


# Health-Related Quality of Life and Psychosocial Functioning in Children With Tourette Syndrome: Parent-Child Agreement and Comparison to Healthy Norms

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## Abstract

This study aimed to evaluate the degree of agreement between parent proxy- and child self-report on measures of child psychosocial functioning and health-related quality of life in children with Tourette syndrome. Participants included 28 children with Tourette syndrome and their parents. All participants provided ratings of children's level of quality of life and psychosocial functioning. Results revealed strong, positive relationships between child self- and parent proxy-reports on all quality of life and psychosocial functioning domains. Parents perceived significantly higher levels of depression compared to their children, whereas children reported significantly lower Physical quality of life compared to their parents. Results suggest that assessment of quality of life and psychosocial functioning should include multiple reporters whenever feasible. Caution should be used when exclusively relying on parent proxy-reports of quality of life and psychosocial functioning, as these reports may not accurately reflect children's difficulties or perceptions of their functioning.

## Keywords

Tourette syndrome, parent-child agreement, health-related quality of life, psychosocial functioning

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Tourette syndrome is a neurobiological disorder characterized by the childhood onset of recurrent motor tics and the presence of at least 1 vocal tic.<sup>1</sup> In the United States, Tourette syndrome is estimated to occur in 3 of every 1000 school-aged children,<sup>2</sup> with higher prevalence rates in males.<sup>3</sup> Children with Tourette syndrome frequently present with comorbid psychological and neurodevelopmental disorders,<sup>4</sup> with larger clinical samples suggesting only 10% of individuals do not have a comorbid condition.<sup>5</sup> Consistent with this population's lower levels of psychological functioning, children with Tourette syndrome also have significantly lower levels of health-related quality of life compared to healthy peers.<sup>6</sup> Given this population's risk for lower levels of health-related quality of life and higher comorbid psychopathology (see the work of Cavanna and colleagues<sup>7</sup> for a recent systematic literature review of health-related quality of life in this population), a thorough and accurate assessment of children's psychosocial functioning is a critical step in conceptualizing their symptoms and providing effective intervention services.

Childhood psychosocial issues are typically assessed via multiple informants (eg, parent, child, and teacher reports),

as single informant approaches have been shown to have inherent limitations.<sup>8</sup> However, the degree to which different informants' reports correspond varies.<sup>9</sup> Despite the prevalence of comorbidities in children with Tourette syndrome, there has been little research examining the level of agreement between parent proxy- and child-reported psychological functioning in this population. A study examining children with tic disorders, including Tourette syndrome, found that parents reported significantly more child emotional and behavioral problems than the children themselves.<sup>10</sup> Another study investigating agreement between maternal proxy- and child self-reports of emotional and behavioral problems in children with Tourette syndrome found that mothers tended to endorse significantly more problems for children in all domains except externalizing

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problems and symptoms of withdrawal.<sup>11</sup> A better understanding of the potential discrepancies between parent proxy- and child self-reports for children with Tourette syndrome would enhance the process of assessing their psychological functioning.

In the area of health-related quality of life, Pearson product-moment correlations between parent proxy- and child self-reports have been used to examine co-variation among scores. Pearson *r*, however, is not a measure of inter-rater agreement.<sup>12</sup>

In a sample of pediatric patients with Tourette syndrome, parent proxy- and child self-reports were positively correlated for all health-related quality of life domains for children between the ages of 8 to 11 years.<sup>6</sup> For adolescents in the sample, there were no significant correlations between parent proxy- and adolescent self-reported health-related quality of life, suggesting that parent-child agreement may vary by age group. This study did not indicate whether child and parent proxy reports yielded statistically similar or different scores for different domains of health-related quality of life. Further research is needed to more thoroughly assess agreement between parent proxy- and child self-reported health-related quality of life in other samples of children with Tourette syndrome.

The documented instances of reporter discrepancies in the literature highlight the importance of evaluating whether parents and their children provide similar or discrepant information. Currently, there is limited research in the Tourette syndrome literature examining the extent to which child self- and parent proxy-reports agree with one another. To address this gap in the literature, the present study will use numerous analytical techniques to examine the level of agreement between child self- and parent proxy-reports on psychosocial functioning and health-related quality of life in children with Tourette syndrome. Based on the review of literature on parent-child agreement in pediatric populations, it was hypothesized that (a) children with Tourette syndrome and their parents would report significantly lower levels of health-related quality of life and psychosocial functioning compared to normative data and (b) parent proxy reports would demonstrate lower ratings of children's psychosocial functioning and health-related quality of life when compared to child self-reports. Exploratory analyses were conducted to examine the degree to which parent proxy and child self-reports agreed with one another, given the lack of existing literature available to guide hypotheses.

