



Assessment of stigma associated with attention-deficit hyperactivity disorder: Psychometric evaluation of the ADHD Stigma Questionnaire

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ABSTRACT

This study evaluated the psychometric properties of the attention deficit hyperactivity disorder (ADHD) Stigma Questionnaire (ASQ) among a community sample of 301 adolescents ages 11–19 years at high ($n = 192$) and low risks ($n = 109$) for ADHD. Study subjects were drawn from a cohort study assessing ADHD detection and service use. The 26-item ASQ demonstrated good internal consistency. Confirmatory factor analysis using random parceling supported a three-factor structure with highly correlated subscales of disclosure concerns, negative self image, and concern with public attitudes, and a Schmid–Leiman analysis supported an overall stigma factor. Test–retest stability was assessed after two weeks ($n = 45$) and found to be adequate for all three subscales. Construct validity was supported by relationships with related constructs, including clinical maladjustment, depression, self-esteem, and emotional symptoms, and the absence of a relationship with school maladjustment. Findings indicate that the ASQ has acceptable psychometric properties in a large community sample of adolescents, some of whom met Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria for ADHD.

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1. Introduction

The Surgeon General identifies stigma surrounding mental illness and its treatment as a potent barrier to help-seeking (U.S. Department of Health and Human Services, 1999). A review of population-based studies highlighted the extent to which stigma surrounds mental illness (Angermeyer and Dietrich, 2006); however, this review also demonstrates that stigma associated with many mental illnesses has been understudied, since most stigma research has focused on depression, schizophrenia, and bipolar disorder. Furthermore, stigma exists at various levels; persons with mental illness not only encounter public stigma, expressed as prejudice and discrimination, but may also suffer from self-stigma, through acceptance of the prejudices that surround them (Ruesch et al., 2005), and their families or intimates may experience courtesy stigma based on kinship or affiliation with the stigmatized person (Goffman, 1963).

A recent study on stigma associated with child mental health conditions identified substantial stigma concerns among participating adults from a nationally representative sample (Pescosolido, 2007). Moreover, when responding to vignettes depicting several stigmatizing conditions including attention deficit hyperactivity disorder (ADHD), depression, “normal troubles” and physical illness, a gradient of rejection of these groups was reported such that individuals with

ADHD and depression were rejected the most and those with “normal troubles” and physical illness were rejected the least (Martin et al., 2007). These stigmatizing reactions were higher toward adolescents than children. When presented with similar vignettes, children and adolescents (ages 8–18) participating in a national survey were more likely to make negative attributions about peers with ADHD and depression than peers with asthma, particularly with respect to the likelihood of antisocial behavior and violence (Walker et al., 2008). In addition, participants reported a desire to maintain social distance from peers with ADHD or depression. Social aversion toward people with ADHD was also endorsed by an older sample (i.e., college undergraduates) asked to rate the social desirability of targets with ADHD, minor medical problems, and “no appreciable weakness” (Canu et al., 2008). Because concerns about stigma may be particularly pertinent for adolescents who are developmentally sensitive about others' opinions and seek peer approval, their stigma perceptions may prevent help-seeking or prompt treatment discontinuation.

In light of these reports, it is surprising that there are currently no specific assessment instruments available to evaluate stigma associated with ADHD. For this study, we hypothesized that assessment tools originally developed to measure relevant stigma constructs in other health conditions might lend themselves to adaptation. In particular, the utility and validity of an instrument designed to assess stigma associated with human immunodeficiency virus (HIV) has been established (Berger et al., 2001), and three of its four subscales address domains potentially relevant to ADHD, namely disclosure concerns, negative self-image, and negative public perceptions toward

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Table 1
Participant characteristics.

