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Internalised stigma in adults with autism: A German multi-center survey

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ABSTRACT

The aim of this study was to evaluate the extent of internalised stigma and possible predictors in adults with a diagnosis of autism spectrum disorder (ASD). We measured internalised stigma in a sample of 149 adults with ASD and an IQ ≥70 (79.2% male, mean age 31.8 years), using the Brief Version of the Internalized Stigma of Mental Illness Scale (ISMI-10). The mean ISMI-10 score was 1.93 (SD = 0.57), with 15.4% of participants reporting moderate or severe internalised stigma. Moderate or severe stigma was more frequent in persons aged ≥35 years (OR: 4.36), and in individuals with low educational level (OR: 6.00). IQ, sex and ASD diagnostic subtype (ICD-10) did not influence stigma severity. Compared to other mental disorders, the level of internalised stigma in adults with ASD without intellectual disability appears to be lower.

1. Introduction

1.1. Stigma: Definition, categorisation, impact

Stigma is a multifaceted phenomenon which has cognitive, emotional, and behavioral dimensions that can include blame, prejudicial attitudes, negative stereotypes, and various other forms of social exclusion and discrimination endorsed by a sizeable group about a subgroup (Corrigan, 2000; Rössler, 2016). Especially with regard to individuals with mental and behavioral disorders – a group that experiences stigmatization much more frequently than other groups in society – stigmatization has a century-long tradition, occurring cross-culturally (Rössler, 2016).

When occurring in the form of negative attitudes, prejudice, stereotypization or discrimination by members of the general population against members of a certain group, this form of stigma is termed *public stigma*. Such public stigma can also be internalized by affected individuals, which is then called *self-stigma* or *internalized stigma* (Rüsch et al., 2005), with internalized stigma and perceived public stigma showing a positive association (Bradstreet et al., 2018). Not only affected individuals, but also their family members, caregivers or friends can suffer the impact of public stigma, e.g. through low self-esteem, or self-blame, which is then termed *affiliate stigma* (Corrigan et al., 2005).

Stigmatization often leads to social exclusion of affected individuals, and is also known to have a negative impact on their employment, income, housing, and quality of life (Alonso et al., 2009; Sharac et al., 2010). Moreover, public stigma of psychiatric disorders has the potential to negatively influence mental health, help-seeking behavior, treatment utilization, and suicidality (Evans-Lacko et al., 2012; Schomerus et al., 2015). For internalized stigma, a meta-analysis of 45 studies showed a negative association of stigma with hope, self-esteem, treatment adherence, and a positive association with psychiatric symptom severity (Livingston and Boyd, 2010).

1.2. ASD-related stigma

1.2.1. ASD and public stigma

According to the few existing studies, the public stigma of ASD appears to be less negative than that of other mental disorders, e.g. schizophrenia, bipolar disorder, or ADHD (Baeyens et al., 2017; Durand-Zaleski et al., 2012). In some studies – probably because of the perception of ASD being associated with intelligence and creativity – the public stigma of ASD was even positive in comparison (Jensen et al., 2016; Thys et al., 2014). There also is some evidence for cross-cultural differences regarding the level of public stigma towards ASD

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(Obeid et al., 2015), with lower stigma towards ASD potentially being related to better availability of autism resources and higher public awareness in the respective country.

1.2.2. ASD and affiliate stigma

In contrast to the field of ASD and public stigma, there is a significant body of literature on *affiliate stigma*, i.e. perceived stigma among caregivers of individuals with ASD. The vast majority of studies so far have focused on parents and caregivers of children with ASD. In these studies, caregivers frequently reported perceived stigmatization, regardless of their respective cultural background. For example, in a survey of 758 caregivers of children with ASD from South Europe (Albania, Bulgaria, Croatia, and Turkey), between 29% and 52% of caregivers "agreed" or "strongly agreed" to the affective dimension items of the Affiliate Stigma Scale (Daniels et al., 2017). Interestingly, affiliate stigma appears to be higher among caregivers of individuals with ASD than in caregivers of individuals with physical disabilities, or with intellectual disabilities (Werner and Shulman, 2015), with affiliate stigma being associated with decreased subjective well-being (Werner and Shulman, 2013). The only study on affiliate stigma in caregivers of adults with ASD so far, which used qualitative methodology, found ASD-related stigma to be one out of three factors resulting in social exclusion (Marsack and Perry, 2018).

