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Are Adult ADHD Patients Good Informants of Their Symptoms? A Qualitative Literature Review of Concordance Between Clinician and Self-report ADHD Symptoms

Jessica Abrams, BA^a [Clinical Research Coordinator], Stephen V. Faraone, PhD^b [Director of Research], K. Yvonne Woodworth, BA^c [Assistant to Dr. Biederman], Thomas J. Spencer, MD^d [Associate Chief], Itai Biederman, MBA^e [Project Manager], Joseph Biederman, MD^f [Chief]

^aClinical and Research Programs in Pediatric Psychopharmacology and Adult ADHD, Massachusetts General Hospital, Boston, MA, United States

^bDepartment of Psychiatry, and Distinguished Professor of Neuroscience and Physiology, SUNY Upstate Medical University, Syracuse NY, USA; K.G. Jebsen Centre for Research on Neuropsychiatric Disorders, University of Bergen, Bergen, Norway

^cClinical and Research Programs in Pediatric Psychopharmacology and Adult ADHD, Massachusetts General Hospital Boston, MA, United States

^dClinical and Research Programs in Pediatric Psychopharmacology and Adult ADHD, Massachusetts General Hospital, Boston, MA, United States; Associate Professor of Psychiatry, Harvard Medical School

^eClinical and Research Programs in Pediatric Psychopharmacology and Adult ADHD, Massachusetts General Hospital, Boston, MA, United States

^fClinical and Research Programs in Pediatric Psychopharmacology and Adult ADHD and Director, The Alan and Lorraine Bressler Clinical and Research Program for Autism Spectrum Disorders, Massachusetts General Hospital, Boston, MA, United States; Professor of Psychiatry, Harvard Medical School

Abstract

To conduct a comprehensive review on the agreement between clinician-rated and self-reported attention-deficit/hyperactivity disorder (ADHD) symptoms in adults, the following terms were searched in PubMed: “ADHD self-concordance,” “Self-report AND ADHD AND Valid,” “(self-report) AND ADHD AND clinician,” and “(self-report) AND ADHD AND versus AND investigator.” Nine articles met our inclusion and exclusion criteria (English language, operationalized measures of clinician-rated and self-reported ADHD, and neither a review nor opinion article). Among the clinical studies, correlation coefficients were on average 0.69 for the total ADHD symptoms score. The epidemiological studies had an average kappa statistic of 0.58

Corresponding author: Joseph Biederman, MD, Department of Pediatric Psychopharmacology and Adult ADHD, Massachusetts General Hospital, 55 Fruit Street, Warren 705, Boston, MA 02114, [jbiederman@partners.org] Phone: (617) 726-1743.

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for ADHD diagnoses. The studies of adult relatives of youth with ADHD had an average correlation coefficient of 0.74 for the ADHD total symptoms score. Our review supports the informativeness of self-reported assessments of ADHD symptoms, which has important implications for management and monitoring of ADHD.

Keywords

Self-report; ADHD; symptoms; concordance

Introduction

Attention-deficit/hyperactivity disorder (ADHD) is a highly morbid neurobiological disorder (Faraone et al., 2015), and estimated to affect at least 5% of adults in the United States and the world (Kessler et al., 2006). While the validity of the clinician-based diagnosis of ADHD in adults has been well recognized (Barkley et al., 2010), questions remain as to whether adults with ADHD are good informants of their own symptoms. Surprisingly, limited information is available on the informativeness of self-reported ADHD symptoms.

Whether self-reported ADHD symptoms are informative has important clinical, scientific and public health implications. If informative, clinicians may be able to use self-reports to monitor patients' treatment and progress. Scientifically, informative self-reports may ease the burden of assessment procedures in clinical trials of ADHD treatments by allowing a portion of outcome measures to come from the self-reports. From the public health perspective, it can facilitate the screening of ADHD in community and primary care settings.

