Published in final edited form as:

Compr Psychiatry. 2014 January ; 55(1): . doi:10.1016/j.comppsy.2013.06.009.

Tic Related Activity Restriction as a Predictor of Emotional Functioning and Quality of Life

Christine A. Conelea, Ph.D.^a, Andrew M. Busch, Ph.D.^b, Mark A. Catanzaro^c, and Cathy L. Budman, M.D.^d

^aRhode Island Hospital/Alpert Medical School of Brown University, Providence, RI

^bThe Miriam Hospital/Alpert Medical School of Brown University, Providence, RI

^cThe University of Indiana at Bloomington, Bloomington, ID

^dHofstra University School of Medicine, Hempstead, NY, USA

Abstract

Objectives—Tourette Syndrome (TS) is a chronic neuropsychiatric condition that frequently persists into adulthood. Existing research has identified demographic and symptom-level variables associated with psychopathology and poor quality of life in TS. However, behavior patterns associated with enhanced or adaptive psychological and global functioning among adults with TS have yet to be empirically identified. The current study examined whether tic-specific activity restriction is related to emotional functioning and quality of life in adults with TS.

Methods—Participants were 509 adults from the Tourette Syndrome Impact Survey who completed self-report measures of demographics, tic severity, emotional functioning, quality of life, and tic related general and social activity restriction.

Results—Partial correlations controlling for tic severity indicated that tic related general and social activity restriction were significantly correlated with lower quality of life and poorer emotional functioning. Hierarchical linear regression models indicated that activity restriction significantly predicted lower quality of life and poorer emotional functioning when controlling for tic severity and demographic variables.

Conclusions—Adults who restrict fewer activities due to tics, regardless of tic severity, experience greater quality of life and better emotional functioning. Clinically, adults with chronic tics may benefit from interventions focused on enhancing engagement in valued life activities.

1. Introduction

Tourette Syndrome (TS) and other Chronic Tic Disorders (CTD) are heritable neuropsychiatric conditions characterized by tics (i.e. repetitive involuntary movements and/or phonations) for at least one year duration [1]. TS is more common in males and is highly comorbid with Attention Deficit Hyperactivity Disorder (ADHD; about 60% comorbidity rate), Obsessive Compulsive Disorder (OCD; about 27% comorbidity rate), non-OCD

© 2013 Elsevier Inc. All rights reserved.

Correspondence to: Christine Conelea, Ph.D., Bradley/Hasbro Children's Research Center, Coro West 2nd Floor, 1 Hoppin St., Providence, RI 02906, Phone: (401) 793-8783, Fax: (401) 444-8742, Christine_Conelea@brown.edu.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Anxiety Disorders (about 18% comorbidity rate), and Mood Disorders (about 20% comorbidity rate) [2]. The onset of tics occurs during early childhood (age 5–6 years), followed by a peak in severity during late childhood (age 10–12 years) with gradual decline in severity across adolescence [3]. Epidemiological studies estimate that TS occurs in at least 0.3% and possibly in up to 1% of the general population [4, 5]. Although some data suggest that the prevalence of TS may be lower in adults, affecting an estimated 1 in 2000 [6], objective longitudinal assessment of TS reveals that up to 90% of those who have tics as children continue to have tics as adults [7]. Unfortunately, there is no cure for this chronic condition. While empirically supported treatments exist, it is estimated that only 30–70% of adults with TS respond to medication (often with unwanted side effects) and only 38% respond to behavior therapy [8]. Therefore, even with maturation and the option for standard therapeutic interventions, many adults with TS continue to experience significant symptoms.

The functional burden for adults with TS has been highlighted by numerous studies that demonstrate lower employment rates, income, and job satisfaction in comparison to healthy populations [9–12]. Considerable evidence indicates poor perceived quality of life (QoL) in adults with TS [13–15]. When compared with healthy control populations, reported QoL in those with TS is lower with respect to several domains, including emotional, physical, social, home, academic, and occupational performance [16–18].

Research on emotional functioning and QoL in TS has focused on identifying factors that contribute to impairment or poor global functioning. Factors of interest have typically been static historical variables, TS-specific symptomatology, or symptoms of co-occurring psychopathology. Several of these factors have been shown to be predictors or correlates of poor emotional functioning and reduced QoL in TS, including age [17], family history of TS [13], tic severity [14, 17], premonitory urge severity [13], presence of any co-occurring psychopathology [16], depression [16, 17], symptoms of OCD and ADHD [18], and ADHD symptom severity [15].

