

ASSESSMENT OF HEALTH-RELATED QUALITY OF LIFE (HRQOL) IN A SAMPLE OF
CHILDREN REFERRED FOR AN ADHD EVALUATION

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ABSTRACT

The present study examined the reliability and validity of the Pediatric Quality of Life Inventory – Version 4.0 (PedsQL 4.0) generic core scales as a measure of Health Related Quality of Life (HRQOL) among children referred for an ADHD Evaluation. Additionally, a multiple regression analysis was used to determine which of certain parent and child variables (number of psychiatric diagnoses, child’s adaptive skills, child’s externalizing and internalizing behavior difficulties, child’s functional impairment, and parental stress) are significantly associated with HRQOL as measured by the PedsQL. Results revealed strong internal consistency for all but the school functioning subscale as well as good test-retest reliability. Agreement between parent and child ratings approached significance. As predicted, parent ratings on the PedsQL were moderately correlated with ratings on the Impairment Rating Scale. The strongest predictors of HRQOL were parent ratings of internalizing behavior and adaptive behavior (BASC-2). Results suggest that administering the PedsQL may be useful in assessing the adverse impact of ADHD symptoms on children’s everyday functioning.

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CHAPTER 1

INTRODUCTION

Overview

The health-related quality of life (HRQOL) concept first emerged as an evaluation and outcome measure in medical research and practice. It has since been extended into the pediatric field to assess the well-being and functional status of children with chronic illnesses. In recent years, researchers and practitioners in clinical and health psychology have extended the concept to consideration of psychological and emotional difficulties. Psychological disorders are often of a chronic and longstanding nature and are associated with lower levels of perceived and reported quality of life (Bastiaansen, Koot, Ferdinand, & Verhulst, 2004).

HRQOL appears to be related to the concept of “functional impairment,” which is an important component in diagnosing and treating mental disorders. In fact, most categories included in the DSM-IV-TR (APA, 2000, p. 356), require that the individual’s symptoms cause “clinically significant distress or impairment in social, occupational, or other important areas of functioning” in order to meet diagnostic criteria. The assessment of domains of functional impairment as part of the initial and ongoing psychological evaluation provides clinicians with information regarding particular areas of maladjustment and degree of severity, contributing to better understanding of a client’s unique situation. This additional knowledge has the benefit of allowing the creation of a more individualized and comprehensive treatment plan and facilitates monitoring of the child’s progress over the course of treatment (Goldstein & Naglieri, 2009).

The most common reason for which children are referred to mental health practitioners is the parent and/or teacher's observation of disruptive behaviors, such as arguing, fighting, distractibility, inattention, hyperactivity and impulsivity. Furthermore, Attention-Deficit/Hyperactivity Disorder (ADHD) is one of the most commonly diagnosed disorders among children and adolescents referred for treatment (Barkley, 2006). Areas of impairment related to the behaviors associated with symptoms of ADHD include academic difficulties, poor peer relationships, family conflict and familial stress (Fabiano et al., 2006). ADHD often co-occurs with other childhood psychological disorders, particularly Oppositional Defiant Disorder (ODD), anxiety disorders, and learning disorders (LD). Children with comorbid psychiatric conditions (i.e. those who meet criteria for more than one diagnosis) typically exhibit greater intensity and range of impairment (Barkley, 2006; Biederman, Koot, Ferdinand & Velhurst, 2004). In addition to specific areas of impairment across environments (i.e. home, school), ADHD and comorbid disorders contribute to reduced quality of life (Varni & Burwinkle, 2006; Klassen, Miller & Fine, 2004).

Identification of level of severity and comorbidity has important implications beyond guiding psychological treatment, as policies surrounding eligibility for special educational and other supportive services are often based on the degree of impairment. The current standards for diagnosing ADHD are based on DSM-IV criteria (APA, 2000). Consequently, children who present with subclinical ADHD-related symptoms may not be referred for treatment, regardless of the degree of symptom-related impairment. In fact, some researchers and clinicians have proposed that children with subclinical symptoms who do not meet criteria for diagnosis may still experience high levels of impairment and could benefit from psychological treatment and additional services (Costello & Shugart, 1992). Thus, emphasizing ADHD diagnosis alone may

not lead to the most effective approach to treatment of this population. Including a measure of well-being as part of the ADHD battery may provide the clinician with a more complete picture of the child's functioning, beyond what is gleaned from a DSM-IV category diagnosis.

The sections that follow will review existing research pertaining to HRQOL, including the development of the notion, methods of measurement, and common applications in research and practice within the context of assessment and treatment of both physical and mental health conditions. More specific attention will be given to the implementation of HRQOL measures within the field of clinical child psychology and, particularly to the assessment and treatment of children presenting with ADHD-related symptoms. Additionally, the following review will address how assessment of HRQOL may potentially contribute to improved services and outcomes given the adverse impact of symptoms of ADHD and other disruptive behavior disorders on the child's everyday functioning and perceived level of well-being.

CHAPTER 2

REVIEW OF RELATED LITERATURE

Health-Related Quality of Life

The Concept of Health-Related Quality of Life

As defined by the World Health Organization (WHO), “health” refers to well-being and satisfaction with various domains of life “not merely in the absence of disease or infirmity” (The WHOQoL Group, 2006, p.1). As a consequence of the expanded conceptualization of health, HRQOL measures began to emerge in the late 1970s with the aim of providing a more comprehensive assessment of health by formulating questions pertaining to the impact of disease or illness on an individual’s overall functional status.

The broader concept of quality of life (QOL) relates to dimensions of daily functioning and satisfaction that have been determined to be important to people in general (Eiser & Morse, 2001). HRQOL assessments focus on QOL factors that are directly related to the person’s physical and mental health. More specifically, HRQOL measures address the individual’s functional status across different life domains as they relate to or are affected by physical and/or mental health conditions. HRQOL also includes the impact that the treatment of a disease or disorder has on the individual. Therefore, they take into consideration any side or secondary effects that emerge as a result of biological or psychosocial interventions.

Health-related quality of life measures are used for a variety of purposes and practices that have developed and changed over time. From an initial focus on identifying population-

based variables in order to guide public policies and services, application of HRQOL has expanded to include the assessment of individual patients within the context of healthcare practice (Guyatt, Feeny, & Patrick, 1993). Currently, public health professionals conduct research using HRQOL measures to assess the effects of various disorders and conditions on the general population as well as to identify impairment areas for particular subgroups. Additionally, healthcare professionals use measures of HRQOL to examine and understand the extent to which an illness or disorder interferes with an individual's daily functioning and overall sense of well-being.

HRQOL Measures and Physical Health Conditions

Initial measures of HRQOL were developed with adult normative samples and intended to assess the impact of adult illnesses or injuries on various life domains (Aaronson et al., 1991). The growing amount of research pertaining to HRQOL in adults has been fueled by several factors, including advancement in medical technology, a push toward cost reduction in healthcare, and increased interest in assessing impairment with individuals who have chronic health conditions. Methods of assessment include generic measures of HRQOL, which are applicable to patients across different disease categories as well as scales that are specifically geared to assess HRQOL within a particular health condition, population, or area of function (Guyatt et al., 1993).

The decision of whether to use a generic vs. specific measure of HRQOL depends on the research or diagnostic question as well as methodological and practical considerations (Patrick & Deyo, 1989). Generic measures are most useful for comparing outcomes among different interventions or populations. This is done in studies pertaining to cost effectiveness as well as in research directed at comparing degree of impairment and burden across different illnesses or

syndromes. However, specific measures are likely to be more sensitive in detecting small changes of importance to patients and healthcare providers (Guyatt et al., 1993). Of course, specific measures are not available for every illness, syndrome, or patient population and, thus, generic measures are generally studied to assess their applicability and usefulness within different contexts.

Two generic measures of HRQOL commonly used in research and practice are the EuroQol 5-Dimensions (EQ-5D) and the Short-Form 36 Health Survey (SF-36). The EQ-5D (The EuroQol Group, 1990) measures health-related impairment for five specific areas of functioning: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. For each item on the scale, the respondent is asked to rate their health on that particular day on a three-point scale. The SF-36 (Ware, Gandek, Kosinski, & Snow, 1993) consists of 36 items corresponding to eight areas of functioning: vitality, physical functioning, bodily pain, general health perceptions, physical role, emotional role, social role, and mental health. Both of these scales are examples of brief, self-report measures of HRQOL that can be easily and quickly administered to adults in a wide variety of research and practice settings. For example, the SF-36 has been used in research studies of over 200 health conditions, those of which most commonly include arthritis, back pain, cancer, cardiovascular disease, chronic obstructive pulmonary disease, depression, and diabetes, among others (Turner-Bowker, Bartley, & Ware, 2002).

Children, like adults, experience adverse effects, beyond direct symptoms, as a result of health conditions. In fact, there is evidence that suggests that children are particularly at risk for experiencing developmental and adjustment problems as a consequence of invasive medical procedures, frequent hospitalizations, as well as stress and uncertainty related to chronic illness and disease (Spieth & Harris, 1995). The overall general definition of pediatric HRQOL is

similar to that of adults', and consists of a subjective, patient-centered, assessment of functioning and well-being across multiple life dimensions. However, areas of child functioning that are potentially affected differ from those of adults as a consequence of developmental stage and associated roles within family, peer group, school and other contexts. For instance, functioning within the domains of academic performance and peer/family relationships is of particular importance in assessing HRQOL in the pediatric population. Thus, health outcome research in pediatrics has increasingly focused on issues of defining and conceptualizing HRQOL in children, addressing methodological issues particular to this population (e.g., age/developmental differences, eliciting parent-proxy vs. self-report), and developing and validating generic and specific measures of child HRQOL (Matza, Swensen, Flood, Secnik & Kline Leidy, 2004).

