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Living with tics: Reduced impairment and improved quality of life for youth with chronic tic disorders



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ABSTRACT

Pharmacological and behavioral interventions have focused on reducing tic severity to alleviate tic-related impairment for youth with chronic tic disorders (CTDs), with no existing intervention focused on the adverse psychosocial consequences of tics. This study examined the preliminary efficacy of a modularized cognitive behavioral intervention (“Living with Tics”, LWT) in reducing tic-related impairment and improving quality of life relative to a waitlist control of equal duration. Twenty-four youth (ages 7–17 years) with Tourette Disorder or Chronic Motor Tic Disorder and psychosocial impairment participated. A treatment-blind evaluator conducted all pre- and post-treatment clinician-rated measures. Youth were randomly assigned to receive the LWT intervention ($n=12$) or a 10-week waitlist ($n=12$). The LWT intervention consisted of up to 10 weekly sessions targeted at reducing tic-related impairment and developing skills to manage psychosocial consequences of tics. Youth in the LWT condition experienced significantly reduced clinician-rated tic-impairment, and improved child-rated quality of life. Ten youth (83%) in the LWT group were classified as treatment responders compared to four youth in the waitlist condition (33%). Treatment gains were maintained at one-month follow-up. Findings provide preliminary data that the LWT intervention reduces tic-related impairment and improves quality of life for youth with CTDs.

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1. Introduction

Tourette Disorder and other chronic tic disorders (hereafter collectively referred to as CTDs) are neuropsychiatric conditions characterized by the presence of motor and/or phonic tics lasting at least a year. Approximately 0.3–0.8% of youth are estimated to be affected by CTDs (Centers for Disease Control and Prevention, 2009). Although tics are the hallmark symptom of CTDs, youth with CTDs regularly present with co-occurring psychiatric conditions [e.g., attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), non-OCD anxiety disorders; Freeman et al., 2000; Specht et al., 2011; Lebowitz et al., 2012], social and emotional difficulties (Carter et al., 2000; Tabori Kraft et al., 2012; McGuire et al., 2013) and disruptive behaviors (Sukhodolsky et al., 2003; Tabori Kraft et al., 2012). Youth with CTDs experience significant impairment

(Conelea et al., 2011) that often affects multiple domains of functioning (Storch et al., 2007a). Indeed, relative to their peers, youth with CTDs report a diminished quality of life (Storch et al., 2007b; Eddy et al., 2011b).

In response to the impairment and diminished quality of life reported by many youth with CTDs, interventions have focused on alleviating tic severity. A meta-analysis of randomized controlled trials (RCTs) of typical and atypical antipsychotic medications (e.g., haloperidol, risperidone) has demonstrated their efficacy in reducing tic symptom severity compared to placebo (Weisman et al., 2012). Although efficacious, these medications are frequently accompanied by side effects that may limit tolerability and acceptability (Scahill et al., 2006a). Similarly, a meta-analysis of alpha-2 agonists medications (e.g., guanfacine, clonidine) demonstrated their efficacy in reducing tic symptom severity, albeit with modest results (Weisman et al., 2012). Behavior therapy (e.g., habit reversal training, comprehensive behavioral intervention for tics) has also demonstrated efficacy in reducing tic symptom severity in RCTs for youth and adults (Piacentini et al., 2010; Himle et al., 2012; Wilhelm et al., 2012), with a meta-analysis of behavior therapy RCTs

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identifying comparable treatment effects to antipsychotic medications (McGuire et al., 2014).