Existing research has helped to identify demographic and symptom-level variables associated with psychopathology and poor QoL. By contrast, very little research has attempted to identify *behavior patterns* associated with *satisfactory or enhanced* psychological and/or global functioning among those with TS. Findings in youth samples suggest that some with TS thrive despite severe tics, while others experience significant impairment despite relatively mild tics [19, 20]. Anecdotal accounts of adults who report satisfactory adaptation and functioning despite persistent tics abound in media [21], autobiographical books [22], and in the literature of patient-support organizations [23]. However, researchers have yet to empirically identify specific behavior patterns associated with such enhanced outcomes. Identifying potential resilience or coping behaviors that are associated with positive adaptive functioning in TS is extremely important for improving care and optimizing outcomes of adults living with this chronic condition.

The central aim of the current study is to explore one behavioral mechanism that may predict emotional functioning and quality of life regardless of tic severity: the extent to which one avoids or diminishes engagement in valued life activities due to tics (i.e., tic-related activity restriction). Research across a variety of chronic medical conditions (e.g., cancer, COPD, arthritis, stroke) has demonstrated that activity restriction due to physical symptoms predicts depression and poor QoL both concurrently [24, 25] and prospectively [26]. Further, even after controlling for physical symptom severity in certain medical illnesses, activity restriction has been shown to predict depression [27].

There are several mechanisms by which tics may interfere with valued activity engagement in those with TS. First, tics may directly physically disrupt or interfere with completion of

some activities (e.g., speaking on a telephone, driving a car, sitting quietly in meetings). Secondly, those with tics (often with the intentional or unintentional endorsement of family members) may avoid activities that could be physically completed due to anticipated embarrassment, discrimination, and fears of social rejection [28]. To our knowledge, no study has explored the effects of activity restriction due to tics in TS.

The current study reports on data provided by the TS Impact Survey using a large virtual community sample of adults with TS and CTD obtained by Internet sampling methods [14]. We explored whether the extent to which an affected individual continues to engage in valued life activities despite his/her tics was related to self-reported QoL and emotional functioning. Specifically, we hypothesized that lower levels of social and general activity restriction would be associated with higher perceived QoL and with worse emotional functioning, even after controlling for tic severity and relevant covariates.

2. Method

2.1. Participants and procedures

The study used data collected as part of the omnibus web-based Tourette Syndrome Impact Study described by Conelea et al. [14]. Research comparing data collected in person versus over the internet has demonstrated that results are similar across administration formats, consistent with results from studies using traditional methodology, and without adverse impact by repeat or false responders [29, 30].

Participants were recruited with the assistance of the Tourette Syndrome Association (TSA; <http://www.tsa-usa.org>), which placed a link to the survey on its national website and directed members to the link in newsletter and email announcements. The survey was posted online for 8 consecutive months (March–November 2008). The entire survey took approximately 60 minutes to complete. Participants indicated their consent to participate by checking a box on the first page of the survey and were allowed to skip individual questions or entire measures to encourage entirely voluntary sharing of information. The study was approved by the University of Wisconsin–Milwaukee Institutional Review Board.

Adult participants (age 18 years and older) were included in the current study if they 1) reported being formally diagnosed with TS or CTD ($N = 684$), 2) reported an onset of tics prior to the age of 18 ($N = 672$ of those meeting inclusion criterion 1), 3) completed the Yale Global Tic Severity Scale ($N = 574$ of those meeting inclusion criteria 1–2), 4) completed all items on the general activity restriction scale ($N = 505$ meeting inclusion criteria 1–3) or the social activity restriction scale ($N = 532$ of those meeting inclusion criteria 1–3; $N = 540$ had at least one of these scores) and 5) had valid data for the DASS-21 total score ($N = 486$ of those meeting inclusion criteria 1–4) or the PQOL ($N = 457$ of those meeting inclusion criteria 1–4; $N = 509$ had at least one of these scores). No suspected repeat responders were identified [14]. Based on these criteria, a total of $N = 509$ participants from the Conelea et al. [14] study were included in the current study.

2.2 Measures

2.2.1. Tourette Syndrome Impact Survey (TSIS) [14]—Select items from the TSIS were used in the current study to assess age, household income, and self-report of formal psychiatric disorder diagnoses. Six items from the survey assessed activity restriction and were grouped together to form two activity restriction scores.

