Mindfulness-based Stress Reduction for Tourette Syndrome and Chronic Tic

Disorder: A Pilot Study

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### Abstract

Objective: In this pilot study we sought to develop and test a modified form of Mindfulness-based Stress Reduction (MBSR-tics) for the treatment of TS and CTD. Our specific aims were: 1) To determine the feasibility and acceptability of an 8-week trial of MBSR-tics in individuals 16 and older with TS or CTD and 2) To determine the efficacy of an 8-week trial of MBSR-tics individuals 16 and older with TS or CTD.

Methods: Eighteen individuals ages 16 - 67 completed an uncontrolled open trial of MBSR-tics. The intervention consisted of 8 weekly 2-hour classes and one 4 hour retreat in the fifth or sixth week of the program. Symptomatic assessments were performed as baseline, post-treatment, and one-month follow-up.

Results: MBSR-tics proved to be a feasible and acceptable intervention. It resulted in significant improvement in tic severity and tic-related impairment. 58.8% of subjects were deemed treatment responders. Therapeutic gains were maintained at 1-month follow-up. Improvements in tic severity were correlated with increases in self-reported levels of mindfulness.

Conclusions: This pilot study provides preliminary support for the acceptability and efficacy of MBSR-tics for individuals 16 or older with TS or CTD. A future, randomized controlled trial with blind assessment is necessary to confirm these initial, promising, findings.

Trial Registration: Partners Clinical Trials Registry Number 2011P000606 (clinicaltrials.partners.org)

Keywords: Chronic Tic Disorder, Mindfulness, Psychosocial, Tourette Syndrome, Treatment

Despite recent advances in the treatment of individuals with Tourette Syndrome (TS) and Chronic Tic Disorder (CTD), there remains room for improvement. Pharmacological treatments, although effective, carry a substantial risk of unpleasant side effects (1). Psychosocial interventions, such as Comprehensive Behavioral Intervention for Tics (CBIT; (2)) offer meaningful symptomatic relief without burdensome side effects but also fail to help a significant number of individuals (e.g., (3-5). Thus, it is essential that we continue to develop and test alternative treatments. In this pilot study we sought to develop and test a modified form of Mindfulness-based Stress Reduction (MBSR) for the treatment of TS and CTD.

MBSR was originally developed in 1979 by Jon Kabat-Zinn at the University of Massachusetts (6). Through direct practice in meditation, MBSR promotes the development of nonjudgmental moment-to-moment awareness of one's perceptions, bodily sensations, thoughts, and emotions. Participation is highly experiential and centers around four primary meditative practices: sitting meditation, the body scan, yoga, and walking meditation. In each of these exercises participants gain experience in directing their attention to the content of their moment-to-moment experience while refraining from any efforts to change their experience. Participants are encouraged to adopt a curious, patient, accepting, non-striving, and non-judgmental attitude toward themselves and their inner experience. MBSR has garnered empirical support as a treatment for a range of medical and psychological conditions including chronic pain, fibromyalgia, anxiety, binge eating disorder, and recurrent major depression (for review (7, 8)). Of particular relevance to TS and CTD, mindfulness-based interventions have recently shown promise in the treatment of two commonly comorbid disorders: Obsessive-Compulsive Disorder (OCD; (9, 10) and Attention Deficit Hyperactivity Disorder (ADHD; (11, 12)).

The behavioral model of tic maintenance (2, 13, 14) posits that while tics are of neurobiological origin, there are important internal and environmental factors that make them more likely to occur. The most central assumption in the model is that tics are negatively reinforced every time that they relieve the individual from the discomfort associated with the premonitory urge to tic. Indeed, many individuals report that their tics are voluntary automatic reactions to the premonitory urge to tic (15). Additional internal factors (e.g., stress or anxiety) and external factors (e.g., social attention, certain activities, caffeine) have also been associated with tic worsening (16). Consistent with this model, we hypothesized that a modified version of MBSR for individuals with TS or CTD (MBSR-tics) might benefit individuals with TS and CTD in three possible ways. First, meditation has been shown to improve attentional control (for review (17)). Thus, we hypothesized that improved attentional control might increase participants' awareness of when their tics are about to occur, occurring, and the factors that make them better or worse. This awareness is essential in enabling the individual to respond differently to the urges to tic. Second, meditative practice in observing and allowing one's internal experiences without trying to change them may help individuals sit with the discomfort of the premonitory urge and allow it to subside on its own without engaging in the tic, thereby breaking

the cycle of negative reinforcement. And third, MBSR has also been shown to decrease physiological arousal and emotional reactivity (for review (18). Thus, we hypothesized that the intervention may reduce the stress, anxiety, and frustration that are commonly associated with tic exacerbation.