Palermo, Long, Lewandowski, Drotar, and Quittner (2008) conducted a review and analysis of the most commonly used measures of HRQOL as reported by pediatric psychologists. Four generic measures of HRQOL were identified as meeting criteria for classification as "well-established" evidence-based assessment scales: The Child Health and Illness Profile (CHIP; Starfield, Riley, & Green, 1999), the Child Health Questionnaire (CHQ; Landgraf, Abetz & Ware, 1996), the Pediatric Quality of Life Inventory 4.0 (PedsQL; Varni, Seid & Kurtin, 2001), and the Youth Quality of Life (YQOL; Edwards, Huebner, Connell, & Patrick, 2002; Patrick, Edwards, & Topolski, 2002). The CHIP (ages 6-17), CHQ (ages 5-18), and PedsQL 4.0 (ages 2-18) have different forms for obtaining parent report and child self-report while the YQOL (ages 12-18) elicits information exclusively from the adolescent's perspective. The CHIP and PedsQL provide different versions of the scale for different age groups, while the CHQ and the YQOL use the same form across age groups. All four measures assess impairment across different domains including physical and emotional functioning. Also, some measures include additional

subscales: such as “social functioning” in the PedsQL, which evaluates relationships with peers, and the assessment of child’s health impact on family and parenting in the CHQ (Palermo et al., 2008).

The PedsQL is unique among other generic measures of HRQOL in that it offers several supplemental scales that include items specifically associated with various health conditions such as asthma, diabetes, and cancer. This gives practitioners the option of using the generic core scales alone or in conjunction with one of the disease-specific modules. Using the generic scale together with a disease-specific scale increases the sensitivity of the measurement, allowing the practitioner to obtain a more accurate assessment of HRQOL in particular patient populations (Palermo et al., 2008).

HRQOL Measures and Pediatric Psychiatric Disorders

Although most research to date has focused on children with physical conditions (Connolly & Johnson, 1999; Eiser & Morse, 2001; Ronen, Rosenbaum, Law & Streiner, 1999), the HRQOL concept has also emerged in research involving children with mental health needs and psychological disorders (Bastiansen, Koot & Ferdinand, 2005). Children with a psychiatric diagnosis have been noted to have considerably lower HRQOL compared to a non-clinical population. Furthermore, the HRQOL of children with psychiatric disorders appears to be lower for social and emotional functioning domains compared to children with physical illness (Sawyer, Whaites, Rey, Hazell, Graetz & Baghurst, 2002). Additionally some research suggests it is possible for treatment to result in increased functionality and improved well-being even though particular symptoms of the disorder may persist (Baastiansen, Koot, & Ferdinand, 2005; Moore, Hofer, McGee & Ring, 2005), providing further rationale for the inclusion measures of HRQOL in mental health assessment.

In further expanding the assessment of HRQOL into the realm of mental health, researchers have followed the same process that has been used for developing tools for assessment with different physical conditions and patient populations. That is, research has focused on examining the applicability of existing generic measures to a number of psychiatric diagnoses and psychological domains (Matza et al., 2004). For example, pediatric measures previously used to assess HRQOL in children with chronic illnesses, such as those mentioned in the previous section, are now being applied to childhood psychological problems such as ADHD (Sawyer et al., 2002; Varni & Burwinkle, 2006).

Klassen, Miller and Fine (2004) studied HRQOL in children who had been referred to an ADHD clinic at British Columbia Children's Hospital. In their assessment, they used the parent version of the Child Health Questionnaire (CHQ; Landgraf, Abetz & Ware, 1996) to examine the extent to which ADHD symptoms affected several areas of functioning, including physical domains (physical functioning, role/social limitations as a result of physical health, bodily pain/discomfort, and general health perception) and psychosocial domains (role/social limitations as a result of emotional-behavioral problems, self-esteem, mental health, general behavior, emotional impact on parent, and time impact on parents). Additionally, the questionnaire includes a single item measure of family cohesion and a separate domain which assesses limitations in family activities. Overall, the researchers found that children with ADHD had poorer HRQOL (as reported by their parents) in all domains of psychosocial health as compared to children who did not receive an ADHD diagnosis. They found no difference between the groups in the physical health dimension. This study provided some evidence that ADHD is related to significantly poorer well-being among children, especially in areas related to psychosocial health.

In a different study, Klassen, Miller, and Fine (2005) sought to explore the issue of discrepancy between child and parent proxy reports when assessing quality of life in children with ADHD. Parents and children between the ages 10 to 17 who had been referred for an evaluation and diagnosed with ADHD were asked to complete the CHQ based on child functioning. In addition to ADHD diagnosis, they also collected information on comorbid disorders and severity of ADHD symptoms. They found that several factors predicted discrepancies in parent versus child report of quality of life. These included the presence of a comorbid oppositional defiant disorder diagnosis, a psychosocial stressor, and more severe ADHD symptoms. In general, children reported better quality of life, compared to their parents, in the areas of self-esteem, behavior, mental health and family cohesion. However, the children reported significantly lower quality of life in the area of physical functioning. Given the limited research that has examined quality of life issues in children diagnosed with ADHD and their families, the researchers suggested that their study be replicated and expanded to include other predictors. They also indicate that their sample, which consisted of children diagnosed with ADHD and presenting for treatment, may not accurately represent the experiences of children who exhibit symptoms of ADHD but have not received a diagnosis or sought treatment. They suggest that children with sub-syndromal symptoms ought to be examined as they may also experience diminished HRQOL regardless of whether or not they meet official criteria for a psychiatric diagnosis.

Attention-Deficit/Hyperactivity Disorder

ADHD and Functional Impairment

ADHD is estimated to occur in approximately 3-7% of the childhood population with a male to female ratio of 3:1. Symptoms of Attention Deficit/Hyperactivity Disorder (ADHD) are typically first seen before the age of seven, and contribute to impairment across settings. In about

50-80% of cases the disorder persists into adolescence and, within these cases, about 30-50% persists into adulthood (Barkley, 2006). Over time, the underlying symptoms of ADHD (i.e., inattention, hyperactivity, and impulsivity) are manifested in different behaviors according to the individual's developmental level. In childhood, ADHD is likely to be related to poor academic performance, impairment in social relationships, and conflict with family members (Barkley, 2006; Frick, Kamphaus, Lahey, Loeber, Christ, Hart, et al., 1991). In adolescence, academic and interpersonal problems may continue and additional maladaptive behaviors may emerge. For instance, adolescents with ADHD may begin experimenting with substance use at an early age, drive recklessly, and are at higher risk of expulsions, driving violations, and delinquency. In adulthood, the inattentive/impulsive nature of ADHD may continue to cause impairment in social relationships, marriage, and in the occupational setting (Kessler et al., 2006).

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders 4th Edition - Text Revision (DSM-IV-TR) distinguishes between three symptom categories for ADHD: inattention, hyperactivity, and impulsivity. Inattention refers to child behaviors such as difficulty staying focused, following directions and completing tasks, becoming easily bored, daydreaming, and frequent instances of forgetfulness. The hyperactivity domain includes behaviors like fidgeting and squirming, talking nonstop, difficulty staying seated and often running and climbing about. Impulsive behaviors include interrupting conversations, difficulty waiting and taking turns, and blurting out inappropriate comments and/or acting without consideration of consequences (APA, 2000). For the full DSM-IV-TR diagnostic criteria for ADHD, see Appendix A.

Children referred for an ADHD evaluation typically exhibit behaviors that are problematic in the home and/or school setting. These behaviors may interfere with the child's

ability to be successful academically as well as in their relationships with family members and peers. Children with ADHD-related symptoms are likely to exhibit behaviors (e.g., disrupting their classroom, not paying attention, annoying other children) that put them in situations that can hinder emotional, social, and school functioning (Frick et al., 1991). Furthermore, research shows ADHD is a predisposing factor for a variety of risky behaviors which may impact health functioning in late childhood/adolescence including substance abuse (e.g., smoking, drinking, illicit substance use), vandalism, theft, and other criminal behavior (Bijour, Golding, Haslum & Kurzon, 1988; Burke, Loeber & Lahey, 2001; Chilcoat & Breslau, 1999).

The risks associated with ADHD symptoms and behaviors are often exacerbated by co-occurring psychological disorders. Common comorbid diagnoses include oppositional defiant disorder (ODD), learning disorders (LD), anxiety disorders, and, in late childhood/adolescence, conduct disorder and substance abuse/dependence (Biederman, Newcorn, & Sprich, 1999). Although the estimated rate of comorbidity has somewhat varied, several statistics have been published regarding the issue. In general, studies have found that an average of 67%, and as many as 84%, of all children diagnosed with ADHD have at least one other diagnosable psychiatric disorder, meeting criteria for an average of 1.4 additional disorders (Barkley, 2006). An estimated 32% have two other distinct disorders, and up to 11% have three or more additional diagnoses (Barkley, 2006). Most commonly, children with ADHD also meet criteria for comorbid oppositional defiant disorder (45 to 84%), next most common is comorbid learning disorders (8 to 39%), and then anxiety disorders (25 to 35%) and mood disorders (25 to 30%; Barkley, 2006). Children with ADHD who present with comorbid disorders, and particularly externalizing behavior problems (e.g., aggression, argumentativeness, defiance), appear to experience increased levels of impairment, compared with children without comorbidities

(Barkley, 2006). Furthermore, children displaying ADHD with both externalizing and internalizing comorbid diagnoses (e.g., comorbid conduct and anxiety disorders) exhibit the highest level of impairment (Newcorn et al., 2004).

Assessment and Diagnosis of ADHD

A standard ADHD diagnostic battery consists of a clinical interview with the parent or legal guardian, ratings of child behavior from the parent/guardian and teacher, and behavioral observations (Barkley, 2006). Additionally, the practice parameters for the assessment of ADHD, published by the American Academy of Child and Adolescent Psychiatry (2007), recommend the inclusion of measures of intelligence and academic achievement.

Several broad behavior rating scales exist which provide diagnostic information regarding childhood behavior problems. Some of the most common ones include the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001) and the Behavior Assessment System for Children (BASC-2; Reynolds & Kamphaus, 2004). Rating scales are typically completed by the parent/caregiver and teacher; child self-report versions may be included for older children. These scales consist of items describing symptoms the child might display and ask the respondent to rate the extent to which the child exhibits a particular symptom based on frequency and severity.

