they did?" This line of questioning invariably leads to the
"why" of the failure event. Robert Latino (n.d.) terms the point of arriving at the "why" of the
event as uncovering the "latent" roots. He contested that if one were to stop the investigation at
"how" this failure took place then the "why" would never be uncovered leading to, in his
opinion, a repetition of the failure or the inaccurate attribution of error on the individual or
individuals implicated in the "human roots" portion of the "Logic Tree."

The last step defined by Latino (n.d.) is the development of recommendations for
systems, organizations, and/or personnel to act upon in order to prevent future failures. He
suggested that because repeat failures can become accepted as the norm the personnel must be
given the tools and skills (i.e., RCFA) to solve the problems as they encounter them in their
work.

*Root Cause Analysis*

Conducting a root cause analysis (RCA) should identify the causes of treatment "failure."
This was predicated on the assumption that subjective treatment "failures" can be reduced or
reevaluated by directing attention to root causes and erroneous assumptions of treatment
"failure" versus "success." In this way it was hoped that the likelihood of a problem recurrence
could be minimized and a protocol for use in the field of psychology developed, or at the very
least, suggested for further study and development.

Paradies (1991) recommended that the failure should first be defined with the specific
purpose of identifying the "failure sequence" which, according to the author, is rarely a single
event in any complex system, is usually a sequence of events, and generally includes multiple
"failures" and "omissions." The RCA can be modified to provide the investigative goal of
reducing the likelihood of a problem recurrence and provision of a protocol for use in the field of
psychology. This can be accomplished through the identification of the most basic causes (RCA)
of the failure with a specific focus on creating a checklist of items, gleaned from the literature,
that have traditionally been shown to predict the likelihood of treatment success. It can be
reasonably assumed that items that have been proven to increase the likelihood of treatment success, if not properly attended to during the delivery of treatment, may also play a role in treatment failure. Also, the identification of items that may have contributed to treatment failure (along with the subsequent development of a checklist) will facilitate fixing, or preventing altogether, failures in treatment.

According to the author (Paradies, 1991) it is important to avoid using an RCA to place blame. This is built upon the premise that most people in a "system" are trying to do a good job and the goal of the investigation is not to engage in a "witch-hunt" but instead to eliminate the items in the therapeutic system employed that may have lead to failure. As suggested the RCA should be made easy to use and thus should be simplified to eliminate excessive failure points in the investigation. In other words, "what 20% of the possible events are plausible causes of 80% of the failure?" To this effect, the RCA should utilize only those few items identified in the literature that have been shown, empirically, to increase or decrease the efficacy of treatment specifically for OCD and the PANDAS subtype in particular.

Failure Modes and Effects Analysis

Without the ability of divination, prescience is man’s primary tool for avoiding future failures. However, one could spend days attempting to predict the future and never uncover the myriad of potential pitfalls, obstacles, and failures that tomorrow may hold. In effect, attempting to predict and prepare for the unknown may be seen as an abject waste of time, at best, and a life crippling cognitive pursuit at worst. Utilizing a modified Failure Modes and Effects Analysis (FMEA) approach as presented by Kenneth C. Latino (NPRA Conference, May 1996) we can determine in what areas failures have occurred in the past and determine what their probable
impact and frequencies may have been in regards to the future. Considering the potential myriad of points of failure in a therapy case of this complexity (e.g., OCD, PANDAS, inpatient, training case, length of affliction, medications, surgery) a narrowing of possible failure events is necessary. The Pareto principle, credited to the famous Italian Economist Vilfredo Pareto implies that for any event nearly 80% of the effects come from only 20% of the causes.

Summary of Failure Analysis

The goal of any failure analysis (i.e., RCFA, RCA, FMEA) is to find out what happened, why it happened, and what to do to prevent it from happening again. They are tools for identifying prevention strategies and are specifically designed as a way to move beyond placing blame on individuals for systemic failures. The investigative procedure of a failure analysis has the express goal of preventing the recurrence of the failure event(s). It should involve experts from the frontlines who are most familiar with the situation(s) in question. By continually asking how and why at each level of inquiry the changes that need to be made to the system that failed can be made in an impartial manner. The RCA is used to determine the human and/or other factors that are the underlying causes and effects of the failure within the processes and/or systems. This process must culminate in recommendations for improvements within the processes and/or systems that reduce or end the failure(s) in question. Accordingly an adaptation of the FMEA, RCFA, and RCA approaches are suggested for use in the field of psychology:

1. develop a definition of "failure"
2. collect data via interview with individuals who are significant in the case
3. use the literature to investigate empirically supported causes of treatment success vs. failure
4. determine the "significant few" (i.e., 20% or less of the items that have resulted in 80% of the failure)

5. in a reverse step-wise manner ask appropriate questions such as; "how can this significant item lead to failure"; "why did the person decide to do what they did?"; "what was their rationale?"; "what about the systems in which they were operating, allowed them to do what they did?"

6. determine "why," if indicated, that the item(s) caused failure

7. develop solutions for avoiding future, similar, failures

8. disseminate results

*Failure Defined*

Failure is defined, variously, as the omission of occurrence of performance; a failing to perform an expected action; a lack of success (*Merriam-Webster Online Dictionary, 2010*) or in other words as a state or condition of not meeting a desirable or intended objective, thus failing to meet an expected outcome. However, failure may also be seen as subjective, that is to say failure may indeed mean success depending upon ones perspective as there may be intrinsic learning value in a supposed failure.

*Interview data*

Kenneth C. Latino (1996) suggested that in order to uncover the most likely "20%" an interview should be conducted with the people "closest" to the work performed. In this case the most significant treating clinician available was Johan Rosqvist PsyD., the director of the Solutions for Anxiety Clinic at the PSC. He acted as the primary psychologist working with Lisa, as well as the primary supervisor of the student clinicians who were assigned to Lisa’s case. Also
available for interview was Lisa herself. Dr. Rosqvist suggested the following factors may have been linked to the failure in Lisa's case: family accommodations, poor insight, PANDAS subtype OCD being treatment recalcitrant, the patient's social delay, lack of prompt recognition and treatment of PANDAS during her primary childhood infections, poor client adherence to treatment protocol, reliance on quantitative outcome measures versus qualitative markers of success, the difficulty of obtaining good treatment outcomes with "just so" tactile sensory obsessions, pharmacotherapy interference with habituation, poor outcomes related to psychotherapy, and the subjective nature of "success" and "meeting expectations."
CHAPTER II

METHODS

Participants

The patient in question, Lisa, was a 20 year old Caucasian woman who at the time of intake (November 7, 2005) was a part-time college student. She was referred by McLean Hospital in Boston Massachusetts for intensive, outpatient team treatment with lead therapist Johan Rosqvist, PsyD. at the PSC's Solutions for Anxiety Clinic in Portland Oregon. Dr. Rosqvist was the other participant of this study acting as a consultant and interviewee concerning his interactions with Lisa and his expertise in treating both Lisa, OCD, and PANDAS subtype OCD specifically.

Measures

The Yale-Brown Obsessive Compulsive Scale (Y-BOCS, Goodman, Price, Rasmussen, Mazure, Delgado, et al., 1989; Goodman, Price, Rasmussen, Mazure, Fleischman, et al., 1989) had been administered on a regular basis to Lisa throughout her treatment at the PSC. It is a clinician-administered and -rated 10-item scale that indicates the severity of a patients obsessions and compulsions with respect to amount of time, interference, distress, resistance and control. The Y-BOCS also includes a Symptom Checklist to identify OCD subtypes for severity ratings. The Y-BOCS is considered internally consistent with high test-retest reliability, as well as concurrent and discriminate validity.

Procedures

A brief literature review was performed to determine which factors are capable of impacting the prognosis and treatment outcome in OCD. This was necessary in order to
determine the factors that may contribute to both successful treatment as well as less than desirable outcomes. In-person interviews of available and significant individuals involved in this case (i.e., Dr. Rosqvist and Lisa) were conducted in order to obtain witness accounts and opinions relevant to the case outcome. A review of the available data contained within the clients file was performed in order to determine if evidence existed refuting or supporting the literature review and interviews. Lastly, a failure analysis was conducted on the gathered literature, interview, and file data to determine the root cause(s) of treatment failure in Lisa’s case.
CHAPTER III

RESULTS AND DISCUSSION

Case Introduction

Lisa, a 21-year-old, single, Caucasian, high school educated female, contracted PANDAS etiological OCD at 10 years of age. Her particular presentation was one of tactile sensory "just so" obsessions. In other words, it was the way particular things "felt" to Lisa, which caused her distress. Her particular compulsions took the form of repetition, checking, washing, and rinsing. Lisa suffered with severe PANDAS subtype OCD to such an extent that she had been intermittently housebound for 10 years upon first contact with the PSC. Lisa was profoundly affected in the domains of school, work, socialization, and appeared interpersonally delayed to those that knew and worked with her.

Repeated observations by student and supervising clinicians alike seem to indicate that she did not appreciate the impact that the disorder had on her and others. She knew, and often commented that her symptoms of OCD were "bad" but she appeared unable to express, in any meaningful way, how impactful they really were. For example, she had the top floor of the family home to herself, no one was allowed in her bedroom, and she was not required to eat with the family. All of this served to shield her from experiencing distress in the face of "contamination." This level of accommodation was suspected to result in a lack of insight into the severity of her disorder. A typical comment of Lisa’s was "I don’t like how this feels." By this she meant that some "contaminate" gave her a tactile feeling of discomfort, a sort of itchiness per se. She never commented that tactile feelings experienced by her body were unreasonable. She never stated an understanding that these "feelings" were unreasonable or
illogical. Nor would anyone, suffering with an "itch," ever believe that they are not itching or think that this feeling is unreasonable. This would be akin to not believing in the feelings derived from sensory organs, which is simply irrational. This is common in the PANDAS subtype OCD, and may be one reason the outcome is commonly not good.