Our specific aims were: 1) To determine the feasibility and acceptability of an 8-week trial of MBSR-tics in adults with TS or CTD and 2) To determine the efficacy of an 8-week trial of MBSR-tics in adults with TS or CTD. We hypothesized that MBSR-tics would be feasible and acceptable to individuals with TS or CTD, as measured by dropout rate, patient satisfaction, patient feedback, and adverse events. We also hypothesized that MBSR-tics would result in a significant reduction in the frequency of tics and the degree of ticrelated impairment from pre- to post-treatment, as measured by the Yale Global Tic Severity Scale (YGTSS).

# Method

#### Overview

In this open trial, all participants received MBSR-tics. Participants completed 13 visits over approximately 12 weeks. We first assessed participants for eligibility at a screening visit. Eligible participants then returned for a baseline assessment in the week prior to the start of classes. The MBSR-tics course consisted of 8 weekly 2-hour classes and one 4-hour retreat on a Saturday or Sunday during the 5<sup>th</sup> or 6<sup>th</sup> week of the program. Participants returned for a post-treatment assessment within one week of the last class, and a follow-up assessment approximately 1-month after the last class.

All study procedures were approved by the Partners Human Research Committee and carried out in accordance with the Code of Ethics of the World Medical Association. All participants provided written informed consent prior to completing any study procedures.

# Independent Assessment

All clinician-rated outcome measures were administered by an independent evaluator (IE) who was not otherwise associated with the study. The IE had a doctoral degree in clinical psychology and received training from experienced raters on the study measures. Moreover, every assessment was recorded and 20% of the baseline assessments were randomly selected for co-rating by an experienced rater. To determine inter-rater reliability we computed Shrout-Fleiss intraclass correlation coefficients (ICC (3,1); (19) for our primary outcome measure: total tic severity score of the YGTSS. Inter-rater reliability was acceptable (ICC (3,1) = 0.89).

#### Participants

We recruited participants via the Tourette Syndrome Association of Massachusetts, our program website, a clinical trials registry, flyers, and neighboring clinics. To be eligible for the study, individuals had to be 16 years of age or older with a primary diagnosis of TS or CTD and a total tic severity score on the YGTSS  $\geq$  20 (for individuals with motor *and* vocal tics) or 12 (for individuals with motor *or* vocal tics only). Participants were also required to be either not taking any tic suppressant or other psychotropic medication or on a stable dose for 6 weeks prior to and throughout the study. Participants were excluded from the study if they were receiving concurrent psychotherapy for tics, had a comorbid Axis I disorder necessitating a higher level of care (e.g., psychotic disorder, bipolar disorder), current substance abuse or dependence, or had previously completed an MBSR program.

# Intervention

MBSR-tics generally adhered to the original curriculum as outlined by Kabat-Zinn (1990) and briefly described above. To adapt the course for individuals with tics we made the following modifications: offered shorter (2 hours), smaller (5-7 participants) classes, provided psychoeducation regarding tics and the theory motivating this approach, developed a tic-specific sitting meditation, and developed practices for promoting mindfulness of the factors that make tics better or worse. The tic-specific sitting meditation became a cornerstone of the experiential practice and was incorporated into every class after its introduction in class three. Briefly, the meditation encouraged participants to mindfully notice any urges to tic, and to ride the urge to tic, like a wave, until it subsided independently, without engaging in a tic or otherwise trying to change or eliminate the urge in anyway.

