

AD/HD HEALTH RELATED QUALITY OF LIFE QUESTIONNAIRE COMPLETED BY CHILDREN OR ADOLESCENTS**Deborah Erickson***Lock Haven University***Simon Clarke***Westmead Hospital, NSW***Michael Kohn***Children's Hospital, Westmead, NSW*

Assessing health-related quality of life (HQOL) for children or adolescents with attention-deficit/hyperactivity disorder (AD/HD) to corroborate a diagnosis and monitor treatment outcomes, is usually relegated to parent, teacher and physician observation of the child/adolescent. Allowing adults to act as proxy reporters for children/adolescents increases the bias and contributes to subjective evaluation of the child/adolescent's HQOL. This article describes the development and validation of a HQOL scale that children or adolescents can complete themselves. The areas assessed included relationships with friends and family, reactions to medication, school achievement and ability to focus and attend. A factor analysis used to achieve construct validation yielded a 21 item scale. Reliability and criterion validation results were determined to be adequate. This new, short, self-report AD/HD HQOL scale for children and adolescents can be administered in a school setting or a physician's office by administrative staff to support other AD/HD assessment measures and monitor treatment outcomes.

Attention-Deficit/Hyperactivity Disorder (AD/HD) is one of the most prevalent and intensively studied childhood disorders. It is a challenging behavioral disorder characterized by developmentally inappropriate manifestations of inattention, impulsivity, hyperactivity and/or psychosocial interactions (American Psychiatric Association, 2000). It has a broad impact over multiple domains of the child or adolescent's life including academic performance, social interactions and familial relationships (Barkley, 1998). Assessment and diagnostic methods for the disorder have traditionally included full psychological batteries examining levels of cognitive functioning and academic performance (Sattler, 1988). Since these batteries are not designed to focus entirely on attention problems, other methods are used to augment the diagnostic process for determining Attention Deficit Hyperactivity Disorder (AD/HD) (American Academy of Pediatrics, 2000; Anastopoulos & Shelton, 2001; Barkley, 1998). Diagnostic interviews with parents and teachers, completion of behavior rating scales and/or symptom checklists by adults in the child or adolescent's life, examination of school records, anecdotal reports of symptoms and critical behaviors characteristically found in students with AD/HD as described in the Diagnostic Statistical Manual (DSM)-IV- TR (American Psychiatric Association, 2000) and direct observations of students in the classroom and on the playground assures a multiple measure assessment process and a more accurate diagnosis (DuPaul, 2003; Sattler, 1988). Many of the traditional assessment tools have also been used to evaluate and monitor treatment effects even though they were not designed for that purpose (Klassen, Miller, & Fine, 2004).

The results of a ten-year review of rating scales for assessing AD/HD found scales to be adequate measures of symptoms of AD/HD described in the DSM- IV (Collet, Ohan, & Myers, 2003). Behavior rating scales and symptom checklists have established reliability and validity and are used as one method for diagnosing children and adolescents with AD/HD (McCandless & O'Laughlin, 2007). An example of a traditional assessment tool specifically designed for AD/HD that uses just parent and teacher reports is the Connor's Behavioral Checklist (Conners,1997). Other traditional symptom checklist or behavioral rating scales that include a child/adolescent self-report have very general items focusing on many childhood challenges and are not specifically designed for diagnosis of just AD/HD

(e.g., CBCL: Achenbach, 1991a). Importantly, these scales and checklists were not developed to assess and monitor treatment outcomes, therefore, they are not sensitive to change in a health-related condition such as when a child is receiving pharmacotherapy for AD/HD (Klassen, et al., 2004).

In addition, there is a major bias related to the process of adults completing the scales and using their own perceptions to describe what is happening with the child or adolescent challenged by this disorder (Gomez, Burns, & Walsh, 2003). While correlations between different adult raters such as teachers and parents are often low to moderate, correlations between adult ratings and child self-reports can be very low (Gadow, Sprafkin & Salisbury, 2004). This low correlation between adult and child reports could be related, in part, to inflated self-perceptions of children and adolescent with AD/HD as compared to a normative control group (Hoza, et.al., 2005). These low correlations are also due to adult perceptions of children and youth that reflect their tolerance for certain behaviors, understanding of the nature of the scale item, socio-cultural background and normative values related to behavior and sense of competence when dealing with children and adolescents with these behaviors (DuPaul, 2003; Sattler, 1998). All self-report instruments are subject to bias, and to minimize the bias, different sources must be assessed (Sattler, 1998).

