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ORIGINAL ARTICLE

Internalized stigma, anticipated discrimination and perceived public stigma in adults with ADHD

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Abstract

The objective of this study is to assess internalized stigma, perceived public stigma, anticipated discrimination and their associations with demographic, psychiatric and psychosocial characteristics in adult ADHD. Stigmatization was assessed with the *Internalized Stigma of Mental Illness Scale*, *the Questionnaire on Anticipated Discrimination and the Questionnaire on Public Stereotypes Perceived by Adults with ADHD*. The sample comprised $n = 104$ adults with ADHD, of whom $n = 24$ (23.3%) reported high internalized stigma, $n = 92$ (88.5%) anticipated discrimination in daily life and $n = 70$ (69.3%) perceived public stigma. Internalized stigma and/or anticipated discrimination correlated with ADHD symptoms, psychological distress, self-esteem, functional impairment and quality of life and was associated with ADHD family history and employment status. Most frequently perceived stereotypes were doubts about the validity of ADHD as a mental disorder. Internalized stigma and anticipated discrimination are highly prevalent in adult ADHD and correlate with the burden of disease. ADHD is associated with characteristic public stereotypes, which are distinct from stereotypes related to other mental disorders. Stigmatization should be considered in the clinical management of adult ADHD and evaluated further in future studies.

Keywords ADHD · Stigma · Discrimination · Internalized stigma · Psychosocial

Introduction

The World Health Organization recognizes stigmatization of mental disorders as "the most important barrier" to professional mental health care (World Health Organization 2001, p. 98). Stigmatization is a multifaceted phenomenon comprising a variety of distinct, but related mind sets and behavior including public stigma and public stereotypes, discrimination, marginalization and self-stigmatization (Corrigan 2005, p. 16). Public stigma of mental disorders refers to the attitudes and beliefs of a community or general public to negative attributes toward persons with mental health problems. Common stigmatizing public stereotypes associated with mental disorder are dangerousness, character weakness or incompetence and mostly apply to a generalized, not disease-specific conceptualization of mental disorders (Link and Phelan 2001). Evaluation of disorder-specific stigmatizing public stereotypes is still in its beginnings. Most stigma research was conducted on psychotic disorders, depression or a generalized category of mental illness to date.

In daily living, individuals with mental disorders often recognize related public stigmatization and discrimination on a daily and repeated basis. The integration of those negative experiences in the definition of identity can result in self-devaluation and self-stigmatization, which is a characteristic and well-known phenomenon in mental disorders. It is also often referred to as "second or hidden disorder," as it adds additional burden of disease including impaired psychosocial functioning, withdrawal from society and social isolation (Finzen 2001; Krajewski et al. 2013; Sibitz et al. 2013). The mediating and resilience mechanisms, which explain why discrimination and public stigma are in some individuals associated with self-stigmatization but in

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others not, are far from clear and probably heterogeneous. First studies point out that self-stigmatization is related to subjective awareness of public stereotypes and anticipation of being discriminated due to a mental disorder and thus to the extent to which individuals are worried about negative reactions and devaluations from others if they reveal their mental illness or if others become aware (Livingston and Boyd 2010; Corrigan and Rao 2012; Drapalski et al. 2013).

In social contexts, some of the characterizing symptoms of attention-deficit/hyperactivity disorder (ADHD) may be perceived as unreliability, unpredictability, disinterest in others, impoliteness, character weakness or emotional immaturity. In mass media, critical reports about stimulant treatment of ADHD, doubts about its neurobiological etiology or even diagnostic validity are repeatedly published. These phenomena may increase the risk for stigmatization and stigmatizing stereotypes in individuals with ADHD. On the basis of a literature review of 38 studies investigating stigma in children and adults with ADHD, Mueller et al. 2012 conclude that the stigma associated with ADHD is an underestimated risk factor for negative outcome and affects treatment adherence and efficacy, symptom severity, life satisfaction, and mental well-being of individuals with ADHD. However, most published studies have examined facets of stigmatization in children and youth with ADHD. Research on the stigma of adults with ADHD is still scarce and focuses on public stigma (Fuermaier et al. 2012; Mueller et al. 2012; Lebowitz 2016).

So far and to the best of our knowledge, no quantitative studies on subjective stigmatization experiences have been carried out in adults with ADHD. The aim of this study is to assess ADHD-related stigmatization from the subjective perspective of adults with ADHD. It is the first study, which quantitatively assesses the subjective stigma dimensions internalized stigma, perceived public stigma and anticipated discrimination in adults with ADHD as well as their association with demographic and clinical parameters, psychosocial functioning and health-related quality of life.