The BASC-2 (Reynolds & Kamphaus, 2004) is a multidimensional measure which assesses for both positive and negative child behaviors. The BASC-2 has different versions that are intended for parents, teachers, and children to complete separately and ask the respondent to evaluate the behavior and self-perceptions of the child. Thus, the BASC-2 allows for different perspectives of the child's behavior. There are also three different forms intended for children of different age groups: early childhood (2 to 5 years), school-age child (6 to 11 years), and

adolescence (12 to 21 years). The CBCL (Achenbach & Rescorla, 2001) is another broad behavior rating scale normed for children aged 6 to 18 and, like the BASC-2, has different forms for parents, teachers, and youth self-report as well as for different age groups. Broad range rating scales have the advantage of assessing a wide range of possible behavior difficulties which is helpful in considering possible comorbid diagnoses. However, very few ratings scales include assessment of impairment. One exception is the Vanderbilt ADHD Rating Scale (Wolraich et al., 2003) which has a parent and teacher version and includes questions pertaining to impairment in the home, in school, and social settings in addition to DSM-IV criteria for ADHD and comorbid disorders.

Some lines of research have suggested that children with ADHD-like symptoms might be better served by a diagnostic system that places children along a spectrum of symptom severity within the dimensions (hyperactive/impulsive and inattentive/disorganized) (e.g., Achenbach, Howell, Quay, & Conners, 1991). More recently, researchers and clinicians have argued for incorporating a dimensional component for the ADHD diagnostic criteria in the DSM-5, which is currently under development (Hudziak, Achenbach & Althoff, 2008). This system of classification would make it easier for children with sub-clinical syndromes to receive psychological treatment as well and not limit interventions to those that meet DSM-IV diagnostic criteria. Furthermore, such a system would provide additional information for clinicians regarding level of impairment and allow for more individualized treatment planning. Some have also suggested that a more comprehensive diagnosis should include measures of the child's quality of life, which would provide information not only about the child's symptoms but also about how the child is functioning in different health-related domains (Sawyer et al., 2002).

HRQOL and the Assessment and Treatment of ADHD

HRQOL and Functional Impairment

Over the past decade, there has been increased emphasis on assessment of child impairment (Fabiano et al., 2006) across settings and determination of the source of impairment (i.e. possible sleep disorder, medical causes, comorbid conditions). Impairment is a more specific concept, as compared to HRQOL. In fact, an individual's assessment of his/her own level of impairment is an important component of HRQOL measures. Whereas functional impairment has been defined as limitations in the individual's ability to perform physical, social and personal activities that are part of everyday life (Stein & Jessop, 1990), HRQOL consists of an assessment of the person's self-perception of the impact of physical and mental health conditions on his/her overall health status, social functioning, and emotional well-being. For instance, the PedsQL 4.0 generic core scales self-report version includes items such as "I feel sad or blue" and "It is hard for me to run" which the child rates on a scale from one to five depending on how he or she perceives trouble with sleep and running to be problematic. The first of these items contributes to the emotional functioning domain while the second is considered part of the physical functioning dimension. In this sense, the measure is intended to provide an idea of how the child views his/her own functioning in different areas rather than "actual" specific limitations.

In looking at the constructs of functional impairment and HRQOL, the two concepts can be thought of as having an inverse relationship with one another, with higher HRQOL corresponding with lower functional impairment and the other way around. Although, some researchers have argued that distinct differences exist in the definitions of these two concepts, it can be reasonably expected for scores on a measure of impairment to have a moderate correlation with scores on a measure of HRQOL (Palermo et al., 2008).

HRQOL Assessment and ADHD

Including HRQOL measures as part of a comprehensive psychological evaluation could provide helpful information related to areas of functioning more/less impacted by the disorder. In this sense, obtaining information regarding what the child and caretakers perceive to be a problem area can give clinicians a better idea of the types of interventions that might be most helpful to a particular individual.

Treatment of ADHD is often comprehensive and, if possible, involves the child, the parents, and the child's school teachers. The first step usually consists of psychoeducation about the disorder, followed by training in behavior modification and behavior management techniques that should be implemented across settings. In some cases, the child may be referred for additional special education resources and/or assistance, such as speech therapy or tutoring. In addition to psychological interventions, some children might be referred to a medical professional for psychoactive medication therapy (Barkley, 2006; Barkley, 1998). Nevertheless, the type of treatment that is selected depends upon the clinician's assessment of the child's needs. Thus, the processes of assessment and diagnosis have a direct impact on the type of treatment that is chosen as well as any additional services that are recommended for the child. For instance, the frequency and duration of therapy, and possible inclusion of multiple therapy modalities (e.g., individual, group, family) may be determined based on the severity of the child's symptoms and the areas of functioning deemed to be impacted by the disorder.

ADHD and child psychopathology in general tends to be chronic and persistent. Although symptoms may persevere over time, it is possible that with adequate treatment, psychopathology symptoms may become less disruptive and more manageable (Conners et al., 2001). The HRQOL concept provides a construct by which to identify and measure the child's

day-to-day well-being and guide the initial and ongoing planning of intervention strategies. More specifically, HRQOL can help provide a more complete conceptualization of a particular client, including not only information related to a diagnosis or diagnoses but also an idea of how the individual perceives his or her own life functioning across domains to be impacted by the symptoms and associated problems of a physical or psychological disorder (Landgraf, Rich & Rappaport, 2002).

The Pediatric Quality of Life Inventory (PedsQL) and ADHD

Existing Research. Over the past few years, several studies have presented results indicative of the usefulness of HRQOL measures in providing additional information regarding the functional status of the child. (Baastiansen et al., 2005; Sawyer, et al., 2002). Overall, the PedsQL has been found to correlate with other HRQOL measures and to effectively distinguish between children with and without chronic conditions (Palermo et al., 2008). However, only a few studies have examined use of the PedsQL as a measure of HRQOL for children with ADHD. These have mostly been conducted by the author of the instrument (Varni & Burwinkle, 2006).

In the initial study exploring use of the PedsQL with a pediatric ADHD population, Varni & Burwinkle (2006) examined parent proxy and child self-report ratings of HRQOL. They obtained information via mail survey for 20,031 children ages 5 to 16 years whose families were new enrollees in the State's Children's Health Insurance Program (SCHIP) of California. They also examined the PedsQL parent and child ratings from an existing database consisting of children with chronic physical conditions (i.e., cerebral palsy and cancer). Participants recruited from the SCHIP survey were assigned to the ADHD or “healthy” group depending on parent-reported diagnosis. Children from the chronic physical conditions database were age-matched to participants in the SCHIP sample in order to create a chronic illness comparison group. Thus, the

study compared the differences in overall and subscale PedsQL scores, as reported by both children and parents, among children with ADHD, “healthy” children, and children with cancer and cerebral palsy.

In presenting their results, Varni & Burwinkle (2006) indicated that the PedsQL had been demonstrated to be a feasible, reliable, and valid measure of HRQOL for children with ADHD and their parents. They found good internal consistency for both parent and child self-report PedsQL with alpha coefficients for individual subscales ranging from a low of .52 to a high of .95. For the total PedsQL scale for both parent and child self-report (all ages), alpha coefficients approached or exceeded the reliability criterion recommended for analyzing individual patient scale scores, ranging from .74 to .92. Overall, parents of children with ADHD reported significantly lower scores on the PedsQL compared to parents of “healthy” children. The difference was statistically significant for dimensions related to psychosocial health but not for physical functioning. Parent ratings for children with ADHD were comparable to children with chronic medical conditions. Additionally children with ADHD obtained higher scores (indicating better quality of life) within the physical functioning domain as compared to children with chronic medical conditions for both parent and child self-report. Based on these observations, Varni and Burwinkle (2006) concluded that the PedsQL is a reliable and valid measure of HRQOL in children with ADHD. Limitations of this study included the lack of experimental control in administering a mail-in survey as there is no way to determine whether or not the children and parents completed the forms independently. Additionally, children were grouped based exclusively on the parent’s report and no objective measures of ADHD symptoms or degree of impairment were administered.

Limbers, Ripperger-Suhler, Boutton, Ransom, and Varni (2010) compared scores on the PedsQL between children with ADHD being treated in a general pediatric clinic and children with ADHD being treated in a psychiatric clinic. ADHD diagnostic information for both groups was based on their physician's report. Additionally, this study looked at family impact and symptom severity reported by parents of children in both groups. Results found that parents of children with ADHD who were being treated in the general pediatric clinic reported significantly higher PedsQL scores, indicating better adjustment for their children compared to parents of children with ADHD treated in a psychiatric clinic. Although the same pattern was observed for scores obtained from the child-report (i.e., better HRQOL in the pediatric vs. psychiatric setting), the differences were not statistically significant. Additionally, both ADHD groups obtained significantly higher scores for parent and child report compared to a "healthy" children comparison group. These group differences were particularly noted in the dimension of psychosocial health, which included subscales of emotional, social, and school functioning. Finally, parents of children with ADHD who were treated at the general pediatric clinic reported significantly less negative family impact in comparison to parents of children with ADHD treated at the psychiatric clinic. Overall, the data suggested that children with ADHD treated in a psychiatric setting experience greater impairment in HRQOL, evidenced by lower PedsQL scores, as compared to children treated in a general pediatric context. However, children with ADHD treated in a general pediatric clinic still manifest deficits in HRQOL. It is possible that children being treated in the psychiatric clinic setting may have exhibited more comorbid disorders, resulting in lower PedsQL scores. Nevertheless, comorbidity was not assessed as part of this study and the researchers suggest that subsequent studies focus on the impact of co-occurring disorders on HRQOL. Additionally, they suggest that future research assess a group of

children more representative of the general population, given that their particular sample consisted exclusively of children receiving treatment.

Factors associated with informant-related characteristics. Patient self-report has been considered a defining feature of HRQOL measurements (Riley, 2004). However, there are situations in which a child may not be able to adequately complete a measure. For instance, factors associated with health conditions such as pain, fatigue, and limited mobility may interfere with the child's ability to complete the task. Additionally, some researchers have argued that some children may simply be too young to reliably report their own symptoms and functional impairment. For these reasons, parent and/or other informants are often asked to report on the child's HRQOL (Quittner, Davis, & Modi, 2003).