1.2.3. ASD and internalized stigma

Regarding *internalized stigma* in individuals with ASD, to our knowledge to date there exist only two studies covering this topic: In the study of Shtayermman (2009), which suffers from a rather circumscript sample (ten adolescents/young adults diagnosed with Asperger's syndrome), participants were asked five self-designed questions about potential areas of stigma. On average, participants answered three out of five questions positively. From an online survey of adults self-identifying as having ASD ($N = 1139$), McDonald et al. (2017) reported Stigma Scale scores that were lower than those in the original Stigma Scale validation study (55.58 vs. 62.6) (King et al., 2007).

Apart from the afore-mentioned studies, there is a lack of research on internalized stigma in ASD. This is unfortunate, as the perspective of affected individuals in terms of perceived stigma is essential both from a scientific, and from a societal perspective. The aim of this study therefore was to evaluate internalized stigma in a cohort of adults with medically confirmed ASD diagnoses.

2. Methods

This study was conducted as a part of the ASD-Net, a research network with focus on ASD that is funded by the German Federal Ministry of Education and Research (Kamp-Becker et al., 2017). The study protocol was reviewed and approved by the respective institutional ethic committees of the participating study centers.

2.1. Participants

Data for this study was collected in four German ASD outpatient clinics at academic psychiatric departments between November 2015 and June 2016 from adults with an ASD diagnosis. In all patients, the diagnosis according to ICD-10 criteria had been confirmed by experienced clinicians, using the current diagnostic gold standard in ASD, i.e. the Autism Diagnostic Observation Schedule (ADOS) and/or the Autism Diagnostic Interview-Revised (ADI-R; if parental informants were available) (Bölte et al., 2006; Kamp-Becker et al., 2017; Rühl et al., 2004). Patients aged ≥18 years were included if they had a confirmed ICD-10 autism diagnosis (F84.0, F84.1, F84.5, F84.8, F84.9; in contrast to the DSM-5, the ICD has not yet incorporated the concept of autism as a "spectrum disorder", and therefore offers different diagnostic categories for patients with autism), and no intellectual disability (IQ ≥70). The IQ cut-off value of 70, which was derived from the ICD-10 classification of IQ levels, was chosen in order to ensure that participants were able to sufficiently understand the items, and answer the questionnaire on their own.

2.2. Questionnaire and data collection

A questionnaire on health care service use, sociodemographic data (including the level of education), and stigma in individuals with ASD was developed and mailed to the participants. Participants were asked to consent on pseudonymized data linkage between the questionnaire data and some of their clinical data (e.g. age, sex, diagnosis, IQ). Several weeks after the initial contact, participants received a reminder. Data from the questionnaires were entered into an electronic Case Report Form (eCRF) created in OpenClinica® (OpenClinica Enterprise Version: 3.3), and were reviewed by a second person.

2.3. Instruments

2.3.1. Brief version of the internalized stigma of mental illness scale (ISMI-10)

To determine the extent of internalized stigma, we used the brief version of the Internalized Stigma of Mental Illness scale (ISMI-10) (Boyd et al., 2014), which has been derived from the Internalized Stigma of Mental Illness (ISMI) scale (Ritsher et al., 2003). The ISMI-10 consists of ten stigma-related items which are each answered on a four-point Likert scale. The total sum is then divided by the number of answered items, resulting in a possible score range of 1 to 4. As suggested by the ISMI-10 authors, we dichotomised the total score into 1.00–2.50 (no stigma to mild internalized stigma) and 2.51–4.00 (moderate stigma to severe internalized stigma). The ISMI-10 covers the same five dimensions of internalized stigma (alienation, stereotype endorsement, discrimination experience, social withdrawal, stigma resistance) as the original 29-item ISMI. In two samples, the internal consistency was $\alpha = 0.75$, and $\alpha = 0.81$, respectively, and the correlation with the original ISMI was high ($r = 0.91$) (Boyd et al., 2014).