Methods

Recruitment and sample

The study was approved by the Medical Ethics Committee II of the Medical Faculty of Mannheim, University Heidelberg, Germany. Informed consent was obtained from all individual participants included in the study. Data were collected between April 2015 and May 2016. The sample was recruited from adult ADHD self-help groups via cooperation with the umbrella organization of German ADHD self-help groups "ADHS Deutschland e. V.," at the Adult ADHD Outpatient Clinics at the Central Institute of Mental Health, Mannheim, Germany (CIMH) and at the Adult ADHD Inpatient Program at the AHG Clinics for Psychosomatic Medicine, Bad Duerkheim, Germany (AHG Clinics). We choose different recruitment sites from clinical and non-clinical settings to prevent recruitment bias and obtain a heterogeneous sample of adults with ADHD. Inclusion criteria were: age between 18 and 65 years, clinical diagnosis of ADHD, sufficiently fluent in German to provide written informed consent and understand the questionnaires, ADHD self-rating questionnaire ≥ 15 (Rösler et al. 2004).

Assessment instruments

Sociodemographic questionnaire

Sociodemographic characteristics and information about the clinical history were assessed with a self-designed questionnaire.

Stigma variables

Internalized stigma Internalized stigma was assessed with the validated German version of the Internalized Stigma of Mental Illness Scale (ISMI; Boyd Ritsher et al. 2003; Sibitz et al. 2013). ISMI is a widely used instrument in stigma research with well-established psychometric properties. In international validation studies, internal consistency was .83 to .94 and test–retest reliability was .62 to .92 (Boyd Ritsher et al. 2003; Boyd et al. 2014). In the German validation study of ISMI, internal consistency was .92 and test–retest reliability was .71 (Sibitz et al. 2013). ISMI consists of 29 items, which are self-rated on a four-point Likert scale (1: strongly disagree to 4: strongly agree). It comprises the subscales stereotype endorsement, which assesses individuals' commitment to general stereotypes about mental illness; alienation, which assesses the commitment to not being a fully functioning, valuable member of society; discrimination experiences, which assesses if individuals encounter discrimination; and social withdrawal, which assesses if individuals are marginalized due to mental illness. It further contains the subscale stigma resistance, which assesses the individual's resilience to stigmatization. Total and subscale ISMI scores range from 1 to 4; "low to medium severity of internalized stigma" is indicated by total score ≤ 2.5, "high severity of internalized stigma" by a total score > 2.5 (Sibitz et al. 2013; Boyd et al. 2014). The subscale stigma resistance is not included in the calculation of the total ISMI score, but considered as a separate, distinct construct (Boyd Ritsher et al. 2003; Sibitz et al. 2013; Firmin et al. 2016).

Anticipated discrimination Anticipated discrimination was assessed with the German version of the Questionnaire on Anticipated Discrimination (QUAD; Gabbidon et al. 2013).

QUAD assesses if an individual expects to be treated unfairly when he or she reveals his/her mental disorder across a range of contexts including employment, education, dating or relationships. QUAD comprises 14 items, which are rated on a four-point Likert scale (0: I strongly disagree to 3: I strongly agree). Items scored 2 or 3 (agree/strongly agree) are indicative for expected discrimination; a count score of items scored 2 or 3 (agree/strongly agree) is calculated to assess the total number of daily life situations in which discrimination is expected. Total count score ranges from 0 to 14. Internal consistency of the original QUAD is .86 to .88, retest reliability is .81 (Gabbidon et al. 2013). For our study, the original English QUAD version was translated to German, back translated to English and approved by the authors of the original QUAD version.

Perceived public stereotypes Perceived public stereotypes were assessed with an adapted version of the Questionnaire on Stigmatizing Attitudes toward Adults with ADHD (QPS; Fuermaier et al. 2012). QPS comprises 37 items, which are self-rated on a six-point Likert scale (−3: strongly disagree to +3: strongly agree) and the subscales: Reliability and Social Functioning, Malingering and Misuse of Medication, Ability to Take Responsibility, Norm-Violating and Externalizing Behavior, Consequences of Diagnostic Disclosure and Etiology. The original questionnaire had high internal consistency of .91. However, as it was designed to measure public stigma and common stereotypes toward adults with ADHD in healthy controls, whereas we wanted to assess how adults with ADHD perceive others' stereotypes related to their ADHD, we used an adapted version with rephrased items from "I" to "other." Wording was now f. ex.: "Other people [instead of I] believe that adults with ADHD misuse their medication." Though there are so far no established cut-offs, for explorative data analysis we defined a QPS total or subscale score >0 as subjective perception of public stigma over the total scale or subscale, respectively.