The main aim of this study was to investigate the informativeness of self-reports of ADHD symptoms in adults. To this end, we conducted a comprehensive literature search of the available literature examining the association between clinician-assessed symptoms of ADHD and patient self-reports. We hypothesized that self-reports would be informative in adults with ADHD. To the best of our knowledge this is the first comprehensive review of the literature on this important subject.

Methods

We conducted a comprehensive literature review on the topic of agreement between clinician and patient assessed symptoms of ADHD. We used the following search terms in PubMed: "ADHD self concordance," "Self-report AND ADHD AND Valid," "(self-report) AND ADHD AND clinician," and "(self-report) AND ADHD AND versus AND investigator." To be included in our review, we restricted the literature to studies that met the following criteria: (1) studies in the English language and (2) operationalized measures of clinician-rated and self-reported ADHD. In addition, review and opinion articles were excluded.

The following variables were extracted: (a) numbers of participants (b) sample source (clinical, epidemiological, assessment of relatives) (c) method of clinician assessment (d) method of self-assessment and (e) correlation coefficients (Pearson, Spearman, or Intraclass) or kappa statistics.

Results

The initial search identified 102 relevant articles. As shown in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram, articles were eliminated if they (1) did not operationalize ADHD, (2) contained a patient sample whose primary clinical concern was not ADHD, (3) did not report statistics comparing self-reported and clinician-assessed symptoms. This elimination process reduced the number of manuscripts to only five. The bibliographies of these five articles were searched for additional references, producing another three manuscripts that fit our a priori criteria. An additional article published after the original search identified one further article for inclusion. Thus, the final sample used in this review consisted of nine articles that met all our inclusion and exclusion criteria.

As shown in Table 1, of the nine articles included, two were epidemiological studies, five clinical studies, and two examined relatives of youth diagnosed with ADHD. To assess clinician-rated ADHD, four studies used semi-structured clinical interviews and seven used rating scales (two studies used both). The clinician rating scales included a variety of validated scales including the ADHD Rating scale (ADHD-RS) (DuPaul et al., 1998), the Conners Adult ADHD Rating Scale (CAARS) (investigator assessment) (Conners et al., 1999), the Wender-Reimherr Adult Attention Deficit Disorder Scale (WRAADDS) (Wender, 1995), and the Adult ADHD Investigator Symptom Rating Scale (AISRS) (Spencer et al., 2010).

To assess patient-reported ADHD, a variety of self-report scales were employed including the 31-item, 18-item, and 6-item Adult ADHD Self-Report Scale (ASRS) (Ustun et al., 2017; Kessler et al., 2005a; Kessler et al., 2005b), CAARS self-assessment (both English and German versions) (Christiansen et al., 2013; Conners et al., 1999), and a custom DSM-IV based rating scale (Kooij et al., 2005).

Clinical Studies:

Five of the studies examined agreement within a clinical setting; two in the context of an outpatient clinic (Adler et al., 2006; Morstedt et al., 2015), two as part of a clinical trial (Adler et al., 2008; Kooij et al., 2008), and one at both an outpatient ADHD clinic and primary care practice. In three of the studies, patients were not receiving pharmacological or behavioral therapy at the time of assessment and in one (Adler et al., 2006), most patients were receiving treatment. Silverstein et al. 2017 did not report on subjects' treatment status. Four of the five clinical studies had cross sectional assessments of agreement and one (Adler et al., 2008) collected both baseline and follow-up data. In three of the five studies, clinician and self-report rating scales were matched in that clinicians asked the same questions that patients completed in self-report measures. In Morstedt et al. 2015, they measured concordance between ADHD diagnosis based on DSM-V criteria self-ratings from the CAARS-S:L. In Silverstein et al. 2017, they examined the concordance of the 31-item ASRS (which includes an additional 13 items on executive function and emotional dyscontrol) with the clinician-administered 18-item AISRS. Morstedt et al. 2015 and Silverstein et al. 2017 had control groups of patients who did not meet the criteria for ADHD.

