

***Commentary on The Case of “Hiro”: Treating Tourette Syndrome by
Comprehensive Behavioral Intervention for Tics (CBIT)***

**Perspectives on Training Clinicians to Effectively Implement
Evidence-based Treatment for Tourette Syndrome**

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ABSTRACT

Tourette Syndrome is a common childhood disorder that is often misunderstood by the public and undertreated due to a lack of knowledge among medical and mental health professionals. This paper describes how the Tourette Syndrome (TS) Program at Rutgers University provides and disseminates specialized care to the TS community while allowing psychologists-in-training to develop expertise in evidence-based assessment and intervention for individuals with TS. Discussion will focus on training doctoral students in clinical and school psychology to specialize in this area. We will utilize Lichtman’s (2017) case study of Hiro, which was implemented within the TS Program at Rutgers, to emphasize important training issues and illustrate some common pitfalls of novice clinicians conducting this treatment.

Key Words: Tourette Syndrome; Tics Disorders; Comprehensive Behavioral Intervention for Tics (CBIT); Habit Reversal Training (HRT); cognitive-behavioral training (CBT); dissemination; clinical training; supervision; case studies; clinical case studies

Tourette’s Syndrome (TS) is a neurodevelopmental disorder characterized by motor and vocal tics that appear before age 18 (APA, 2013). While prevalence data varies, a recent Centers for Disease Control and Prevention (CDC) study found that 1 of every 360 (0.3%) children 6 - 17 years of age in the United States have been diagnosed with TS (Bitsko et al., 2014). Other studies that have included children with undiagnosed TS have estimated that 1 of every 162 children (0.6%) meet criteria for the disorder (Knight et al., 2012), suggesting that about half of children with TS are undiagnosed. Tourette Syndrome is expressed along a spectrum of severity, and is further complicated by a number of common comorbid conditions, estimated at approximately 80-90% (Cavanna, Servo, Monaco, & Robertson, 2009).

Considering this high rate of comorbidity, many difficulties identified by individuals with TS result from associated conditions such as Attention Deficit Hyperactivity Disorder, Obsessive-Compulsive Disorder, other anxiety disorders, mood disorders, learning disorders, and Oppositional Defiant Disorder (O'Hare, Helmes, Reece, Eapen, & McBain, 2016). Living with TS and associated conditions may affect an individual's health, education, family relationships, socialization, and employment, resulting in wide-ranging impact on physical, mental, and emotional well-being. Children with TS often require a number of healthcare visits, special educational services, medication, and psychological and behavioral intervention. While people have become more aware of TS over time, there is still much misunderstanding and lack of knowledge, even among health and education professionals. This lack of understanding of TS among health care professionals can lead to delays in diagnosis and difficulty accessing effective treatments (<https://www.cdc.gov/features/tourette-syndrome-data/>).

THE TOURETTE SYNDROME PROGRAM AT RUTGERS

The Tourette Syndrome Program at Rutgers University's Graduate School of Applied and Professional Psychology, known as the "TS Program" at "GSAPP," addresses this important public health need by bridging the gap between individuals with TS who may benefit from behavioral treatment and the lack of mental health professionals with specialized training in this area. The TS Program provides evidence-based treatment programs to address the needs of individuals with TS and their families, delivered by doctoral students in Clinical Psychology or School Psychology enrolled in GSAPP. The mission of the Tourette Syndrome Program is to serve families affected by TS while training the next generation of psychologists to be experts in the evaluation and treatment of TS and related difficulties. A full description of the services provided by the TS program is provided described on its website: <http://psychologicalservices.rutgers.edu/ts-clinic.php>.

The TS Program represents a unique and mutually beneficial partnership between GSAPP and the New Jersey Center for Tourette Syndrome (NJCTS), a not-for-profit organization committed to the advocacy of children and families with Tourette Syndrome and associated disorders (www.njcts.org). NJCTS provides an annual stipend that partially funds operational costs of the TS Program, which in turn provides a trusted resource to refer individuals with TS for affordable and effective psychological and behavioral assessment and treatment. Funding from NJCTS also makes it possible for the TS Program to offer behavioral care to clients on a sliding scale based on household income, allowing middle- and lower-income families to access much needed, affordable services.

Since the TS Program began keeping track in 2005, it has had clinical contact (assessment, consultation, or treatment) with approximately 700 children, adolescents, and adults. The TS Program has also had telephone contact with nearly twice as many individuals. The content of these telephone conversations include disseminating knowledge about TS by answering questions and providing referrals for medical management and or psychological services in closer proximity to family's homes.