2.2.2. General Activity Restriction—Three items assessed restriction of activities broadly defined and required participants to rate the truthfulness of the statement on a scale

of 0 (“Not at all true”) to 4 (“Very true”). Items were as follows: “I don’t try out new things if I’m afraid I will tic,” “I stop doing things that are important to me when I’m having a bad tic day,” and “When I feel depressed or anxious about my tics, I am unable to take care of my responsibilities.” Items were summed to yield a total score (range = 0–12), such that higher scores indicate greater restriction of general activities. Internal consistency in this sample was good ($\alpha = .76$).

2.2.3. Social Activity Restriction—Three questions assessed activity restriction related to social situations, including *social events* (“In the past 12-months, have you avoided going to social events (i.e., parties, reunions) or entertainment activities (i.e., sporting events, concerts, plays) because of your tics?”), *group activities* (“In the past 12-months, have you refrained from group activities because of your tics?”), and *public places* (“In the past 12-months, did you avoid going out into public places because of your tics?”). We considered summing the “yes” answers for a 0–3 scale; however, summing these questions created a bi-modal distribution (i.e., most participants either answered “no” to all 3 or “yes” to all 3). Thus, social activity restriction was coded as a dichotomous variable (i.e., 1 = participant avoids any of the three social activities, 0 = participant avoids none of the three social activities due to tics).

2.2.4. Yale Global Tic Severity Scale (YGTSS) [31]—The YGTSS assesses tic severity and was modified to fit a self-report format for the current web-based study. Participants identified the presence of specific motor and vocal tics occurring over the past 7 days and rated the number, frequency, intensity, complexity, and interference of motor and vocal tics separately. Each domain was rated on a 0- to 5-point scale, with higher scores indicating greater severity. Item scores were summed, yielding a total severity score ranging from 0 to 50. The measure demonstrated good internal validity in this sample ($\alpha = .89$).

2.2.5. Depression Anxiety Stress Scale 21-Item Version (DASS-21) [32]—The DASS-21 is a self-report measure of negative emotion that produces three empirically derived subscales (depression, anxiety, and stress) and a total score. The subscales scores are reported, but only the total score was entered into regression analyses. Each scale consists of 7 items rated on a 4-point scale (ranging from 0 “Did not apply to me at all” to 3 “Applied to me very much or most of the time”) according to the extent to which depression/anxiety/stress symptoms were experienced over the previous week. Items are summed and multiplied by 2, yielding a range of possible total scores from 0 to 126, such that higher scores indicate greater symptom frequency. In the current sample, internal consistency for the Depression ($\alpha = .92$), Anxiety ($\alpha = .81$), Stress ($\alpha = .87$), and total score ($\alpha = .93$) scales were acceptable.

2.2.6. Perceived Quality of Life Scale (PQOL) [33, 34]—The PQOL is a 19-item selfreport measure of perceived quality of life. Items related to satisfaction with physical, social, cognitive health, and well-being are rated on an 11-point scale ranging from 0 (“extremely dissatisfied”) to 10 (“extremely satisfied”). The measure yields a total score, with higher scores indicating greater satisfaction with QoL [34]. Internal consistency for the PQOL in the current sample was acceptable ($\alpha = .93$).

2.3. Analytic Plan

Previous research using this sample showed a significant and positive correlation between tic severity on the YGTSS and DASS-21 Scales (Depression: $r = 0.25$, $p = .01$; Anxiety: $r = 0.34$, $p = .01$; Stress: $r = 0.39$, $p = .01$) and a significant and negative correlation between the YGTSS and PQOL ($r = -0.21$, $p = .01$) [14]. Tic severity has also been shown to be associated with QoL and functional impairment in other studies [13]. Therefore, we planned

a priori to control for tic severity in all analyses. We first conducted partial correlations between both activity restriction scales and emotional functioning and QoL controlling for YGTSS total score. Next, hierarchical linear regression was used to determine whether activity restriction variables were significantly associated with QoL (PQOL) and emotional functioning (DASS-21 total score) above and beyond tic severity (YGTSS) and demographic characteristics. Four separate, two-step linear hierarchical regressions were conducted. YGTSS total score, age, gender, household income, and education level were entered in Step 1 for all models. Step 2 added either social activity restriction or general activity restriction.

3. Results

Of the 509 participants, the majority were male ($N = 300$, 59.1%, $N = 1$ not reported), and the mean age was 36.6 years ($SD = 13.4$, 1 not reported). Modal education level was “high school or GED” (34.5%, $N = 2$ not reported), and modal household income was \$75,000+ (44.3%, $N = 28$ not reported).