She had also been treated with a variety of pharmacological interventions (i.e., Duloxetine HCL, Aripiprazole, Dextroamphetamine, Eszopiclone, Gabapentin, Atomoxetine, Memantine, and Escitalopram) with little or no appreciable effect. Throughout multiple pharmacological dosage schedules her Y-BOCS scores never changed by more than a couple of points. These medications appeared to do little more than stabilize her condition, if that. She had participated in both outpatient and inpatient treatments with one three-month stay at McLean Hospital in Belmont, Massachusetts. She had also traveled to Umeå University Hospital in northern Sweden to submit to a bilateral anterior capsulotomy and then some years later a unilateral anterior capsulotomy with negligible success. This appeared to do nothing for her condition, as she returned to pre-surgical severity within weeks of recovering from these surgeries.

The Y-BOCS outcome data in Lisa’s case remained nearly flat (in the severe range) for the duration of her treatment (see Figure 1). This was despite extensive, in-home ERP that has been demonstrated to be effective for even refractory cases of OCD (Rosqvist, Thomas, Egan, & Haney, 2002). The treatment regimen exceeded 344 clinical hours in a total of 159 sessions. The sessions were conducted by three expert level doctoral clinicians and more than 18 master's and doctoral level psychology student clinicians over the course of approximately two years.
Repeated instances of resistance to treatment were at times described as "adolescent rebelliousness." There were repeated reports suggesting poor adherence to interventions which she had already been participating in during prior therapy sessions. There were also questions, which always remained, as to whether or not she was performing homework outside of sessions. Although she would report completing homework on her own, when pressed she often conceded that she sometimes was not doing as instructed. There were some reports of the client needing to be physically "pushed" into exposures, sometimes calling into question whether this client truly engaged in self-directed response prevention (thought to be an important ingredient to ERP success).

The narrow-band Y-BOCS data clearly marked this as an abject failure, with little or no discernable reduction in symptom severity from start to finish of treatment. However, there was a clear, and nearly miraculous qualitative change in Lisa’s psychosocial functioning. During the time of treatment Lisa went from completely housebound (e.g., no school, friends, outside contact) to a functional long-term relationship with a member of the opposite sex, attendance at college, leaving the home, grocery shopping, clothes shopping, picking up her own prescriptions and equal chore responsibilities on the premises; all of which involved touching objects of questionable sanitation (from Lisa’s perspective, at least).

The question at hand is which is more meaningful or significant in this case, narrow-band severity indicators or qualitative and functional behavior change?
Figure 10. Lisa's average monthly Y-BOCS scores.
Analysis

Probable Causes

Based on the failure event (Y-BOCS data remaining flat) and the association with the failure mode (treatment failure) a literature, file review, and interview with Dr. Rosqvist and Lisa uncovered multiple failure hypotheses within the following categories: client factors (i.e., treatment recalcitrant PANDAS subtype OCD, "just so" tactile sensory obsessions, poor insight); social and family environment (i.e., family expressed emotion and accommodation); treatment design and implementation (i.e., prompt recognition and treatment of PANDAS, pharmacotherapy influences, psychosurgery effects); and measures of treatment effectiveness (i.e., quantitative and qualitative measures).

Client Factors

Treatment recalcitrant PANDAS subtype OCD

Obsessive-Compulsive Disorder Phenomenon, Treatment, and Failure. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000), obsessions are "recurrent and persistent thoughts, impulses or images that are experienced, at some time during the disturbance, as intrusive and inappropriate and that cause marked anxiety or distress." For example, obsessional doubt could be seen in recursively questioning whether or not the individual had locked the door upon leaving the house. Additionally, these thoughts, impulses and images are considered ego-dystonic, and as such do not simply represent excessive worries about real-life problems. The content of these obsessions are generally considered to be outside of the person’s control, and as such they are experienced as uncomfortable, unwanted, and as alien to the self. Experiencing thoughts, for example,
whether or not one actually locked the door upon leaving may in fact be useful and seen as adaptive and as self-generated; however, having distinct anxiety-provoking obsessional doubt of not having locked the door and intrusive thoughts of catastrophe of the worst kinds being the result (e.g., robbery, death of a loved one) would not be useful, adaptive, or wanted.

Compulsions are defined as "repetitive behaviors or mental acts that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly" (DSM-IV-TR; American Psychiatric Association, 2000). Some examples of compulsions include (but are not limited to): washing, checking, arranging, praying, counting, or mental rituals, as well as avoidance of situations that provoke the obsessions. These behavioral compulsions and other mental acts are utilized by the individual suffering with OCD to neutralize, prevent or reduce discomfort of some imagined anxiety provoking situation. However, neither compulsive behaviors nor mental acts are necessarily or realistically connected in any meaningful way with the anxiety provoking stimuli it is meant to ameliorate or prevent, or it is clearly in excess. For example, a person returning to the door not once, but repeatedly, to check and see if he or she had indeed locked it while turning the lock a prescribed number of times on each return. This act is meant to neutralize, prevent, or at least reduce the anxiety associated with the aversive stimuli; whatever the act, while connected thematically, often has no realistic connection with what it is supposed to neutralize or prevent, or clearly it is beyond what is necessary or reasonable.

It may be difficult to imagine just how disruptive an obsessional urge to check the security of one’s front door may become, until becoming intimately familiar with the insidious nature and the subsequently time-consuming and starkly disabling compulsions a severe sufferer of OCD may endure (Rachman & Hodgson, 1980). These troubling and intrusive thoughts can
obtain such a tenacious grip on the sufferer as to render them incapable of productive work, maintaining supportive relationships, or may outright imprison them in their own home. It would be a gross underestimation of the severity of suffering seen in OCD to assume that it can be anything less than life-altering in its course as it consumes grossly disproportionate amounts of time (Hersen & Bellack, 1999).

OCD symptoms insidiously spread into the sufferer’s entire life affecting their social, occupational and family relationships (Jenike, Baer, & Minichiello, 1998). It is in this way that compulsive rituals or the avoidance of obsessional content begin to interfere in clinically significant ways with everyday life (Salkovskis, Richards, & Forrester, 2000). In fact, OCD sufferers endure great social and work dysfunction, being as much as four times as likely to be unemployed than a member of the "normal" population (Franklin, Abramowitz, Kozak, Levitt, & Foa, 2000), and are far less likely to marry (Steketee & Pruyn, 1998).

Fortunately efficacious treatment strategies now exist for OCD. Dar and Geist (1992) specifically described ERP, which has been shown to have positive effects in approximately 70%, and upwards of 80%, of patients treated in this manner (Abramowitz, 1996; Baer & Minichiello, 1998; Koran, 1999; Steketee & Tynes, 1991), with many ending treatment within the "non-clinical" range (Foa, Franklin, & Kozak, 1998) and gains being maintained upwards of a half a decade (Baer & Minichiello, 1998).

ERP gradually, and systematically, exposes the patient to the very stimuli that they fear until they cease to be upset. Over time this process, known as habituation, affords the patient familiarity with their feared stimuli. The recommended length of time for these exposures is anywhere from 90 minutes to upwards of several hours. In this way ensuring that the patient
actually becomes accustomed to the very situations that have upset them (i.e., arriving at spontaneous decay). However, the length of time spent in these exposures can vary greatly. Initial exposures may take much longer than subsequent ones as the intensity of the fear is greater in the beginning and the patient’s familiarity with the treatment is less. Over time, as the patient gets accustomed to the process, less time may be needed in order to arrive at a satisfactory reduction in arousal. As the patient begins to habituate, with each encounter becoming less and less distressing, the exposures begin to advance up a hierarchy of feared situations until the patient, ultimately, confronts their worst fears. During exposures, the patient must refrain from engaging in their rituals that they have typically used in the presence of fear as compulsions will prevent habituation from occurring. Likewise, escape or avoidance behaviors will interfere with the extinction of anxiety. Without habituation, the feared stimulus maintains its ability to induce fear; therefore, the patient should not exit the exposure until experiencing at least a 50% reduction in their fear for the particular situation.

Despite the promise of behavioral treatments, up to 30% of patients appear treatment refractory and as many as 20% drop-out prematurely (Baer & Minichiello, 1998; Koran, 1999; Kozak et al., 2000). Some researchers have proposed that it is the irrational beliefs, reasoning, and attitudes of people with OCD that significantly reduces the efficacy of purely behavioral treatment for OCD (Steketee, Frost, Rhéaume, & Wilhem, 1998) and necessitates the use of cognitive techniques designed to address this shortcoming. They propose doing this by specifically targeting the cognitive domains (Rachman, 1997, 1998). These cognitive interventions appear to produce significant therapeutic gains in reducing irrational beliefs, but when studied carefully, ERP produces changes in irrational beliefs and obsessions as well
(Marks, 1997; Steketee, Frost, Rhéaume, & Wilhelm, 1998). Some researchers have suggested that BT actually changes cognitive sets, thus reducing obsessions while exposure therapy changes OCD patients’ cognitions via learning through exposure what is dangerous and what is not (Foa & Steketee, 1979; Whittal & McLean, 1999). Through repeated exposures the patient learns not only which situations are actually much safer than they had previously believed, they learn that the process fueling their fear is the way they are thinking. Not only are the patients contextually based cognitions changed in this manner, these fears are changed at the process level.

For those patients with OCD who find exposure therapy to be aversive, a course of CBT may be effective when expressly aimed at helping patients gauge probabilities, clarifying the reasonability of outcome projections, and increasing self-efficacy. This is done through the utilization of "behavioral experiments", much like in ERP, but without the express goal of habituation and extinction. Instead, the focus is on facing feared stimuli and gathering information that instead tests the veracity and accuracy of the maladaptive beliefs about the dangerousness and importance attributed to the stimuli themselves. According to reviews by several experts, ERP is the "gold standard" of treatment for obsessive thoughts, cognitive rituals, and is the psychosocial treatment of choice for OCD (e.g., Foa, Franklin, & Kozak, 1998; Whittal and McLean, 1999; McLean et al, 2001; Abramowitz, 2002). However, when coupled with CBT there are even greater improvements in checking rituals (Baer & Minichiello, 1998) and significant reductions in irrational beliefs (Marks, 1997).