None of the rating scales examined in the ten-year review study (Collet, et al., 2003) and frequently used in assessment (Barkley, 1998) are considered Health Related Quality of Life (HQOL) scales. HQOL scales are designed to gather information regarding physical functioning across a range of health conditions and to monitor treatment outcomes (Erickson, Stapleton, & Erickson, 2006; Patrick & Deyo, 1989). Multi-dimensional, generic, HQOL scales include items related to social, role and mental health functioning in addition to the physiological and physical functioning items. These scales can be used for corroborating other traditional assessment tools. HQOL scales assist health-care practitioners examine how a patient perceives the symptoms related to the disorder from the patient's own subjective framework. The scales are designed specifically for monitoring treatment outcomes (Erickson, Stapleton, & Erickson, 2004).

Assessment of HQOL in children raises more issues than for adults due to the reporting factor, developmental differences, and the contextual variables such as family and peers (Matza, Swensen, Flood, Secnik, Leidy, 2004b; Spieth & Harris, 1996). There are examples of HQOL scales developed for children as generic health scales, as compared to condition-specific measures (Matza, et al., 2004b; Patrick & Deyo, 1989) and validated for use for children with a specific condition such as AD/HD using the parent report form such as Child Health Questionnaire (Rentz, Matza, Secnik, Swensen, & Revicki 2005; Klassen, et al., 2004). Other HQOL scales including a sub-section related to AD/HD using parent and/or teacher reports are available (Gadow, et al., 2004; McCandless & O'Laughlin, 2007) as well as HQOL scales developed as a disease-specific measure for ADHD using a parent report method (Landgraf, Rich, & Rappaport, 2002).

However, these adult proxy report scales add bias to the overall sensitivity of the scale and minimize the use of the scale to assess treatment outcome changes (DuPaul, 2003). It is essential that sensitivity and accuracy of slight change in behavior and feeling during treatment is detected related to the symptoms of the specific health-related disorder such as AD/HD (Matza, et al., 2004a) and this is most accurately achieved through asking the patient directly.

There are a few self-report generic HQOL for children (e.g., Child Health Questionnaire: Raat, Bonsel, Essink-Bot, Landgraf & Gemke, 2002; PedsQL: Varni, Seid, & Kurtin, 2001). These generic self-report scales are not health condition-specific for children and adolescents. Condition-specific scales are necessary for disorders to accurately assess slight clinical changes due to development or treatment (Matza, et al., 2004b; Patrick & Deyo, 1989). Using the child/adolescent as the source of the report is especially important when examining treatment outcomes of any intervention plan for modifying the disruptive behaviors related to AD/HD. A sensitive, child/adolescent self-report instrument is needed to ascertain specific change in the behavior of the child/adolescent with AD/HD across settings (e.g. school, home) and related to the treatment intervention (Matza, et al., 2004b). Since treatment for AD/HD consists of a multi-modal approach including classroom modifications, behavioral contracts, family counseling, pharmacotherapy (Barkley, 1998; Biederman, et al., 1997) the HQOL assessment tool must include a variety of items that describe a range of behaviors, emotions and physiological feelings across different environment and settings to best assess treatment outcomes. More appropriate, valid, assessment processes related to treatment modalities and the assessment of a person's quality of

life due to the disorder and treatment are needed for children and adolescents with AD/HD (Snyder, Drozd, & Xenakis, 2004).

The purpose of this project was to develop a new, short, self-report AD/HD HQOL scale for children and adolescents that can be administered in a school setting or a physician's office by administrative staff to support other AD/HD assessment measures and monitor treatment outcomes.