The mean YGTSS Total Tic Score was 22.3 ($SD = 10.3$; $N = 509$), representing a moderate level of tic severity. The mean score for general activity restriction was 2.5 ($SD = 2.9$, $n = 499$). Of participants reporting social activity ($n = 501$), 46.5% answered “yes” to at least one of the social activity restriction questions. The mean total score on the PQOL was 6.6 ($SD = 1.7$; $N = 457$), which (as expected) is lower than that reported by well adults (mean = 8.4, $SD = 1$) and below the measure cut-off for low life satisfaction [33].

All DASS-21 subscales and the total score were significantly skewed. Thus, we report medians in addition to mean and SDs. The mean of the DASS-21 total score was 36.0 ($SD = 25.5$, median = 30.0, $N = 486$). The Depression Scale of the DASS-21 had a mean score of 10.6 ($SD = 10.6$, median = 6.0, $N = 500$). The Anxiety Scale of the DASS-21 had a mean score of 8.2 ($SD = 8.5$, median = 6.0, $N = 502$). The DASS-21 Stress scale had a mean of 17.3 ($SD = 10.3$, median = 16.0, $N = 500$). Means and medians for all DASS-21 scales were significantly above those of the US general population (e.g., Total DASS-21 score in the US general population has a mean of 17.8, $SD = 20.1$, median = 12) [35].

DASS-21 subscales were highly correlated with the total score ($r_s = .86-.88$) and with each other ($r_s = .58-.68$), so only the DASS-21 total score is presented in below analyses below to avoid redundancy. Due to the significant positive skew (skew = 1.0, SE of skew = .11), the DASS-21 total score was transformed for regression analyses below using the following formula: (DASS-21 total score + 1). The resulting transformed variable was normally distributed (mean = 5.7, $SD = 5.6$, skew = .15, SE of skew = .11). Partial correlations indicated that, independent of tic severity, general activity restriction was significantly related to QoL (PQOL; $r = -.42$, $p < .001$) and emotional functioning (DASS-21 total transformed; $r = .47$, $p < .001$). Social activity restriction was also significantly related to QoL (PQOL; $r = -.30$, $p < .001$) and emotional functioning (DASS-21 total transformed; $r = .33$, $p < .001$) independent of tic severity. The directions of these relationships indicate that those who restrict fewer activities due to tics experience greater quality of life and better emotional functioning.

Regression models examining general activity restriction as a predictor of PQOL and DASS-21-Total are presented in Table 1. For the PQOL, tic severity and demographic variables explained 10.2% of the variance ($R^2 = .102$, $F(5, 421) = 9.54$, $p < .001$). Adding general activity restriction to the model explained an additional 13.0% of the variance in PQOL scores (R^2 change = .130; $F(1, 420) = 71.5$, $p < .001$). Tic severity and demographic variables explained 19.0% of the variance on the DASS-21-Total score ($R^2 = .190$, $F(5, 444)$

= 20.9, $p < .001$). Adding general activity restriction to the model resulted in an additional 16.9% of DASS-21 total variance explained (R^2 change = .169, $F(1, 443) = 116.4$, $p < .001$).

Regression models of social activity restriction as a predictor of PQOL and DASS-21 total score are presented in Table 2. Tic severity and demographic variables explained 10.0% of the variance on the PQOL ($R^2 = .100$, $F(5, 419) = 9.3$, $p < .001$). Adding social activity restriction to the model resulted in an additional 6.1% of variance in PQOL scores explained (R^2 change = .061, $F(1, 418) = 30.2$, $p < .001$). For the DASS-21 total score, tic severity and demographic variables explained 18.7% of the variance ($R^2 = .187$, $F(5, 443) = 20.4$, $p < .001$). The addition of social activity restriction to the model increased variance explained by an additional 5.9% (R^2 change = .059, $F(1, 442) = 34.5$, $p < .001$).

4. Discussion

Historically, treatment for TS has primarily focused on tic reduction as an avenue to improved global functioning. Evidence from some treatment outcome research suggests that emotional functioning and QoL improve when tics are successfully treated [36]. However, while tic reduction is clearly an important treatment target in this regard, tic reduction is not always achievable and, importantly, may not be the only path to positive global outcome. Both research and anecdotal accounts indicate many people live well “with their tics,” suggesting that particular behavior patterns may be advisable for adults with TS. The current study identifies one behavioral pattern that appears highly associated with positive outcome: continued activity engagement (i.e. low activity restriction due to tics). Specifically, results indicate that activity engagement significantly predicts emotional functioning and QoL even when controlling for tic severity, suggesting that those who continue to engage in important activities “with their tics” experience better outcomes than those that restrict activities due to tics. These findings are highly clinically relevant since clinicians can provide a clear therapeutic message for affected individuals and their families: whenever possible, continue to engage in enjoyable or personally meaningful activities rather than avoiding activities because of tics.