ADHD, associated symptoms and psychosocial impairment

ADHD self-rating scale ADHD symptoms were assessed according to DSM-IV criteria with the German ADHD self-rating scale (ADHS-Selbstbeurteilungsskala, ADHD-SR; Rösler et al. 2004). ADHD-SR is widely used in Germany for clinical and scientific purposes. Retest reliability ranges between .72 and .89, and internal consistency ranges between .72 and .90. The diagnostic cut-off for ADHD of ≥ 15 used for this study provides a specificity of 75% and a sensitivity of 77%.

Brief Symptom Inventory 18 Associated psychiatric symptoms and overall psychological distress were assessed with the German version of the Brief Symptom Inventory 18 (BSI-18; Franke et al. 2017), which is widely used for clinical and scientific purposes. BSI-18 comprises the subscales Somatization, Depression, Anxiety and the Global Severity Index (GSI). Each item is rated on a five-point Likert scale, subscale scores range from 0 to 24 and GSI score from 0 to 72. Internal consistency of the German BSI-18 ranges from .84 to .93, reliability from .84 to .91 (Franke et al. 2011, 2017). GSI scores indicating clinically relevant psychological distress are ≥ 10 for men and ≥ 13 for women (Zabora et al. 2001).

Rosenberg Self-Esteem Scale Self-esteem was assessed with the German version of the Rosenberg Self-Esteem Scale (RSE; Collani and Herzberg 2003). In a German general population sample, internal consistency and reliability were .88 (Ferring and Filipp 1996; Roth et al. 2008). Maximum attainable sum score is 30, and a sum score <15 indicates low self-esteem.

Weiss Functional Impairment Rating Scale Functional impairment was assessed with the German version of the Weiss Functional Impairment Rating Scale Self-Report (WFIRS; Weiss and CADDRA 2011; Retz et al. unpublished). WFIRS assesses functional impairment in different life domains including family, work, school, daily activities and risk-taking behavior. Items are self-rated on a four-point Likert scale (0: not at all to 3: very much), and mean WFIRS total score ranges from 0 to 3. No cut-off scores are yet provided.

Quality of Life Satisfaction and Enjoyment Questionnaire-Short Form Quality of life was assessed with the Quality of Life Satisfaction and Enjoyment Questionnaire-Short Form (Q-LES-Q-SF), which is among the most frequently used outcome measures in psychiatry research (Endicott et al. 1993). Internal consistency of the English version of Q-LES-Q-SF was 0.9 and test–retest coefficients 0.93 (Mick et al. 2008; Stevanovic 2011). The total score ranges from 14 to 70, with higher scores indicating higher quality of life, and no cut-off scores are provided.

Data handling and statistical analysis

Statistical tests were performed using SPSS version 23.0. Descriptive summary statistics were calculated for demographic, clinical, psychiatric, psychosocial and stigma variables. Missing data for questionnaires were handled according to manual recommendations. If manuals did not indicate how to deal with missing values, the individual's mean was imputed for missing items for all cases with at least 80% of items present (Downey and King 1998; Shrive et al. 2006). Cases with less than 80% of items present were excluded from analysis via pairwise deletion. We calculated

Pearson's correlations between stigma questionnaires (ISMI, QUAD, QPS) and continuously distributed psychosocial and clinical variables (RSE, Q-LES-Q-SF, BSI-18, ADHD-SR, WFIRS). Correlations were indicated as small ($r \geq 0.1$), medium ($r \geq 0.3$) and large ($r \geq 0.5$) according to Cohen's convention (Cohen 1988). Associations between stigma variables and categorical demographic and clinical variables were explored by analysis of variance (ANOVA) with stigma measures as dependent and clinical and psychosocial parameters as independent variables. In case of significant associations ($p < 0.05$), post hoc tests with pairwise comparisons were calculated.

Results

Sample recruitment

We asked $n = 252$ adults with ADHD for participation via mail or personal contact, and $n = 109$ data sets (43.3%) were returned. All participants, who were recruited from CIMH Adult ADHD Outpatient Clinics and from the ADHD Inpatient Program at AHG Clinics, were clinically diagnosed with ADHD according to DSM-V-criteria by experienced psychiatrists (E. S., B. A., P. D.). All participants, who were recruited from ADHD self-help groups, reported to be diagnosed with ADHD by their local psychiatrists. Five participants, who reported only self-suspected, but not clinically diagnosed ADHD, were excluded from statistical analysis. The final sample consisted of $n = 104$ adults with clinically diagnosed ADHD. Fifty-seven (54.8%) participants were recruited from CIMH, $n = 25$ (24.0%) from AHG Clinics and $n = 22$ (21.2%) from ADHD self-help groups. The three groups were not mutually exclusive, as $n = 15$ of the participants from CIMH or AHG Clinics also participated in ADHD self-help groups. Altogether, $n = 37$ (35.6%) participants were currently participating in ADHD self-help groups.