Studies of psychological assessment that include measures completed by both the parent and the child client suggest that discrepancy between the two sources of information is common. Some research suggests that children with symptoms of ADHD may provide less accurate self-reports as compared to their parents' proxy-report (Barkley, 2006). Additionally, parent and teacher reports of child behavior are more strongly correlated than parent and child reports (Achenbach, McConaughy & Howell, 1987; Biederman, Faraone, Monuteaux & Grossbard, 2004) suggesting that adult perceptions of child behavior differ from child self-perception. As mentioned earlier, in their study of parent-child agreement on HRQOL ratings, Klassen, Miller, and Fine (2005) found greater discrepancy to be associated with comorbid oppositional defiant disorder, psychosocial stressors, and more severe ADHD symptoms. Several possible explanations have been offered, including a difference in perspectives regarding the child's symptoms and adjustment. Barkley (2006) suggests that children with ADHD exhibit particularly diminished self-awareness and impulse control, resulting in poor self-reflection and under-

reporting of disruptive behavior symptoms. However, it is important to note that children may be more accurate than parents in reporting their own internalizing symptoms (Hinshaw, 1994). Given the high rates of comorbidity observed for ADHD and other psychiatric disorders, it is possible for parents and teachers to report disruptive behavior while “missing” comorbid anxiety or depression. Therefore, obtaining a self-report from the child in addition to the parent might be the most accurate and complete method of assessment for diagnostic and treatment planning purposes.

Another reason for assessing the child’s own perception of his/her own well-being is that a parent’s report regarding their child might be influenced by the parent’s level of stress and general psychological adjustment. In fact, behaviors associated with ADHD symptoms, in particular, are often difficult for parents to manage and may contribute to increased family conflict, including parenting difficulties and marital discord (Johnston & Mash, 2001). Parents of children with ADHD express more dissatisfaction in their parenting role (Podolski & Nigg, 2001) and exhibit higher rates of divorce (Wymbs et al., 2008) compared to parents of children without an ADHD diagnosis. Thus, the parent’s own stress, possibly relating to parenting a difficult child and/or other unrelated difficulties is likely to influence the quality of the home environment as well as to color both the child’s and parent’s perception of the child’s adjustment. Given the emphasis on self-perception and personal experience in HRQOL assessment (Eiser & Morse, 2001), each source of information likely represents a unique perspective that is useful in conceptualizing the child’s and family’s current functioning and/or impairment.

CHAPTER 3

THE PRESENT STUDY

Overview

As mentioned, quality of life refers to an individual's subjective satisfaction with several life domains, including his or her physical, emotional, and social functioning. Unlike symptom checklists and other measures of psychopathology, which only yield information regarding the severity of the disorder, HRQOL addresses a wider range of aspects about the individual's functional adaptation to everyday life, as a result of physical or mental health conditions.

Although several studies have found differences in HRQOL among children with ADHD compared to other groups (Klassen et al., 2004; Limbers et al., 2010; Varni, & Burwinkle, 2006), there is currently no research examining the usefulness of this type of measure as part of an ADHD assessment battery. Given the potential benefits of assessing HRQOL in children with emotional or behavioral difficulties, and specifically ADHD (e.g., obtaining more complete diagnostic information, assessing the child's own perspective, addressing non-symptom specific areas of impairment), it appears that further research assessing the usefulness and validity of HRQOL for this client population is warranted. Additionally, it would be useful to determine which factors are stronger predictors of lower HRQOL in order to aid clinicians and other professionals in more effectively planning and implementing treatment with children presenting with symptoms associated with ADHD (Pelham, Fabiano, & Massetti, 2005).

The present study explores the clinical utility of including assessment of HRQOL as part of child evaluation for ADHD using the PedsQL (Varni et al., 2001). This study also examines the validity and reliability of the PedsQL in a sample of children referred for an ADHD evaluation. The study replicates previous research (e.g., Varni & Burwinkle, 2006; Limbers et al., 2010) exploring the relationship between ADHD and the child's HRQOL by examining the validity and reliability of the PedsQL as a measure of HRQOL in children referred for an ADHD evaluation. Specifically, this study considered test-retest reliability by comparing parent report on the PedsQL at the time of an initial evaluation to parent report during a later feedback session and assessed validity by comparing parent ratings on the PedsQL with parent ratings of child impairment. Additionally, the current study expands on previous literature by assessing the degree to which certain variables (i.e., number of psychiatric diagnoses, child's adaptive skills, child's externalizing and internalizing behavior difficulties, parental stress, and child's functional impairment) predict parent report of HRQOL.

Specific Predictions

1. Given past evidence of discrepancy between parent and child self-report, particularly for children with ADHD (Barkley, 2006), a low to moderate correlation coefficient was expected between parent and child PedsQL ratings.
2. It was expected that the analysis comparing the parent's report of HRQOL during the diagnostic interview with the parent's report during the feedback session would yield a moderate to high correlation coefficient, which would indicate good test-retest reliability.
3. In order to attain evidence for concurrent validity, we expected to find a moderate correlation between the overall raw score of the PedsQL and the overall sum of the IRS ratings. It was expected that the correlation would be moderate rather than high,

since indicated strong correlation would suggest that the two scales measure a similar construct, which would have implications for the value of using the PedsQL as an additional measure of well-being.

4. Based on prior findings (Barkley, 2006; Newcorn et al., 2004) it was expected that level of impairment (IRS) and parent report of externalizing behavior (BASC-2) would be the strongest predictors of HRQOL as measured by the parent reported PedsQL raw score.

CHAPTER 4

METHODOLOGY

Design

The primary purpose of this study was to examine the validity, reliability and clinical usefulness of the Pediatric Quality of Life Inventory – Version 4.0 (PedsQL 4.0) generic core scales as a measure of Health Related Quality of Life in a sample of children referred for an ADHD evaluation. Correlational analyses were used to examine concurrent validity between the PedsQL and the Impairment Rating Scale (IRS) as well as inter-rater reliability (i.e., comparing the parent with the child report), and test-retest reliability (i.e., comparing the parent's report during the evaluation and with parent's report during feedback).

In order to explore factors associated with HRQOL, a regression analysis was conducted, entering functional impairment, number of diagnoses, externalizing behavior difficulties, internalizing behavior difficulties, adaptive skills, and parenting stress as potential predictors of parent report of the child's HRQOL.

Participants

A total of 63 parents and their children, ages five to twelve years old ($M = 90$ months, $SD = 19$ months), referred for assessment at a university- based ADHD Evaluation Clinic participated in the study. Children were typically referred for evaluation by a teacher, general physician, or parent as a result of behavior and/or academic problems. Of the 63 children who participated, 68.3% were male and 31.7% were female. Consistent with the demographics of the

area, the majority (87.3%) of children were identified as Caucasian. The remaining children were identified as biracial (9.5%), African American (1.6%), or Hispanic (1.6%) ethnic background. Of the 60 parents who provided information regarding their household income, 63.3% reported a yearly income of \$30,000 or less, while 15.1% indicated annual incomes above \$60,000. Table 1 contains frequencies and percentages for participant demographic information. As a result of the evaluation, 74.6% of the children who participated in this study received a diagnosis of ADHD, 17.6% were diagnosed with a different psychiatric disorder, and 7.9% did not meet full criteria for a DSM diagnosis (see Table 2 for more specific diagnostic information). Of those who were diagnosed with ADHD, 53% received at least one additional comorbid psychiatric diagnosis. Comorbid diagnoses included Oppositional Defiant Disorder (n = 13), Anxiety/Depressive Disorder (n = 10), Learning Disorder (n = 5), Pervasive Developmental Disorder (n = 4), and other diagnosis (n = 5).

Measures

Clinical Measures

Measures included in the ADHD assessment battery. The assessment battery used at the ADHD Evaluation Clinic at Indiana State University adheres to best practices recommendations and includes a DSM-IV based clinical interview with a parent/caregiver (which includes an adapted version of the Impairment Rating Scale), parent and teacher behavior rating scales, a measure of parenting stress, measures of child intelligence and academic achievement, a computerized test of attention, and a developmental history questionnaire. For the present study information from the clinical interview (i.e., IRS items), the developmental questionnaire, the Parenting Stress Index, a broad range behavior rating scale (BASC-2), and the child's clinical diagnosis were used.

Conners-March Developmental Questionnaire (CMDQ). The CMDQ (Conners & March, 1996) is generally completed by the child's parent or guardian and includes demographic information, (i.e., age, ethnicity, education level), child educational, developmental and health history; medication use; and psychiatric history of the child and family. Demographic information including child age, ethnicity, family income and whether or not the child is on medication was used in this study.

Parenting Stress Index- Short Form (PSI-SF). The PSI-SF (Abidin, 1995) is also completed by the child's parent or guardian. This scale assesses the degree and possible source of stress that a parent may be experiencing. The short form of the PSI used in this study is a 36-item, self-report scale on which parents rate on a 5-point scale (strongly disagree, disagree, not sure, agree, strongly agree) how much they agree that each item describes their child, themselves, or their current life situation. The measure yields scores for four clinical sub-scales: Total Stress, Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC). The Total Stress scale provides information on overall parenting stress level. The PD scale gauges a parent's distress related to feelings of incompetence as a parent, insufficient social support, feelings that his/her other life roles are restricted because of being a parent, negative interactions with the child's other parent, and depression. The P-CDI scale measures how a parent views his/her relationship to his/her child, with high scores indicating interactions are not reinforcing to the parent and that the parent-child bond has either never been adequately established or is close to rupturing (Abidin, 1995). Finally, the DC scale assesses child behavioral traits that affect how easy (or hard) it is to manage the child's behavior. The PSI-SF has been demonstrated to be a reliable measure (test-retest reliability coefficient = .84, internal consistency coefficient alpha = .91) and has been used in prior studies of treatment

compliance by parents of children diagnosed with ADHD. For the purposes of the present study, overall PSI scores were used as a measure of parenting stress.