2.3.2. IQ tests

The IQ was assessed using the German versions of the following instruments: Wechsler Intelligence Scale for Children (WISC-R (Tewes, 1983), WISC-III (Tewes et al., 1999), WISC-IV (Petermann and Petermann, 2011)), Wechsler Adult Intelligence Scale (WAIS-R (Tewes, 1991), WAIS-III (von Aster et al., 2006), WAIS-IV (Petermann, 2012)), Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III (Petermann et al., 2009)), Kaufman Assessment Battery for Children (Melchers and Preuß, 2009), Wortschatztest (Schmidt and Metzler, 1992), Raven's Standard Progressive Matrices (Horn, 2009), and Raven's Coloured Progressive Matrices (Bulheller and Häcker, 2002). IQ levels were classified into the following bands: learning disability (IQ 70–84), average IQ (85–114), and above-average IQ (≥115).

2.3.3. International standard classification of education

The level of education was defined in accordance with the International Standard Classification of Education (ISCED) (UNESCO, 1997, 2012), and classified into three groups: low (ISCED level 0–2B), medium (level 2A) and high education (level 3A). Referring to the German school system, low educational level complies with 9 years of schooling, or leaving school without having acquired any school-leaving qualification. Medium educational level is equivalent to 10 years of schooling, and high educational level complies with 12 or 13 years of schooling and a school-leaving qualification, which opens access to higher education institutions (Schneider, 2008; Schroedter et al., 2011).

2.4. Data analysis

Baseline data were analyzed using descriptive statistics. For each ISMI-10 item, as well as for the total score, the arithmetic mean, standard deviation and interquartile range was calculated. The reliability of the ISMI-10 was evaluated using Cronbach's alpha. The prevalence of moderate to severe internalized stigma was determined, stratified by age group (18–24, 25–34, ≥35 years), sex (male, female), ASD subgroup (Asperger syndrome, other ASD diagnoses), intellectual functioning (learning disability (IQ 70–84), no learning disability (IQ ≥85)), and highest educational level (low, medium, high). Additionally, the associations between stigma and the above-mentioned predictors were evaluated in a logistic regression model (binary logit model with Fisher scoring optimization). Crude as well as multiple adjusted odds ratios (OR) and 95% CIs were derived. All statistical analyses were performed using SAS, version 9.4 (SAS Institute, Cary, USA).

3. Results

3.1. Sample characteristics

The questionnaire was sent to 782 adults with ASD. In 52 cases, mailings could not be delivered due to a wrong address. Two hundred and six persons returned the questionnaire including a signed consent form (response rate: 26.8%). In 10 cases, pseudonymized data linkage was not possible, leaving 196 questionnaires that could be evaluated.11.6% of the non-responders and 31.6% of the responders were aged ≥35 years. Of the 196 responders, 149 had both an IQ ≥70, and had answered at least one question of the ISMI-10 and were thus included as study population. The sample characteristics are presented in Table 1. One hundred and eighteen (79.2%) participants were male, and the mean age was 31.8 years (range: 18–67). The most frequent diagnoses were Asperger's syndrome (69.1%), childhood autism (19.5%), and atypical autism (9.4%). 82.6% of participants were of average or above-average intelligence and more than half had a high level of education (53.7%).

3.2. ISMI-10 results

Of the 149 participants, a total of 144 (96.6%) answered all questions of the ISMI-10, and in five participants there were one to five missing values. The Cronbach's alpha of the ISMI-10 scale was >0.83.

Table 1
Sample characteristics (n = 149).