A modified version of ERP referred to as Danger Ideation Reduction Therapy (DIRT; Jones & Menzies, 1997, 1998) utilizes cognitive exposures and reappraisals of the dangerousness
of contaminants. This is done in six stages: 1) Teaching the patient to identify unrealistic thoughts related to contamination and then to re-evaluate them via cognitive restructuring; 2) Watching filmed interviews of individuals who work in situations that are commonly feared by obsessive-compulsive patients; 3) The patient is asked to review the facts about their feared contaminant, and read information about the harmful effects of their obsessions (i.e., hand washing); 4) Discussing bacterial culturing experiments undertaken at the University of Sydney on common items (e.g., door handles, money, etc.); 5) Probability exercises that are designed to establish realistic probabilities of catastrophic events; 6) Focused meditation exercises designed to increase attentional focus. The reduction in danger expectancies and threat-based perceptions concerning disease have been demonstrated to better account for anxiety and avoidance in OCD washers than other variables (i.e., perceived responsibility and perfectionism [Menzies, Harris, Cumming, & Einstein, 2000]). Jones and Menzies (1998) demonstrated a reduction in obsessive compulsive symptoms using DIRT without ERP. In 1998, these authors did a follow-up with a controlled trial of DIRT, administering it to 21 patients. Although, they found significant results at the end of treatment, these improvements were not as large as expected in this second study. Their post-treatment scores were slightly larger than the scores obtained by patients being treated with ERP. Additionally, the scores at post-treatment were substantially higher than those obtained by "normals." The authors deduced that the first pilot group was made up of all ERP refusers (i.e., motivation for an alternative treatment option was very high), and they were treated by individual means. The controlled trial contained people who had mixed experiences with ERP, whom were treated in a group format, thus reducing attention to idiosyncratic details of obsessions and compulsions. To further complicate these studies, the reporting format of the data
does not lend itself to critical analyses so it becomes impossible to know how these studies contribute to or detract from the general trend of CT for OCD. Even so, intractable cases, with poor insight, were returned to normal functioning in as little as 14 weeks (Krocmalik, Jones, & Menzies, 2001). Govender, Drummond, and Menzies (2006) also demonstrated the effectiveness of this treatment for recalcitrant OCD hand washers with gains maintained at 6 months post-treatment.

In order to engage patients in a novel way some clinicians and researchers (Rosqvist, Thomas, Egan and Willis, 2000; Willis, Rosqvist, Egan, Baney, & Manzo, 1998) have utilized a Home-Based CBT approach with demonstrated efficacy in the treatment of refractory OCD cases.

**PANDAS Phenomenon, Course, and Effects**

PANDAS is an uncommon childhood neurological disorder. Its relationship to OCD is in the neurosubstrate of the anterior cingulate that appears to be affected by multiple childhood bacterial infections. Swedo and his colleagues (1998) publication of the first 50 cases of PANDAS marked the emergence of this highly controversial subtype of OCD into the literature. These authors suggested that an abnormal immune response to this infection might be etiological in the development of OCD and/or tic disorders. Specifically identified in many cases is Sydenham’s chorea, the Group A Beta-Hemolytic Streptococcal (GAS) bacteria that triggers an autoimmune response that reacts to the basal ganglia of genetically susceptible hosts leading to OCD and/or tic disorder (Garvey, Griedd, & Swedo, 1998). They identified the following criteria for PANDAS: Presence of OCD and/or tic disorder, pediatric onset (three years to puberty), episodic course of symptom severity, association with group A beta-hemolytic streptococcal
infections, and association with neurologic abnormalities (motor hyperactivity, adventitious movements, or choreiform movements).

The symptom severity experienced in PANDAS subtype OCD is in stark contrast to the general linear course of severity seen in childhood-onset OCD (Leonard et al., 1993). PANDAS-related OCD symptoms have a rapid onset (which can manifest in a single day) and there are acute exacerbations of symptoms associated with GAS infections (Swedo et al., 1998). These exacerbations can last for months and are marked with elevations in PANDAS-related symptoms followed by a rapid reduction to baseline.

Murphy and Pichichero (2002) reported on the atypical presentation (in contrast to childhood-onset OCD) of PANDAS patients. They reported that one-third of PANDAS patients in their study showed obsessional urges to utilize the restroom prior to leaving the home with a subsequent genital hygiene wiping ritual that may be performed upwards of 10 times in a single hour. Only small amounts of urine were excreted during each bladder voiding.

Effective treatment for PANDAS subtype OCD generally has taken the form of intravenous immunoglobulin exchange (IVIG). It has been hypothesized that IVIG would remove the deleterious autoimmune antibodies and allow a return to normal functioning for the PANDAS sufferer. In a pilot study for effective treatment of PANDAS as an autoimmune disease, Perlmutter et al., (1999) managed a 45% decrease in obsessive-compulsive symptoms in 10 patients treated with IVIG. Further, 82% of this group continued to show decreased symptoms one year post-treatment. Murphy and Pichechero (2002) commented on a study of 12 subjects who were treated with a course of antibiotics during the initial onset of PANDAS and subsequent obsessive-compulsive symptoms. All subjects demonstrated a remission of obsessive-compulsive
symptoms with half of these subjects experiencing a return of obsessive-compulsive symptoms during subsequent GAS infections. This illustrates the likely organic nature of PANDAS subtype OCD with multiple indications that an autoimmune response to infection via GAS may contribute significantly to PANDAS subtype OCD symptomology.

As previously mentioned individuals who suffer with PANDAS subtype OCD rarely achieve satisfactory outcomes, often experiencing a "saw-tooth" clinical course (Swedo et al., 1998), with even poorer outcomes associated with those who have an onset before age 20 (Skoog & Skoog, 1999). The probable impact of PANDAS on efficacious, effective, and efficient treatment may lay both in the early onset of the symptoms, which has been related to poor outcomes for OCD (Skoog & Skoog, 1999) and/or in the damage done to the anterior cingulate by the streptococcal bacteria.

File Review and Interview. In an interview with Dr. Rosqvist he reported that typical of other patients that he has treated in the past with PANDAS subtype OCD, Lisa’s presentation was one of treatment recalcitrance. The hundreds of hours of ERP, psychotropic medications, and psychosurgeries led to "less than optimal treatment outcome" as measured by the Y-BOCS (J. Rosqvist, personal communication, August 22, 2008). A review of the treatment notes revealed a consistently elevated Y-BOCS score in the severe range throughout the course of her treatment. It also revealed that despite the apparent evidence of unabated symptom severity the clinicians in this case worked diligently to obtain the best possible treatment effects. Given what is known of PANDAS subtype OCD's recalcitrant nature this represents a herculean effort on the part of the clinicians.
In the treatment hypothesis section of the intake report dated November 7th, 2005 the treating clinicians stated that Lisa’s "OCD can be treated **effectively** with intense exposure response prevention. By exposing her to contaminated objects and breaking her rules, and preventing her from washing, she can break the strong associations between her obsessions and compulsions." The treatment plan indicated that the Y-BOCS would be used as the primary source of "evidence" that Lisa's treatment was successful (i.e., Y-BOCS scores reducing from severe to moderate-mild). On December 2, 2005 the treating clinician commented that the effects of ERP should "generalize to some degree when underlying beliefs about contamination are confronted and dissolved." This was in response to Lisa expressing her fear that her symptoms would never abate and she would have to "habituate to every item she ever encounters throughout her life." On December 13, 2005 the treating clinician commented that "the goal of treatment was to **beat** the OCD." These comments would certainly be true had Lisa’s symptoms been of the garden variety OCD for which ERP is the gold standard treatment of choice. However, PANDAS subtype OCD is a treatment recalcitrant variation that is not always treated **effectively** nor is it often **beaten** by ERP. This knowledge did not appear to diminish the clinician’s resolve to put forth their best effort to effect the best possible outcome in Lisa's case.

In an interview with Lisa (personal communication, August 22, 2008) she reported that she never got better (here referring to her level of distress in regards to obsessional content) but that she was able to tolerate significantly higher levels of previously aversive stimuli due to repeated exposures. The consistent efforts made by Lisa and the treatment team, in the face of an apparently treatment impervious condition, had a significant positive effect on this patients quality of life.
**Analysis.** This cause could not be ruled out. There was ample literature, file review data, and interview evidence supporting the negative effects of treatment recalcitrant PANDAS subtype OCD on prognosis. A literature review and interview with Dr. Rosqvist and Lisa (personal communication, August 22, 2008) illuminate this as a primary cause of treatment failure. However, one must consider the subjective definition of success. There is ample evidence available in the literature, as well as anecdotal knowledge concerning PANDAS subtype OCD’s treatment recalcitrant nature. There were indications that the treatment team may have had more faith in the effectiveness of ERP in successfully ameliorating Lisa's symptoms than could have been possible. However, this "zealousness" contributed significantly to increases in Lisa's psychosocial functioning. There was an astounding amount of qualitative success (i.e., increases in psychosocial functioning) in this case as was illuminated by file review and interviews with Dr. Rosqvist and Lisa. Thus, the subjective sense of failure in this case was related to clinician expectations of greater treatment effects than are possible, reliance on quantitative measures (i.e., Y-BOCS data) as the sole indication of treatment effectiveness, and ignoring qualitative markers of success.

"Just So" Tactile Sensory Obsessions

"Just so" tactile sensory obsessions constitute the use of an internal reference point stopping criteria for compulsive neutralization of anxiety related to obsessions (Salkovskis, 1999). In other words, utilization of the way one "feels" in relationship to the prescribed ritual, and only terminating it when it has reached a point of "just so" tactile or sensory "perfection." This counter-productive termination criteria utilized by some obsessive-compulsives, especially those with PANDAS etiology, significantly reduces treatment effectiveness (J. Rosqvist,
personal communication, August 18, 2008). Rasmussen and Eisen (1992) described an inner
drive in patients with OCD that appeared to be connected to a wish for things to be perfect,
certain, or completely under control. These patients were driven to perform obsession related
compulsions and rituals until they had achieved a tactile or sensory state equated to a "just so"
sensation. It would appear as if, for these individuals there is a mismatch between sensory input
and the perceptual expectations of the individual themselves. If these mismatched sensory and
perceptual experiences are interpreted by the individual sufferer as catastrophic the result would
likely be anxiety and distress (Coles, Frost, Heimberg, & Rheaume, 2003). Foa, Abramowitz,
Franklin, and Kozak (1999) found that individuals whose symptoms were motivated by "just so"
tactile sensory perceptual experiences showed a trend towards having more severe post-treatment
symptom scores than those who were articulating a symptom cluster motivated by fear of
catastrophic outcomes of blocked compulsions and/or rituals. In other words, having a "not just
so" experience was the feared consequence. Wahl, Salkovskis, and Cotter (2008) discussed
perceptual mismatch of physical sensations, emotional states, and stopping criteria for OCD
sufferers who utilized a "just so" paradigm when washing their hands could accurately predict
compulsive and ritualized behaviors from "normal" behaviors. Typical exposures would likely eliciting "not just so" experiences, but specifically designing exposure exercises with the express
goal of eliciting these dissonant perceptual experiences would be necessary to improve treatment
outcomes.