	Overall sample (n = 301)	High risk at baseline (n = 192)	Low risk at baseline (n = 109)
Age			
Baseline: mean (S.D.)	7.8 (1.7)	7.8 (1.7)	7.9 (1.8)
Range in years	5–11	5–11	5–11
Follow-up: mean (S.D.)	15.6 (1.8)	15.0 (1.7)	16.7 (1.3)
Range in years	11.6–19.4	11.6–18.3	14–19.4
Disclosed history of ADHD problems (at follow-up)			
Parent – yes	176 (58%)	158 (82%)	18 (16.5%)
Child – yes	112 (37%)	93 (48%)	19 (17%)
Met DSM-IV criteria for ADHD ^a	102 (34%)	102 (53%)	0
SNAP-IV ARI^b (baseline)			
Inatten: mean (S.D.; range)	1.0 (0.9; 0–3)	1.4 (0.8; 0–3)	0.3 (0.3; 0–1.2)
Hyp/Imp: mean (S.D.; range)	0.9 (0.8; 0–3)	1.3 (0.8; 0–3)	0.3 (0.3; 0–1.7)
Vanderbilt ARI (follow-up)^c			
Inattention: mean (S.D.; range)	0.7 (0.7; 0–3)	1.4 (0.8; 0–3)	0.5 (0.5; 0–2.9)
Hyp/Imp: mean (S.D.; range)	1.1 (0.8; 0–3)	0.9 (0.8; 0–3)	0.2 (0.4; 0–2.4)
Gender – male			
	130 (43%)	88 (46%)	42 (38%)
Race			
Black	97 (32%)	70 (36%)	27 (25%)
White	204 (68%)	122 (64%)	82 (75%)
Lunch			
Free/subsidized	156 (52%)	110 (57%)	46 (42%)
Full pay	145 (48%)	82 (43%)	63 (58%)

^a These data are missing for four participants.

^b ARI = Average rating per item.

^c These data are missing for three participants.

affected persons. The HIV Stigma Scale is designed for completion by persons with HIV who are willing to acknowledge their membership in a stigmatized group; thus it inquires about personal experiences, yielding a fourth factor, personalized stigma. This first-person approach precludes the assessment of stigma perceptions with respondents who do not have or do not wish to acknowledge personal experience of the stigmatized condition. In order to broaden the usefulness of an ADHD stigma assessment tool, we deemed it desirable to eliminate the need to admit personal ADHD experience and instead focus on the assessment of public stigma perceptions. The aim of this study is to describe the design of an ADHD Stigma Questionnaire (ASQ) through adaptation of the HIV Stigma Scale, and to examine its psychometric properties. We addressed the following questions: (1) Does confirmatory factor analysis of the ASQ corroborate the hypothesized three-factor structure adapted from the HIV Stigma Scale, omitting the personalized stigma factor? (2) Are the three factors sufficiently represented by an overall stigma factor? (3) Does the ASQ demonstrate acceptable internal consistency? (4) What is the retest stability of the ASQ? (5) Does the ASQ demonstrate adequate construct validity, as assessed by relationships with related constructs, including clinical maladjustment, depression, self-esteem, and emotional symptoms?

2. Methods

2.1. Participants and procedures

Participants were drawn from a longitudinal study designed to produce a representative community sample of students at high and low risks for ADHD and followed over four study waves between 1998 and 2008. Details of the study design are described elsewhere (Bussing et al., 2003); this paper uses data from the initial assessment (i.e., baseline, ADHD risk status determined) and wave 4 (i.e., follow-up, ADHD stigma perceptions assessed).

Baseline parent telephone interviews included inquiries into the child's health status, parental knowledge and attitudes about ADHD, a structured ADHD detection and service use assessment, and Swanson, Nolan and Pelham Parent Rating Scale, Version IV (SNAP-IV) behavior ratings (Swanson, 1992; Bussing et al., 2008). Based on baseline interview results, children were classified as at "high risk" for ADHD if any of the following applied: (a) current or past ADHD diagnosis or treatment; (b) parents or teachers had expressed concern about a possible ADHD diagnosis; or (c) parents or teachers had expressed other behavioral concerns (not specifically ADHD), and the child was rated in the elevated range (>1.5 S.D.) on the SNAP-IV parent rating scale. Children without previous ADHD diagnosis, treatment or concern and with normative SNAP-IV scores were classified as "low risk."

Follow-up parent and child interviews with 192 of the high-risk and 109 of the low-risk participants were conducted on average 7.8 years later. In-person interviews were conducted simultaneously with parents and adolescents. Parents were interviewed by graduate student research assistants, and adolescents were interviewed by undergraduate research assistants. Interviewers were trained by the study coordinator and were videotaped while conducting practice interviews until acceptable inter-rater reliability was established. Interviewers also completed human subjects training prior to conducting interviews. The study was approved by the University Institutional Review Board and the school district research office. Informed consent and/or assent was obtained from all participants.

