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## Cognitive functioning in adult ADHD

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## 2.4.1

### Study 7: Stigma in ADHD

Mueller, A.K. \*, Fuermaier, A.B.M. \*, Koerts, J., & Tucha, L. (2012). Stigma in attention deficit hyperactivity disorder. *ADHD Attention Deficit and Hyperactivity Disorders*, 4 (3), 101-114. (\* *shared first authorship*).



## ABSTRACT

**Objectives:** Attention Deficit Hyperactivity Disorder (ADHD) is a frequently diagnosed developmental disorder with a high impact affecting multiple facets of social life. Therefore, patients suffering from ADHD are at high risk to be confronted with stigma, prejudices and discrimination.

**Method:** A review of the empirical research in the field of ADHD with regard to stigma was performed. The findings of investigations in this field were clustered in different categories, including stigma in children with ADHD, stigma in adults with ADHD, stigma in relatives or in people close to a patient with ADHD and the influence of stigma on authorities' attitudes towards patients with ADHD.

**Results:** Identified variables that contribute to stigma in ADHD are public's uncertainty concerning the reliability/validity of an ADHD diagnosis and the related diagnostic assessment, public's perceived dangerousness of individuals with ADHD, socio-demographical factors (such as age, gender and ethnicity), stigmatization of ADHD treatment (e.g. public's skepticism towards ADHD medication) and disclosure of the diagnostic and medication status of the individual with ADHD.

**Conclusion:** The impact of stigma associated with ADHD can be conceptualized as an underestimated risk factor, affecting treatment adherence, treatment efficacy, symptom aggravation, life-satisfaction and mentally well-being of individuals with ADHD. Public as well as health professionals' concepts about ADHD are highly diverse, setting individuals with an ADHD diagnosis at greater risk to get stigmatized.

The present chapter presents a summary of the article *Stigma in attention deficit hyperactivity disorder*, published in the journal *ADHD Attention deficit and hyperactivity disorders* (Mueller, Fuermaier, Koerts & Tucha, 2012). The original article provides a comprehensive review of empirical studies on stigmatization towards children, adolescents and adults with ADHD. However, since the present thesis focuses solely on adults with ADHD and because the next two studies (Study 8 and Study 9) examine public stigma, the original article has been summarized in the present chapter and focuses particularly on stigmatization towards adults with ADHD.

## INTRODUCTION

During the last 10 years, the number of studies examining the impact of stigma, prejudice and discriminating behavior on the mental health and life satisfaction of people at risk for, or already diagnosed with a mental disorder (Brohan et al. 2010), increased considerably. In general, stigma reflects the expression of a discrediting stereotype deriving from falsely assumed associations between a group of people and unfavorable characteristics, attributes and/or behaviors (Demaio 2006). Three qualities of stigma can be differentiated, including *public stigma*, *self-stigma* (Corrigan and Shapiro 2010) and *courtesy stigma* (Goffman 1963). According to Corrigan and Shapiro (2010) *public stigma* can be noticed when a large population collaboratively accepts discrediting stereotypes about out-group members or more cursory, individuals from groups that are perceived to differ in physical, behavioral or other intrinsic characteristics. *Self-stigma*, as described by Fabrega (1990), is the individual's internalization of a "new degraded identity" that negatively impacts the individual's social functioning and quality of life. Consequently, the individual's loss of social- or work related status is one of the likely consequences of stigma (Fabrega 1990). *Courtesy stigma* represents the phenomenon that family members or people close to a stigmatized person get negatively judged due to their mere association with the stigmatized target (Tuchman 1996; Kendall and Hatton 2002; Norvilitis et al. 2002; Koro-Ljungberg and Bussing 2009; dosReis et al. 2010). Recent investigations on stigma in mental disorders emphasize that stigma may even initiate a transition from formerly light deviant symptoms to full psychiatric, thus, clinical significant disorders. This cascade is at least partly evoked by strengthening the patient's disorder perception and restraining the individual from disclosing symptoms to others (Zelst 2009; Demaio 2006). With regard to ADHD it appears that the existence of stigma and its impact on the diagnosed individual's life is highly under-investigated. This is surprising considering the disorder's vulnerability of eliciting stigmatizing perceptions in the public. Goffman (1963) assumed that disorders with a highly unknown and arbitrary etiology or with symptoms that are believed to be under the individual's control are more