Families and individuals who seek services at the TS Program benefit from various treatments: Clients learn to accept and understand a complex and stigmatizing disorder, manage problematic tics using Comprehensive Behavioral Intervention for Tics (CBIT; Woods et al., 2008a), develop and practice ways to advocate for themselves in their school and work environments, decrease the impact of debilitating comorbid conditions through evidence-based behavioral interventions, and gain a greater sense of self-efficacy. The TS Program also offers an annual, 10-week socioemotional skills group aimed at helping group members learn about TS and share their experiences with understanding peers.

Providing high quality, research-informed training to the next generation of psychologists is both a priority and strength of the TS Program. Each year, four doctoral students are accepted into the TS Program as their applied training practicum placement. Professional presentations, dissertations, and publications reflecting on evidence-based practice, such as needs assessment, program evaluation, and clinical case studies are encouraged and supported. The Clinical Director, a part-time position filled by a licensed clinical psychologist with expertise in TS, oversees the training program. There have been three Clinical Directors since the TS Program took its current form in 2005, two of whom were previous practicum students in the TS Program during their graduate training. In 2010, the program also began accepting half-time postdoctoral psychologists to provide treatment for more complex cases and to gain experience training and supervising practicum students on TS cases. Two of the four post-doctoral fellows had previously been practicum students in the clinic. This professional lineage exemplifies how the TS Program has already begun to successfully accomplish its mission of training a future generation of psychologists with expertise in TS.

The TS practicum program is composed of several components to support students' clinical work with clients. In addition to weekly individual supervision, including video review of sessions, the practicum provides weekly group supervision and a weekly training seminar. The seminar is structured similarly to a traditional graduate level course, with a structured syllabus and corresponding assigned readings to provide students with a foundation in understanding TS, specialized assessment (e.g., Yale Global Tic Severity Scale; Leckman et al., 1989), and interventions for TS (e.g., CBIT). The seminar also provides an overview of common comorbid conditions. While it is beyond the scope of the practicum to provide a comprehensive review of child psychopathology, the goal is to provide an introduction that will allow students to accurately identify comorbid conditions that warrant attention in treatment and gain a basic understanding about what those treatments entail (with further guidance being provided in individual supervision). The weekly training seminar includes didactic instruction, interactive exercises, discussion, and role-play of relevant clinical skills.

JEREMY LICHTMAN'S (2017) CASE OF "HIRO"

Lichtman's case study of Hiro presents impressive data which demonstrate that Hiro was quite successful in reaching his therapeutic goals and those of his family. Specifically, to support this conclusion, Lichtman presents positive qualitative information provided by Hiro and his parents and confirmatory quantitative assessment demonstrated with the Yale Global Tic Severity Scale (YGTSS) post treatment and at 3 and 6 month follow up. From our perspective,

Lichtman's success was associated with the strength of his rapport with Hiro and Hiro's parents, and dialoguing with Hiro about his tic symptomatology. Lichtman applied the core components of the CBIT manual properly, as a guide to conceptual understanding and implementation of core treatment procedures, but with flexibility and creativity about how to communicate concepts and engage clients and their families. On the other hand, in our collective experience training doctoral students, we have identified a few common pitfalls made by novice clinicians conducting CBIT for the first time, illustrated by Lichtman in his case of Hiro, which we believe are helpful to address.

Assessing the Whole Individual in the Context of His or Her Family

The first issue we would like to address is the overall approach to treating individuals with TS. We strongly believe in adopting a broad lens from which to assess the whole individual and his or her functioning within relevant systems (e.g., home, school, and workplace). Sometimes, clinicians who are unfamiliar with TS, as well as parents, develop tunnel vision about an individual's tics and rush to intervene. We do not intend to minimize the impairment and stigma that tics can create, and are grateful for Habit Reversal Training (HRT), the behavioral component of CBIT aimed at directly reducing tic frequency. However, we want to emphasize that not every individual with tics wants, needs, or is ready to engage in HRT. The motivation, commitment, and hard work required for an individual to effectively engage in HRT should not be taken for granted.