Demographic characteristics

Mean age of participants was 41.8 (± 11.2) years, $n = 57$ (54.8%) participants were female, $n = 47$ (45.2%) were male, $n = 66$ (63.5%) were currently living in a partnership or were married, $n = 38$ (36.5%) were single, divorced or widowed, $n = 56$ (53.8%) had children, $n = 85$ (81.7%) had graduated with university entrance qualification, university of applied sciences entrance qualification or intermediate secondary school certificate, $n = 19$ (18.3%) had a certificate of secondary education, $n = 67$ (65.0%) had completed vocational training, $n = 35$ (34.0%) had graduated from university or university of applied sciences, $n = 1$ (1%) had not completed any vocational training, $n = 66$ (65.4%) currently worked full or part time, $n = 7$ (6.9%) attended vocational training, $n = 16$ (15.8%) were retired or homemakers, and $n = 12$ (11.9%) were currently unemployed.

Clinical characteristics

The sample included participants at every stage of treatment including newly diagnosed patients with ADHD and patients being diagnosed and treated for years. Mean time since first diagnosis of ADHD was 6.3 (± 5.4) years. Mean ADHD-SR score was 29.3 (± 9.5). Thirty-nine participants (37.5%) reported a positive family history for ADHD. Sixty-seven (64.4%) participants were treated pharmacologically, $n = 48$ (46.2%) received immediate, sustained or extended release methylphenidate, $n = 8$ (7.7%) non-stimulant ADHD medications (bupropion or atomoxetine) and $n = 11$ (10.6%) received a combination of methylphenidate and non-stimulants.

Mean BSI-18 GSI score was 18.8 (± 12). Seventy-one (68.3%) scored BSI-18 GSI Score above the cut-off for relevant psychological distress (women: 13, men: 10). Mean somatization score was 4.1 (± 3.5), mean depression score was 7.7 (± 6.0), and mean anxiety was 7.0 (± 4.6). Mean RSE-score was 17.0 (± 6.6), $n = 46$ (37.5%) scored equal or below the cut-off for reduced self-esteem (< 15). Mean WFIRS score was 1.1 (± 0.4). Mean Q-LES-Q-SF raw score was 42.6 (± 9.2). Though no cut-offs are provided for Q-LES-Q-SF, this is below the average score of 56.8 (± 6.1) reported for healthy controls (Mick et al. 2008). Please see Table 1 for details.

Internalized stigma

Total ISMI score was 2.1 (± 0.5). Twenty-four participants (23.3%) reported high internalized stigma (ISMI total score > 2.5), $n = 441$ (39.8%) reported high levels of alienation, $n = 34$ (33.7%) reported high levels of discrimination experiences, and $n = 31$ (30.4%) reported high levels of social withdrawal. Only $n = 2$ participants (1.9%) reported high levels of stereotype endorsement and $n = 72$ (69.2%) reported high stigma resistance. For details please see Table 2.

Anticipated discrimination

Ninety-two (88.5%) participants reported anticipated discrimination (QUAD score ≥ 2) in one or more aspects of daily life. Mean number of daily living situations, in which participants anticipated discrimination, was 6.0 (± 3.8) out of 14.

Anticipated discrimination was highly prevalent in the occupational, educational and institutional services context. Work: $n = 74$ (71.8%) participants anticipated discrimination from their employer, $n = 68$ (66%) from their work

Table 1 Clinical symptoms, psychosocial functioning and quality of life

	n	Mean	SD	Median	Max.	Min.
ADHD-SR	103	29.3	9.5	28.0	50.0	15.0
BSI-18 (GSI)	104	18.8	12.0	16.0	49.0	.0
BSI-18 soma	104	4.1	3.5	4.0	15.0	.0
BSI-18 depr	104	7.7	6.0	6.0	21.0	.0
BSI-18 anx	104	7.0	4.6	6.0	21.0	.0
RSE	104	17.0	6.6	16.5	30.0	2.0
WFIRS	86	1.1	.4	1.0	2.3	.3
Q-LES-Q-SF	102	42.6	9.2	42.0	67.0	25.0