Method

Participants

Study 1: Validation of ADHD HQOL. Ninety-one children and adolescents were recruited from two private practices of pediatric specialists in the area of AD/HD. The participants were currently being treated for attention deficit with hyperactivity disorder and had sought a second opinion of a specialist. Diagnosis for AD/HD was originally made by the referring physicians; therefore, therefore the diagnostic process was not necessarily based upon a standardized procedure. However, this study was part of a new diagnostic procedure within the private practice areas of the pediatric specialists participating in the study. Participants received the AD/HD HQOL questionnaire at the initial visit and the medications reported were based upon the referring physician's diagnosis and prescription.

Children and adolescent's average mean age was 13.2 (SD =2.3; range 9-17). 85% of the sample was boys and 14% of the patients were not taking medication at the time of the initial visit. 49% were on Ritalin (Novartis Pharmaceuticals Corporation, Cambridge, MA), 37% were on Dexadrine (GlaxoSmithKline, Research Triangle Park, NC).

The pediatric offices were located in Sydney, Australia within a homogeneous population setting with 100% speaking English as their first language and socio-economic status reported as middle to high income.

Study 2: Test-retest, Internal Consistency and Intraclass Reliability. Twenty-two children and adolescents were recruited from the same population described above, and re-administered the short version of the survey and tested again with this same short version 6 weeks later. The average mean age of this group was 13.8 (SD =1.5; range 10-16).

Study 3: Criterion-related Validity. The parents and teachers of the twenty-two children and adolescents recruited for the test-retest reliability study and administered the Connors Parent Rating Scale-R (Short Version):Connors, 1997 or the Connors Teacher Rating Scale-R(Short Version):Connors, 1997.

All studies were approved by the Institutional Review Board at the University of Sydney, Australia.

Procedure

Study 1: Validation of ADHD HQOL. Patients were recruited at their initial visit to the pediatric specialists by the interview nurse. Signed consent was obtained and the 101 item HQOL questionnaire was administered by a University of Sydney graduate student enrolled in the masters of clinical psychology program. Parents were involved in the initial intake interview regarding age, gender, school and medication. The children and/or adolescent were then allowed to answer the items themselves, with the graduate student answering any questions they had for clarification of items, or reading words they could not read. This allowed the participant to answer the questions accurately.

Study 2: Test-retest, Internal Consistency and Intraclass Reliability. In subsequent visits, 22 of the original 91 patients were administered the final 21 item short version of the ADHD HQOL, then re-tested 6 weeks later. A graduate student enrolled in the masters of clinical psychology program was available for item clarification or reading words to participants.

Study 3: Criterion-related Validity Parents of the 22 students recruited for the reliability study and willing teachers were asked to complete either the Connors Parent Rating Scales-R (Short Version): Connors, 1997 or the Connors Teacher Rating Scale-R (Short Version) : Connors, 1997).

Measures

Study 1: Validation of ADHD HQOL. The newly developed ADHD HQOL of 101 items was administered in this study. Items were developed through focus group interactions, a thorough review

of the literature, and comparison to other quality of life surveys for children, and from a pilot study conducted on the clarity and readability of the items. Readability levels of items were examined through comparison of the SMOG readability formula (McLaughlin, 1969). Most items could be considered at a 3rd grade readability level, with some items using words such as *medication* and *embarrassed* creating a 6th grade readability level.

Areas focused upon for item development included: perceived school academic success; perceived comfort with social interactions; comfort in family life; sense of mood and perceived physical sensations related to medication.

Study 2: Test-retest, Internal Consistency and Intraclass Reliability. The newly shortened ADHD HQOL of 21 items was administered. The shortened version was developed through item reduction processes using Principal Component Factor Analysis with varimax rotation (SPSS version 10). Final item areas included; 5 items related to interacting with friends; 4 items examining subjective well-being; 3 items related to perception of school; 3 items related to perceived physiological sensations; and 3 items examining functional reaction to medication; and 3 items in perceived success (self-efficacy) on goal directed activities

Study 3: Criterion-related Validity The 27-item Conner's Parent Rating Scale-R (Short Version): Conners, 1997 and Teacher Rating Scale-R (Short Version) Conners, 1997 are standardized questionnaires designed to assess parent and teacher perception of the child /adolescent behavior both at home and in school, respectively. The questionnaires yield scores ranging from normal to clinically significant in the areas of oppositional defiance, cognitive focus and inattention problems, and hyperactivity. There is also an overall ADHD index. The technical manual indicates that the scale is valid and adequately reliable (test-retest subtest scores range from .47 to .86).