## Method

### Participants

Thirty-six children with Tourette syndrome between the ages of 8 and 18 years (mean age = 12.60, standard deviation = 2.95) and their parents (mean age = 42.17, standard deviation = 8.26) participated in this study. All children and parents in the sample were white. Thirty-one percent of the children and 67 percent of parents were female. The majority of caregivers were biological parents (90%), followed by adoptive parents (3.4%), foster parents (3.4%), and other (3.4%). Approximately, 76% of parents were married. Annual family income was as follows: 6.9% reported earning \$10 000 to \$24 999, 27.6%

reported earning \$25 000 to \$49 000, 13.8% reported earning \$50 000 to \$74 999, 17.2% reported earning \$75 000 to \$99 999, 13.8% reported earning \$100 000 or more, and 20.7% preferred to not report annual family income. Common psychological comorbidities included attention-deficit hyperactivity disorder (ADHD; 58.3%) and obsessive-compulsive disorder (47.2%). Less frequent psychological diagnoses were endorsed by 27.8% of the sample (eg, autism spectrum disorder, anxiety, depression).

## Measures

**Demographic and health information.** A brief online questionnaire was used to collect basic demographic information, including age, sex, race, and family income. Parents provided all demographic and health information. Health-related information, including psychological comorbidities, was obtained by study personnel via chart review.

**The Pediatric Quality of Life Inventory, generic core scales, version 4.0.**<sup>13</sup> The Pediatric Quality of Life Inventory, generic core scales, version 4.0, is a 23-item measure used to assess health-related quality of life in pediatric populations and healthy children. Parallel self-report and proxy-report forms were included. The Pediatric Quality of Life Inventory assesses 4 different domains of health-related quality of life including Social functioning, School functioning, Emotional functioning, and Physical health. A Psychosocial composite score can be obtained by averaging the scores from the Social, School, and Emotional functioning subscales. A Total health-related quality of life score is obtained by averaging all individual subscale scores. Higher scores indicate higher levels of quality of life. In the current study, internal consistency for the child-reported Pediatric Quality of Life Inventory scales ranged from  $\alpha = .71$  to  $\alpha = .95$ . Cronbach alphas for all proxy-report Pediatric Quality of Life Inventory subscales ranged from  $\alpha = .53$  to  $\alpha = .92$ . All subscales showed acceptable internal consistency, with the exception of the School functioning subscale, with  $\alpha = .53$ . The construct validity and internal consistency of the Pediatric Quality of Life Inventory has been demonstrated to be acceptable elsewhere in the literature.<sup>13</sup> Previously published normative data were used to evaluate the quality of life of children in the current study.

**Behavioral Assessment System for Children, second edition (BASC-2; Reynolds and Kamphaus<sup>14</sup>).** The Behavioral Assessment System for Children is a well-established measure used to assess emotional and behavioral functioning in children and adolescents.<sup>15</sup> The self-report (BASC-2-SRP) and proxy-report (BASC-2-PRS) forms were used. Only the depression, attention problems, and hyperactivity subscales were included in this study. *T* scores were used to compare the responses of children and parents in the sample to that of age- and gender-matched healthy norms. All subscales in the current study demonstrated adequate internal consistency, with Cronbach alphas ranging from .78 to .88 for child self-report, and from .87 to .96 for parent proxy report.