Characteristic	n	(%)
Sex		
Male	118	79.2
Female	31	20.8
Mean age in years (± SD; range)	31.8 (11.4; 18–67)	
Age groups in years		
18–24	49	32.9
25–34	49	32.9
≥35	51	34.2
Diagnoses		
Childhood autism (F84.0)	29	19.5
Atypical autism (F84.1)	14	9.4
Asperger syndrome (F84.5)	103	69.1
PDD-NOS (F84.9)	3	2.0
Intellectual functioning		
Learning disability (IQ 70–84)	26	17.5
No learning disability (IQ ≥85)	123	82.6
Level of education		
Low	25	16.8
Medium	44	29.5
High	80	53.7

The distribution of all ISMI-10 items is shown in Table 2. Nearly half of the participants (47.3%) agreed or strongly agreed that “people without ASD could not possibly understand me” (item 6). Only 6.1% agreed or strongly agreed that “people with ASD tend to be violent” (item 1) and 82.4% agreed or strongly agreed that they “can have a good, fulfilling life despite their ASD” (item 9). Overall, the prevalence of moderate or severe internalized stigma was 15.4% in the total sample. There was no significant difference between ISMI-10 scores between the participating study centers. Results stratified by sex, age, diagnostic subgroup, and level of education, are shown in Table 3. The greatest difference was found for education, with 28.0% of those with a low level of education reporting moderate or severe internalized stigma, compared to 10.0% of those with a high level of education.

In the crude regression model, low educational level was associated with higher level of internalized stigma (Table 3). When applying a multiple regression model, age ≥35 years and low level of education were significantly associated with higher stigma when adjusting for all other covariates.

4. Discussion

4.1. Extent of internalized stigma

In this study, adults with ASD without intellectual disability had a mean score of 1.93 (0.57) on the brief version of the Internalized Stigma of Mental Illness scale (ISMI-10). In comparison to most other studies employing the ISMI-10, the score in our study is somewhat lower: In the study of Boyd et al. (2014), the mean score was 2.32 (± 0.41) within a sample of 127 US patients with serious mental illness, and in a corresponding cross-validation sample with 760 participants, the mean score was 2.27 (± 0.51). Another US study, which evaluated the internalized stigma of 159 psychiatric outpatient veterans taking psychotropic medication, yielded a mean ISMI-10 score of 2.19 (± 0.52) (Boyd et al., 2015). A study from the Czech Republic included 354 psychiatric patients, with psychiatric diagnoses mainly encompassing neurotic disorders, mood disorders, substance use disorders, psychotic disorders, and personality disorders, and found a mean ISMI-10 score of 2.16 (± 0.54) for the total sample (Ociskova et al., 2016). Stratified by diagnostic subgroups, mean ISMI-10 scores were 2.09 (neurotic disorders), 2.22 (psychosis), and 2.36 (personality disorders), respectively. The only piece of research yielding lower ISMI-10 scores than our study in adults with ASD was the study of Dossing et al. (2015), who measured internalized stigma in 30 Danish patients with bipolar disorder. In their study, the mean ISMI-10 score was 1.59 (± 0.38), thus being considerably lower than in our sample. The reason for this lower level of internalized stigma probably lies in the nature of bipolar disorder itself, with affected patients often experiencing elevated mood, and not being aware of societal judgments or norms. Finally, it should be noted that a direct comparison of ISMI-10 scores for different populations is limited in its validity, as a generic measure like the ISMI-10 is not designed to fully accommodate the specific characteristics of a range of psychiatric diagnoses.

The level of internalized stigma in ASD, which appears to be lower than in most other mental disorders (see above), corresponds well with the level of ASD-related public stigma, which is also lower than in other mental disorders (Durand-Zaleski et al., 2012; Thys et al., 2014). It also matches the subjective quality of life in adults with (high-functioning) ASD, which lies on an intermediate level between healthy subjects and those with other mental disorders, e.g. schizophrenia (Kamp-Becker et al., 2010).

4.2. Factors influencing internalized stigma

Regarding influencing factors, low educational status was associated most strongly with higher internalized stigma. This is in line with the literature on perceived stigma in psychiatric disorders in general

Table 2
Internalized stigma according to the ISMI-10 (n = 149).