Behavior Assessment System for Children- 2nd Edition (BASC-2). The BASC-2 (Reynolds & Kamphaus, 2004) is a broad range behavior rating scale completed by the parent and /or teacher of the child based on observations of the child's behavior in the home or school setting. The various items ask the respondent to rate a specific behavior on a four point scale depending on the frequency of the behavior (i.e., never, sometimes, almost always, or always). The BASC-2 yields three primary scales consisting of "externalizing behaviors" (e.g., hyperactivity, oppositionality, disruptiveness), "internalizing behaviors" (e.g., withdrawal, anxiety, depression) and "adaptive functioning" (e.g., age appropriate self-care and social skills). The BASC-2 is a well-established and widely used instrument in child assessment with norms developed for each of different age groups and demonstrated high content, criterion, and construct validity. Reliability for the instrument has been also been found to be high with and internal consistency coefficients for the aforementioned scales yielding an average of about .80. This study looked specifically at the externalizing behaviors, internalizing behaviors, and adaptive skills functioning subscales of the parent versions of the BASC-2.

Impairment Rating Scale (IRS). The IRS (Fabiano et al., 2006) is intended to measure functional impairment in a child's everyday life. Items included in the IRS correspond to areas of functioning known to be compromised in children with ADHD. The IRS is typically completed by the child's parent and/or teacher and assesses the child's relationships with peers, siblings, parents, teachers, academic progress, influence on family and classroom functioning, self-esteem, and overall impairment. The IRS has been demonstrated to have good concurrent, convergent, and discriminant validity in assessing functional impairment in children with

ADHD. The measure was also found to have good inter-rater reliability for both parent and teacher versions. The current study utilized a version of the IRS specifically adapted for use in the ADHD evaluation clinic, which is administered verbally to parents as part of the diagnostic interview. The adapted version is nearly identical to the original IRS, with the exception of omitting one item. A list of the IRS items administered as part of this study can be found in Appendix B.

Research Measures

Pediatric Quality of Life Inventory – Version 4.0 (PedsQL 4.0) Generic Core Scales.

The PedsQL 4.0 (Varni et al., 2001) is designed to measure health-related quality of life (HRQOL) in healthy children and adolescents as well as in those with acute and chronic health conditions. The PedsQL has generic core scales and additional disease-specific modules for a number of particular health conditions that affect children. For the purpose of the study, the generic core scales of the PedsQL were used to assess HRQOL in children referred for an ADHD evaluation. The generic core scales consist of 23 items including questions about the child's physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). The scales are available in both child self-report and parent proxy-report formats, with three child self-report (for ages 5 to 7, 8 to 12, and 13 to 18 years) and four parent report (for ages 2 to 4, 5 to 7, 8 to 12, and 13 to 18 years) versions. The items on all forms are essentially identical, differing only in terms of developmentally appropriate language and verb tense, depending on the age of the child and the intended respondent. The PedsQL scales were designed to measure the core dimensions of health as delineated by the World Health Organization, as well as school functioning. The four subscales of the PedsQL include physical functioning (eight items), emotional functioning (five items), social functioning (five items), and

school functioning (five items). Sample items for The PedsQL 4.0 Parent Report Version and Child Self Report Version for children ages 8 to 12 and 5 to 7 can be found in Appendix C.

The PedsQL has been used in numerous studies to assess HRQOL in pediatric populations with both physical and psychiatric chronic health conditions. Past research has found the PedsQL to correlate significantly with psychiatric symptom rating scales, such as the Child Behavior Checklist, and assessments of child emotional difficulties, such as the Children's Depression Inventory and the State-Trait Anxiety Inventory for Children (Varni, Seid, & Rode, 1999). Additionally, children with ADHD have been found to obtain higher scores (indicating worse HRQOL) on the PedsQL as compared to a "healthy" control group, particularly for the emotional, school, and social functioning subscales (Varni & Burwinkle, 2006).

In examining parent-child agreement rates for PedsQL subscales with children ages five to 16, Varni and Burwinkle (2006) reported correlation coefficients ranging from a low of .59 to a high of .75. The correlation between parent and child overall scale score on the PedsQL was .71. Limbers et al. (2010), reported good internal consistency reliability (i.e., $\alpha > .76$) for all scales except child self-report of emotional functioning ($\alpha = .66$) and parent report of school functioning ($\alpha = .68$) when assessing children with ADHD being treated in a general pediatric clinic. For participants in the current study, the alpha coefficients for the total scale scores were .91 for child self-report and .92 for parent report, exceeding the recommended reliability criterion ($\alpha = .90$) for analyzing individual scale scores.

Procedure

Following approval by the Indiana State University Institutional Review Board (IRB), information about the study was provided to parents of children being seen at the ADHD Evaluation Clinic at Indiana State University. Parents were given a flyer (see Appendix D) with brief information about the study when they arrived at the clinic for their child's evaluation.

Parents that expressed interest in participating were given a consent form (Appendix E) and the research measures to be completed along with the questionnaires that are routinely used in the assessment battery while seated in the waiting area of the ISU clinic. Parents also completed a HIPPA consent form allowing use of information collected as part of the ADHD Evaluation (e.g. BASC-2, information from Conner's Developmental Questionnaire, Impairment Rating Scale and Parenting Stress Index), to be used in the present study (Appendix F). Since children were asked to complete the child self-report of the PedsQL, assent was elicited from the children as well. For children younger than age 7, verbal consent was solicited and children age 8 and older were asked to provide both verbal and written consent (see bottom of parent consent form).

Children completed the self-report questionnaire at the end of the evaluation as part of the routine child interview conducted during the ADHD evaluation. There are two versions of the PedsQL for children. Children between the ages of five and seven responded verbally or orally to the young child report version of the PedsQL which asks the child to point to one of three faces showing different facial expressions in response to items that are read aloud by the examiner. Children between eight and twelve completed the older child report version of the PedsQL which includes written items only and does not include the faces. For older children (ages 8 to 12), the evaluator read directions to each child and made sure they understood the questionnaire by reading individual items to the child as necessary. Children completed the PedsQL in approximately 5-10 minutes, responding to the 23 items. Parents were asked to complete the PedsQL a second time during the feedback session, which took place 2-4 weeks following the initial evaluation. Parents were also provided with information about their child's responses and their own responses to the PedsQL during the feedback session. All clinical services provided through the ADHD evaluation clinic are supervised by a licensed psychologist.

Measures administered for the present study (i.e., PedsQL) were scored and entered into a secure database by either a graduate or undergraduate research assistant that had completed IRB training and had been trained in the appropriate methods of data entry. Research questionnaires were labeled by subject number and not child or parent's name. Similarly, subject number served as the identifier in the data file to ensure participants' privacy and to maintain the confidentiality of their responses. Research measures were kept in a locked file cabinet in a research lab and all assessment data was also kept in a locked file cabinet in the ISU Psychology Clinic.

Statistical Analyses

Missing data on the research questionnaires was replaced with means reflective of the participant's other responses within a particular scale or set of scales representing a construct. All statistical analyses were conducted using SPSS Version 18.0 for Windows.

First, descriptive statistics were calculated for participant demographic information (e.g., child age, ethnicity, family income). In order to assess the internal consistency of the PedsQL, Cronbach's alpha coefficients were calculated for the raw scores on the parent-reported PedsQL. This was done for both overall scores as well as the four PedsQL subscales (i.e., physical, emotional, social, and school).

Correlation analyses were utilized in order to assess inter-rater reliability, test-retest reliability, and concurrent validity. For inter-rater reliability, correlation coefficients were computed comparing parent and child PedsQL raw overall and scale scores. To assess test-retest reliability, a correlation coefficient was computed comparing the parent's score on the PedsQL at the time of the evaluation to the parent's score at the time of the feedback appointment (2-4 weeks later). Assessment of concurrent validity entailed computing a correlation coefficient comparing overall raw score on the parent reported PedsQL and the sum of the parent-reported IRS ratings.

Finally, a multiple regression analysis was conducted with six predictor variables: parental stress (total PSI score), child impairment (sum of IRS ratings), number of DSM diagnoses (ranging from 0 to 3), parent reported child adaptive skills (BASC-2), parent reported internalizing behavior problems (BASC-2), and parent reported externalizing behavior problems (BASC-2). The criterion variable was the parent report of child HRQOL (overall PedsQL raw score). All predictor and the criterion variables were continuous. A correlation between the child's age and their score on the PedsQL was also computed. Since this analysis did not yield a significant coefficient, the variable of child age was not included as a covariate in the regression analysis.

CHAPTER 5

RESULTS

Overview

Results are presented in the following sections. First, descriptive analyses are presented followed by an analysis of the psychometric properties of the PedsQL, including internal consistency, inter-rater reliability, test-retest reliability, and concurrent validity. Next, results of a regression analysis of variables predicting HRQOL are presented. Finally, the results of an additional regression analysis conducted, predicting discrepancy between child and parent report on the PedsQL, are presented as well.

Preliminary Analyses

Tables 3 and 4 present means, standard deviations, and ranges for all research variables. As would be expected, for children being referred for possible ADHD, the mean for the externalizing scale was in the “at risk” range and higher than the mean for the internalizing scale, which was in the average range. The mean for the adaptive functioning scale of the BASC-2 was also in the “at risk” range, indicating that many parents reported behaviors suggesting problems with day-to-day functioning in areas such as activities of daily living, adaptability, functional communication, leadership, and social skills. The mean for the parent and child total on the PedsQL was similar (see Table 4).

Internal Consistency

Internal consistency of the PedsQL was assessed by calculating Cronbach's alpha coefficient for parent ratings on the four subscales and the total score. Internal consistency was high for the total PedsQL ($\alpha = .89$) as well as three of the four subscales: Physical ($\alpha = .82$), Emotional ($\alpha = .81$) and Social ($\alpha = .81$). Internal consistency was considerably lower for the School Functioning scale ($\alpha = .54$).