Analysis

Study 1: Validation of ADHD HQOL. Exploratory Factor Analysis was conducted to evidence construct validity (Clark, & Watson, 1995). Principal Component Factor Analysis (SPSS: Version 10) is considered an effective method for initial data reduction and for examining underlying constructs summarizing a set of data (Kim, & Mueller, 1978). The number of factors representing the underlying constructs should explain greater than 50% of the variance (Streiner, 1994). Specific items load on different factors, indicating that the items are correlated with that underlying construct. A commonly acceptable level of factor loading for an item is above 0.04 (Floyd, & Widaman, 1995), although many consider 0.03 as an acceptable cutoff (Tabachnick, & Fidell, 1996). The process of deleting items loading below a designated cutoff assists in shortening the scale for the next factor analytical iteration. The weight of the loadings is also important in considering the size of the sample (Floyd, & Widaman, 1995). If the loading are high (>0.06) in the initial iteration, a sample size around 100 is considered acceptable (Guadagnoli, & Velicer, 1988).

Study 2: Test-retest, Internal Consistency and Intraclass Reliability. Test-Retest reliability was obtained through Pearson-r correlations of the two administrations of the 21 item ADHD HQOL Scale 6-8 weeks apart. Internal Consistency was obtained through Cronbach's Alpha coefficient correlation. Intraclass Reliability was also obtained through statistical analysis on SPSS (Version 10).

Study 3: Criterion-related Validity Although it is difficult to obtain criterion-related validity with a new concept scale (e.g. ADHD QOL administered to children), and it is not essential in scale development when there are no instruments assessing exactly what the new one purports to measure (Streiner & Norman, 1995) examining the ADHD QOL scale to parent and teacher perceptions of some related areas was considered useful. Therefore, selected parents and teachers completed the 27-item Conner's Parent Rating Scale-Revised (Short Version): Conners, 1997 and Teacher Rating Scale-Revised (Short Version): Conners, 1997.

The overall Conner's subtests (opposition, inattention and hyperactivity) and the overall AD/HD index was compared to the total subtests scores on the 21 item AD/HD HQOL: interacting with friends; subjective well-being; perception of school; perceived physiological sensations; functional reaction to medication and perceived success on goal directed activities. Pearson-r Correlations were conducted.

Results

Study 1: Validation of ADHD HQOL. One-hundred and one items were submitted to exploratory factor analysis using principal components analysis with varimax rotations and conducting 6 iterations deleting items below the cut-off of .5. A scree plot indicated 6 factors relevant to this analysis. A final version of 21 items accounting for 72% of the variance was created through this iterative process (see Table 1). Categories of items clustered into areas related to friendships, subjective well-being and self-esteem, school, functional reaction to medication, perceived physiological sensations and perceived success in goal-directed activities. Areas not represented in the final analysis that were included in the original 101 items pertained to general family interactions, except for one item related to siblings and explicit mood states. However, in the category labeled subjective well-being, mood is implicit in some items.

Table 1
Items Accounting for 72% of Variance across the 6 Relevant Factors

Variables	Component					
	Friends	Wellness	School	Medications	Symptoms	Goal-directed
I like my friends	.843					
I have a friend who knows me well	.818					
I know my friends like me	.782					
I like being with others at lunch time	.719					
Things in my life just keep getting worse		.826				
I wish I were different		.728				
I am dumb next to my friends		.717				
I get along with my sisters/brothers		-.639				
I can't wait to quit school			.886			
I find school boring			.857			
I like being at school			-.737			
I do better at school work when I'm on medication				.807		
I do better at my favorite sports when I'm on medication				.799		
I feel embarrassed about taking medication				-.795		
I feel weird					.893	
I have aches and pains in my body					.828	
I feel strange					.528	
I finish my homework						.849
I finish my homework without taking a break						.768
I get my work done on time						.639

Rotated Component Matrix. Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization. Rotation converged in 6 iterations.