Although pharmacological and behavioral interventions both demonstrate efficacy in alleviating tic symptom severity, these treatments primarily focus on tic severity reduction predicated on the assumption that tic severity is wholly responsible for the impairment and diminished quality of life experienced by youth with CTDs. Despite this assumption, the interplay between tic severity, impairment, and quality of life remains unclear among youth with CTDs. For instance, several reports have identified a modest association between tic severity and quality of life (Storch et al., 2007b; Cutler et al., 2009), whereas others have failed to find a significant relationship (Bernard et al., 2009; Eddy et al., 2011a). This ambiguous relationship is further complicated by research suggesting that co-occurring OCD and ADHD (Eddy et al., 2012), depressive symptoms (Muller-Vahl et al., 2010), negative self-perception (Khalifa et al., 2010; Eddy et al., 2011b), and social deficits (McGuire et al., 2013) can negatively impact quality of life for individuals with CTD. The relationship between tic severity and quality of life may be more nuanced as many youth with CTDs experience problems secondary to their tics (e.g., social interference, discrimination, peer victimization; Storch et al., 2007c; Conelea et al., 2011; Zinner et al., 2012) that can impact domains central to their quality of life to varying degrees.

Although many individuals with CTDs report that tics subside in early adulthood (Bloch et al., 2006), tics often do not remit entirely and, at the least, a child must endure them for many years. Similarly, evidence-based treatments yield significant reductions in tic severity, but infrequently result in tic remission. Thus, youth with CTDs have to develop effective coping strategies for tics even when receiving evidence-based treatment. While experts acknowledge that tics can have adverse psychosocial consequences that may endure even after tics diminish and/or remit (Scahill et al., 2013), there has been limited research on helping youth with CTDs develop skills to cope with these psychosocial consequences. When adults with CTDs were surveyed about their experiences, many stated that they continued to feel different from peers because of their tics, relied on social avoidance to manage tics, experienced social impairment, and believed that tics contributed to other psychological problems (Conelea et al., 2013). Thus, adults with CTDs continue to experience considerable adverse psychosocial consequences associated with tics that likely started in childhood. Therefore, interventions are needed for youth that not only reduce tic symptom severity, but also provide skills to manage the adverse psychosocial problems associated with tics (Peterson and Cohen, 1998). Targeted interventions may mitigate the impairment caused by tics, positively impact quality of life during childhood and adolescence, and curtail social difficulties into adulthood.

Although co-occurring problems are recognized as an important aspect of treatment in evidence-based practice parameters (Murphy et al., 2013), few treatment protocols have attempted to target co-occurring problems among youth with CTDs (Scahill et al., 2006b; Sukhodolsky et al., 2009), and have not directly addressed the psychosocial challenges associated with tics themselves. To date, only a single open-label case series has examined an intervention to address associated negative social consequences of tics in youth with CTD. Storch and colleagues developed a modular cognitive behavioral intervention called Living with Tics (LWT) and found that it reduced tic-related impairment, improved psychosocial functioning, and increased quality of life among eight youth with CTDs (Storch et al., 2012). This therapeutic approach is important because it addresses aspects of treatment not directly targeted by existing pharmacological or behavioral interventions, and can serve as either a primary or adjunctive component of existing evidence-based interventions.

The current study extended up the preliminary findings by Storch et al. (2012) by incorporating additional modules into the LWT intervention and evaluating its efficacy relative to a waitlist condition of equal duration in a randomized controlled pilot trial. We

hypothesized that the LWT intervention would be superior to the waitlist condition in reducing clinician-rated tic impairment and improving quality of life for youth with CTDs. Secondary aims explored the effects of the LWT intervention on tic symptom severity, obsessive-compulsive symptom severity, and anxiety symptom severity relative to the waitlist condition.