File Review and Interview. A review of the file indicated that "Just so" tactile sensory
obsessions were present in the patient and they were a direct target of exposure sessions. In the
intake report dated November 7, 2005 it was noted that Lisa's primary presenting problem was a
sense that something catastrophic would happen to her loved ones (i.e., the death of her dog or
father) if she came into contact with objects or people that were "dirty" or "contaminated" (i.e.,
computer keyboards, smokers, the inappropriately dressed, poor, homosexual, her mother). She
did not fear death or illness as a result of contact with contaminated people; rather, she was
afraid of feeling dirty and then "not caring about being dirty." Lisa indicated she would engage in
cleaning rituals to reduce her catastrophic sense of impending doom until she felt "just right" or
"perfectly" cleansed (meaning a tactile perceptual sensation). This theme appeared consistently
throughout the treatment notes contained in the file. On May 25, 2007 Lisa was even noted as
endorsing "feeling gross" (meaning a tactile sensation) while in contact with "contaminated"
items and being unduly disturbed by this. Dr. Rosqvist confirmed that continual efforts to
eliminate the "just so" obsessions met with "limited" success (J. Rosqvist, personal
communication, August 22, 2008). He reported that although the client gradually "tolerated"
more exposure to stimuli that were not conducive to her "just so" tactile sensory obsessions, the
severity of her distress appeared to remain unaccountably high. He reported that this should have
been expected considering the treatment resistant nature of these particularly vexing obsessions,
and described her increased tolerance of discomfort in their presence as "treatment success."

A personal interview with the client (Lisa, personal communication, August 22, 2008)
confirmed Dr. Rosqvist’s observation. She reported that although she could "stand it longer"
(referring to "just so" obsession exposures) her distress never wavered. Also, she reported that as
a result of her greater tolerance for distress, obtained through exposure therapy, she was able to
function more independently. It should be noted that that even when she performed more
activities that were unpleasant for her, the Y-BOCS data never decreased. The likely conclusion
is that her functioning was better than her Y-BOCS data suggested. When she began treatment with Dr. Rosqvist and his team she was nearly disabled with OCD yet her Y-BOCS scores were the same as when she was performing well during treatment. As her level of discomfort was always in the severe range the real issue in this case was how much was she capable of doing despite her terrible tactile discomfort. Thus the treatment resistant nature of "just so" tactile sensory obsessions led to what would appear to have been a quantitative failure (i.e., Y-BOCS data remaining in the severe range) while there was a subjective sense of treatment success for both Dr. Rosqvist and the patient.

Analysis. This cause could not be ruled out. There was ample literature, file review data, and interview evidence supporting the negative effects of tactile sensory obsessions on prognosis, especially for PANDAS subtype OCD. However, the failure in this case is in relation to clinician expectations that amelioration of "just so" tactile sensory obsessions could be effected and would be evidenced by a reduction in Y-BOCS scores. There was ample evidence that the client was able to tolerate higher levels of distress and displayed the ability to function independently, even when encumbered by persistent and severe "just so" tactile sensory obsessions that contributed to continually elevated Y-BOCS scores.

Poor insight

Poor insight has been considered a poor prognostic indicator (Kozak & Foa, 1994) with overvalued ideation in regards to seemingly senseless obsessions and compulsions being correlated with an attenuated response to even psychological and pharmacological treatments that have been shown to be otherwise efficacious in the treatment of OCD. Determination of poor insight, other than clinical interview and clinician insight can be done utilizing a single item
on the Y-BOCS (Goodman et al., 1989). Item number 11 which is rated on a 5-point scale reads "I think my obsessions or compulsions are unreasonable or excessive", which is a 0, to "I am sure that my obsessions or compulsions are reasonable, no matter what anyone says", which is a 5. At least two studies have found correlations between severity of OCD symptoms and poor insight as indicated on item 11 of the Y-BOCS (Catapano et al., 2001; Matsunaga et al., 2002). It is interesting to note that these two studies also mentioned comorbid depression and cited it as, when co-occurring with OCD, to be related to poorer insight and outcomes.

A single item on one instrument is likely insufficient for assessing the insight of an individual on such a complex presentation as OCD. To that effect there are at least three instruments which have been developed for making determinations of the level of insight that an individual with OCD may possess (none of which were used in the case of Lisa). These scales are the Overvalued Ideas Scale (OVIS; Neziroglu, McKay, Yaryura-Tobias, Stevens, & Todaro, 1999), the Brown Assessment of Beliefs Scale (BABS; Eisen et al., 1998), and the Fixity of Beliefs Questionnaire (FBQ; Foa & Kozak, 1995).

It should be noted that a rather thorough search for scholarly articles related to treatment outcomes in OCD with poor insight returned very little data. This is surprising given the rather extensive research that has been done on OCD in general. In at least one study (Tolin, Maltby, Diefenback, Hannan, & Worhunsky, 2004) ERP was found to be generally effective for treating individuals with OCD, poor insight, comorbid disorders, and who had failed several trials of pharmacotherapy while another (Foa, Abramovich, Franklin, & Kozak, 1999) found extremely poor insight to be correlated with less symptom reduction in response to ERP when compared to OCD patients with higher levels of insight. A few studies (Catapano et al., 2001; Neziroglu,
2004) were found that related a poor response to pharmacotherapy with serotonin reuptake inhibitors (SRI’s) and poor insight (as measured by item 11 on the Y-BOCS) but only as related to compulsions.

*File Review and Interview.* A file review uncovered that during her initial intake at the PSC dated November 7, 2005 Lisa reported that she knew her obsessions were "stupid" and "weird." At this time she was also noted as being "mildly depressed." On November 29, 2005 she was noted as saying that she was afraid she would "never get better" and felt like "my OCD is the boss." On December 2, 2005 she stated that she was concerned she would "have to habituate to every item" she ever encountered throughout her life. On December 13, 2005, April 4, 2006, and again on June 9, 2006 she reported feeling "hopeless" about ever getting "better." This is a significant level of insight into the severity of her obsessions. Especially when considering that her symptoms, as measured by the Y-BOCS, self report, and clinician observation, were not abating, and PANDAS subtype OCD is generally treatment recalcitrant. Interestingly this evidence of insight also coincides with either low levels of depression or none at all as measured by client report or BDI-II. In the intake report dated November 7th, 2005 the treating clinicians stated that they intended to "break the strong associations between her obsessions and compulsions" as a treatment strategy.

When interviewed about the veracity of her obsessions (Lisa, personal communication, August 22, 2008) she stated that she "knew" they were "ridiculous" but that did not decrease the amount of distress she felt when she resisted them. This was supported by multiple selections of "I think my obsessions or compulsions may be unreasonable or excessive" a 2 (indicating fair insight) on item 11 on the Y-BOCS (i.e., November 17, 2006; December 1 & 8, 2006; January
12 & 26, 2007; February 2, 9, & 16, 2007; July 26, 2007). It should be noted that on at least four occasions she endorsed "I don't think my obsessions or compulsions are unreasonable or excessive" a 3 (indicating poor insight) on item 11 of the Y-BOCS (November 9 & 27, 2006; February 2 & 19, 2007) perhaps indicating an overvalued ideation. She further reported that she often times "just went along with her obsessions because it was too hard to fight it all the time."

Dr. Rosqvist described Lisa's difficulty fighting her obsessions as "akin to having an itch." Having an "itch" was an undeniable sensation that could not be challenged as unreasonable because of the organic nature of this particular manifestation of PANDAS subtype OCD. Thus, challenging her obsessions may have been unreasonable and unlikely to succeed. The only option was to increase the level of "itch" she could tolerate, as her symptoms would never truly abate. If she was unable to continually increase her "itch" tolerance, and because she would never be able to make that go away nor disprove its veracity, then she must learn to tolerate it. Only by habituation could this happen. However, Dr. Rosqvist reported that she was constantly accommodated by her family, occasionally displayed poor therapeutic and homework engagement and completion, and her tolerance never permanently increased. Instead her reactivity followed a saw tooth course, marked by changes in her psychosocial functioning, but generally remained high.

Analysis. This cause could not be ruled out. There were indications that Lisa recognized the severity of her disorder and its treatment recalcitrance. She also often recognized that her obsessions were unreasonable and excessive. However, the interview and file review suggests that Lisa lacked insight into the link between her compulsive behaviors in response to her obsessions and how these compulsions drastically altered her, and her families, quality of life.
This link between behavior and quality of life was not the direct target of therapy. The intake report dated November 7th, 2005 indicated that the target for therapy was to "break the strong associations between her obsessions and compulsions," which is the standard target of treatment for OCD. This may have contributed to Lisa consciously deciding not to challenge her obsessions consistently. Considering the severities of her particular symptoms, the recalcitrant nature of PANDAS subtype OCD in general, and accommodations provided by her family this acquiescence comes as no surprise.
Figure 11. Client factors logic tree.
Social and Family Environment

*Family expressed emotion and accommodation*

Chambles and Skeketee (1999) found that non-hostile family criticism directed towards the client was associated with better outcome while relatives' emotional over-involvement and hostility predicted higher rates of treatment dropout. Family criticism, hostility, and emotional over-involvement towards clients, referred to as expressed emotion (EE), may directly influence the severity of OCD (Steketee, Van Noppen, Lam, & Shapiro, 1998; Van Noppen & Steketee, 2003). Links to more severe symptoms in childhood OCD and high parental EE were made by Hibbs et al. (1991), while relapse in adults with OCD and high familial EE was predicted by Emmelkamp, Kloek, and Blaauw (1992). Steketee (1993) reported lower gains from clients who reported angry and critical interactions with their families. Clients who perceived hostile criticism and emotional over-involvement from their families were found to have higher dropout rates and poorer treatment outcomes (Chambles & Steketee, 1999). Family criticism, whether real or imagined, conveys a lack of trust in the client’s ability to master their symptoms, fostering rather than reducing OCD symptoms (Fredman, Chambless, & Steketee, 2004). Perceived criticism was also found to be predictive of negative treatment outcomes for patients with OCD and panic with agoraphobia (Chambles & Steketee, 1999).