Rather, a thorough assessment should reveal comorbid conditions, areas of impairment, and the goals of the client and various informants or support people, which are not always aligned. These findings should guide a collaborative discussion about the goals of treatment, aimed at making meaningful changes in impairment identified by individuals and their families. When tics are causing minimal impairment, treatment focused on tic reduction may not be required, and in some cases may be counterproductive because it distracts from a more pressing problem. For example, sometimes interventions for comorbid conditions should take priority due to their levels of impairment being higher than the tics themselves. In other situations, individuals and their families benefit most from education about tics and connecting with the TS community. Meeting other individuals affected by TS helps normalize tics and improve one's attitudes toward tics.

The close relationship that the TS Program has with the NJCTS has facilitated our ability to address these goals with many of our clients by providing access to the numerous community-based programs it offers. Therefore, we train our clinicians to provide straightforward feedback and recommendations about what we believe to be the most beneficial course of treatment based on the information that was obtained from the evaluation. Sometimes it can be difficult for clinicians in training to provide feedback that will be contrary to the wishes of parents who are intent on addressing their child's tics with HRT. We attempt to guide student clinicians away from the pitfall of being persuaded to proceed with HRT despite concerns that HRT may not be the best first line of treatment for their client.

Of course, there are also times that HRT is warranted because tics are causing considerable impairment, but clients lack motivation or express hesitance to engage in HRT. There are a myriad of reasons why clients may be reluctant. Some of the most common we have encountered include anxiety about paying attention to their tics, fears that HRT will be ineffective or increase tics, and family dynamics that inadvertently reinforce tics. We believe it is vitally important to adequately address motivation and provide thorough psychoeducation about HRT before initiating the treatment protocol.

In the case of Hiro, we agree that the client was a reasonable candidate for HRT. However, given that the Yale Global Tic Severity Scale (YGTSS) suggested only mild impairment caused by tics, and Lichtman's assessment at the beginning of treatment that Hiro's parents appeared to be more invested in treatment than Hiro himself, we would have recommended that additional clinical attention be paid to motivation from the start. It was unclear as to the conditions under which the client endorsed "minimal" (10) on the impairment scale of the YGTSS. If Hiro identified anything specific, such as tics interfering with his ability to play video games to his highest potential, or making him self-conscious meeting new people, the prospect of future improvement in these areas could have been reflected back during challenging moments as motivational reasons to persist with the treatment. If the endorsed impairment primarily represented Hiro's parents' views, we would advise having a family discussion to explain their perspective and to see whether Hiro could acknowledge these reasons for intervention. The clinician could also dedicate additional time with Hiro to determine whether he ever experienced or noticed his tics interfering with his goals, which could have also resulted in some concrete motivation for treatment. The CBIT workbook (Woods et al., 2008b) contains a "Tic Hassles Form" (p. 18) that encourages clients to identify reasons why one's tics are "inconvenient, embarrassing, or distressing," to help guide this conversation. Lichtman notes that he conducted this exercise with Hiro but did not recount what types of inconveniences the client identified or whether it was utilized later in treatment to address his lack of motivation.

Given the concerns that Lichtman identified regarding Hiro's initial level of motivation for HRT, we would have recommended that Lichtman proactively facilitate parental involvement earlier in the process rather than reactively engage parents once problems with homework adherence arose. In fact, we advocate for significant parental involvement for all young children participating in HRT. Including parents in sessions from the inception of treatment allows for accurate understanding of HRT procedures and rationale, realistic expectations, and competent social support throughout the process. Additionally, as illustrated nicely by Lichtman in Hiro's case, another reason for involving parents is to empower them to guide their child through the procedure of HRT for potential future tics that emerge after treatment has terminated. The parental involvement described by Lichtman at the end of treatment was exemplary, but we believe that it would have been beneficial for everyone if it had occurred earlier in the treatment.

The Function-Based Assessment and Intervention Module in CBIT

The Function-Based Assessment and Intervention module (Woods et al., 2008a, Chapter 3, pp. 27-38) is a component of CBIT that can be particularly useful in cases such as Hiro's where the child lacks motivation. CBIT is based on a behavioral model of tics, which posits that

internal and external antecedents and consequences can increase or decrease the likelihood that tics will be exhibited (Silva, Munoz, Barickman, & Friedhoff, 1995). Function-based assessment aims to isolate these factors, and function-based intervention plans are designed to modify those factors in order to reduce tics. The reason why Lichtman bypassed this module in the case of Hiro is unclear to us, as the text simply notes that this intervention was “unnecessary and unwieldy.” Certainly, some families have difficulty identifying antecedents and consequences, and others struggle to implement and follow through with mutually agreed upon interventions. Clinicians may also skip this component because they are eager to get to HRT procedures, or feel pressured by parents to do so. However, Lichtman’s case study does not provide enough information for us to be able to comment on any particular difficulty implementing this component.