The course was co-taught by Dr. Reese and Ms. Vallejo. Dr. Reese has a Ph.D. in clinical psychology and extensive experience providing psychosocial interventions to individuals with tics. Ms. Vallejo has over 30 years of practice in mindfulness and over 10 years experience teaching it to others. She is also a certified MBSR instructor and has previous experience successfully adapting the intervention for specific populations.

# Measures

**Structured Clinical Interview for DSM-IV (SCID).** The SCID is the goldstandard in semi-structured diagnostic interviews to establish DSM-IV diagnoses (20). We administered the SCID at screening to assess for the presence of current or past Axis I disorders. Consistent with recently published NIMH-funded ADHD research trials (21), we also administered supplementary questions from the Kiddie Schedule for Affective Disorders and Schizophrenia- Epidemiologic Version (K-SADS-E; (22) modified for use in adults to assess for the presence of comorbid ADHD.

**Yale Global Tic Severity Scale (YGTSS).** The YGTSS is the gold-standard clinician-rated instrument for assessing tic severity (23). Motor and phonic tics are rated separately from 0 to 5 on five dimensions including: number, frequency, intensity, complexity, and interference. Thus, motor and phonic tic scores range from 0 to 25 and the combined total tic severity score ranges from 0 to 50. Additionally, an overall impairment score indicates the overall burden due to tics and is rated from 0 to 50. The YGTSS has demonstrated excellent internal

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reference(s) we could cite for your prior MBSR adaptations? Thanks!).

consistency, and convergent and divergent validity (23). We administered the YGTSS at screening, baseline, endpoint, and follow-up.

**Clinical Global Impression-Improvement (CGI-I) Scale.** The CGI-I is a wellestablished clinician-rated measure of improvement (24). It is a 7-point measure of patient improvement relative to baseline. We administered the CGI-I at endpoint and follow-up. Consistent with other treatment outcome studies in TS and CTD (e.g., (3, 4), we defined treatment response as a rating of 'Very Much Improved' or 'Much Improved' on the CGI-I.

Adult Tic Questionnaire (ATQ). The ATQ is a 28-item self-report measure modeled after the Parent Tic Questionnaire (25) assessing the presence, frequency, and intensity of motor and vocal tics. The ATQ yields two subscales: frequency and intensity that can be summed for a total score. We administered the ATQ at baseline, endpoint, and follow-up to determine the effect of the intervention on self-reported tic severity.

The Work and Social Adjustment Scale (WSAS). The WSAS (26) is a 5-item self-report measure of the degree of impaired functioning attributable to a specific syndrome/disorder. It has demonstrated good internal consistency and test-retest reliability. We administered the WSAS at baseline, endpoint, and follow-up to determine the effect of the intervention on self-reported level of impairment associated with the tics.

**Five Facet Mindfulness Questionnaire (FFMQ).** The FFMQ (27) is a widelyused 39-item self-report measure of five aspects of mindfulness: observing, describing, acting with awareness, non-judging of inner experience, and nonreactivity to inner experience. The scale was constructed from a factor analysis of five psychometrically-sound and independently developed mindfulness questionnaires. We administered the FFMQ at baseline, midpoint, endpoint, and follow-up to determine the effect of the intervention on self-reported levels of mindfulness and the relationship between any observed symptomatic changes and changes in mindfulness.

**Client Satisfaction Questionnaire (CSQ).** The CSQ (28) is an 8-item scale that assesses client satisfaction with treatment. Each item is scored from 1 to 4 with higher scores indicating greater satisfaction. Total scores range from 8 to 32. We administered the CSQ at endpoint to determine degree of participant satisfaction with the intervention.

#### Results

### Participant Characteristics

A total of 38 individuals contacted our program about the study. Thirtythree individuals conducted a preliminary phone screen to assess for eligibility. Twenty-three individuals signed consent to participate in the study and completed the in-person assessment for eligibility. Five individuals were not eligible for the following reasons: did not meet diagnostic criteria for TS or CTD (n = 1), insufficient symptom severity (n = 1), unstable medication (n = 2), insufficient symptom severity and unstable medication (n = 1). See Figure 1 for a complete consort diagram. Of the 18 individuals who were eligible for the study and began treatment ten were male and eight were female. They ranged in age from 16 to 67 years (M age = 34.8 years). Sixteen participants identified as Caucasian, one as Asian, and one as more than one race. One participant identified as Hispanic or Latino, 17 did not.