ADHD-SR ADHD self-rating scale, *BSI-18 (GSI)* Brief Symptom Inventory 18 (Global Severity Index), *BSI-18 soma* BSI-18 subscale somatization, *BSI-18 depr* BSI-18 subscale depression, *BSI-18 anx* BSI-18 subscale anxiety, *RSE* Rosenberg Self-Esteem Scale, *WFIRS* Weiss Functional Impairment Rating Scale Self-Report, *Q-LES-Q-SF* Quality of Life Satisfaction and Enjoyment Questionnaire

Table 2 Internalized stigma

	n	Mean	SD	Median	Max.	Min.	> 2.5 (*n*, %)
ISMI total	103	2.1	.5	2.1	3.3	1.0	24, 23.3
ISMI stigma resistance	104	2.8	.4	2.8	4.0	1.8	72, 69.2
ISMI alienation	103	2.4	.7	2.5	4.0	1.0	41, 39.8
ISMI discrimination experiences	101	2.2	.7	2.2	3.8	1.0	34, 33.7
ISMI social withdrawal	102	2.1	.7	2.0	4.0	1.0	31, 30.4
ISMI stereotype endorsement	102	1.6	.4	1.6	2.9	1.0	2, 1.9

ISMI total Internalized Stigma of Mental Illness Scale; > 2.5 (*n*, %): number and percentage of participants with ISMI or subscale means > 2.5, indicating high internalized stigma

colleagues and $n = 57$ (55.9%) from public benefit officials (e.g., the Jobcenter); education: $n = 55$ (53.4%) anticipated discrimination from teachers or professors. Nineteen (18.3%) participants anticipated discrimination from medical health care staff.

Somewhat less pronounced but still frequent participants anticipated discrimination in private interpersonal relationships. Fifty-five (52.9%) anticipated discrimination from their adult neighbors, $n = 49$ (47.6%) from children or teenagers in their neighborhood and $n = 45$ (43.4%) when dating someone. In close social relationships, $n = 26$ (25.2%) anticipated discrimination from family members and $n = 20$ (19.4%) from friends (please see Fig. 1).

Perceived public stereotypes

Mean QPS score was 0.4 (± 0.8), indicating slight perception of public stigma on the group level. Seventy (69.3%) participants reported perception of public stereotypes (QPS total score > 0). Seventy-seven participants (74.0%) reported perception of public stereotypes related to the QPS subscale "Ability to Take Responsibility," $n = 68$ (66.0%) related to "Norm-Violating and Externalizing Behavior," $n = 68$ (65.4%) to "Consequences of Diagnostic Disclosure" and $n = 59$ (56.7%) to "Malingering and Misuse of Medication." Most frequently perceived single public stereotypes were: "ADHD is a childhood disorder not seen in adults" (88.5%), "Adults with ADHD act without thinking" (87.3%), "ADHD is caused by bad parenthood" (82.4%), "ADHD is invented by drug companies" (76.0%), "ADHD is caused by extensive exposure to video games or TV shows" (73.3%), "Adults with ADHD simulate their symptoms" (72.8%). For details, please see Table 3.

Correlations of stigma measures, psychosocial characteristics, clinical symptoms, quality of life and psychosocial functioning

We found medium to large correlations between all assessed stigma measures: Internalized stigma (ISMI) and perceived public stigma (QPS) ($r = .33$, $p < .001$); ISMI and anticipated discrimination (QUAD) ($r = .48$, $p < .001$); QUAD and QPS ($r = .51$, $p < .001$).

We found medium to large correlations between internalized stigma, clinical symptoms, psychosocial functioning and quality of life: ISMI and ADHD symptoms (ADHD-SR) ($r = .46$, $p < .001$); ISMI and associated psychiatric symptoms (GSI BSI-18) ($r = .50$, $p < .001$); ISMI and functional impairment (WFIRS) ($r = .61$, $p < .001$); ISMI and self-esteem (RSE) ($r = -.64$, $p < .001$); and ISMI and quality of life (Q-LES-Q-SF) ($r = -.56$, $p < .001$). In a partial correlation, internalized stigma (ISMI) correlated with poorer