Overall, we recommend Function-Based Assessment and Intervention, and especially in cases such as Hiro’s because it requires high levels of parent involvement while depending less on the child’s efforts. It can be a great common ground for families in which parents are eager to “do something” to help, and for children who are still resistant or ambivalent about HRT. It inherently includes psychoeducation about tics, the behavioral model of tics, and how family dynamics may be inadvertently maintaining or exacerbating tics. Finally, it may also produce some reasonably quick and easy tic reduction that will be reinforcing and motivating to everyone involved.

Where to Begin? Selection of the Initial Target Tic

Our last comment related to engaging reluctant or ambivalent clients focuses on the selection of the tic with which to begin HRT procedures. Similar to many other types of interventions, early success often cures ambivalence and resistance. We believe it is important for the eventual success of HRT that the first attempt is at least moderately effective in reducing the targeted tic. However, clients, parents, and novice clinicians are often tempted to begin by addressing the most frequent or most impairing tic. While this decision may be warranted in some situations, generally, we urge clinicians to consider multiple factors when working with clients and parents to decide which tic to address first.

In our opinion, the best context for teaching HRT procedures to a new client is a motor tic that involves a gross motor rather than fine motor movement, which is moderately frequent and moderately impairing. Motor tics that involve large muscle groups (e.g., arms, legs, and/or neck), may be easier to anticipate i.e., to identify the premonitory urge, and will generate more options for Competing Responses compared to fine motor tics (e.g., face and/or eyes) or vocal tics. Gross motor tics will also be easier for clinicians and parents to observe in order to facilitate practice compared to fine motor tics. Tics that are extremely frequent may overwhelm a client who is initially learning the procedures, whereas tics that are not exhibited frequently enough make it difficult to practice in session where feedback can be provided. Lastly, tics that are extremely impairing come with high expectations, meaning that if HRT is challenging, as it often is at first, clients may lose motivation and hope that HRT will be effective for them. Alternatively, tics that cause minimal or no impairment may not feel worth the effort for clients who are just starting out.

We understand that every individual may not have a tic that fits these criteria, but we advise using these guidelines when possible. In the case of Hiro, many of his tics were vocal or fine motor movements, leaving tough choices for the first target. Lichtman fell into the trap of initially choosing the most impairing, but very difficult, fine motor eye roll tic, although quickly and correctly switched course to focus on the jaw clench tic. He does not provide information about frequency, so we are unable to comment on that aspect of the decision, but based on the hierarchy provided in Table 6 in Lichtman (2017, p. 37), we advise that one of the head shaking tics may have been the best choice for beginning HRT.

The Competing Response

A related and important area to address involves the concepts of identifying, utilizing and understanding the Competing Response (CR). The CR is an integral component of the treatment and its purpose and implementation needs to be carefully understood by the clinician, client, and the client's support person (Woods, Piacentini, & Walkup, 2007). A CR is a behavior or vocalization that competes with a tic, with the goal of preventing the tic from occurring. However, it is unclear exactly how the CR affects change. Some hypothesize that it competes with the tic for prominence in the circuitry of the basal ganglia (the deep brain structures that help control movement), while others suggest that the CR forces the patient to habituate (get used to) to the premonitory urge (Woods et al., 2008a). Therefore, the only guidelines for selecting a CR are that the movement or vocalization should be: 1) physically incompatible with the tic, or if unavailable, a more natural, relaxed version of the tic or part of the tic, 2) more socially inconspicuous than the tic, and 3) be able to be held for one minute or until the premonitory urge subsides (Woods et al., 2008a, 2008b). In a recent CBIT training workshop facilitated by Doug Woods attended by the first author, he suggested an additional pragmatic rule that the CR should ideally be able to be implemented in any situation. For example, the CR should not be reliant on the individual's clothing (e.g., hands in pockets), any particular posture or position (e.g., sitting on hands), or a prop (e.g., fidget).