Seventeen individuals met primary DSM-IV diagnostic criteria for Tourette Syndrome. One individual met primary DSM-IV diagnostic criteria for Chronic Motor Tic Disorder. Age of onset ranged from 4 to 13 years of age (M = 8.8; SD = 3.0). Comorbid diagnoses were as follows: OCD (n = 8), ADHD (n = 2), Generalized Anxiety Disorder (n = 8), Other Habit Disorder (Skin picking/Nail Biting; n = 6), Social Anxiety Disorder (n = 5), Major Depressive Disorder (n = 2), Body Dysmorphic Disorder (n = 2), Trichotillomania (n = 2), Dysthymia (n = 1), Post Traumatic Stress Disorder (n = 1), Binge Eating Disorder (n = 1),

Twelve individuals were taking a stable dosage of concomitant medication at study entry. The types of medications taken included: antidepressants (n = 7), alpha agonists (n = 6), benzodiazepines (n = 6), stimulants (n = 3), anticonvulsants (n = 1), antipsychotics (n = 1), and migraine medication (n = 1).

# Statistical Analysis

One participant dropped out of treatment after 3 sessions. He completed the post-treatment assessment at week 4 but did not complete a one-month follow up assessment. We have included his data when available. One participant started two new medications during the course of the study. We have excluded this participant. A second participant increased the dosage of one preexisting medication between post-treatment and one-month follow-up. We have excluded this participant from follow-up analyses only. In the case of missing items, total scores were imputed if less than 10% of items were unanswered by multiplying the total number of items in the scale by the mean score of the completed items. If 10% or more of the items in a questionnaire were unanswered then the questionnaire was considered missing.

# Aim 1: Feasibility and Acceptability

Dropout

Of the 18 individuals who began treatment, one (5.5%) withdrew from the study prematurely. He decided to pursue alternative treatment.

#### Satisfaction

Participant satisfaction, as measured by the CSQ, was high. Scores ranged from 21 to 32 with a mean level of 27.8 (*SD* = 3.7). *Qualitative Feedback* 

To interpret qualitative feedback from participants, we used a coding scheme outlined by Auerbach and Silverstein (29). Participants provided written feedback after each class. We identified repeating ideas in the feedback by reading through a master list of text from the feedback forms and grouping together ideas that appeared to express the same meaning. These repeating ideas were subsequently arranged into larger themes. In the final step of the coding process, themes were grouped together under theoretical constructs, which aimed to integrate the qualitative data with relevant constructs from the literature, when possible.

Several dominant themes emerged: the calming, nurturing environment, the learning and transfer of awareness, mindfulness, and metacognitive skills, the challenges of meditation, the extension of the mindfulness practice to other domains of their lives, and the value of the group setting. In what follows, we will describe each of these themes in more detail.

Several participants remarked on the "extremely nurturing and encouraging" environment. They described the classes as being characterized by a "calm energy" and as a "time to pause and be surrounded by positive energy." Individuals could leave class "much calmer than when I arrived". The feeling that "there were no restrictions or expectations placed on any activity regarding the way we experience it or the outcome" was especially freeing to some.

The learning and transfer of awareness, mindfulness, and metacognitive skills were frequently commented on by participants. Individuals identified noticing "emotions/thought patterns", "learning how to live with/hold the discomfort", and connecting to one's body as techniques of particular utility. Participants "liked learning about thinking of things with a 'new mind'" and articulated the relevance of some of the central tenants of mindfulness to their tics, "I liked…being aware, and learning how to live with/hold the discomfort--that gets to the heart of what triggers most of my tics—discomfort over something."

Despite the relaxation that often accompanied mindfulness exercises, learning to meditate and to sit with urges and thoughts could be both challenging and uncomfortable for participants. Individuals noted that they sometimes "disliked the discomfort of sitting meditation. I look forward to more, but there is a lot of ache that comes with it." Participants commented on a range of emotions during meditation from frustrated, pained, and distracted to relaxed and empowered. For many, meditation was a skill that they had to work towards "getting used to" at the outset. At the same time, participants had a range of activities and mindfulness techniques that they found particularly helpful or relaxing, and these specific preferences varied by person. They noted that they "liked the idea of giving us such a broad range of tools" so they could "figure out what works best for us."