Although findings support the benefit of activity engagement, it is likely that factors other than those entered in the regression model (tic severity and demographic characteristics) influence an individual’s pattern of avoidance and engagement. When extending these findings to the clinical context, it is important to ideographically identify contributing factors. For example, tics themselves may pose realistic barriers to engagement in particular activities, such as *physical* obstacles (e.g., severe motor tics interfering with cooking or grooming) or realistic *practical* or *social* limitations (e.g., tics that are disruptive or socially unacceptable actions or vocalizations). It is likely counterproductive to encourage blind engagement in activities when such realistic barriers are present. However, there may be opportunities to problem-solve adaptations to these activities to make them more possible, and existing data suggest that replacements for restricted activities can mitigate the negative psychological effects of activity restriction [37, 38]. Thus the message to TS patients regarding these types of activities may be: *given the physical barriers and practical limitations of your tics, how can you 1) adapt this activity so it is possible for you, or 2) find a replacement for this activity.*

In other instances, actual intermittent external punishment or anticipated punishment may generate unnecessary avoidance and activity restriction. For example, any social event may be avoided due to fear of negative evaluation due to tics. For many adults with TS, these fears are based on real past experiences of discrimination, such that even a small number of aversive experiences may lead to sustained avoidance. However, avoidance likely compounds problems, leaves no opportunity for “corrective” successful experiences, and

likely worsens emotional functioning in the long term. Engaging in such activities may cause transient increases in emotional discomfort but may also lead to greater engagement in socially and personally meaningful behaviors that are likely to have long-term benefits in terms of QoL and emotional functioning.

This acceptance message may feel counter-intuitive to some persons with TS and/or their families, who in efforts to diminish anxiety associated with social discomfort and/or anticipated rejection may regard avoidance as a sensible life strategy in many settings. Thus it is important for the clinician to highlight the costs of avoidance (i.e., social isolation, increased dependency on friends and family) and to consider introducing new activities in a gradual fashion. Efforts to encourage such experiential approach or acceptance may be enhanced by connecting the activity to the individual's personal values [39].

In interpreting these results, consideration of contextual differences that may influence patterns of activity restriction across this sample is important. It is likely that some of our participants live in more "tic-friendly" environments that facilitate activity engagement (i.e., where there is a higher level of public health awareness and tolerance about TS in general and about the uncontrollability of tics specifically) [40]. Hence, educational interventions to enlighten peers and family and organizational efforts to inform the public may promote activity engagement and other resilient behaviors in persons with TS.

While the questions we used to measure activity restriction were specific to tics, it is unclear if this tic specific activity restriction is part of a more global pattern of avoidance that is consistent with co-existing psychiatric conditions such as social phobia disorder, ADHD, OCD, or other anxiety or mood disorders. For example, untreated ADHD symptoms may adversely impact group participation, and untreated social anxiety may increase fear of embarrassment due to tics in social situations. Therefore, recognizing and treating psychiatric comorbidities may be another path to minimizing activity restriction and further optimizing functioning in those with TS.

Treatments that specifically target reduction of activity restriction may have potential to improve global functioning in people with TS. Since TS is a chronic condition with waxing and waning symptoms, therapeutic interventions that best promote successful adaptation to chronic tics may be most promising. For example, Behavioral Activation (BA) is a psychotherapy designed to improve mental health through collaborative scheduling of pleasant, goal directed, and personally valued activities in order to increase patient contact with positive reinforcement [41]. BA is a well-established empirically supported treatment for depression and shows promise for those with chronic medical illnesses [42], including chronic neurological illnesses [43, 44].

Missing data due to internet survey methodology and the fact that recruitment only occurred through the TSA are limitations of the current study. This study also utilized study specific activity restriction scales that have not been validated, but no validated tic specific measures of activity restriction yet exist. Future studies should develop such measures. Other limitations specific to internet methodology are also notable, such as the absence of face-to-face diagnostic evaluation to confirm tic and emotional symptoms. Future work with tic related activity restriction should focus on measure development, identification of factors that contribute to activity restriction (i.e., physical, practical, or emotional barriers), further empirical examination of behavior patterns common to those living well with tics, and development of self- or clinician-guided interventions to improve activity engagement.