Study 2: Test-retest, Internal Consistency and Intraclass Reliability. Evidence of reliability for HQOL scales include the use of test-retest, internal consistency as evidenced by Cronbach's coefficient alpha and intraclass reliability analyses. The test-retest reliability was Pearson $r=.660$ ($p=.004$), Internal consistency coefficient alpha = .706 and Intraclass correlation was also .706.

Study 3: Criterion-related Validity Pearson r correlations demonstrated some statistically significant relationships (see Table 2) between Conner's Parent Rating Scale – Revised (Short Version): Conners,

1997 or Teacher Rating Scale - Revised (Short Version): Conners, 1997 subtests oppositional defiance, inattention, hyperactivity and overall index and subtests of the newly developed ADHD HQOL friends, subjective well-being/wellness, school, functional reactions to medications, perceived physiological sensations and perceived success in goal –directed activity. Teachers overall perception of the student with challenges demonstrated by the index score on the Conner's, correlated with the HQOL area of wellness ($p = .043$). Parental perception of the child's challenges with inattention as demonstrated by scores on the Conner's, correlated with the HQOL school subset ($p = .038$). Parental perception of the child's challenges with hyperactivity correlated with the HQOL physiological sensations subtest ($p = .014$). Overall scores for AD/HD from the Conner's Parent report correlated with the HQOL school ($p = .017$) and physiological symptoms ($p = .014$).

Table 2

Pearson r Correlations between Conners Scales and ADHD HQOL index and subtests

Categories	Friends	Wellness	School	Medication	Symptoms	Goal-Directed	Total
Teacher score on Opposition	.100 .667	-.259 .256	-.257 .248	.329 .135	-.004 .986	-.403 .063	-.163 .493
Teacher score on Inattention	.033 .886	-.415 .061	-.305 .168	.211 .345	-.150 .506	-.270 .225	-.300 .199
Teacher score on Hyper	.069 .766	-.182 .431	-.041 .855	.233 .297	.011 .962	-.122 .588	-.065 .784
Teacher score on Total	.026 .912	-.446* .043	-.187 .404	.343 .118	-.045 .841	-.340 .122	-.271 .248
Parent score on Opposition	.131 .570	.128 .579	.347 .113	-.351 .110	-.280 .207	.226 .313	.195 .411
Parent score on Inattention	.000 .999	-.164 .478	.445* .038	-.161 .474	-.256 .251	.183 .416	.034 .888
Parent score on Hyper	-.056 .809	-.402 .071	-.011 .960	-.278 .210	-.514* .014	.069 .760	-.399 .082
Parent score on Total	.101 .662	-.199 .388	.502* .017	-.241 .281	-.515* .014	.244 .273	-.006 .981

* $p < .05$; two-tailed test; $n = 21$

Teacher and Parent scores are based upon the Conner's Rating Scales –Revised Short Version

Conclusion and Discussion

This is a valid, reliable self-report instrument for assessing Health Related Quality of Life in children and adolescents with AD/HD. Construct validity and criterion-related validity evidenced the potential usefulness of this scale. It is short, and can be administered by school personnel, health care practitioners and support administrators. Therefore, this new scale is useful in a variety of educational and clinical settings to both corroborate the diagnosis of AD/HD and monitor treatment outcomes. The most important contribution of this new scale to a battery of assessment tools, is the addition of the child or adolescent's perception about their own condition. This in combination with traditional parent and teacher evaluations will yield a more accurate assessment of any clinical and behavioral changes related to treatment.

Limitations of the study include the use of a convenience sample of patients diagnosed by many different referral sources. While this was not ideal, the results from both the Conner's and the factor analysis of the newly developed items, suggests that there was a consistency among the referring physicians in terms of the correct diagnosis, even though the process used for diagnosis was inconsistent among the referring physicians. Another limitation was the lack of control for what type of pharmacotherapy was prescribed and further research should control for this to assess if treatment outcome change is related to one type or another of the medications used in treatment of AD/HD.

Further studies should also be conducted to demonstrate the scale's effectiveness in monitoring change and sensitivity in the different areas it is designed to assess.

In conclusion, this new valid and reliable self-report HQOL for AD/HD in children and adolescent's can be useful for both research and clinical purposes in a variety of settings. This self-report instrument can be used as one of the assessment tools available to monitor the effectiveness of treatment over time and over a variety of functional dimensions.

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