Emotional over-involvement may be linked to familial accommodations (i.e., participation in rituals, modification of personal routines, accommodating avoidance, taking on client responsibilities), and is more common in families with high levels of intrusiveness, poor boundaries, and lack of role definitions (Calvocoressi et al., 1995). Presumably these family accommodations are meant to reduce the distress accompanying symptoms and treatment, but
 unknowingly encourage increased symptom severity, dysfunction, and relatives stress. Amir, Freshman, and Foa (2000) reported attenuated response to behavioral treatments in clients whose relatives accommodated their compulsions while Grunes, Neziroglu, and McKay (2001) found improved responses to behavioral treatments for clients whose families disengaged from accommodating compulsions. Family accommodations have been linked back to family over-involvement (Leonard et al., 1993; Steketee et al., 1998).

**File Review and Interview.** An interview with Dr. Rosqvist uncovered information that indicated exceptionally high levels of emotional over-involvement and family accommodation was taking place. It was noted in the intake dated November 11, 2005 that Lisa's "parents and family also accommodate her symptoms, as evidenced by providing her a home and following her rules." Both Dr. Rosqvist and Lisa agreed during the interview on August 22, 2008 that Lisa's "rules" resulted in multiple accommodations. For example the family had practically "given" Lisa a significant portion of the top floor of the house to use as her own while the family generally stayed in the basement. She also had no chore responsibilities while the rest of the family had multiple. She had her own door into the house that no one else was allowed to use. She was given her own bathroom and bedroom which were off limits to the rest of the family. Her family paid all of her bills, kept her truck full of gas but never touched it, etc., etc. She was allowed to live in an OCD bubble as it were, symptoms rarely challenged, and in fact because of the secondary gain associated with her illness, and significant discomfort of challenging her symptoms, it may have been more beneficial for her to never improve. Also, her parents set up a large savings account that would ensure her ability to continue existing "as is" (even if she was completely disabled due to the severity of her OCD) without ever changing. She would have
enough money, should her parents pass on, to continue therapy, medication use, eating, car payments, and so on. They also supported her in not completing high school, shopped for her, picked up her medications; in short they did everything for her that she did not want to do.

**Analysis.** This cause could not be ruled out. There was ample literature, file review data, and interview evidence supporting the negative effects of family expressed emotion and accommodation on prognosis. Family accommodations were consistently present in the patients file from the initial intake up until the termination of therapy. Lisa reported, and Dr. Rosqvist confirmed (personal communication, August 22, 2008), that these factors were still, and in fact had always been, present. She did report significant increases in her ability to perform her own chores, shop for her medications, as well as use other areas of the house and allow others to use some of hers. However, she reported that it was "easier to not fight the OCD" and often was "better to just go with it." It was Dr. Rosqvist’s opinion, based upon his years of experience treating patients with OCD, that if her environment never changed, her stasis would remain unchallenged, and under those conditions change, for her, would be undesirable, difficult, or impossible to obtain. Considering the consistent, severe, and refractory nature of Lisa's symptoms one can imagine just how difficult it must have been for her family to wage an apparently endless battle with PANDAS subtype OCD. This would have been exhausting and demoralizing as hours, days, months, and then years passed without symptom abatement. It comes as no surprise that they engaged in accommodation when faced with this seemingly insurmountable challenge.

*Social delay*
In a personal communication with Jay Thomas, Ph.D, ABPP (September 05, 2008) he suggested that if a person had a reasonably normal lifestyle before a disorder, then, unless there were negative changes in factors such as family support, money, and so on, then the treatment of the disorder and symptom amelioration should allow them to return to, at least closely, the previous lifestyle. However, if the individual never developed a lifestyle that was before or outside of the disorder, then he or she may have nothing to return to. In order to deal with a situation such as this he suggested that treatment would need to include "building a new lifestyle." Considering the early onset of symptoms in Lisa's case it would be hard to imagine a lifestyle, at least an adult one, with all of its associated components (e.g., social contacts and skills, responsibilities, learning opportunities, etc.), having ever been developed. Unfortunately, a literature search produced no empirically validated studies relating social delay to poor prognosis in OCD in general or the subtype related to PANDAS.

File Review and Interview. An interview with Dr. Rosqvist (J. Rosqvist, personal communication, August 22, 2008) revealed that Lisa did appear to be socially delayed. Statements made by Lisa during intake (November 11, 2005) indicated that she struggled significantly with social delays due to her OCD. She reported "having no close friends in the Portland area" and expressed a desire to "have friends" but was "scared and worried" that her "OCD behaviors and rules" would interfere with enjoying their company. Dr. Rosqvist stated that she often appeared to him to be 4-6 years younger than her stated age. She was intermittently housebound over the course of 10 years and had not attended public schools during much of that time. Clearly the formative experiences that many would take for granted, and that are necessary to become an effective adult, simply could not have been available to Lisa. Dr. Rosqvist stated
that social skills training was a part of Lisa’s treatment, and evidence of her increasing efficacy in this area could be noted in her work with the various therapist and providers involved in her case. There was also undated photographic evidence of Lisa being taken on social events with the clinicians (e.g., rock climbing, a park, the zoo). Despite this, in an interview with Lisa (personal communication, August 22, 2008) she reported substantive social difficulties. An example she gave was maintaining the relationship with her boyfriend due to her fears of "contamination" and "icky feelings" caused by contact with his body and the stress associated with her OCD rituals to make contact feel "right." She also reported confusion when dealing with complicated social interactions, a sense of "disconnection" from peers of her own age, and fears of becoming contaminated when she went to the university. Her reaction to this was to avoid human interaction whenever possible or engaging in rituals to reduce discomfort. This was supported by file evidenced found in the intake (November 7, 2005) in which she reported often engaging in "obsessive-compulsive behaviors in class due to contaminated people" significantly reducing her ability to function amongst and with her peers.

**Analysis.** This cause could not be ruled out. There was ample file review data and interview evidence supporting the negative effects of social delay on prognosis. Interviews with Lisa and Dr. Rosqvist and a review of the file data indicated that Lisa was considered to be "socially delayed," thus lacking the skills that are necessary to function adequately at an adult level. However, there is some evidence that Lisa was able to negotiate social interactions outside of medical professionals, therapists, and family. However, she was unable to maintain this level of functioning and in fact she returned home to college and became partially housebound again. The likely cause of her inability to continue to function at his level was directly related to her
severe and recalcitrant symptoms associated with PANDAS subtype OCD. Thus, social delay appears to have been as much a result of her symptoms as it was an exacerbating factor.
Figure 12. Social and family environment logic tree.
Treatment Design and Implementation

Prompt recognition and treatment of PANDAS

The efficacy of pharmacological treatments has been supported for PANDAS subtype OCD. Specifically intravenous immunoglobulin and plasma exchange (Perlmutter et al., 1999; Murphy et al., 2006) were found to be associated with a 45% to 58% decrease in Y-BOCS scores at 1 month. At 1 year reductions on the Y-BOCS were even more significant at 58% to 70%. However, both of these procedures are extremely invasive and often came with severe side effects (i.e., dizziness, nausea, and headache) and many youths experienced residual symptoms at a 1 month follow-up. Antibiotic prophylaxis was found to be effective in those with new-onset OCD and GAS infection showing a rapid reduction in PANDAS-related OCD symptoms (Murphy & Pichichero, 2002). However, once the infection has cleared antibiotics are no longer clinically indicated. This form of treatment is only effective in the acute phases of the disorder.

There is strong data to support the application of CBT alone or in combination with sertraline for pediatric OCD (Pediatric Treatment Study Team, 2004). Barrett et al. (2004, 2005) remarked on immediate and sustained improvements associated with individual or group CBT family based therapy. In one case involving a 6-year-old with PANDAS subtype OCD (Storch et al., 2004) the results were nothing short of miraculous with Children’s Yale-Brown Obsessive Compulsive Scale (CY-BOCS) going from 34 (severe) to an 8 (mild) post-treatment with treatment gains maintained at 1 year. Storch et al. (2006) confirmed the viability of CBT for use in pediatric PANDAS subtype OCD with a waitlist controlled open trial in which six of seven patients (ages 9 to 13) were treatment responders and three of the six remained so at follow up.
**File Review and Interview.** A file review uncovered a lengthy medical history relevant to this investigation. Between four and eight years of age Lisa had 22 doctor visits for sore throats, fever, swollen lymph glands, headaches, ear aches, coughs, and fatigue. She was diagnosed with strep throat at the age of five. At the age of six she was diagnosed with "anxiety" and at the age of eight her mother noted that Lisa began showing symptoms of OCD contamination fears. In the Fall of 1996 when Lisa was 10 years old she had an OCD "symptom flair" and she was taken to a specialist who theorized that Lisa was suffering from PANDAS. Lisa was prescribed a course of penicillin. At this time it is also noted that there was an inflammatory process in Lisa's caudate nucleus and her OCD symptoms significantly worsened. She continued to receive antibiotic treatment for a total of two years. In a note written by Lisa's mother on November 14, 2005 she stated that treatment with penicillin "did not have a noticeable effect of OCD symptoms or on illnesses." This observation of treatment resistance was supported by a notation made by the treating specialist on June 6, 1998 in which he stated, in regards to antibiotic treatment for Lisa's symptoms, "I can't see that it is doing any good." An interview with Dr. Rosqvist and Lisa (personal communication, August 22, 2008) revealed that she did not receive any PANDAS specific biological treatment other than penicillin prior to therapy with the treatment team at the Psychological Service Center.