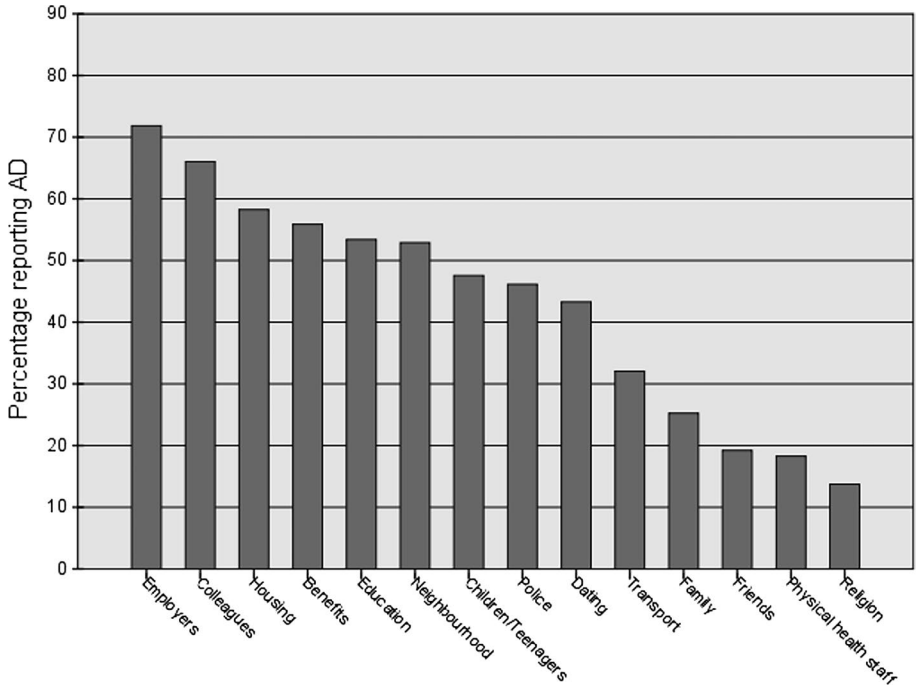

Fig. 1 Percentage of participants reporting anticipated discrimination (AD) per life domain in the Questionnaire on Anticipated Discrimination (QUAD)

Table 3 Perceived public stigma

	n	Mean	SD	Median	Max.	Min.	> 0 (*n*, %)
QPS	101	.4	.8	.4	2.2	− 1.4	70, 69.3
3 Ability to Take Responsibility	104	.8	1.1	1.0	2.8	− 2.0	77, 74.0
4 Norm-Violating and Externalizing Behavior	103	.7	1.1	1.0	2.8	− 2.0	68, 66.0
2 Malingering and Misuse of Medication	104	.5	1.2	.3	3.0	− 2.8	59, 56.7
5 Consequences of Diagnostic Disclosure	104	.5	1.0	.6	2.6	− 2.0	68, 65.4
6 Etiology	103	.4	1.3	.8	3.0	− 3.0	68, 66.0
1 Reliability and Social Functioning	103	.1	1.0	.1	2.6	− 1.8	68, 65.4

QPS Questionnaire on Public Stereotypes Perceived by Adults with ADHD; > 0 (*n*, %): number and percentage of participants with a QPS mean or subscale means > 0, indicating slight or stronger perception of public stigma

self-esteem (RSE) even when controlling for depressive symptoms (BSI-19 subscale depression) and ADHD symptoms (ADHD-SR) ($r = -.49$, $p < .001$).

Internalized stigma was also associated with personal characteristics. In ANOVA with post hoc pairwise tests, we found associations of ISMI and family history (children) with ADHD [$F(1,101) = 5.133$, $p < 0.05$] and occupational status [$F(4,96) = 3.164$, $p < 0.05$]. Patients with children with ADHD or who were employed reported lower internalized stigma than participants without children or children without ADHD or than participants who were not working, retired or homemakers. We did not find associations of ISMI with gender, family status or highest educational degree.

QUAD correlated with WFIRS ($r = .26$, $p < .05$), negatively with Q-LES-Q-SF ($r = -.21$, $p < .05$) and was also associated with personal characteristics. ANOVA with post hoc test showed an association of QUAD and partnership status [$F(1,101) = 6.58$, $p < 0.05$]. Participants who were single, separated, divorced or widowed reported higher anticipated discrimination than participants who were married or in a partnership.

We did not find correlations or associations of QPS with clinical symptoms, psychosocial functioning or personal characteristics, nor between any of the stigma measures and characteristics of patients' status (inpatient, outpatient, self-help group participation, medication, time since diagnosis).

Discussion

Research on the stigma of mental disorders has mostly focused on schizophrenia and depression so far. Stigmatization of adult ADHD has yet received little scientific attention. Only few published studies with small sample

sizes, that examined public stigmatization of adult ADHD, are available to date (Mueller et al. 2012; Lebowitz 2016). This is the first study that assessed subjective stigmatization experiences including internalized stigma, anticipated discrimination and perceived public stereotypes in adults with ADHD and their association with clinical, psychosocial and sociodemographic characteristics.