## Procedure

All study procedures were approved by the Institutional Review Board of the investigators' institution. Recruitment was conducted as part of a 1-week summer camp designed for children with Tourette syndrome. This manuscript is part of a larger study. All families registered to attend camp were contacted via email, informed about the study, and invited to participate. Interested families were provided

**Table 1.** Health-Related Quality of Life in Children With Tourette Syndrome Compared to a Normative Sample.<sup>a</sup>

PedsQL domain	Sample		Normative		Mean difference (95% CI)	t	Cohen <i>d</i> <sup>b</sup>
	M	SD	M	SD			
Child report Total score	66.96	19.90	83.91	12.47	-16.95 (-24.66 to -9.23)	-4.51***	1.02
Psychosocial health	62.94	21.09	81.83	13.97	-19.06 (-27.24 to -10.89)	-4.78***	1.06
School functioning	57.32	20.93	81.31	16.09	-25.42 (-33.99 to -16.84)	-6.08***	1.29
Social functioning	70.17	24.59	84.97	16.71	-15.51 (-25.34 to -5.67)	-3.24***	0.70
Emotional functioning	62.94	23.08	79.21	18.02	-16.27 (-25.22 to -7.32)	-3.73***	0.79
Physical health	74.83	19.48	87.77	13.12	-12.94 (-20.49 to -5.39)	-3.52***	0.78
Parent report Total score	68.97	16.83	82.29	15.55	-13.32 (-19.84 to -6.79)	-4.19***	0.82
Psychosocial health	63.45	18.04	81.24	15.34	-17.79 (-24.78 to -10.80)	-5.22***	1.06
School functioning	57.32	20.93	78.27	19.64	-20.06 (-29.06 to -12.83)	-5.30***	1.03
Social functioning	70.17	24.59	83.05	19.66	-12.88 (-22.42 to -3.34)	-2.77***	0.58
Emotional functioning	62.86	19.50	81.20	16.40	-18.34 (-25.91 to -10.78)	-4.98***	1.02
Physical health	79.33	18.02	84.08	19.70	-4.71 (-11.70 to 2.28)	-1.38***	0.25

Abbreviations: CI, confidence interval; ICC, intraclass correlation coefficient; M, mean; PedsQL, Pediatric Quality of Life Inventory; SD, standard deviation.

<sup>a</sup>Normative data for healthy children and their parents were drawn from prior research conducted by Varni et al.<sup>16</sup>

<sup>b</sup>Small effect size:  $d = .20$ , medium effect size:  $d = .50$ , large effect size:  $d = .80$ .

\* $P \leq .05$ ; \*\* $P \leq .01$ ; \*\*\* $P \leq .001$ .

**Table 2.** Psychosocial Functioning in Children With Tourette Syndrome.

BASC-2 scale	Mean <i>T</i> score	SD	<i>T</i> score range	Mean difference (95% CI)	t	Cohen <i>d</i> <sup>a</sup>
Child report						
Depression	49.29	9.11	40-75	-0.71 (-4.25 to 2.82)	-0.42***	0.07
Hyperactivity	59.36	13.48	37-83	9.36 (4.13 to 14.58)	3.67***	0.79
Attention problems	59.04	11.74	40-80	9.04 (4.48 to 13.59)	4.07***	0.83
Parent report						
Depression	58.12	16.24	39-93	8.11 (1.81 to 14.41)	2.64***	0.60
Hyperactivity	62.57	17.56	38-94	12.57 (5.76 to 19.38)	3.79***	0.88
Attention problems	57.57	11.32	40-78	7.57 (3.18 to 11.96)	3.54***	0.71

Abbreviations: BASC-2, Behavioral Assessment System for Children, 2nd edition; CI, confidence interval; SD, standard deviation.

<sup>a</sup>For Cohen *d*, small effect size:  $d = .20$ , medium effect size:  $d = .50$ , large effect size:  $d = .80$ .

\* $P \leq .05$ ; \*\* $P \leq .01$ ; \*\*\* $P \leq .001$ .

access to an electronic hyperlink that directed them to a secure online data collection platform (Qualtrics<sup>®</sup>) where they were able to read additional information about the purpose and goals of the study. Parents and children interested in participating provided online informed consent and assent, respectively. Online measures were completed approximately 1 to 6 weeks prior to camp. Children who participated in the study received a \$2 gift voucher to be used at the camp's store as compensation for their time. No compensation was provided for participating parents.