**Analysis.** This cause could not be ruled out. There was ample literature supporting the negative effects that late recognition and treatment of PANDAS has on prognosis. File review evidence indicated that PANDAS was not suspected until Lisa was 10 years old. By that time Lisa had at least 22 visits to the doctor for strep like illnesses. Lisa was treated with a course of antibiotics at 10 for PANDAS but it appeared to be resistant to this intervention and in fact her
symptoms continued to worsen during treatment. The failure in this case appears to be related to clinician expectations of greater treatment effects than may have been possible. By the time Lisa was undergoing treatment at the PSC it was confirmed that she had been suffering from treatment recalcitrant PANDAS subtype OCD for at least 12 years. Treatment goals relying on reductions in Y-BOCS scores as evidence of success and clinician expectations of symptom abatement would not be reasonable given what is known about this particularly vexing manifestation of OCD.

*Pharmacotherapy Influences*

As previously noted effective pharmacological treatment for PANDAS subtype OCD generally has taken the form of intravenous immunoglobulin exchange (IVIG, Perlmutter et al., 1999). Patients treated with this modality had a 45% decrease in obsessive-compulsive symptoms with 82% of this group continuing to show decreased symptoms one year post-treatment. Antibiotics are also a first line treatment of choice (Murphy & Pichechero, 2002). Subjects who were treated with a course of antibiotics during the initial onset of PANDAS and subsequent obsessive-compulsive symptoms demonstrated a remission of obsessive-compulsive symptoms with half of these subjects experiencing a return of obsessive-compulsive symptoms during subsequent GAS infections. This illustrates the likely organic nature of PANDAS subtype OCD with multiple indications that an autoimmune response to infection via GAS may contribute significantly to PANDAS subtype OCD symptomology.

Greist and colleges (1995) robust meta-analysis of four large multicenter placebo-controlled studies indicated that patients with OCD respond well to serotonin reuptake inhibitors (SRI’s) and selective serotonin reuptake inhibitors (SSRI’s). These beneficial effects were
maintained as long as treatment continued. These studies suggest that approximately 70% of OCD patients will see moderate improvements in symptoms through the use of these drugs with at least 50% of these patients seeing a 50% symptom reduction (Ballenger, 1999). The specific action of these drugs is on the serotonergic neurotransmitter system, with antiobsessive effects (Zohar, Mueller, Insel, Zohar-Kadouch, & Murphy, 1987). Two studies (Catapano et al., 2001; Erzegovesi et al., 2001) compared the effects of SSRI’s on OCD patients with poor insight and found significant improvement in those with and without poor insight.

Despite the 70% treatment efficacy of SRI and SSRI’s some patients may be considered treatment-resistant. Augmentation may be called for when there is partial or no responses to the SRI and SSRI’s. Antipsychotics and atypical antipsychotics have been found to be somewhat effective in alleviating OCD symptoms in some partial responders or non-responders (Ravizza, Barzega, Bellino, Bogetto, & Maina, 1996; Hollander, Baldini, Rossi, Sood, & Pallanti, 2003; Bystritsky et al., 2004; Erzegovesi, Guglielmo, Siliprandi, & Bellodi, 2005). Neuroleptic medications, most commonly used to treat psychotic disorders such as schizophrenia, have been found to be an effective method of augmenting SRI and SSRI medications for OCD symptoms in partial or non-responders (Mcdougal, 1997; Fitzgerald, MacMaster, Paulson, & Rosenberg, 1999).

Augmentation of SSRI’s with psychostimulants (i.e., Dextroamphetamine and Atomoxetine) have been found to be effective for patients with childhood-onset OCD with partial or no response to SSRI treatment. Patients treated in this way showed subsequent reductions of their symptoms when SSRI medications were augmented with psychostimulants (Albucher & Curtis, 2001; Owley, Owley, Leventhal, & Cook, 2002).
Augmentations with Gabapentin, an anticonvulsant medication, has some anecdotal evidence of possible efficacy in OCD treatment when used in conjunction with SSRI’s (Cora-Locatelli, Greenberg, & Martin, 1998).

A report of two cases of refractory OCD treated with an augmentation of memantine (Memantine) at 15 mg/day (Pasquini & Biondi, 2006). The first case did not benefit from such treatment, while the second showed immediate and substantial improvement. Another study (Poyurovsky, Weizman, Weizman, & Koran, 2005) found memantine to be well tolerated and resulted in clinically significant reduction of OCD symptom severity. These authors reported that memantine may be an option for treatment-resistant OCD, but controlled studies are needed to substantiate this observation.

*File Review and Interview.* In an interview with Lisa she reported, to the best of her recollection that she had never been treated with IVIG or plasma exchange. The medical records indicate that she began treatment with antibiotics (i.e., penicillin) at the age of 10 when PANDAS had first been hypothesized and this continued for two years. After two years the treating physician was noted as saying that he couldn't "see that it was doing any good." This observation was echoed by Lisa's mother in a note found in the file dated November 14, 2005. In that note Lisa's mother stated that "penicillin did not have a noticeable effect on OCD symptoms or on illnesses."

Lisa reported having been treated with a variety of pharmacological interventions. These included: Duloxetine HCL, a Selective Norepinephrine Reuptake Inhibitor (SNRI) for depression; Aripiprazole, a neuroleptic antipsychotic used to augment her SRNI and SSRI use, Dextroamphetamine used to augment her SSRI use; Eszopiclone, for insomnia; Gabapentin, an
anticonvulsant, used to augment her SSRI use; Atomoxetine, also for ADHD, used to augment her SSRI use; Memantine, a drug commonly used for the treatment of Alzheimer’s disease, used to augment her SSRI use; and Escitalopram, an SSRI use for treating her symptoms of OCD. It is clear from the Y-BOCS data that these medications, despite their demonstrated efficacy in treating OCD both separately and as augmenting agents, had little appreciable effect on changing her scores; her Y-BOCS scores remained nearly flat throughout treatment. The types of drugs utilized were found in the file, along with dosages taken, schedules, and accurate data indicating when medication changes were made. An interview with Lisa supported the file data. She reported having been through multiple pharmacological dosage schedules, yet her symptoms never abated.

Analysis. This probable cause does not appear to be appropriate in this case. During treatment at the PSC Lisa went through multiple pharmacological dosage schedules and her Y-BOCS scores never changed by more than a couple of points. Lisa reported taking them as scheduled, as prescribed, and consistently. These medications, despite their demonstrated efficacy in treating both the symptoms of PANDAS and OCD, never appeared to effect a significant or profound change in her condition.

However, there is another way of viewing the effects of medications on Lisa's condition. Although the medications appeared to have "failed," the failure was actually related to other factors. Either Lisa was treated to late (i.e., antibiotics prescribed years after multiple strep like infections), her condition only partially responded, was treatment resistant, or was completely recalcitrant. It has been demonstrated repeatedly that Lisa's particular PANDAS subtype OCD has been highly resistant to other well supported efficacious treatments (i.e., ERP,
psychosurgery, antibiotics) and outright recalcitrant (i.e., Y-BOCS scores consistently in the severe range). Thus, she was unlikely to habituate completely during exposure sessions and medications appeared to contribute in some was to stabilizing her condition. Had these medications not been utilized it is difficult to say if she would have been able to participate at all in therapy, socializing, or any of the activities she was able to do during her life.

**Psychosurgery effects**

Historically psychosurgery, specifically anterior capsulotomy, enjoyed some popularity as a viable treatment option. The aim of an anterior capsulotomy is to interrupt the supposed fronto-thalamic connections in the anterior limb of the internal capsule. This is where the fronto-thalamic connections are hypothesized to pass between the top of the caudate nucleus and the putamen. The exact area that is targeted is in the anterior third of the anterior limb of the internal capsule 5 mm behind the tip of the frontal horns, 20 mm lateral to the midline at the level of the intercommisural plane (Bingley, Leksell, Meyerson, & Rylander, 1977). Lesions are then created by thermocoagulation using a bipolar electrode system or using a Gamma knife. Bingley et al. (1977) reported that of 116 patients, 50% of patients with obsessional neurosis and 48% of depressed patients had a satisfactory response; whereas, only 20% of patients with anxiety neurosis and 14% of patients with schizophrenia were improved. Only patients who were free of symptoms or markedly improved were included in the satisfactory response data. Nine patients with schizophrenia, 4 with depression and 3 with OCD were rated as worse after capsulotomy. In another series of operations reported by Mindus et al. (1987) 35 patients with OCD underwent capsulotomy 16 of which were rated as free of symptoms and 9 were considered "much improved" for an overall satisfactory result of 70%. In a review of all cases of capsulotomy
previously reported in the literature, Mindus et al. (1987) found sufficient evidence to place 137 of 213 patients in the satisfactory results category. There was no evidence of cognitive dysfunction reported out of 200 capsulotomy patients studied (Mindus et al., 1987). Two patients required reoperation with only one achieving satisfactory result. Burzaco (1981) performed a second operation on 17 of 85 patients and reported satisfactory results in all cases.

Despite its former popularity, more recently Mindus and Nyman (1991) reported on 24 patients with complications from the surgery which included confusion during the first week in 19 of 22 patients, with occasional nocturnal incontinence. One patient suffered an intracranial hemorrhage and another suffered seizures. One patient committed suicide and another 8 patients suffered from depression severe enough to require treatment. Excessive fatigue was noted in 7 patients, 4 demonstrated memory impairments. Two patients showed slovenliness and weight gain was also found to be common after capsulotomy (mean weight gain of 10% for all patients). Kullberg (1977) reported on six of 13 capsulotomy patients who were improved after surgery. However, marked deteriorations in mental status were noted in the patients after cingulotomy was performed.

More recent studies report far less impressive results than earlier ones (Irle, 1998; Jenike, 1991; Baer, 1995. They reported significant therapeutic response (> 35% reduction in Y-BOCS score) to capsulotomy in only 30-60% of surgical patients. With the inherent risk involved in making permanent changes to the brain, and with newer, less invasive and efficacious therapies available psychosurgery has become an intervention of last resort.

File Review and Interview. In an interview with Lisa she reported feeling less socially inhibited in the months following her surgery, which may have led to slightly improved
psychosocial functioning. This was confirmed by Dr. Rosqvist. Lisa also stated that there was very little appreciable or lasting effects from these surgeries on her OCD symptoms; this was also confirmed by Dr. Rosqvist. The Y-BOCS data also indicated that psychosurgery had little or no appreciable effect of her scores; they remained nearly flat throughout treatment.