Inter-Rater Reliability

In order to examine inter-rater reliability, correlation coefficients were computed comparing parent and child ratings on the PedsQL. These analyses were completed for the 57 parent-child dyads for which both parent and child PedsQL data was available. Parent-child agreement on the total PedsQL approached significance ($r = .25, p = .06$). In regards to individual scales, agreement was significant for the emotional scale ($r = .27, p = .04$). Agreement was not significant for the physical ($r = .07, p = .59$), social ($r = .12, p = .34$) or school ($r = .15, p = .25$) subscales. Table 5 presents correlation coefficients for parent and child report on the PedsQL scales.

Test-Retest Reliability

Parents were asked to complete the PedsQL on two different occasions, once during the initial assessment and again during their feedback for the evaluation, approximately 2-4 weeks later. A correlation coefficient was computed for the 38 parents that completed the PedsQL on both occasions. Results of this comparison indicated good test-retest reliability ($r = .80, p < .001$).

Concurrent Validity

In order to examine concurrent validity of the PedsQL, parents' ratings on the PedsQL were compared to parent ratings of child impairment on the Impairment Rating Scale (IRS).

Whereas the IRS yields a score representing impairment in daily function, the PedsQL yields a score representing enhancement of daily functioning. Thus a negative correlation between the two measures was predicted. As predicted, results revealed a moderate negative correlation ($r = .48, p < .001$) between the PedsQL scores and the IRS, suggesting good concurrent validity.

Predictors of HRQOL

Several variables were taken into account as possible predictors of HRQOL: parental stress (PSI), child's level of impairment (IRS), number of psychiatric diagnoses, parent report of child level of adaptive functioning, and parent report of child externalizing (e.g., hyperactivity, impulsivity, oppositionality, defiance) and internalizing (e.g., withdrawal, anxiety, depression) behavior difficulties on the BASC-2. As seen in Table 6, the strongest correlation between the six predictors was $r = .60$ between child externalizing symptoms (BASC-2) and parental stress (PSI), thus indicating an acceptable level of multicollinearity.

A multiple regression analysis was conducted in order to determine which of the aforementioned variables predicted parent report of child HRQOL. In the first step of the model, the BASC-2 Internalizing scale was found to explain 36% of the variance. In the second step of the model, the parent BASC-2 adaptive functioning scale entered and accounted for an additional 15% of the variance, yielding a total of 51% of the variance accounted for by these two variables (see Table 7). None of the other four variables (number of diagnoses, parenting stress, level of impairment, parent report of externalizing behavior) entered into the regression.

Additional Analyses

An additional regression analysis was conducted using the child's report of his/her own HRQOL (i.e., child self-report on the PedsQL) as the criterion variable. However, none of the predictor variables (parental stress, child's level of impairment, number of psychiatric diagnoses,

parent report of child level of adaptive functioning, parent report of child externalizing, and parent report of child internalizing) entered into the regression (see Table 8).

A third regression analysis was conducted in order to determine possible predictors of the discrepancy between parent and child report of HRQOL. For this analysis, child age, number of DSM diagnoses, and parent report of child's ADHD symptom severity (BASC-2 externalizing) were included as predictors of the difference between parent and child report on the PedsQL. None of the predictor variables entered into the regression (see Table 9).

In order to further examine inter-rater reliability (parent-child agreement) on the PedsQL, separate correlational analyses were conducted for each of two child age groups (i.e., 5-7, 8-12 years old). In the older group, correlations were significant for the emotional ($r = .58, p < .001$) and social ($r = .55, p < .001$) subscales and approached significance for the total PedsQL score ($r = .39, p = .07$). In contrast, none of the parent-child correlations were significant for the younger age group. Table 10 presents correlation coefficients by age group for each subscale as well as the total raw scores of the PedsQL.

CHAPTER 6

DISCUSSION

Overall Considerations

The present study considered the potential usefulness of administering the Pediatric Quality of Life Inventory (PedsQL; Varni, Seid & Kurtin, 2001), a measure of HRQOL, in a population of children referred for an ADHD evaluation. More specifically, this study addressed internal consistency, inter-rater reliability, test-retest reliability, and concurrent validity. Additionally, the study assessed the degree to which certain variables (i.e., number of child's psychiatric diagnoses, level of parenting stress, parent's ratings of child impairment, child's externalizing and internalizing behavior, and child's adaptive skills) contribute to decreased HRQOL, as measured by the PedsQL. Overall, results of this study provided psychometric support for the PedsQL as well as support for its clinical usefulness in assessing the adverse impact of ADHD symptoms on children's functioning.

Internal Consistency

Internal consistency was assessed by Cronbach's alpha (Cronbach, 1951). The alpha value obtained for total PedsQL parent score was high and approached the alpha value of .9 recommended for individual comparisons (Nunnally & Bernstein, 1994). Internal consistency for most of the PedsQL subscales (i.e., Physical, Social and Emotional) was within an acceptable range. Internal consistency for the School subscale was much weaker as compared to the other subscales. A possible explanation for the low alpha coefficient is the difference in content among

items of the School Functioning scale. The first three items on the subscale, which directly address attention, forgetfulness, and keeping up with schoolwork, are much more likely to be endorsed by parents of children exhibiting ADHD symptoms, compared to the last two items which relate to missing school due to illness or doctor's appointments. Given the high overall internal consistency, the parent report version of the PedsQL seems to be a reliable tool for individual client assessment decisions in clinical practice.

Test-Retest Reliability and Validity

Results of the present study also provide support for good test-retest reliability and well as good concurrent validity. The high correlation found between parent ratings on the PedsQL at the time of evaluation and parent ratings on the PedsQL during feedback indicates good test-retest reliability for the parent-report version of the PedsQL. Since child participants responded to the PedsQL on only one occasion, test-retest reliability was not assessed for the child report version of the PedsQL. Future studies may consider addressing this issue as it appears to be a gap in existing literature concerning HRQOL assessments (Palermo et al., 2008).

The moderate correlation obtained between the ratings on the PedsQL and the IRS suggests that the constructs of HRQOL and functional impairment are related but distinct. This indicates that HRQOL measures, such as the PedsQL, have the potential of adding to ADHD evaluation batteries information beyond symptoms and impairment (e.g., sense of wellbeing in different life domains).

Parent-Child Agreement

As predicted, there was a low to moderate correlation between parent and child ratings on the PedsQL. The low inter-rater reliability between parents and children is consistent with past research that has found minimal parent-child agreement on behavior rating scales, particularly for children with ADHD (Barkley, 2006). Furthermore, prior research has found that a number of

factors influence parent-child agreement on HRQOL measures, including: ODD comorbidity, psychosocial stressors, ADHD symptom severity (Klassen et al., 2005; the age of the child (Cremeens, Eiser, & Blades, 2006); and the type of HRQOL domain being assessed (Klassen et al., 2005; Cremeens et al., 2006, Eiser & Morse, 2001).

Child age, ODD comorbidity, and ADHD symptom severity were included as predictors of parent-child agreement in the exploratory regression analysis conducted as part of the present study. However, the results did not find any of these predictors to be significant. It is difficult to determine exactly how the child's age influences reporting of HRQOL, given that results are contradictory in this area. While Eiser and Morse (2001) found no difference in concordance rates based on children's age, Cremeens et al. (2006) reported that, in their study, older children's reports tended to differ more from their parents' as compared to younger children. Other studies (e.g., Annett, Bender, DuHamel, & Lapidus, 2003) have found concordance rates in reporting HRQOL to be greater for younger vs. older children and their parents.

In an effort to better understand the impact of age on parent-child agreement, additional correlational analyses were conducted for the relationship between parent and child report. Correlation coefficients were calculated separately for two different child age groups: five to seven and eight to twelve years of age. As mentioned earlier, there are different versions of the PedsQL corresponding to the child's age. Since the children who participated in this study ranged from ages five to twelve, two different forms were used. Children five to seven years old responded to the young child report version of the PedsQL which asks the child to point to one of three faces showing different facial expressions in response to items read aloud by the examiner. Children between eight and twelve completed the older child report version consisting of written items only. For this older group, the evaluator read the initial directions and made sure the child

understood the questionnaire (only reading individual items to the child if necessary). The results of these additional correlational analyses (splitting the sample by child age group) indicate that parent-child agreement was better for the older (eight to twelve year-old) group. While none of the parent-child correlations were significant for the five to seven years of age group, correlations were significant for the emotional and social subscales and approached significance for the total PedsQL score in the older child group. These results are consistent with Cromeens et al. (2006) finding that agreement tends to be better for older vs. younger children and their parents. One factor to consider is that the older child group completed the version of PedsQL that was more similar in structure and method of administration to the parents' version (i.e., participant read questionnaire items and responded by circling written options) as compared to the young child version (i.e., participant was read items by examiner and responded by pointing at the faces). However, prior research has found that parent-child agreement in reporting psychiatric symptoms does tend to increase with age (Edelbrock, Costello, Dulcan, Conover & Kalas, 1986). Finally, Cromeens et al. (2006) suggest that the different results obtained across studies looking at parent-child agreement on HRQOL measures may be attributed to the varying population types assessed and/or the statistical method used to analyze parent-child agreement.

Consistent with prior research, results of the present study found that parent-child agreement differed among individual subscales of the PedsQL. Parent and child reports were significantly correlated for the emotional subscale. Parent-child agreement for the physical, social and school subscales was not significant. Other studies addressing parent-child concordance rates have also found agreement to differ among different dimensions of HRQOL. For instance, Klassen, Miller, and Fine (2005) propose that parent-child agreement tends to be better for HRQOL domains consisting of observable (e.g., physical health) vs. non-observable

(e.g., mental health) areas of functioning. Similarly, Cromeens et al. (2006) found that the type of health domain assessed (i.e., individual PedsQL subscale) was one of three factors affecting agreement on the PedsQL (the two other factors being child age and the parents' own HRQOL). However, while both the Klassen, Miller, and Fine, (2005) and the Eiser and Morse (2001) studies found agreement to be higher for physical as compared to socioemotional aspects of HRQOL, Cromeens et al. (2006) obtained seemingly contradictory results, with parent-child correlations being higher for emotional vs. physical health domains. It is worth noting that the latter study was conducted with a sample of “healthy” children only, while the other two included children with ADHD (Klassen et al., 2005) and chronic physical health conditions (Eiser & Morse, 2001).