likely to trigger public stigmatization. Indeed, Slopen and colleagues (2007) pointed out that antisocial behavior and dangerousness of individuals with mental illnesses were one of the main topics of the American press when reporting on psychiatric disorders. Prejudices about symptom etiology (Clarke 1998) further strengthen stigmatizing beliefs that either the individuals by themselves or their environments are to be blamed for their condition (e.g. ADHD is caused by excessive sugar consumption, poor parenting or unfavorably behaviors during pregnancy, such as smoking or alcohol consumption) (Clarke 1998). Finally, general mistrust and the increase in public debates about the immediate and long-term effects of ADHD medication (Stine, 1994) may further contribute to the stigmatization of individuals suffering from ADHD.

## **METHOD**

A review of English published literature of several databases (PsycInfo, SocIndex, Web of Science, PubMed) on the key terms “ADHD” and “stigma” revealed a total of 33 articles that were closely related to stigma in patients with ADHD. Investigations on stigma in ADHD cite from 1990 to 2011 with the majority of studies being conducted in the first decade of the 21<sup>st</sup> century. Further elaboration on themes as social representations, rejection and perceptions associated with ADHD led to another four articles, discussing the relevance of stigma in ADHD.

## **RESULTS**

Table 7.1 presents an overview of the studies related to stigma in ADHD which were taken into consideration for the present review.

Table 7.1.1. Studies related to stigma in ADHD which are taken into consideration in the present review

| Authors   | Title  | Year published |
|---|--|----------------|
| Bell, L., Long, S., Garvan, C., Bussing, R.   | The impact of teacher credentials on ADHD stigma perceptions   | 2011           |
| Brohan, E., Slade, M., Clement, S., Thornicroft, G.                                     | Experiences of mental illness stigma, prejudice and discrimination: a review of measures   | 2010           |
| Corrigan, P.W., Shapiro, J.R.   | Measuring the impact of programs that challenge the public stigma of mental illness  | 2010           |
| Davis-Berman, J., Pestello, F.G.  | Medicating for ADD/ADHD: Personal and social issues  | 2010           |
| dosReis, S., Barksdale, C.L., Shertman, A., Maloney, K., Charach, A.                    | Stigmatizing experiences of parents of children with a new diagnosis of ADHD   | 2010           |
| Kellison, I., Bussing, R., Bell, L., Garvan, C.   | Assessment of stigma associated with attention-deficit hyperactivity disorder: Psychometric evaluation of the ADHD Stigma Questionnaire          | 2010           |
| Singh, I., Kendall, T., Taylor, C., Mears, A., Hollis, C., Barry, M., Keenan, S.        | Young people's experience of ADHD and stimulant medication: A qualitative study for the NICE guideline   | 2010           |
| Coleman, D., Walker, J.S., Lee, J., Friesen, B.J., Squire, P.N.                         | Children's beliefs about causes of childhood depression and ADHD: A study of stigmatization  | 2009           |
| Koro-Ljungberg, M., Bussing, R.   | The management of courtesy stigma in the lives of families with teenagers with ADHD  | 2009           |
| Canu, W.H., Newman, M.L., Morrow, T.L., Pope, D.L.W.                                    | Social appraisal of adult ADHD: Stigma and influences of the Beholder's Big Five personality traits  | 2008           |
| Harpur, R.A., Thompson, M., Daley, D., Abikoff, H., Sonuga-Barke, E.                    | The attention-deficit/hyperactivity disorder medication-related attitudes of patients and their parents  | 2008           |
| Pescosolido, B.A., Jensen, P.S., Martin, J.K., Perry, B.L., Olafsdottir, S., Fettes, D. | Public knowledge and assessment of child mental health problems: Findings from the National Stigma Study--Children                               | 2008           |
| Vance, T.A., Weyandt, L.  | Professor perceptions of college students with attention deficit hyperactivity disorder  | 2008           |
| Walker, J.S., Coleman, D., Lee, J., Squire, P.N., Friesen, B.J.                         | Children's stigmatization of childhood depression and ADHD: Magnitude and demographic variation in a national sample                             | 2008           |
| Eisenberg, D., Schneider, H.  | Perceptions of academic skills of children diagnosed with ADHD   | 2007           |
| Jastrowski, K.E., Berlin, K.S., Sato, A.E., Davies, W.H.                                | Disclosure of attention-deficit/hyperactivity disorder may minimize risk of social rejection   | 2007           |
| Law, G.U., Sinclair, S., Fraser, N.   | Children's attitudes and behavioural intentions towards a peer with symptoms of ADHD: Does the addition of a diagnostic label make a difference? | 2007           |
| Martin, J.K., Pescosolido, B.A., Olafsdottir, S., McLeod, J.D.                          | The construction of fear: Americans' preferences for social distance from children and adolescents with mental health problems                   | 2007           |