Acknowledgments

Sources of Support: The Tourette Syndrome Association assisted with participant recruitment. Dr. Conelea's effort on this manuscript was supported by F32MH095274-01. Dr. Busch's effort on this manuscript was supported by K23HL107391-03.

References

1. APA. Diagnostic and Statistical manual of mental disorders. 4th ed. Revised ed.. Washington, DC: American Psychiatric Association; 2002.
2. Freeman RD, Fast DK, Burd L, Kerbeshian J, Robertson MM, Sandor P. An international perspective on Tourette syndrome: selected findings from 3,500 individuals in 22 countries. *Dev Med Child Neurol.* 2000; 42(7):436–447. [PubMed: 10972415]
3. Leckman JF, Bloch MH, King RA, Scahill L. Phenomenology of tics and natural history of tic disorders. *Adv Neurol.* 2006; 99:1–16. [PubMed: 16536348]
4. Knight T, Steeves T, Day L, Lowerison M, Jette N, Pringsheim T. Prevalence of tic disorders: a systematic review and meta-analysis. *Pediatr Neurol.* 2012; 47(2):77–90. [PubMed: 22759682]
5. Scharf JM, Miller LL, Mathews CA, Ben-Shlomo Y. Prevalence of Tourette syndrome and chronic tics in the population-based Avon longitudinal study of parents and children cohort. *J Am Acad Child Adolesc Psychiatry.* 2012; 51(2):192–201. e5. [PubMed: 22265365]
6. Apter A, Pauls DL, Bleich A, Zohar AH, Kron S, Ratzoni G, et al. An epidemiologic study of Gilles de la Tourette's syndrome in Israel. *Arch Gen Psychiatry.* 1993; 50(9):734–738. [PubMed: 8357298]
7. Pappert EJ, Goetz CG, Louis ED, Blasucci L, Leurgans S. Objective assessments of longitudinal outcome in Gilles de la Tourette's syndrome. *Neurology.* 2003; 61(7):936–940. [PubMed: 14557563]
8. Wilhelm S, Peterson AL, Piacentini J, Woods DW, Deckersbach T, Sukhodolsky DG, et al. Randomized trial of behavior therapy for adults with Tourette syndrome. *Arch Gen Psychiatry.* 2012; 69(8):795–803. [PubMed: 22868933]
9. Haddad AD, Umoh G, Bhatia V, Robertson MM. Adults with Tourette's syndrome with and without attention deficit hyperactivity disorder. *Acta Psychiatr Scand.* 2009; 120(4):299–307. [PubMed: 19486328]
10. Shady G, Broder R, Staley D, Furer P, Papadopolos RB. Tourette Syndrome and employment: Descriptors, predictors and problems. *Psychiatric Rehabilitation Journal.* 1995; 19(1):35–42.
11. Bruun R, Budman C. The Natural History of Tourette Syndrome. *Adv Neurol.* 1992; 58:1–6. [PubMed: 1414612]
12. Robertson MM, Trimble MR, Lees AJ. The psychopathology of the Gilles de la Tourette syndrome. A phenomenological analysis. *Br J Psychiatry.* 1988; 152:383–390. [PubMed: 3167374]
13. Cavanna AE, David K, Orth M, Robertson MM. Predictors during childhood of future health-related quality of life in adults with Gilles de la Tourette syndrome. *Eur J Paediatr Neurol.* 2012; 16(6):605–612. [PubMed: 22381812]
14. Conelea CA, Woods DW, Zinner SH, Budman CL, Murphy TK, Scahill LD, et al. The impact of Tourette syndrome in adults: Results from the Tourette syndrome impact survey. *Community Ment Health J.* 2011; 49:110–120. [PubMed: 22052430]
15. Pringsheim T, Lang A, Kurlan R, Pearce M, Sandor P. Understanding disability in Tourette syndrome. *Dev Med Child Neurol.* 2009; 51(6):468–472. [PubMed: 19018838]
16. Jalenques I, Galland F, Malet L, Morand D, Legrand G, Auclair C, et al. Quality of life in adults with Gilles de la Tourette Syndrome. *BMC Psychiatry.* 2012; 12(1):109. [PubMed: 22888766]
17. Muller-Vahl K, Dodel I, Muller N, Munchau A, Reese JP, Balzer-Geldsetzer M, et al. Health-related quality of life in patients with Gilles de la Tourette's syndrome. *Mov Disord.* 2010; 25(3):309–314. [PubMed: 20063404]
18. Eddy CM, Cavanna AE, Gulisano M, Agodi A, Barchitta M, Cali P, et al. Clinical correlates of quality of life in Tourette syndrome. *Mov Disord.* 2011; 26(4):735–738. [PubMed: 21506153]