Therefore, we believe that it is important to emphasize to clinicians in training that there is no *correct* CR for any particular tic, and in fact, two clients with similar tics may develop different CRs. The process of identifying each CR should be a collaborative process with the client, and at times, may require some trial and error. In our experience, it is vital that the client agrees that a specific CR is sufficient to prevent the tic from occurring, rather than simply being instructed in which CR to use. Sometimes experimenting with different ideas may be necessary before mutually deciding upon the CR that works best based on the aforementioned guidelines.

Only once the collaboratively chosen CR is identified should clinicians instruct clients to practice using the CR contingent upon the premonitory urge that precedes the tic. During this practice period, many clients begin to experience a level of frustration with the CR due to uncomfortable sensations produced by inhibiting the tic behavior in favor of the CR. Clients often express doubt in the CR they chose, and request to switch to a different CR. This is tempting for clinicians unfamiliar with HRT, who may also doubt whether they guided the client to an adequate CR. However, before changing course, we recommend that the therapist remind the client that this uncomfortable sensation is to be expected by reiterating that this is necessary

for the hypothesized mechanism of habituation to occur. They should encourage the client to keep holding the CR, until the urge to tic decreases to a level where they no longer feel the need to tic. This time period can vary from client to client, but in our experience, usually lasts for longer than one minute at the beginning of their practice sessions. Therefore, the more the client practices the CR, the less time it usually takes for them to experience a reduction in their premonitory urge and therefore the less time they have to be using the CR.

As discussed above, a possible reason for this reduction in the duration of the premonitory urge is that the client is habituating to the urge (Specht et al., 2013). We have heard our clients describe that the “sound” or intensity of the urge decreases over time from the beginning of using the CR to the time where they are able to feel an urge and do nothing about it (not tic or use the CR). It can be helpful to discuss this with clients to create the buy-in we need to help them through the sometimes-frustrating process of competitive response training. In order to convince the most skeptical or hesitant clients, we sometimes also recommend that clinicians keep track of the time this takes by periodically requesting ratings of discomfort, as evidence that the urge will eventually subside. Of course, sometimes this does not occur, likely because the CR was not sufficiently incompatible with the tic, or was not able to be held for long enough by the client, and in those situations, clinicians should revert back to brainstorming and experimenting with other CRs. However, it is important to emphasize that we advise against clinicians assigning homework practice of the CR until some acknowledgement of a reduction in premonitory urge, and therefore, confidence in a CR is achieved.

In terms of Hiro’s case, the client’s level of understanding about how the CR worked in terms of decreasing the frequency and intensity of his tics and how the clinician and client went about collaboratively choosing the CR is unclear. Lichtman often referred to various CRs as “*not holding up*” or “*not working*,” or he stated that the client requested a “*stronger*” CR. It was unclear what was meant by these phrases, but we took these descriptions to suggest that the client may not have had a through understanding of the habituation process or that the clinician allowed the client to give up on a CR too hastily. Lichtman described the addition of a “visualization” element, imagery of battle between good and bad characters from a video game, to “bolster” the CR. Lichtman did not suggest that this cognitive exercise was a CR itself, but we want to underscore the technical point that this cognitive exercise was not a CR because a CR must be a physical movement. On the other hand, it is important to note that this cognitive technique seemed to serve the function of externalizing the tic and increasing motivation to persist beyond the discomfort created by holding the CR and not engaging in the tic behavior.

Assigning Homework Practice Periods

Finally, another area in need of clarification in regards to CR training implementation is the manner in which homework practice periods were assigned. It is generally recommended that CR homework be practiced for 30 minutes per day between sessions (Woods et al., 2008a, 2008b). Once the individual becomes fluid with using the CR procedure for a given tic then they are asked to engage in using the CR throughout their day whenever the urge arises (Woods et al., 2008a, 2008b). Therefore engaging in CR practice between sessions for longer than 30 minutes,

as was done in Hiro's case, is not necessary. This overpractice had the potential to further decrease Hiro's motivation to engage in treatment.

In sum, we believe that Lichtman's case of Hiro documents an impressively successful case of addressing TS symptoms, with particular therapist strengths in flexibility, creativity, and the capacity to establish strong, positive therapeutic relationships with both Hiro and his parents. On the other hand, Lichtman's functioning as a therapist using the CBIT manual for the first time, as described in his case study, illustrates a few common pitfalls made by novice clinicians, which we have set forth above. We believe that the kind of detailed and systematic case study presented by Lichtman can be very helpful in identifying the type of conceptual and procedural issues we have discussed above that can improve the use of the CBIT model.

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