*Analysis.* This probable cause can be ruled out. After two psychosurgeries Lisa’s Y-BOCS scores never changed by more than a couple of points. Surgical interventions appeared to do very little to improve her OCD symptoms. However, she did report feeling less socially inhibited in the months following her surgery, which may have led to slightly improved psychosocial functioning. This was confirmed by Dr. Rosqvist. Thus, although the psychosurgery was a "failure" per se (i.e., did not alleviate OCD symptom distress), the positive changes in Lisa's psychosocial functioning, the subjective treatment success in this case, was apparently boosted to some degree by the psychosurgery.
Figure 13. Treatment design and implementation logic tree.
Measures of Treatment Effectiveness

*Quantitative Measures: Yale-Brown Obsessive Compulsive Scale*

Of particular interest for the quantitative assessment of OCD is the Y-BOCS, which represents a simple yet comprehensive symptom checklist and severity rating system. The Y-BOCS is designed as a measure of symptom severity for OCD that can be used regardless of the type of obsession or compulsion that is present. It includes symptom descriptions, examples, checklists, parameters, and investigative items of interest. The Y-BOCS is considered to be valid, contains a high degree of internal consistency, and has strong interrater reliability (Goodman, Price, Rasmussen, Mazure, Delgado, Heninger, & Charney, 1989; Woody, Steketee, & Chambless, 1995; Steketee, Frost, & Bogart, 1996). Worth noting is the fact that 85 to 90% of ordinary people experience the same intrusive thoughts, images, and impulses as clinical samples do (e.g., death, disease, germs, harm to self or others, illogical or magical thinking, [Ladouceur et al., 2000; Rassin et al., 2000; Steketee, 1999]) yet do not appear to reach clinically significant levels of distress. Those who do suffer clinically significant distress (i.e., sufferers of OCD) do so because they place significant and distressing meaning upon these intrusive thoughts. It is in this fashion that, coupled with excessive cognitive monitoring for these ego-dystonic thoughts, the sufferer of OCD begins to feel a sense of anticipatory dread and heightened anxiety (Wroe & Salkovskis, 2000). Amelioration of these unwanted intrusions is attempted through ritualistic behaviors aimed at reducing them, with the paradoxical effect of increasing the occurrence rate and severity of intrusive thoughts (Purdon & Clark, 2000; Salkovskis, Forrester & Richards, 2000). The Y-BOCS appears to be a reliable, internally consistent, valid, effective and is the "gold standard" means of measuring the severity of symptoms in OCD.
**File Review and Interview.** A review of the file indicated that the Y-BOCS was administered consistently, correctly and under the direction of the clinical supervisor. Then this data was collected and summarized in the notes. As was previously noted the Y-BOCS was used as the primary source of "evidence" of whether or not Lisa's treatment was successful (i.e., Y-BOCS scores reducing from severe to moderate-mild). In fact the entire treatment hypothesis for decreasing "the severity of OCD" of the intake report dated November 7th, 2005 was based on this Y-BOCS "evidence."

An interview with Dr. Rosqvist indicated that the use of quantitative data collected from the Y-BOCS, may have been inappropriate as a complete gauge of therapeutic change (J. Rosqvist, personal communication, August 22, 2008). He cited extensive qualitative changes made by the client throughout treatment as a better indicator of treatment success. During the time of treatment Lisa went from completely housebound (no school, friends, or outside contact) to a semi-functional long-term relationship with a member of the opposite sex, attendance at college, leaving the home, and equal chore responsibilities on the premises. Thus, indications of treatment success could not have been gleaned from the Y-BOCS data alone as it is not capable of capturing this type of qualitative change.

**Analysis.** This cause could not be ruled out. However, it is only in association with clinician expectations and therapeutic goals which relied far too heavily on changes in the "gold standard" Y-BOCS scores. The use of quantitative data alone has been shown in this case to not be capable of capturing the significant qualitative transformation that the patient went through during treatment.
Qualitative measures: the Global Assessment of Functioning Scale

The Global Assessment of Functioning (GAF) is considered the standard method for communicating a clinician's professional opinion of a patient's overall psychosocial functioning. It is the most commonly used qualitative measure of impairment for psychiatric and substance use disorders alike (Endicott, Spitzer, Fleiss, & Cohen, 1976; Piersma, Boes, 1997). The clinician makes a subjective judgment about the patient's psychological, social, and occupational functioning. In DSM-IV-TR, the GAF is on a scale ranging from 1 (severe impairment) to 100 (superior functioning) (DSM-IV-TR; American Psychiatric Association, 2000).

The GAF was designed as a supplement to existing diagnostic information about the patient's symptoms and diagnoses. According to DSM-IV-TR (DSM-IV-TR; American Psychiatric Association, 2000), the information obtained through the GAF "is useful in planning treatment and measuring its impact and in predicting outcome."

The severity of symptoms and diagnosis should be associated with scores arrived at in the GAF. More severe psychiatric disturbances should show higher levels of impairment than less severe disorders (Phelan, Wykes, & Goldman, 1994; Alaja et al., 1999; Brekke, 1992; Coffey, Jones, & Thornicroft, 1996; Moos, McCoy & Moos, 2000; Robert et al., 1991; Skodol, Link, Shrout, & Horwath, 1998a, 1998b). Despite the GAF having been originally designed as a quantitative scale of social and occupational functioning, the ratings tend to be more closely associated with diagnoses and psychiatric symptoms (Skodol et al., 1988; Faravelli, Servi, Arends, & Strik, 1996).
The associations between GAF ratings and social or occupational outcomes (Moos, McCoy, & Moos, 2000; Mueser, et al., 1997; Vetter & Koller, 1996; Rosenheck & Seibyl, 1997; Mellsop, Peace, & Fernando, 1987; Beiser, Fleming, Fleming, Iacono, & Lin, 1998) have been consistently weaker than the association between patients’ GAF scores and improvement in psychiatric and substance use problems during and after treatment (Farrell, 1999; Piersma & Boes, 1997; Goldman, Dequardo, Tandon, Taylor, & Jibson, 1999; Ezquiaga, Garcia, Bravo, & Pallarés, 1998; Furukawa, Awaji, Nakazato, & Sumita, 1995; Howes, Haworth, Reynolds, & Kavanaugh, 1997; Linehan, Tutek, Heard, & Armstrong, 1994; Walton, Berk, & Brook, 1996). In at least one study GAF ratings obtained during treatment were only minimally associated with self-reported symptom outcomes and social or occupational outcomes (Moos, McCoy, & Moos, 2000).

Another study found that GAF ratings provided little or no information about social or occupational functioning independent of clinicians' judgments about severity of symptoms and psychiatric diagnoses (Brekke, 1992; Skodol et al., 1998; Roy-Byrne, Dagadakis, Unutzer, & Ries, 1996). They also found little or no relationship between GAF scores and symptom, social, or occupational outcomes.

File Review and Interview. A review of the file indicated that the GAF scores were often inconsistent with the psychosocial information contained within the notes. The GAF scores at the time of the first treatment note dated November 11, 2005 were in the 31-40 range (e.g., impairment in reality testing, communication, major impairment in work, school, family relationships, judgment, thinking, mood), and they never rose above the 51-60 range (i.e., moderate symptoms, and impairment in social, occupational, and school functioning).
The treatment notes indicated that clinicians and treatment teams generally alternated days with Lisa. Each clinician or teams GAF score for their particular rotation was, in many cases, the same as it had been during their last rotation with Lisa, despite changes in psychosocial functioning (either positive or negative). These GAF scores often fluctuated as much as 20 points from session to session even within the same week. These scores were not consistent between clinician raters but were generally consistent within clinician raters. In other words, clinician X would give a GAF score of 31-40 on Monday then on Tuesday clinician Y would give a GAF score of 51-60, then later that same week clinician X would again give a GAF score of 31-40. This suggests that the GAF scores were heavily influenced by individual clinician subjectivity and were likely a poor indication of actual client psychosocial functioning. This trend ended on September 1, 2006. After this time the GAF score was noted to be stable at 41-50 (e.g., severe symptoms, suicidal ideation, severe obsessional rituals, no friends, unable to keep job) until the termination of therapy. Dr. Rosqvist (J. Rosqvist, personal communication, August 22, 2008) believed that this may have indicated a lack of attendance to GAF scores with the treating clinicians either "copying" the score from their last note and/or using symptom severity alone as a guide for the level of psychosocial dysfunction present at the time of encounter. The lack of change in Lisa's GAF scores is despite significant increases in Lisa’s psychosocial functioning during the course of treatment. She was noted to have gone from completely housebound, no friends, or outside contact to a semi-functional long-term relationship with a member of the opposite sex, attendance at college, leaving the home, and
equal chore responsibilities on the premises. Thus, a distinct qualitative change occurred that was not fully captured.

Dr. Rosqvist further suggested that the treating clinicians should have attended to the GAF scores more closely and juxtaposed them against the Y-BOCS data (which was always in the severe range). If this had been done, he hypothesized that the treating clinician's may have noted the significant discrepancy between psychosocial functioning and the patients reported level of symptom severity. Had that happened his opinion was that they could have begun to look at the GAF score and psychosocial function as a better gauge of treatment response and outcome, especially if one considers that a patient suffering with PANDAS subtype OCD could never realize symptom amelioration, only symptom tolerance.

*Analysis.* This cause could not be ruled out. There was a clear association between clinician expectations, therapeutic goals which relied too heavily on Y-BOCS data, inconsistent GAF scores, and the supposed treatment "failure." The use of quantitative and consistent qualitative data in this case may have illuminated attainment of a positive treatment outcome. The amazing qualitative transformation that the client went through during treatment was not sufficiently or consistently captured, thus, clinician and patient realizations of positive treatment outcomes were never attained. This factor contributed significantly to subjective treatment failure.
Figure 14. Measures of Treatment Effectiveness logic tree.
Discussion of Failure Modes and Recommendations

The purpose of this investigative process is the identification of effective solutions that are within clinician and client control, meet treatment goals, and do not cause other failures. Although the recommendations in this section are most relevant to patients like Lisa (e.g., PANDAS subtype OCD, "just so" tactile sensory obsessions, socially delayed, etc.) they could be readily applied to any psychiatric disorder as a means of reducing treatment failure. These recommendations and comments in no way constitute an all inclusive list of solutions; instead it should be viewed as a "guide" for clinicians to use as a means of reevaluating their own difficult cases and an example of thinking "outside the box."