Beyond mindfulness skills targeted specifically to tics, participants expressed an appreciation for the transfer of these techniques from the classroom setting to their interpersonal lives and to more generalized coping skills. Exercises aimed at integrating mindfulness into these broader constructs were received positively. Participants noted of one session that "the most important part was beginning to talk about anger and forgiveness" given that "anger is never a primary emotion, and teaching from where it starts, how to spot it, and how to not be STUCK IN IT [is] one of the most important things." Participants also enjoyed "the discussion of stress in broader terms than just when it applies to ticking" and "talking about really listening to someone, how to differentiate from NOT really being present--and how that affects your sense of wellbeing." Finally, many group members commented on the group setting as a valuable format for sharing experiences, receiving support, and interacting with individuals with similar experiences. For many participants, the study provided them with the first opportunity to speak openly about their tics with individuals outside of their immediate family. Participants articulated that it was "helpful to hear others express the same emotions and fears/anxiety about their tics, and "listening to others speak" allowed them to "know I am not alone." One participant stated, "The support and insight of the other group members...was tremendous". This interpersonal connection and sharing of experiences was nearly universally commented upon by the participants.

Adverse Events

Adverse events were monitored at every visit. Over the course of the study, seven participants reported temporary tic exacerbation. Most individuals attributed this increase in tic frequency to stressors in their personal lives or the normal fluctuation in tic severity. However, two of the participants attributed the transient worsening of tics to anticipation of the MBSR group setting. Three individuals reported temporary increases in depression and anxiety symptoms. One participant reported experiencing back spasms, one reported muscle and nerve pain, and three reported injuries (ankle, finger, and shoulder). None of these events were judged to be related to the intervention.

### Aim 2: Efficacy

# Primary Outcomes

## Tic severity

At baseline, participants had a mean YGTSS total tic severity score of 26.76 (range: 10-44). Total tic severity significantly decreased from pre- to post-treatment, t(16) = 4.13, p = .001, d = 1.03. The average decrease was 5.41 points which is equivalent to a 20.2% reduction in tic severity.

#### Tic-related impairment

At baseline, participants had a mean YGTSS impairment score of 21.76 (range: 10 - 40). Tic-related impairment significantly decreased from pre- to post-treatment, t(16) = 4.67, p < .001, d = 1.17. The average decrease was 8.24 points which is equivalent to a 38% reduction in tic-related impairment.

# Global Improvement

Ten participants were rated as 'much improved' or 'very much improved' on the CGI-I at post-treatment. Thus, 58.8% of participants were deemed treatment responders at post-treatment.

#### Durability of Treatment Gains

Examination of the 1-month post-treatment data reveals that treatment gains were maintained at follow-up. Total tic severity scores remained reduced from baseline, t(14) = 5.29, p < .001, d = 1.41, and did not significantly differ from post-treatment t(14) = .28, p = .79. Impairment also remained reduced from baseline, t(14) = 4.00, p = .001, d = 1.07, and did not significantly differ from post-treatment, t(14) = 0, p > .99. As before, ten participants were rated as

'much improved' or 'very much improved' on the CGI-I and therefore deemed treatment responders.

# Secondary outcomes and exploratory analyses

# Self-reported tic severity

Self-reported tic severity, as measured by the ATQ, also declined from baseline to post-treatment, t(16) = 2.13, p = .049, d = .53, and remained significantly reduced at 1-month follow-up, t(14) = 2.17, p = .048, d = .58.

# Work and Social Adjustment

Tic-related impairment, as measured by the WSAS also significantly decreased from baseline to post-treatment, t(16) = 2.45, p = .026, d = .61, and remained significantly reduced at 1-month follow-up, t(14) = 2.83, p = .013, d = .76.