2. Method

2.1. Participants

Thirty-four youth and their parents were invited to participate in this study. Youth were recruited from the normal clinic flow within an outpatient OCD and CTD specialty clinic in the southeastern United States. Study inclusion criteria required that youth (1) have a principal diagnosis of CTD; (2) be between 7 and 17 years of age; (3) have a Yale Global Tic Severity Scale (YGTSS; Leckman et al., 1989) Total Impairment Score ≥ 20 and a YGTSS Total Tic Severity Score ≥ 10 ; (4) be English speaking; (5) have at least one parent be available to attend relevant sessions; and (6) be medication-free or on a stable dose of medication for at least eight weeks prior to treatment. Youth were excluded from participation for the following reasons: (1) presence of comorbid psychosis, bipolar disorder, autistic disorder, or current suicidal intent; (2) presence of an untreated primary psychiatric condition that warranted more immediate treatment (e.g., OCD, ADHD); and (3) were receiving another psychological intervention. Tic disorder diagnoses were confirmed via a clinical interview with a child and adolescent clinical psychologist or psychiatrist experienced with CTD, and administration of the YGTSS by a trained clinician. Co-occurring diagnoses were determined via the Anxiety Disorders Interview Schedule-DSM-IV-Child and Parent Version (Silverman and Albano, 1996). Twenty-four youth met inclusion criteria, and participated in the study. A CONSORT diagram is shown in Fig. 1, and a summary of participant characteristics is provided in Table 1.

2.2. Measures

Yale Global Tic Severity Scale (YGTSS; Leckman et al., 1989). The YGTSS is a clinician-rated semi-structured interview with demonstrated reliability and validity that measures tic symptom severity over the previous week (Leckman et al., 1989; Storch et al., 2005). The YGTSS produces a Total Tic Score (range: 0–50), and a Total Impairment Score (range: 0–50), with higher rating indicating greater tic severity and impairment, respectively.

Anxiety Disorders Interview Schedule for Children-DSM-IV: Child and Parent Version (ADIS-IV-C/P; Silverman and Albano, 1996). The ADIS-C/P is a clinician-administered structured diagnostic interview based on DSM-IV criteria. Diagnoses reflect endorsement of symptoms, as well as a severity rating (patient impairment/distress) of at least four on a 0–8 scale. The ADIS-C/P has demonstrated strong psychometric properties including test–retest reliability, inter-rater reliability, and concurrent validity (Silverman et al., 2001; Wood et al., 2002).

Clinical Global Impression-Severity (CGI-Severity; Guy, 1976). The CGI-Severity is a 7-point clinician rating of illness severity that ranges from *no illness* (0) to *extremely severe illness* (6). The CGI-Severity served as an overall measure of tic severity and tic-related impairment experienced by youth. The CGI-Severity has been widely used in RCTs of youth with CTDs (Piacentini et al., 2010; Himle et al., 2012).

Clinical Global Impression-Improvement (CGI-Improvement; Guy, 1976). The CGI-Improvement is a clinician-rated measure of improvement that is rated on a 7-point Likert scale ranging from *very much worse* (0) to *very much improved* (6). The CGI-Improvement was administered at the post-treatment (or post-waitlist) assessment by an independent evaluator blind to treatment condition. The CGI-Improvement is well validated in treatment studies of CTDs (Storch et al., 2011; Jeon et al., 2013), with a rating of either “very much improved” or “much improved” corresponding with a positive response to treatment.

Children's Yale–Brown Obsessive Compulsive Scale (CY-BOCS; Scahill et al., 1997). The CY-BOCS is a clinician-administered semi-structured interview used to assess obsessive compulsive symptom severity over the past week, with total severity scores ranging between 0 and 40. The CY-BOCS has demonstrated strong psychometric properties and sensitivity to treatment (Scahill et al., 1997; Storch et al., 2004).

Pediatric Quality of Life Inventory-Child Version (PedsQL; Varni et al., 2003). The PedsQL version is a 23-item child-rated measure that assessed youth's quality of life. Items are rated on a 5-point scale, with higher scores corresponding to better quality of life. The PedsQL Total Score provides a metric of overall child-rated quality of life. Extensive validity and reliability data have been published across multiple clinical presentations in support of the PedsQL (e.g., Varni and Burwinkle, 2006; Lack et al., 2009).

Multidimensional Anxiety Scale for Children (MASC; March et al., 1997). The MASC is a psychometrically sound 39-item child-report questionnaire that assesses symptoms of general, social, and separation anxiety in youth (March et al., 1997).

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