| Authors   | Title  | Year published |
|---|--|----------------|
| McLeod, J.D., Fettes, D.L., Jensen, P.S., Pescosolido, B.A., Martin, J.K.   | Public knowledge, beliefs, and treatment preferences concerning attention-deficit hyperactivity disorder                           | 2007           |
| Pescosolido, B.A.   | Culture, children, and mental health treatment: Special section on the National Stigma Study-Children                              | 2007           |
| Pescosolido, B.A., Fettes, D.L., Martin, J.K., Monahan, J., McLeod, J.D.  | Perceived dangerousness of children with mental health problems and support for coerced treatment                                  | 2007           |
| Angermeyer, M.C., Dietrich, S.  | Public beliefs about and attitudes towards people with mental illness: A review of population studies                              | 2006           |
| Demaio, C.M.  | Mental illness stigma as social attribution: How select signals of mental illness affect stigmatizing attitudes and behavior       | 2006           |
| Hoza, B., Mrug, S., Gerdes, A.C., Hinshaw, S.P., Bukowski, W.M., Gold, J.A., Kraemer, H.C. Jr., Wigal, T., Arnold, L.E. | What aspects of peer relationships are impaired in children with attention-deficit/hyperactivity disorder                          | 2005           |
| Ruesch, N., Angermeyer, M.C., Corrigan, P.W.  | Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma  | 2005           |
| Burch, R.J.   | Attention Deficit/Hyperactivity Disorder: A disorder of self-awareness   | 2004           |
| Corrigan, P.W., Penn, D.L.  | Lessons from social psychology on discrediting psychiatric stigma  | 2004           |
| Fausett, Y.M.   | Elementary school children's stigmatization of children with mental illness  | 2004           |
| Kendall, J., Shelton, K.  | A typology of management styles in families with children with ADHD  | 2003           |
| Schmitz, M.F., Filippone, P., Edelman, E.M.   | Social representations of Attention deficit/hyperactivity disorder, 1988-1997  | 2003           |
| Kendall, J., Hatton, D.   | Racism as a source of health disparity in families with children with attention deficit hyperactivity disorder                     | 2002           |
| Norvilitis, J.M., Scime, M., Lee, J.S.  | Courtesy stigma in mothers of children with attention deficit/hyperactivity disorder: A preliminary investigation                  | 2002           |
| Throckmorton, P.H.  | Perceptions of practicing psychologists toward colleagues diagnosed with psychological problems                                    | 2000           |
| Adler, A.K., Wahl, O.F.   | Children's beliefs about people labeled mentally ill   | 1998           |
| Clarke, C.H.  | An exploratory study of the meaning of prescription medication to children diagnosed with attention deficit hyperactivity disorder | 1998           |
| Cornett-Ruiz, S., Hendricks, B., Fabrega, H.  | Effects of labeling and ADHD behaviors on peer and teacher judgments   | 1993           |
|   | Psychiatric stigma in the classical and medieval period: A review of the literature  | 1990           |