About one quarter of our sample (23.3%) reported a high degree of internalized stigma with an ISMI total score > 2.5. This compares to the percentage of patients with high internalized stigma reported for schizophrenia, depressive episodes and other psychiatric disorders, which ranges from 10.0 to 41.7% (Boyd et al. 2014; Sibitz et al. 2013). On the ISMI subscale level, between 30.4 and 39.8% of our participants reported high severity of discrimination experiences, social withdrawal and alienation, which is also similar to results reported for schizophrenia and other psychiatric disorders (Boyd et al. 2014; Sibitz et al. 2013). Our results thus indicate that the dysfunctional affective dimension of internalized stigma, like feelings of self-devaluation and alienation, the dysfunctional behavioral dimension, like withdrawal from social interactions, and the percentage of severe discrimination experiences are similarly pronounced in adult ADHD as in other psychiatric disorders.

Sixty-nine percent of our participants reported high stigma resistance, which is strikingly above the 12.0–50.8% of patients with high stigma resistance reported for other psychiatric disorders (Boyd et al. 2014). Though the analysis of the underlying reasons was not the topic of this study, published studies in other mental disorders point out that having other role identities than being a person with a mental illness and being socialized with peers with mental disorders, who are resisting stigma, may explain higher stigma resistance scores in patients with mental disorders (Firmin et al. 2016). As an association of high stigma resistance and a more favorable course of the mental disorder and its psychosocial outcome has been reported (Firmin et al. 2016), reasons and consequences of high stigma resistance in adults with ADHD could be a promising topic for further research.

Only 2% of our participants reported high stereotype endorsement on the referring ISMI subscale. This was much lower compared with the up to 30% reported for patients with schizophrenia or other psychiatric disorders (Boyd et al. 2014; Sibitz et al. 2013). One explanation is that the finding is artificial and results from an assessment bias, as the general stereotypes related to mental disorders assessed by the ISMI stereotype endorsement subscale possibly do not cover ADHD-related stereotypes. The data obtained from QPS argue for this notion, as 69.3% of our participants reported perceptions of ADHD-specific public stereotypes. Most frequently perceived public stereotypes were related to doubts about the validity of ADHD diagnosis ("ADHD does not exist in adults": 88.5%; "ADHD results from bad parenting": 82.4%; "ADHD is invented by drug companies": 76.0%; "ADHD results from watching too many video games or TV shows": 73.3%; "Adults with ADHD simulate their symptoms": 72.8%). Accordingly, studies of youth's beliefs about ADHD etiology showed that stigmatizing attributional beliefs, such as low effort, inadequate parenting or substance abuse causing ADHD were also common in this group (Canu and Carlson 2003; Stroes et al. 2003; Coleman et al. 2009). These public stereotypes seem to be specific for ADHD but not related to other psychiatric disorders and are not assessed with the ISMI stereotype endorsement subscale.

The mean QPS score of 0.4 (±0.8) in our study is strikingly higher than the mean QPS score of −1.3 (±0.59), reported by Fuermaier et al. (2012) in a sample of teachers, physicians and controls without ADHD. This is an interesting finding and possibly results from an absence of social desirability bias or more awareness for ADHD-related stereotypes among affected participants than among non-affected external observers as assessed by Fuermaier et al. (2012). In any case, it points to the frequently reported gap in self- and observer evaluation of a phenomenon.

Our study also found that 88.5% of participants anticipated discrimination in a broad range of daily living situations, with a mean number of 6.0 (±3.8) situations. Discrimination was most often anticipated in the occupational context, with 66.0–71.8% expecting discrimination from colleagues or employers, in the education context, with 53.4% anticipating discrimination from teachers or professors, and in interpersonal relationships, with 43.0–52.9% anticipating discrimination from neighbors or when dating someone as well as up to 25.2% anticipating discrimination even from family members or close friends. These findings are compared to the prevalence of anticipated discrimination reported for other psychiatric disorders. In a recent study, which used the QUAD in 202 individuals with schizophrenia, depression and bipolar disorder, 92.6% anticipated discrimination in a median number of seven areas of daily living. More than two-third anticipated discrimination from employers, colleagues or when dating and up to 50% anticipated discrimination from family members or close friends (Farrelly et al. 2014). Two other studies in patients with depressive episodes and schizophrenia reported that 43.5–49.3% had stopped themselves from applying for work or education and that 58% had stopped themselves from dating due to anticipated discrimination (Üçok et al. 2012; Hansson et al. 2014).

Our finding that 18.3% of participants anticipated discrimination from healthcare staff is of special concern in terms of work ethics and quality of health care. This result roughly compares to the 17.1–27.0% of patients with depressive episodes or schizophrenia who anticipated and/or experienced discrimination from healthcare staff according to published studies (Thornicroft et al. 2007; Farrelly et al.