Client Factors

The failure in regards to poor insight appeared to be directly related to the treatment recalcitrant PANDAS subtype OCD and the "just so" tactile sensory nature of Lisa's symptoms. The clinicians in this case had targeted the obsessions with the goal of reducing the association between her obsessions and compulsions; this is the standard therapy target when dealing with obsessions. This is predicated on the assumption that once this association is broken the patient would no longer allow the obsessions to dictate their behavior. However, due to severity and the "itch" like quality of Lisa's symptoms the treating clinician's may have been unable to consistently elicit optimal treatment compliance from the patient in the form of reduced compulsive behavior. This is where the failure in regards to treatment recalcitrant PANDAS subtype OCD and "just so" tactile sensory obsessions became most relevant.

In this case the treatment target should shift from breaking the association between obsessions and compulsions to the behavior – quality of life linkage. In other words Lisa, and
other patients with a similar presentation, must be convinced that when they "just go along with" their obsessions they are accepting only small gains of comfort while simultaneously reducing their chances of a large gain in the form of an increased quality of life. They are also significantly increasing their chance of relapsing to a prior state of symptom severity or dysfunctional behavior.

Should poor insight be suspected, utilize any one of several instruments (e.g., Overvalued Ideas Scale [OVIS; Neziroglu, McKay, Yaryura-Tobias, Stevens, & Todaro, 1999]), the Brown Assessment of Beliefs Scale [BABS; Eisen et al., 1998]), and the Fixity of Beliefs Questionnaire [FBQ; Foa & Kozak, 1995]) to assess the level of insight actually possessed by the patient. Conjecture and a single item such as is found on the Y-BOCS (i.e., item 11), while suggestive, are not an optimal means for assessing level of insight and accurately targeting treatment. An inaccurate assessment of insight can contribute, as it did in the case of Lisa, to inappropriate treatment targeting and less than optimal treatment outcomes.
Figure 15. Client factors logic tree with solutions.
Social and Family Environment

Based on the analysis there was clear evidence that family accommodation and emotional over-involvement was taking place and as a result treatment effects were less than desirable. Clinicians must be vigilant to the presence of these factors, prepared to educate the family on their potential deleterious effects on treatment, and proactive about including the family in treatment planning, goal setting, and family therapy. Specifically, the clinician should focus attention on converting any negative expressed emotion to appropriate criticism and end the instances of enabling the patient’s dysfunctional behavior patterns.

Family responses to OCD such as the family expressed emotion and accommodation could be addressed with family or group therapy. One such empirically validated approach is multifamily behavioral treatment (MFBT, Van Noppen and Steketee, 2003). MFBT has been designed for treatment-refractory OCD patients who have not benefitted from standard CBT and pharmacological methods. In this form of treatment up to seven patients and their families together receive education about OCD, exposure treatment, and the family contracts for behavior change in the form of reduced negative expressed emotion and accommodations. Family members and significant support persons are trained as collaborators in delivering ERP in the home, are taught positive interaction skills, and aided in reducing then eliminating altogether any enabling or accommodating behaviors thus effectively breaking the cycles that perpetuate symptoms of OCD. MFBT also offers family members and significant others an outlet for dealing with frustration, anger, demoralization, and exhaustion by providing access to others with a shared experience.
Should a multifamily group be contraindicated for some reason then the principals of MFBT could be adapted for use with an individual family. The treatment manual is readily available and was even found on the internet with a simple Google search.

Incorporating some social skills training during the course of treatment allowed Lisa to go from completely housebound to a semi-functional long-term relationship with a member of the opposite sex, attendance at college, and eventually leaving the home to live on her own. What this suggests is that the addition of social skills training had been helpful in transitioning Lisa towards independence and replacing distress with some positive feelings associated with social interaction. However, it should be noted that once therapy was terminated Lisa was unable to maintain this level of independence. In fact she returned home from college, and to a partially "housebound" level of functioning.

The inclusion of a relapse prevention plan is necessary when faced with recalcitrant conditions like PANDAS subtype OCD. This plan should include adequate social support networks to maintain gains acquired during therapy. The adequacy of social support is directly related to a client's reported severity of symptoms and can help mediate stress and the development of psychological symptoms (Monroe, Imhoff, Wise, & Harris, 1983). This is consistent with the evidence that extra-therapeutic factors are responsible for 40% of the variance in therapy outcome (Lambert, 1992). The clinician must identify the resources that the patient already has in their current life and activate or modify them to achieve optimal treatment outcomes (Bankoff & Howard, 1992). This could include offering the patient the ability to call the therapist, later a clinician trained family member, and eventually one or more peers. The
inclusion of MFBT could also aid in relapse prevention and bolstering social skills in the form of social contacts and interactions with other group members.
Figure 16. Social and family environment logic tree with solutions.
Treatment Design and Implementation

It is critical that prompt recognition and treatment of PANDAS subtype OCD take place as the severity and recalcitrance associated with delayed recognition makes effective symptom amelioration impossible. However, as this cannot possibly take place with 100% certainty, it is important to remember that PANDAS subtype OCD is an organic disorder that will predictably achieve less than optimal treatment outcomes. An effective treatment approach therefore should consider this factor and provide outcome goals that are consistent with this knowledge and realistic in nature.

In Lisa's case the failure in regards to treatment recalcitrant PANDAS subtype OCD and "just so" tactile sensory obsessions is directly related to the subjective nature of "success" and "meeting expectations." These factors led to premature, inappropriate failure conclusions on the part of the clinicians. That is to say that one must take into account the limits inherent in treating specific phenomenon (to what degree does PANDAS tactile sensory OCD actually "improve"). Narrowly focusing on outcome measures may take away from a successful process such as can be found in more aspirational outcomes (e.g., autonomous functioning).
Figure 17. Treatment design and implementation logic tree with solutions.
Measures of Treatment Effectiveness

The clinicians in this case appeared to concentrate almost solely on symptoms distress (i.e., Y-BOCS scores) as a measure of treatment effectiveness. The Y-BOCS, considered to be the "gold standard" measure for OCD, focuses primarily on symptom distress and not behavior. In order to accurately gauge treatment progress clinicians should measure symptom distress and behavioral change. Behavioral changes can be gauged with GAF scores. However, the GAF scores which were assigned in this case were often inaccurate, inconsistent, or not attended to. Further, GAF scores did not appear to be used to gauge treatment effectiveness nor were they a part of the treatment plan. Given the subjective nature of GAF scores it would be reasonable, should GAF scores be intended for use as a gauge of therapeutic effectiveness, to utilize a standardized GAF score instrument. This is especially true if there will be multiple individuals or treatment teams, likely at differing levels of familiarity or experience with the GAF, and inter-rater reliability will be in question.

One such instrument is the modified Global Assessment of Functioning scale which has more detailed criteria and a structured scoring system (Caldcott-Hazard & Hall). This scale has been shown to have higher correlation coefficients (0.81) for GAF scores compared with raters who used the original GAF (0.62). Further, the authors specifically noted that the modified GAF would be particularly useful when inter-rater reliability is in question when clinicians of varying skills and levels of GAF familiarity must rate the same patients.

Another GAF instrument is the Kennedy Axis V (K Axis; Kennedy, 1992) which has been recently upgraded for use with the DSM-IV-TR (2000). It provides a multi-dimensional evaluation of a patient's functioning in six areas. (i.e., psychological impairment, social skills,
violence, activities of daily living, substance abuse, medical impairment). A formal inter-rater reliability study (Bilezikian, 1998) found that the K Axis had high inter-rater reliability for psychological impairment (r = .90), social skills (r = .89), violence (r = .80), activities of daily living skills (r = .87), substance use (r = .83), medical impairment (r = .91), and GAF scores (r = .93). These results were substantiated by Higgins and Purvis (2000) in a later evaluation of the K Axis.

GAF scores which can be arrived at reliably by the treating clinicians can then be compared to the Y-BOCS, or other measures of symptom distress, in order to gauge improvements in psychosocial functioning in comparison and contrast to reductions in symptoms distress. It may be useful to separate quantitative measures of treatment “success” from more subjective observations of global functioning. When data and GAF scores are discrepant it is time to begin looking into other modes/means of measurement. A more careful assessment of psychosocial functioning could reveal exceptional treatment successes. This is especially true when the particular psychiatric disorder (e.g., PANDAS OCD) is known to be treatment recalcitrant and even more so when it is known that symptom amelioration is unlikely. Symptom reductions, and its quantitative evidence, are inadequate measures of success.

Clinicians must be willing to consider other, more subjective means of judging treatment effects. Clinicians must be willing to “take a step back” from time to time and critique progress in all domains and from multiple angles. Relying on one measure of success/failure is short sited at best and poor client care at worst.
Figure 18. Measures of treatment effectiveness logic tree with solutions.
Limitations of Current Study

This investigation was limited to the analysis of a single self-report measure of improvement (i.e., Y-BOCS), archived treatment file data, and interviews with only two (i.e., Lisa and Dr. Rosqvist) out of a multitude of individuals involved in this case. Therefore, this investigation may provide an incomplete view of the factors related to treatment failure and the presumed impact of therapy on this patient.

The number of hours involved in completing this particular investigation may prohibit its use in day-to-day clinical practice. It should be noted, however, that the high number of hours involved in completing this investigation was likely due to the complicated and unusual presentation of the patient.

Because of the complex nature of this particular type of investigation there is some concern that the costs of using failure analysis may outweigh the potential benefits. Application of such a detailed investigative technique may simply be unrealistic in routine practice. The benefit of the current investigation and the subsequent dissemination of the findings lies in its ability to guide clinicians towards an alternative way of viewing and approaching cases that achieve less than adequate treatment outcomes.

Future research is necessary if it is to be understood what components, if any, of failure analysis help clinicians to solve poor treatment progress and achieve better outcomes with their most difficult patients. Replication of this study with other populations and varying degrees of clinical complexity are an important first step. Finally, clinical trials and process research are necessary for better understanding how clinicians may use the results of failure analysis.
investigations to improve outcomes for their patients. Further research on this interesting method is encouraged.
References