19. Rosenberg LA, Brown J, Singer HS. Behavioral problems and severity of tics. *J Clin Psychol.* 1995; 51(6):760–767. [PubMed: 8778123]
20. Singer HS. Discussing outcome in Tourette syndrome. *Arch Pediatr Adolesc Med.* 2006; 160(1): 103–105. [PubMed: 16389220]
21. Kent, EG. I have Tourette's but Tourette's doesn't have me. Kent, EG., editor. USA: 2005.
22. Cohen, B.; Wysocky, L. Front of the class: how Tourette syndrome made me the teacher I never had. 1st ed. New York: St. Martin's Griffin; 2008.
23. Korman, CB. Tourette syndrome and resilience. New York: Tourette Syndrome Association; 2012.
24. Mausbach BT, Chattillion EA, Moore RC, Roepke SK, Depp CA, Roesch S. Activity restriction and depression in medical patients and their caregivers: a meta-analysis. *Clin Psychol Rev.* 2011; 31(6):900–908. [PubMed: 21600868]
25. Bailey R, Kaskutas V, Fox I, Baum CM, Mackinnon SE. Effect of upper extremity nerve damage on activity participation, pain, depression, and quality of life. *J Hand Surg Am.* 2009; 34(9):1682–1688. [PubMed: 19896011]
26. Landreville P, Desrosiers J, Vincent C, Verreault R, Boudreault V. The role of activity restriction in poststroke depressive symptoms. *Rehabil Psychol.* 2009; 54(3):315–322. [PubMed: 19702430]
27. Williamson GM. Extending the activity restriction model of depressed affect: evidence from a sample of breast cancer patients. *Health Psychol.* 2000; 19(4):339–347. [PubMed: 10907652]
28. Prestia K. Tourette's Syndrome: Characteristics and interventions. *Intervention in School and Clinic.* 2003; 39:67–71.
29. Gosling SD, Vazire S, Srivastava S, John OP. Should we trust web-based studies? A comparative analysis of six preconceptions about internet questionnaires. *Am Psychol.* 2004 Feb-Mar;59(2): 93–104. [PubMed: 14992636]
30. Wetterneck CT, Woods DW, Norberg MM, Begotka AM. The social and economic impact of trichotillomania: Results from two nonreferred samples. *Behavioral Interventions.* 2006; 21:97–109.
31. Leckman JF, Riddle MA, Hardin MT, Ort SI, Swartz KL, Stevenson J, et al. The Yale Global Tic Severity Scale: initial testing of a clinician-rated scale of tic severity. *J Am Acad Child Adolesc Psychiatry.* 1989; 28(4):566–573. [PubMed: 2768151]
32. Lovibond, SH.; Lovibond, PF. Manual for the Depression Anxiety Stress Scales. Sydney: Psychology Foundation; 1995.
33. Patrick DL, Kinne S, Engelberg RA, Pearlman RA. Functional status and perceived quality of life in adults with and without chronic conditions. *J Clin Epidemiol.* 2000; 53(8):779–785. [PubMed: 10942859]
34. Patrick, DL. Perceived Quality of Life Scale User Manual. Washington, Uo, editor. 1992.
35. Sinclair SJ, Siefert CJ, Slavin-Mulford JM, Stein MB, Renna M, Blais MA. Psychometric evaluation and normative data for the depression, anxiety, and stress scales-21 (DASS-21) in a nonclinical sample of U.S. adults. *Eval Health Prof.* 2012; 35(3):259–279. [PubMed: 22008979]
36. Deckersbach T, Rauch S, Buhlmann U, Wilhelm S. Habit reversal versus supportive psychotherapy in Tourette's disorder: a randomized controlled trial and predictors of treatment response. *Behav Res Ther.* 2006; 44(8):1079–1090. [PubMed: 16259942]
37. Benyamini Y, Lomranz J. The relationship of activity restriction and replacement with depressive symptoms among older adults. *Psychol Aging.* 2004; 19(2):362–366. [PubMed: 15222831]
38. Busch AM, Borrelli B. Valued life activities and readiness to quit smoking among mobility-impaired smokers. *Health Psychol.* 2012; 31(1):122–125. [PubMed: 21875204]
39. Hayes, SC.; Strosahl, K.; Wilson, KG. Acceptance and commitment therapy: an experiential approach to behavior change. New York: Guilford Press; 1999.
40. Woods DW, Marcks BA. Controlled evaluation of an educational intervention used to modify peer attitudes and behavior toward persons with Tourette's Syndrome. *Behav Modif.* 2005; 29(6):900–912. [PubMed: 16204422]
41. Kanter, J.; Busch, AM.; Rusch, LC. Behavioral activation: distinctive features. New York, NY: Routledge; 2009.