Items of the ISMI-10[a]		n	Mean (SD)	Agree[c]
1.	People with ASD tend to be violent.	148	1.51 (0.61)	6.1%
2.	People with ASD make important contributions to society.[b]	148	3.02 (0.78)	79.1%
3.	I don't socialize as much as I used to because the ASD might make me look or behave "weird".	149	1.95 (1.00)	31.5%
4.	Having ASD has spoiled my life.	149	1.89 (1.00)	27.5%
5.	I stay away from social situations in order to protect my family or friends from embarrassment.	148	1.80 (0.95)	23.7%
6.	People without ASD could not possibly understand me.	148	2.42 (0.93)	47.3%
7.	People ignore me or take me less seriously just because I have ASD.	147	2.18 (1.05)	34.0%
8.	I can't contribute anything to society because I have ASD.	148	1.61 (0.86)	12.8%
9.	I can have a good, fulfilling life, despite my ASD. [b]	148	3.31 (0.79)	82.4%
10.	Others think that I can't achieve much in life because I have ASD.	146	2.21 (0.91)	35.6%
Overall score		**149**	**1.93 (0.57)**	15.4% [d]

[a] Answers are coded on a 4-point Likert scale: 1 (strongly disagree), 2 (disagree), 3 (agree), and 4 (strongly agree).
[b] Items 2 and 9 are reverse-coded for calculating the total score only.
[c] Proportion of respondents who agree or strongly agree (i.e. answering the item with 3 or 4).
[d] Regarding the overall score, the proportion of respondents who agree or strongly agree represents those with an overall score in the range of 2.51–4.00.

Table 3
Prevalence of moderate and severe internalized stigma and results of the multivariate logistic regression (n = 149).

Characteristic	Moderate or severe stigma	Crude logistic regression		Multiple adjusted logistic regression[a]	
	Prevalence	OR	(95% CI)	OR	(95% CI)
Sex					
Male	14.4%	1	(reference)	1	(reference)
Female	19.4%	1.43	(0.51–3.99)	1.24	(0.42–3.69)
Age groups in years					
18–24	10.2%	1	(reference)	1	(reference)
25–34	12.2%	1.23	(0.35–4.33)	1.78	(0.47–6.71)
≥ 35	23.5%	2.71	(0.88–8.38)	**4.36**	**(1.23–15.51)**
Diagnoses					
Other ASD diagnosis	17.4%	1	(reference)	1	(reference)
Asperger syndrome	14.6%	0.81	(0.32–2.07)	1.14	(0.37–3.51)
Intellectual functioning					
Learning disability (IQ 70–84)	19.2%	1.39	(0.46–4.16)	1.00	(0.26–3.78)
No learning disability (IQ ≥ 85)	14.6%	1	(reference)	1	(reference)
Level of education					
Low	28.0%	**3.50**	**(1.12–10.93)**	**6.00**	**(1.47–24.51)**
Medium	18.2%	2.00	(0.69–5.76)	2.57	(0.84–7.90)
High	10.0%	1	(reference)	1	(reference)

[a] adjusted for all other variables shown.

(Alonso et al., 2009), and also with the results of Ociskova et al. (2016) on internalized stigma associated with mental health problems. Another important factor positively associated with internalized stigma was higher age, i.e. being 35 years or older. While this finding is not congruent with the majority of other studies (Livingston and Boyd, 2010; Ociskova et al., 2016), it may constitute an ASD-specific factor for internalized stigma: Most older individuals with ASD have either been diagnosed decades ago as children (when ASD were not yet widely known), or later in their life (mean age at diagnosis: 19 to 47 years (Begeer et al., 2013; Rutherford et al., 2016)), after struggling with the symptoms of ASD without having a diagnosis (Bachmann et al., 2018; Lai and Baron-Cohen, 2015). Compared to children diagnosed today (mean age of diagnosis in Germany: 6.5 years (Höfer et al., 2019)), the adult participants in our study may have not received optimum therapy or societal support and understanding for their illness, which may have led to a higher level of experienced stigmatization. Notably, female sex was not associated with higher levels of stigma. While this is in line with other studies on stigma in mental illness (Livingston and Boyd, 2010; Ociskova et al., 2016), in the case of ASD this is somewhat surprising, because the (positive) stereotype of ASD is usually associated with males (Baron-Cohen, 2010), and females may perceive themselves more "alien" to society than males (Krahn and Fenton, 2012). Nevertheless, the lack of association between female sex and stigma may also have been caused by the sample size.