2014; Harangozo et al. 2014). However, anticipated discrimination from healthcare staff has never been assessed in adults with ADHD before. Thus, in addition to the lack of specific training and awareness for the disorder (Tatlow-Golden et al. 2016), active denial of adult ADHD by clinicians (Moncrieff and Timimi 2010) may be a further explanation why the administrative prevalence of adult ADHD is much lower than its epidemiologic prevalence (Ramos-Quiroga et al. 2013).

We found medium to large correlations between all assessed stigma measures, which may mirror a self-maintaining circle of experiencing and internalizing stigma and anticipating discrimination (Gabbidon et al. 2013; Quinn et al. 2015; Kao et al. 2016) as well as a conceptual overlap (Livingston and Boyd 2010). We also found medium to large correlations between internalized stigma, clinical symptoms, psychosocial functioning and quality of life. Though this has never been quantitatively evaluated in adult ADHD before, a meta-analysis of 45 studies accordingly showed correlations between internalized stigma, psychosocial variables and psychiatric symptom severity in a variety of psychiatry disorders (Livingston and Boyd 2010). The correlation of internalized stigma and reduced self-esteem persisted even when controlling for the effect of ADHD and depressive symptoms, which matches previous findings by Corrigan and Rao (2012) for other psychiatric disorders.

Anticipated discrimination, albeit with smaller effect size, also correlated with impaired psychosocial functioning and reduced quality of life. Anticipated discrimination and internalized stigma were also associated with some of participants' personal characteristics. Intensity of anticipated discrimination was associated with lack of partnership, which may be mediated by social fear, e.g., withdrawal from social interactions like dating due to anticipated negative appraisal. Higher internalized stigma was associated with unemployment, which may result from the high societal value of work and economic restrictions associated with unemployment in Western societies.

Perceived public stereotypes did correlate with neither personal characteristics nor clinical symptoms or psychosocial functioning. This points out that the perception of stigmatizing stereotypes per se not automatically implies intraindividual dysfunction but requires mediating processes, which are probably linked to internalizing stigma and anticipating discrimination.

Taken together, our results point out that the subjective processing of public stigmatizing experiences can add additional burden of disease on ADHD and exacerbate social dysfunction related to ADHD in a variety of daily living domains. This has never been described for ADHD before, but is a well-known finding from other psychiatric disorders (Livingston and Boyd 2010). As internalized stigma and anticipated discrimination can be addressed via cognitive behavioral methods, it could be a promising topic of future psychotherapeutic research to assess whether psychosocial dysfunction, self-esteem, avoidance behaviors and procrastination that are often associated with adult ADHD could be improved by modifying subjective stigmatization perceptions.

Limitations

Some methodological limitations should be considered. All components of subjective stigmatization experiences were assessed by self-rated questionnaires and thus exclusively rely on participants' information. However, ISMI and QUAD are established assessment instruments with good psychometric properties and have been used extensively in stigma research before. The sensitivity of the original version of the QPS to measure public stigma toward adults with ADHD has been shown in a validation study (Fuermaier et al. 2012). The authors state that the view of individuals with ADHD themselves would provide valuable information and recommend this use of the QPS for future research. However, as we used an accordingly adapted, but not validated version of the QPS, our results on public stigma perceived by individuals with ADHD are exploratory and need further evaluation.

Twenty-one percent of our participants were recruited from self-help groups and reported that ADHD was diagnosed by an experienced clinician. Thus, there may be some misdiagnosed patients in this group. However, it was required that all participants score ADHD-SR > 15 and above the diagnostic cut-off for ADHD. All participants, who were recruited at the AHG clinics and CIMH, were diagnosed by clinicians with longstanding experience with adult ADHD (B.A., E.S., P.D.) and according to German guideline recommendations. Due to the exploratory nature of the study, we did not correct for multiple testing, which possibly overestimates the findings. As stigmatization is highly influenced by sociocultural contexts, generalizability of our results to adults with ADHD outside Western culture is limited and between-country differences in Western countries should be considered (Krajewski et al. 2013).

However, despite these limitations, our study revealed some significant findings related to stigmatization of ADHD. First, it showed that internalized stigma and anticipated discrimination are frequent phenomena in adult ADHD and related to worse disorder outcome. Second, it showed that anticipated discrimination from healthcare staff is a common concern in adults with ADHD. Third, it showed that adult ADHD is associated with characteristic public stereotypes mostly related to the etiology of the disorder, which are different from public stereotypes related to other psychiatric disorders.

Compliance with ethical standards

Conflict of interest Esther Sobanski: advisory boards Shire Germany and Medice. All other authors declare that they have no conflict of interest.

Funding The study received no funding.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed consent Informed consent was obtained from all individual participants included in the study.

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