Epidemiological Studies:

Two studies assessed agreement between clinician and patient self-report in the context of epidemiologic studies assessing the prevalence of ADHD in the community (Kessler et al., 2005b; Kessler et al., 2007). Both studies were cross-sectional and investigated the agreement of the 6-item ASRS screener with clinician diagnoses based on the 18-item DSM-IV criteria. In addition, Kessler et al. 2005 assessed the concordance between the 18-item ASRS with clinician diagnoses.

Assessment of Relatives

Two articles investigated agreement between clinician and participant self-reports in relatives of children with ADHD (Belendiuk et al., 2007; Magnusson et al., 2006). In both studies, clinician diagnoses were determined by the Kiddie Schedule for Affective Disorders and Schizophrenia (KSADS) (modified version to determine present symptoms of ADHD in adults). In Magnusson et al., the self-report ADHD scale was based on the 18 DSM-IV behavioral criteria for ADHD while Belendiuk et al. relied on the CAARS, a 93-item questionnaire.

Correlation coefficients and kappa statistics were computed to determine the strength of the relationship between investigator-administered and self-rated assessments. To summarize the strength of clinician and patient agreement for each category of study (clinical, epidemiological, assessment of relatives) with consideration to the differing sample sizes, we calculated weighted averages of the reported correlation coefficients or kappa statistics. For the studies that provided a range of correlation coefficients, we used the median of the range as the value in the weighted average calculation. For the Adler et al., 2008 study, which did not provide a single correlation coefficient, we used the average of the baseline total symptoms intraclass correlation coefficient (ICC) and endpoint total symptoms ICC in the weighted average calculation. For Kooij et al. 2008, we used the mean of the Inattentive symptoms ICC and the Hyperactive symptoms ICC. For Silverstein et al., 2017, we used the average Spearman's ρ for the five scales/subscales reported. Overall, among the clinical studies, the correlation coefficients had a weighted average of 0.69 for the total ADHD symptoms score. The epidemiological studies had a weighted average kappa statistic of 0.58 for ADHD diagnoses. In the studies of adult relatives of youth with ADHD, the correlation coefficients had a weighted average of 0.74 for the ADHD total symptoms score.

Discussion

Our review of the extant literature identified eight studies evaluating agreement between clinician-assessed and patient self-reported symptoms of ADHD in various contexts: clinical settings, epidemiological studies, clinical trials, and assessment of relatives. Findings revealed a generally good agreement between clinician-assessed symptoms of ADHD and patient self-reports of the same symptoms supporting the hypothesis that patient self-reports are informative.

The high level of agreement between clinician and patient observed in clinical studies support the informativeness of self-report measures in both an outpatient setting as well as in

the context of clinical trials. The reviewed literature also shows that self-reports are useful for both new patients and existing patients.

The high agreement between clinician-assessed ADHD and the 6-item ASRS screener in epidemiological studies strongly suggest the 6-item screener is a valuable tool for screening subjects for the presence of ADHD in the community and in the primary care setting. In addition, the 31-item ASRS v.1.1 Expanded Symptom Checklist is useful for additionally identifying symptoms of emotional dysfunction and dyscontrol within ADHD. Likewise, the strong association identified in the studies that examined the informativeness of self-reports in relatives of probands with ADHD have important implications for the use of self-report measures in genetic and pedigree studies.

Our results need to be viewed in light of some methodological limitations. We were able to identify only nine studies that systematically addressed the informativeness of self-report measures. These studies reported on data using different assessment methodologies, therefore, we were not able to perform a meta-analysis. Despite the methodological variability, we found agreement between clinician and subject self-reports on symptoms of ADHD to be strong. Only one study assessed the longitudinal informativeness of patient self-reports throughout treatment. This information is particularly important during the process of long-term monitoring of patients on a medication regimen. This knowledge allows the treating clinician to remain confident that the patient-reported data on their symptomatic picture are accurate. More research is needed in this type of clinical sample, which is more ecologically valid since these patients reflect clinical realities. Other limitations pertain to some studies' differences in the questions between self-report and clinician-assessed symptoms, which makes it difficult to assess agreement when the questions asked differ. In addition, all but one study was cross sectional providing limited information on how agreement changes over time.