The sample for the current study consisted of 301 children and adolescents (171 females and 130 males). Of these, 192 had been classified as high risk for ADHD and 109 as low risk based on findings of the baseline screening interviews. High-risk children ranged in age from 11 to 18 years of age with a mean of 15.0 years (S.D. = 1.7), and children in the low-risk group were between 14 and 19 years of age, with a mean of 16.7 years (S.D. = 1.3). Among the high-risk cohort 53.1% met Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) criteria for ADHD at interviews conducted either at wave 2, using the Diagnostic Interview Schedule for Children, Version 4.0 (Shaffer et al., 2000), or at wave 4, using the Kiddie Schedule for Affective Disorders and Schizophrenia, Present and Lifetime Version (K-SADS-PL) (Kaufman and Schweder, 2003); none of the low-risk cohort met the ADHD criteria on the K-SADS-PL at wave 4. Also at wave 4, we determined whether a child was considered to have a history of ADHD problems from the family's perspective, by the parent's answer to the question, "Has your child ever had a problem with attention, impulsivity, hyperactivity or behavior in the past?" which was elicited as part of the in-person interview. See Table 1 for further description of study participants.

2.2. Adaptation of the ASQ

Adolescents completed the ADHD Stigma Questionnaire (ASQ), a 26-item adaptation of the 40-item HIV Stigma Scale. The HIV Stigma Scale was developed by Berger et al. (2001) in order to measure stigma perceptions of individuals with HIV. Items were based on the literature on stigma and the psychosocial aspects of having HIV. Two rounds of content review were performed and the surviving items were distributed through HIV-related organizations throughout the United States. Of 318 adults who responded, 19% were women, 21% African American, and 8% Hispanic. The results of exploratory factor analysis indicated four factors: personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes. This four-factor structure explained 46% of variance. Extraction of a single higher-order factor provided evidence of an overall stigma factor. Relationships with the related constructs self-esteem, depression, social support, and social conflict provided support for construct validity. Internal consistency reliability was excellent, since coefficient alphas were between 0.90 and 0.93 for the subscales and 0.96 for the overall stigma factor. Test-retest correlations between the original questionnaire and a follow-up questionnaire sent 2–3 weeks later supported the temporal stability of the subscales and the overall instrument.

The adaptation process to develop the ASQ consisted of the following steps: First, items from the HIV Stigma Scale were re-worded for use in an ADHD population, and these items were subjected to review by eight clinicians and educators in the fields of psychiatry, clinical psychology, social work, education, school psychology, counseling and statistics. Reviewers were asked to determine item relevance for assessing perceived stigma associated with a diagnosis of ADHD. Based on this review process items with poor conceptual fit (i.e., two questions referring to infectious etiology) were eliminated. Furthermore, because the ASQ was intended for use with teachers and non-clinical populations (in addition to individuals diagnosed with ADHD), the language was transformed from the first person to the third person (e.g., "I work hard to keep my ADHD a secret" was changed to "People with ADHD work hard to keep it a secret"). In other words, the focus was shifted to perceptions of public stigma, so participants would not be required to have personal ADHD experiences or reveal their personal ADHD histories. As a result of this transformation, four items were removed from the original scale because the wording in third person became too convoluted (e.g., "Some people close to a person with ADHD are afraid others will reject them if it becomes known that person has ADHD"). Lastly, eight items with low item-total correlations in total and subscale analyses were also eliminated, resulting in a 26-item instrument. As in the original scale, each stigma item was rated on a 4-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = agree, and 4 = strongly agree) with higher scores indicating higher stigma perceptions. A copy of the ASQ is shown in Appendix A.

2.3. Additional measures

2.3.1. Swanson, Nolan and Pelham, Version IV (SNAP-IV)

At wave 1 severity of ADHD problems was assessed using the parent report form of a standardized screening measure, the SNAP-IV checklist. The SNAP-IV is a rating scale consisting of operationalized DSM-IV criteria for ADHD. Internal consistency of the original SNAP-IV was reportedly high (>0.9 for all symptom clusters), and 2-week test-retest reliability was 0.7 for inattention items, 0.8 for impulsivity items, and 0.9 for hyperactivity items. Norms have been established for the SNAP-IV for elementary-aged children for average rating per item (ARI) (Swanson, 1992). Scores falling 2 S.D. above the norm indicate severe symptom levels. Screening and diagnostic utility have also been established (Bussing et al., 2008).

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