Results of the present study are more closely in line with Cromeens et al. (2006), in that parents and children displayed better agreement for the emotional as compared to the three other PedsQL subscales. While it may be the case that the differing results for agreement for various health dimensions are the product of the statistical method used, as suggested by Cromeens et al. (2006), another possible explanation is that parent-child concordance varies depending on the type of population being assessed. For example, when examining populations of children with chronic physical health conditions, agreement may be higher for the physical domain due to parents and children having a history of frequently communicating about the effects of particular symptoms/side effects due to regular doctor’s appointments, treatments, and taking medications. Eiser and Morse’s (2001) observation that agreement between parents and children with chronic physical health conditions is better as compared to healthy children supports this theory. However, Klassen, Miller, and Fine’s (2005) results indicating higher agreement for physical domains for children with ADHD do not. Thus, the relationship between health domain and

parent-child agreement remains unclear. Based on the results of the present study, it appears that agreement between children presenting with externalizing behavior concerns and their parents is more similar to the “healthy” vs. physical illness samples. However, future research may want to compare concordance rates among all three groups (i.e., “healthy”, mental health and physical illness), using the same measure, in order to determine how parents and children differ in reporting on different HRQOL domains.

The discrepancies between parent and child report provide support for the usefulness of obtaining both self-and proxy HRQOL information. Children and parents likely process and interpret situations differently, and both perspectives are important in understanding the child’s difficulties. Lower agreement may also result from parents being unaware of some aspects of the child’s everyday life. For instance, the child may not share feelings of distress about being teased in school with the parent, and so parent and child reports of social and/or school functioning could be very different. Thus, it is recommended that both self-report and parent proxy ratings of HRQOL be elicited. When this is not possible, it is important to consider that the parent’s assessment of the child’s HRQOL is likely to differ from the child’s own perception. Finally, Cromeens et al. (2006) suggest that agreement may be influenced by the parent’s own HRQOL. Consequently, it may be appropriate to consider the parent’s own perception of his or her well-being in order to understand how the parent’s functional impairment is impacting their child’s adjustment. Interventions can then be planned to target the appropriate parent and/or child problematic behaviors.

Predictors of HRQOL

Contrary to predictions, parent ratings of impairment (IRS) and externalizing difficulties (BASC-2) were not found to be the strongest predictors of HRQOL. Instead, parent reports of child internalizing and adaptive difficulties (BASC-2) were found to be the most significant

predictors of HRQOL. Although ADHD is an externalizing disorder, these results suggest that children with ADHD-related symptoms also experience a great deal of internalizing and adaptive functioning problems which negatively impact their well-being. An examination of the items in the PedsQL social and emotional scales may help to explain why the total PedsQL score was more closely associated with internalizing vs. externalizing problems. Items included in the PedsQL social and emotional scale include: Problems with “feeling afraid or scared,” “feeling sad or blue,” “other kids not wanting to be his or her friend,” and “getting teased by other children.” These items in particular would appear to be closely related to internalizing symptoms (e.g., feeling sad, worrying). In contrast, none of the individual items on the PedsQL appear to correspond with externalizing behavior, which likely explains why externalizing difficulties (BASC-2) didn’t enter into the equation as a predictor. Thus, HRQOL measures, and more specifically, the PedsQL have the potential to be clinically useful in detecting impairment/loss in wellbeing specifically due to internalizing symptoms that may be overlooked in a standard ADHD evaluation, which focuses largely on the impact of externalizing symptoms (e.g., inattention, hyperactivity).

The regression model predicting the child’s HRQOL accounted for 51% of the variance. There are likely many other factors, not considered in the present study, that influence parent rating of child HRQOL. As mentioned earlier, the parent’s own HRQOL has been found to influence parents’ ratings of their child’s HRQOL (Creeman et al., 2006). Thus, assessing the parent’s HRQOL and including this variable as a predictor of child HRQOL might increase the predictive value of the model.

Limitations, Suggestions for Future Research, and Conclusions

Some limitations of this study include the fact that the research sample was limited in terms of race, ethnicity, and socio-economic diversity. Consequently, the sample may not

necessarily be representative of the general population. Thus, it is proposed that further research of this sort be conducted with diverse and more representative samples. Additionally, this study did not include a control group to which children presenting for the evaluation could be compared. Future studies should utilize the same HRQOL measure (e.g., PedsQL) with various “health” status groups (i.e., children presenting with ADHD and other mental health concerns, children presenting with physical illness, and “healthy” children) in order to determine how scores may differ for different HRQOL domains. Future research of this sort could not only provide more nuanced information regarding the general usefulness of the PedsQL with children presenting with ADHD-like symptoms, but also gain further insight into the factors that influence differences in parent and child reports of the child’s HRQOL.

Another suggestion is for future research is to focus on exploring and identifying areas of HRQOL which may be particularly impaired in children with ADHD and other psychiatric concerns in order to develop a HRQOL scale specific to this population. The PedsQL currently has a number of disease specific modules, which are designed to be used in conjunction with the generic core scales. The addition of a PedsQL module specifically geared towards children experiencing mental health concerns, and particularly ADHD, would likely be the most comprehensive way to assess HRQOL within these populations. As mentioned earlier, the PedsQL generic core scales do not include any items relating directly to externalizing difficulties. Thus, including items that correspond to social, emotional and academic problems that occur as a result of inattentive and/or impulsive behavior might be an important consideration in creating a condition-specific scale that reflects the impairment experienced by children with ADHD. Some areas of wellbeing that could be considered for an ADHD-specific module might include: problems with getting into trouble at school/home, making/keeping

friends, getting along with siblings, keeping up with class lectures, successfully completing homework/assignments, feeling frustrated with self, and feeling discouraged. Additionally, for children taking stimulant medication, the ADHD-specific module could include items pertaining to physical functioning (e.g., decreased appetite, sleep problems).

Regardless of the aforementioned limitations, the present study adds to existing research by providing further evidence in support of the reliability and validity of the PedsQL with children who present with symptoms of inattention and/or hyperactivity. This study also found support for the potential benefits of using the PedsQL with children presenting for an ADHD evaluation, which include: assessing the child's (in addition to the parent's) perspective regarding his/her own current difficulties, obtaining a more complete diagnostic picture (e.g., parent's influence on child's adjustment, possible internalizing difficulties), and addressing non-symptom specific areas of impairment in the child's everyday life (i.e., information not included in diagnostic criteria or symptom/behavior rating scales). In this sense, including the PedsQL generic core scales as part of an ADHD assessment would likely provide useful information regarding the extent and nature of impairment on daily functioning and, thus, help clinicians create more appropriate and effective treatment plans and interventions.

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Table 1

Participant Demographic Information

	Frequency	Percentage
Child Gender		
Male	43	68.3
Female	20	31.7
Child Ethnicity		
Caucasian	55	87.3
African-American	1	1.6
Hispanic	1	1.6
Biracial	6	9.5
Family Income		
Less than \$30,000	38	63.3
\$30,000 to \$60,000	13	21.7
More than \$60,000	9	15.1
Years of Education Completed by Parent		
Fewer than 12	2	3.4
12	24	40.7
13 - 15	16	27.2
16	14	23.7
17 or More	3	5.1

Table 2

Frequencies and Percentages for DSM-IV-TR Diagnoses

	Frequency	Percentage
Primary Diagnosis		
ADHD	47	74.6
ODD	2	3.2
Depression/Anxiety	2	3.2
Learning Disorder	3	4.8
PDD	3	4.8
Cognitive Impairment	1	1.6
No Diagnosis	5	7.9
ADHD Subtype		
Primarily Inattentive	8	17
Primarily Hyperactive	2	4.3
Combined	29	61.7
ADHD-NOS	6	12.8
ADHD Provisional/Rule Out	2	4.3
Total Number of Diagnoses		
None	5	7.9
One	28	44.4
Two	24	38.1
Three	6	9.5

Table 3

Means, Standard Deviations, and Ranges for BASC-2, PSI and IRS (Parent Report)

	M	SD	Range
BASC-2			
Internalizing	52.94	12.94	33 – 81
Externalizing	62.35	14.53	39 – 102
Adaptive Skills	39.00	8.51	20 – 56
PSI	60.69	35.22	1 – 99
IRS	18.90	10.01	0 – 39

Table 4

Means, Standard Deviations, and Ranges for PedsQL Raw Scores

	M	SD	Range		M	SD	Range	PedsQL Possible Range
Parent Report				Child Report				
Physical	7.21	6.12	0 – 24	Physical	8.95	6.99	0 – 24	0 – 40
Emotional	6.22	4.41	0 – 16	Emotional	7.00	4.62	0 – 20	0 – 25
Social	5.64	4.05	0 – 15	Social	7.56	4.53	0 – 16	0 – 25
School	8.74	3.19	2 – 15	School	8.62	4.10	0 – 18	0 – 25
Total	69.41	14.73	36 – 95	Total	64.82	14.19	29 – 89	0 – 115

Table 5

Pearson Correlations for Parent and Child Report PedsQL Scales

Variable	Child Total	Child Physical	Child Emotional	Child Social	Child School
Parent Total	.25	.11	.32*	.01	.25*
Parent Physical	.17	.07	.22	-.10	.31*
Parent Emotional	.17	.06	.27*	.03	.10
Parent Social	.24	.15	.24	.12	.15
Parent School	.18	.07	.28*	.01	.15

* $p < .05$

Table 6

Pearson Correlations among Predictor Variables and Parent PedsQL Total Raw Score

Variable	Parental Stress	Impairment Level	Number of Diagnoses	BASC-2 Internalizing	BASC-2 Externalizing	BASC-2 Adaptive
Parental Stress						
Impairment Level	.41**					
Number of Diagnoses	.37**	.32*				
BASC-2 Internalizing	.27*	.38**	.11			
BASC-2 Externalizing	.60**	.57**	.41**	.27*		
BASC-2 Adaptive	-.53**	-.56**	-.31*	-.27*	-.58**	
PedsQL Total	.47**	.48**	.22	.62**	.46**	-.54**

** $p < .01$, * $p < .05$

Table 7

Multiple Regression Analysis Predicting Parent Reported HRQOL

<i>Predictors</i>	<i>R²</i>	<i>df</i>	<i>F</i>	<i>p</i>	<i>β</i>
Model 1	.36	1, 57	31.36	<.001	
<i>Variables Entered</i>					
BASC-2 Internalizing					.60***
<i>Variables Not Entered</i>					
BASC-2 Adaptive					-.40***
Parenting Stress					.33*
BASC-2 Externalizing					.32*
Functional Impairment					.33*
Number DSM Diagnoses					.16
Model 2:	.51	2, 56	28.54	<.001	
<i>Variables Entered</i>					
BASC-2 Internalizing					.49***
BASC-2 Adaptive					-.40***
<i>Variables Not Entered</i>					
Parenting Stress					.17
BASC-2 Externalizing					.15
Functional Impairment					.15
Number DSM Diagnoses					.05

*p < .05. **p < .01. ***p < .001.