#### Mindfulness

We observed marginally significant increases in self-reported mindfulness, as measured by the FFMQ, from baseline to mid-treatment, t(15) = 2.01, p = .063, d = .52. By post-treatment, self-reported mindfulness was significantly increased from baseline, t(16) = 3.71, p = .002, d = .93, and remained significantly increased relative to baseline at 1-month follow-up, t(13) = 4.43, p = .001, d = 1.23. Moreover, baseline to mid-treatment increases in mindfulness were significantly positively predictive of symptomatic improvement, as measured by the YGTSS, from baseline to post-treatment were also significantly positively correlated with symptomatic improvement from baseline to post-treatment, r(17) = .57, p = .018. We observed a similar pattern of results at 1-month follow-up but the correlation was no longer significant, r(14) = .22, p = .46.

# Discussion

In this initial pilot study, MBSR-tics proved to be a feasible and acceptable intervention for individuals ages 16 and older with TS or CTD. Only one participant withdrew from the study prematurely which corresponds to a lower drop-out rate than is often observed in other psychosocial interventions for tics (e.g., (4, 30). Participants also reported high satisfaction with the intervention as measured by the CSQ and qualitative feedback. Similar to other psychosocial interventions for tics, the treatment was also associated with only mild, transient adverse effects (e.g., transient anxiety in anticipation of the program) in the minority of participants suggesting that it may be a safer alternative to medication treatment.

MBSR-tics also resulted in significant reductions in tic severity and ticrelated impairment. Our conclusions regarding efficacy must be interpreted as preliminary given the limitations inherent in an uncontrolled, open trial. However, the symptomatic improvement associated with MBSR-tics compares favorably to that associated with CBIT, the current psychosocial treatment of choice for TS and CTD. For example, in a recently completed randomized controlled trial of CBIT for individuals ages 16 and older with TS and CTD (4), 10 weeks of treatment with CBIT resulted in a 25.8% reduction in tic severity and a 38% reduction in tic-related impairment. Similarly, after 8 weeks of MBSR-tics, we observed a 20.2% reduction in tic severity and a 38% reduction in tic-related impairment. The rate of positive treatment response (CGI-I score of much improved or very much improved was higher for MBSR-tics (58.8%) than for CBIT (38.1%). Future research employing a credible comparison condition and blinded assessment would enable us to confirm these promising initial findings.

The correlation between increases in mindfulness and symptomatic improvement supports the idea that an increased ability to attend to, describe, and not react to one's experiences led to symptomatic improvement. Future research employing a comparison condition would allow us to conduct meditational analysis to confirm this proposed mechanism of change. It would also be interesting to test whether these self-reported findings could be replicated with behavioral measures of attention, inhibition, and emotional reactivity.

The qualitative data we gathered provided us with some insights into the aspects of treatment that participants found to be helpful. A number of participants found it helpful to have a range of different tools and exercises for practicing mindfulness. The diversity of exercises found in MBSR-tics may have enabled more individuals to understand the approach and gain practice employing it. Employing multiple strategies for teaching and practicing treatment approaches is something that could potentially improve any psychosocial intervention for tics. Participants also commented on the usefulness of applying mindfulness to their emotions, particularly anxiety and anger, and relationships. Given the association between tic exacerbation and emotional arousal and stress. it is likely that a more general reduction in distress and improvement in relationships could lead to downstream reductions in tic severity. Again, incorporation of strategies aimed at improving emotion regulation and reducing stress would improve any psychosocial intervention for tics. And finally, participants nearly universally commented on the value of the group setting. For many of our participants this was the first time they were able to share their experiences with tics with someone else going through the same thing. They also found it very useful to share their experiences with the treatment with each other. This speaks to the importance of connecting members of the TS community to each other and suggests that group treatments may be a feasible, efficient, and cost-effective means of treatment delivery.

We have made great strides in the treatment of TS and CTD, but there is still much work to be done. A novel treatment approach such as MBSR-tics adds to the range of interventions currently available to patients with TS or CTD. Future research confirming the efficacy of this intervention is, of course, necessary. Should our preliminary support for the acceptability and efficacy of this intervention be supported, MBSR-tics may also prove to be particularly wellsuited for dissemination. Traditional MBSR has been adopted by over 200 major medical centers nationwide. Thus, an adapted form of the treatment could perhaps be more easily disseminated to sites with these services already in place.

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