## Results

### Comparison to Healthy Norms

**Health-related quality of life.** Self- and proxy-reports of children's health-related quality of life were compared to Pediatric Quality of Life Inventory scores obtained from a normative sample of 10 241 families previously collected by Varni and colleagues.<sup>16</sup> Details on results comparing the current sample and the normative sample are displayed in Table 1. *T*-test analyses revealed that children with Tourette syndrome experienced significantly lower levels of health-related quality of life across all

domains of functioning, including Physical health, Psychosocial functioning, Social functioning, School functioning, Emotional functioning, and overall health-related quality of life. These significant differences yielded Cohen *d* effect sizes ranging from 0.70 to 1.29. Proxy-reports of children's health-related quality of life also indicated significantly lower levels of health-related quality of life across all domains, except Physical health. These differences yielded Cohen *d* effect sizes that ranged from 0.58 to 1.06.

**Psychosocial functioning.** As detailed in Table 2, parents reported significantly higher levels of depression, attention problems, and hyperactivity among children with Tourette syndrome compared to a normative sample. These differences yielded Cohen *d* effect sizes that ranged from 0.60 to 0.88. Child report of emotional and behavioral functioning similarly revealed significantly higher levels of attention problems and hyperactivity. Cohen *d* effect sizes for these differences ranged from 0.79 to 0.83. Child report of depressive symptoms was not significantly different from symptoms reported by healthy peers.

**Table 3.** Comparison of Child and Parent Report of Health-Related Quality of Life.

PedsQL domain	Child		Parent		Mean difference (95% CI)	t	ICC
	M	SD	M	SD			
Total score	66.96	19.90	68.97	16.83	-2.01 (-7.14 to 3.12)	-0.80	.854***
Psychosocial health	62.94	21.09	63.45	18.04	-0.68 (-7.25 to 5.88)	-0.21	.777***
School functioning	57.32	20.93	57.32	20.93	-1.43 (-8.72 to 5.86)	-0.40	.770***
Social functioning	70.17	24.59	70.17	24.59	-0.71 (-10.63 to 9.22)	-0.15	.652**
Emotional functioning	62.94	23.08	62.86	19.50	0.09 (-6.28 to 6.45)	0.03	.832***
Physical health	74.83	19.48	79.33	18.02	-4.50 (-8.72 to -0.27)	-2.18*	.897***

Abbreviations: CI, confidence interval; ICC, intraclass correlation coefficient; M, mean; PedsQL, Pediatric Quality of Life Inventory; SD, standard deviation.  
\* $P \leq .05$ ; \*\* $P \leq .01$ ; \*\*\* $P \leq .001$ .

**Table 4.** Comparison of Child and Parent Report of Psychosocial Functioning.

BASC-2 scale	Child		Parent		Mean difference (95% CI)	t	ICC
	M	SD	M	SD			
Depression	49.29	9.11	58.12	16.24	-8.82 (-14.25 to -3.40)	-3.34**	.531**
Hyperactivity	59.36	13.48	62.57	17.56	1.46 (-2.63 to 5.56)	-1.17	.722***
Attention problems	59.04	11.74	57.57	11.32	-3.21 (-8.85 to 2.42)	.734	.738***

Abbreviations: BASC-2, Behavioral Assessment System for Children, 2nd edition; CI, confidence interval; ICC, intraclass correlation coefficient; M, mean; SD, standard deviation.

\* $P \leq .05$ ; \*\* $P \leq .01$ ; \*\*\* $P \leq .001$ .

### Child-Parent Agreement

To determine the degree of convergence between child and parent report of the child's health-related quality of life and psychosocial functioning, intraclass correlation coefficients and *t*-test analyses were conducted. The use of both approaches has been recommended in the literature as a more methodologically rigorous way to evaluate interrater agreement.<sup>12</sup> Results from the current study revealed significant intraclass correlation coefficients between child self- and parent proxy reports on all health-related quality of life and psychosocial functioning domains (see Tables 3 and 4), indicating significant agreement between children and parents. Intraclass correlation coefficients ranged from .65 to .90 for the Pediatric Quality of Life Inventory and from .53 to .74 for the Behavioral Assessment System for Children-2. In contrast, *t*-test analyses revealed no significant differences across most health-related quality of life domains, except for the Physical health subscale. Children reported lower physical health than was reported by their parents. For measures of children's psychosocial functioning, *t*-test analyses indicated significant differences for the Depression subscale, but there were no significant differences for either the Attention problems or Hyperactivity subscales of the Behavioral Assessment System for Children-2. Children reported lower symptoms of depression than was indicated by parent proxy report.