Table 8

Multiple Regression Analysis Predicting Child Reported HRQOL

Variable	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
Number of DSM Diagnoses	1.63	2.55	.09	.63	.53
BASC-2 Externalizing	.19	.18	.20	1.04	.30
BASC-2 Internalizing	.09	.15	.09	.62	.54
BASC-2 Adaptive	.24	.29	.15	.84	.41
Parenting Stress	.03	.07	.07	.41	.69
Functional Impairment	.06	.24	.04	.23	.82

Table 9

Multiple Regression Analysis Predicting Discrepancy between Parent and Child Report of HRQOL

Variable	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
Child Age	.04	.08	.07	.52	.61
BASC-2 Externalizing	.12	.13	.13	.91	.91
Number of Diagnoses	-2.05	1.88	-.15	-1.09	.37

Table 10

Pearson Correlations for Parent and Child Report PedsQL Scales by Age Group

Variable	Child Total		Child Physical		Child Emotional		Child Social		Child School	
	Ages 5-7	Ages 8-12	Ages 5-7	Ages 8-12	Ages 5-7	Ages 8-12	Ages 5-7	Ages 8-12	Ages 5-7	Ages 8-12
Parent Total	.19	.39	.11	.21	.28	.35	-.14	.39	.21	.33
Parent Physical	.38*	.11	.19	.04	.41**	.03	-.12	.08	.45**	.22
Parent Emotional	.02	.40	.03	.18	.03	.58**	-.12	.38	.08	.14
Parent Social	.06	.55**	.05	.36	.14	.41	-.10	.55**	.03	.38
Parent School	.16	.29	.07	.15	.33*	.16	-.09	.37	.07	.29

** $p < .01$, * $p < .05$

**APPENDIX A: DIAGNOSTIC CRITERIA FOR ATTENTION-
DEFICIT/HYPERACTIVITY DISORDER**

A. Either (1) or (2):

- (1) six or more of the following symptoms of inattention have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level:
 - (a) often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities
 - (b) often has difficulty sustaining attention in tasks or play activities
 - (c) often does not seem to listen when spoken to directly
 - (d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions)
 - (e) often has difficulty organizing tasks and activities
 - (f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)
 - (g) often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books, or tools)
 - (h) is often easily distracted by extraneous stimuli
 - (i) is often forgetful in daily activities
- (2) six or more of the following symptoms of hyperactivity-impulsivity have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:
 - (a) often fidgets with hands or feet or squirms in seat
 - (b) often leaves seat in classroom or in other situations in which remaining seated is expected

- (c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- (d) often has difficulty playing or engaging in leisure activities quietly
- (e) is often “on the go” or often acts as if “driven by a motor”
- (f) often talks excessively
- (g) often blurts out answers before questions have been completed
- (h) often has difficulty awaiting turn
- (i) often interrupts or intrudes on others (e.g., butts into conversations or games)

B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before age 7 years.

C. Some impairment from the symptoms is present in two or more settings (e.g., at school [or work] and at home)

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Attention-Deficit/Hyperactivity Disorder, Combined Type: if both Criteria A1 and A2 are met for the past 6 months

Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive Type: if Criterion A1 is met but Criterion A2 is not met for the past 6 months

Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive-Impulsive Type: if Criterion A2 is met but Criterion A1 is not met for the past 6 months

Taken from Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, American Psychiatric Association, 2000.

APPENDIX C: PEDIATRIC QUALITY OF LIFE INVENTORY 4.0 GENERIC CORE

SCALES DIRECTIONS AND SAMPLE ITEMS

	Parent Report Both Child Age Groups	Child Self-Report Ages 5 – 7	Child Self-Report Ages 8 – 12
Directions	<p>On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child in the past ONE month by circling:</p> <p>0 if it has never been a problem 1 if it is almost never a problem 2 it is sometimes a problem 3 it is often a problem 4 it is almost always a problem</p>	<p>On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you in the past ONE month by circling:</p> <p>0 if it has never been a problem 1 if it is almost never a problem 2 it is sometimes a problem 3 it is often a problem 4 it is almost always a problem</p>	<p>Read by the examiner:</p> <p>“I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you. If it is not at all a problem for you, point to the smiling face. If it is sometimes a problem for you, point to the middle face. If it is a problem for you a lot, point to the frowning face.”</p>
Sample Items by Subscale			
Physical	<ul style="list-style-type: none"> ▪ Walking more than one block ▪ Lifting something heavy 	<ul style="list-style-type: none"> ▪ Is it hard for you to walk ▪ Is it hard for you to pick up big things 	<ul style="list-style-type: none"> ▪ It is hard for me to walk more than one block ▪ It is hard for me to lift something heavy
Emotional	<ul style="list-style-type: none"> ▪ Feeling afraid or scared ▪ Feeling sad or blue 	<ul style="list-style-type: none"> ▪ Do you feel scared ▪ Do you feel sad 	<ul style="list-style-type: none"> ▪ I feel afraid or scared ▪ I feel sad or blue
Social	<ul style="list-style-type: none"> ▪ Getting along with other children ▪ Getting teased by other children 	<ul style="list-style-type: none"> ▪ It is hard for you to get along with other kids ▪ Do other kids tease you 	<ul style="list-style-type: none"> ▪ I have trouble getting along with other kids ▪ Other kids tease me
School	<ul style="list-style-type: none"> ▪ Paying attention in class ▪ Missing school because of not feeling well 	<ul style="list-style-type: none"> ▪ Is it hard for you to pay attention in school ▪ Do you miss school because of not feeling good 	<ul style="list-style-type: none"> ▪ It is hard to pay attention in class ▪ I miss school because of not feeling well

APPENDIX D: STUDY RECRUITMENT FLYER**STUDY PARTICIPANTS NEEDED**

You are invited to participate in our study on the impact of ADHD behaviors on parent and child perceptions of well-being in school-aged children

As a result of participating in this study, you may gain valuable insight into how your child currently views his or her own well-being

Participation in this study will entail:

- ❖ You (the parent) filling out an additional questionnaire today and during your feedback session (which will take 5 to 10 minutes each time)
- ❖ Your child answering a few additional questions during today's assessment (which will take 5 to 10 minutes)
- ❖ All your responses will be kept confidential

Please let the examiner know if you are interested in participating in this study

If you have any questions or concerns regarding this study, please contact Liz O'Laughlin, Ph. D at 812-237-2455.

Your participation is greatly appreciated!

APPENDIX F: HIPAA AUTHORIZATION FORM

HIPAA ¹ AUTHORIZATION TO USE AND DISCLOSE INDIVIDUAL HEALTH INFORMATION FOR RESEARCH PURPOSES

- 1. Purpose.** As a research participant, I authorize Liz O’Laughlin, Ph.D and the researcher’s staff to use and disclose my and my child’s individual health information for the purpose of conducting the research project entitled “**Assessment of Health Related Quality of Life**”
- 2. Individual Health Information to be Used or Disclosed.** Individual health information from my child’s evaluation that may be used or disclosed to conduct this research includes: information from the clinical interview and developmental history questionnaire, parent/guardian and teacher responses to the behavior ratings scales (*Behavior Assessment Scale for Children-2, ADHD-IV Rating Scale, Parenting Stress Index, Developmental Questionnaire, Impairment Rating Scale*) .
- 3. Parties Who May Disclose My Child’s and My Individual Health Information.** The researcher and the researcher’s staff may obtain my child’s and my individual health information from:
Indiana State University Psychology Clinic, 750 N 7th, Terre Haute, IN 47809
- 4. Parties Who May Receive or Use My Individual Health Information.** The individual health information disclosed by parties listed in item 3 and information disclosed by me during the course of the research may be received and used by the two directors of the ADHD Clinic: Liz O’Laughlin, Ph.D. and Alisha Ford, Ph.D. as well as research assistants.
- 5. Right to Refuse to Sign this Authorization.** I do not have to sign this Authorization. If I decide not to sign the Authorization, I may not be allowed to participate in this study or receive any research related treatment that is provided through the study. However, my decision not to sign this authorization will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.
- 6. Right to Revoke.** I can change my mind and withdraw this authorization at any time by sending a written notice to Liz O’Laughlin, Ph.D. to inform the researcher of my decision. If I withdraw this authorization, the researcher may only use and disclose the protected health information already collected for this research study. No further health information about me or my child will be collected by or disclosed to the researcher for this study.
- 7. Potential for Re-disclosure.** My individual health information and that of my child disclosed under this authorization may be subject to re-disclosure outside the research study and no longer protected. For example, researchers in other studies could use my and my child’s individual health information collected for this study without contacting me if they get approval from an Institutional Review Board (IRB) and agree to keep the information confidential.
- 7A.** Also, there are other laws that may require my or my child’s individual health information to be disclosed for public purposes. Examples include potential disclosures if required for mandated reporting of abuse or neglect, judicial proceedings, health oversight activities and public health measures.

This authorization does not have an expiration date.

I am the research participant or personal representative authorized to act on behalf of the participant.

I have read this information, and I will receive a copy of this authorization form after it is signed.

signature of research participant or research participant's
personal representative

date

printed name of research participant or research participant's
personal representative

description of personal representative's authority
to act behalf of the research participant

¹ HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.