## CONCLUSION

Stigma in ADHD was found to be a highly prevalent issue which has been relatively neglected in previous research. Diversity in the disorder's etiology as well as the disorder's heterogeneity across age groups (Burch 2004) have been shown to enhance the disorder's proneness to stigma, partly through questioning the disorder's diagnosis, assessment and treatment (Stine 1994; Clarke 1998; Schmitz et al. 2003; Pescosolido et al. 2007; Harpur et al. 2008; Davis-Berman and Pestello 2010; dosReis et al. 2010). As public awareness concerning the disorder's associated ambiguity increases, it is likely that individuals with ADHD are becoming the focus of stigmatizing cognitions of undiagnosed social accompanists and/or patients with psychiatric conditions itself (Harpur et al. 2008; Coleman et al. 2009; Kellison et al. 2010). The impact of media in strengthening misperceptions and stigmatizing beliefs about patients suffering from ADHD was stressed (Slopen et al. 2007) and can be seen as a likely source open to be challenged through public education implementing information about stigma. Additional information about the etiology of ADHD has been shown to help people close to the affected individual to antagonize public stigma (Liffick 2000; Throckmorton 2000; Biederman and Faraone 2004). Likewise, informing the public about existing stigmatizing dynamics might serve the goal of lessening patients' burdens caused by stigma (Rüsch et al. 2005; Corrigan and Shapiro 2010). Empirical data of the discussed studies nearly unequivocally stressed the idea that stigma related to ADHD affects treatment adherence and treatment efficacy adversely (Stine 1994; Burch 2004; Harpur et al. 2008) by lowering the individual's self-esteem and/or level of self-efficacy (Rüsch et al. 2005). Moreover, symptom aggravation in response to internalized self-stigma and anticipated public's degradation was mentioned (Burch 2004). Whereas some studies supported the idea that neither diagnostic labeling itself (Cornett-Ruiz and Hendricks 1993; Law et al. 2007; Sandberg 2009) nor medicational disclosure (DeSantis et al. 2008; Sandberg 2009; Davis-Berman and Pestello 2010; Singh et al. 2010) elicit greater stigmatizing tendencies of undiagnosed fellows, more stigmatization was found when healthy participants were actual exposed to ADHD symptoms (Cornett-Ruiz and Hendricks 1993; Norvilitis et al. 2002; Kendall and Shelton 2003; Hoza et al. 2005; Singh et al. 2010). Exposure of individuals without ADHD to ADHD associated behavior (e.g. as presented on videotapes) increased the tendency in the individual to rate the presented person less favorably.

Furthermore, perceived dangerousness of the diagnosed person was a reoccurring theme in the literature on ADHD which had an impact on stigmatizing prejudices towards ADHD (Slopen et al. 2007; Pescosolido et al. 2007; Walker et al. 2008). This perceived dangerousness was most often described to arise from heightened levels of externalizing

behavior of persons with ADHD and the public's expressed aversion to get in contact with individuals diagnosed with ADHD. Corrigan and Shapiro (2010), however, stressed the importance of getting in contact with members of stigmatized groups in order to reduce negative affect (and by this stigma towards the individual). Moreover, many studies acknowledged that the public is handling different moralistic frameworks when rating disorder-seriousness and disorder-reliability with regard to ADHD versus medical conditions, such as asthma (Liffick 2000; Martin et al. 2007; Pescosolido et al. 2008). The aim of future studies should be to evaluate to what extent ratings on self-administered questionnaires reflect ecologically valid attitudes towards individuals with ADHD. Since most of the studies investigating this issue made use of vignettes depicting characters suffering from various conditions, followed by the performance of questionnaires which measure the respondents' willingness to approach an individual with ADHD, one might question whether attitudes measured by self-administered paper-pen assessments (such as a questionnaire approach) are sensitive enough to predict actual behavior towards a particular group of people. This applies also to our knowledge on stigma related to authorities, in particular to teachers, which is mainly based on self-rated assessments. Observational studies in the class environment, including the class dynamics, might support the attempt to objectify the qualities affecting teacher-student interactions. Furthermore, when assessing self-stigma due to ADHD diagnosis, objective measures of the stigmatized individuals (e.g. the frequency of missed school attendance) and the individuals' levels of stigma perception might be matched in order to objectify consequences of stigma on the individuals' daily life. Other shortcomings are that most literature on stigma focused on children with ADHD and that studies on stigma on ADHD in adulthood primarily examined students from undergraduate programs. Also, many studies were of correlational nature or represented inventories of anecdotal statements. All these factors limit the representativeness of current knowledge on stigma towards adults with ADHD and more research is needed which takes these factors into account.