42. Hopko DR, Armento ME, Robertson SM, Ryba MM, Carvalho JP, Colman LK, et al. Brief behavioral activation and problem-solving therapy for depressed breast cancer patients: randomized trial. *J Consult Clin Psychol*. 2011; 79(6):834–849. [PubMed: 21988544]
43. Ciechanowski P, Chaytor N, Miller J, Fraser R, Russo J, Unutzer J, et al. PEARLS depression treatment for individuals with epilepsy: a randomized controlled trial. *Epilepsy Behav*. 2010; 19(3):225–231. [PubMed: 20609631]
44. Verkaik R, Francke AL, van Meijel B, Spreeuwenberg PM, Ribbe MW, Bensing JM. The introduction of a nursing guideline on depression at psychogeriatric nursing home wards: effects on certified nurse assistants. *Int J Nurs Stud*. 2011; 48(6):710–719. [PubMed: 20619411]

Table 1
General Activity Restriction as a Predictor of Quality of Life and Emotional Functioning

	PQOL Total Score (N = 427)					DASS-21 Total Score (Square root Transformed; N = 450)				
	B	SE B	B	R ²	ΔR ²	B	SE B	β	R ²	ΔR ²
Step 1				.10**					.19**	
YGTSS Total	-0.03	0.01	-0.14**			0.08	0.01	0.39**		
Age	-0.01	0.01	-0.09			-0.00	0.01	-0.02		
Gender	-0.05	0.17	-0.01			-0.41	0.19	-0.09*		
Household Income	0.27	0.06	0.25**			-0.01	0.06	-0.01		
Education Level	0.09	0.07	0.07			-0.18	0.07	-0.11*		
Step 2				.23	.13**				.36	.17**
YGTSS Total	-0.00	0.01	-0.01			0.05	0.01	0.22**		
Age	-0.01	0.01	-0.08			-0.00	0.01	-0.02		
Gender	-0.11	0.15	-0.03			-0.29	0.17	-0.07		
Household Income	0.20	0.05	0.18**			0.05	0.06	0.04		
Education Level	0.03	0.06	0.02			-0.10	0.07	-0.06		
General Activity	-0.24	0.03	-0.40**			0.33	0.03	0.46**		
Restriction Total										

*
p < .05,

**
p < .01

Note: YGTSS = Yale Global Tic Severity Scale, PQOL = Perceived Quality of Life scale, DASS-21 = Depression, Anxiety, and Stress Scale

Table 2

Social Activity Restriction as a Predictor of Quality of Life, Depression, and Anxiety

		PQOL Total Score (N = 425)					DASS-21 Total Score (Square root Transformed; N = 449)				
		B	SE B	B	R ²	ΔR ²	B	SE B	β	R ²	ΔR ²
Step 1					.10**					.19**	
YGTSS Total		-0.02	0.01	-0.14**			0.08	0.01	0.38**		
Age		-0.01	0.01	-0.10*			-0.00	0.01	-0.02		
Gender		-0.03	0.17	-0.01			-0.41	0.19	-0.10*		
Household Income		0.26	0.06	0.24**			-0.01	0.06	-0.01		
Education Level		0.09	0.07	0.07			-0.19	0.07	-0.12*		
<hr/>											
Step 2					.16	.06**				.25	.06**
YGTSS Total		-0.01	0.01	-0.07			0.07	0.01	0.31**		
Age		-0.01	0.01	-0.08			-0.01	0.01	-0.04		
Gender		-0.11	0.16	-0.03			-0.31	0.18	-0.07		
Household Income		0.23	0.05	0.21**			0.03	0.06	0.02		
Education Level		0.05	0.06	0.04			-0.13	0.07	-0.08		
Social Activity		-0.93	0.17	-0.26**			1.11	0.19	0.26**		
Restriction Total											

* $p < .05$,

** $p < .01$

Note: YGTSS = Yale Global Tic Severity Scale, PQOL = Perceived Quality of Life scale, DASS-21 = Depression, Anxiety, and Stress Scale