Conclusions

Despite these considerations, this comprehensive review of the literature strongly supports the informativeness of patients' self-report of ADHD symptoms in clinical, epidemiological and research settings.

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In 2017, Dr. Biederman is a consultant for Aevi Genomics, Akili, Guidepoint, Ironshore, Medgenics, and Piper Jaffray. He is on the scientific advisory board for Alcobra and Shire. He received honoraria from the MGH Psychiatry Academy for tuition-funded CME courses.

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Figure I:
PRISMA Diagram

Table 1:

Authors & Year	n	Sample Source	Method of Clinician Assessment	Method of Self Assessment	Main Findings & Comments
Clinical Setting					
Adler, Spencer et al. (2006)	60	Outpatient with both new and existing patients	ADHD-RS	ASRS (18-item)	There was a strong relationship between self-reported and clinician rated symptoms ($ICC = 0.84$).
Adler, Faraone, et al. (2008)	536	Double-blind clinical trial	CAARS (investigator assessment)	CAARS (self assessment)	Moderate to high agreement between self-report and clinician rated symptoms at baseline (Total sxs $ICC = 0.51$; Inatt= 0.45; Hyper= 0.65) and endpoint (Total sxs $ICC = 0.87$; Inatt=0.84; Hyper=0.87).
Kooij, Boonstra, et al. (2008)	120	New patients referred to outpatient setting to participate in research studies	Semistructured interview on childhood and persisting ADHD symptoms (Kooij, 2003)	DSM-IV based ADHD Rating Scale (Kooij et al., 2005; Kooij et al., 2004)	Patient-investigator agreement was moderate (Inattn $ICC = 0.35$ and Hyper= 0.44).
Morstedt, Corbisiero, et al. (2015)	114	Outpatient	Diagnoses based on the DSM-V	CAARS-S: L	Moderate correlation ($\rho = 0.53$) between patient reported and investigator rated symptoms. No information provided regarding response to treatment.
Silverstein, Faraone, et al. (2017)	299	1) Referred sample from outpatient ADHD program and 2) PCP practice	ASRS	ASRS v.1.1 Expanded Symptom Checklist (31-item)	High correlation between ASRS v.1.1 and AISRS (Spearman's ρ : Total 18-item score = 0.89, Inattentive subscale= 0.86, Hyperactivity subscale=0.85, Emotional dyscontrol subscale = 0.79, and Executive dysfunction subscale = 0.90)
Epidemiological					
Kessler, Adler et al. (2005)	154	Subscribers to a large health plan in the US	ADHD RS-IV + Semistructured clinical interview	ASRS (18-item) & ASRS (6-item)	Agreement between self-reported and investigator rated symptoms was moderate for the 18-item ASRS ($k = 0.58$) and high for the 6-item ASRS ($k = 0.76$)
Kessler, Adler et al. (2007)	218	Nationally representative household survey	ADHD RS-IV & Semistructured clinical interview for recent DSM-IV adult ADHD	ASRS (6-item)	6-item ASRS had moderate concordance with investigator rated symptoms (6-item $k = 0.52$)
Assessment of Relatives					
Magnússon, Smari, et al. (2006)	126	Research sample of relatives of youth with ADHD	K-SADS	Based on the 18 DSM-IV criteria for ADHD	There was a strong correlation between self-reported and investigator assessed symptoms for both men and women (correlation coefficients range from 0.72-0.83)
Belendiuk, Clarke, et al. (2007)	69	Research sample of mothers with ADHD of children who also had ADHD	K-SADS	CAARS	There was a moderate to strong correlation ($r = 0.61-0.74$) between self-reported and investigator assessed symptoms

Intraclass correlation coefficient