4.3. Strengths and limitations

A main strength of this study is the high quality of the ASD diagnoses within our sample, as all participants have been thoroughly diagnosed in centers with high expertise in ASD (Kamp-Becker et al., 2018). While this study is only the second of its kind, it draws on a much larger and more diverse sample than that in the study of Shtayermman (2009). The sample also represents a balanced mixture of ICD-10 autism subgroups, and contains a considerable portion of females with ASD.

Regarding limitations, participants were patients of highly-specialized outpatient clinics at university hospitals, therefore the results of this study lack generalizability, and there is also the possibility that the comparably lower level of internalized stigma in our sample is due to this high-quality and supportive therapeutic environment. While the response rate of 26.8% is not high, it has to be kept in mind that lower response rates of surveys do not necessarily lead to biased results (Choung et al., 2013).

The method of measuring self-reported stigma raises the question of the validity of these ratings, as individuals with ASD may lack the introspective skills necessary for adequately answering self-referential questions. While there is evidence of a significant deficit in self-representation in individuals with ASD (Lombardo et al., 2007, 2010), which can affect self-referential cognition (Decety and Jackson, 2004), on the other hand there are also indicators that ASD patients can rate

their own emotions appropriately: Hobson et al. were able to demonstrate that impaired self-reflection may only concern selected emotional domains, e.g. embarrassment, but not pride or guilt (Hobson et al., 2006).

While the ISMI-10 questionnaire employed in this study is a robust and widely used instrument, its wording is not well-suited for persons with intellectual disability. This may have biased the results of this study, as lower IQ is often associated with higher levels of stigma. Also, the questionnaire is not designed specifically for ASD-specific stigma perceptions. For example, the ISMI-10 does not ask about being bullied, but on the other hand includes an item about "not socializing as much as one used to". While the latter item is not an optimal fit for pervasive developmental disorders like ASD, its omission would not have altered the study results significantly.

Altogether, the ISMI-10 offers some basic comparability of stigma levels between populations with different psychiatric or neurodevelopmental disorders.

Within the group of ASD patients, the conceptualization of and identification with autism of affected individuals differs (McDonald, 2017). In our questionnaire, we did not ask whether participants regarded ASD as a disorder, or as a variation of "neurodiversity". While the former stance may induce higher stigma (Gillespie-Lynch et al., 2017), the latter one may lead to lower levels of stigma. Therefore, we may have overlooked bias in any of these directions within our sample. Another potential bias is the relatively high portion of participants with high educational level, which may have contributed to decreased levels of perceived stigma. We also did not evaluate psychotropic medication use, and psychiatric comorbidity, which both have a high prevalence in ASD (Jobski et al., 2017; Joshi et al., 2013; Simonoff et al., 2013), and might have had a mitigating or aggravating influence, respectively, on participants' internalized stigma. Finally, as all participating academic departments are located in larger cities, individuals with ASD from rural environments with higher levels of stigma attached to mental disorders (Stewart et al., 2015; Townley et al., 2017) may have been under-represented in our sample.

4.4. Implications

As autism acceptance from external sources and a resulting personal acceptance significantly predicts mental health in individuals with ASD (Cage et al., 2018), ways to increase the acceptance of ASD in society should be explored in order to decrease stigma. So far, interventions targeting stigma associated with ASD have mainly been designed for school or college settings (Gillespie-Lynch et al., 2015; Ranson and Byrne, 2014; Staniland and Byrne, 2013). Therefore, anti-stigma interventions for workplace environments or the general public might be worthwhile in order to overcome ASD- related stigma, thus improving quality of life and mental health of affected individuals. Such measures might also have the potential to reduce affiliate stigma in carers of individuals with ASD. On the other hand, given the relatively low level of ASD-related stigma in our study, it is debatable whether a specific intervention targeting ASD-associated stigma is preferable, or whether general anti-stigma measures in the field of public mental health (Thornicroft et al., 2016) might be sufficient in order to reduce stigmatization in adults with ASD.

Compliance with ethical standards

Declaration of interest

None.

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.

Informed consent

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

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.psychres.2019.04.023.

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