### Discussion

The current study aimed to compare child self- and parent proxy reports of health-related quality of life and psychosocial

functioning to healthy norms, as well as examine parent-child agreement on these domains in a sample of children with Tourette syndrome. For health-related quality of life, both child self- and parent proxy reports were significantly lower than those of healthy norms on all domains, except for parent-reported Physical health functioning. These findings were generally consistent with previous studies examining health-related quality of life in children with Tourette syndrome,<sup>6</sup> particularly those similar to this sample, in which participants have a number of comorbid conditions, and report even lower health-related quality of life than individuals with only Tourette Syndrome.<sup>17</sup> Contrary to a previous study,<sup>6</sup> children in our sample reported significantly lower Physical health functioning compared to norms. It is possible that children with Tourette syndrome viewed their symptoms as having a greater influence on their ability to engage in physical activities (eg, running) and complete activities of daily living (eg, bathing) than their parents. Also, parents may view Tourette syndrome as a condition that significantly affects children's emotional, social, and school functioning, but has a lesser influence on physical functioning. Another possible explanation has to do with differences in parent-child reference points. It is possible that parents are comparing their child's current physical functioning to the child's physical functioning abilities prior to diagnosis, whereas children may be more likely to compare their physical abilities to the abilities of healthy children and same-aged peers.

For psychosocial functioning, both child self- and parent proxy reports were significantly lower than those of healthy norms for all domains, except child-reported depressive symptoms. Both



children and parents indicated that children in our sample had significantly more symptoms of attention problems and hyperactivity when compared to normative data. While parent proxy reports indicated that children also had significantly more symptoms of depression, child self-reported depressive symptoms were no different from those of healthy peers. These findings were generally consistent with previous studies, in which parents of children with Tourette syndrome tended to report significantly more emotional and behavioral problems than the children themselves.<sup>10,18</sup> Additionally, both parents and children appeared to perceive that children with Tourette syndrome have more symptoms of inattention and hyperactivity, which likely reflects this population's prevalence of comorbid ADHD.<sup>2</sup> It is possible that parents of children with Tourette syndrome may perceive their children as demonstrating more depressive symptoms, such as sadness and withdrawal, because they have a chronic condition that is associated with social difficulties.<sup>19,20</sup> Children with Tourette syndrome, on the other hand, may perceive themselves as having better emotional adjustment and may be more resilient in the face of having a chronic condition than parents recognize.

With regards to interrater agreement between child self- and parent proxy reports of the child's health-related quality of life and psychosocial functioning, results demonstrated statistically significant intraclass correlation coefficients across all domains of functioning assessed. Consistent with previous research in children with Tourette syndrome suggesting that parent- and child-reported scores are related,<sup>6</sup> parent-child agreement on all domains of health-related quality of life was excellent. On domains of emotional functioning, parent-child agreement was also good to excellent, with the lowest levels of agreement occurring on the Depression subscale. This finding is consistent with a large body of literature demonstrating that parent-child agreement on internalizing symptoms is typically low to moderate.<sup>21</sup> Overall, these results suggest that parents of children with Tourette syndrome may be well attuned to the levels of difficulty that their children are experiencing. Given the high rate of comorbidities present in this population, and the fact that comorbid psychosocial distress has been related to lower HRQOL,<sup>22</sup> parent-child discussions about emotional functioning and quality of life may occur frequently, as these children typically see a number of providers for medical and psychological services.<sup>23</sup> These discussions surrounding psychosocial functioning may facilitate communication between the parent and child about how to cope with psychosocial issues, which in turn may improve parents' ability to accurately perceive and report on children's psychosocial functioning.

In addition to high intraclass correlation coefficients, child self- and parent proxy-reported health-related quality of life indicated similar levels of functioning on all domains (ie, Total Score, Psychosocial, School, Social, and Emotional), with the exception of Physical health functioning. This finding is contrary to that reported in a previous study on children with Tourette syndrome, suggesting that children and parents have different views on how the condition may affect health related quality of life.<sup>24</sup> The previous study used Tourette syndrome-specific measures of quality of life rather than generic

measures used in the current study, which may have accounted for differences in findings. The current finding is also in contrast to existing literature in other pediatric populations suggesting that parents and children tend to agree more on Pediatric Quality of Life Inventory domains that are observable (eg, physical functioning) compared to less observable life domains.<sup>25</sup> As previously mentioned, it is possible that children compared their physical functioning to other healthy same-aged peers, whereas parents compared children's current physical functioning to how they perceived their children before receiving a Tourette syndrome diagnosis.

Parents and children also reported similar mean levels of emotional functioning on domains of inattention and hyperactivity, which was consistent with prior literature demonstrating that parents and children with Tourette syndrome and their parents typically report similar levels of externalizing symptoms.<sup>11</sup> In contrast to the general child clinical literature,<sup>21</sup> children self-reported lower levels of depressive symptoms than their parents reported. However, the direction of the current findings was consistent with some literature examining depressive symptoms in children with Tourette syndrome, with some studies finding higher levels of depressive symptoms reported by parent informants.<sup>26</sup> The equivocal nature of these findings indicates the need for additional research and replication of results in this area.

The current investigation adds to the existing body of literature on Tourette syndrome, but there are methodological limitations that must be considered while interpreting our findings. First, there was little sociodemographic diversity in the sample and, as a result, findings may not apply to diverse families and children with Tourette syndrome. Future studies should aim to recruit culturally diverse individuals to further our understanding of the extent to which parent-child agreement on measures of psychosocial functioning compares to findings in the current study. Second, the measures used in the current study helped delineate the extent to which parents' and children's perceptions of children's general psychosocial functioning converged, but did not capture specific aspects of living with Tourette syndrome. It is possible that different patterns of agreement exist for Tourette syndrome-specific domains of functioning, such as tic severity or impairment due to Tourette syndrome, and warrant further examination. Furthermore, the use of disease-specific health-related quality of life measures such as the Gilles de la Tourette Syndrome Quality of Life Scale for children and adolescents (C&A-GTS-QOL)<sup>27</sup> might provide greater sensitivity to both children's health perceptions and tic-related symptoms that are likely to affect health-related quality of life in this population. In a recent study by Cavanna and colleagues,<sup>28</sup> for example, the use of a Tourette syndrome-specific health-related quality of life measure was found to be sensitive in differentiating children with Tourette syndrome from children with Tourette syndrome and additional comorbid diagnoses in regard to obsessive-compulsive symptoms. Future studies should include disease-specific measures to complement more widely used generic measures. Another limitation of the study is the lack of a control sample. Future research

should include control samples to examine how children with Tourette syndrome may be differentially affected on various health-related quality of life domains as compared to children with other pediatric conditions.<sup>29</sup> An additional limitation of this study includes the presence of a potential sample bias given that families who participated in study were recruited from a camp for children with Tourette syndrome. Participants in the current sample may be different from families who did not attend the camp. Future investigations should aim to replicate our findings with participants recruited from different sites, such as specialist or primary care settings. Lastly, our findings need to be replicated with a larger sample. A greater number of participants would provide greater statistical power to explore single-item agreement and response patterns within certain subgroups (eg, age, sex).

Overall, results from this study demonstrated that compared to normative data, children with Tourette syndrome and their parents report lower health-related quality of life and more psychological symptoms. Additionally, this study indicated significant agreement between child self- and parent proxy reports of functioning, though differences in the magnitude of these levels of functioning varied by domains. Although there was a high level of interrater agreement, results overall support the well-established practice of collecting data from multiple informants with regards to a child's functioning, and expand this notion to a new population of children with Tourette syndrome. In a clinical setting, obtaining multiple perspectives may support a more accurate conceptualization of the child's overall functioning that would likely inform treatment planning. Furthermore, this practice may assist in providing comprehensive care to children with Tourette syndrome and ensuring that they receive services from which they would most benefit.

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### Author Contributions

AMGC, CKE, JLL, and RLB designed the study and coordinated and executed the study, with RLB's oversight. AMGC and CKE performed data collection, and AMGC and JLL interpreted the data. AMGC generated the manuscript idea, and along with JLM performed statistical analysis. Further, AMGC, CKE, JLL, and JLM wrote the manuscript and revised it. CKE, JLL, and RLB were responsible for IRB management. RLB provided statistical consultation and was responsible for critical revisions of the manuscript and general supervision of the research project.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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### Ethical Approval

All study procedures were approved by the Institutional Review Board of the University of Georgia on May 31st 2013. The IRB approval number for this study is STUDY00000003.

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